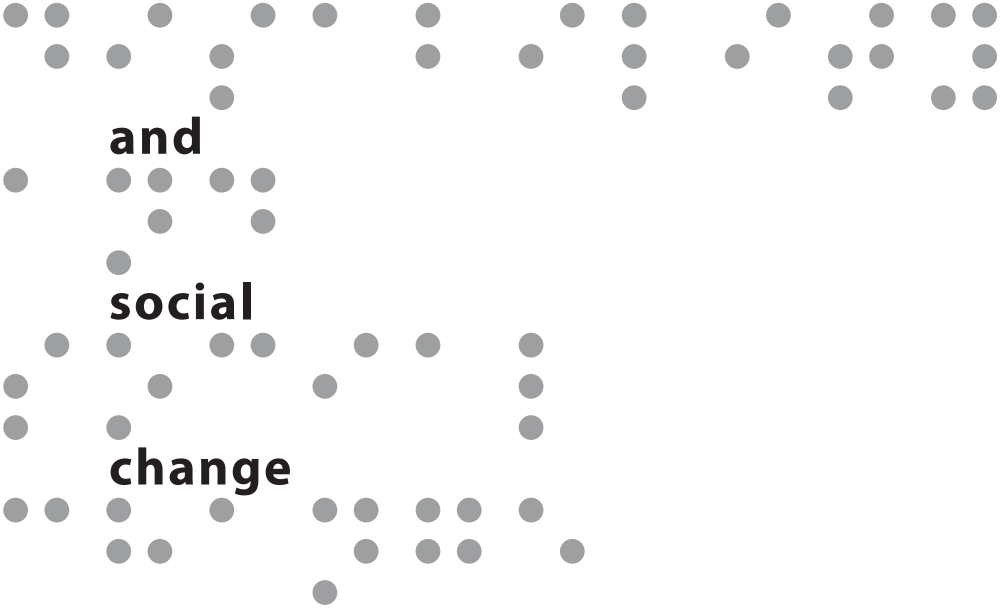
disability and social change



disability and social change

a south african agenda

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Foreword

In the world today, disabled people are lobbying the United Nations to advance the rights of disabled people by adopting the Disability Convention. In Africa, disabled people and their governments are implementing the African Decade of Disabled People (2000–2009) to ensure improvement in, and equalisation of, opportunities for disabled people. In South Africa, in 2006 we celebrate the tenth anniversary of the adoption of our Constitution, a document we can all be proud of and that promotes the rights of all South Africans. Unlike many other such documents, our Constitution specifically mentions the right of disabled people to equality.

As we advance our struggle on all these fronts, it is therefore fitting that this book, Disability and social change: A South African agenda, should appear, representing one more step towards the realisation of rights for all South Africans.

In 1997, the then Deputy President of South Africa, Thabo Mbeki signed the *White Paper on the Integrated National Disability Strategy* – the INDS. The INDS placed the issue of disability firmly in the centre of concerns around what it takes to make a society that is accessible and provides equal opportunities for all. The INDS called for research to promote the rights and participation of disabled people in our society. This major book, supported by the Disability Movement in South Africa, and with its many authors and wide range of topics, answers that call. It also asks all South Africans to continue thinking about and researching the rights of disabled people, to continue to build a more inclusive society, and to take on board the slogan of Disabled People South Africa, 'Nothing about us, without us!'. The book makes it clear how far we have come since the INDS – it is very unlikely that such a document would have been published even ten years ago. It also makes it clear that we still have a long way to go, in relation to the challenges of unemployment, and in making transport and social services truly accessible.

The editors and authors of this book come from a variety of sectors in South Africa, and are diverse with respect to disability, gender, race, and class. Collectively they issue us with a powerful challenge – to intensify our efforts to make the provisions of our Constitution real for all South Africans. Read this book – it may well spur you on to make your own best efforts to address the disability agenda. The best compliment you could pay to the authors of this remarkable volume would be to make your own contribution to enhancing the rights and opportunities of disabled people in South Africa. I call on all members of the Disability Movement to engage in this disability and social agenda.

Lewis Nzimande, MP and National Chairperson, Disabled People South Africa
1999 to 2006

Acknowledgements

The contributors to this volume are drawn from a broad cross-section of the diverse and complex nation that is South Africa. As editors, we have attempted to bring together a range of voices within our country's disability movement, and we owe a great debt of gratitude to all the authors, for enriching our work with their experiences, insights and images. This has been a long process and a difficult one; we thank all the authors for both their generosity and their patience.

The Human Sciences Research Council (HSRC) has, over the past four years, shown substantial commitment to researching disability. The publication of this book, thus, is but one of a range of disability research initiatives in which the HSRC is engaged, and for which the organisation deserves our recognition and thanks. From all at the HSRC Press we have had particular support. In the broader HSRC, Professor Linda Richter made possible the establishment of a research focus that has lead to this book and to a number of other outputs in the field of disability research.

Stellenbosch University generously allowed Leslie Swartz a secondment to the HSRC very soon after he had arrived at the university, and this provided him with the opportunity formally to establish disability work at the HSRC.

The Disability Studies Programme at the University of Cape Town, in which a number of the editors and contributors have been involved, has two important relationships, both of which are reflected in this publication. The British Council facilitated and funded a link between the Disability Studies Programme and the Centre for Disability Studies at Leeds University. This link has done much to develop disability work in South Africa. The linkage has been supported by the participation of Disabled People South Africa (DPSA) and particularly by the consistent and helpful support of Mzolisi ka Toni, who is not only a contributor to this book, but also a key person in ensuring that it has come into being.

Through the arduous process of writing and editing, Brian Watermeyer and the editorial team were ably assisted by Ann Turner. Hayley MacGregor was a great help and support early on in the process. Thomas Alberts deserves very special mention – without his considerable editing skills, and his rare mix of commitment, enthusiasm, hard work, and great humour under pressure, this book would have been of far less value.

Many of the chapters in this book refer to the daily lives and the ongoing struggles for equality, dignity, and access for many disabled South Africans. This book is neither comprehensive nor the last word. We hope, though, that what we have done provides some recognition, from the research and academic sectors, of the importance of your lives – not only in terms of disability but also for all who are serious about democracy in South Africa.

The editors

Acronyms and abbreviations

AFUB	African Union of the Blind
AIDS	Acquired Immunodeficiency Syndrome
AIHW	Australian Institute of Health and Welfare
ARI	African Rehabilitation Institute
BCM	black consciousness movement
CBR	community-based rehabilitation
CEDAW	Convention on the Elimination of Discrimination Against Women
CMH	Cape Mental Health Society (SA)
CRC	Convention on the Rights of the Child
CREATE	Community-based Rehabilitation Education and Training for Empowerment
CRF	community rehabilitation facilitator
CSIR	Council for Scientific and Industrial Research
DeafSA	Deaf Federation of South Africa
DEC	Disability Employment Concerns
DICAG	Disabled Children's Action Group
DoE	Department of Education
DoH	Department of Health
DoL	Department of Labour
DoSD	Department of Social Development
DPI	Disabled Peoples International
DPO	disabled peoples organisation
DPSA	Disabled People South Africa
DSFSA	Down Syndrome Forum of South Africa
DSI	Danish Council of Organisations of Disabled People
DSM	*Diagnostic and Statistical Manual of Mental Disorders*
EEFP	Economic Empowerment Framework Programme
ESCAP	UN Economic and Social Commission for Asia and the Pacific
EWP6	*Education White Paper 6 on Special Needs Education*
GAF Scale	Global Assesment of Fuctional Scale
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICCD	Interdepartmental Co-ordinating Committee on Disability
ICF	International Classification of Fuctioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
ID	intellectual disability
INDS	*White Paper on an Integrated National Disability Stategy*

ISGSA	Individual Scale for General Scholistic Aptitude
IUPHC	Institute of Urban Primary Health-Care
LHR	Lawyers for Human Rights
MPDP	Membership and Policy Development Programme
MRC	Medical Research Council
NCCD	National Co-ordinating Committee on Disability
NCPPDSA	National Council for Persons with Physical Disabilities South Africa
Nedlac	National Economic Development abd Labour Council
Nepad	New Economic Partnership for African Development
NF	National Forum
NPHE	National Plan for Higher Education
NWC	National Working Committee
OSDP	Office on the Status of Disabled Persons
OT	occupational therapy
PAFOD	Pan African Federation of the Disabled
PANSALB	Pan South African Language Board
QASA	QuadPara Association South Africa
RURACT	Rural Disability Action Group
SABC	South African Broadcasting Corporation
SADI	South African Disability Institute
SAFCD	South African Federal Council on Disability
SAFMH	South African Federation for Mental Health
SAFOD	South African Federation of Organisations of the Disabled
SAHRC	South African Human Rights Commission
SANCA	South African National Council for the Aged
SANCB	South African National Council for the Blind
SANEL	South African National Epilepsy League
SAPS	South African Police Services
SASL	South African Sign Language
SASO	South African Students Organisation
SAVE	Sexual Assault Victim Empowerment Programme
SDS	Society for Disability Studies
SHAP	Self-Help Association of Paraplegics
Stats SA	Statistics South Africa
UDF	United Democratic Front
UPIAS	Union of Physically Impaired Against Segregation
VABS	Vineland Adaptive Behaviour Scales
WHO	World Health Organization

1 *Introduction and overview*

Leslie Swartz and Brian Watermeyer

If one approached a South African in the streets of Cape Town, Soweto or Polokwane, and asked him or her to provide associations to the notion of 'race', the answers one would gather would be rich, layered and heavily imbued with personal and political signification. The painful legacy of institutional racial discrimination shared by all South Africans, and the remarkable emergence of our nation from decades of conflict, have left an awareness of the oppressive appropriation of the race paradigm indelibly etched on the national psyche. Similarly, though more latterly, an awareness of gender as a potentially oppressive marker of differentness has grown amongst the South African populace, not least as a result of anti-sexist legislation being enshrined in the new constitution of 1996. A history tainted by the systematic and brutal marginalising of the majority of South Africans has left us aware of what it means to have one's identity, one's self devalued or excluded.

It is in the wake of this sweeping imperative towards recognition of our racist past that we, as South Africans, begin to explore and interrogate further markers of difference, which carry their own weight of discrimination. The idea of 'oppression' is firmly attached within South African colloquial culture to the idea of race; however, the marker of disability has yet to achieve this status. When confronted with the notion of 'disability', our minds do not turn instinctually to an exploration of possible modes of systematic discrimination and disadvantage. Rather, we remain strongly attached to modes of attribution which prize the explanatory system of the body, in accounting for the inequalities we see. In short, the story of disability – in our country as well as any other – is a story of social oppression.

This book aims to firmly establish this attributive link, within a uniquely South African context. Disabled South Africans are, collectively, amongst the nation's poorest, even within a country characterised broadly by atrocious levels of economic inequality. By exploring the predicaments of a range of disabled citizens, this book attempts to make an initial step in the forging of attributive links between modes of discrimination and unnecessary, systematic exclusion, and the economically and socially marginal destinies of the majority of disabled South Africans. As will be familiar to readers acquainted with the politics of disability, it is often deeply striking how, when one first begins to comprehend the reality that (for the most part), our society has been designed and constructed with only the interests of a portion of South Africans – the so-called nondisabled – in mind, overwhelming evidence of discrimination seems to begin bursting forth from one's surroundings. This is because this evidence of discrimination – the stairs, the printed word, the buses and trains, the inaccessible toilets, and the hostile or patronising attitudes, to name a very small few – remains invisible to those socialised within a disablist environment, until an awareness begins to be actively created. Similarly, our internal assumptions regarding what disability means, with their attendant ideas regarding what disabled people 'need', or 'should strive for', typically remain invisible and unquestioned within us until we are required to acknowledge and examine them. With *Disability and social change: A South African agenda*, the editors have aimed to begin – in the printed form – a dialogue, and a growing exploration, regarding what it means to be a disabled South African. This investigation necessarily involves not only an examination of the experience of disabled citizens, but, more importantly, an investigation of the ways in which physical environments, policies, practices, conventions, laws, beliefs and all other cultural artefacts serve to reproduce the disadvantage of those individuals designated as disabled.

As in many other parts of the world, the common-sense understanding of disability which predominates amongst South Africans could be described as falling within an individual model. In other words, the social and economic destiny of disabled people tends to be understood as the logical – and politically sanitised – consequence of impairment of the body. Such an understanding obviates any interrogation of the positioning or treatment of disabled persons by society, as it is at the level of the individual that the 'disability problem' is engaged with. Across the world, as the disability movement has gained momentum, such an individualising understanding of disability has come under damning criticism. Proponents of a new, social model approach to disability argue vociferously for the central consideration of discrimination and systematic exclusion as the definitive factors in shaping the social destinies of disabled people.

Beginning in the United Kingdom in the 1970s, the social model movement embarked upon a vigorous and ever-burgeoning critique of social responses to disabled people, thus also creating and developing Disability Studies as a coherent and discrete discipline. This approach viewed more traditional, individual understandings of disability as oppressive, in that the origin of disadvantage tended to be located within bodily difference. By identifying such bodily difference conceptually as *impairment*, and *distinguishing* this from the social and ideological notion of disability, early social model theorists underscored their contention that it is the social and political aspects of disability, not the bodily aspects, which afford the profound levels of disadvantage under which disabled people struggle. Instead of rehabilitation (the core business of what is termed the 'medical model' of disability), the call was for political emancipation, and the recognition of the myriad of forms of disablism which permeate our societies as the insults to human rights and human dignity which they are.

Social model theorists critically termed earlier individual accounts of disability – notably that traditionally propounded within biomedicine – as 'personal tragedy theory'. This was to point out the manner in which such accounts constructed disability as a random tragedy – as something which simply 'happens', by chance, to individuals, who thus are, and remain, exclusively responsible for their hapless situation of limited or non-existent participation in the production of culture within society. Instead, the social model theorists argued that disability is not random or natural, but a social accomplishment – disability is created by a disablist society, through the perpetuation of barriers to the participation of persons with impairments. It is with these barriers, and the disablist ideology which serves to reconstruct, perpetuate and obscure them, that the discipline of Disability Studies is concerned. Likewise, it is with the disabling aspects of South African society that the contributors to this book have turned their attention, in order to co-create one small step in the journey towards the creation of a barrier-free society.

Whilst this book may be viewed as a pioneering one, in the sense that it brings the South African disability arena into the realm of academic debate and critical examination, the disability movement in our country is a well-established one. Rooted within a close alliance with the now ruling African National Congress during the struggle against apartheid, Disabled People South Africa (DPSA) is a broad-based and vibrant political organisation of disabled citizens, which continues its efforts in mobilising change. Whilst South Africa is fortunate to have amongst its disabled population leaders, activists and campaigners who carry immense experience and knowledge of the nature of disability politics, a distinctly South African Disability Studies literature is yet to emerge and develop. This publication, thus, aims to provide a forum for South African researchers to be identified with, and contribute to, this literature, whilst also aiming to provide an opportunity for perhaps hitherto unpublished writers – disabled and nondisabled – to develop into contributors to the voice of disabled South Africa. The development of a vibrant culture of research discourse within the disability arena in our country will, in our opinion, form the essential basis for the driving of change within civil society. It is imperative, if change is to be fostered, that the predicaments of disabled people in our country be explored and documented, such that the very substantial human rights provisions of our constitution be elaborated and implemented via the securing of state accountability for the provision of citizenship rights.

Overview of chapters

Section 1 opens the debates by examining theoretical approaches to, and representations of, disability in South Africa – from formal theory to popular and colloquial culture. In Chapter 2, Schneider introduces the reader to the complex difficulties surrounding systems of defining and circumscribing disability, whereafter, (in Chapter 3), Priestley sketches both the theoretical and social roots of Disability Studies, as well as critically examining questions of the cross-hemisphere application and adoption of theory. Watermeyer (in Chapter 4) presents an argument for the utility – within the local context – of the psychoanalytic lens as a mode of interrogation of disablist society.

Section 2 shifts the focus to governmental and civil society responses to disability. Howell, Chalklen and Alberts set the scene in Chapter 5 with a historical account of DPSA, which attempts to locate the reader temporally and culturally within the South African disability milieu. The following three chapters introduce the reader to three key organisations working to foster inclusivity within our country. In each case, a senior staff member of the organisation was interviewed by two of the editing panel, whereafter the chapter was compiled, and finally altered and approved by the interviewee. The organisation described in Chapter 6 is the Office on the Status of Disabled Persons, a division of the Presidency, which is mandated to monitor and develop the integration of disability issues in the design and delivery of services across all government departments. The Africa Decade of Disabled Persons is managed from its secretariat in Cape Town, and seeks to foster continental co-operation towards disability equity – the activities of this initiative are described in Chapter 7. In Chapter 8, the mandate and activities of the South African Human Rights Commission are described, particularly as these pertain to disabled persons. Since disability discrimination is a human rights issue, the eradication of barriers to full inclusion of disabled people falls squarely within the ambit of this organisation. Another serious human rights concern throughout the world and in sub-Saharan Africa is that of the HIV/AIDS epidemic. In Chapter 9, Swartz, Schneider and Rohleder show how embryonic our thinking is in linking disability and HIV issues.

The final two chapters in Section 2 carry the issue of the state's role in securing the human rights of disabled people somewhat further. In Chapter 10, Dickman, Roux, Manson, Douglas and Shabalala present and interpret data regarding the judicial process surrounding the abuse of intellectually disabled persons, including issues relating to the provision of evidence. In Chapter 11, Heap and Morgans address the gross historical inequities in language policy surrounding the education of deaf children and adults in South Africa, which has rendered a current crisis in the availability of South African Sign Language (SASL) interpreters.

Section 3 turns to a variety of aspects of education, as these pertain to the oppression – and hence the liberation – of disabled people. In Chapter 12, Soudien and Baxen urge the reader to sceptically examine the discursive underpinnings of the popular notion of 'inclusion' in school education, as the South African schooling system finds itself at a crossroads, in the wake of the racially-based denial of education to disabled learners, which characterised the apartheid period. The debate then moves on, from school education, to tertiary institutions in South Africa, with the challenges for disability equity transformation being examined and described in Chapter 13 by Howell. An essential aspect of the development of disability studies in South Africa, and, more broadly, of the development of a culture of writing about disability across our country, is the provision of tertiary tuition in critical approaches to disability. In Chapter 14, Lorenzo, Ka Toni and Priestley describe the development, at the University of Cape Town, of a postgraduate programme in Disability Studies, which aims to reach a broad band of trainee professionals from a range of areas, thus, over time, cementing disability issues philosophically within the realm of broad inclusivity. A comprehensive strategy for literacy education amongst Deaf community members – against the backdrop of the language policy inequities and atrocities outlined in Chapter 11 – is described by Glaser and Lorenzo in Chapter 15.

Section 4 addresses the area of poverty and social security for disabled persons. First, in Chapter 16 Emmett volubly demonstrates the assertion that disablist oppression, as well as impairment, are not random occurrences, but intricately patterned in terms of pre-existing systems of power within society. Specifically, the relationship between disability and the key social categories of race, gender and class are examined, rendering clear and powerful trends. In Chapter 17 Swartz and Schneider discuss the complexity of issues surrounding the provision of social security for disabled South Africans. The key issue of the assessment of disability, as this pertains to various sources of economic security, such as state disability grants and insurance claims, is thoroughly handled by Watson, Fourie and Andrews and her colleagues in Chapter 18.

Section 5 gathers five chapters concerned with the complex politics which permeate service provision relationships surrounding disability. In Chapter 19, Mgwili and Watermeyer demonstrate how the psychoanalytic model (outlined in Chapter 4) may be used, as they interpret and analyse the responses of health-care professionals to physically disabled users of reproductive health clinics. The relationship between the disability rights movement and 'rehabilitation' professionals has historically been a fraught one; Rule, Lorenzo and Wolmarans in Chapter 20, describe a community-based rehabilitation strategy which is aimed at integration and empowerment within the community context. In Chapter 21, Siyabulela K and Duncan, in a brave and innovative contribution, collaborate to examine the experience of a South African psychiatric services user, juxtaposed with the reflections of a highly experienced mental health-care professional. McKenzie and Müller in Chapter 22, develop the debate surrounding the politics of rehabilitation, through the experience of parents of disabled children, and the vexed nature of relationships with therapeutic professionals.

Section 6 invites the reader to consider the issue of disability in relation to human spaces; physical as well as economic and philosophical. Napier, Coulson and Matsebe begin Chapter 23 by providing a rich account of physical spaces in which a population of South African disabled respondents find themselves. This moving account leaves the reader in no doubt as to the capacity for physical spaces to dehumanise. A substantial population of disabled people in our country have, in one important sense, no space; these are the homeless disabled, with whom Mji gathers qualitative data in a rich and personal account provided in Chapter 24. Seirlis in conversation with Swartz, continues the theme in Chapter 25, recounting his experience of the challenges facing disabled people attempting to establish a place in the economy through entrepreneurship – an option often necessitated by a range of exclusions which impact on participation in other professions. Stadler in Chapter 26 and McDougall in Chapter 27 address issues concerning the perceptual spaces we all inhabit in different ways – those of the media. It is fitting that a book centrally concerned with putting disability issues on the agenda in South Africa concludes with these considerations of how disability is portrayed in the media.

A note on the style of this book

This book represents a diversity of styles, voices and approaches to disability concerns. Disability is a diversity issue. It goes to the heart of whether we can build a society which tolerates and celebrates difference. In this book, we have deliberately invited authors to write in a range of styles. Contributions read in different ways, from the more formally academic, to the more personal, and even to the style of interview format. We believe that this diversity of voice and style reflects something South Africans should welcome – a common area of debate engaged with in many ways, allowing for new forms of discussion and cross-pollination of ideas. Some authors traverse the same paths – for example, those of the social model, and those of human rights issues – but in slightly different ways. We have intentionally not edited out what may appear to be repetitions and, perhaps more importantly, inconsistencies, across chapters, because the nuances of difference across different chapters are important.

This makes for a book which may read less fluently and less coherently than may be expected. We make no apology for this. To engage with the complexity of disability issues requires an active response from the reader, and requires some readiness to live with debate and uncertainty. We have chosen not to homogenise the contributions we have received into an easily palatable whole, but rather to invite the reader to engage both with what different contributors say and with the spaces implicit amongst the contributions. Disability Studies is not about the rapid demarcation of a new area of expertise, a new discipline which can jostle for space against others in an already overcrowded landscape. On the contrary, it is about challenge, debate, uncertainty and new forms of academic production. We hope that this book, in all its complexity and unevenness, does challenge and provoke. We hope for response as diverse as the contributions seen here.

Section I
Theoretical approaches to disability

2 *Disability and the environment*

Marguerite Schneider

Until the latter part of the 1900s, disability was understood to be entirely a problem of the individual, with the focus of intervention thus being solely on specific individuals. This view is associated with the medical model of disability, or an individualistic perspective. As many other chapters in this volume show, since the 1970s this way of thinking about disability has come under sharp criticism from members of the disability rights movement (Oliver, 1990; Swain et al., 1993). These criticisms are reflected, for example, in documents such as the *Integrated National Disability Strategy* adopted by the South African government in 1997 (ODP, 1997; see also Chapter 6, this volume).

With the rise of the disability rights movement, the perspective changed and the problem is now understood to be situated in the environment, with interventions being environmental rather than individual. There were, and still are, many people who maintain the individualistic perspective and do not see the central role of environmental factors in creating disability.

However, the environment's definitive influence in creating disability has now been firmly established and is seen as integral to the definition of disability. Disability is an experience that arises out of the interaction between a person with a health condition and the context in which they live. If the environment changes, then the experience of disability will also change. Disability thus includes external environmental factors and internal personal factors. In effect, one must look at both the individual and the environment if one is to describe a person's experience of disability accurately and comprehensively. The *International Classification of Functioning, Disability and Health* (ICF) refers to this as the biopsychosocial model (WHO, 2001).

Disability can no longer be seen as a static feature of an individual but rather as a dynamic and changing experience determined by the changing nature of the environment. This change from focusing on the individual to focusing on the individual plus the environment has important implications for measuring and researching disability, as well as developing policies on disability.

This chapter looks at the notion of environment in some detail and uses examples from a South African disability survey to show some measures and effects of environmental factors in creating the experience of disability for people in South Africa. The chapter concludes with some thoughts on priorities for the future.

What is the environment?

The environment includes all aspects of a person's external world – the physical world (assistive technology, accessibility, level of distractions), the attitudinal world (how people and society view disability) as well as the social world and how it is organised (services, societal norms, policies, systems for implementing and monitoring policies). Environmental factors can be described using a classification of domains that include all of these aspects. The ICF provides such a classification which covers the major areas of products and technology, the natural environment and human-made changes, support provided by others, attitudes of individuals and society, and services, systems and policies (WHO, 2001). Each of these major areas has a range of domains within which further detail can be elaborated (Schneider et al., 2003).

Environmental factors can have one of two effects. Firstly, they can facilitate a person's functioning, such as through the use of a walking stick, availability of ramps, positive attitudes, and/or inclusive policies and availability of services. Secondly, environmental factors such as lack of services and assistive technology, inaccessible buildings, negative attitudes and discriminatory policies that exclude and isolate people with impairments can create disabling barriers. Any measures of disability must include an assessment and description of the environmental factors and their role as facilitators or barriers.

The ICF defines disability as the outcome of the interaction between a person's health condition and the context in which the person finds themselves. The context includes both factors external to the person (environmental factors) and those internal to the person (age, sex, education and skill level, coping style, personality). In order to fully describe the interaction and understand the relationships between all the different elements that lead to the experience of disability, we need information on the elements listed below. These apply both to negative and positive outcomes.

- The person and their personal characteristics;
- An external environment described both by the person and by an objective outsider;
- The process of interaction between these different elements (e.g. whether environmental factors (EFs) are facilitators or barriers, how the EFs interact with each other);
- Outcome of the relationship – either as disability or functioning (Schneider et al., 2003).

If any one of the first three aspects changes, the outcome will also change. The obvious example is the wheelchair user who experiences severe disability when confronted with an inaccessible environment. The same person will experience very little disability, if any, when confronted with an entirely accessible and supportive environment. For this process of interaction to result in an experience of disability, there must be a health condition at the start, as it is the interaction of that health condition (or a person with a health condition) with the context which creates the outcome. This health condition may not make the person feel ill or need medical care. For example, blindness is a permanent health condition but does not require ongoing medical care and does not make the person feel ill.

It is important here to differentiate between two ways of understanding a health condition. On the one hand, a health condition is a feature of the individual which interacts with the context in which the person lives to create disability. This is similar to the notion of an individual experiencing racism because of their skin colour or ethnic group membership. The skin colour or ethnic group membership is the precondition to experiencing racism, in the same way as the health condition is the precondition to experiencing disability. The health condition and race/ethnic group are both aspects that give rise to being perceived as different.

On the other hand, there is the issue of whether the health condition needs intervention from the health service or not. This is not an element of deciding whether the person experiences disability or not. It is merely an aspect of intervention planning once the experience of disability has been identified.

Environmental factors that lead to disability are different to those environmental health risks that lead to a person developing a health condition (e.g. asbestosis from working in mines). However, there is overlap, with some factors acting both as environmental health risks (before onset of the health condition) and environmental barriers for disability (after onset of the health condition). An example is air pollution, which is a risk factor for causing respiratory problems as well as being an environmental barrier for someone who already has respiratory problems. A person with asthma who lives in a polluted area will have their difficulty with breathing aggravated by the pollution, possibly leading to difficulty in walking.

Levels of functioning

The outcome of the interaction process can be described at three levels of functioning: the body, the person and the societal level (WHO, 2001). Each of these levels and the impact of the environment are discussed below.

The physical level deals with individual body parts, organs or systems. For example, an amputation is an impairment of the lower limb structure, and a memory loss is an impairment of mental functions. Often impairments at the physical level are manifestations of an underlying health condition or problem. For example, schizophrenia is a health condition which is diagnosed by observing the person's behaviour rather than with a laboratory test. The person will show impairments in different domains of mental functions (e.g. thought function) and this will be reflected in their behaviour. Similarly, hay fever is the manifestation of an underlying allergic condition.

Environmental barriers and facilitators impact on the physical level in a number of ways. Firstly, environmental barriers can trigger a manifestation of a health condition. For example, a person with allergies will only experience impairments of the respiratory system (physical level) when allergens are in the environment. A person who has a tendency to experience depression might only have manifestations of this health condition (e.g. impairments of mental functions) when encountering an environment of stress and other precipitating factors.

Secondly, lack of services can be a barrier, such as the worsening of an impairment resulting from lack of medical or surgical treatment (e.g. lack of adequate emergency care for people with spinal cord injuries, or a lack of psychiatric services and medication). The person with a spinal cord injury will have a more severe impairment if not treated rapidly after the initial injury; a person with a severe psychiatric illness may experience increasing difficulties if the necessary medication and support is not available.

The same environmental factors can be facilitators if they impact in a manner that allows the person to manage their health problem without further deterioration. The person with an allergic condition will not experience any impairment if allergens are not evident in the environment. Similarly, the person with depression might not experience any of the impairments associated with this health condition if their environment has little stress, and the person with a spinal cord injury will have the least permanent impairment if they receive rapid and effective emergency treatment. The person with a severe psychiatric condition will have fewer impairments of mental function if the necessary treatment and support is available.

Personal level of functioning

Here we are addressing the whole person, undertaking or executing complex activities necessary for daily living. These include activities of learning, handling stress and making decisions, communicating, mobility, personal interactions, personal care, house work, working, attending school, taking part in recreation, and so on.

The personal level considers the person's inherent ability to execute these activities without significant interference of environmental factors. In other words, we are looking at what the person can do without the use of assistive technology, for example, or how well a person can learn in an environment that does not have too many distractions.

The impact of environmental factors on this level of functioning includes aspects such as the availability of rehabilitation services to improve, for example, the ability to walk by increasing muscle tone, balance, and so on. Another example would be the reduction of pollutants in the environment. This will reduce the severity of an asthmatic person's symptoms and hence improve their ability to undertake activities such as walking.

Societal level of functioning

The third level of functioning is the societal one. This level considers the same domains of activity as for the personal level, but this time with the impact of the person's environment being taken into account. In other words, we are looking at what the person does or does not do as a result of their environment. For example, a person with a psychiatric illness who can work (i.e. can maintain employment at the person level of activity) might not in fact work (i.e. does not work in their environment at the societal level) because of attitudinal barriers from employers. This person can work but does not do so because of environmental barriers. A facilitating environment would be one where the person has an employer who provides an appropriately accommodating environment at work. Another example would be a person with a spinal cord injury who cannot move around (i.e. cannot do the activity). If this person has all the necessary environmental facilitators (e.g. accessible buildings, supportive family and friends, necessary assistive technology), he or she will in fact move around quite effectively. In this case, at the personal level, the person cannot do an activity, but in their environment (societal level) they do in fact participate in the activity, because of facilitators. In summary, the main impact of environmental factors is at the societal level, but the environmental impact at the other levels should not be ignored.

The examples provided are largely focused on the immediate or micro environment of the person (e.g. assistive technology, or attitudes of individuals towards the disabled person). However, there are many environmental factors that operate at a much broader or macro level. Examples of these are facilitating national policies that focus on reducing discrimination (e.g. the Employment Equity Act in South Africa, which pushes for the employment of disabled people) or hindering policies that create barriers for disabled people (e.g. building regulations that do not require the built environment to be accessible).

Lack of environmental consideration

Following on from the way in which the environment impacts on different levels of functioning, let us reflect on the problems that we would encounter if we did not take environmental factors into consideration. The following are some examples of such problems encountered and the benefits reaped when they are included in the analysis and management of a person's situation.

The first example is of a person with a spinal cord injury who has undergone rehabilitation in a specialised unit. The individual is sent home without a thorough investigation of their home circumstances. The skills learnt in the rehabilitation unit are not transferable to the home context as the person does not have the necessary infrastructure, such as an accessible toilet and bathroom, and has little support from their family. The outcome is an experience of severe disability for the person, the development of pressure sores and eventual readmission to hospital. This outcome could have been avoided if a thorough analysis of the home environment had been undertaken, necessary adaptations made and training provided to the individuals's family.

The second example is of a person with a moderate to severe hearing loss, which results in particular difficulty in hearing in noisy situations and discriminating between different speech sounds. The intervention required must consider the context of the person's home, work and recreational environments to ensure that all possible adaptations are brought about to allow the person to participate in communicative and other related activities. These adaptations could include training others in how to maximise lip-reading, reducing extraneous noises as much as possible and enhancing the light to maximise lip-reading. If these environmental factors are not taken into account, interventions at the individual level (fitting of a hearing aid, enhancing lip-reading skills) will have only limited benefit. If the person is prevented from participating fully in work, home and recreational activities, he or she may withdraw from these activities and become isolated. This could also lead to secondary impairments such as depression. The intervention has to occur both for the individual and within the environment to obtain the most beneficial outcome in terms of functioning.

The third example is of a person with a moderately severe psychiatric illness. This person needs the environmental facilitators of access to psychiatric services, including medication provision and monitoring, as well as a home, work and recreational environment that is supportive and inclusive. If work colleagues, family members and friends are able to notice signs of symptoms worsening, this can assist in preventing a full-blown attack. Furthermore, positive attitudes can ensure that the person's strengths are appreciated and used to overcome the difficulties he or she experiences.

The above examples highlight the importance of considering and including environmental factors in the analysis of the disability experience of individuals, and in the compiling of comprehensive intervention plans for the individual to participate in all activities of life. They also provide some insight into how the disadvantages and inequalities experienced by so many disabled people arise.

If the environmental factors (micro and macro) are not carefully considered, we will not understand how to start redressing these disadvantages and inequalities experienced by disabled people.

Environment at a national level

The importance of considering environmental factors is not only relevant at an individual level but also at a national level. Information on environmental factors in this context is crucial for developing relevant policies and systems for monitoring these. Policies must be inclusive of people with impairments to ensure that they are able to manage these impairments without experiencing isolation and lack of independence. Independence here refers to a person's ability to make choices about when and how they undertake activities, even if she or he is in fact unable to do the activities without assistance. For example, a person with difficulties in mobility may not move independently without assistance from others and assistive technology, but can be independent in choosing when and where they want to move to if they have the necessary personal or technological support.

This section reviews some of the results of the South African baseline survey on disability undertaken in 1998, which dealt specifically with environmental barriers and facilitators and their impact on people's experience of disability. The study was a national, population-based survey of 10 000 households. People identified as having limitations in one or more domains of activity (seeing, hearing, communication, mobility and getting around, daily life activities, intellectual ability, learning, emotional or other), were asked a further series of questions to understand their experience of disability.

The results presented below highlight some of these experiences. Only selected and very general aspects are presented to make the point about the role of environmental factors, rather than presenting a comprehensive report on the survey findings. The reader is referred to the full survey report for further details on the methodology and the results (Schneider et al., 1999).

Services as environmental factors

The respondents were asked whether they had ever needed any services and whether they had received any of the services they needed. The services asked about included health services, assistive devices, medical rehabilitation, traditional healer services, welfare services, counselling services for self or family, educational services and vocational training services. The results indicate that health services were the most commonly received when needed, with 76 per cent of those needing this service in fact receiving it. Hence, assuming that services received were adequate and appropriate, health services impact as an environmental facilitator generally, with the lack of the service being a barrier to 24 per cent of the population. Similarly, for people who needed a traditional healer, 62 per cent who needed this service received it.

The situation changes dramatically for the other services requested. Welfare services (only 22 per cent received), counselling services for disabled person (only 22 per cent received), counselling services for family of a disabled person (only 6 per cent received) and educational services (23 per cent received), were all services that were clearly lacking. The lack of these services impact as an environmental barrier.

The low percentage of people who actually received welfare services has a significant impact on the number of people accessing disability and care dependency grants from the state. This in turn has an impact on the experience of these people in that they have little chance of being economically independent.

Assistive devices and personal assistance as environmental factors

The respondents were asked to rate the severity of their disability experience without any assistance at all, and with assistive devices and personal assistance individually and combined. The results show a clear decrease in severity with the addition of one or more types of assistance. With no assistance, only 6 per cent of respondents rated themselves as having no problem. With use of assistive devices, this increased to 11 per cent, and with personal assistance, to 13 per cent. With both assistive devices and personal assistance, the percentage of people reporting no problem increased to 24 per cent. This demonstrates the significant environmental impact of assistance on a person's experience of disability. Assistive devices and personal assistance are both facilitators, having a positive impact on a person's functioning.

If we look at the percentage of respondents who rated their experience as severe, we find a decrease from 58 per cent of respondents with no assistance to a mere 4 per cent with both assistive devices and personal assistance. This further confirms the facilitating role of assistive devices and personal assistance.

Level of education

The section on education was only administered to those respondents who had an onset of disability before or during the period of formal education (i.e. before the age of 18 years). The level of education reached is a feature of the individual (a personal factor), but it is one that is determined by the impact of environmental factors at an earlier stage. Lack of access to educational services or educational services that do not meet the needs of learners are environmental barriers that create an outcome of poor education for adults.

When considering all respondents together, including those with onset after school-going age, there is a marked difference between the highest level of education attained by disabled people versus the general population. While 33 per cent of the disabled people only obtained primary school education, 24 per cent of the general population has reached this level, showing that disabled people are more likely to stop schooling early. Only 10 per cent of the disabled people reached matric, while 23 per cent of the general population reached this level. The figures for the general population are taken from the 1996 Census in South Africa (Stats SA, 1998). These differences would be more marked if the analysis was limited to people with onset of disability before or during school-going ages.

As we saw with the services above, the number of people needing educational services who actually received them was very low. This was further substantiated by the fact that a high proportion of respondents did not attend school, especially at the preschool and high school stages of education. Of the respondents who were disabled before or during preschool age, 48 per cent did not attend preschool. Similarly, of those disabled before or during high school age, 47 per cent did not attend high school. This suggests that the lack of education services has resulted in low school attendance.

When respondents were asked to give reasons for not reaching their desired educational level, common reasons given included shortage of money, lack of schools catering for their needs, and family pressure. All three of these reasons are examples of environmental barriers that prevent the people from participating in education. The outcome of the interaction between people with a health condition and environmental factors is one of poor functioning in relation to the domains of learning and education.

Personal factors

While environmental factors are crucial in understanding how disability is created, personal factors also play a significant role. Together, environmental and personal factors make up the context in which the person lives. When personal factors such as race, age of onset and number of domains in which the person has difficulty are considered, the survey results indicate that these play a crucial and significant role in determining the outcome of disability. The situation in South Africa at the end of the 1990s shows that the disadvantages experienced by black disabled people are consistently worse than these experienced by white disabled people. This highlights how the personal factor of race will add its impact to that of disabling environmental factors to result in a compounded outcome of disadvantage and inequality.

When considering a series of questions analysed together to obtain an integration score, age of onset and number of domains affected were the two most significant factors determining level of integration within the family, based on a loglinear analysis. For this latter example, it is important to note that further research is needed to really understand what environmental factors are playing a role in this outcome of integration. For example, early onset was associated with lower levels of integration compared to later onset. This could be a result of lack of services, negative attitudes and lack of support, which together create an outcome of poor integration. Hence, the survey results do not provide a conclusive answer on how the outcome is determined, and further research using a detailed framework of environmental factors, is required.

Comparisons with other countries

A report by the Australian Institute of Health and Welfare (AIHW) on the use of aids and the role of environment (Bricknell, 2003) suggests that lack of services is also an issue in a developed country like Australia. The unmet needs identified included 'a limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and the decline in equipment supply from traditional dispensing units such as hospitals' (Bricknell, 2003, p. 15). The AIHW report also highlights the lack of systems for provision of financial assistance for obtaining assistive devices, which makes it difficult for people to access the devices. This highlights the different levels of the environment, where the actual assistive devices are part of the close or micro environment of the person while the systems are part of the more distant or macro environment. However, these two levels are intricately related in their impact.

In the USA, a policy of Universal Design is advocated in efforts to make health-care systems, assistive technology and community activities more accessible. This is seen as a new strategy for societal inclusion (Duncan, 2003; Mace, 1997). Universal Design is defined as 'the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design' (Mace, 1997, p. 1). This definition highlights the role of Universal Design as an environmental facilitator, not only in terms of making environments more accessible, but by starting from the principle of designing for everyone, with or without impairments or activity limitations. This is an inclusive policy which is part of a macro environment that benefits the whole population.

The same report lists the major barriers restricting the participation of disabled adults in social activities as inadequate transport, architectural barriers, policy and practice barriers that lead, for example, to unemployment or underemployment of disabled people, communication barriers, attitudinal barriers, unsafe, inaccessible and segregated low-income housing, and inadequate school-based opportunities for social participation during and after hours (Mace, 1997).

Priorities for the future

The role of environmental factors in determining outcomes in terms of disability or functioning has been recognised as crucial and steps must be taken to ensure that the description, measurement, monitoring and evaluation of environmental factors is undertaken systematically. The priorities for the future should include:

- A clear and consistently applied definition of disability and the components that make up the experience of disability;
- A comprehensive description of environmental factors and their role as facilitators or barriers;
- The development of policies that abide by principles of universal design, to ensure the inclusion of disabled people in all aspects of life.

We need relevant and accurate measures of disability, which include the role of environment as an integral component to monitor and evaluate the necessary levels of intervention required for effective participation by disabled people in all aspects of life.

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3 *Developing Disability Studies programmes: the international context*

Mark Priestley

The essence of this book is to offer a distinctively South African agenda for thinking and practice on disability and social change – an agenda for the liberation of disabled people. Knowledge and ideas play an important role in any liberation struggle and educational programmes in Disability Studies have a significant contribution to make. The way we understand disability and the way we learn about it affects the way we respond to disabled people in society. However, the social, economic and political factors affecting disabled people in different countries vary considerably. Effective educational programmes must address this diversity. Therefore, an agenda for social change in South Africa must be based on an understanding of disability from a South African perspective and our Disability Studies programmes must reflect local need, local knowledge and local experience. As US disability activist Judy Heumann (1998) argues, the global struggle for disabled people's inclusion requires the development of knowledge at national and local levels.

Yet, in the modern South Africa, as elsewhere in the world, knowledge and social action are not simply national concerns. National agendas for change are influenced also by regional and global factors. Ideas, images, people and money move ever more easily across national borders in a rapidly globalising economy, and this is certainly true in Disability Studies. South African disability activists, policy makers and academics have links with many parts of the world, through international communities, networks and collaborations (indeed, the writing of this chapter arose from one such collaboration). The disability agenda in South Africa is therefore influenced by much that has been learned elsewhere. But there remains much to be learned. We need to look more closely at what other countries are doing and think about ways that we can benefit from the different political and philosophical approaches that other countries are taking. We need to look at work being done in other parts of the world so that we can learn from the strategies other countries are developing. Similarly, other countries have much to learn from developments in South Africa. We should deepen the exchanges that this kind of reciprocity encourages. As Vic Finkelstein argues:

> In my experience it is not possible to give a global response to the vastly different situation facing disabled people in majority world countries. Answers do require direct contact with each situation and engaging disabled people in a dialogue about priorities and solutions.

> …I think the more we become familiar with disability-related activities in different countries the more we discover that there are an awful lot of things going on which we in the developed world should also learn about. (Finkelstein, 2001a, p. 15)

In recent decades, Disability Studies has become a vibrant and distinct international academic discipline. The discipline can now claim a large body of literature, a number of international journals and an increasing number of university courses at both undergraduate and postgraduate level. As with so many other fields of knowledge production, the new Disability Studies literature has been dominated by contributions from authors and publishing houses in rich countries and by material written in English. In particular, writings from Northern Europe, North America and Australia have focused attention to the experience and resistance of disabled people in those parts of the world. Much of this work has great potential for thinking about disability in the South too. Yet it is equally important to retain some caution about the ease or desirability of transferring Northern solutions to Southern problems (Fanon, 1967; Wirz & Hartley, 1999). After all, Africa is no stranger to the legacy of European imperialism and there are risks in building new educational programmes based on the cultural and economic assumptions of the North. As Majiet points out, from a South African perspective:

> If one looks at the [disability] agenda, we can ask who sets that agenda globally for human rights. My impression and humble opinion is that this agenda is very much set by the North and that we need to take issue with that. (Majiet, 1998, p. 1)

So, to further an agenda for disability and social change in South Africa we need to ensure that Disability Studies programmes are informed by developments in an international context, but that they remain rooted in knowledge and action for change in South Africa (and more broadly within the southern African region). We need to question where ideas about disability come from and how they can be used to best effect. Whose agenda is it? And whose should it be? This chapter outlines some of the ideas, resources and politics that have shaped Disability Studies programmes in the North and examines their implications for developing parallel programmes in South Africa.

New ways of thinking about disability

The first and most important point to consider is how our ideas about disability have changed. It is impossible to plan programmes in 'disability studies' without first thinking about what 'disability' means. The development of a new and critical Disability Studies (as in Britain or North America for example) has been driven both by the political activism of disabled people and by new ways of thinking about disability in a social world. Critical Disability Studies, as we now know it in the

North, was founded on a dramatic shift in thinking. We have moved a long way in the past 30 years – away from a focus on the physical condition of disabled people and towards a focus on tackling the oppression that disabled people experience in society.

To understand the significance of this change it is important to think about the kinds of definitions and concepts that were dominant in the early years of Disability Studies. For example, if we look back to the International Year of Disabled People in 1981, the dominant way of thinking about disability was based on knowledge about medicine and rehabilitation. At that time, the definitions that guided the study of disability were primarily those of the World Health Organization's International Classification of Impairment, Disability and Handicap (ICIDH). Historically, 'disability' meant something very specific in this model – an individual limitation that prevented a person with 'impairment' from performing everyday tasks in the normal way, often resulting in a social 'handicap'. So, as Oliver (1996) points out, the dominant model was a causal one. The traditional view within social science and medicine was to assume that the social disadvantage experienced by disabled people was an individual problem caused by impairment. If the problem was an individual one, then the most appropriate social response was either to correct the impairment or to help the person 'come to terms' with their assumed disadvantage, by negotiating different (less valued) social roles. Everything began from impairment and biological difference. It was the biological deficit that caused the restriction of activities that resulted in a loss of normal social roles. Consequently, it came as little surprise to rehabilitation professionals and policy makers that disabled people appeared to be socially excluded and dependent on the care of nondisabled people in society. If the problem for disabled people was seen as their impairment then the only solution was to manage or correct the impairment.

This approach is a very long way from the kinds of models and definitions we use in Disability Studies today. Today we would regard this model as quite negative and largely unhelpful to disabled people. The new Disability Studies challenge the idea that disability is biologically determined, or that it is a property of the individual (Thomas, 1999). A social interpretation of disability turns this whole idea on its head by relocating the 'problem' from the individual to society. With this shift in analytical focus, disability could be seen as a social problem caused by social processes. So, when we talk about 'disability' in the context of Disability Studies programmes we are using a very different definition to the kind used in the past by medicinal and rehabilitation professionals. Disability, in this sense, is clearly defined by disabled people's organisations as '…the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Disabled Peoples International, 1982).

Understanding this approach also helps to explain why many within the disabled peoples movement and the new Disability Studies have been resistant to talking about 'people with disabilities' (Titchkosky, 2001). For example, as Clark and Marsh (2002, p. 2) point out:

> The British civil rights movement has rejected the term 'people with disabilities', as it implies that the disabling effect rests within the individual person rather than from society. The term 'disabilities' when used in this context refers to a person's medical condition and thus confuses disability with impairment. In addition it denies the political or 'disability identity' which emerges from the disabled people's civil rights movement.

After all, if we adopt the definitions developed by disabled people's organisations then it is not the person who has the 'disability' (hence the term 'disabled people' used in this chapter and in Disabled People South Africa), but that disability is caused by the way society fails to include people of difference. Then the most appropriate response must then be to transform the society that creates this oppression. Moreover, armed with this new way of thinking about the problem, disabled people may be less likely to look to the traditional authority of medical and 'caring' professions for the solutions to their problems and instead to those who are campaigning for social transformation and civil rights. This is indeed a radical shift in thinking, but one that should be familiar to those with experience of social transformation in post-apartheid South Africa.

These contrasting ways of thinking about disability have been developed more formally in the Disability Studies literature as two competing models – commonly known as the individual model and the social model. Grasping the underlying distinction between individual and social models of disability is therefore the key to understanding the development of Disability Studies in its Northern context. The distinction between individual and social models of disability was first articulated in a formal academic context by Mike Oliver (1983) and has been developed at length since then. However, the original concept came from ideas developed within the disabled people's movement. In particular, Oliver drew on a distinction made in the 1970s by activists within a small British organisation called the Union of Physically Impaired Against Segregation (UPIAS). In analysing their situation, disabled people within UPIAS argued that:

> In our view, it is society which disables… Disability is something imposed on top of our impairments; by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS/Disability Alliance, 1976, p. 3)

From this definition flows much of what we now recognise as the new Disability Studies. There is a clear separation of impairment from disability and clear assertion that disability has social causes rather than biological ones. There is also recognition that disabled people are not simply individuals, but an oppressed and disadvantaged group within society. There is clear evidence that the UPIAS approach, with its social interpretation of disability, has directly influenced key academics as well as activists within the international disability movement. There have been other influences too, flowing from disabled people's increasing political awareness and struggles around the world (Charlton, 1998). Activists from Africa, Latin America and Asia were closely involved in founding the international disabled people's movement and in taking these ideas forward through its development.

In the context of this book, it is also worth noting that one of the leading figures in developing the UPIAS arguments in Britain was Vic Finkelstein – a disabled white South African, exiled in England following a banning order for his opposition to apartheid in the 1960s (see Finkelstein, 2001a). Indeed, Finkelstein drew directly on the analogy of South African apartheid to show how disabled people in Britain (and elsewhere) were systematically classified as a separate group and how they were systematically segregated from full participation in nondisabled society (for example, in residential institutions, segregated schools, special buses, sheltered employment, and so on). Thus, the apartheid system created within the welfare state and policed by its 'caring' professionals left many disabled people segregated and 'socially dead' to the world at large. Adopting a social interpretation of disability allowed disabled people to both challenge the idea that their segregation was in any way inevitable and to focus on strategies for social change.

Like South Africans under apartheid it is not a matter of research or debate whether we are socially dead (whether our 'disabilities will be permanent' in Nelson Mandela's memorable phrase). Rather, the central questions are what to do about oppression and what is the route to emancipation? (Finkelstein, 2001a, p. 7).

To summarise then, contemporary approaches to Disability Studies have tended to adopt a more critical interpretation of disability that emphasises that disability is a form of social inequality or disadvantage resulting from oppressive social structures and processes, rather than from individual difference or biology. This social interpretation provides new ways of thinking about disability and offers different ways of understanding and learning about the situation of disabled people in society. Disability Studies is about understanding how disabled people become oppressed and about understanding the social relations and barriers that prevent their full participation, equality and citizenship. It is also about understanding strategies for challenge and resistance to that oppression.

Studying disability

The next challenge is to consider how changing ideas about disability affect the development of educational programmes in Disability Studies. Bearing in mind the concerns outlined at the beginning of this chapter, it is also important to question the transferability of international models and theories to educational programmes in southern Africa. Wirz and Hartley (1999) raise similar challenges in relation to partnerships between Northern universities and community based rehabilitation initiatives in the South and identify achievements and failings on both sides. On the one hand, while some Northern disability activists and academics may have pioneered theoretical frameworks, few have applied themselves to explaining the situation of disabled people in the South. On the other hand, while many creative and effective strategies for local change have been developed by Southern activists and practitioners, few are widely known about or adequately theorised outside of southern Africa. They conclude that:

> The challenge for Southern colleagues is to determine which lessons from the North are appropriate, and how. The challenge for universities in the North is to develop genuine partnerships and actively listen to and learn from colleagues in the South. (Wirz & Hartley, 1999, p. 103)

So, we might well ask what Disability Studies programmes in southern Africa can gain from models and approaches used in other parts of the world. The language of the social model is internationally widespread in Disability Studies but is still regarded by many as a particularly British approach (in its strict sense at least), while the term ‘disability studies’ originated in the USA with the naming of the Society for Disability Studies (SDS) in 1986. The SDS mission statement is quite helpful in identifying a focus for Disability Studies:

> Disability Studies encourages perspectives that place disability in social, cultural, and political contexts. Through our work we seek to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to contribute to social change. (SDS, 2004)

There are three points of focus for learning and teaching here: an understanding of disability, an awareness of disabled people’s experiences and a contribution to social change. These broad principles are widely shared by those claiming the label of Disability Studies for their educational programmes. However, there are considerable differences of interpretation and approach (Albrecht, et al., 2001; Linton, 1998; Oliver & Barton, 2000; Priestley, 2003). For example, there are differences of emphasis in explaining how societies can disable people. While some authors prefer to emphasise the role of discrimination in cultural traditions and values, others place more emphasis on economic arguments or on the role of state policies or institutions (Gleeson, 1997; Priestley, 1998). Similarly, Disability Studies programmes in southern Africa face the challenge of determining how disability may best be understood and represented in its regional context. Understanding how the diverse cultures and political economies of the region impact on disabled people’s lives and how these processes compare with other regions of the world will require much new research and discussion. But that, in turn, should provide ample opportunity for the development of a vibrant new community of South African disability scholars (as evidenced by the contributions in this book).

As the first part of this chapter illustrates, critical approaches to Disability Studies have been based on a fundamental re-definition of what disability means. Depending on the kinds of models adopted, Disability Studies programmes will approach the subject in very different ways. Programmes based on individual model thinking will tend to focus the students' attention on understanding the assumed functional limitations of individual disabled people; programmes based on social model thinking will focus on understanding the limitations of disabling societies and on strategies for removing barriers to social participation.

For example, there is a strong tradition in medicine and therapy concerned with measuring and investigating the limitations of the body. Similarly, there is a strong tradition in psychology and counselling that also locates disability as a property of the individual, with an emphasis on how disabled people cope with their 'limitations' and how they negotiate social roles. It is worth repeating that both these approaches assume that disability is a property of the individual. They are individual model approaches because they assume that it is the individual that has the problem. In this sense, they do not represent what we might usually think of as Disability Studies.

If we consider the alternative, then a social model approach might include studying oppressive social structures, environmental barriers and material or economic relationships of power. The emphasis here is on investigating the limitations of environments and social structures rather than individuals. To summarise:

> disability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society. (Oliver, 1996, p. 33)

From a social model perspective, the task of Disability Studies is to focus on the limitations and barriers within society rather than the limitations and barriers within the individual. In this way, Disability Studies is not simply theory; it may be an academic discipline, but it is also a political project that aims to remove disabling barriers and to support the liberation struggles of disabled people. That project is intimately connected with the knowledge and experience of disabled people. Indeed, the social model approach is not simply an academic construction – it has emerged from the political activism of disabled people, based on their experiences of discrimination and oppression. However, as Finkelstein (2001b) points out, 'disabled people are not the subject matter of the social interpretation of disability'.

In this way, Disability Studies is less concerned with the study of disabled people and more concerned with the study of disability as a form of social exclusion. For example, there would be a similar difference between programmes concerned with the study of racism and historical disadvantage and programmes that simply studied African people's cultures and identities. They are two sides of the same coin but it would be inappropriate to pry into the lives of historically disadvantaged communities without also examining the structures of power and privilege that create that disadvantage. Disability Studies is about understanding and changing disabling societies so that they become more inclusive. Listening to disabled people's stories and experiences is essential in learning about disadvantage and liberation, but Disability Studies programmes demand more than this. They demand that students learn to critically assess nondisabled society and the way in which its expectations, institutions and practices can lead to greater exclusion or inclusion of disabled people.

If Disability Studies programmes require students to engage with issues of equality and disadvantage and to think about the creation of a more inclusive society, then they must also consider how disability relates to other aspects of diversity and social inequality. In a critical review of Disability Studies in Britain, Oliver and Barton express their concern that connections between disability, class, race, gender, sexuality and age have remained marginal and under-examined. Thus, they argue that:

> It is essential that Disability Studies courses examine, for example, issues of equity, social justice, citizenship, exclusion and inclusion and thus with factors that are beyond the question of disablement. Thus, the ultimate concern is with the establishment of a non-oppressive, inclusive society. This requires the development of a dialogue with members of staff working on related issues in other departments. This will, hopefully, result in reciprocal, beneficial, learning experiences involving theoretical, practical understandings and struggles. (Oliver & Barton, 2000, pp. 11–12)

This is a model that should be particularly transferable to the South African context, where academics have been actively engaged in considering themes such as diversity, gender equality and racism. There is a particular opportunity in the development of Disability Studies in South Africa to link disabled people's experiences to those of other disadvantaged groups in society. It is also an area where those in Northern universities may be able to learn a great deal from developments and interdisciplinary programmes in South Africa.

Establishing Disability Studies programmes

Early advocates of the new Disability Studies in Britain and North America were initially isolated, and often regarded with some suspicion or hostility by those who dominated the existing disability field (for example, in medicine, rehabilitation, special education, social work, or medical sociology). The first challenge was to find spaces within universities where teaching and research based on a social model could develop, free from the control of traditional approaches.

In Britain, the earliest examples of these new approaches were at the Open University as far back as the late 1970s. Their early courses were significantly different from traditional approaches for three reasons. First, they did not offer a professional training for students and existed outside the control of powerful professional groups. Second, disabled activists and academics were involved in writing the course materials and employed as course tutors. Third, they were based on a social interpretation of disability rather than a medical or therapeutic approach. Within British universities, the new Disability Studies developed largely within the disciplines of sociology and social policy, while in the United States it has perhaps been more closely linked with cultural studies and the humanities.

It is important to emphasise that disabled people have played the leading role in developing new ideas and putting them into practice within academic institutions. Disabled people have contributed a much stronger voice within this new field than they previously achieved within the traditional disciplines. New writing about disability has also challenged the traditional academic disciplines by adopting a more political and personal style. The development of a new literature has been crucial to the emergence of Disability Studies in Britain and the journal *Disability & Society*, first published in 1986, has been especially important in this respect. The writings of disabled people (both academic and non-academic) have established a powerful foundation for this new literature and access to these writings has brought students in the new Disability Studies closer to disability culture and the disabled people's movement.

Although there is a long history of academic research journals in the field of disability, until the emergence of the social model these titles were dominated by clinical and therapeutic perspectives. Even when new, critical discourses began emerging, authors often encountered considerable resistance to their writing from academic referees because editorial boards were dominated by the same professional elites that defined traditional approaches to disability. More progressive approaches were evident in research on inclusive education, but this addressed only one aspect of disabled people's needs. The development of a peer-reviewed journal in the field of Disability Studies was therefore an important step for two reasons: firstly, it provided a focus for theory and research within a social model approach, and secondly, it provided an important step in legitimising Disability Studies as a credible discipline in its own right. The first edition of *Disability & Society* was published in 1986 (initially *Disability, Handicap and Society*) and disabled people were included on the editorial board. Barton and Oliver describe the aims of the journal at that time:

> Two major motivations were particularly significant in contributing to the creation of this journal. On the one hand, there was a powerful

> desire to provide an alternative forum for the generation of ideas and the encouragement of dialogue and debate. This included establishing a serious and sustained critique of the medical model of disability which legitimated individualised and personal tragedy perspectives. On the other hand, was the intention to create a journal that would endeavour to develop a balance between academic and non-academic needs.
> (Barton & Oliver, 1997, pp. ix-x)

Initially, the focus for discussion and writing was primarily grounded in the national context of British policy and experience which was reflected both in the content of the early journal papers and in the composition of the editorial board. However, over time, a more international perspective emerged and the journal is now more widely acknowledged as a global forum. The American journal *Disability Studies Quarterly* has developed in a similar way, with the inclusion of more papers and symposia concerning countries beyond North America. Other significant North American journals include the *Journal of Disability Policy Studies* and, more recently, the *Review of Disability Studies*. Amongst the European journals that have adopted a more critical and social perspective on disability are the French journal *Handicap: Revue de Sciences Humaines et Sociales* and the Scandinavian *Journal of Disability Research*. However, there remains a conspicuous absence of new disability writings in the mainstream literature from majority world perspectives or addressing the issues facing disabled people in the countries of the South.

This is an area of considerable concern for the development of new Disability Studies programmes in southern Africa and elsewhere. Educational programmes rely heavily on published work, both academic and non-academic, as the core material for student learning and research. The historical dominance of Eurocentric accounts and Northern perspectives in the literature continues to marginalise the concerns of disabled people across most of the world (and particularly the concerns of poor disabled people in poorer countries). The development of a new critical Disability Studies in the North would not have been possible without access to the writings of disabled people and their allies and the same could be said of attempts to develop Disability Studies in the South.

If new programmes are to accurately reflect local and regional experiences and to produce graduates focused on tackling local and regional issues, then there is an urgent need to support the publication of more work that deals with those issues. The greater availability of such material, especially that written by and with disabled people, would not only support learning for change in South Africa, but would assist Northern universities to redress the considerable gaps in their own teaching and research. The publication of this book is hopefully an important first step in taking forward that project.

Conclusion

In this chapter I have summarised some of the basic principles of Disability Studies, as seen from a European perspective, and to draw out some of the implications for developing similar programmes in southern Africa. The development of Disability Studies in the North emerged out of thinking about disability in new ways that foregrounded a social interpretation of disability, prioritised disabled people's ideas and experiences, and emphasised and drew from political activism. From small beginnings, Disability Studies has become widely established as a distinctive field of study within universities and research centres around the world. Where it is strong, it maintains its engagement with the political and social claims of disabled people and provides research and teaching that contribute to their full participation and equality in society. To develop a progressive agenda for Disability Studies in South Africa it will be essential to foster and support continuing links with the disabled people's movement, to document the struggles of disabled people, and to ensure that students are able to learn from these experiences. For this to happen, there is a need to develop and make available many more resources on the disability situation and the struggles of disabled people across the region. Without the development of regional resources, Disability Studies programmes in southern Africa are likely to be constrained by the histories, priorities and writings of (predominantly white) writers from Europe and North America.

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4 Disability and psychoanalysis

Brian Watermeyer

Introduction

In the context of this book, a focus on psychoanalytic theory may, to some, seem surprising or out of place. Our common-sense associations with the idea of psychoanalysis render images of a small, plush room in an urban, western setting, with an analyst's couch, and professional and patient engaging in a lengthy and very expensive process of individual psychotherapy – a far cry from the often stark development needs of South African disabled people. We tend, to our detriment, to be less aware of the remarkable critical power of the psychoanalytic model to make sense of behaviour at the broadest social level, as well as the individual. What the model provides us with is a means to begin to interrogate what happens inside us, at the emotional level, and how these processes in turn profoundly influence and shape collective action within society. In this chapter, I aim to provide a concise introduction to how the psychoanalytic model may usher us into a new level – and era – of thinking surrounding the oppression of disabled people. More traditional sociological approaches to disability may, on their own, lack some articulation of the more intrinsic human origins of oppression; it is in this area that a critical psychoanalytic approach to interrogating social phenomena finds an eloquent and often dramatically enlightening voice. During the course of the following pages, I will attempt to demonstrate this assertion.

Why psychoanalysis?

What might the psychoanalytic framework have to offer to Disability Studies? Deborah Marks, in her landmark work on psychoanalytic approaches to disability (Marks, 1999), asserts that modes of interrogating the disability phenomenon which do not examine the influence of intra-psychic states, will inevitably fall short of satisfactorily accounting for the resilience and perpetuation of disablist oppression. She notes how interventions such as 'awareness training' have failed to impact on prejudice surrounding disability, demonstrating that disablism is not simply the result of a lack of knowledge about disabled lives (Marks, 1999, p. 12). Rather, in the oppression of disabled people, there is 'something more' at work. It is this 'something more' that psychoanalysis attempts to circumscribe. The psychoanalytic lens provides us with the opportunity to examine how ideas and images of disability are experienced emotionally by all of us (Marks, 1999, p. 1), and how the nature of this experience shapes the ways in which our society treats disabled people. Disability fascinates and intrigues us; it draws us closer, but also repels us (Sinason, 1992). Our emotional responses to disability are often conflicted, but almost always rich. If disability evokes such strong emotional responses in us, surely these feelings must influence the decisions we make regarding our individual and collective reactions to disabled people, and mediate our judgments regarding policies on disability. Marks (1999) regards the following questions as central areas in which psychoanalytic understanding can provide telling insights:

- What is the origin of the excessive emotional energy (be it sadistic, fearful or kind) evoked by images of disability?
- How do we account for patronising, hostile, or avoidant responses of nondisabled people?
- What 'emotional payoff' is achieved by nondisabled persons' involvement in 'altruistic' disability-related work?
- What typically unacknowledged existential anxieties have disability come to symbolise?
- Why are persons with disabilities repeatedly represented in popular media as dangerous, helpless, disordered or infantile?

How does disability make us feel?

A central idea to which psychoanalysis directs our attention is the fact that disability makes us anxious. Consider, for example, how we feel when confronted with a disabled stranger. Feelings of apprehension and uncertainty may arise; we are unsure whether or not to offer assistance; we may be drawn to looking, but fear that we might stare. These and many other experiences all carry with them a level of anxiety. This anxiety may be viewed as a defensive response to difficult parts of our own experience which disability reminds us of – those memories, fears, struggles and losses which we all carry.

The unconscious

In the latter period of the century before last, Sigmund Freud introduced the world to the revolutionary idea that we, as humans, all have a part of our minds which is outside of awareness. He termed this part the unconscious. Quite simply, we all have parts of our emotional experience which we find difficult to tolerate, and thus to hold in our awareness – those feelings that are 'too hard to bear'. These parts – painful feelings, memories and fears – thus become 'pushed down' (repressed), and are forced out of our awareness (Freud, 1912/1991). These parts of our selves are kept at bay in the unconscious by the use of what Freud termed defence mechanisms. These are strategies which the psyche employs in order to protect our conscious minds from things we would rather forget, or disown altogether. But what are these parts of self with which we struggle?

Psychoanalytic thinking proposes that human experience is universally composed of both pleasurable and deeply painful parts. All of us, at one time or another, have experienced the following:

- A sense of vulnerability or shameful dependency;
- Experiences which left us feeling ashamed or unlovable;
- The fear that we are unacceptable to others ;
- Feelings of not being capable or adequate;
- The fear of being ostracised;
- The fear that our bodies are ugly or undesirable;
- The fear that we are a burden to others.

Now, of crucial importance is the assertion that ideas and images of disabled people have, in many cultures, become attached to these unwanted parts of human experience. In other words, disabled people have, in many societies, come to symbolise the most damaged, undesirable, shameful and unwanted parts of our humanity which we all bear within us (Marks, 1999; Murphy, 1995; Shakespeare, 1994).

When we cannot manage to consciously 'hold', or tolerate, parts of our emotional experience, we tend to manage the situation by experiencing our feelings through others. In other words, without being aware of our actions, we experience our own painful parts as if they reside in, and belong to, others. This allows us the refuge of believing – in our conscious minds – that we do not possess these unwanted and shameful aspects of ourselves (Marks, 1999, p. 170). Rather, it is the other who is the owner, the custodian, of what we would rather disown (Oliver, 1990; Priestley, 1999).

Othering

This term refers to the idea that our identities are often created and maintained via distinctions which we draw between ourselves and those we view – or construct – as very different from us (Hollway, in Kitzinger & Wilkinson, 1996; Tajfel & Turner, 1979). Implicit throughout this book is a social constructionist view (Gergen, 1985) of disability, which regards disability not as an essential and identifiable reality, but rather as a construct which is negotiated and ascribed through particular political relationships (Corker & French, 1999). In other words, what it means to be disabled in our society – to carry that identity – is a social accomplishment in which we all have some part, rather than a unitary reality. The nature of the disabled identity in societies such as ours is argued to be strongly mediated by the process of othering (Fiedler, 1978; Murphy, 1995). This refers to a process whereby we identify a devalued 'other' in society, in order that we may then attribute to members of that group those parts of our own experience and selfhood which we wish to disown. By constructing and regarding disabled people as broken, damaged, defective and dysfunctional, members of the broader nondisabled society are able to reaffirm and reinforce an identity of being the opposite of these unwanted characteristics. This is a process very similar to what we may observe in racism, where racist stereotypes tend to exemplify parts of human experience which the political majority wishes to disown, and thus attributes to ethnic minorities (Burman, 1996; Kitzinger & Wilkinson, 1996). Hence, oppressed racial groups are often stereotyped as being stupid, lazy, immoral, primitive, and so forth. In this vein, but addressing disability, Jenny Morris writes:

> It is fear and denial of the frailty, vulnerability, mortality and arbitrariness of human experience that deters us from confronting such realities. Fear and denial prompt the isolation of those who are disabled, ill or old as 'other', as 'not like us'. (Morris, quoted in Shakespeare, 1994, p. 286)

Thus, it becomes evident that the oppressive construction of disabled people as damaged may carry a certain payoff to members of broader society. That is, we may carry psychic investments in reconstructing stereotyped ideas about disabled people – Marks describes these as 'emotional investments which function to reassure the nondisabled viewer of their "normality"' (Marks, 1999, p. 170). Shakespeare (1994, p. 287) captures this predicament of disabled people in describing 'them' as 'dustbins for disavowal' – as the psychic dustbins into which we throw our unwanted, and hence disavowed, characteristics. These characteristics then become culturally cemented to disabled people (Shakespeare, 1994; Wendell, 1996). It is unsurprising, in the light of these ideas, that many societies have implemented policies of institutional segregation of disabled people, in order, perhaps, to avoid contact with reminders of disavowed internal life. Gliedman and Roth describe how disabled persons are constructed as 'the Other – a living symbol of failure, frailty and emasculation; a counterpoint to normality; a figure whose very humanity is questionable' (Gliedman & Roth, quoted in Murphy, 1995, p. 143). In attempting, now, to demonstrate the relevance and utility of these ideas, let us turn to a practical situation.

Interaction and projection

Let us return to consideration of a meeting of strangers involving a visibly impaired person – for example, a wheelchair user or a blind person – whom I or you meet in the street. Let us place ourselves imaginatively in the situation, and feel what ensues. There is a level of free-floating anxiety regarding what is appropriate. Consciously, this may surround an uncertainty regarding whether to shake hands or not, whether to offer assistance or not, or a range of other worries. Why are we anxious? In a classic text entitled *Stigma*, Erving Goffman called such meetings 'sticky interactions', permeated as they are with a nervous sense of things being unmanageable. At times we may manage this anxiety by taking control, and providing uninvited assistance. But what is happening unconsciously?

If we are experiencing an uncertainty regarding how to interact with this disabled person (as against our experience of a 'normal' interaction), we must be assuming something about their life. The urge to offer assistance is common, and must be based on assumptions regarding the needs, capabilities and vulnerabilities of the person before us. If we examine ourselves closely, what do we unthinkingly assume about this individual? What – perhaps beginning with the assumption of their needing assistance – are our associations with this image of disability? These assumptions may be deeply conditioned in us, and might therefore require a degree of reflection in order for us to identify them. Interestingly, it really is quite plausible that we would assume that a perfect stranger needs our assistance. This assumption may be flanked by more subtle and embedded ideas regarding their life-role within the community, possibly a marginal and socially isolated one. We may, naturally and unthinkingly, assume that they do not have a healthy sense of self-esteem, or a fulfilling experience of sexuality. We may imagine that this person inevitably feels unattractive, and possibly shameful. These and many other assumptions are often implicit – and only partially conscious – in such an interaction. What has happened in this interaction?

Logically, since we have no knowledge of the stranger before us – of their life experiences, internal world, sense of self, abilities and shortcomings, hopes and fears – there is no question that whatever our subtle assumptions and associations are, these ideas can only have originated within us. As noted above, these associations may be hidden, evident only by inference from our behaviour. If we carefully interpret and reflect upon our emotional responses and behaviour, we may then begin to uncover what are, in fact, our own fantasies about the experience of disability. What has occurred in this interaction is that exposure to the image of disability before us has aroused in us those parts of our own experience which are particularly difficult for us to own. Notions and images of disability are so firmly attached to ideas of vulnerability, frailty and damage, that by consequence, our own internal struggles are brought rapidly near the surface of consciousness. However, rather than identifying these fears and struggles as our own, in one inadvertent and unconscious moment, our tendency is to experience these feelings as if pertaining to, and belonging to, the disabled person before us. In effect, then, we begin to interact, as evidenced by our anxiety and vivid assumptions, not with a stranger whom we need to get to know, but rather with a living personification of our own fears and fantasies regarding what we imagine it would be like for us to live with the impairment we see. The disabled person before us is left in circumstances of being related to in a manner informed in no way by the nature of their life, but rather as a container or vessel for the fears of the observer.

The challenge for us is to attempt to identify, name and re-own the feelings and fears we have that disability brings to the surface, in order to avoid the process of projection described above. This undertaking is imperative if we are to open honest and clear channels of communication, which are not obscured by our own unrecognised feelings and fears. In interaction with people who seem disabled or different to us, if we are internally overcome with frightening feelings, which we attribute to the perceived reality of the life we see before us, we will not be in a position to hear and engage with the lived reality which the individual may describe to us. In other words, if our fantasy is that the lives of disabled people are as we fear they are, we will inevitably position 'them' – in interpersonal as well as societal terms – in a manner which silences the potential for self-definition, and consequently robs us of the opportunity to disconfirm our assumptions. We need to recognise that the negative associations are our own, in a manner which returns to the individual the right to determine and describe their own identity and experience.

Defence mechanisms

As noted above, Freud conceived of the idea of our conscious minds managing the threat of painful or difficult feelings which encroach from the unconscious via the deployment of defence mechanisms. These are strategies which the psyche uses to deflect, disguise or re-order feelings, memories and parts of self which we cannot bear to know in their original, un-censored form. It is important to note that these mechanisms are not a sign of illness – on the contrary, we all have and deploy defences constantly as a natural mode of managing our internal worlds. However, as shall become clear, the use of certain defences deployed to manage the difficult feelings which disability evokes in us, can, and does, have important implications in shaping the ways in which disabled people come to be constructed – and hence treated – within a society such as ours. In short, our defences may at times cause us to need to view disabled people in particular ways for our own peace of mind – that is, in order to protect us from our own feelings of damage and struggle.

In a South Africa rapidly being permeated by western, capital-driven ideals, it is salient to note how intrinsic the drive for perfection has become in our lives. Through vigorous socialisation, we are required to strive for the ideal body shape, for success in highly competitive educational environments, for maximal accumulation of wealth, status and independence in the workplace, for the achievement of the desired persona, in terms of looks, dress, role and ability. Within such a 'narcissistic culture' (Marks, 1999, p. 21), it makes sense that those parts of our selves that do not fit well with these expectations may feel deeply unacceptable to us. Thus, the immense pressures on us to approximate the ideal, the 'normal', may lead to our more vulnerable experiences being repressed and excluded from conscious awareness. We then may disown, or 'split off', these parts, and experience them as belonging only in the lives of those 'socially constituted as damaged' (Sandler et al., quoted in Marks, 1999, p. 21). Key defence mechanisms relevant to the construction of disabled people are the following:

Splitting

This is a defence which tends to bias our thinking towards a belief that the world can be divided clearly into a set of binary opposites, such as good and evil, a sort of black and white categorical form of thinking. This thinking assumes that the boundary between these opposing categories is a clear one, and that consequently there are no 'grey areas' in the world, leading to individuals being endowed with 'all good' or 'all bad' qualities (Marks, 1999, p. 22). Such thinking tends to arise when we feel anxious at being confronted with the complexity of the world, and consequently need to establish a sense of control, achieved by categorising what we see. The illusion that people can be clearly divided into categories of disabled and nondisabled reflects a form of split thinking. Further, an examination of stereotypical ideas about disabled people reveals a mix of idealising and denigrating caricatures, which emerge as a result of our need to manage the anxiety-provoking parts of our experience which disability evokes. Disabled people tend to be viewed either as dependent invalids, or superhuman individuals who have overcome enormous odds. Representations of disabled people in literature, movies and popular media reflect characters which tend to be either saintly and pure, or evil villains. In the film, *Scent of a Woman* (Universal Studios, 1992), Al Pacino plays an embittered and isolated blind man, who, despite his limitations, undertakes a range of breathtaking feats, including dancing a dramatic tango after enquiring about the dimensions of the dance floor, and driving a sports car at breakneck speed under the instructions of a terrified and unwilling navigator. Here, the blind person is represented at both extremes of a split construct of what it means to be disabled. The first of these positions portrays Pacino's character as the stereotype of an emotionally damaged and isolated disabled person whose impairment has caused him massive psychological damage. This image arguably forms a reflection of fantasies – held by the screenplay writer, and echoed by societal stereotypes – of 'how I would feel if I did not have sight'. These fantasies then form the basis for a unidimensional and damaged character. The 'coping' afforded here by the splitting defence refers to the observer who, in the face of threatening fears about what a blind person's life may (in fantasy) be like, achieves a sense of mastery and control by deciding that the blind person's life is, in fact, the way it is fearfully imagined to be. It often feels more manageable for nondisabled people to view a disabled person as 'necessarily' damaged and vulnerable, than to feel the evocation of these sorts of feelings within themselves, and not know whether or not they apply. More interesting, though, is the character's ability to perform heroic acts.

Idealisation

This defence is often employed in conjunction with splitting. As the name implies, it involves the attribution of excessive, unreal, overly positive characteristics. Al Pacino's ability to perform the antics that he does in *Scent of a Woman* may reflect a need within the observer to overcome the fear that, due to his blindness, he is in fact utterly restricted and capable of nothing. Thus, what we see may be a response to a more basic attribution, where the observer has originally disowned and given over feelings of deep inadequacy and incapability evoked in response to the idea of living with blindness, and thereafter has managed these feelings by a form of reversal, which presents the need to portray the blind person as heroic and unusually (if implausibly) capable. In some sense, therefore, Pacino's character has been shaped in a manner which allows the observer to feel reassured that his life is not the unmitigated tragedy which we fear, and 'know', it to be.

What the foregoing may mean for disabled people is extremely important. First, this type of thinking feeds the all-too-familiar imperatives placed on disabled people to 'overcome' their 'disabilities', which are often couched in the rhetoric of 'anything is possible', 'there is no such word as can't', and the like. Second, such views embody a wholesale disregard for the unique (human) lived experience of disabled people, over and above the clear echoes of an individualising model of disability. Disabled people remain unknown within a view which constructs them – in an unreal manner – as heroic or helpless. Disabled people are thus denied the possibility of being viewed and constructed in a manner which reflects the complexity and diverse aspects of a unique human life, including strengths and vulnerabilities, hopes and losses, competence and inadequacy. Instead, this 'normative humanness' and self-definition is often drowned out by a flood of assumptions emanating from the unconscious conflicts which exposure to disability may evoke in the observer. Disabled people may thus be left feeling unknown, unrecognised, or forced to endure being viewed as the personification of stereotypes.

Melanie Klein views this defence in a somewhat more sinister light. Applied to disability-related situations, her model would understand such idealisations as are evident in Al Pacino's character as a defensive response to an unconscious sadism (cited in Marks, 1999). If disabled people do, indeed, represent to us dark parts of our psyches which we cannot tolerate in ourselves, it is logical that we might be driven, in an instinctive manner, to blotting out, obscuring or destroying this shameful evidence of our own damage and defects.

One need not look far in the history of disabled people to find evidence of attempts at social extermination, including violent ostracism, institutional control and segregation, abortion, euthanasia and eugenics. Such attempts at forceful exclusion or extermination of disabled people may be understood as stemming from a need to symbolically (or literally) kill off disabled people, in order to simultaneously eradicate from awareness those parts of self that disabled people represent. However, harbouring such homicidal feelings about disabled people tends to feel unacceptable and wrong to us – that is, it is very difficult for us to consciously acknowledge to ourselves that we have these feelings. Consequently, idealisation occurs, which inverts our original hostile and sadistic feelings, and causes us to endow disabled people, instead, with ideal characteristics. These may take the heroic form of Pacino's character, or such qualities as the childlike innocence, religious insight, psychic gifts, or spiritual strength often irrationally attributed to disabled persons.

Projection

As referred to earlier, this is a defence which involves disabled people being re-constructed as the custodians of feelings which observers cannot tolerate in themselves. Consider, with Marks (1999), the scenario of a physically impaired child (say, a wheelchair user) being taken on a walk in a public park by a carer. Some passers-by look directly at the child, but most adults seem to deliberately look away. Parents anxiously gesture to their children that they should not stare. Some observers are deeply moved by the image of the child, and experience the urge to assist, or to comment to one another on the child's braveness, sweetness or tragic fate. The disabled child and carer seem to command a host of conflicted and rich emotional responses evoked in the observers, and again, not a word has been spoken between the individuals involved. What is occurring here is that the child and carer are having a rich array of the observers' internal feelings attributed to them. Unthinkingly, and for unconscious reasons, the child and carer are made into the vulnerable, admirable, wretched, courageous, tragic, damaged, isolated, unable and virtuous people that the minds of the observers, for their own unconscious reasons, need them to be. In the gaze of the observers, they become the Other, objects on whom to confer unwanted qualities. Marks (1999, p. 23) regards projection as the 'key tool for understanding the psychic mechanisms of prejudice against disabled people'.

Reaction formation

This mode of defence involves going to the opposite extreme to avoid acknowledging feelings and impulses evoked in us by images of disability. Marks (1999) asks that we carefully interrogate the hidden meanings underpinning a desire for involvement in altruistic work surrounding disability. As noted above, if disability does, indeed, remind us of disavowed parts of ourselves, it is likely that our instinctive response to disabled people would be one of wanting to obliterate or conceal such reminders. Is it possible that our irrational tendency to pity disabled people emanates, to some extent, from a more primary hostile urge? Freud, along with psychoanalytic authors such as Lacan and Fenichel, associates pity with disavowed sadism, implying that pitying or altruistic responses to disabled people may embody a guilt-ridden attempt to make up for more basic hostile urges that underpin these more socially acceptable feelings (Marks, 1999). If disability is as evocative and provocative as this chapter suggests, it seems reasonable to assert that individual motivations to undertake caring professions associated with disability, or disability-related altruistic or charity work, are probably highly complex, and worthy of careful exploration. It is likely that individuals are drawn into such work for reasons which are, at least partially, unconsciously determined.

What this may create is a situation in which decisions relating to the management of disability-related issues may be skewed and shaped by unconscious factors. Consequently, constructions of disabled people, with their corresponding implications in terms of ideas regarding what disabled people need, may become distorted and perverse, based more on the unconscious conflicts of practitioners than on a rational and even-handed analysis of fact. The long and ongoing struggle waged by disabled people for the right to a clear and powerful voice in the design of disability-related social services bears testament to needs within the practitioner community to retain control and exclusive influence regarding how disability is managed. The emotional charge evident in the heated exchanges surrounding this issue may be understood as relating to the unconscious need, within practitioners and carers, to take decisive charge of the lives of disabled people, and, by so doing, to simultaneously take charge of the unconscious feelings and fears which 'they' represent.

In the manner sketched above, it is possible to interpret a 'latent content' underpinning a vast array of societal responses to disability. Control, institutionalisation, adult re-socialisation (Scott, 1969), segregation, enforced rehabilitation, zealous attempts at medical 'normalisation' – these and many other responses to the spectre of disability may be interpreted as reactions not only to disabled people, but as specific modes of managing the internal evocations which exposure to disability stimulates.

Thus, eugenic policies seek to exterminate the internal by murdering disabled people; segregationism attempts to put disabled people out of sight, in order to thereby create the illusion that the internal struggles which they represent do not really exist; institutional control seeks to dominate and take decisive charge of disabled people, in order to symbolically achieve mastery over the fear of a lack of control which emerges when internal feelings represented by disability are touched upon – these and every other disability-related policy and practice carry unconscious, and often profoundly influential, meanings and motivations.

Rationalisation

In the case of this defensive strategy, individuals construct a conscious justification for their actions, whilst remaining unaware of the unconscious motivations which underpin what they do (Marks, 1999, p. 24). Marks asks us to consider the example of a building designed with wheelchair ramps at the back, rather than at the main front entrance. Consciously, those involved regarded this arrangement as being more convenient for disabled people. Marks, however, asserts that the decision 'may express not just the material self-interest of the owner's wishing to avoid the expense of building another entrance, but also serve as psychic rationalisation for the wish to keep disabled people out of sight and mind' (Marks, 1999, p. 24). Thus, overt social responses to disabled people may be carefully accounted for in rational terms, but yet carry – and be determined by – unconscious motivations.

Embarking on psychoanalytic interrogation

The concepts described above provide us with the means to undertake a broad-based investigation of the unconscious underpinnings of the full range of societal responses to disability. The term 'responses' here may be read as referring to everything from what happens in social interactions with disabled people, to the design and nature of disability social service policies and installations; from the architectures of our built environments to our ideas about the sexuality of disabled people; from the rules enforced in special schools to the culture of charity organisations surrounding disability – in short, every way in which we, individually and collectively, react to disability. It is an extraordinary strength of the psychoanalytic model that it remains incisive throughout such a range of contexts, bringing into vivid relief the ways in which so much of our planning, thinking and actions surrounding disability have been informed more by fearful and irrational forces than by rationality. Currently, Disability Studies is at the point of departure of this project of interrogating society's responses to disability, whilst viewing these responses as the external concretisation of internal patterns of defence organised to manage feelings brought to the surface by exposure to disability.

An even cursory scan of the history of institutional reactions to disability within society will immediately reveal a plethora of policies, interventions and arrangements which may strike the observer as odd, perverse, illogical, inhumane, bizarre, obsessive, grotesque, punitive, demeaning, or simply crazy. From a severely physically impaired man in an institutional setting being coerced into utterly exhausting himself in order to remove his socks 'independently' (French, 1993d), to visually impaired children in a special school being harnessed to their desks, or forced to wear bags over their faces in order to 'save' their (remaining) sight (Chapman, 1978) – the evidence of unconscious mediation is everywhere. Notably, too, there is no reason to believe that individuals in powerful decision-making positions surrounding disability (such as organisational board members, civil administrators, and the like) are somehow necessarily less influenced by unconscious forces. On the contrary, it is likely that individuals who choose to move into the disability field do so in part as a response to a resonance between the notion of disability and unconscious aspects of the self, resulting in potentially substantial unconscious influence in the mediation of disability work.

For the purpose of clarity, the ideas of this chapter have largely been communicated in a manner which implies that it is *nondisabled* people exclusively who are prone to responding irrationally to disability, as a result of unconscious evocations. Of course, this is not the case. Disabled and nondisabled alike, we all struggle with difference, and all carry the universal fallibilities of our humanness, which emerge to trip us up in the face of threat. As a disabled person, I wholeheartedly include myself in the vigorous process of reflecting on motivations and investments which I advocate. Furthermore, there is no shame in carrying these anxious responses to disability. Again, we are all products of a stupendous project of social engineering, which has left us with no more than our own fearful fantasies about the lives of those who seem different to us. To make a comparison with the race paradigm, as a South African, I feel that it is necessary for all of us to explore the issue of racism internally. Crucially, though, for me the question here is not 'is there racism within me?', but rather 'how do I respond to the racist responses which I carry?' There is nothing shameful, or even special, about carrying conditioned racially differentiated responses in a nation where racial segregation, and the relentless ideological signification of racial markers, is a part of all of our history. The difference lies in between, with the personal meaning of that difference lying within. Thus, in my view, with regard to the issue of race as well as disability, if we are to erode prejudice it is essential that we create an environment in which individuals (black, white, nondisabled, disabled) feel sufficiently safe and accepted to be able to 'let in' and share their fearful, anxious and politically incorrect responses to those different from them. Certainly in the world of disability, it is the shameful disavowal of such negatively sanctioned, and thus secret, internal feelings and impulses that carries the most potential for the perpetuation of a disordered, pernicious and ultimately oppressive societal response to disabled people. It is imperative that we allow one another to reflect on and name what disability does to us internally, in order to get beyond our projections, and to a point where the voices of disabled people may take up an equitable and audible position amongst others in the shared production of culture within our society.

Conclusion

With this chapter I have endeavoured to demonstrate how the many ways in which we as a society respond to the 'disability phenomenon' tend to be deeply imbued with motivations and meanings which are not readily or obviously apparent. Instead, our individual, and hence collective, reactions to disability are complex, and reflect motivations which are often deeply embedded within our histories and ourselves, requiring our investigation if we are to clear the air of our own investments. Disabled people, as a group, have suffered profound political and economic subjugation, and are thus, like any oppressed minority, vulnerable to the ascription – or infliction – of an identity based on stereotyping, denigration and othering. Our collusion with the infliction of this devalued identity may often be an unwitting one; it is in the working nature of ideology that we be drawn into perpetuating a set of meanings without, perhaps, having the opportunity to examine or interrogate their implications.

Of central importance in critiquing the ways in which our society positions, constructs and treats disabled people is the exploration of the unconscious aspects of our individual relationships with disability. It is these parts of ourselves that can raise our anxiety, profoundly obscure our perception, confuse our thinking (Bion, 1988), and render a situation in which our positions on disability issues are mediated more by our own psychic needs than by the voice of the disabled community. Let us embark upon the interrogation of disablist oppression in our society by beginning with a gentle, but earnest, exploration of ourselves.

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Section II
Government and societal responses to disability

5 A history of the disability rights movement in South Africa

Colleen Howell, Schuaib Chalklen and Thomas Alberts

> An image the world will remember of the first democratic elections in South Africa in 1994 is that of thousands of disabled people queuing at voting stations across the country under the hot African sun. They came to exercise their right to vote under the most difficult of circumstances. They came in wheelchairs, on crutches, navigating their way by means of white canes, in wheelbarrows and even physically carried on the backs of relatives and friends. Why did they come?
>
> They came because they knew that the policy and practice of apartheid had only served to compound their experience of discrimination, indignity and poverty as a result of society's response to their differentness. They came to participate in one of the most empowering experiences ever. They came because they had a vision of a better dispensation under new conditions of liberation and democracy. (Mbeki, 1998)

When the ANC came to power in 1994, as the first democratically elected government, one of the first things it did was to establish a Constitutional Assembly to discuss and debate the cornerstones of democracy in South Africa. Building on the principles of the Interim Constitution negotiated between the apartheid government and the liberation movement, the culmination of the work of the Constitutional Assembly was the adoption of a new Constitution on 8 May 1996. In his speech to Parliament on that day, then President Nelson Mandela paid tribute to civil society representatives for their extensive participation and contribution to the process. Yet the constitution was not only important for the way in which it included their input and reflected the aspirations of so many different people throughout the country. The new Constitution was especially important because it extended basic human rights to all citizens for the first time in South Africa's history. It gave all people the right to vote and outlawed unfair discrimination against any person on a number of grounds. The Constitution also promoted equity among all South Africans by recognising the need to implement specific measures that would address the disadvantages that particular groups of people had experienced. These provisions have since provided the basis for important legislative and policy changes.

The new constitutional framework also marked an important milestone in the struggle of disabled people. The Constitution's recognition that disabled people have been, and continue to be, discriminated against because of their disability, means that disability has become an important consideration in new legislation and in policy documents that make up South Africa's legal and policy framework. As a 'historical moment' in the history of the disability rights movement in South Africa, this recognition reflects the struggle of disabled people to be treated equally to all other people. It has also provided the basis from which new and often more complex struggles have been waged.

This chapter tells the story of some of the most important of these struggles. It is aimed at informing people inside and outside the disability movement about the people, activities, strategies, interventions and decisions that have shaped where the movement finds itself today. The information used to compile the document of which this chapter is an abridgement[1] has been collected through a small research project undertaken by Disabled People South Africa (DPSA) for the Office on the Status of Disabled Persons (OSDP). Through interviews with a sample of key activists involved in making this history and by analysing important documents from this period, the organisation has put together a picture of this struggle. It is hoped that this can be used to reflect on where we have come from and what can be learnt from this history to inform where we want to go in the future.

Although it is important to recognise that disabled people in South Africa have been struggling on a number of levels and often in many unrecognised ways to obtain their rights for decades, in this project we have chosen to focus on the last 20 years. This has been arguably the most significant period in the disability rights struggle and in the struggle for democracy in South Africa. While we focus on this period of history for this study, we acknowledge the many struggles that went before and those still to come before disabled people occupy their equal and rightful place in society.

As with any small project of this nature, there have been a number of limitations to the research process. Thus the picture that has been drawn can only reflect the interpretations and understandings of the small sample of people interviewed and the documents analysed. There are a number of people whom the research team was unable to reach or consult, as a result of time or resource constraints – reasons that are inevitable for a project of this nature. While these limitations need to be acknowledged, it is hoped that this study will provide the impetus for other more in-depth and substantial investigations into the history of the disability rights movement. There are many stories that still need to be told. For now, we hope that the story told here will go some way towards recording a rich history of one community's struggles towards overcoming injustice and building democracy.

The study focuses largely on the history of the disability movement through the eyes of the activists who came into the movement through DPSA. It mainly focuses therefore on the history of DPSA and the role its activists have played in bringing about the changes we see today. While DPSA has certainly been at the forefront of this struggle, it is also recognised that many smaller organisations and individuals outside of the formal structures have contributed to shaping this history. Although it has not been possible within the scope of this project to discuss all these contributions and interventions, we hope that these people will regard this as their history too and continue to work with DPSA within the broader disability rights movement in South Africa.

The formation of Disabled People South Africa (1980–1990)

The history of the disability rights movement in South Africa is one that has been shaped by many different forces, people and organisations. Collectively, the events and circumstances which contributed most strongly to the movement as we know it today arose from the experiences of disabled people living under the system of apartheid.

Under apartheid, the experiences of disabled people were also the experiences of a deeply divided people living in a profoundly unequal society. The lived experiences of black and white disabled people under apartheid were very different and reflected the general inequalities between white and black people in South Africa. For the majority of black disabled people, their lives were about struggling on a daily basis to cope with the poverty, deprivation and violence of the apartheid system, a struggle compounded by their disability. However, it is important to recognise that under apartheid all disabled people, black and white, were discriminated against and marginalised because of their disability and had very limited access to fundamental socio-economic rights such as employment, education and appropriate health and welfare services. This kind of discrimination and marginalisation occurred because disabled people in general were seen as people who were sick or in need of care, rather than as equal citizens with equal rights and responsibilities.

While the apartheid system impacted differently on the lives of black and white disabled people, these experiences collectively shaped the nature and form of the first organisation that disabled people set up themselves in the 1980s. DPSA was started by a group of disabled activists in 1984. As the largest cross-disability organisation in the country, controlled and led by disabled people, it has played a central role in shaping the nature of the struggles fought by disabled people in South Africa over the last twenty years.

The individual activists who were responsible for the formation of DPSA felt strongly that overcoming the political and economic oppression of the apartheid system was central to the liberation of disabled people. However, to achieve such liberation it was also necessary to reject a way of understanding disability, dominant under apartheid, that disempowered all disabled people by keeping them in positions of dependency and preventing them from being able to express their own needs and rights. So the struggle of disabled people had to be both a struggle against apartheid and against how people understood and responded to disability.

DPSA's beginnings

A number of influential events took place in South Africa and internationally in the early eighties that provided the impetus needed to get the organisation off the ground. These events brought together individual activists, white and black, who had been involved in different initiatives around disability that had somehow challenged the status quo and had contributed to new ways of looking at disability.

In 1980 one of these people, Mike du Toit, later the Secretary General of DPSA attended the international conference of Rehabilitation International (RI) in Winnipeg, Canada (Du Toit, interview, 2001). At this conference, substantial changes took place in the development of the world disability-rights movement, changes whose impact was felt and harnessed in South Africa. The conference saw disabled people from around the world challenging the dominance of health professionals in structures such as RI and, eventually walking out after their proposal that at least 50 per cent of the board of RI should be disabled people was rejected. This walk-out led to the setting up of an international organisation that would be led by and controlled by disabled people themselves. The establishment of Disabled People's International (DPI), led to other important world initiatives that challenged the ongoing marginalisation and oppression of disabled people. These included the declaration by the United Nations of 1981 as International Year of Disabled Persons (IYPD). This was followed the next year by the anouncement of 1982–1992 as the Decade of Disabled Persons. In 1982, the United Nations also developed the World Programme of Action Concerning Disabled Persons, thus outlining the first substantial policy framework towards overcoming discrimination and creating equal opportunities for disabled people throughout the world.

The events at the 1980 RI congress were important in putting disability more securely on the human rights agenda of the United Nations and for the establishment of an international organisation of disabled people. However, they also contributed to a growing awareness among disabled activists in South Africa of the need for such an organisation locally. While international events influenced the decision to set up DPSA, the organisation's roots, the particular issues it would take up and its programme of action, were strongly formed by the experiences of being disabled in South Africa.

For the majority of white disabled people in South Africa, the experience of disability at this time was closely linked with the existing health and welfare system. They were largely reliant on the provision of support from organisations and the state in the form of a small social security grant and limited welfare services. Despite their relatively privileged position in relation to black disabled people at the time, white disabled people's experience was one of being dependent on a health and welfare system run by nondisabled people. It was a system where professionals spoke on their behalf and generally created conditions in which disabled people were 'cared for', often in institutions separate from society, rather than living independently, integrated into mainstream society. This marginalisation created by the health and welfare system was exacerbated by the divided apartheid education system that segregated education provision on the basis of race, and on the basis of a dominant 'mainstream' system and an inadequate 'special-education' system for learners with disabilities.[2]

While many white disabled people were caught in this experience, a few had begun to challenge this system. Firstly, they challenged it in their own lives, and then, they came together to discuss their experiences and to find ways to break down these barriers. Some had also initiated contact with black disabled activists living in townships who, as will be discussed later, despite having been profoundly disadvantaged through the apartheid system, had also begun to challenge the status quo.[3]

If the experience of disability for white disabled people was largely about discrimination on the basis of disability, the experience of disability for the majority of black disabled people was strongly influenced by the inequalities and oppression of the apartheid system. Not only were many black people disabled through the repressive and structural violence of apartheid (Cock, 1988), but once disabled they 'face(d) inadequate rehabilitation and health services in apartheid hospitals and then (were) discharged back into the same conditions of deprivation and discrimination which led to their injuries in the first place and where there (was) little or no follow up and aftercare' (Du Toit, 1992). But as black people in South Africa, they were also denied fundamental rights as citizens. So the 'formation of DPSA was influenced by the environment at the time, during which people wanted their freedom. What the majority of disabled people understood was that they were black and that they were affected by the apartheid system' (Tshabalala, interview, 2001).

Despite the enormous barriers that they experienced, during the late 1970s and early 1980s, some disabled people, especially those living in townships, had begun organising themselves into local organisations of disabled people or self-help groups. There is no doubt that these initiatives largely resulted from the vision and commitment of people such as the late disability activist Friday Mavuso. These groups were instrumental in finding practical ways to organise disabled people through self-advocacy and an over-riding commitment to economic empowerment and self-reliance. Probably the most important of these initiatives was the Self-Help Association of Paraplegics in Soweto (SHAP) of which Mavuso was a founding member.

Through the emergence of SHAP and similar smaller initiatives, a group of black and white disabled activists, mainly in the Gauteng region, had begun to recognise the need to build a strong consumer organisation of disabled people in South Africa. Despite their different life experiences, these activists 'complemented each other (and) were bound together…by the fundamental principles of self-representation and the need for dignity' (Nkeli, interview, 2001). Maria Rantho, a past chairperson of DPSA and the first disabled person to be appointed to the National Assembly in South Africa, explains the thinking of people at this time:

> We felt that there was a need to create a voice of our own, where we would, for the first time, be able to advocate for our own rights, without having to depend on professionals to speak on our behalf…We felt that there was a need for such an organisation to be formed…because when we speak of service-provider organisations, we know that disabled persons are deemed to be perpetually dependent on others to do things for them. (Rantho, interview, 2001)

According to Kathy Jagoe, another activist from the time, the philosophy of self-representation and the desire to form an organisation of disabled people to fight for change was especially influenced by the black consciousness movement (BCM) of the 1970s (Jagoe, 2002). Disabled activists took inspiration from the analysis and leadership of Steve Biko and the South African Students' Organisation (SASO), particularly two key principals underlying the BCM's vision. Firstly, like the black students who broke away from the white dominated National Union of South African Students, they felt that they needed to take control of their own destinies, speak for themselves and not be spoken for by other people, especially professionals, however well meaning these people were. Secondly, taking inspiration from Biko's analysis of the South African situation, they felt that the society around them was responsible for the marginalisation and deprivation that they experienced. In other words, the problem was with an unequal and unjust society. They did not want to be integrated into a society that remained unequal and discriminatory because of differences between people. They wanted to contribute to a new society where all people would be regarded as equal and would be able to contribute equally to the social, economic and political life of that society.

Other events taking place in the country also influenced these disability activists. Two events in particular were important in influencing the thinking of the disability activists. These were the student uprisings of 1976 and the formation of the United Democratic Front (UDF) in 1983.

On 16 June 1976, 20 000 students marched through Soweto, the large black township outside Johannesburg, in a mass demonstration as part of a wider process of opposition to the inadequate education system available to black children and the use of Afrikaans in these schools (Christie, 1985). Although the demonstration was peaceful, police opened fire on the students, killing some and disabling many others. Students and youth throughout the country, including those in the universities, began to support the Soweto students with their own protest actions and demonstrations. These uprisings were followed and supported by similar uprisings by workers, parents, and men and women from local communities throughout the country resulting in a nationwide uprising (Christie, 1985). The apartheid state responded with massive repression. In the year following the June 16 protests, 21 537 people were prosecuted for events relating to the uprising (*SASPU National,* 1983) and many people died, often in police detention.

These events of 1976 and 1977 had a profound effect on people inside and outside the country. Despite the massive repression by the apartheid government, the student struggles inspired people and engendered 'a sense of confidence' that shaped the struggle into the eighties (*SASPU National*, 1983). For disabled people in South Africa, the student uprisings were especially important in two ways. Firstly, many people were disabled through the violence of this period. Some of the activists who are involved in the disability rights movement today were shot by the police, tortured in detention, or hurt in other ways linked to the violence of this period that resulted in them becoming permanently disabled. Secondly, these events also politicised many disabled people who now recognised more clearly how the liberation of disabled people could only happen through the liberation of the majority of South Africans and the establishment of democracy in the country. They felt inspired by what the students had done and recognised the importance of disabled people organising themselves to take forward their struggle.

In 1983, the UDF and the National Forum (NF) were formed, two important national umbrella bodies, which brought together many different organisations opposed to apartheid. Although there were some differences, these forums were very important in uniting people against the apartheid state and laid the foundations for the intensive struggle against apartheid that took place during the eighties. These objectives were clearly stated by the UDF in its founding declaration, which was adopted by 575 organisations at a huge launch in Rocklands, Cape Town on 20 August 1983. The UDF declaration stated that:

> We, the freedom loving people of South Africa, say with one voice to the whole world that we cherish the vision of a united, democratic South Africa based on the will of the people, will strive for the unity of all people through united action against the evils of apartheid, economic and all other forms of exploitation.
>
> In accordance with these noble ideals, and on this 20th day of August 1983 at Rocklands Civic Centre, Mitchells Plain, we join hands as trade unions, community, women's, student's, religious, sporting and other organisations to say no to apartheid. (SAIRR, 1984)

The philosophy of the BCM, the legacy of the student uprisings of 1976, and the mushrooming of anti-apartheid organisations in the early 1980s all had a profound effect on the thinking of the disability activists who had been involved in setting up self-help projects such as SHAP. Their desire to set up an organisation of disabled people in South Africa was also strongly influenced at the time by the existence and success of the Zimbabwean Movement of Disabled Persons. This organisation, which had its roots among ex-cadres of the liberation struggle in Zimbabwe, was led by Joshua Malinga, whom Mike du Toit had met at the 1980 RI conference. Joshua Malinga, who became the African representative in the original start-up committee of DPI and later a chairperson of DPI, was approached to assist in helping the South Africans to set up an organisation similar to the Zimbabwean one.

In September 1984, DPSA was officially launched at the 4th Congress of Disabled People. These congresses had been organised by a group of service providers working in the rehabilitation area, especially in the KwaZulu-Natal region, together with some disabled activists with whom they had made contact. The 1984 conference was attended by most of the disabled activists involved in the various self-help and advocacy initiatives around the country as well as by Joshua Malinga, who came down from Zimbabwe for the event. Dr William Rowland from the South African National Council for the Blind (SANCB) was elected chairperson of the new organisation.

Rowland's election as the chairperson of the organisation also brought to the fore DPSA's commitment to building a cross-disability movement. The move towards the establishment of a cross-disability movement of disabled South Africans was both a principle of the organisation and a natural move in the South African context. Where the societies of Europe and America tended to organise themselves according to disability type, DPSA felt that this division of disabled people actually weakened the effectiveness of the movement in South Africa. Division according to disability type focuses on the nature of the person's impairment and has the potential to create competition among disabled people for resources.

Organising according to disability type may also draw attention away from the human-rights and development approach to disability where the focus is on the creation of equal rights and opportunities for all disabled people, not on the nature of their impairment. It is important to recognise, however, that the principle of building a cross-disability movement did not mean that DPSA did not recognise that some kinds of disabilities were more marginalised than others. Early on in DPSA's development, the organisation's constitution was amended to create ex-officio positions on the executive for a representative of national single-disability organisations. This was to make sure that the organisation was as fully representative as possible of all kinds of disabilities. The cross-disability strategy was also the organising principle adopted by DPI in building the disability movement throughout the world.

DPSA's programme of action

The DPSA's programme of action developed out of efforts to mobilise and organise disabled people throughout the country through building and supporting self-help organisations, with a particular emphasis on capacity building initiatives and training programmes. In the 20 years since DPSA's inception, the central objectives have remained essentially the same: to 'create a voice for disabled people' through self-advocacy and 'to create an economic base so that the majority of disabled persons would have some form of employment, even if it is self-help employment so that the quality of their lives would be improved' (Rantho, interview, 2001).

DPSA's strategy of building local organisations to create the capacity for people to take control of their lives more substantially was not limited to DPSA. During this time, South Africa saw a mushrooming of community organisations with similar objectives. Central to all these organisations, including DPSA, was the urgency of challenging the apartheid system. For the majority of people involved in the self-help groups affiliated to DPSA, their experiences were shaped by being disabled and being black in South Africa. It was recognised within DPSA that the liberation of disabled people was fundamentally intertwined with the liberation of the vast majority of people in South Africa. To this end, the organisation aligned itself with the principles of the anti-apartheid movement, located itself within the mass democratic movement, and developed relationships with other civil society organisations. In fact, Thulani Tshabalala argues, 'the government saw us as an ANC structure. This made us very strong in the community' (Tshabalala, quoted in Bugg, 2001, p. 155).

Interactions with the apartheid government

The apartheid government did not recognise the United Nation's 1981 International Year of Disabled Persons. Rather, it declared 1986 the National Year of the Disabled and established a committee, largely made up of service providers, called the Interdepartmental Co-ordinating Committee on Disability (ICCD). The task of the ICCD was to advise the government on policy reform in response to the World Programme of Action Concerning Disabled Persons (1982). Despite producing 37 volumes of information and many recommendations on disability, many felt the ICCD study was a waste of time and money because it failed to provide the information and insights needed to create equal opportunities for the majority of disabled people, and because it failed to acknowledge the fundamental role that the apartheid system played in creating the conditions of poverty and discrimination which disabled people experienced.

DPSA raised its opposition to apartheid and highlighted the links between the violence and poverty of the apartheid system and disability at every opportunity, yet the organisation also recognised that it had to engage strategically with government to try to ensure that state-sponsored programmes became more relevant and that disabled people would be ensured of some say in formulating policy. To this end, the organisation agreed in principle to participate in the activities of the 1986 South African Year of the Disabled and to accept a grant from the government. William Rowland recalls that the organisation debated 'very openly whether we should take the money or not…[We decided] perhaps we should, provided there were no strings attached. That became our policy position, provided that there were no strings attached. We desperately needed funds and certainly, perversely or strangely, the government provided the first money injection to get DPSA functioning' (Rowland, interview, 2001). Other than this grant, DPSA received no further money from the government and relied on other sources of funding.

An important moment in DPSA's tenuous relationship with the apartheid government came at a government-organised conference on disability in Bloemfontein in 1986. Organised as part of the Year of the Disabled programme, through which the state sought to demonstrate its commitment to equal opportunities, the irony was compounded by increased state repression, deepening resistance to apartheid, and the declaration of a state of emergency by Prime Minister PW Botha which granted even greater powers to the police and army.

As the Bloemfontein conference progressed, many of the DPSA delegates became more and more incensed with the government's rhetoric on its commitment to change. Kathy Jagoe explains that the DPSA delegates became increasingly frustrated and angry, 'Cries and energy started generating in the room', until the chairperson stood up and declared that 'there would be no politics in the conference' (Jagoe, interview, 2002).

The assertion by the chairperson that 'no politics' should be discussed at the conference was unacceptable to the DPSA delegation and they decided to withdraw en masse, causing the government significant embarrassment and frustration. Eventually it was agreed that DPSA would return to the conference on condition that they be given the platform to read a public statement. William Rowland explains:

> In the event, Pindi Mavuso and I then wrote a very strong statement attacking policy, citing the health conditions and the poverty of people. I wish that we still had that statement, it was truly historical in capturing on the first real occasion what was wrong. (Rowland, interview, 2001)

One of the most important ramifications of DPSA's involvement in the Year of the Disabled and the grant they received from the government was the setting up of the Development Fund (now the Thabo Mbeki Development Trust) under the control of the South African Federal Council. A large amount of the money from the fund was used to provide assistive devices to people working in the movement who otherwise would not have been able to be independent and move around organising people throughout the country. So the money was used to increase the capacity of the movement to grow stronger.

By the end of the 1980s, DPSA had begun to establish itself as a strong organisation with sufficient membership and funding to employ permanent staff and undertake a number of advocacy initiatives. It had a permanent office in Soweto where the National Development Officer was based and a Secretary General's office in East London. Mike du Toit describes the end of this period in the following way:

> We had some money, but not a lot…enough to say that people were travelling (and) there were lots and lots of meetings, lots of new groups being established (and) structures being put into place…then there was a huge wave of activity after 1990. (Du Toit, interview, 2001)

Putting disability on the transformation agenda (1990 –1994)

In February 1990, the ANC and other political organisations were unbanned and Nelson Mandela and other political prisoners released. The years between 1990 and 1994 are probably regarded as the most significant in formally shaping the establishment of democracy in South Africa and removing, at least at a political level, the system of apartheid.

These were important first steps. Yet the real challenge lay in creating conditions in the country where all people could contribute equally and freely to building a new South Africa. One of the most important issues that undermined attempts to get the negotiations process off the ground was the ongoing violence in the country, with strong evidence pointing to the apartheid government as either deliberately fuelling the violence or at best failing to address it in any meaningful way. During this period many people were killed and, of course, many people were disabled. Finally, negotiations were formally initiated in December 1991 at the Convention for a Democratic South Africa (CODESA) and the framework for a new constitution for South Africa was agreed (see Collinge, 1992).

As early as August 1990, DPSA began formal contact with the ANC as the 'new government-in-waiting'. It started to impress upon the ANC leadership the importance of integrating disability issues into the party's position papers and documents that would serve as the new government's legislative and policy framework.

The early 1990s was a key period for the DPSA. It entered the decade a relatively strong and vibrant organisation. It had secured sufficient funding to employ a small group of full-time staff and had built up a significant membership base. Most importantly, it had challenged fundamental assumptions about the manner in which the government and many service providers viewed and understood disability.

As the transition process got underway, the organisation experienced unprecedented membership growth and positioned itself as the voice of disabled people in the transformation process. A number of specific advocacy campaigns and groups within DPSA were crucial to the DPSA's expansion during this period, including the Disability Rights Charter Campaign, the Rural Disability Action Group, Disabled Children's Action Group, and Women's Programme.

The Disability Rights Charter Campaign

As DPSA's membership increased and it become known in communities, more and more people began to approach the organisation with problems that required legal or paralegal assistance. Following Jerry Nkeli's proposal to Mike du Toit that DPSA establish an advice office (Nkeli, interview, 2001), the Discrimination Watch Programme was established. As more complainants came forward, DPSA approached the Canadian Embassy for funding. The embassy explained that it had been funding a non-governmental organisation called Lawyers for Human Rights (LHR) and suggested that LHR would be the appropriate organisation to provide legal advice to disabled people. After discussions with LHR, it was agreed that a unit would be set up. Initially called the Socio-Economic Rights Unit, it changed to the Disability Rights Unit and was headed by Advocate Michael Masutha. While the unit performed a number of roles, including providing paralegal advice to individual disabled people and taking up cases of direct discrimination, it will always best be remembered for its role in mobilising disabled people throughout the country towards the development of the *Disability Rights Charter of South Africa (LHR 1992)*.

Michael Masutha explains that the Disability Rights Charter was the outcome of a human rights advocacy campaign that had as its central purpose 'to mobilise opinion from disabled people themselves, based on their life experiences, to shape national policy and thinking on disability' (Masutha, interview, 2001). Following a lengthy process of consultation through local and regional worhshops, a draft charter of demands was compiled.

The level of mobilisation and awareness brought about by the Disability Rights Charter Campaign was already evident at DPSA's congress in September 1992 when the Charter was adopted. Delegates were so incensed with the ongoing discrimination and marginalisation experienced by disabled people in accessing services that they decided unanimously that a protest march would be held in the centre of Durban. It is difficult to describe the excitement and significance of this day for the disability rights movement in South Africa. An eyewitness account by one of the marchers that was reported in the *disAbility* magazine perhaps best captures the events of that day:

> An action committee worked out the logistics while the slogan committee got down to serious business producing placards; cars were pulled into a procession…and then…two hours and a flat tyre later…we took off for West Street in Durban. We hit the streets at 15h30 on Friday afternoon…West Street was blocked…and eventually this resulted in a total collapse of Durban's traffic system. The message of disabled people demanding their rights and rejecting charity was carried through the streets and offices. As onlookers gazed in amazement, the Charter of the Rights of Disabled People of South Africa was adopted in the streets of Durban. (*disAbility*, No. 5, 1992).

Few people would disagree that the formulation of the Disability Rights Charter was an extremely important moment, not only providing an opportunity for disabled people throughout the country, both in and outside formal structures, 'to band together' (Machobane, interview, 2001), but also providing the movement 'with a weapon…to get into the new democracy' (Bogopane, interview, 2001). Jerry Nkeli argues that this weapon was most important because it located disability 'within a human rights approach', and as a 'progressive document, [it] served as the basis for subsequent discussions with the ANC' (Nkeli, interview, 2001). The Charter described the minimum demands of disabled people in South Africa to enable them to 'live independently…in a society free from all forms of discrimination, exploitation and abuse' (LHR, 1992, p. 1). It was also regarded as a living document that reflected the 'experiences of many disabled people from different sectors of our society' (LHR, 1992, p. 1).

The significance of the human rights and development approach to disability is that it recognises the fundamental needs of all people and their right to have these needs met. The basic need for dignity, freedom, a healthy lifestyle, education, housing, the opportunity to work and create and participate in all aspects of society, are important for all people. All the rights that any person is entitled to just because they are a human being constitute human rights. The Charter embodies the human rights and needs of disabled people. This includes their rights as citizens of South Africa and their developmental needs such health services, education, work, housing etc.

Membership expansion

A central principle of DPSA since its inception has been a commitment to self-advocacy and economic empowerment through the development of self-help groups of disabled people throughout the country. At the ninth DPSA congress in 1992, Friday Mavuso, then Co-Chairperson of DPSA responsible for development, reported that the organisation had seen a phenomenal growth in the number of self-help groups affiliating to DPSA (Mavuso, 1992). As membership grew, the organisation recognised that it would need to expand its staff to set up offices in different regions. Each region needed at least one staff member who could support the emerging groups and take responsibility for the recruitment of disabled people in local communities.

With the growth of DPSA's membership, the organisation developed regional structures that brought together representatives from each of the affiliated self-help groups in that region. The structures were called regional teams and consisted of 'two members of each self-help group within a specific region; one male and one female. This encourages that women are represented and that the regional structures are democratic and accountable to the DPSA members in the region' (*disAbility*, No. 4, 1992). These teams not only served to bring disabled people in the region together, but they also enabled DPSA to establish a strong presence in the regions and impact on discrimination and violations of rights at this level. In order to strengthen and support regional development workers, regional teams and individual groups, DPSA appointed Shuaib Chalklen in February 1992 as the National Training Officer.

Rural Disability Action Group

In 1986, a number of service providers, particularly those orientated toward community-based rehabilitation (CBR), had formed the Rural Disability Action Group (RURACT). Primarily started as 'a supportive mechanism for service providers and disabled people (to enable them) to meet and discuss issues identified by them as critical and needing attention' (*disAbility*, No. 6, 1993), RURACT's membership was drawn from service providers as well as disabled people working and living in rural areas. William Rowland, formerly a chairperson of RURACT, comments that, at its inception, RURACT had three key objectives, 'to share information between people that were starting to work in rural areas,…to stimulate income generating projects, and establish CBR according to the model produced by the World Health Organization' (Rowland, interview, 2001).

In 1992, RURACT became an action group within DPSA. Lidia Pretorius, an occupational therapist who had been centrally involved in early initiatives organising disabled people in rural areas, was appointed to co-ordinate its activities. Its expanded goals included: 'the setting up of a resource library with information on community-based rehabilitation, development agencies, publications etc.…to compile a resource manual for rural workers, to improve contact and co-operation with international sources of expertise on rural rehabilitation, and to improve liaison with national progressive organisations' (Pretorius, interview, 1992).

Self-advocacy and self-empowerment were central to RURACT's efforts to strengthen CBR, which at that time was a relatively new concept and seen by many as a challenge to traditional rehabilitation methods. To this end, service providers involved in RURACT committed themselves to developing a partnership model to deliver rehabilitation services to disabled people. Similarly, in line with the WHO's definition of CBR, they were intent on intervening in the immediate environment of the disabled person and addressing the systemic barriers in society that prevented their social integration.

RURACT recognised that its principles could not be fully realised in an environment where the rights of disabled people were continually violated. It was especially concerned with the limited, inadequate and racially divided provision of rehabilitation services in rural areas, based on a deficit/medical model of disability. RURACT's participation in the Disability Rights Charter Campaign included setting up workshops for the LHR team in rural areas as well as helping draft Article 3 of the Charter that deals with health and rehabilitation. They were instrumental in linking service providers and disabled people in a progressive structure and raising awareness about CBR and the plight of disabled people in rural areas.

Towards the mid 1990s, as the political landscape changed, including the deployment of disability rights activists, it was agreed that RURACT should be disbanded. William Rowland explained the thinking that influenced the decision:

> There was a point where [we] felt RURACT had served its purpose and we either had to re-invent a reason to exist or to discontinue it. I think the right thing is when a thing is done well and it has served its purpose, you can actually close this down as a chapter and that's what we did. (Rowland, interview, 2001)

Disabled Children's Action Group

Like the formation of DPSA, the origins of the Disabled Children's Action Group (DICAG) can be traced to initiatives by individual activists working in circumstances that forced them to confront and challenge the status quo. In the late 1980s and into the early 1990s, Vuyo Mahlati was working as an occupational therapist with children disabled as a result of ongoing violence in the informal settlement of Crossroads in Cape Town. Mahlati and a number of parents formed the Siyazama Parents' Society for Disabled Children in 1991. Through contact with the Vukuhambe Self Help Group for Disabled Persons, who were affiliated to DPSA, Vuyo was exposed to the disability rights movement. The mushrooming of interest and commitment to addressing the concerns of disabled children as well as a recognition on DPSA's part that this voice had largely been absent in the organisation, led to the formation of DICAG as an action group within DPSA in 1992. As a project within DPSA, DICAG was able to access some initial funding which enabled it to employ Vuyo Mahlati as its first national co-ordinator in July 1992 (Mahlati, interview, 2001). DICAG was officially launched in Cape Town in September 1993 as a DPSA project, but functioned as a non-racial national organisation with representatives on the DPSA national executive (*DICAG Newsletter*, 1993). DICAG remained a structure within DPSA until 1997, when it became a separate organisation with its own funding base.

Washeila Sait, Vuyo Mahlati's successor in 1993, explains that parents often came into the movement seeking support from other parents who understood their situation, especially their poverty and isolation as parents of disabled children (Sait, interview, 2001). However, it is largely through DICAG's involvement with the broader disability-rights movement and DPSA that parents have 'become more acutely aware of the rights issues' (Sait, interview, 2001). DICAG members were centrally involved in the Disability Rights Charter Campaign and in consultations with the ANC prior to the 1994 elections. The organisation also held a number of national conferences in which the voice of parents and thus of their children were raised and their experiences translated into an ongoing programme of action for the organisation that essentially remains the same today.

At the same time that DICAG was struggling to ensure that the rights of disabled children were taken up as part of the broader disability rights struggle, the organisation was also campaigning to ‘mainstream’ disabled children’s issues into broader initiatives around children’s rights in South Africa. In the post-1994 period, DICAG’s advocacy work served to deepen the children’s rights movement in South Africa by including the rights of disabled children in a number of key areas. It has also continued to grow and develop its profile and legitimacy as a force in the struggle for the rights of disabled children in South Africa.

Women’s Programme

From its inception, DPSA had recognised the additional disadvantage experienced by disabled women in a patriarchal society. Under the apartheid system, black disabled women were one of the most marginalised sectors, experiencing the most severe effects of poverty and social exclusion. Strong women within the organisation therefore began to push for a particular programme targeted at the empowerment of disabled women.

In 1993, DPSA secured some initial funding for the training and orientation of disabled women members of DPSA and a five-year plan was developed for the long term development of a Disabled Women’s Development Programme. While a specific programme targeting disabled women had now been set up, the organisation itself had done much within its own structures to address questions of gender equity and promote the equal participation of disabled women. Thulani Tshabalala remembers that:

> It soon became apparent to many members of DPSA that meetings and activities of the organisation were excluding disabled women. We therefore used international experience to guide us in developing and implementing strategies to include disabled women. For example, no self-help group could attend a meeting without a women representative. (Tshabalala, interview, 2001)

The Women’s Programme began to develop momentum and received sufficient funding to employ Henrietta Bogopane as the full-time co-ordinator of the programme from January 1996. The programme identified three key areas for intervention: leadership and development; training and entrepreneurial development; and exchange visits and information sharing. Henrietta Bogopane comments that as ‘a change agent’ within the organisation, the programme aimed ‘to prepare disabled women for leadership positions within DPSA and outside of the organisation. The aim was also to enable disabled women to participate with other women on an equal footing’ (Bogopane, interview, 2001).

Although much still needs to be done, the programme has remained a key strategic imperative for the organisation in the post-1994 period. Significant progress has been made, however, as evidenced by the leadership roles and responsibilities that many of the early women activists have taken on in the post-1994 period.

The Bill of Rights and building an alliance with the ANC

The early 1990s marked a period of intense political activity in South Africa as the transition from apartheid to democracy was negotiated between the apartheid regime and the new political players. For the disability rights movement, this was an opportunity to integrate disability issues into the policy framework and government of a post-apartheid South Africa. The integration of disability issues revolved around two central tenets. Firstly, new legislation and policy should prevent discrimination against disabled people and protect their rights in the same way as for any other citizen. Secondly, based on the recognition that disabled people had been discriminated against, a post-apartheid order should promote opportunities for disabled people to have equal access to basic services, including education, health, social security, transport, etc. It also argued, however, that fundamental to the achievement of these rights was respect and adherence to the principle of self-representation by disabled people.

During this period, DPSA attempted to remain non-aligned with regard to any specific political party. It recognised that people had come into the movement as a result of their varied experiences of disability and as such the organisation 'lent itself, by its very nature, to cross-party situations' (Masutha, interview, 2001). At the same time, however, it was important to work closely with the ANC as effectively the 'government in waiting' (Masutha, 2001). There was also a strong ideological bond, a common vision for South Africa, and many DPSA leaders were also members of the ANC. In its turn, the ANC showed a willingness to 'embrace our struggle for rights, dignity, self-representation and equality' and was 'prepared to embrace disability issues' (Nkeli, interview, 2001).

The DPSA made a concerted effort to engage the ANC around disability issues. At a series of meetings held between DPSA and the ANC in the early 1990s, following Mike du Toit's initial submission to the ANC National Executive in 1990, DPSA endeavoured 'to introduce the issue of disability rights and market the Disability Rights Charter' and further to 'make sure that the necessary preparatory work had been done to ensure that the ANC in government would be able to develop the kind of policies and laws that would improve the situation for disabled persons' (Masutha, interview, 2001). DPSA's initiatives to integrate disability issues into ANC policy frameworks were followed up by submissions and lobbying at CODESA, with the result that the Constitution recognises the prevention of unfair discrimination on the basis of disability as well as the implementation of measures designed to redress inequalities experienced by disabled people in the past.

Much of the focus of DPSA's activities at this time was on placing disability within a human-rights framework. However, the organisation was also intent on ensuring that all political organisations were integrating disability issues into their political programmes and manifestos and that they were actively seeking consultation with disabled people around these issues. To this end, DPSA convened a political summit in 1994, where the major political parties were invited to present their plans for accommodating the rights of disabled people. Following an extremely poor response, DPSA approached the ANC leadership 'to discuss both the ANC's poor response to the summit, and also its election manifesto' (Masutha, interview, 2001).

DPSA entered into negotiations with the ANC leadership around political representation of disabled people, leading to the ANC's commitment to include at least two disabled people on the ANC's election list (Rantho, interview, 2001). In taking up this offer it is important to recognise that DPSA also made a strategic decision to 'review its policy of non-alignment' and to enter into a formal partnership with the ANC (Nkeli, interview, 2001). DPSA decided to propose Maria Rantho and William Rowland as their candidates on the election list. William Rowland decided after much thought to decline the position for personal reasons and to remain in civil society (Rowland, interview, 2001). Maria Rantho entered the National Assembly in 1995.

The South African Federal Council on Disability and the National Co-ordinating Committee on Disability

As has been recounted above, attempts to engage strategically with the apartheid government during the 1980s were frustrated by the government's marked lack of commitment, despite the UN Decade of the Disabled and the state's own initiatives in 1986. As state repression increased, DPSA's already ambivalent willingness to continue to engage the government lessened. By 1990, no working relationship existed and the ICCD, established during the Year of the Disabled in 1986, was finally disbanded in 1991. Although briefly replaced by another forum, it 'became clear [to DPSA] that the government had not been acting in good faith and was attempting to co-opt the NGO disability community into implementing its own unpopular policies' (Rowland, interview, 2001). DPSA decided to effectively disengage with the apartheid government and 'for two years there was no communication with the government on disability issues as a deliberate policy, until liberation was imminent' (Rowland, interview, 2001).

While relations with the apartheid government disintegrated, co-operation between DPSA and the non-governmental service-providing organisations strengthened, with an agreement between these parties to revive the old Federal Council on Disability. In August 1992, the new South African Federal Council on Disability (SAFCD) was launched. Rather than attempting to engage with the apartheid government, the structure would 'concentrate on the development of disability policy and concept legislation for a post-apartheid South Africa, interfacing with the negotiating process…rather than the present government' (*disAbility*, No. 4, 1992).

However, in 1993, the outgoing government acknowledged the need for a national co-ordinating structure that would create an interface between government and the organised disability sector (Disability Rights Unit, 1993). Despite misgivings that a new structure would not achieve anything more than the forums of the past, the disability sector felt it important to work toward the recommendation of the United Nation's *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* which states that: 'States are responsible for the establishment and strengthening of national co-ordinating committees, or similar bodies, to serve as a national focal point on disability matters' (UN, 1993). SAFCD therefore entered into a structure with the outgoing government in 1993 called the National Co-ordinating Committee on Disability (NCCD). However, it soon became apparent that the forum was not providing a way to engage meaningfully with the state (Thompson, interview, 2001). The NCCD died a natural death as a range of new structures and initiatives by both the disability sector and the new government were launched in the post-1994 period.

International and regional initiatives

As a member of DPI, delegates from DPSA were invited to attend the international DPI conference in Vancouver, Canada in 1992, marking the eleventh anniversary of the founding of DPI. It was the end of the UN's Decade of Disabled Persons and it was ten years since the adoption of the UN's World Programme of Action Concerning Disabled Persons. Despite the important developments which had taken place throughout the world in these ten years, particularly in the development of disabled people's organisations and movements, the 2000 plus delegates at the conference noted in their closing declaration that their struggle was far from over and that, particularly in the developing world, disabled people remained the poorest of the poor.

Although it is generally agreed that the decade did not result in any significant changes in the lives of the majority of disabled people throughout the world, the most important outcome was the adoption by the UN General Assembly on 20 December 1993 of the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (UN, 1993). The rules took forward the key concepts of the World Programme of Action and provided an instrument to guide states in realising equal opportunities for disabled people; they deal with key socio-economic rights and provide guidance on models which states should adopt in facilitating the inclusion of disabled people and their organisations in processes of decision-making. It is important to recognise that while the rules provide a strong moral and human rights framework to guide states, they are not binding on any government in the same way as a UN convention is. Despite this limitation, DPSA was able to use them, in the same way as the Disability Rights Charter, as a strong lobbying tool to inform their deliberations, and as a strong framework to guide the development of South Africa's

White Paper on an Integrated National Disability Strategy. (ODP, 1997) discussed in the next section.

Since its inception, DPSA has maintained strong ties with activists in other southern African countries through its involvement in the Southern African Federation of Organisations of the Disabled (SAFOD). William Rowland, then chairperson of DPSA, also served as SAFOD chairperson for a long time and was involved with other SAFOD members in a number of regional initiatives which included helping establish disability movements in those countries (Rowland, 2001). The southern African organisations now work with other African disability movements through the Pan African Federation of the Disabled (PAFOD). DPSA members, such as Maria Rantho, have also held leadership positions in SAFOD.

One of the most important SAFOD initiatives during the early 1990s was the setting up of a working group to look into equality legislation for disabled persons. In March 1991, SAFOD organised a symposium on equal opportunities legislation for disabled people in Harare. Nine southern African countries were represented as were the United Nations and international aid bodies. The key outcome of this symposium was the ratification of the *Harare Declaration on Legislation for Equalisation of Opportunities for Disabled People*, providing another important tool to guide the disability movements in lobbying for legislation in their countries. Zimbabwe was especially active in taking forward the recommendations from the symposium and managed to secure the passing in 1992 of the Zimbabwe Disability Discrimination Act.

Integrating disability into reconstruction and development: post-1994 initiatives

There has been an enormous growth in the number of initiatives launched by the disability rights movement following South Africa's first democratic elections in 1994. These have laid a structural and ideological basis for the recognition of disability as a human-rights and development issue and the creation of equal opportunities for disabled people.

Many of the initiatives which took place in the post-1994 period came about through careful planning and strategic thinking within DPSA and its allies, but there were also times when the movement responded to 'gaps' and 'opportunities' that arose through the broader transformation process taking place throughout the country. Because it is not possible within the limitations of this chapter to do justice to all the important things that have happened in the disability sector since 1994, this section deals only with those that, particularly at a public level, can be regarded as being most important in the creation of new policy and legislation and the setting up of structures to impact on the delivery of government services towards the creation of opportunities for economic development and self-sufficiency. However, it is important to recognise the very important and often unrecorded initiatives that have been undertaken by disabled people and parents of disabled children in their local communities. These in fact are the very initiatives that have led to the larger and more evident changes that we see in place today.

The preceding discussion has focused on the activities of DPSA or its role within broader structures. The initiatives discussed below should be recognised as also reflecting DPSA's strong partnerships with other organisations within the disability rights movement and more broadly. The achievements discussed would not have come about without these partnerships and the commitment from the activists involved in developing and sustaining them. While the taking up of the disability rights struggle in the country now appears broader than the activities of DPSA and its close allies, it should be remembered that the activists behind these struggles are still those who were trained through the civil-society movements of the 1980s and early 1990s.

Office on the Status of Disabled Persons and the Integrated National Disability Strategy

One of the most important tasks that the new democratic government undertook after its election in 1994 was setting up the Reconstruction and Development Programme (RDP), situated in the President's Office. Its centrality was designed to facilitate and monitor reconstruction and development initiatives across all line-function ministries as well as to set up specific projects for this purpose, with a focus on particular groups who had experienced the most severe forms of marginalisation and therefore required particular attention in the transformation process. Not long after the inception of the RDP, a Gender Desk and a Children's Desk were set up within the programme. The disability rights movement felt strongly that a similar Desk focusing on disability issues should also be established.

Historically, disability had been seen and addressed as a health and welfare issue. For some time, however, and in line with the argument that disability is a human-rights and development issue, the disability-rights movement had been arguing that disability issues needed to be equally addressed by all line-function ministries and integrated into all aspects of their planning and service delivery. Establishing a Disability Desk within the RDP would create a government structure to address disability issues that would 'cut across all ministries' (Rantho, interview, 2001).

The Disability Desk was set up within the RDP in the President's Office at the beginning of 1995. Initially set up by Maria Rantho, with assistance from Lidia Pretorius, Shuaib Chalklen took over the running of the Desk until the RDP was disbanded early in 1996 and its various projects moved to the different line-function ministries. The Disability Desk, along with the Gender and Children's Desks, was then moved and established as a programme in the office of the then Deputy President, Thabo Mbeki. The Office on the Status of Disabled Persons (OSDP) was officially established on 1 May 1997 and came with a larger staff complement as well as increased funding. In 1999, after the second democratic elections, the OSDP was moved to the President's office, where it is presently located.

Although the OSDP's programme has grown significantly since its establishment, its objectives have essentially remained the same since its inception, that is, to ensure that:

- The executive arm of government embraced disability as a major issue;
- The various departments were mindful of and sensitive to the issues of disability;
- Government programmes were disability friendly, taking cognisance of the ideological issues of disabled people. (Nkeli, interview, 2001)

Linked with the work of influencing the policy process was the importance of developing the Disability Rights Charter into an overarching and comprehensive policy for the creation of equal opportunities for disabled people in South Africa. Efforts to synthesise the various policy proposals circulating between DPSA and its allies into a single policy framework began in earnest in 1995, when the Disability Desk, in consultation with all the key stakeholders in the disability sector, developed the *Framework for the Development of an Integrated National Disability Strategy*. The publication of the Framework was followed by the holding of public hearings in all nine provinces. Like the Disability Rights Charter Campaign, the public hearings process around the Framework provided both an opportunity to hear and record people's responses to the document, and to raise awareness among disabled people and government officials in particular, about disabled people's concerns.

Following the provincial public hearings, a national public hearing on the Framework was held in Parliament, after which a team drawn from DPSA, the National Co-ordinating Committee on Disability, the SAFCD and the Disability Desk was established to collate the responses and develop the Framework into a White Paper to be ratified as official government policy. In November 1997, the *White Paper on an Integrated National Disability Strategy* (INDS) was published by the government.

Much of the OSDP's work since the publication of the INDS has involved working closely with government officials and influencing key policy processes and associated programmes. As part of the OSDP's monitoring and support role, it has set up management systems to co-ordinate inter-sectoral collaboration around disability issues. The capacity-building and monitoring role of the OSDP remains an ongoing and essential objective of its work. The establishment of the OSDP and the publication of the INDS, like the formation of DPSA back in 1984, can be regarded as critical milestones in the history of the disability rights struggle in South Africa. The ODSP has become one of the most important institutional mechanisms to bring about change for disabled people in South Africa, and because of its central and senior location in government, it has the power to change the conditions of disabled people on the ground.

Yet while there is widespread agreement that the setting up of the OSDP reflects a major achievement for the disability-rights struggle, it is also recognised that there may be weaknesses to the office as well. Essentially these are structural. For example, the OSDP can only influence and monitor policy in key areas; it does not have direct responsibility for the implementation of this policy – this is the responsibility of each line-function department. Also, because of its location at the senior government level, the OSDP is not sufficiently in touch with the direct concerns of the majority of disabled people on the ground. Also, some activists argue that the policy document has gaps that affect its implementation, in particular, insufficient explanations and guidance about what the proposed changes actually mean in practice. Many of these implementation issues are at the heart of the challenges identified by the disability rights movement for future activism and lobbying.

Early on in the Disability Desk's existence, the sector recognised that the success of national structures required interventions at provincial and local government level. Negotiations were therefore begun between disability activists in the provinces, the national Desk and the provincial governments to set up similar Desks in each of the offices of the nine provincial premiers. On 1 April 1997, the first provincial Disability Desk was set up in the Office of the Premier of Mpumalanga. Provincial Disability Desks have since been established in all nine provinces.

A breakthrough early on in the interaction between the government and DPSA was the request for the then Deputy President, Thabo Mbeki, to become patron of DPSA. He accepted and as the present President of the Republic, he remains patron of the organisation.

National, provincial and local government presence

Article 2 of the Disability Rights Charter states that 'Disabled people shall be entitled to represent themselves on all matters affecting them and resources shall be made available to enable them to fulfill this role' (LHR, 1992). It is evident from the history described thus far that this principle has been central to the strategies and tactics adopted by the movement since its inception. In the post-1994 period, this principle has been most clearly implemented through the placement of disabled people in key governance and decision-making forums throughout the country.

As discussed previously, the ANC had committed itself to placing two disabled people on its election list in 1994. Following William Rowland's withdrawal, DPSA chairperson Maria Rantho remained the sector's only parliamentary candidate. However, despite the ANC's commitment to include disabled people in Parliament, as Maria Rantho explains, not only was she on her own, but the parliamentary institution was an extremely difficult and challenging environment to take up the disability struggle.

To support their parliamentary candidate, DPSA secured funding for a new programme from the Danish government through DPSA's sister organisation in Denmark, the Danish Council of Organisations of Disabled People (DSI). The Membership and Policy Development Programme (MPDP) was to be based in Parliament and would provide research and policy support to its parliamentary candidate. While the primary function of the programme was to support Maria Rantho in Parliament, the programme also provided broader support to DPSA structures throughout the country. An advocacy/paralegal advisor was appointed in the programme, who, among other responsibilities, represented the disability sector in the newly established National Economic Development and Labour Council (Nedlac), a key consultation and decision-making body with representation from government, organised labour, business and civil society. As the programme developed and the need to impact on policy progress increased, smaller policy units began to emerge in some of the DPSA's provincial offices.

Maria Rantho's presence in Parliament, together with the support of the MPDP, ensured that disability issues were placed firmly on the parliamentary agenda. The impact which Maria Rantho's presence in Parliament had on the institution itself was most publicly evident in 1998, when the official opening of Parliament that year was organised to give a particular focus to disability. It was aimed at raising the 'level of visibility of disabled people and also to celebrate the launch of the *Integrated National Disability Strategy*' (DPSA, 1998b). A civilian guard of honour, including representatives from a range of organisations within the disability sector, welcomed the President and parliamentarians into the National Assembly and for the first time in Parliament's history, the President's State of the Nation Address was translated into Sign Language.

One of the most important pieces of legislation for disabled people is the Promotion of Equality and Prevention of Unfair Discrimination Act, ratified in 2000. DPSA explains:

> [The Act] recognises the existence of systemic discrimination and inequalities, particularly in respect of race, gender and disability in all spheres of life as a result of past and present unfair discrimination, as well as the need to take measures at all levels to eliminate such discrimination and inequalities. (DPSA, 1998a)

Although the general equality provisions of the Constitution are especially important for all disabled people, the Constitution has also been extremely important in providing a framework for the recognition of Sign Language in South Africa and recognises Sign Language as an official language for Deaf South Africans. Similarly, the Constitution mentions Sign Language as one of the languages that the Pan South African Language Board (PANSALB) must 'promote and create conditions for the development and use thereof' (DPSA, 1998). While much remains to be done, the recognition of Sign Language in the Constitution has been extremely important.

It provides Deaf activists with a basis to argue for its recognition and inclusion in important pieces of legislation and policy, particularly in the area of education. Sign Language is now recognised as an official language for educational purposes, and the right of Deaf learners to receive education in Sign Language is protected by the South African Schools Act of 1996.

In 1998 Maria Rantho left Parliament to become a commissioner at the Public Service Commission. In recognition of the strategic importance of having a disabled person in Parliament as well as the milestones reached and achievements accrued to the disability rights movement during the period of the first democratic Parliament, it was therefore decided to approach the ANC with a view towards putting forward disabled people for inclusion on the ANC's 1999 election list at both national and provincial levels.

The five people nominated by DPSA who, at the time of writing, sat in the National Assembly, were Louis Nzimande (also the present DPSA Chairperson), Joseph Mzondeki, Henrietta Bogopane, Michael Masutha and Wilma Newhoudt Druchen. They were joined by two other disabled people, Maxwell Moss, also representing the ANC in the National Assembly, and Boyce Willem, an ANC representative in the National Council of Provinces. In Free State province, Zanele Dlungwana and Butana Khompela (subsequently deployed to the National Assembly) from DPSA represent the ANC in the provincial legislature. Flora Masakhona Raedani, a DPSA leader in Limpopo Province (previously Northern Province), was also an ANC representative in the provincial legislature.

Probably the most important development that has taken place at the parliamentary level since 1999, is the establishment by Parliament of the Joint Monitoring Committee on Improvement of Quality of Life and Status of Children, Youth and Disabled Persons, chaired by Henrietta Bogopane. In line with its monitoring functions, the committee is empowered to call on the government to account for non-delivery of services or where implementation has not been properly undertaken.

In the first democratic election, DPSA focused most of its attention on ensuring representation of disabled people at national and provincial levels. In anticipation of the local government elections in 2000, it began raising awareness about the importance of disabled people preparing themselves for participation in local and district councils. At the same time, DPSA representatives at national and provincial levels began advocating within the ANC and parliamentary structures the importance of self-representation of disabled people at the local level. Following their submission to Parliament on the White Paper on Local Government advocating direct representation of disabled people at local levels, DPSA sent a statement of intent to the ANC indicating DPSA's wish to work with the ANC in placing disabled people in local and district councils (Ka Toni, interview, 2002). At the DPSA Biennial Congress in October 2001, Mzolisi ka Toni, DPSA Secretary General, reported:

> More than forty disabled people (were) elected as councilors throughout the country. Particularly successful amongst these were Northern Province with twenty and Free State with eight. (Ka Toni, interview, 2001)

Statutory bodies

The disability rights movement's 'institutionalisation' of the principle of self-representation was not restricted to parliamentary and local governance structures. It was also felt that the voice of disabled people should be heard in all relevant public bodies set up by the government or through the Constitution.

Shortly after the establishment of the South African Human Rights Commission, Jerry Nkeli was appointed a commissioner. While he has a particular responsibility within the Commission around the promotion and protection of disability rights, another person with a disability who is involved in the disability sector, Charlotte McClain Nhlapo, also serves as a commissioner. DPSA was also able to secure representation on the South African Youth Commission (Ngwanakopi Ramushu) and the Gender Commission (Beatrice Ngcobo). Maria Rantho is a commissioner at the Public Service Commission.

Disabled people are also represented at Nedlac and DPSA, as the representative organisation of disabled people in South Africa, fields the disability sector representatives. At the time of writing, Fadila Lagadien and Petronella Linders represent DPSA at the Development Chamber within Nedlac. Fadila Lagadien is also the overall convener for the community constituency in Nedlac. Through DPSA's involvement with Nedlac, Mzolisi ka Toni now sits as one of the community constituency representatives in the National Skills Authority, the statutory body set up under the National Skills Development Act of 1998.

A number of disability activists have also taken up positions as board members in other important public bodies. These include the boards of the South African Broadcasting Corporation (SABC), South African Tourism (Satour), Ntsika Enterprise Promotion Agency, National Development Agency and the National Board for Further Education and Training. The disability sector is also represented on a number of the national standard generating bodies under the National Qualifications Authority (SAQA) as well as on the board of the Road Accident's Fund, the Film and Publications Review Board, Umsobomvu Youth Board, Independent Development Trust (IDT) and Proudly SA. Disability activists have also played key roles in particular transitional government commissions, especially in specific sectors such as Education, Welfare and Labour. Raising awareness about disability issues in these structures is an ongoing struggle and often requires enormous commitment and dedication from the representatives who, in many cases, are operating in a climate which at best has little awareness of disability and in some cases may even be reticent to address issues which they regard as complicated and difficult.

DPSA recognises that it has an important role to play in supporting disability sector representatives in the various bodies. Therefore, together with the OSDP, it has undertaken a number of initiatives to do this. One such initiative has been the setting up of the National Working Committee (NWC), a ‘forum for disabled activists who have been deployed into key institutions, or who are working for these institutions, to come together to debate issues that impact on the lives of disabled people’ (DPSA, 2001). Dominique Souchon from the OSDP explains that these meetings have been important as they have provided individual activists with an opportunity to debate issues in a supportive environment without necessarily having to take their organisation’s positions (Souchon, interview, 2002). Another valuable initiative was the *lekgotla* (meeting) organised by OSDP and DPSA in May 2001, during which position papers on transport, education, economic empowerment, social security and access to justice were prepared and campaigns proposed.

Transformation of the South African Federal Council on Disability

It has been explained that prior to the setting up of the OSDP, the disability NGOs had interfaced with the government through the National Co-ordinating Committee on Disability (NCCD) located in the Department of Welfare. The disability sector participated in the NCCD through the SAFCD, the umbrella body of the non-governmental organisations. People in the disability sector felt that, in line with the Standard Rules, an umbrella body like the SAFCD should interface with the government through the newly constituted governmental structures (the OSDP and the provincial disability Desks) and not the NCCD. Consequently, the South African Disability Institute (SADI), a small research arm of the NCCD, developed a proposal outlining strategies for transforming the SAFCD and effectively disbanding the NCCD. The final proposals were ratified on 26 October 1998. The primary objective of the council was noted as being:

> A well co-ordinated civil society-based disability sector that has the structure and resources to support government with its commitment to achieve the full participation and equalisation of opportunities for all disabled persons at all levels of South African society. (SADI, 1999)

Although some tensions have arisen since the formation of the SAFCD, particularly around the role it was envisaged to play, there appears to be a strong sense among disability activists that the SAFCD’s value lies with facilitating consultation between the different players to co-ordinate the development of common strategies. Similarly, Philip Thompson, Executive Director of the SAFCD at the time of writing, argues that the structure serves as an important interface between service providers, government and organisations of disabled people and parents. As a collective, he argues, they are also better placed to access resources for the movement. Most importantly, he suggests that the SAFCD has also managed to impact on the transformation of existing service-providing organisations, leading to greater authority by disabled people within these structures (Thompson, interview, 2001). At the time of writing, the following organisations are affiliated to the SAFCD: DPSA, DICAG, Deaf Federation of South Africa (DeafSA), South African National Council for the Blind (SANCB), Down Syndrome Forum of South Africa (DSFSA), Quadriplegic Association South Africa (QASA), National Council for Persons with Physical Disabilities South Africa (NCPPDSA), South African National Epilepsy League (SANEL), South African Federation for Mental Health (SAFMH), South African Foundation of Cheshire Homes, the Cancer Association of South Africa (CANSA) and South African National Council for the Aged (SANCA).

Strategic interventions

The recognition of the need for disabled people to enjoy economic self-sufficiency has been a cornerstone of the movement's development from its inception. Although the disability-rights movement, over the past 20 years, has made a number of different interventions towards economic empowerment of disabled people, both Mzolisi ka Toni, the DPSA Secretary General at the time of writing, and his predecessor, Mike du Toit, argue that the interventions have been broadly around two strategic areas (Ka Toni, interview, 2002; Du Toit, interview, 2001). On the one hand, the movement has concerned itself with activities and programmes aimed at income generation and poverty alleviation, aimed both at individuals and organisations of disabled people. On the other hand the movement has also sought to address the employment of disabled people in the open labour market, mainly through breaking down discriminatory barriers, promoting legislation and raising awareness, but also through interventions that actually create conditions for disabled people to take up employment opportunities in the open labour market.

Although this area really requires a separate history of its own, a number of interventions made by the movement, particularly in the post-1994 period, stand out for reflecting the dual commitment to income generation and employment opportunities. In 1995, the late Friday Mavuso was able to attend and make a critical intervention at a Presidential Conference in Durban on small, medium and micro-enterprise development. At the conference, Mavuso argued strongly for the need for disabled people to be centrally involved in economic development initiatives within the country. As awareness outside the disability sector around the importance of including disabled people in the planning and implementation initiatives increased, DPSA began to move towards the development of a policy framework that would guide and provide direction in the area of economic empowerment strategies. The most important outcome of this initiative was the development of an Economic Empowerment Framework Programme (EEFP) that was submitted to the OSDP in December 1997. A proposed business plan on the implementation of the EEFP as a joint programme of the OSDP, the SAFCD and DPSA was submitted for discussion and consideration at the Presidential Jobs Summit in October 1998. The recommendations of the EEFP were endorsed and at its 1999 Biennial congress, DPSA reported:

> Significant gains for disabled people through the Presidential Jobs Summit (have been made), including: commitments to achieve the targets of two per cent public-sector quota for employment at all levels; two per cent private-sector target incentive through employment and accommodation tax credits; and employment equity implementation that is economically sound in terms of practicality and cost of accommodation, but which has enforcement teeth. (DPSA, 1999)

With a mind to developing the EEFP and providing support to DPSA and disability activists working in this area, DPSA set up an economic empowerment think tank 'to provide critical qualitative and quantitative analysis that will assist persons with disabilities, the business community, civil society and the public sector realise the potential outcomes of the EEFP' (DPSA, 2001a).

The think tank has also been involved with the development of a draft Code of Good Practice on Disability to guide the implementation of the Employment Equity Act (No. 55 of 1998). The Act not only prohibits unfair discrimination against disabled people, but also provides for affirmative action measures to promote employment equity.

Another important initiative has been the setting up of Disability Employment Concerns (DEC), a registered trust 'established to engage in business ventures and to promote the employment and economic empowerment of disabled people in ventures with which the DEC is concerned' (DPSA, 2001a). The first business venture DEC embarked upon was investing in the BayGen Power Manufacturing Company (BPM) that manufactured wind-up radios and torches for export and housed the Perkins Brailler Project. The capital outlay for this investment was made from funding initially received from the Liberty Life Foundation (Du Toit, interview, 2001). Since this initial venture, DEC has become an investment partner in a number of important businesses in South Africa, including consortia that have won bids to set up Classic FM radio station, e.tv and the National Lottery. DEC operates within the black economic empowerment framework, a key policy framework of the South African government where ownership, management and control of the economy is progressively transferred to the majority of its citizens, specifically targeting race, gender and disability.

The strategic approach of income generation for allied organisations and the creation of employment opportunities for disabled people still remain central to DEC's objectives. However, in recognition of the changing funding climate for non-governmental organisations, DEC has specifically recognised the importance of establishing sustainable income streams to DEC's seven national NGO beneficiaries. Over and above the need for sustainable funding is the imperative of employment equity in the open labour market. DEC is working towards deepening the opportunities for building employment equity for disabled people in the open labour market.

Another important intervention initiated in response to the changing funding climate was the establishment of the TM Mbeki Development Trust in December 1999. In contrast to the DEC initiative, the activities of the Trust are aimed at providing short-term funding solutions to the disability NGO sector. While it has a range of broad economic empowerment objectives, a key activity of the Trust is the management and distribution of the money that the disability NGOs now receive from the National Lottery.

Other sectoral interventions

The disability sector's strategic positioning through the establishment of the OSDP, the parliamentary presence, the strengthening of a co-ordinated civil society interface with government, and representation on key bodies has opened up opportunities for disability issues to be raised and addressed in a number of key sectors. While many gains have been made, each has required sustained commitment and ongoing struggles for the disability activists involved. Some of these struggles have been successful while others remain areas that require continued pressure, input and monitoring.

Of particular importance here are the sector's efforts directed towards building an inclusive education and training system. Largely through determined and sustained lobbying and through participation of key activists in the policy development processes in this area, the Deparment of Education finally published the long awaited *White Paper 6* on special-needs education in July 2001 (DoE, 2001). Like other policy documents, this policy challenges previous stereotypes about disabled people and the learning process and commits the government to realising the right of disabled people to equal education opportunities within a single, integrated education and training system.

Important interventions have also been made into the area of social security. During 2001, a consortium under the SAFCD undertook a research study for the Department of Social Development's Committee of Inquiry into a Comprehensive Social Security System. Aimed at providing guidelines for policy options around social security benefits for disabled people, the study is presently under review by the Committee (Thompson, interview, 2001).

Simultaneous with such formal interventions, disability activists continue to fight against the discrimination of disabled people in accessing disability grants. Notable among these is the legal challenge launched against the Eastern Cape provincial government in 1998 by the Legal Resources Centre. The challenge marked the beginning of an ongoing legal battle between disabled people and the provincial government regarding the payment of disability grants. Organisations such as the

Black Sash, Lawyers for Human Rights and the Legal Resources Centre, supported by DPSA, have continued to fight to resolve the ongoing problems.

Another important area where substantial interventions have been made is around issues of accessibility. These include the provision of accessible and safe public transport, accessible low-cost housing, ensuring that buildings and services are accessible and safe for all disabled people and access to information for blind and deaf persons in particular. Pressure from disabled people's groups, which included the blockading of the Johannesburg Bus Depot with wheelchairs and chains, resulted in at least two municipalities acknowledging that their responsibilities to the public include the provision of accessible transport for disabled people. While the number of designated parking bays for disabled people has increased and some local government authorities provide 'door-to-door' services for people with severe mobility impairments, many activists argue that these initiatives only impact on a small number of disabled people. They argue strongly that substantial changes still need to be made to public transport facilities such as public buses and trains to make these services accessible to the majority of disabled people. Thus, while substantial gains have been made in some areas, extensive barriers still exist for disabled people on the ground in accessing public transport, information, houses and public services. These barriers continue to exclude disabled people from opportunities, including employment and equal participation in society.

Interventions have also been made in the health sector, particularly in the development of appropriate guidelines for rehabilitation services and the adequate provision of necessary assistive devices. Emphasis has been placed on the inclusion of disabled people in existing health services and 'the restructuring and integration [of existing disability services] within the health system' (DPSA, 2000). Of particular concern to the sector is ensuring that existing education programmes around HIV/AIDS are accessible to disabled people.

While this provides a very brief sketch of some of the sectoral interventions, it should be remembered that the activities covered here largely reflect those addressed at a more formal public level. As such activities have been taking place, many smaller more locally orientated struggles have been occurring in a range of areas all essential to the creation of equal opportunities.

Reaching the most marginalised sectors

While efforts since 1994 have largely been orientated towards impacting on the broader transformation process in the country, DPSA itself has continued to recognise the importance of reaching and empowering key sectors within the disability movement. Since 1994, attention has been paid to the strengthening of the Disabled Women's Programme, which remains a key focus area of the organisation. Despite an internal commitment within DPSA and the importance of representation in the Gender Commission and Joint Monitoring Committee on Improvement of

Quality of Life and Status of Children, Youth and Disabled Persons, women with disabilities still experience substantial inequalities. As Mzolisi ka Toni commented at the DPSA congress in October 2001: 'The visibility of women in positions of influence both as leaders and staff [within the organisation] is still very low. The organisation will have to review its intervention strategy if we are to realise effective transformation in this area' (Ka Toni, 2001).

The mobilisation and organisation of disabled youth has also been recognised as a gap within the movement as disabled youth 'didn't qualify to be members of DICAG and their needs and aspirations were less catered for in DPSA' (DYSA, 1988). DPSA and DICAG organised a joint workshop in April 1997 in Durban to which they invited youth with disabilities. With the exception of three, the provinces each sent two youth delegates to the meetings at which a national committee was elected to spearhead the formation of Disabled Youth South Africa (DYSA). During the course of 1998, it was agreed that DYSA should become a national programme of DPSA and in March 1998 Muzi Nkosi was appointed as the National Co-ordinator of the programme, with a key task to mobilise youth at a provincial level.

The programme has played an important role in facilitating the participation of disabled youth, both within the organisation and within national youth initiatives. It has also ensured that the voice of disabled youth has been heard with that of other disabled people in initiatives such as the Presidential Jobs Summit. While the programme has been able to impact on the transformation process in this way, Mzolisi ka Toni, in his report to the DPSA congress in October 2001, argues that the organisation has not been able to realise its goals sufficiently towards the mobilisation of disabled youth, impacting on the organisation's ability to build new leadership to sustain the organisation in the future (Ka Toni, 2001).

In many respects, the development of the parents' movement and particularly DICAG's impact on the transformation process since 1994 requires a history of its own. As Washeila Sait argues 'DICAG is the only organisation in South Africa which has consistently placed the disabled child on the map of the government's agenda' (Sait, interview, 2001). It became clear during 1996 that sufficient funding and capacity existed for DICAG to become a separate organisation to DPSA. DICAG became independent from DPSA in September 1997 and now operates as its sister organisation. The strong link between the two organisations is maintained not only through joint initiatives, but also through the ex-officio appointment of the DICAG chairperson to the DPSA Council. The DICAG chairperson occupies the position of Deputy Chairperson: Disabled Children on the DPSA.

DICAG has made substantial inroads not only in organising parents of disabled children, but also in integrating the needs and rights of disabled children into mainstream initiatives around children's rights, particularly with regard to key government policies. In June 1995 South Africa ratified the United Nations Convention on the Rights of the Child. This was followed by the development and implementation of a National Plan of Action for Children as part of the country's responsibilities as a signatory to the Convention. Significant lobbying and advocacy interventions undertaken by DICAG ensured that disabled children were specified in the plan as a particularly vulnerable group (Sait, 2001).

Although this reflects only one of DICAG's critical interventions, it is important to recognise that these often resulted from intense lobbying and ongoing interventions from the activists involved. Washeila Sait argues that the parents' movement has had 'to continually struggle to be part of general initiatives in South Africa and have sometimes had to gate crash to be heard'. Despite the gains already made, there is 'still a lot of lobbying and awareness raising that has to take place, especially with government' (Sait, interview, 2001).

While reaching and organising disabled women, children and youth continue to be recognised as priorities within the movement, the post-1994 period also saw the growth of organisations that represented especially marginalised disabled people, even within the sector itself. Of importance in this regard was the establishment of DeafBlind South Africa in 1996. By 2000, this organisation had managed to raise enough funds to set up a national office to facilitate the identification and organisation of DeafBlind people throughout South Africa. To date, approximately 100 DeafBlind people have been identified in South Africa, with an estimated 3000 DeafBlind people still to be identified and reached (Souchon, interview, 2002).

Conclusion: challenges for the future

In many respects this study has drawn on the lived experiences of a small group of core activists and developed this picture from their memories of the events of which they were part, or from their recordings of the happenings at the time over the last 20 years. While acknowledging the limitations of this snapshot, both in its scope and subjective interpretations, it is still able to provide us with a sense of the passion, commitment, anger and vision that were behind the changes that have come about.

These changes reflect a movement that has achieved a phenomenal amount, unprecedented in the disability rights struggle throughout the world. This picture also shows the implementation of strategies that have sought to challenge a dominant discourse about disability and the attitudes and institutional practices that have perpetuated some of the deepest inequalities and most severe forms of discrimination in our country's history. But the strategies have also gone further to bring about structural and legislative changes that create an infrastructure for ongoing transformation towards the equalisation of opportunities for disabled people in South Africa.

One of the greatest achievements of the movement has been the institutionalisation of the principle of self-representation of disabled people. This includes their participation in the national Parliament, provincial parliaments, local government, and key public bodies and in the highest levels of government. As Jerry Nkeli says 'disabled people represent themselves and are not represented by professionals' (Nkeli, interview, 2001). A closely related achievement is the changing attitudes towards disability, 'a major achievement for the development of humanity itself' (Masutha, interview, 2001).

The shift in attitudes has been influenced by the strong human-rights focus placed on disability issues. Disability has been equally recognised as a basis of direct and indirect discrimination and a central factor contributing to inequality and the marginalisation of people in the past. New laws and policies now make provision for the removal of disability discrimination in key areas and create opportunities for addressing the needs of disabled people as a previously disadvantaged group in society.

The gains made by disabled people in South Africa have been mirrored by important developments for disabled people throughout the African continent, the most important of which is the declaration of 1999 to 2009 as the African Decade of Disabled Persons. Since the decade was launched, DPSA, the SAFCD and the OSDP have started to jointly plan and participate in implementation initiatives for the decade.

A process of radical change, such as we have seen in South Africa over the last ten years, always brings with it new challenges. From the picture gained through this study, two key areas stand out. While important for disability rights activists in South Africa to consider, they are also discussed here as a way of providing disability rights activists throughout Africa and the world with insights into lessons learnt from the struggle in South Africa.

As can be expected, the first challenge relates to the movement itself and its ability to effect internal changes necessary to meet the challenges of the new democracy. The second ongoing challenge relates to the problems inherent in policy implementation and the ongoing need to ensure that progressive advances achieved through new policies are translated into actions that will lead to fundamental changes in the lives of the majority of disabled people in the country. Although these two areas appear to be separate challenges with an internal and external focus respectively, ongoing monitoring and pressure to ensure effective service delivery is dependent not only on government capacity but also on strong organisations in civil society. These two key areas of challenge cannot therefore be separated from each other and need to be confronted holistically.

There is a strong sense among the majority of activists interviewed for this study that a central weakness within the movement has been its inability to sufficiently reproduce itself. More specifically, it is felt that at the time of writing, insufficient attention is being paid to building new leadership within the organisations and that there is a reliance on the same people to represent and take the movement forward. Similarly, as with other organisations in civil society, key activists have been deployed into strategic positions within the new democracy, taking them out of their organisations. It is emphasised that part of this challenge involves a clearer effort to target disabled youth and women to ensure that sustainability of the organisation (Masutha, interview, 2001; Ka Toni, 2001).

Weaknesses within the organisations themselves are also reflected in what William Rowland identifies as a loss of momentum within the movement (Rowland, interview, 2001). Michael Masutha takes this further by arguing that, 'the sense of advocacy and activism which prevailed then has, in my view, subsided. That comes at a cost because it is especially at this time when opportunities are presenting themselves that we need to seize the opportunities' (Masutha, interview, 2001).

For some people this involves strategies to renew some of the lost energy or activism of the past twenty years. For others this is about lobbying, advocacy, awareness campaigns and education. It also extends to the organisations themselves to develop and sustain an informed, dynamic and committed membership base. Related to this is the imperative to improve funding strategies so that the organisations have long-term sustainable sources of income (Ka Toni, 2001).

For a number of activists, responding more adequately to the changed political climate also involves what Jerry Nkeli identifies as a need to move more substantially from rhetoric to effective action and research (Nkeli, interview, 2001). Just because a 'social model' of disability now prevails in the way disability issues are spoken about does not mean that it is being appropriately understood and addressed at the grassroots level, especially in the delivery of services. It is only the disability movement that can deepen understandings of what the model means, for changing conditions on the ground provide the direction and insight to what a human rights and development approach to disability means in practice.

The story told in this chapter demonstrates that the activists involved in the disability rights struggle have achieved a profound impact on the new policy and legislative framework developed in South Africa since 1994, including drafting a comprehensive government strategy document to address disability from a human rights and development perspective and a range of key sectoral policies and laws. Similarly, the movement has established structures and participates in representative bodies that give direction to and monitor policy implementation.

That said, a number of people in the disability rights movement feel strongly that the changes taking place have not impacted sufficiently in changing conditions on the ground. This was clearly demonstrated at the 2001 congresses of DPSA and DICAG, where huge backlogs and lack of substantial improvements in areas such as accessible public transport, housing, health services and social security were noted. Similarly, parents of disabled children continue to experience enormous difficulties in accessing health, welfare and education services for their children. The DPSA Congress also noted with concern the 'absence of information on the impact of

HIV/AIDS on disabled people (and) the ignorance and denial by disabled people of their own vulnerability with regards to HIV/AIDS' (DPSA, 2001b).

The continued exclusion of disabled people from accessing basic socio-economic rights is exacerbated by the high levels of poverty that still confront the majority of disabled people in South Africa. While the movement has made important interventions towards prioritising economic empowerment initiatives, this continues to be identified as a central and ongoing challenge.

The challenge for the movement to strengthen itself and at the same time bring about more substantial changes in the accessing of basic socio-economic rights by disabled people provides the impetus for a recent OSDP/DPSA initiative. In February 2002, the OSDP signed a contract with DPSA that is aimed at building the capacity of the DPSA membership to campaign around and influence necessary changes in five key areas. These include:

- Ensuring maximum accessibility for all disabled people in the new taxi recapitalisation initiative and through new bus contracts;
- Supporting the implementation of EWP6 towards the building of an inclusive education and training system;
- Appropriate and supported recognition of South African Sign Language and the provision of Sign Language interpreters for Deaf people;
- The inclusion of disabled people in mainstream government initiatives towards small business development and employment equity;
- Ensuring that all disabled people who qualify for a disability grant are registered with the appropriate authorities and receive their grants on a regular basis. (Souchon, interview, 2002)

The Equality Act discussed earlier also provides a strong tool for taking typical cases of discrimination to the courts, especially in the area of socio-economic rights. Using the newly developed legislative framework more actively is therefore also recognised as a priority for the future.

While the gains of the past 20 years strategically situate the movement to confront the challenges of the socio-economic obstacles that continue to confront disabled people in South Africa, its situation requires it to give direction to and support of government initiatives. At the same time, DPSA and its allies recognise the importance of continuing to apply pressure on government to ensure that the creation of equal opportunities for disabled people remains a government priority. The opinions put forward and the challenges raised by the activists interviewed for this study suggest that this can be a contradictory position that is unlikely to change in the near future. They point rather to a need for the movement to recognise that the creation of equity for disabled people will continue to be about struggling to ensure that the forms of marginalisation and deprivation experienced by the majority of disabled people are constantly exposed, challenged and overcome. For them, this struggle will always include the need for self-representation by disabled people – through the building of strong organisations and most importantly a process of self-liberation. As the Minister in the Presidency, Essop Pahad argued at the DPSA Congress in October of 2001, there is a need for all disabled people in South Africa to be able to say 'I am disabled and I am proud'. This message is central to taking forward DPSA's 2001 congress theme to 'force open the doors to equity and delivery'.

Notes

1 This chapter is a shortened version of the document *Disability, Our Voice, Our Rights: The history of Disabled People South Africa and the struggles of the disability rights movement in South Africa (1980–2001)* compiled by Colleen Howell and Schuaib Chalklen for the DPSA and the OSDP in 2003.

2 It is important to recognise that while most white disabled children were accommodated in 'special schools', very little provision existed for black disabled learners. Where provision did exist, it was largely in the form of mission or church schools which provided for a small number of black disabled learners. The inequities and injustices that learners with disabilities, particularly black disabled learners, experienced in education are discussed in the joint report of the National Commission on Special Needs in Education and Training and the National Committee on Education Support Services (1997). These commissions were set up by the Ministry of Education at the end of 1996.

3 Some important initiatives started by white disabled people at the time were Kathy Jagoe's Disability Action Research Project at the University of the Witwatersrand and Neville Cohen's work around physical access to the built environment for people with disabilities.

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6 Integrating disability within government: the Office on the Status of Disabled Persons

Sebenzile Matsebula, Marguerite Schneider and Brian Watermeyer

How the Office on the Status of Disabled Persons came about

With the adoption of the South African Constitution in 1996 came the creation of bodies and organisations whose role it would be to implement, monitor and evaluate this constitution. The Constitution is very clear on the issue of disability, and the need to eradicate any form of discrimination on the basis of disability. For government, the national Office on the Status of Disabled Persons (OSDP) was established within the Presidency[1] at national level, and within the Premier's office in the nine provinces. Currently, the process of establishing disability desks and units in local municipality offices is ongoing across the nation.[2]

The establishment of the OSDP and, prior to that, the inclusion of disability within the Constitution, were both key products of the activity undertaken by civil society disability organisations since the early 1980s, leading up to the constitutional process. Their vision was to establish strong representation of disabled people both within government and within civil society. This led to not only the OSDP being established, but to the coming together of all disability organisations within civil society under the umbrella of the National Co-ordinating Committee on Disability (NCCD) and later the South African Federal Council on Disability (SAFCD).

This chapter aims to review the structure, role and functioning of the OSDP at national level, including examples of activities carried out so far in the implementation of the Constitution's stipulations in relation to disability.

The OSDP's mandate

The aim and mandate of the OSDP is to mainstream disability issues into all sectors of society. To this end, the *White Paper on an Integrated National Disability Strategy* (INDS) was developed by the OSDP and endorsed in 1997 by the South African Government as the framework for integrating disability issues into all aspects of government functioning.[3]

Initially, the OSDP's focus was very broad, including all possible scenarios for mainstreaming. With time, this focus has been narrowed to a mandate of co-ordinating and facilitating that mainstreaming, with a more recent and current focus on monitoring and evaluation. The co-ordination function was particularly important in the initial stages of the OSDP's work, which aimed to enable and assist government departments to develop their particular policies in respect of integrating disability into all their initiatives.

After 1999, this focus shifted to one of implementation, in line with the general trend set by the national government, which had proclaimed implementation as the nation's new central priority. For the OSDP, this function is translated into that of monitoring the implementation of policies and programmes within government.

Link with civil society

The OSDP is a government department, and as such its primary responsibility is to co-ordinate, facilitate, monitor and evaluate integration of disability issues within government. However, as was clear from the onset, the OSDP must also have strong links to civil society organisations in order to retain coherence and relevance in relation to the needs of South Africa's population. As indicated above, this was embodied in the very close and strong link between organisations of disabled people and the OSDP at the time of its establishment. The civil society organisations were those organisations of and for disabled people, such as Disabled People South Africa (DPSA), Disabled Children's Action Group (DICAG), as well as national councils such as the National Council for the Blind, National Council for the Deaf, and so on.

The understanding was that civil society organisations would provide some guidance and oversight to the OSDP in relation to its work within government. The NCCD was the first national body or structure set up to co-ordinate activities within civil society, and to present issues arising to the OSDP. The NCCD was succeeded by the South African Federal Council on Disability (SAFCD), whose function remained essentially the same.

While this initial intention was upheld in the early period of the OSDP work, problems did arise which made the relationship difficult to maintain. One such problem was the perception within the disability movement that the OSDP would be a direct service provider to disabled people. Clearly this did not match the OSDP's actual aim of facilitating disability integration into government policy development and implementation. This has led to some dissatisfaction with the OSDP among disabled people, as well as a certain level of tension between organisations of disabled people and the OSDP. The Minister within the Presidency, Minister Essop Pahad, has played a significant role in attempting to resolve much of this tension.

The growing resolution of the tension allowed the relationship between the disability movement and OSDP to settle into a mutually co-operative, collaborative and closely aligned modus operandi. One important example of collaboration was in the area of research, which, in the interests of appropriately intersecting with need, was informed and structured by the organisations of disabled people.

Another problem plaguing the relationship between civil society and the OSDP is the significant exodus of skilled disability activists from civil society organisations into the first democratic government in 1994, or into other structures outside of the disability sector. This is a development that had an impact not only on the disability sector, but on many other sectors of civil society, such as the trade unions. The disability movement was consequently left depleted of skills and leadership, rendering the movement to some extent constrained in its efforts to play a role both in society and in relation to government. The disability organisations are currently facing a crisis, with the SAFCD's structure and functioning having to be greatly reduced around the time of writing.

Legislation

Since the re-integration of South Africa into the international community in 1994, social change in South Africa has been a source of pride for South Africans and of interest to the rest of the world. The policies developed by the South African democratic government have been viewed as one of the most progressive in the world to date. South Africa is one of a handful of countries to have included disability issues within their constitution, proclaiming that no one in South Africa may be discriminated against on the basis of disability. Following from this, a number of related pieces of legislation have been promulgated, which target disability discrimination specifically.

Thus, various important pieces of legislation have been enacted by government which have particular relevance for disability and development. These include, among others, the Employment Equity Act, No. 55 of 1998, and the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000. The Employment Equity Act:

> acknowledges that people with disabilities are unfairly discriminated against in society and in employment, because of widespread ignorance, fear and stereotypes. As a result, people with disabilities experience high unemployment levels and, if they are employed, often remain in low status jobs and earn lower than average remuneration. In terms of the Act, all legal entities that employ more than 50 people must submit Employment Equity Plans to the Department of Labour, showing how many people with disabilities are employees and what positions they hold. (SAHRC, 2002, p. 22)

The Promotion of Equality Act expands 'on the Constitutional provisions prohibiting unfair discrimination and guaranteeing equality before the law…Significantly, the

Act…rules that the promotion of equality is the responsibility of persons operating in the public *and* private domains' (SAHRC, 2002, p. 21, original emphasis).

These pieces of legislation provide an excellent basis for promoting the human rights of disabled people. While South Africans' pride in our societal transformation is real, there is a risk that it may dissipate due to insufficient follow-through with implementation programmes. The President's focus on implementation in his inauguration speech in April 2004 reflects this need to move from policy development to policy implementation. The challenge for the OSDP, therefore, is to ensure that these pieces of legislation are accurately and adequately implemented within government departments.

OSDP programmes and activities

In 1998, the OSDP established an Interdepartmental Co-ordinating Committee on Disability (ICCD) to facilitate departmental collaboration within government in the implementation of the INDS. The ICCD is a national body of representatives from national government departments, which aims to ensure an effective and efficient mainstreaming of disability issues within South African society. The Inter-Provincial Forum (IPF), similarly, is a collaboration of provincial OSDP offices.

The activities of the OSDP have ranged from co-ordinating and facilitation within government departments to training and capacity building within the disability sector itself, and developing integrated policies with specific government departments. These activities were supported through funding made available by Swedish International Development Aid (SIDA).

In relation to monitoring and evaluation of the integration of disability within government departments, there is an attempt to develop a set of indicators to measure changes arising from the implementation of new policies. The OSDP aims to provide assistance to the different departments to develop relevant indicators to this end. In addition, the Presidency is setting up an electronic data-management system which collates all information collected on these indicators, and makes this information readily and easily accessible. The aim is to have information available at a single, central point, without having to make specific requests via line departments, which may lead to delays. The process of developing a relevant bank of indicators is a task to be undertaken by the various 'clusters' of government departments, under co-ordination provided from the Presidency. These clusters include the Social Cluster, the Justice Cluster and the Economic Cluster, among others. While disability issues are a strong focus of the Social Cluster, it is essential for all to become aware that these issues typically cut across many clusters. For example, abuse of disabled children and women would be an issue to be considered by the Justice Cluster as well as the Social Cluster, and perhaps others.

The system of clusters aims to ensure that issues such as disability, requiring a multidisciplinary approach, are addressed in this manner. For example, the policy decision that disabled children should be educated within mainstream schools requires services to be provided by the Departments of Transport and Public Works – as well as Education – to ensure adequate transport to schools that are accessible, as well as an education system that addresses the needs of disabled children. These departments must work together to meet the shared objective of educating a disabled child satisfactorily.

Within the Presidency, a framework is currently being developed in which the functions and issues of the Office of the Status of Women (OSW), the Office on the Rights of the Child (ORC) and the OSDP are operationalised in a co-ordinated and integrated manner throughout government. This is known as the Gender, Disability and Child (GDC) framework. Two of these offices have specific policy frameworks that guide their work, namely, the *National Policy Framework on Women's Empowerment and Gender Equality* (in the case of the Office on the Status of Women), and the *Integrated National Disability Strategy* (in the case of the OSDP). There is currently no policy framework for the ORC.

The offices are also guided by international instruments such as the Convention on Elimination of Discrimination Against Women (CEDAW) and the Convention on the Rights of Children (CRC). Currently there is no Convention on the Rights of Disabled Persons.[4]

It is envisaged that the GDC framework will facilitate the integration of these three target groups into governmental policy implementation, since it is integration which is at the heart of the philosophy of all three. For example, the OSDP is reviewing the specific conventions endorsed by each of the other two groups with a 'disability lens', to assess the level of integration of disability issues. Thus, within CEDAW, issues pertaining to disabled women must be thoroughly considered and integrated, whilst within the ORC, issues of disabled children must likewise be present. Similarly, it is essential that the Office on the Rights of the Child reviews the integration of issues pertaining to the girl child within CEDAW, and of disabled children generally in the light of the International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (cf. footnote 4).

Other activities of the OSDP include a recently initiated campaign aimed at addressing awareness – particularly among employers – surrounding disability and integration of disabled people in the workplace. This campaign also aims to examine the portrayal of disability in the media, as well as foster and showcase creative works of disabled people (including writing, art, theatre, dance and music). The central theme and focus of the campaign is the promotion of disability rights.

A report undertaken in 2000 to review the effectiveness of disability integration within government departments, concluded that little effort has been made to integrate disability issues within government (Research Dynamics South Africa, 2000). This has led to the OSDP undertaking training of government officials in the mechanisms for achieving this integration.

Challenges

The OSDP has faced – and continues to face – significant challenges. Some of these are internal to the Presidency; others are within broader government departments and within civil society.

The challenges from civil society have been described above. These centre around the initial expectations of the disability movement with regard to direct service provision, as well as the current difficulty experienced by the disability movement regarding capacity and transitional leadership, following the move of many key figures to government and other sectors.

At the time of writing, the situation of the OSDP within the Presidency is challenging in the sense that commitment to, and understanding of, disability integration is not shared by all levels of staff. While the President and the Minister in the Presidency have consistently shown strong leadership and commitment to disability, this has not always transferred to other levels within the Presidency. The result is that the OSDP must continuously reassert its position that a multisectoral vision is essential to protection and promotion of the rights of disabled people, and that it is essential that disability issues remain a focus within the work of the President's Office, as against being relegated to a single ministry, such as Social Development. Other chapters in this book provide clear arguments for this broad, multisectoral strategy required for a human rights and development approach to disability. A further difficulty experienced is the large number of requests that are made to the OSDP which require a more extensive staff complement to ensure that all are addressed satisfactorily. This is particularly crucial in the current period of working towards integrated policy development and implementation. It might be less crucial once disability has reached a certain level of integration and the process becomes more self-sustaining.

Despite ongoing efforts to work with all government departments, the response in terms of integrating disability is slow. There have been some movements with certain departments creating dedicated posts and sections for dealing with disability issues, for example, in the Department of Communication. This approach of establishing disability units in line-function government departments has both advantages and disadvantages. On the one hand it highlights the need to consider disability issues, while on the other it keeps these issues within the ambit of the person's responsibility, rather than pushing for integration. This is probably a necessary phase in the process of full integration, but should be monitored closely to ensure that integration, and not segregation, is being fostered. As outlined in the Situational Analysis Report (Research Dynamics South Africa, 2000), progress with respect to policy and programme integration of disability is very slow.

Conclusion and way forward

The establishment of the OSDP was clearly an important factor in starting the process of disability integration. However, the work of the OSDP could be greatly advanced by accelerating the process of formulating the INDS into legislation. This is a position that is proposed by the disability sector – both in government and civil society. Members of the sector are of the view that the lack of legislation dealing specifically with disability further marginalises attempts to integrate disability into the societal mainstream, as there is no enforcement mechanism for support.

The transitional nature of South African society means that the contribution of the OSDP should be continuously reviewed to ensure that it is maintaining the necessary links with civil society, specifically the disability movement, as well as achieving its goal of full integration within all government departments. This is especially important with regard to monitoring and evaluation of the OSDP's ongoing work. The current programme of the African Decade on Disability emphasises the strengthening of organisations of disabled persons in order to ensure a dynamic and successful programme to mainstream disabled persons. The OSDP is in line with the objectives of the African Decade and currently leads in the implementation of the programme. However, much work still remains to be done in order that disabled persons in South Africa may fully participate in all aspects of society and enjoy their rights as citizens of South Africa. The OSDP requires the necessary infrastructural support in order to be able to realise its mandate as a unit to mainstream disability in the Presidency.

Notes

1 Initially the national office was set up under the office of the Deputy President, Thabo Mbeki, and then moved to the Presidency when Mbeki became president.

2 This chapter is the outcome of an interview that Marguerite Schneider and Brian Watermeyer conducted with Sebenzile Matsebula of the OSDP in the President's Office. The interview was taped and transcribed, and Marguerite and Brian wrote the chapter, which was then sent to Sebenzile for comment and final approval.

3 The INDS has not been promulgated into law.

4 However, the United Nations has embarked on a process to develop one through the workings of the ad hoc committee for the Elaboration of the United Nations comprehensive and integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. The OSDP is actively involved in this process and leads the South African delegation, which participates at the United Nations meetings in New York.

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7 *Establishing the Secretariat for the African Decade of Persons with Disabilities*

Shuaib Chalklen, Leslie Swartz and Brian Watermeyer

The United Nations Decade of Disabled Persons (1983–1992) created the expectation worldwide that member states would implement the World Programme of Action Concerning People with Disabilities. It was hoped that this decade would lead to an improvement in the quality of life of disabled people throughout the world. The UN Decade led to many successes, including the promulgation of the *Standard Rules on the Equalisation of Opportunities for People with Disabilities* (UN, 1993). There were, however, some concerns, particularly from lower-income countries, that the UN Decade had not achieved enough to change the situation for disabled people globally.

Stemming from the UN Decade, an Asian and Pacific Decade of Disabled Persons (1993–2002) was declared. A similar drive to create local solutions to local problems informs the African Decade of Persons with Disabilities (1999–2009).[1] The 12 specific objectives for the African decade are to:

1. Formulate and implement national policies, programmes and legislation to promote full and equal participation of persons with disabilities;
2. Promote the participation of persons with disabilities in the process of economic and social development;
3. Promote the self-representation of people with disabilities in all public decision-making structures;
4. Enhance support services for disabled persons;
5. Promote special measures for children, youth, women and elderly persons with disabilities;
6. Ensure and improve access to rehabilitation, education, training, employment, sports, the cultural and physical environment;
7. Prevent causes of disability;
8. Promote and protect disability rights as human rights;
9. Support and strengthen the development of disabled persons' organisations;
10. Mobilise resources;
11. Provide mechanisms for co-ordination, monitoring and evaluation of the activities of the African Decade of Persons with Disabilities;
12. Advocate and raise disability awareness in general, and awareness of the African Decade of Persons with Disabilities in particular.

The African Rehabilitation Institute (ARI) was tasked by the Organisation for African Unity (later the African Union) to spearhead work on disability issues in Africa. In 2003, the Africa Regional Consultative Conference resolved to establish a continent-wide NGO to continue and deepen the work of the African Decade. The Board of the Secretariat consists of representatives from the Pan African Federation of the Disabled (PAFOD), The African Union of the Blind (AFUB), Inclusion Africa, Psychiatric Users Africa, African Federation of the Deaf, ARI, a representative of the South African Government, and a representative of the South African Human Rights Commission. An office was established in Cape Town and the work of the Secretariat for the Decade began. The Secretariat also established links with the Asian and Pacific Decade (which has been extended) and with the recently-proclaimed Arab Decade.

Setting up the Secretariat

Running a continental NGO is not without its challenges. Firstly, an NGO cannot dictate to a government what it should or should not be doing. Furthermore, the importance and intricacy of managing relations with governments across the continent is complicated by the need to influence what happens in sovereign countries, while operating from a base in one country.

In the light of these factors, the Secretariat has prioritised the provision of information to all countries in the region about issues that affect disabled people – including information on policies, on UN processes, on the World Bank position on disability, and also on poverty eradication and income generation for disabled people. Along with this provision of information, there is a clear need for the building of capacity. The focus here is on training and developing skills in management, leadership, lobbying and advocacy. It is sometimes the case that the well-known gap between rhetoric and what is actually occurring can appear – and widen. It is therefore important to remain alert to empty rhetoric if information and training are to be accurately targeted. Travel within the continent helps to ensure that words are translated into action, as experiencing a society first-hand allows the Secretariat to see what is happening on the ground, as well as to forge positive and productive relationships with local agencies.

Understanding the context

In the experience of the Secretariat, there are also less tangible socio-emotional factors to be taken into account in the development of the Decade. In some countries, the disability sector is highly energised and very active in advocacy work. In others, the lack of motivation and sense of despondency is palpable and distressing. Faced with demanding and complex problems, and severely under-resourced, many workers in these countries are filled with despair. This apparent despair is often linked with broader social challenges and not just with disability specifically. Without a constant in-country presence, the Secretariat of the Decade has a difficult task trying to bolster and maintain enthusiasm, mobilisation and progress in some contexts.

One way in which the facilitating conditions for sustained development can be built is through the growing of infrastructure. The *Continental Plan of Action for the African Decade of Persons with Disabilities* commits countries to 'establish and strengthen national co-ordinating committees with emphasis on the adequate and effective representation of disabled persons and their organisations and define their roles in these committees' (African Union, 2003, p. 14).

Although the plan commits all African countries to establishing the required organisational infrastructure, this has not always happened. In many instances, the first task of the Secretariat is to encourage the government and disabled people's organisations (DPOs) in a country to establish the requisite national co-ordinating committee. This immediately gives the Secretariat a body with which it can liaise. In addition, and crucially, a national co-ordinating committee provides a clear local infrastructure through which resources can be allocated and managed, and their utilisation co-ordinated to maximum effect. However, in requesting that a country's commitment to establish a national co-ordinating committee be honoured, it is crucial that the Secretariat is not perceived to be meddling in the affairs of that country, as such a perception may have a negative impact on disabled people's rights. It would be easy – as well as patronising – to say this or that country is not doing what it should. Far more difficult (but more constructive) is to find ways of encouraging and facilitating movement towards the desired situation.

Essential to the Secretariat's credibility is its internal governance and accountability. The Secretariat is accountable to the board mentioned earlier comprising representatives of continental organisations of disabled people. The practical and logistical challenges of setting up board meetings are immense. For example, if a board member is based in Burkina Faso and wants to come to a board meeting in South Africa, that person has to drive to Mali or Senegal to obtain a visa, as there is no South African embassy in Burkina Faso. There are also, obviously, expenses involved – which are sometimes difficult to anticipate, and potentially difficult to explain to funders. Furthermore, the Secretariat currently employs only three people who assume responsibility for making all these arrangements – a large workload.

Building and strengthening partnerships

Facilitating relationships between DPOs and governments present further challenges. In order to understand these challenges it is helpful to think about the context of DPOs in wealthier countries. In the US, for example, there is a tradition of litigation around social issues, though access to courts is severely limited by costs. Therefore, issues related to poverty and disability may have less chance of reaching the courts than other issues. In western Europe, a history of social welfare and social democratic policies ensures there is considerable financial provision for disabled people. However, this provision, paradoxically, may mask broader issues of social exclusion. Where people are the recipients of welfare, they are not always seen as part of the mainstream of society and as full contributors to the development of that society.

The situation in Africa differs radically from that in the US or Europe for a number of reasons. Most fundamental is the issue of poverty. Severe poverty disempowers people and severely limits the extent to which people can organise themselves into successful DPOs. More pressing still than the disempowerment of poverty is the difficulty of survival. For example, though a person with a spinal-cord injury in a wealthier country, or even in South Africa, has a long life expectancy, some have estimated the life expectancy for a person with a spinal-cord injury in a poorer African country at between four months and two years. Environments that can't be kept clean breed bacterial infections, which can have fatal consequences for people with spinal-cord injuries – especially when there is little or no access to antibiotics. Similar challenges face people with other impairments, rendering an overall scenario of substantial barriers to the meaningful organisation and self-representation of disabled people.

Despite these and other challenges, the response to the Secretariat and to the Decade has been very positive. It is important to be realistic, though, about what can be achieved, and to understand how disability issues interface with broader governance issues. Disability rights cannot thrive in a situation where other rights are not broadly enjoyed in the society. As one begins to ask questions about the rights of disabled people, one soon enters into more general debates about what any citizen in a country can expect in terms of participation in democratic processes, and in society as a whole.

Clearly, these broader debates pose questions about societal power relationships, beginning with the issue of who holds and maintains power, and why. While on the one hand, it is not the place of a continental NGO dealing with disability to comment on and seek to influence the broad political processes of a country, on the other hand, it is not possible to divorce disability issues from these contextual factors. Thus, the Secretariat must walk a tightrope if it is to have any influence at all.

Where there are wars – and there are many wars in Africa – these may contribute to more people becoming disabled in various ways, but also, crucially, may decrease participation of disabled people in the broader society. Civil society as a whole is unlikely to have a large influence in a country dealing with internal or external military conflict. As Armatya Sen has noted, development is freedom – it is not possible to have development in a context where there is no freedom.

Strategic challenges

Given these realities, much of the response to these challenges comes down to strategy. International policy documents (including that of the Decade itself, along with UN disability policies, and especially the Convention on the Rights of Disabled Persons) are helpful in that they oblige national governments to make movements towards prioritising disabled people's rights. As many countries are signatories to such documents and processes, the imperatives they contain can be invoked as a means to exert influence and apply pressure upon countries across the continent. Clearly, there are huge resource constraints, and many countries cannot do everything they would like to. But where enabling documents exist, countries cannot cite resource limitations to excuse their lack of action in advancing the goals they have agreed to. Where goals are not immediately attainable, it is reasonable to expect that a plan exists outlining a longer-term programme of action that will realise these goals. This is similar to the principle of 'progressive realisation' by which the South African government commits itself to making demonstrable progress towards long term delivery goals.

Since Nepad (New Economic Partnership for African Development) is committed to good governance, peer review, infrastructural development, and so on, the Nepad infrastructure also provides opportunities for the realisation of strategic goals – all of which are essential for the realisation of rights and opportunities for disabled people. South Africa has a particular role to play both in Nepad and in terms of the Decade, not least because South Africa has a strong economy and a stable financial environment; further, South Africa is not involved in internal conflict or war, and has inculcated a broad human rights culture. However, this should not undercut the particular contributions that other countries must and can make. For example, there is very good representation of disabled people in high levels of government in a number of countries in Africa, including Uganda and Lesotho, to name just two. In accessing and using Nepad to advance the rights of disabled people and the goals of the Decade, it is useful to emphasise and build on the particular contributions that different countries offer.

Conclusion – looking to the future

At the time of writing, Shuaib Chalklen, CEO of the Secretariat, was in the process of setting up the office and putting in place the operational infrastructure. Thomas Ngolo from Kenya was due to take up a senior project-management post, as were more staff from the Democratic Republic of Congo. It is important that the office staff be representative of the continent, and thus the infusion of new staff from around the continent with different skills (including the ability to speak different languages) is important. Though there is much to be done, the groundwork has been thorough, and exciting developments for disabled people across the African continent can be expected.

Note

1 This chapter is the outcome of an interview Leslie Swartz and Brian Watermeyer conducted with Shuaib Chalklen. The interview was taped and transcribed, and Leslie Swartz and Brian Watermeyer wrote the chapter, which was then sent to Shuaib Chalklen for comment and final approval.

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8 Disability and human rights: the South African Human Rights Commission

Charlotte McClain Nhlapo, Brian Watermeyer
and Marguerite Schneider

Introduction

Within the broad political context of South Africa's history of apartheid segregation and unequal development, disabled people within our society have endured a massive and arduous alienation from the means to exercise fundamental human rights. Such domains of governance as education, employment, transport, housing, media, and many other aspects of societal living, have been developed and shaped without consideration or integration of the needs of disabled people.[1]

The South African Human Rights Commission (SAHRC) has a national mandate to protect and secure the rights of all citizens, including, and especially, those citizens vulnerable to the abuse of their fundamental human rights. Disabled people, as a group whose history is characterised by oppression, exclusion and marginality, fall into this category.

This chapter aims to provide a concise introduction to the function and working nature of the SAHRC, particularly as this pertains to the rights of disabled South Africans. Whilst it is not the intention here to provide an exhaustive review of the status of South African human rights law, aspects of legislation relevant to the emancipation of disabled people will be referred to. A brief section of case material is also provided, in order to exemplify one aspect of the SAHRC's work – that of taking legal action on behalf of complainants whose rights have been contravened.

The South African historical and legal context

South Africa's new and highly progressive Constitution of 1996 radically foregrounds principles of human dignity and the right to freedom and equality for all. As a result of the concerted efforts of Disabled People South Africa (DPSA) in undertaking extended negotiations with the African National Congress (ANC), the Bill of Rights contains specific mention of the imperative toward equality and non-discrimination for disabled people. This specific stipulation is made in addition to the global declaration of basic rights that apply to all, which includes the right to health care, food, education, housing, social assistance, water and a healthy environment.

Four years earlier, in 1992, DPSA had, in collaboration with Lawyers for Human Rights, launched the *Disability Rights Charter of South Africa* (LHR, 1992). The Charter declares the rights of all disabled citizens to the opportunity to live independently, in a safe environment, and in a society free from all forms of discrimination, exploitation and abuse. Later, the influence of DPSA led to the deployment of disability rights activists in important government roles, subsequent to the ANC's coming to power in 1994. Disabled people are now represented in a broad range of state organs, including Parliament, the National Council of Provinces, the Provincial Legislatures, the Commission on Gender Equality, the National Youth Commission, the South African Broadcasting Corporation, the National Development Agency, the Public Service Commission and the National Economic Development and Labour Council. Of central importance here was the drive towards inclusion of disability issues within the context of a human rights and development framework, as opposed to outdated and oppressive 'welfarist' approaches to disability (ODP, 1997).

The role of the South African Human Rights Commission

As an organ of state charged with the monitoring and protection of the human rights of South African citizens, a key initial question regarding the development of a charter for disability rights pertained to the question of whether the SAHRC should manage disability issues as part of its mandate, or whether a separate commission should be established exclusively for managing disability rights. Extended consultation with the disability sector rendered the decision that the rights of disabled people should be managed in the 'mainstream', along with the human rights of all other citizens. Thus, a particular commissioner was employed to specifically manage cases of the contravention of the rights of disabled people.

The existence and mandate of the SAHRC is stipulated by an Act of Parliament, which also makes provision for the establishment of a Section 5 Committee. This is a panel of experts within a particular field, such as disability, who are employed to support and advise the SAHRC on matters pertaining to their field. Such a committee has been established to deal with the rights of disabled people and it has been instrumental in the development of a policy of action on disability within the SAHRC. The SAHRC was responsible for the drafting of the Promotion of Equality and the Prevention of Unfair Discrimination Act of 2000. The section within the Act on disability discrimination was drafted by a group of lawyers with expertise in disability rights.

The South African Constitution also charges the SAHRC with the responsibility to monitor all state organs in the progressive realisation of economic and social rights for all citizens. This involves ongoing assessment, at national, provincial and local levels, of new policy implementation. The question of the extent to which disability issues have been appropriately considered in the design and implementation of new programmes is central here. A further function of the SAHRC surrounds legal action taken on behalf of complainants who approach the Commission with cases of human rights violation. This is elaborated upon later in this chapter.

The role of the law

Although an anti-discrimination caveat in the Constitution makes specific reference to disability, having such principles present in law does not mean that the rights of disabled people are secured on the ground. Legislation alone cannot guarantee that human rights are realised; rather, it simply provides a framework of directives with which to begin a process of exploration and redress.

Notwithstanding the provisions made in the Bill of Rights, there remains an urgent need to review a substantial store of outdated legislation pertaining to disability. Further enabling legislation needs to be developed and discriminatory legislation from the past must be amended to ensure that the rights enshrined in the Constitution are upheld and enforced in all areas of governance and society. Decisions of the Constitutional Court have affirmed the principles of dignity, freedom, equality and social justice prescribed by the Bill of Rights. In addition, these imperatives are affirmed by South Africa's international obligations under binding treaties and customary international law in the field of human rights, which also promote equality and prohibit unfair discrimination:

> [The rights to] equality and dignity are enshrined in the Constitution. However…these principles must be met through the enactment of legislation, the scrutiny and, where necessary, amendment of existing legislation and the monitoring of constitutional and legislative provisions. (ODP, 1997, p. 44).

In the global context, as a member country of the United Nations, South Africa is a signatory to the United Nations *Standard Rules on the Equalisation of Opportunities for People with Disabilities* (UN, 1993). The SAHRC, South African law and policy makers, and organisations of disabled people are guided by these rules outlining the minimum requirements that United Nations member states need to meet in fulfilling their responsibilities to disabled persons.

Especially vulnerable groups

Certain sub-groups within the community of disabled South Africans have been identified by the SAHRC as particularly vulnerable to abuses of their human rights. The SAHRC views it as appropriate to maintain a specific cognisance of the human rights status of these groups. They include:

- Disabled women, children, youth, and elderly persons;

- Disabled people who are poor, who live in remote rural areas, or who have been displaced by violence or war;
- People with severe intellectual or psychiatric disabilities;
- People living with HIV / AIDS.

South Africa's apartheid history has created a situation where black disabled people in these categories are more likely to suffer the extremes of human-rights abuse than their white counterparts.

Development through dealing with violations

A key aspect of the SAHRC's mandate with regard to disability is that of receiving complaints from citizens whose rights have been violated, and taking appropriate legal action on their behalf. In seeking redress for situations of violation, the Commission has considerable legal powers, including those of search and seizure. Even government documents may be procured in this manner, if the need should arise. Further, the Commission has the power to subpoena, in order to drive speedy and incisive investigation.

Of crucial importance in the promotion of actual change in the lives of disabled citizens is the development of a South African jurisprudence surrounding disability and human rights. It is through legal action, such as that undertaken by the Commission on behalf of complainants, that such an elaboration of law pertaining to disabled people will occur, rendering an ever-increasing picture of what the Constitution's stipulated rights actually *mean* in the lives of disabled people. The Commission's legal service department is committed to taking on complaints lodged by any individual, or any legal entity. Up to the time of writing, the Commission had received surprisingly few complaints relating to the predicaments of disabled people, despite the overwhelming prevalence of human rights abuses in South African society. Sociological evidence for this abuse is clear, but, more interestingly, anecdotal evidence is equally highly prevalent. Nevertheless, these experiences somehow do not become operationalised into formal complaints, thus restricting the Commission's potential for development of legislative prescriptions regarding disability rights.

The requirements for a complaint successfully reaching the Commission are twofold. Firstly, the individual concerned must be aware that their rights have been contravened – in other words, be aware that the Constitution makes provision for the protection of those rights. The issue of education is, of course, relevant here; it is essential that sufficient programmes be implemented to ensure that the knowledge of human rights reaches each individual, if self-advocacy is to be facilitated. Secondly, the individual must be aware that support, in the form of the SAHRC, is available to take up their complaint. Here, more specific publicity regarding the role and workings of the SAHRC is required. The area of community outreach by the

Commission is of key importance in the immediate future, in order to ensure that more complainants are forthcoming. Resourcing of the legal service department also requires an increase in capacity to secure rapid processing of complaints. Currently, the Commission has approximately 2000 complaints on its books – it is simply complaints pertaining to disability that are, unfortunately, relatively uncommon.

Whilst the SAHRC remains committed to taking up the cause of any citizen whose rights have been contravened, certain types of cases hold more promise in terms of social change than others. Ideal cases to be contested are those which carry the interests of a substantial group of the population, in which a change in policy would correspondingly have a broad impact. Successful legal action on behalf of a complainant may lead to the amendment of relevant legislation; thus, it is those complaints which represent the human rights predicaments of the greatest number of disabled South Africans which carry the most promise for social change.

The organisation of class action complaints is most effective, and organisations of disabled people may be able to fill a central role here.

By way of exemplification, the following are concise descriptions of disability-related human-rights abuse complaints that the SAHRC has acted upon:

An inaccessible airline

It was brought to the attention of the SAHRC that a certain airline serving South Africa was enforcing a policy which dictated that physically disabled passengers could not travel on the airline without a companion. Of course, this meant that physically disabled passengers would, in effect, have to pay at least double the fare that other travellers would pay. A variation of this policy stipulated that unaccompanied physically disabled passengers would have to pay an additional R1000 for their ticket, in order to finance 'paramedic assistance' at airports. In both cases, the policy of the airline represents discrimination against disabled people.

What does the South African Constitution stipulate in this regard?

- Section 9(3) of the Constitution (1996) prohibits unfair discrimination on various grounds, including disability;
- Section 9(4) contains additional provision, which states that national legislation must be enacted to make unfair discrimination illegal;
- The Promotion of Equality and the Prevention of Unfair Discrimination Act, No. 4 of 2000, rules that the promotion of equality is the responsibility of persons operating in the public and private domains. The Act defines as discriminatory any practice that disadvantages, withholds benefits from, undermines the human dignity of, or adversely affects the rights or freedoms of a person on the grounds of disability.

Whilst it is the attitude of the courts that legitimate commercial concerns must be considered and respected in the appraisal of disability-equity issues, stereotyping and prejudice masquerading as commercial interest will not be tolerated.

What powers do our courts have in a case such as this?

Section 38 of the Constitution (1996) gives the courts the authority to 'grant appropriate relief, including a declaration of rights'. Further, Section 39 (2) provides that, in interpreting legislation, courts are required to promote the spirit and objects of the Bill of Rights. The Bill specifically prohibits direct and indirect discrimination, by the state or an individual, against anyone on the basis of disability. By implication, therefore, the denial of any other constitutional right on the basis of disability, constitutes a violation of a disabled person's rights. It is noteworthy that the Constitution accepts that discrimination against a person on the basis of that individual's disability is automatically unfair, unless a case can be proved by the body or individual concerned that the discrimination was fair. Hence, the onus to prove unfair discrimination does not lie with the disabled person. In addition, the provision is made in the Constitution for affirmative action in the workplace concerning people with disabilities, in that it allows for positive measures to be taken to promote the achievement of equality for categories of persons disadvantaged by unfair discrimination.

In applying the principles of the Bill of Rights, and issuing orders which are 'just and equitable' (Section 172 [1] [b]), it is also stipulated that the court may choose to limit the 'retrospective effect of the declaration of invalidity'. In other words, in amending the Constitution in order that the prescriptions of the Bill of Rights be adequately adhered to, the potential for the claim of retrospective damages is limited, thus allowing the state a measure of grace in fulfilling its human-rights obligations. This means that, when a piece of legislation is amended, the court may choose to disallow claims for damages from individuals whose rights have previously been compromised by that legislation. In the current case, what this informs is a situation in which the service provider may be forced to alter the discriminatory policy, in line with pronouncements made by the courts, but would not be susceptible to retrospective claims for damages relating to prior contraventions of the newly established policy. Thus, the courts afford the disability movement a substantial resource in driving accountability to the Bill of Rights.

In this case, as should be evident, the SAHRC has substantial legislative channels for action in the interests of disabled air travellers. As per the *Integrated National Disability Strategy*, accessible and equitable transport services for disabled people are an essential aspect of fuller inclusion:

> There is a need for rapid progress in developing a public transport that is flexible and accessible. Without this, people with disabilities will continue to remain largely 'invisible' and unable to contribute to, or

> benefit from, the services and commercial activities available to most of their fellow citizens. (ODP, 1997)

At the time of writing, legal action by the SAHRC in terms of the legislative provisions listed above was ongoing.

A botched operation

The SAHRC received information surrounding the case of a young boy who had undergone a serious operation in a state hospital. The operation had been a failure, substantially worsening his condition and leaving him severely physically impaired. With no consideration of his need for ongoing medical, therapeutic or rehabilitative care, or any action regarding compensation of any form, the boy was simply sent home. In the words of the commissioner concerned, simply 'sent home to die'. The commissioner immediately made direct contact with the provincial Member of the Executive Council (MEC) for health concerned, and stated that the SAHRC required from that health department a documented plan regarding appropriate intervention and care for the boy. The provincial authorities did not respond as required. The SAHRC thus took further action, issuing a subpoena to the MEC herself, in order that she be required to account for the actions of her departmental staff members.

Consequently, the provincial administration was forced to develop and implement a plan of intervention for the boy. This plan was taken up by the local state hospital, which undertook to provide ongoing care. Consequently, the provincial health system was forced to become more broadly accountable regarding its actions surrounding disabled persons. This individual case served as a snapshot of the provincial status quo, placing disability-rights issues more squarely on the high priority agenda of the provincial administration.

Inaccessible prisons

South African prisons, like many other state-owned physical environments, are largely inaccessible to persons with a range of impairments. Consequently, the rights of disabled prisoners are widely contravened. A complaint was brought to the SAHRC surrounding a physically impaired man who had received a fifteen-year prison sentence. He was placed in a prison which, like so many others, had no access facilities for physically impaired persons. The 'solution' of the local prison authorities was to situate him in the prison sick bay, where, by the time of the complaint, he had remained bedridden for a period of three years.

As a result of this case, and others like it, the SAHRC has formally issued a requirement to the Department of Correctional Services that a thorough plan for the development of access for persons with impairments be compiled and implemented. Thus individual complaints can precipitate substantial shifts in policy.

A child refused education

The SAHRC received a complaint that a physically disabled child had been refused access to her local state school. Interestingly, in this case legal action was not required, as the relevant commissioner described the difficulty as arising primarily out of the 'personal disempowerment' of the school principal. Clearly overcome with anxiety and uncertainty over how to 'manage' this impaired child, the principal simply refused her access to the school, citing 'inappropriate facilities' as the reason. A relatively brief conversation between the principal and a commissioner revealed that the presumed 'difficulties' associated with admitting the girl to the school all had quite straightforward solutions. For example, since she could not use stairs easily, her grade was simply moved to a downstairs classroom. The important task in this intervention, as the commissioner noted, was getting the message across to the principal that he has a responsibility to all of his learners and, furthermore, that things are possible if you approach them with the right attitude.

Conclusion

It is the aim of the SAHRC to become an increasingly prominent and familiar presence in the lives of citizens waging struggle in the face of contraventions of human rights. The potential of the SAHRC as a resource to the disability movement is massive, in terms of incrementally obtaining accountability by the state to the Bill of Rights.

The role of organisations of disabled people in facilitating the optimal use of this resource deserves some attention. On an individual level, the promotion of a culture of self-advocacy is an ever present objective. Quite simply, it is imperative that disabled citizens have an awareness of the universal entitlement, within our society, to the protection of human rights. The SAHRC is ready to take up the challenge for those who will step forward and articulate their predicaments. Secondly, and on a more organisational level, the most expedient use of the legal resources offered by the SAHRC will surround complaints which are organised and rationalised in order to promote optimal change. In other words, the greater the extent to which organisations of disabled people can present to the SAHRC cases of widespread, shared experiences of particular forms of human rights contravention, the greater the impact and the broader the extent will be of the action required of the state. Of course, the role of the SAHRC in the interests of the disabled community continues in many other ways, such as the crucial work of monitoring national, provincial and local policy development and implementation.

As should be evident, South Africans are, with the Constitution of 1996, exceptionally fortunate to live in a society which provides powerful legislative tools for the driving of social change. It is up to the disabled community, along with partners such as the SAHRC, to make the Constitution work for rapid change, and an inclusive and equitable society for all.

Notes

1 This chapter is the outcome of an interview Brian Watermeyer and Marguerite Schneider conducted with Charlotte Vuyiswa McClain Nhlapo of the SAHRC, whose primary human-rights work surrounds disability-related violations. The interview was taped and transcribed, and Brian and Marguerite wrote the chapter, which was then sent to Charlotte for comment and final approval. The chapter draws extensively on the SAHRC report *Towards a Barrier Free Society* (SAHRC, 2002). The permission of the SAHRC is gratefully acknowledged.

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9 HIV/AIDS and disability: new challenges

Leslie Swartz, Marguerite Schneider, and Poul Rohleder

Introduction

HIV/AIDS is without doubt the most serious health threat in the world today, with the burden of the epidemic being felt most acutely in sub-Saharan Africa. Since it was first identified in 1980, 20 million people worldwide have already died of AIDS, with 40 million people currently living with HIV (Demographic and Health Surveys, 1998). Across the globe, 12 000 adults and 2 000 children are infected with HIV every day. Frighteningly, at least 95 per cent of these new infections occur in developing countries, with more than 50 per cent affecting women and young children (Lamptey et al., 2002). Without a co-ordinated and substantial response to the pandemic, it is projected that worldwide there will be 45 million new HIV infections by 2010 (Goliber, 2002). More people die of AIDS-related illness in sub-Saharan Africa than of any other cause (Petersen et al., 2004).

Given the impact of the epidemic on every aspect of life, there has been much research on a wide range of topics related to HIV/AIDS – including prevention, treatment, vaccines, studies of prevalence, impact on supply of personnel, impact on children, women and the elderly, to name but a few. Though there are many disagreements about how best to tackle the epidemic and many concerns that we are not doing enough about it, authors concur on the need for good quality research on the impact of the epidemic on us all. In this context, it is shocking and surprising that notwithstanding the efforts of many disabled people’s organisations (DPOs) to develop responses to the epidemic, and government supported initiatives in the disability/HIV field, such as the work of the Policy Project, a USAID-funded initiative of the Department of Health, it remains true to say that in terms of systematic, large-scale research, the impact of HIV/AIDS on disabled people has been widely ignored (DoH, 1997). A recent review found very few studies related to HIV and disability (Mouton, 2003).

Groce and her colleagues (World Bank, 2004) highlight the urgent need for research in the area of HIV and disability. This chapter cannot do justice to the many ways in which the epidemic affects and will affect the lives of disabled people, nor is it designed as an overview of responses on the part of the disability sector to the epidemic – a systematic study of this topic is being conducted by one of the co-authors of this chapter, Poul Rohleder. This chapter simply highlights key intersections between disability and HIV issues, especially in the South African context.

Disabled people at risk

Part of the reason for this lack of research is that in many parts of the world, and in sub-Saharan Africa in particular, sexual transmission is the dominant mode by which the epidemic is spread. There appears to be a common assumption that people with disabilities are not at high risk for HIV infection (World Bank, 2004). People with disabilities are often perceived as asexual (Milligan & Neufeldt, 2001) and hence are viewed as not involved in sexual risk behaviours. It is simply a myth, however, that persons with disabilities are not sexually active (Nosek, et al., 2001).

More serious, people with mental, physical, sensory or intellectual disabilities are perhaps 'at increased risk for every known risk factor for HIV/AIDS' (Groce, 2003, p. 1401). As other chapters in this book indicate in part, people with disabilities are more likely than others to be poor, poorly educated about sex and vulnerable to sexual abuse. It has also been suggested that people with disabilities may be at high risk for substance abuse, though again, the data on this topic are not sufficient. All these are HIV risk factors (World Bank, 2004).

There have been a few southern African studies which confirm that children and women with disabilities are at increased risk for sexual abuse (Collins, 2001; Groce & Trasi, 2004; Kelly, et al., 2002). Nevertheless, people with disabilities are largely ignored in HIV prevention campaigns worldwide, and this is a matter of grave concern.

Various reasons have been advanced for the lack of attention to HIV-prevention issues for people with disabilities. These include:

- Lack of appropriate educational material – for example, Getch, Young, & Denny (1998), found that though schools may have sex education materials for deaf students, there are few materials for students with multiple disabilities;
- Insufficient training of health professionals in dealing with disability – though disabled people often depend on health professionals for sex education (Berman, et al., 1999), professionals may be insufficiently trained (Christian, Stinson, & Dotson, 2002), and anxious about raising issues of sexuality (Parritt & O'Callaghan, 2000);
- Parents' anxieties – parents may avoid raising sexuality issues for fear of promoting sexual behaviours in their children (Committee of Children with Disabilities, 1996; Martorella & Portugues, 1998);
- Social isolation – for example, adolescents with visual impairments are reportedly commonly isolated and experience difficulty accessing services (Philander & Swartz, 2005).

In spite of the fact that people with disabilities are in all probability more vulnerable to infection than many other sectors of the population, the area remains largely unexplored systematically. Every aspect of life which makes people with disabilities more vulnerable than others in general, may make people with disabilities more vulnerable to the epidemic. For example, young women with visual or other impairments may have trouble accessing safe and reliable transport (Philander & Swartz, 2005; see also Chapter 25 by Seirlis & Swartz, this volume). This may lead them into situations in which they enter into potentially abusive and exploitative relationships with men who are able to provide transport (Philander & Swartz, 2005).

Disability, HIV and stigma

Fears of contagion from HIV/AIDS are not only legitimate fears of becoming infected through the transfer of bodily fluids but also irrational fears of being trapped by a socially and psychologically dangerous disease (Deacon, Prosalendis & Stepney, 2005). In this respect, HIV/AIDS and disability share common characteristics of stigmatisation. People with disabilities, like those with HIV/AIDS, are often seen as dangerous, polluting, corrupting and, ultimately, to blame for any difficulties they face in their life-context (Marks, 1999). In spite of the wealth of work in South Africa on HIV/AIDS (e.g. Rohleder & Gibson, 2005), the interleaving patterns of stigmatisation between HIV/AIDS and disability are under-explored.

The HIV rights movement internationally and in South Africa has appropriately spent considerable effort showing that people infected with HIV are not dangerous or morally inferior to others. This attempt to portray HIV-infected people as ‘normal’ may have had some unfortunate unintended consequences for people with disabilities who are facing the epidemic. Ironically, the normalising discourse which has been so important in the struggles for human rights for people infected with HIV, may have served partially to obscure the embedded human rights issues for people with disabilities in the context of the epidemic. For example, Nkosi Johnson, a child who became a spokesperson for people living with AIDS and who subsequently died of AIDS, ended his speech at the thirteenth International AIDS conference in Durban in July 2000, with the following plea:

> I want people to understand about AIDS, to be careful and respect AIDS. You can’t get AIDS if you touch, hug, kiss, or hold hands with someone who is infected. Care for us and accept us – we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else. Don’t be afraid of us. We are all the same![1]

In the context of a highly stigmatising epidemic, Johnson’s plea for acceptance is understandable and commendable. It is also, however, disablist, in that it implies that people who are not physically like others are ‘different’ from other people. People who do not have hands or feet, people who cannot walk or talk, are also entitled to proper respect and care, and not to be discriminated against.

People with disabilities, and especially with disabilities which are more stigmatised, are not commonly presented in a reassuring way to the public as key role models for those living with HIV/AIDS. The example of the LoveLife programme is instructive here. LoveLife is a major player in the field of promoting safer sexual practices. A perusal of the LoveLife website on 6 July 2005[2] revealed many images of young, attractive, men and women with no obvious disabilities. There is some mention of people with disabilities, particularly in the context of sport, but very little systematic coverage of disability and no visual portrayal of disability.

In summary, the interweaving of the relationship between stigmatised aspects of HIV and stigmatised aspects of disability bears further investigation. There are important questions which need to be asked – including that of whether the perfectly understandable focus on 'normalising' HIV may, paradoxically, contribute to a situation in which the epidemic is driven further underground for people with disabilities – and hence increases the risk of infection within this grouping.

HIV/AIDS and disability grants

A hotly contested question in the context of the current state of flux in the social security situation for people with disabilities in South Africa is how to consider questions of HIV status and AIDS illness when decisions are made about disability grants. South Africa has enormously high rates of unemployment, and as the chapter on social security in this volume shows, there has been a huge increase in uptake of disability grants in this country over recent years. In the effective absence of other forms of social security, especially for people aged between 18 and 60 in the case of women, and 18 and 65 in the case of men, the disability grant offers at least one way for whole families to survive financially. Practices by which decisions are made for the award of disability grants are not uniform across the country, as discussed in Chapter 17, and the issue of HIV/AIDS is no exception (Nattrass, 2004). In some cases, decisions to award the grant are based on activity limitations as a result of AIDS-related illnesses; in some cases decisions are based on CD4 counts; and anecdotal reports suggest that there are a wide range of other practices in operation, varying by area and by the person making the decision.

Before the antiretroviral roll-out in South Africa, it was reported that some HIV-positive people were using the disability grant to pay for treatment (Nattrass, 2004). There are now concerns about the public health implications of the disability-grant issue in the context of HIV. Consider, for example, the situation of a person who is ill with AIDS and who is thus unable to work, being awarded a disability grant, an appropriate decision in terms of legislation. If the person goes on antiretroval treatment, however, the person may recover to the extent of now being able to work and to compete with any other person in the open labour market. The chances are, however, that given unemployment rates, the person may not get a job. Technically, this person is no longer eligible for a disability grant. What will the impact on the person's family, the person's health and nutritional status be, if the grant is then removed? Such questions and challenges are continually being faced in South Africa.

There has been much talk of perverse incentives – whereby it is not in the financial interests of an HIV-positive person to adhere to antiretroviral therapy regimes. There is even talk that people will cause themselves to become infected with HIV, so that they can access a disability grant to support themselves and their families. There does not appear to be any firm evidence for this claim, but there is no doubt that the HIV/AIDS and disability issue lays bare the enormous challenges South Africa faces with respect to social security in a context of chronically high unemployment rates.

HIV/AIDS as a cause of disability

AIDS can lead to any number of health conditions and impairments. These include sensory impairments, amongst others (Kennedy, Kuhn & Stein, 2000; Lau, et al., 1990). Cognitive impairments may also result from AIDS (Becker, et al., 2004; Brew, 2004; Honn & Bornstein, 2002), a fact which may cause considerable difficulties for the antiretroviral roll-out in South Africa. Antiretroviral treatment may help reverse cognitive impairment in people who are HIV infected, but cognitive impairment is often viewed as a contra-indication for antiretroviral treatment, as there are concerns that people with cognitive impairments may struggle with adherence to treatment.

Given the spread of the epidemic in South Africa, there seems little doubt that there will be an increase of people who develop disabilities secondary to being HIV positive, quite apart from the more general debate about whether HIV-positivity itself constitutes a form of disablement in itself. This has implications for resourcing for people with disabilities in the country as a whole.

Disabled caregivers of people affected by AIDS

With the spread of the epidemic, more and more South Africans are being called upon to act as caregivers both to people who are ill, and to those whose caregivers are ill or have died (Rohleder & Swartz, 2005). Increasingly, we are seeing a pattern of grandparents looking after grandchildren whose parents are ill or have died (Brodrick, 2004). Given that levels of disability increase with age, it is likely that more and more people will have to cope both with the challenges of their own disabilities and with looking after others affected by the epidemic in various ways. This may contribute to a widening of social roles for some people with disabilities, but may also increase the stress and burden in their lives.

Conclusion

The HIV/AIDS epidemic in South Africa and elsewhere is correctly viewed by many as potentially overwhelming. There is an urgent need to draw together existing expertise in the overlap between HIV and disability, and to consider carefully the priorities for research and action. There has been some good work done on this topic in South Africa, but not nearly enough. We ignore this important issue at our peril.

Notes

1 Nkosi Johnson's speech can be accessed at: http://myhero.com

2 LoveLife's website can be accessed at: http://www.lovlife.org.za

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10

'How could she possibly manage in court?' An intervention programme assisting complainants with intellectual disability in sexual assault cases in the Western Cape

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Introduction

The police officer does not know what label to use, all the words sound insulting. The complainant does not know what words to use, the only ones she has for genitals she knows to be swear words, and this exacerbates how badly she feels about what has happened and deepens her confusion about the process of questioning in which she finds herself. The prosecutor is torn between protectiveness towards the complainant and a vague suspiciousness. Is it true that people like this are oversexed? Surely it is best to withdraw the case? How could she possibly manage in court anyway?

In sexual assault cases involving a complainant with intellectual disability (ID), it is not only the complainant who needs support and preparation. Liaison between all the agencies involved in the case is crucial for a satisfactory outcome.

Victimisation and redress for people with intellectual disabilities

A body of literature now exists on the extent of sexual crimes committed against people with ID, and their difficulties in reporting and obtaining appropriate redress (e.g. see Brown, Stein & Turk, 1995; McCarthy & Thompson, 1997). This needs to be seen in the context of abuse and harassment of various kinds that also go largely unreported (Sharp, 2001). The person with ID may need someone to report on their behalf, or to assist. However, the caregiver may not believe the person, there may be an ethos of non-reporting within facilities, or the caregiver may simply believe that on balance the investigation will do more harm than good for the person concerned. The recognition of sexual crimes against people with ID is made more difficult by the myth of rampant sexuality and the misplaced notion of a genetic threat to society (Szymanski & Jansen, 1980) or, paradoxically, the view that people with ID are asexual (Brown, 1991). Feelings of damage and guilt about disability on the part of the person with ID (Sinason, 1992) and lack of sex education compound the problem.

Sharp (2001) reports that once police are involved, they may respond poorly due to an inability to perceive the need for extra support or due to incorrect assumptions about disability, once it is picked up. It is therefore uncommon for sexual-abuse cases involving a complainant with ID to go to court, and for the complainant to appear, particularly when the complainant is the sole witness (Cooke & Davies, 2001). While some such cases have been reported (see, Green, 2001), we are unaware of published reports on sizeable cohorts.

The prosecution of sexual assault in South Africa

The rate of sexual assault in South Africa is very high. It is very difficult to estimate the prevalence of sexual violence; local estimates range from one in three, to one in five women having been raped in South Africa (HRC, 2002). In 2000, 60 000 sexual offences were reported in South Africa, 9 000 of them in the Western Cape (information obtained from Crime Information Analysis Centre, South African Police Service). Research into conviction rates (SA Law Commission, 2001) found that when cases from selected high-crime areas were examined about two years after the matter was reported, fewer than 10 per cent of rape cases led to convictions. The majority of the cases had not even gone to court – a pattern that was also found in cases involving murder, robbery and fraud. Reasons for this low conviction rate include inadequate support staff and services for police and prosecutors, who carry large caseloads.

While the most striking finding by the South African Law Commission's study is the small percentage of cases finalised after two years, the results also provide a useful baseline in the general population for conviction rates within those cases that are finalised. If the figures for the child and adult complainants are combined, approximately half the finalised cases are withdrawn, and the remaining half are split almost evenly between convictions and acquittals. The specialised Sexual Offences Courts (described below) obtain slightly higher conviction rates. In general, one can expect about a 25 per cent conviction rate in the general population for those cases that go to trial.

Statistics are not kept on complainants with ID within the justice system, so it is difficult to establish how many cases of sexual assault involving complainants with ID were heard in Cape Town per year prior to the operation of the Cape Mental Health Society (CMH) programme described below. According to sources within the South African Police Service (SAPS) and the Department of Justice, prior to 1990, only one or two such cases were considered for prosecution per year in Cape Town.[1]

The Sexual Assault Victim Empowerment programme

In this chapter we provide an overview of an effective intervention programme that has been running for 14 years at CMH, a non-profit, non-governmental organisation which offers a comprehensive mental health service to indigent people living in Cape Town. The majority of CMH's clients have intellectual disability.[2]

CMH was approached in the early 1990s by the SAPS and prosecutors in the Department of Justice to assist in cases of sexual assault involving complainants with ID. The Sexual Assault Victim Empowerment programme (SAVE) was established to assist complainants with ID in sexual assault cases, by providing a psycho-legal assessment and expert evidence as well as support and court preparation for the complainant and the family. Over the 14 years of the programme, there has been a steady increase in the use of its services by the SAPS and the Department of Justice.

As the costs of this programme and the demands on it are high, complainants are included in this programme only if there is evidence that there is disability as well as a strong likelihood that there will be a court case. In cases of sexual abuse reported to CMH that are not pursued through legal routes, social work services are made available to help the families to prevent further abuse and to assist the client over the trauma.

In addition, CMH has run an educational programme for prosecutors and detectives for many years, and input into workshops for magistrates is being planned. Guidelines for police, prosecutors and magistrates are available, based on extensive work outside South Africa (Bull, 1995; Cooke & Davies, 2001; Kebbell, 2001). Complainants with ID may need assistance in order to give an account, but this assistance may lead to distortions due to suggestibility and acquiescence. Bull (1995) provides a very useful interview format in which he outlines how to set the complainant at ease, and what hazards to avoid. People with ID are particularly vulnerable to leading questions (that is, questions that indicate the answer that is expected), and this commonly results in distortions in statements or responses in court. Bull's work was originally a response to concerns about false confessions among suspects with ID, and his approach is therefore useful with vulnerable suspects, as well as witnesses, in any sort of investigation.

Many of the cases with which CMH has worked have been heard in specialised Sexual Offences Courts, pioneered in Cape Town in 1993. An intermediary system is available for complainants younger than 18 years in such courts. Evidence is given using a closed circuit television, with the assistance of a trained intermediary. The extension of this service to adults with ID has been included in proposed new sexual-offences legislation.

In the mid and late 1990s, programmes were run within the SAPS to improve service to survivors of sexual assault at the level of first report (i.e. at police stations) and while these programmes did not deal with disability as such, this may have improved sensitivity to vulnerable groups.

Description of the complainants referred to SAVE, 1990–2004

Two-hundred-and-twenty-five complainants with ID were assessed by SAVE, the majority of whom (94%) were women. The average age was 19 years, with a range from 6 to 60 years. Forty-three per cent were under the age of 16 years. Seventy-two per cent were Afrikaans or English-speakers (mainly Afrikaans) and 28 per cent were Xhosa-speakers. The Afrikaans-speakers were mainly people previously designated coloured. There were only two complainants previously designated white.

The accused was known to the complainant in 88 per cent of the cases, with 5 per cent of the cases being incest and a total of 17 per cent having a familial connection with the complainant. In 3 per cent of cases the accused was a staff member of a work or residential facility. The majority of the accused known to the complainant were acquaintances, neighbours and boarders. None of the accused were considered to be intellectually disabled.

In 12 per cent of cases there was more than one accused, and in 88 per cent the charge included rape. Other charges included indecent assault (which includes sodomy), abduction and attempted rape.

Forty-two per cent of complainants were assessed as falling in the mild category of ID (using the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 1994), which uses the term ‘mental retardation’), and 58 per cent were assessed as moderately or severely disabled. Of the 128 complainants who were 16 years and over (the legal age of consent in South Africa), 58 per cent were found unable to consent to sexual intercourse, while 34 per cent were found able to consent. In the remaining 9 per cent, this determination could not be made. Competence as a witness could not be assessed in 3 per cent of the cases. In 65 per cent of the cases the complainant was found competent to testify. Court preparation was always recommended, and use of an intermediary was recommended wherever possible. Details of the assessment process are provided below.

No formal measure of socio-economic status was included in the assessment. The majority of the group lived under considerable financial insecurity. Extended families often survived on one disability grant or pension. Reliance on casual and intermittent employment was common. Frequently, families suffered financial loss in order to pursue the court case, through losing a day’s wages each time there was an appointment or a court hearing.

In summary, this group largely comprised young, financially disadvantaged women, who laid charges of rape against a known, nondisabled accused. Those previously designated white are under-represented in this group, as are middle-class complainants generally, due to the fact that CMH works with indigent people.

Those with more financial resources would seek help within the private mental-health sector.

The group was almost evenly divided between mild and moderate/severe levels of ID. About a third of those over 16 years were found to be able to consent to sexual intercourse, and 65 per cent were found competent to testify. This was a selected group, whose cases were pursued to the point that a specialist service was brought in. There is no doubt that cases fell out of the system at various points prior to this.

This group tells us, therefore, about the cases that are perceived by the SAPS and the Department of Justice as evidentially strong enough to proceed with investigation and prosecution. It is not surprising, then, that most of the charges were of rape and that cases were pursued when there was an obvious power difference between the complainant with ID and a nondisabled accused. However, there is considerable evidence in the literature that a substantial proportion of abuse of people with ID is carried out by other people with ID (Cooke & Sinason, 1998; McCarthy & Thompson, 1997).

Follow up on cases seen from 1990 to 2000

Cases seen at CMH between 1990 and the end of 2000 were followed up in order to document the outcome, as well as the speed of prosecution (Dickman & Roux, 2005). One hundred cases met the criteria for inclusion – that the complainant had ID and that the investigation was likely to continue, (excluding, for example, cases where the accused could not be identified). These 100 cases represent 94 complainants, some of whom laid more than one charge during this period. Sixty-five of the families agreed to a detailed interview about the services they had received from CMH, the SAPS and the Department of Justice.

Case outcomes

Using CMH files as well as police and court records, the outcome or current status of all but one of the 100 cases was established. Twenty-seven cases were incomplete. Twelve of these were still being finalised, in nine cases (9%) the accused had absconded on bail, and in a further six cases the accused could not be found.

Of the 72 cases that were completed, the accused was found guilty in 20 cases (28%) and was acquitted in 18 cases (25%). The matter was withdrawn in 34 cases (47%). Level of intellectual functioning did not appear to directly affect outcome. Sentences ranged from 6 lashes[3] in one of the early cases where the accused was 14 years old, to a prison sentence of 19 years where the victim was 15 years old and the accused was her stepfather.

Speed of investigation and prosecution

Investigation appeared to have been energetic. The date that the matter was reported as well as the arrest date was known in about half the cohort. There was an arrest the same day in 40 per cent of the cases, and a further 15 per cent the next day, with arrests having been made within two weeks in 79 per cent of cases. In just over half the cases we knew the interval between the report being made to the SAPS and the date the matter was finalised in court. Twenty-five cases were finalised within a year (43 per cent). A further 45 per cent were finalised within the second year.

Evaluation of CMH services by 65 families and complainants

This is a relatively small group, and possibly a biased one, as those who were most unhappy may have decided against participation. Permission was sought from the caregivers before interviewing the complainants, and most requested that the complainant not participate. In nine cases the complainant assisted in the interview and in two cases the complainant was the primary informant.

The evaluation of CMH services indicated most of those interviewed were satisfied with the services from CMH (74%), but this may have been skewed given that the interviewer was a social worker from CMH, albeit not the caseworker. The most important feedback was that active assistance by the social worker, including his or her presence in court, was highly valued. Those who were not accompanied by a social worker during the court case reported that they would have liked this.

A large majority of the group assessing the SAPS, expressed satisfaction with treatment at the charge office (i.e. the first contact with the SAPS at a police station). The main area of complaint was insufficient information about the progress of the case after the initial investigation. This finding no doubt reflects the long delays that are common (due to full court rolls in the South African court system) before the cases go to trial.

In evaluating the Department of Justice, fewer responded as 21 of the 65 complainants had very little or no contact with the Department of Justice, due to decisions not to prosecute. The main complaint was that delays were not explained. In an incidental finding, it emerged that 36 of the 65 families lacked important information about their case. Given the history of marked inequity in services to black and coloured communities in the Western Cape, we analysed the groups separately.

Ten of the 43 Afrikaans families (23%) and 14 of the 22 Xhosa families (64%) had no knowledge of the outcome or current status of the case. Certain families believed the justice system to be corrupt, when in fact convictions had been secured. A further 12 families lacked important information, for example, believing the case to have been closed when the accused absconded on bail, when in fact a warrant of arrest had been issued. There were cases where the families saw the accused some time later and did not realise that an arrest would be affected if they alerted the SAPS.

Summary of the study

As mentioned above, this is a selected group of cases viewed by the justice system as evidentially strong enough to prosecute. Given this selected status, the results show energetic investigation, which is impressive given the enormous pressures on the South African justice system. This study found a similar rate of conviction to that found in the general population (about 25 per cent for those cases that go to trial). This suggests that, in Cape Town, complainants with ID have as much chance of conviction, should the case go to trial, as nondisabled complainants.

Feedback from families and complainants indicate that social-work support is valued during the process of the trial, and that investigating officers and prosecutors need to be sensitive to the effects of delays before and during the trial. There was evidence that the educational programmes run within the SAPS, for police officers taking first statements, have been effective. It should be noted, though, that this research could tell us nothing about the experience of those people whose cases were not pursued.

Most significant was the incidental finding that over half the families we visited lacked important information about the case, or knew nothing at all about the outcome. This, we believe, has more to do with poverty than with disability. Due to financial constraints, people generally would attend court only when subpoenaed and frequently could not attend later hearings. The research enabled CMH to provide feedback to the SAPS and the Department of Justice, with useful discussions about how to improve this situation.

A more detailed look at CMH's assessment process

Introduction

Referral is generally made by the investigating officer, but occasionally referral is made later in the legal process by the prosecutor. Emergency assessments are accommodated, especially when the continued prosecution of the case appears to hinge on this. When the referral is made early in the investigation, there may be a long waiting period for assessment (three to four months), but this is absorbed by the delays in the prosecution due to full court rolls. Usually the investigating officer brings the family to the appointments, and this type of assistance was frequently cited by families in the research as very helpful.

The assessment comprises an initial interview with a social worker in which background information is obtained. Wider social and emotional needs are often identified and most of the families continue to receive services from CMH after the completion of the legal proceedings. Then the complainant and the family attend two appointments with a psychologist, usually one week apart. When necessary, for example when complainants come from nearby small towns, the full assessment is done in one day.

The psychologists are employed as consultants, and work almost exclusively in the SAVE programme. The social workers, who are full-time employees, are the case-managers, and they prepare the complainant for court as well as providing support afterwards. Court preparation involves a visit to the court, meetings with the prosecutor, explanation of who will be present and their roles, and preparation for cross-examination. The complainant is never 'coached' on her account. The importance of truth-telling is emphasised, and a central goal is to empower the complainant to say she does not know – when this is appropriate – and to ask for clarification when necessary.

Two of the three psychologists in the programme are not fluent in Xhosa, and use an experienced (but not formally trained) Xhosa-speaking employee at CMH to assist when they interview Xhosa-speaking complainants. The use of an interpreter in this kind of interview raises complicated issues, and a key concern is that the interpreter maintains respect for the complainant.

Key elements of the interviews

Psychologists and social workers at CMH take care to make the complainant comfortable at the beginning of each interview. The reason for the interview is discussed and clarified, and when the assault is discussed, it is explained why sexual matters will be asked about in detail. The interviewer makes it clear that the person has a right to request clarification or say 'I don't know'. Frequently the complainant feels afraid and guilty, either due to co-operation with the accused before the assault, or, often in an ill-defined way, for any sexual feelings or activities. Interviewers in the SAVE programme attempt to clarify that they need to understand what happened, and that they are not going to judge the person's behaviour. As with many parts of the interview, this lays the basis for court preparation.

Formal assessment of level of functioning

Evaluation of the complainant's level of functioning is a central requirement by the justice system. Section 15 (a) of the Sexual Offences Act No. 23 of 1957 defines sexual intercourse with someone who has moderate and severe intellectual disabilities as a crime. A charge under this act often serves as an alternative to a charge of rape. SAVE provides information in terms of level of functioning, while alerting the courts that intellectual functioning, and specifically IQ, cannot be seen as the sole benchmark for competence as a witness or for ability to consent to sexual intercourse. A functional assessment is required which takes account of the specific skills required in the legal context. A simple diagnostic assessment, providing level of intellectual functioning only, does not offer direct information about capacity in court or ability to consent to sexual intercourse (Murphy & Clare, 1995).

Assessment in this area always includes a number of sources of information. Traditionally, assessment of intellectual functioning is accompanied by an evaluation of everyday adaptive functioning to make the assessment more reliable and informative. These results are examined in the context of the person's developmental history as well as her history of scholastic and occupational placement. The formal assessment tools used are the *Individual Scale for General Scholastic Aptitude* (ISGSA) (HSRC, 1994) and the *Vineland Adaptive Behaviour Scales* (VABS) (Sparrow, Balla & Cicchetti, 1984).[4]

The ISGSA allows psychologists to comment not only on the overall level of functioning but also on specific skills in the areas of literacy and numeracy. However, the ISGSA has been normed on English-, Afrikaans- and Xhosa-speakers, (covering the main languages spoken in the Western Cape) as well as other African languages. While there are justifiable criticisms of tests of global functioning, the ISGSA is a useful screening tool. It is argued in court that the reliability of the assessment is increased by the use of multiple sources of information as well as an eventual evaluation in a broad range of functioning.

The VABS presents a problem in that it is an American tool with no local norms at all. In the absence of locally developed and normed assessment tools, the best available is used, and the VABS provides a detailed picture of everyday aspects of functioning, including self-care, communication ability and social skills. Despite the lack of local norms, limited performance on these items is easily understood in court as an indication of disability. In cases where the accused claims ignorance of the complainant's disability, information about everyday functioning is very helpful to the prosecution, especially as the accused generally has prior knowledge of the complainant. Information about the person's level of social functioning and understanding of social nuance is helpful to the psychologist in determining whether she is able to consent to sexual intercourse, as well as providing a background for the assessment of competence as a witness.

Interesting issues emerge with the use of developmental ages in reporting on level of functioning. While there is no doubt that the 'mental age' concept is easy for police and justice personnel to understand, there are important ways in which an adult with disabilities is different to a child. The myth of the 'perpetual child' has been damaging to the rights of people with ID. In addition, an adult with ID who has experienced years of feeling demeaned, abused and disempowered, has different responses when invited to speak about abuse to those of an able child who has been abused – although both should be seen as vulnerable. The psychologists tread a difficult path in having to use concepts familiar to the court, while making sure the specific strengths and vulnerabilities of the complainant are made clear.

Assessment of competence to act as a witness

As many authors have pointed out, competence depends on the context – for everyone to some extent, and particularly for people with ID (Bull, 1995). Any witness will perform better when they feel supported, informed about the process, free to request clarification, and free of negative judgement. In the SAVE project, the assumption can be made that there is some sensitivity to disability in the courts regularly used for these cases, and in addition, the intermediary system can be recommended for young complainants in the Sexual Offences Courts. With the availability of social work support, it is sometimes decided that the complainant is likely to be competent after court preparation, despite considerable limitations at the time of assessment. Some of the people found to be competent within the SAVE programme would not be found to be so within a less sympathetic system.

While the decision about the competence of the witness rests with the magistrate, the psychologist can offer information to the court in the areas outlined below.

Ability to give a consistent account of the assault

People with ID may need prompts in order to provide an account of the assault. Careful interviewing is required to avoid distortion due to acquiescence and/or suggestibility. The psychologist documents any spontaneous account carefully, in order to comment upon the language used as well as to assess consistency over the two sessions. Inclusion of the verbatim account in the psychologists' report constitutes hearsay, however, and may lay the complainant open to difficulties in court due to minor inconsistencies. In some cases, anatomical dolls have been used with complainants who cannot give a verbal account of the abuse, and communication by gesture and mime have also been found acceptable in court.

Assessment of suggestibility and acquiescence

The capacity to answer simple clarifying questions is always assessed. As described above, complainants with ID have been found to be more susceptible to leading questions (an aspect of suggestibility) and acquiescence (the tendency to always answer 'yes' to yes/no questions). The case study later in the chapter illustrates the way in which this is assessed in the SAVE programme.

Understanding of court procedure

In discussing the purpose of the interview upon first meeting, the psychologist obtains an idea of the complainant's understanding of the investigation. In this section of the assessment, the psychologist assesses whether the complainant understands the purpose of the trial, who is involved and what the procedure is. The complainant's participation in this discussion yields information about her ability to learn and her ability to seek clarification and express her concerns. This part of the assessment allows the psychologist to make recommendations to the social worker about specific needs in terms of court preparation: the complainant may need help specifically with saying that she doesn't know, or requesting clarification.

Ability to take the oath

Swearability, or the ability to take the oath, refers to the commitment to tell the truth in court, a crucial requirement for a potential witness. This requires an understanding of the distinction between truth and falsehood. The concept of the 'whole truth and nothing but the truth' requires that the complainant understands that she must say everything that happened, but must not make up any part of the story. Finally, the complainant needs to understand that there is a special responsibility to tell the truth in court and to the police, and that perjury is punishable. Methods have been documented for taking potential witnesses with ID through the elements of the formal oath, so that they can be sworn in (Gudjonsson, Murphy & Clare, 2000), but an alternative is to alter the expectations of the court in this regard. Many local magistrates have found it adequate to confirm the complainant's understanding of truth-telling, using simple language, as well as concrete examples, when the psychologist's report indicates that this is required. Many of the complainants in this study had an appreciation of the difference between 'truth' and 'falsehood', although they could not provide a conceptual definition. This will be illustrated in the case study.

Care needs to be taken, when assessing swearability, that the complainant does not perceive the interviewer to doubt her account. Psychologists in the SAVE programme have found it useful to explain that everybody who makes a statement to the police and goes to court is required to swear to tell the truth.

Investment in the court case

Although not a formal aspect of competence, there is no question that the investment on the part of the complainant is crucial. When a caregiver is highly motivated to prosecute, the complainant may not feel free to express her reluctance. In some situations, it seems that the complainant is forced to take refuge in what Sinason (1992) calls 'secondary handicap', deciding to alter her account or say that she cannot remember. This, in effect, is a declaration of herself as incompetent. In some cases the assessment was completed and the complainant was able to appropriately express her wish to withdraw from the legal process during the court preparation process with the social worker. Certainly the informed consent of the complainant to proceed with the court case is not always obtained. The role of the consultant psychologist in this regard is unclear; information about the trial is provided in the course of the assessment, and this may be seen as a contribution to the complainant's knowledge and therefore to her ability to make an independent decision. If there are concerns in this area, the psychologist on the SAVE team conveys this to the social worker.

The inverse situation is not uncommon – for example, involving the caregiver who is very ambivalent in cases where the accused is her partner or relative, or when household income would be reduced by a conviction. This difficult situation makes it essential that a social worker is involved.

Case Study: Cheryl

Cheryl is a 14-year-old girl who attends a special class at the local primary school. When she was 12 years old, her parents had an argument in which her father voiced suspicions directed at a neighbour. Her mother asked Cheryl about this and she disclosed to her parents that this man had been sexually abusing her for at least the previous two years. Cheryl had not told anyone, on the neighbour's instructions. Cheryl's mother thus laid a charge against the neighbour. The psychologist responsible for assessing Cheryl was concerned about whether she felt free to express her feelings about the investigation.

On assessment, Cheryl was found to be shy and reserved, but responded well to encouragement. Her functioning was assessed as falling within the mild range of ID, and it was found that she had very limited understanding of sexual matters. As she was underage, her inability to consent to sexual intercourse was not the primary question. In terms of her competence as a witness, Cheryl was unable to recall how many times she had been assaulted, but was able to report many incidents of digital penetration and some of sexual assault. She became very embarrassed when talking about the assaults, but found it easier to talk once the interviewer established the names she used for genitals, and made it clear that these were acceptable ('*koekie*' and '*piepie*' – slang terms for vagina and penis).

Cheryl's account was consistent over two meetings, and consistent with the account given to the police. She was able to answer simple clarifying questions put to her in a manner that was not leading. However, she struggled with reference points for time, and also was inconsistent about the order in which incidents occurred, although she could provide details about the first incident. It was documented that Cheryl did not generally use time markers such as months of the year or days of the week.

Whilst there were some inconsistencies in peripheral details, her central report about the alleged abuse remained constant.

There were particular assaults that seemed to produce confusion, around which Cheryl said she could not remember the details. The interviewer was left with the strong impression that certain incidents were too painful or shaming to talk about, and that the inability to remember was in fact an expression of the desire not to disclose, or even think about these incidents.

> Cheryl's compliant style with the accused, as well as with other adults in her life, required careful investigation, in terms of the assessment of a tendency towards being acquiescent and suggestible. She was not found to be acquiescent (she did not tend to answer 'yes' to incompatible questions that required a 'yes' or 'no' answer), but she was susceptible to incorrect leading questions (for example, in a morning interview: 'It was afternoon when you came along here today, wasn't it?'). The interviewer was then able to comment that Cheryl wanted to be helpful, but that she had to think very carefully because the next questions were going to be tricky. Cheryl responded well. This vulnerability was documented for the court and also for the social worker who was going to carry out the court preparation.
>
> Cheryl was uncertain about the concepts of truth and falsehood, and the interviewer used concrete examples to clarify this. She asked what day of the week it was, and when Cheryl said 'Wednesday', the interviewer said 'that's right! It is Wednesday. Now if I say today is Friday, am I telling the truth?' Similar questions were used, all using concepts within Cheryl's understanding. Once again, this was documented in the report.
>
> Cheryl was very anxious about facing the accused. The psychologist recommended an intermediary, as well as court preparation by the social worker. The sessions with the social worker led to improvements in Cheryl's self-esteem, and initial concerns about her motivation to pursue the case were laid to rest. Cheryl coped well during the trial and a conviction was secured.

Assessment of ability to consent

An assessment of the ability to consent to sexual intercourse is often crucial, as the accused may claim that consensual sexual intercourse occurred. The Sexual Offences Act, No. 23 of 1957 defines people with moderate or severe ID as being unable to consent to sexual intercourse. This is highly problematic, as in our experience this is not necessarily true. As discussed above, this kind of inference cannot be drawn on the basis of level of intellectual functioning alone. Although such a law purports to act in the interests of people with ID, it does not always do so. There is a body of literature on the roots of such laws in the service of social control, based in part on the fear of genetic and moral degeneration of society due to the influence of those with disabilities (for example, Gelb, 1995).

A more detailed, functional assessment of the ability to consent is needed. The components of the ability to consent to sexual intercourse are not laid out in law, locally or internationally, although common law requires that the person understands the nature of the act and possible consequences. Murphy and Clare's 1995 paper is seminal, and includes guidelines for residential facilities to help evaluate whether relationships are fully consensual. Work has also been done on the capacity to consent to medical investigation and treatment (Morris, et al., 1993; Wong et al., 2000). Morris et al. refer to Grisso's three elements of the ability to consent:

- The person must be *knowing*, that is, have an understanding of the relevant facts;
- The person needs *intelligence*, defined by the ability to weigh up the risks and benefits of a particular course of action;
- The decision must be *voluntary*, that is, free of coercion.

Morris et al (1993). make the point that the decision-making processes of many people would fail to meet these requirements, and that people with ID should not be held to a more stringent standard than one would expect in the general population. This is particularly salient in the sexual arena. Many nondisabled people normalise relationships which border on abuse. Many women, especially those who are economically vulnerable, engage in 'transactional sex' where sex is exchanged for money, shelter or other favours (Gordon, 1990; Ulin, 1992) in ways that might appear reckless. This is clearly an area that relies heavily on clinical judgement: how much knowledge and capacity to weigh alternatives should be expected? When is undue influence being applied?

The area of *knowledge* can be divided into two areas:

- *An understanding of the nature of sexual contact*

  If someone is to be seen as consenting to sex, the very least he or she should understand is what is about to happen physically, whether it is in the context of a heterosexual or homosexual relationship. Some authors add a requirement that the person should be able to appreciate the difference between intercourse and masturbation, and should understand that some forms of sexual contact are inappropriate, such as incest and sex with a minor. The idea of the value of sex is also sometimes included here, particularly when some sort of transaction is involved – is sex worth one cigarette, for example? (for a review, see Murphy & Clare, 1995). Within the SAVE programme, a basic understanding of the mechanics of sex is all that is required in this area.
- *An understanding of the possible consequences of sexual contact*

  The appreciation of the possibility of pregnancy and of sexually transmitted diseases is important here. This presupposes a basic understanding of one's own body in sexual terms, for example, appreciating the link between menstruation and fertility. In South Africa, awareness of the risk of HIV infection is vital. Some knowledge about contraception and safe sex is required.

Given that most people with ID receive inadequate sex education, knowledge is often severely curtailed. In addition to the difficulties families and staff of facilities have with this area, educators in the area of HIV and AIDS globally are found to ignore people with disabilities, largely because they perceive them as asexual (Groce, 2003), although efforts have been made in South Africa to reach people with disabilities (see Chapter 9 of this volume). In the SAVE programme, it is frequently observed that, although the person may have had sex education, and can answer questions about sex fairly competently, there are limitations in the person's understanding of social cues. When the person is sexually inexperienced and functioning socially well below her chronological age, she may not appreciate when she has to apply this knowledge.

The areas of *intelligence* (being able to weigh the alternatives) and *voluntary choice* are strongly related. Morris et al., in their 1993 study on the capacity to consent to medical treatment with a sample of people with ID, found that the most difficult area to understand had to do with legal rights. Even when it was exhaustively explained that they had the right to refuse treatment, and that this would be respected, many of the sample insisted that they had no choice in the matter. This clearly reflects the lack of control that people with ID experience in their lives. The question must be asked whether people with ID are in a position to exercise intelligence (in Grisso's terms), given this fundamental experience of disempowerment.

In many of the cases seen by the SAVE programme, there is no question about coercion having been brought to bear. But sometimes this is more complicated, particularly when the complainant appears to have co-operated sexually with the accused. One such case involved a young woman who was sexually abused by her uncle over a long period. She appeared to co-operate with this at times, for example, assisting him to achieve an erection. She had no awareness of how this might appear to others, and there was concern within the SAVE programme about how this would be handled in court. There was clear abuse of power by the uncle, and the complainant's ability to consent was clearly compromised.

Green (2001) describes the case of Ms S. who was allegedly abused by her paid carer. In discussing consent '…Ms S had said that she had been afraid of her carer, who was physically much bigger and whom she said could "make my life hell" if she resisted. Under these circumstances, it was argued that the carer's power undermined Ms S.'s ability to consent. In other words, Ms S. had the capacity to consent, and may have done so, but she may not have done so willingly' (Green, 2001, p. 105).

Emotional consequences

The final area where psychologists are able to help is in documenting any signs of emotional reaction to trauma. Information about behavioural changes after the assault is obtained from the caregiver, and the psychologist documents any signs and symptoms of emotional distress found during interview. Frequently symptoms of post-traumatic stress disorder or depression are identified. Sinason (1986, 1992) has documented the profound effects that sexual abuse can have for people with ID, particularly when the abuse is not acknowledged.

Conclusions

While accurate information is not available on the number of annual prosecutions of rape cases involving a complainant with ID before 1990, it appears that there has been a substantial increase in the attention to such cases within the justice system since the implementation of the SAVE programme. Investigating officers frequently inform CMH that without an assessment, cases cannot be taken further, and prosecutors have informed CMH that the availability of expert evidence has increased the number of cases going to trial. Interest in the programme has been expressed by stakeholders in various regions of South Africa.

We outlined some of the difficult decisions that have to be made within a programme of this nature. In many ways the SAVE programme has to make do with what is available, and those working within it see the potential for considerable development and improvement. At the same time, it is perceived as a valuable resource in the Western Cape, and indeed something of a luxury in the context of the rest of the country. There are many centres that have no Sexual Offences Courts, let alone specialist services. Within the Western Cape, there are many vulnerable complainants without ID who are urgently in need of assistance too.

While our research indicates that this programme assists ID complainants to access justice, many questions remain. For example, about half the cases are withdrawn, a similar proportion to withdrawals in the general population. The question emerges as to whether cases involving a complainant with ID are withdrawn for different reasons, and how often swearability is the issue. We also need to know what happens in cases where the case proceeds to trial, but the psychologist is not called. Crucially, what happens with cases that never get to SAVE at all? Further work with the SAPS and the Department of Justice is required to answer some of these questions, and some can only be answered by gathering information from people with ID who may have attempted to report assaults without satisfactory response. In addition, we need to know more about the experiences of complainants who have gone through the programme, in order to improve our services as well as the service of the justice system as a whole.

Notes

1 Personal communication: Inspector S Boulton, Crime Intelligence, Western Cape, formerly of the Child Protection Unit, and Ms L. Myburgh, formerly Senior Prosecutor, Wynberg Sexual Offences Court.

2 The authors would like to thank those complainants and their families who participated in the research. We would also like to thank the members of the SAPS who have often gone out of their way to assist our clients, and our thanks are also due to the prosecutors and magistrates who have supported this programme.

3 Corporal punishment as a sentence was found to be unconstitutional in S vs Williams 1995 (7) BCLR 861 (CC) leading to the Abolition of Corporal Punishment Act, No. 33 of 1997.

4 The ISGSA was developed in the Stanford-Binet model, with a low baseline and mixed items, and in the experience of the SAVE team, this test is successful in limiting the testee's experience of failure, as the ceiling is not reached by repeated failure on one type of item.

The ISGSA also has separate norms for people with low socio-economic status. Despite concerns about the verbal loading of the Stanford-Binet, the fourth edition of this test has also been found to be the test of choice for children with ID elsewhere (Wilson, 1992).

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11 Language policy and SASL: interpreters in the public service

Marion Heap and Helen Morgans

> What we do to Deaf children [and adults] when we don't expose them to signed languages is that we take away a most basic human right, the one we all take for granted, the right to get our first language for free. (Aarons, 1995, p. 10)
>
> The challenge is to provide [SASL] interpreting services for public areas, like hospitals, courts and police stations. (Louis Barnard, principal of the Noluthando School for the Deaf, Khayelitsha, Cape Town, cited in Smith, 2004, p. 8)

The people for whom South African Sign Language (SASL) is a first language are, generally, those who are born deaf or who become deaf as children. To refer to this group of people we use a particular convention (see Woodward, 1972), writing Deaf with a capital 'D' to indicate the cultural identity of a Deaf person who uses SASL as a first language and who is involved in the Deaf community (Morgan, 2001; see also Padden & Humphries, 1988; for particular reference to South Africa, see Simmons, 1994). In contrast to 'Deaf', a lowercase 'd' denotes deaf, the audiological condition (Woodward, 1972; Padden & Humphries, 1988). Deaf, upper case, does not include those elderly persons who became deaf late in life (many of us have parents or grandparents in this category). These deaf people do not use SASL.

SASL is central to the South African Deaf community's advocacy for equal human rights. This lobby stems from the deeply felt personal experience of Deaf people. It is rooted in their history. With the new dispensation in South Africa in 1994 came new hope for many South African citizens. It meant respect for every person's human dignity, equality, rights and freedom. Many Deaf people, including myself, Helen Morgans, eagerly anticipated that society would at last accord us dignity and treat us with respect. The South African Constitution, recognised as one of the most progressive in the world for the way that it protects and promotes human rights, presents Deaf people with the opportunity to promote SASL within a rights framework. There are many ways this can be done. In this chapter we argue that professional SASL interpreters must become an integral part of the public service (see Kellerman, 1999; Pillay, 1999). They should be readily available in 'public areas, like hospitals, courts and police stations' (Barnard, cited in Smith, 2004).

For the purposes of this chapter, we define 'interpretation' 'as the act of receiving a message in one language and sending exactly the same message in another language' (Pillay, 1999, p. 1). By 'professional' we imply, interpreters, who, like all other professionals, undergo a standard training. They are accredited by a professional board and abide by a code of conduct and ethics. When we say 'integral' we mean just that. A professional SASL interpreter service should not be conceived as ancillary, or supplementary (Pillay, 1999, p. 5). SASL interpreters must become as much part of the public service as doctors and nurses, for example, are part of the public health system, or judges and lawyers are part of the justice system.

The first section of this chapter looks at language policy and human rights in South Africa. We show that currently in South Africa, the principles are in place for a professional SASL interpreter service to form an essential aspect of a language policy that supports human rights. The second section demonstrates the need for this language service. Looking at the current situation of Deaf people in South Africa, we show that the numbers of SASL users is high, but that presently the supply of professional SASL interpreters relative to numbers of Deaf people is low. The socio-economic status of the Deaf is also generally low, relative to their hearing counterparts. We argue that access to SASL, via interpreters, in the public domain, would enable Deaf people to be heard and to communicate. However, Deaf people have already experienced a long line of flawed language policies, as their history suggests, and these are outlined in the third section of the chapter. Though many of these flawed policies originated in the international context, our focus is the local situation and our concern is that the same mistakes are not made again. In the chapter's conclusion we describe the way forward and reiterate recommendations for a professional SASL interpreter service that have already been made, but are yet to be implemented (see Kellerman, 1999).

Language policy and human rights in South Africa

Since 1994, many principles have been adopted and put in place to promote equal rights around language. In this effort, the South African Constitution (1996) has served as a benchmark. It establishes the values and standards to which South Africa aspires. The Bill of Rights outlined in Chapter Two of the Constitution describes two related sets of rights: civil and political rights, referring to rights of freedom, and economic and social rights. To put it simply, civil and political rights refer to rights to equality and human dignity, while economic and social rights refer to human needs in our day-to-day existence, such as education, health, housing, justice and social security. These areas of public service are our focus for SASL interpreters, because these are where the state has a responsibility to provide for its citizens on the basis of equality and without discrimination. Section 9 of the Constitution expressly prohibits the state and private parties from discriminating unfairly, directly or indirectly, on a number of grounds including race, language, culture and ethnic or social origin (Pillay, 1999, p. 1).

Pillay (1999) has argued from a constitutional and legal perspective that language barriers within South Africa's health system discriminate unfairly against patients who are unable to communicate in the dominant language of the health-care system. She concludes her argument: 'Interpretative and translation services within the health system are therefore an integral and indispensable component to the provision of access to health-care services on the basis of equality' (Pillay, 1999, p. 5). Although Pillay argues with particular reference to the right to health, we are sure the same case can be made for all public services.

Pillay's emphasis is South Africa's spoken official languages. However, in support of her argument, she quotes a Canadian Supreme Court case that brought the issue of signed language interpreters before the courts (Pillay, 1999, p. 5). The case has particular local significance because the authors of South Africa's Constitution and Bill of Rights drew on Canada's Charter of Rights and Freedoms. On appeal, the Canadian Supreme Court held that the state's failure to provide signed language interpreters where necessary undermined effective communication in the delivery of health-care services, and therefore constituted a denial of the right to equality (Pillay, 1999, p. 5).

SASL has status, although it is not one of South Africa's eleven official languages. South Africa's Constitution states that '[e]veryone has the right to use the language and to participate in the cultural life of their choice…' (Chapter 2, No. 30, Bill of Rights). Section 6 (4) of the Constitution (1996) provides that all official languages must enjoy parity and esteem and must be treated equitably (see Pillay, 1999: 1). The South African Schools Act, No. 84 of 1996, stipulates: 'a recognised Sign Language has the status of an official language for purposes of learning at a public school' (Chapter 2, No. 6 (4)). In Chapter One of the Constitution (1996, Founding Provisions), it specifically states that the conditions for the development and use of SASL must be created and promoted.

The Pan South African Language Board (PanSALB) was established specifically to provide for the recognition, implementation and furtherance of multilingualism in the Republic of South Africa and the development of previously marginalised languages. PanSALB has already begun ensuring the promotion and development of South Africa's eleven official languages, plus the Khoi, Nama, and San languages, as well as SASL. It has funded several projects, including one for training SASL interpreters. It has also mediated on language rights among different linguistic groups. Interestingly, the Board has also filed a complaint to the South African Broadcasting Corporation (SABC) on behalf of Deaf people. But more needs to be done.

The principles and institutions are in place to ensure equal rights around SASL. However, South Africa's Constitution (1996) is careful to qualify its language policy with phrases such as 'wherever practicable' (Alexander, 2002, p. 91). As Alexander continues, 'we would be guilty of the most cynical behavior if we did not warn that such "safety clauses" allegedly based on technical and economic grounds are more usually the perfect loopholes for reducing the commitment to equality to no more than lip service' (2002, pp. 91–92).

Cost can no longer be offered as an excuse to delay implementation of the multilingual project that could include an interpreter service for SASL as well as South Africa's official languages. A recent costing of the implementation of the proposed multilingualism policy in the South African public service concluded that additional budgetary provisions at the national level would be well under one per cent (Alexander, 2002, p. 183, note 19 citing Heugh, in press, who in turn cites Emzantsi Associates). It is therefore only a question of political will to implement the project. With this in mind, we demonstrate the need for SASL interpreting services for Deaf people.

Language, SASL and SASL users

Language is a (if not *the*) key to our humanity. It has been defined as:

a system of relatively arbitrary symbols and grammatical signals that change across time and that members of a community share and use for several purposes: to interact with each other, to communicate their ideas, emotions, and intentions and to transmit their culture from generation to generation (Baker-Shenk & Cokely, 1980, p. 31).

In other words, language gives individuals the essential tools to think, to dream, to express themselves. It gives society the essential tools to interact within and across the generations.

Most hearing people learn language so easily that they take its importance for granted. Hearing children born to hearing parents pick up the spoken language from those around them. It is not the same for Deaf children. Congenital and childhood deafness puts language acquisition at risk. The majority of Deaf people (up to 90%) are born into, or become deaf in, hearing households. Because Deaf children cannot hear the spoken language around them, they do not acquire language as easily or naturally as hearing children in hearing households.

The consequences of being without language can be severe. We offer an example: Sacks (1991, pp. 38–39) tells the story of a young boy, Joseph. Joseph's deafness was first misdiagnosed as retardation and later as autism. Because his deafness was misdiagnosed, his schooling was delayed and no effort was made to teach him language. By the time Joseph entered school at age 11, he had 'almost no notion of symbolic communication, of what it was to have a symbolic currency, to exchange meaning' (Sacks, 1991: p. 39). He had no notion of even the most basic concepts we take for granted – like the idea of a question. It was not possible to ask Joseph the simple question of how he had spent his weekend. Joseph had a lack of 'historical sense'. He had no notion of 'a day ago as distinct from a year ago' (Sacks, 1991, p. 39).

Signed languages are the natural languages used by communities of Deaf people. For as long as there have been Deaf people there have been signed languages. However, contrary to popular belief, there is no universal sign language. Rather, there is, for example, British Sign Language, American Sign Language, Kenyan Sign Language and SASL. These naturally occurring signed languages have precisely the same linguistic structure as that proposed for all other languages – they are fully fledged languages in every sense of the word (Aarons, 1995). Signed languages are only different in that they are visual-gestural languages that use the modality of space (Valli & Lucas, 1998). Signs are produced by the hands, face and upper body and perceived by the eyes (Baker-Shenk & Cokely, 1980). Signed languages are learnt in just the same way as spoken languages. And, anything that is expressed in spoken language can be expressed in signed language. 'You can gossip, flirt, joke, discuss calculus and politics, give a linguistic lecture, make poetry, all in signed language' (Aarons, 1995, p. 9). Deaf babies 'babble using their hands, just as hearing babies babble using their voices' (Aarons, 1995, p. 9). It is possible to daydream, talk in one's sleep and dream in signed language (Sacks, 1991, p. 35).

Deaf people usually learn signed languages from each other and mainly at school. This is so because, as we have said, it is not possible for the majority of Deaf children born to hearing parents to learn their language in the usual way. Learning sign language at school happened even when oralism was orthodoxy. Oralism is an approach to communicating through the use of speech, lip-reading and hearing aids (see Baker-Shenk & Cokely, 1980). Oralists usually argue that without speech Deaf people cannot engage adequately in a hearing world.

Contesting this, educationalists that promote signed languages as the medium of instruction, argue that the time spent on learning to speak occurs at the expense of academic education and that the end result therefore is a Deaf child who neither speaks well nor is adequately educated (Kittel, 1991; for a South African example, see Lalendle, 1975). When oralism was orthodoxy, signed languages were forbidden (Baynton, 1996). But Deaf people still used signed languages to communicate among themselves. After all, what use is speech when there is no one around who hears? Deaf pupils used signed languages when no hearing persons were present, when 'they relaxed inhibitions and wore no masks', as South African born poet and writer David Wright has put it in his excellent book, '*Deafness: an autobiography*' (1969/1993, p. 60).

Deaf people are not a homogeneous group and SASL users are to be found in all walks of life (see also Padden & Humphries, 1988). The audiological condition knows few if any of the conventional social boundaries of age, social class, gender, geographical location, nation, religion, and in the South African situation, former apartheid categories. Even so, the national socio-economic profile suggests that the majority of Deaf South Africans are more economically disadvantaged than their hearing counterparts, (*Bua*, 1995: 2). The Deaf Federation of South Africa (DeafSA) has estimated that at least 70 per cent of Deaf people are unemployed, 40 per cent maintain subsistence levels lower than that of their hearing counterparts, and up to 68 per cent live in informal housing settlements (*Bua*, 1995, p. 2). Literacy levels are also low. At the end of the 1990s it was estimated that there are only 15 Deaf people in South Africa with university degrees (Aarons & Akach, 1998), although recent figures may be higher.

The number of Deaf people using SASL is not easy to measure and estimates range upwards from 500 000 (see Morgan, 2001, p. 3). Higher estimates from DeafSA, although less recent (1995), are based on WHO estimates for deafness in any given population. These higher estimates put the number of SASL users at over 1.5 million, a number higher than that for speakers of four of the country's 11 official languages, namely Tsonga (1.35 million), Swazi (962 000), Ndebele (799 000) and Venda (763 000) (*Bua*, 1995: 2).

Access to SASL enables Deaf people to comunicate. Studies show that when and where signed languages are freely available, Deaf people are not disabled in any social sense (see, for example, Groce, 1985; Heap, 2003; Sacks, 1991; Washabaugh, 1986; Woodward, 1982). Deaf people love, marry, parent, work, and party just like every one else. On the other hand, the public domain of business and services constitutes considerable barriers to communication. Deaf people struggle to gain equal access in the public sectors, including health care, education, food, legal services, water and social security. To attest to these problems, Ruth Morgan has documented communication problems in the South African law courts and justice system (2001). Deaf people in the law courts are still 'unlikely to be treated in a way that respects their rights and dignity or with justice' (Murray, 2001, p. v). Unfortunately, there is a severe shortage of professional SASL interpreters that would improve this situation.

Table 11.1 summarises the number of SASL interpreters in South Africa by category, by numbers and by ratio of interpreter to SASL users (using both Morgan's lower estimate of 500 000 and DeafSA's higher estimate of 1.5 million SASL users).

Professional SASL interpreters are insufficient to adequately service the needs of Deaf South Africans, and there is as yet no consistency in training. Table 11.1 shows that the professional category comprises two types. The first professional type includes interpreters who have been accredited by the South African Translators Institute. Nationally there are four accredited interpreters. This gives a ratio of 1 interpreter to 125 000 SASL users. This ratio could be even lower (1: 375 000), if measured against the estimate of 1.5 million SASL users. The second category of professional includes those accredited on the basis of their SASL fluency, their experience and their competence. There are between 15 and 20 interpreters in this

Table 11.1: SASL interpreters in South Africa, by category, number and by ratio of interpreters to SASL users

Category	**Number**	**Ratio of interpreters to SASL users 500 000 (low estimate)**	**Ratio of interpreters to SASL users 1.5 million (high estimate)**
Professional on the basis of accreditation by the South African Translators' Institute	4	1: 125 000	1: 375 000
Professional on the basis of SASL fluency, experience and competence	15–20	1: 33 333 for 15 1: 25 000 for 20	1: 100 000 for 15 1: 75 000 for 20
'Grassroots' interpreters Children of Deaf parents, and teachers of the Deaf, etc.	40 selected but awaiting training that was due in 2004	1: 12 500	1: 37 500

Source: Figures supplied by DeafSA (personal telecommunication, Francois Deysel, 26 March 2004)

group. Again the ratio of SASL users to interpreters is low, even if calculations use 20 SASL interpreters for 500 000 users (1: 25 000). In practice, at a provincial level, this ratio can mean, for example, that there are only five professional SASL interpreters available for the entire Western Cape (personal telecommunication, Louis Barnard, the principal of Noluthando School for the Deaf, Khayelitsha, Cape Town, 26 March 2004; see, also Smith, 2004).

'Grassroots' interpreters may include children of Deaf adults who are fluent in SASL or teachers of the Deaf who are fluent. The 40 grassroots SASL interpreters listed in Table 11.1 are not yet formally available, as they are yet to receive formal training. However, even when these professionals are trained, the ratio of SASL users to interpreters will remain extremely low.

The category of SASL 'relay' interpreter also needs to be considered. A relay interpreter is usually a Deaf person, and is often necessary where the hearing interpreter is not familiar with the dialect of SASL used by the Deaf person (see Morgan, 2001, p. 1 and p. 15). In these situations a Deaf person who is familiar with the dialects used by both the client and the interpreter can act as a relay interpreter. A relay interpreter relays what the interpreter says to the Deaf client and then relays what the Deaf client says to the interpreter.

Interpreter services can be costly, although it is often possible for the interpreter and the client to negotiate a fee that suits both parties. DeafSA stipulates a fee of R120 per working hour and R150 per hour outside of normal working hours. However, the minimum fee is R500. Thus, one hour of interpreting in the middle of a week day morning for a clinic or doctor's appointment could cost R500 and more.

Transport may be an additional cost, although it is also possible to negotiate this cost and it may depend on distance. For example, an interpreter may choose not to charge for transport in and around Cape Town, but to charge for the longer distance between Cape Town and Worcester or George or Beaufort West.

The vast majority of Deaf people are forced to rely on hearing 'friends and relatives who may have minimal signing skills' (see Morgan, 2001, p. 9). Some hearing relatives, such as the children of Deaf adults, who are fluent in SASL, have provided a good service for their parents. But the service is uneven and therefore unsatisfactory. Further, these interpreters are not professionals. They have no training in interpretation (being fluent in SASL does not automatically make a good interpreter). Also, such interpreters have no code of conduct. There is thus no guarantee of privacy or confidentiality, or any control of the fee they may charge. They have no training in specialist terminology, such as law or health care may require. There are also many circumstances where it is inappropriate to include relatives, friends and colleagues. Clearly, the system must change. Deaf people deserve it. They have yet to enjoy a language policy that addresses their needs adequately – as history suggests.

Language policy and social change before 1994

In Cape Town, in 1874, a young Irish Deaf woman named Bridget Lynne opened the first school for the Deaf in South Africa (Boner, 2000). When Lynne opened St Josephs, later termed the Grimley Institute for the Deaf, she established Deaf education in this country for all South Africans. By 1921, the school had 40 pupils, and at this time was said to be the only institution in 'the whole of Africa' that was offering an education to deaf children who were not classified European or 'white', as we would understand it in more recent apartheid terms (Oxley, 1921)

When Bridget Lynne opened the first school in Cape Town, the method was manual and the reading and writing language, English. Soon Lynne was able to demonstrate considerable success with her method, as a report in the first public examination of her pupils in September 1874 suggests. Pupils who had never before been offered the opportunity to attend school and be taught in their natural language were reading, writing and doing arithmetic (*The Standard and Mail*, 22 September 1874, cited in Boner, 2000).

Religious concerns played a role in the establishment of the education of Deaf people generally, locally and even in the US. Gallaudet's concern for the souls of the 'heathen deaf' was at the core of his Protestant evangelical interest to establish the first school for the Deaf in the US (Valentine, 1993). Even so, it is also important to look at the role played by spoken language policy in the history of the Deaf. Halliday and Martin suggest that the 'history of language is not separate from the rest of history; on the contrary, it is an essential aspect of it' (cited in Alexander, 2002, p. 98).

The Dutch Reformed Church's concern for the Catholic influence at Grimley was instrumental in the establishment of the second school for the Deaf at Worcester in 1882. But the establishment of this school must also be seen in the social context of the colonial language policy. At this time (1870–1882), English began to take over from Dutch as the dominant language at the Cape. The British Colonial authorities were emphasising '"Englishness" – or white skins, English tongues and bourgeois values' (Bickford-Smith, 1995, p. 40–41). Amongst other factors, a Dutch and later Afrikaner identity emerged in response to this increasing 'Englishness' (Bickford-Smith, 1995). The Dutch language and the Dutch Reformed Church were important aspects of this ethnic identity and Dutch parents wanted the same religious and ethnic identity for their Deaf children. Thus, in contrast with Grimley in Cape Town, the religious ethos at the Worcester school for the Deaf was that of the Dutch Reformed Church, and the spoken language was Dutch and later Afrikaans.

The next major shift in language policy that impacted on Deaf people came with the advent of apartheid. As is well known, apartheid and its Bantustan policy proposed and acted upon a notion of an African population that was divided into 'national units on the basis of *language* and culture…' (our emphasis, preamble to the Promotion of Black Self-Government Act, No. 46 of 1959, cited in West, 1988, p. 106). In this political climate, spoken language and ethnic identity became the criteria around which schools for the Deaf were established across the country. By 1979, there were 19 schools for the Deaf, including the Kutlwanong School at Rustenburg for Tswana, South and North Sotho pupils; the Dominican school at Hammanskraal for the Tswana and North Sotho pupils; Vuleka school at Nkandla for Zulu pupils; St Thomas at Stutterheim for Xhosa pupils; Tshilidzini school at Shayadima for Venda and Tsonga pupils; Bartimea school at Thaba 'Nchu, also for Tswana and South Sotho pupils; Thiboloha school at Witsieshoek for South Sotho pupils; Efata school in Umtata for Xhosa and South Sotho pupils; Eluwa school at Oshakati for the pupils of South West Africa, now Namibia (SANCD, 1979).

At these schools, spoken language became the medium of instruction, in line with the wider international emphasis on oralism at the time. However, as has been the case generally, African Deaf children learnt signed languages from each other and used these among themselves. 'Thus different sign language varieties developed in different geographical regions [and w]hether these varieties developed in different languages or dialects has been a matter of debate', (Morgan, 1986; 2001, p. 7).

Apartheid went further. It increased the number of schools but at the same time stipulated different levels of education for the Deaf, on the basis of racial population classifications. However, even though those classified as white could proceed as far as Grade 12 or matriculation on the higher grade, as it was then known, they were rarely given this choice and wrote the lower or standard grade. These matriculation certificates are not recognised by the Matriculation Board and therefore limit the Deaf entry into tertiary education.

The apartheid era also saw responses of resistance by the Deaf. For example, in Cape Town in 1985, at the height of PW Botha's state of emergency, the Deaf Community of Cape Town (DCCT) was established as a non-government organisation. It was established by Deaf people for Deaf people. The Deaf people involved included Cyril Axelrod, a Deaf Catholic priest and Wilma Newhoudt (now Newhoudt-Druchen, an African National Congress Member of Parliament). DCCT's primary founding concern was the neglected needs of Africans and 'coloureds'.

By 1994, when South Africa enjoyed its first-ever democratic election, oralism was still orthodoxy in most schools for Deaf children/learners in South Africa. Hearing people and professionals were still largely in control of organisations for Deaf people, including the then South African National Council of the Deaf (SANCD). In 1995, SANCD was reconstituted as DeafSA and affiliated to the World Federation of the Deaf (WFD) as part of the Regional Secretariat of Eastern and Southern Africa, or RSESA (*WFD News,* 1998). According to WFD policy, 60 per cent of the leadership of its affiliates must be Deaf. In 1995, Kobus Kellerman took over the leadership of DeafSA, the first-ever Deaf person to hold this senior office in the national organisation's nearly 70-year history (although Nico Beaurain was the first Deaf person to chair the SANCD and later DeafSA).

Since 1994, research has confirmed that there is one SASL (see, for example, Aarons & Morgan, 1998). There may be dialectal variation at the level of vocabulary, as different groups, whether by age, school, spoken language, or other variables, often have different signs. Yet the grammar remains the same for all Deaf people, irrespective of age, ethnicity or geographical region (Morgan, 2001). For example, there are at least four different signs that are used for 'mother', but the same grammatical signals on the face are used across cultural or racial groups (Morgan, 2001). Deaf people in urban areas 'quickly become multi-dialectal once they are exposed to other varieties of SASL' (Morgan, 2001, p. 7). In Cape Town, SASL has been found to facilitate interactions across social boundaries that reflect South Africa's historical divides (Heap, 2003). In their use of SASL and in their interpersonal interactions, these Deaf people in Cape Town offered a glimpse of a South African society that many of us aspire to: not perfect, but more 'fluid' (Alexander, 1996, p. 6; 2002, pp. 99–100) and 'flavoursome' (Frankental, 1998, p. 228). This is a society, according to Alexander's river metaphor 'where the self-defined social groups based on religion, language, region, customs etc., but not on "race" will continue to coexist, and yet be South African as well as open to larger collective identities' (1996, p. 4).

Language policy: a way forward

English is threatening to become the *de facto* language of official discourse and public service, effectively sidelining increasing numbers of ordinary South Africans (Alexander, 2002; Perry, 2003). The democratic right to full citizenship is being compromised. SASL interpreters in the public service offer one way forward towards lifting barriers to ensure equal rights to full citizenship for Deaf people (Kellerman, 1999).

SASL interpreters, interpreting, training and the implementation of services are major topics that cannot be covered in depth here. Some points, however, must be made. To do so we draw on recommendations made by a Deaf person, for a justice system where Deaf people would be treated equally (Morgan, 2001). These recommendations apply just as well to public service more widely. We offer them here with amendments:

- Every Deaf person, irrespective of their functioning, must know their rights, including the right to have a sign language interpreter. Depending on their functional level, they have the right to a back-up or relay interpreter;
- All public services in South Africa need to know about the rights of Deaf people;
- We need a pool of professional interpreters in each province and major city to facilitate these fundamental rights;
- We need professional training for all interpreters.

The Universities of the Free State and Witwatersrand offer courses in SASL, with a view to encouraging careers in interpreting. However, in South Africa, the profession of SASL interpreting – and that of interpretation and translation generally – has still to be accorded value and legitimacy as a profession. Interpreting has proved to be a respectable and well-paying profession in many countries, and visiting heads of state from non-English speaking countries never seem to travel without their interpreters and translators.

In South Africa, interpreters were integral to the country’s Truth and Reconciliation Commission. They ensured that it is almost impossible for South Africans to say that they were not aware of the full extent of the atrocities perpetuated by the apartheid state – at least this was so for hearing South Africans. SASL interpreting was not available at the TRC, or at President Mandela’s inauguration, or at many other occasions of national importance during the first ten years of South Africa’s democracy. It is time to change this. It is time to acknowledge Deaf people. It is time to acknowledge SASL.

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Section III
Education for disabled people

12

Disability and schooling in South Africa

Crain Soudien and Jean Baxen

Introduction

The status of disabled people has long been regarded as an area of special concern in education (see Donald, Lazarus & Lolwana, 1997) and was recently, with the publication of Education White Paper 6 on special-needs education (EWP6) (DoE, 2001), made the subject of state attention. In this document, the state outlined the situation in the field of learning disability and its policy intentions for dealing with learning with respect to disability.

A number of important achievements were made in the process of bringing EWP6 to publication. Included amongst these was the recognition that disability is a site of severe discrimination. Publishing EWP6 also affirmed the work that key special-needs commentators and scholars in the country have been doing to highlight the complex conceptual and practical issues surrounding understandings of the disability field and the lack of provision of services for disabled people, as well as to suggest the policy direction that the state should take with respect to disability. Important to understand about the emergence of the EWP, also, is the fact that it complemented, and in some sense completed, the broad inclusionary policy agenda of the state with respect to education and welfare provision, which began with a sequence of Education White Papers in the early 1990s, the South African Schools Act of 1996 and a raft of subsequent legislative changes and policy innovations. These included, inter alia, the new Curriculum 2005 (following a major revisionary process in 2000–2001), a differentiated subsidy structure for schools in favour of the poor, school-feeding schemes and so on.

EWP6 also brought to light critical disparities in the provision of facilities and funding for the disabled, and showed how significantly the heritage of apartheid has marked the field. Today, for example, in the city of Cape Town there exists a number of special schools for disabled people. However, to a large degree, all these schools continue to carry the heavy imprint of the apartheid era. Indicative of this, the special school in the African township of Khayelitsha, continues to struggle with the full range of serious socio-economic problems that mark its environment, while the schools in the more prosperous areas have prospered and even improved in this new era.

Table 12.1, taken from EWP6 and based on 1996 census data, outlines the distribution of disabled people in the country. Significant in this table is the wide distribution of disabled people across the different provinces. While Eastern Cape, KwaZulu-Natal and Gauteng hold 17.39 per cent, 18.89 per cent and 17.1 per cent of the disabled population respectively, others, such as the Northern Cape, account for only 1.77 per cent.

Table 12.1: Distribution of disabled persons per category, per province

Province	**Sight**	**Hearing**	**Physical**	**Mental**	**Multiple**	**Not specified**	**Total**	**% per province**	**% of population**
EC	161 898	68 531	115 717	41 432	35 997	38 604	462 179	17.39	1.14
FS	133 614	33 045	41 960	13 947	16 461	18 127	257 154	9.68	0.63
G	211 769	59 868	69 936	24 033	26 030	63 906	455 542	17.14	1.12
KZN	183 758	76 034	129 894	42 646	24 895	44 863	502 090	18.89	1.24
M	98 322	31 895	41 381	12 211	9 019	19 085	211 913	7.97	0.52
NC	18 529	6 083	9 052	3 791	2 403	7 137	46 995	1.77	0.12
NP	113 088	51 416	60 078	22 578	16 019	33 690	296 869	11.17	0.73
NW	129 442	37 571	54 706	17 768	16 913	23 134	279 534	10.52	0.69
WC	40 603	18 965	35 051	14 146	6 499	30 174	145 438	5.47	0.36
Total	1 091 023	383 408	557 775	192 552	154 236	278 720	2 657 714	100.00	6.55
% per disability	41.05	14.43	20.99	7.25	5.80	10.49	100.00		
% of population	2.69	0.94	1.37	0.47	0.38	0.69	6.55		

Source: (DoE 2001, p. 14)

Note: EC = Eastern Cape, FS = Free State, G = Gauteng, KZN = KwaZulu-Natal, L = Limpopo, M = Mpumalanga, NC = Northern Cape, NW = North West, WC = Western Cape

EWP6 reads these figures about disability distribution in conjunction with figures for the number of learners in special schools. Table 12.2 provides a view of the number of learners and the number of special schools by province in South Africa.

Table 12.2: Distribution of special schools and learners in special schools, per province

Province	Special schools (n)	Learners in special schools (n)	Learners in special schools (%)	Special schools per province (n)	Per learner expenditure (Rands)
EC	41	6 483	0.28	10.79	13 746
FS	19	3 127	0.40	5.00	22 627
G	96	25 451	1.62	25.26	11 049
KZN	58	7 631	0.28	15.26	21 254
M	15	2 692	0.29	3.95	17 839
NC	8	1 392	0.68	2.11	15 749
L	19	4 250	0.23	5.00	16 609
NW	42	4 364	0.46	11.05	13 015
WC	82	9 213	0.96	21.58	28 635
Total	380	64 603	0.52	100.00	17 838

Source: (DoE 2001, p. 13)

Note: EC = Eastern Cape, FS = Free State, G = Gauteng, KZN = KwaZulu-Natal, L = Limpopo, M = Mpumalanga, NC = Northern Cape, NW = North West, WC = Western Cape

Given that special schools are an infrastructural asset and a service geared towards the needs of a particular segment of the entire disabled population, reading these tables together, as EWP6 does, offers a somewhat distorted representation of disparities in service provision for disabled people across all age groups and provinces.

For example, the report finds that while the Eastern Cape accounts for 17.39 per cent of disabled people in South Africa, the province only has 41 special schools, making up 10.79 per cent of the number of special schools in the country. In contrast, Western Cape has 5.47 per cent of the disabled population but 21.58 per cent – over one fifth – of South Africa's special schools (DoE, 2001, p. 14). That said, these figures do give some sense of the disparities that affect the provision of services and infrastructural support for disabled people in South Africa.

Furthermore, taken together, these tables suggest that much more detailed research and analysis is required to get a handle on exactly where the cleavages lie with respect to provision for the diverse needs of disabled people, including education provision, especially given that redressing such disparities is a powerful factor in setting transformation agendas and identifying and achieving equity goals.

EWP6 makes clear that the disparities suggested by these figures are a direct result of previous apartheid policies where facilities were allocated on a racial basis. Provinces such as the Eastern Cape, with majority black populations, were poorly served, while those with large white populations received generous support. EWP6 also shows how few disabled children were enrolled in special schools. While the total national incidence of disabled people was 6.55 per cent, only 0.52 per cent of learners in the system were regarded as being disabled. Expenditure on disabled children also varies widely across the country. While Gauteng spends only R11 049 per head, Western Cape spends as much as R28 635 per learner, per annum.

Interesting too about EWP6, is the conclusion that it draws about the failure of the system to accommodate all disabled children in the country. Using World Health Organization benchmarks, EWP6 estimates that there are between 293 000 and 346 000 disabled children in the country (between 2.2% and 2.6% of the population of approximately 13 312 000 learners in the system). Given that the system currently only accommodates about 64,200 disabled learners, it is suggested that between 260 000 and 280 000 disabled children are without proper care and provision (DoE, 2001, p. 9).

The policy response to this situation as outlined in EWP6 is to commit the education system to inclusive education and training, based on principles that include the following:

- Acknowledging that all children can learn and that all need support;
- Accepting and respecting that all learners are different in some way;
- Committing the system to meet the needs of all learners;
- Acknowledging and respecting differences in learners, such as age, gender, ethnicity, language, HIV status, disability, language and class;
- The need to maximise the participation of all learners in the curricula and cultures of institutions and to uncover barriers to learning.

Given these principles, the approach taken by the policy is two-fold, namely that of ‘mainstreaming’ or ‘integrating’ and ‘inclusion’. The objective of ‘mainstreaming’ is to integrate learners into the existing system and supporting them so that they can fit, while inclusion is essentially recognising and respecting the differences among learners and building on their similarities.

The thrust of EWP6 is to acknowledge the discriminatory practices that existed within special education during the apartheid period prior to 1994 and to project a new inclusionary policy. It shows how the dominant deficit discourses of race and disability (particularly physical and neurological) of the apartheid era were used to privilege and exclude, and in response, it suggests the discarding of these constructs as organising structures in favour of what is referred to as a more ‘inclusive’ approach to education and training.

While we need to acknowledge the important steps made in the new policy, anxieties still remain. There are sufficient grounds for arguing that both the policy (in its textual form), and the practice surrounding it, have not engaged sufficiently with recent debates and developments in the discussion on inclusion. However, at this point, it is in the country’s favour that the disability arena is not yet one which has

– such as in the US – become a residual and indeed punitive category in which anybody not deemed to possess the range of skills and attributes required by the mainstream is systematically condemned to a 'special class'.

The discussion in the US, certainly amongst sceptics of the placement of learners in special and remedial classes, suggests that increases in the sophistication of categories of disability and the attribution of the label 'disabled' have a great deal to do with the failure of the schooling system and have become part of a complex and questionable justification for why achievements levels in schools are dropping. The Director of the Department of Educational Services in the Fairfield School District in the US comments that, '[t]here has been…a noticeable increase in the identification of disabled students and we're really trying to understand why this is' (Baker, 2002, p. 663). Other commentators have also pointed to the proliferation of programmes, including testing regimes, for disabled people (see Pitoniak & Royer, 2001; Reynolds & Wolfe, 1999; Shaw, 1997). As Lionni and Klass point out, '[s]omewhere along the line our schools had lost the ability to routinely educate children and produce uniformly good results' (quoted in Strydom & Du Plessis, 2002).

South Africa is certainly not in the position in which the US finds itself. While there have been occasions where the integration and inclusion of disabled learners has been advanced as an explanation for low attainment levels achieved in assessment tests,[1] disability and the identification of disability have in general not been used as a displacement device to shift attention away from failures in the education system.

At the same time, however, the basic discourses that permeate the education field with respect to difference and disability in the US continue to function in South Africa, and manifest themselves within the new policy too. As in the US, the disability field in South Africa is a particularly vulnerable one, with lay-people and 'experts' of one kind or another having come to exert influence in the field in different ways. These people bring with them a range of orientations to disability, ranging from a kind of naïve innocence at one end of the spectrum to an insidious condescension at the other. Ever-present is a pervasive stereotyping. Disability commentator Kathleen Shaw suggests that a great deal of what passes for science and rigour in the field has to be seen for the ideology that it actually is. As she puts it:

> Ideology acts as a lens through which specific policies and procedures are developed and enacted. This lens tends to encourage actors to focus on particular strategies of action, while ruling out other types of action. (Shaw, 1997, p. 285).

In light of these criticisms, we argue that South African policy with respect to disability and education needs further investigation. As a point of departure, we take issue with a frequently-expressed view held by both practitioners and commentators in the special-needs field that the realms of the medical and the social constitute, by themselves, discrete and self-sufficient sites of explanation (see also Chapter 4, this volume). The broad approach we take is that in as much as policies and approaches serve and confer recognition, and to the extent that they identify, name and focus on problems, they can also erode people's rights. Put plainly, while addressing some issues and meeting the demands for rights in some respects, policy interventions often, though sometimes not deliberately, serve to perpetrate and perpetuate new injustices.

An important discussion that is lacking from the policy debate pivots on questions of citizenship. Quite simply, it is crucial to examine how South African citizenship is constituted in terms of speech, deportment, demeanour, responsibility and accountability, and to explore the image of the citizen that the new policies project and idealise. Key questions that require interrogation include the following:

- What exclusionary devices operate in the identification of the South African subject?
- What counts as acceptable in the repertoire of difference, and what as unacceptable?
- How is difference imagined?
- What official mechanisms and processes exist for managing alterity?
- How is othering perceived, understood and managed by society generally and by the education system in particular?

These questions are crucial to ask of a transforming society, especially if we hope to anticipate and pre-empt new ways of marginalising and othering, even as we learn each day, astonishingly so, how complicit we are, wittingly and unwittingly, in processes of exclusion. In the midst of this complexity it is our duty to remain alert to these possibilities and to make them a part of wider and, indeed, our own processes of public education. In light of these considerations, it is essential at this point in the argument to take what may appear to be a detour into broader philosophical and political considerations. These form a necessary basis to our conclusions about policy issues.

The problem of definitions

Those working with disabled people themselves have difficulty in developing definitions that do not in one way or another exclude or categorise and make different an oppositional construct. While definitions are constructed to advantage the disabled, the opposite is often true. From understanding disability as a biomedical condition to considering the sociological or economic impact of disability, each definition is embedded within broader constructs of how society works, who is in and who is out, and under what conditions decisions are made. How definitions work to frame, organise and create policies and the social practices that flow from them, is nowhere clearer than in the field of education. It is crucial, therefore, that these definitions be understood as emergent from particular histories and discursive formations.

Early medical definitions of disability emphasised the physical, psychological and/or neurological nature of the disabled body. Disability was equated with deficiency, in the sense that a physical, psychological and/or neurological attribute was identified as lacking from an 'agreed upon' image of the ideal subject. This deficit was then policed through structural and institutional measures. This ideal also generated particular social practices and orthodoxies. In the field of education, these orthodoxies found expression in the building of special schools, training special teachers and making those labelled as disabled the target of endless testing and measurement, with a view to 'curing' or 'fixing' them. This perspective, elaborated philanthropically, economically and sociologically, we argue, projects those assumed to be disabled as the victims of tragedy, status or difference (especially racial and ethnic); in other words, as victims of circumstances beyond their control. Furthermore, by emphasising a notion of victimhood and base 'injustice' implicit in being disabled, this perspective advocates that disabled people be 'especially' treated and managed so that they can be 'compensated' for their 'handicap'. As such, they then become the 'worthy recipients' of 'handouts' or special programmes. Internationally, programmes focusing on upgrading mathematics skills or improving English are reminders of how such definitions are deeply embedded and constructed within broader understandings of what holds social (and economic and political) currency, what is and is not desirable, and how notions of exclusion and inclusion operate within such constructions. Just as definitions are rooted in such discourses, so do social practices flow from them. Simply put, we argue that definitions are not neutral constructions that are disembedded from their contexts, but instead are deeply situated and embedded in discourses of corporeality that convey powerful normative messages about what is acceptable and desirable, as against that which is neither. Contextualised by these discursive formations, definitions can be seen to highlight certain markers of what is valued and what is not.

Value(s) and the 'marked body'

Disability as a site of difference finds its origins in the generic discussion about the ideal subject. While it is true that many understandings of subjecthood exist in the many social contexts, cultures and settings that make up the world, the discourse that has come to dominate and frame its current understanding begins with the ancient Greeks' reflections on the constituents of ideal societies, moves through the European Enlightenment that saw the elevation of rationality to a virtue with the concomitant rise of the scientific method, and continues in contemporary debates, to which we will return in a moment.

Plato, to begin with, was of the view that there are important natural differences, and indeed inequalities, among people and that if a society is to prosper, social planners ought to recognise and attend to these (Kamtekar, 2002). The criterion for superiority in Plato's world was moral virtue. Kamtekar argues that Plato's view was hyper-elitist: '[v]irtue is too rare to belong to a whole race or ethnicity…True virtue belongs to the smallest class, namely philosophers' (2000, p. 9). Aristotle too classified human beings around the nature of the body. 'Natural' slaves, he argued, were more like the body than the soul, 'more like the beast than the human, and this reflects their function to be working with their bodies…nature's purpose makes the bodies of free and slave different' (Ward, 2002, p. 25). While there is insufficient space here to pursue this discussion, the point which is raised, ambiguously, is that the body is the site upon which 'virtue', in Plato's terms, or 'the soul', in Aristotle's terms, are 'marked'.

This ambiguity continues through the European Enlightenment, as seen in the work of Hobbes, Locke and Rousseau, and into the work of more modern thinkers such as Nietzsche (see Squadrito, 2002). Nietzsche, for example, while arguing, contrary to popular belief, that the ideal race is secured not through birth but through cultural practices, at the same time acknowledges that blood is an important determinant of cultural advancement. Nietzsche writes in *The Will to Power*: 'for spirit alone does not make noble; rather there must be something to ennoble the spirit. What then is required? Blood' (quoted in Conway, 2002, p. 173).

Much of the ambiguity in these and similar discussions relates to whether the marked body could be improved or what the marked body could pass on to its progeny. It is important to note that we are dealing with concepts that are not dissimilar to those found in discussions relating to race. Race, like disability, is often derived from physical 'marks' on the body.

In the modern era, this ambiguity produces sufficient moral space for a range of supremacists to argue for the improvement of the quality – the value – of human stock. Amongst supremacists, central are those eugenicists who, after Francis Galton opens the discourse in 1883, become preoccupied with the management of social hierarchies through the manipulation of marked bodies. In practice, as Bernadette Baker succinctly sums up, this means:

> constructing and privileging certain kinds of whiteness over certain kinds of color, certain kinds of masculinity over certain kinds of femininity, certain kinds of ability over certain kinds of 'corporeally anomalous' body-minds, and tolerating only narrow versions of heteronormativity and religious devotion. (Baker, 2002, p. 665)

In this process, different bodies are relativised in a hierarchy that accords certain bodies higher value than others. Historically, the undervalued have presented their bodies as objects of inspection, trade, amusement and service to the valued, as much as the valued have appropriated these same bodies. In the worst cases, as with the example of Sara Baartman, the Hottentot Venus, black bodies had to be explained to account for their difference and degeneration. When explanation was not forthcoming, black bodies had to be subjugated – manacled and caged – to manage that which remained unknown and stubbornly refused to reveal itself. Later, the disabled had to be physically erased – murdered, as during the Holocaust – as a way of ridding society of 'useless eaters'.

Extreme as these examples are, they show how Western discourses of the body have determined that a person's worth be calculated according to an economy of values attached to markers selected from their body. Of course, Western discourse is not alone in the ways that it reads human value off human bodies; in many other cultures it is not unknown for disfigured new-born babies to be disposed of at birth. However, what makes Western discourses significant in ways that similar examples drawn from other cultures and locations are not, is that, firstly, the way the West marks and values bodies is discursive. That is to say, it powerfully shapes the way 'embodiedness' is imagined and consequently determines social practices in relation to the body, especially marked bodies. Secondly, this economy of values holds currency in diverse locations and contexts where it has gradually displaced and usurped alternative paradigms for imagining and valuing human difference. Without labouring the point, it is enough to recognise that Western discourses of the body have come to dominate how human value is thought and spoken about as well as estimated, particularly in relation to estimating the value of 'disabled people', people whose bodies are seen to fall significantly short of a discursively imagined ideal body. It follows that these same discourses powerfully shape responses to the perception of deficit, whether those responses be in the form of uncritical social practices that exclude and marginalise, or reflective social practices, such as policy interventions, that seek to include and mainstream.

Frameworks, bodies and the body politic

If this discourse on the marked body has deep and unfolding implications for how society is organised, this is particularly true for education because it is especially through the organisation of education that these values play themselves out. Decisions made by government (at all levels, from municipal to national) about how to organise the provision of education reflect how governments believe people should be treated educationally. These beliefs, outlined through policy, are based on their understanding of the kind of person their decisions are referring to.

The place of eugenics in this discussion is important to understand. The impact of eugenics on society is wide, if uneven. It is deeply implicated in the 'purification' project of the Nazis, and even after the Holocaust continues to fire the imagination of various scientists such as Julian Huxley and Francis Quick, who argue for the sterilisation of particular groups of people – African Americans in the US and 'genetically unfavorable' parents in the United Kingdom. While eugenicists certainly do not become hegemonic in modern society, to the extent that their thinking permeates and seizes the high ground in politics, the academy and social life, they undoubtedly shape modern thinking with respect to how difference might be approached. This influence is profoundly present in the already-existing scientific practice of classification. It becomes key in what Foucault calls 'dividing practices'. Baker explains:

> [t]hese practices of categorization and classification assumed a divisibility to being and became important to social government between the world wars and well after… It was…a central…impetus to the development of a raft of tests, categories and administrative arrangements – IQ tests, psychological tests, personality tests, clinics, visiting medical services, observation wards and the like that emerged in the late nineteenth and early twentieth century to deal with the crisis of problem populations. (Baker, 2002, p. 672)

Once the point had been reached in Western thinking that an ideal body existed and that such an ideal constituted the site upon which value rests, the inevitable next step was to address how one determined whether particular bodies constituted and formed a part of the ideal community. It is through this next step that imagining who the ideal is, moves to become what one might see as a framework, because frameworks are now needed to translate the imaginary ideal into the world of the real. In the social world and particularly in educational settings, the mechanisms for doing this are located in practices of measuring, testing and classifying. To find value one has to test for value.

And so in Western science, a fixation takes root with classification that inevitably leads to a constant anxiety about who measures up and who does not, who is in and who is out, who is part of us and who is not. Critically important about this, of course, is where the normative power rests; who is doing the classifying and in terms of which norm. It is at this point that the discourse of ideal and deficit bodies finds its translation into a medical scientific framework that measures and classifies. The sum result is the de-emphasis of this question of normative power and a discursive re-emphasis of the abstract calculus of measuring and classifying, a tandem movement that simultaneously allays the anxiety of some (the valued, the powerful, 'us'), by excluding and marginalising those that 'don't measure up'. It also obscures the social consequences and injustices that flow from such dividing practices, by abstracting the violence that is at the base of the discourse's power.

The politics that are set in train by these developments are important to understand. Questions of community, citizenship and belonging perforce lead, in the realms of the political, social and philosophical, to concerns about inclusion and exclusion. Inevitably, as the 'ideal' takes 'shape', so do questions arise about the consequences of these idealisations. The general sentiment in these debates is that inclusion is by definition good and exclusion is bad. Thus, goes the line of thought, the end of inclusion policies is to overcome exclusion.

Important for our argument is that this general position fails to recognise the possibility that integration – as a strategy that promotes inclusion – might produce new forms of exclusion. Little recognition is given to the possibility that the notion of inclusion operates on normative principles. Norms determine how groups are defined and constituted in their ideal forms, and, in opposition, their 'un-ideal' forms. Yet little understanding develops around how these norms, through their delimitation of un-ideal forms, come to describe and fix the characteristics of 'out' groups and, as a consequence, 'explain' what it is that such groups lack in terms of their 'abilities' to articulate their rights and access certain services.

The politics of inclusion and exclusion that arises in relation to these perceptions seldom becomes explicit and the subject of public discourse. By failing to take into account the power relations (economic, social and especially epistemological) that define the normative order, this politics underplays the existing and complex social relations in society that give rise to and perpetuate inequity. Critically, the politics of inclusion and exclusion, and the discursive formations that underpin it, elides differences between and within groups, communities and individuals. This is because, firstly, it abstracts and reifies people and, therefore, ignores the subjecthood and agency of who is being excluded and included. Secondly, it lacks the means to approach the complex ways in which difference is produced, particularly the ways in which specific differences interlock and constellate, as well as how differences are articulated specifically, collectively and discursively. Because identified and marked groups (un-ideal groups) are always read through what are understood to be the dominant characteristics of that group, differences within these groups are obscured. Discourses of exclusion and inclusion fail to specify the relationships between disability, race, class, gender, and other forms of difference and inequity in society and fail to show how these articulate with each other. This, we argue, is the major problem with current approaches to dealing with disability.

Returning to the policy

Having had this discussion, what might we now say about EWP6 and the current policy with respect to disability and education? How inclusive is EWP6, what notions of inclusion does it work with, and how does it operate as a site for new kinds of exclusions?

The first point is about EWP6's concerns and its understanding of rights. Close scrutiny of EWP6 will show that a distinct conception of rights is used in the document. This conception is derived from the South African Constitution (1996) in terms of which education is conceived as the fundamental right of every learner, 'whether disabled or not' (DoE, 2001, p. 11). The Constitution, built on the 'values of human dignity, the achievement of equality and the advancement of human rights and freedom' compel 'all of us to take up the responsibility and challenge of building a humane and caring society, not for the few, but for all South Africans' (DoE, 2001, p. 11). Alluring as it might be, we suggest that this rights discourse is suggestive of an ideal body against, off and from which others are 'read'. Embedded in this document and the rights discourse from which it takes inspiration, is a normative ideal. This ideal is nowhere specified, but is indeed taken for granted. Against the 'healthy body' is the deficit body, lacking in certain things and consequently made the subject of inspection, categorisation and remedial action, and only recognised through a process of entitlement in relation to that imagined in the ideal and measured in the norm. Given this, it is difficult to discard the fundamental categorisation of 'us' and 'them', the 'ideal' and 'not ideal'.

Flowing from this, the thrust of the policy is essentially assimilationist. While mainstreaming begins and ends with the idea of inclusion, the inclusion into which the subject of difference – in this case, disabled people – is invited, is essentially the world of the normative, the ideal, even where it is argued here, special provision and thought is given to those who are regarded as disabled. The policy acknowledges difference but is unable to show how it might work with difference other than through the 'ideal' value of that which is dominant. In this respect, the policy is little different to approaches to multiculturalism that subsist in unproblematised understandings of difference. The power valences that sustain and are responsible for the naming and recognition of difference are never themselves the subject of interrogation. Instead the full focus of the policy outlined in EWP6 is on that which is different to the supposed norm and its assimilation of that named difference. Principally, the idea is to provide for the full range of disabilities in a way that might make them 'ideal' or manage them in such a way that they may become part of the ideal. The ideal itself, and the processes leading to the privileging of the ideal, including naming practices and dividing practices, as suggested above, are not problematised.

Inherent in this difficulty is a deep ontological challenge in which 'being human' is essentialised in very limited ways. The effect of policies such as these, as with policies intended to manage multicultural environments, is ultimately to stereotype difference. It is assumed that the difference that supposedly comes with a particular form of disability is homogenised and fixed. Little recognition is given to the reality that every manifestation of difference is also surrounded and influenced by and articulated with other forms of difference; that disabled people also experience difference in terms of their gender, racial classification or social class, for example. EWP6 fails to recognise that disability is experienced within a complex of factors that variously mediate delimitations of inclusion and exclusion, and that all play a role of one kind or another in that person's experience of his or her difference.

The policy reiterates again and again that disability does not lie with the individual, but rather, is systemic, structural and organisational. By implication, structures have to be adjusted and organised to provide access through, inter alia, ensuring physical access (e.g. building wheel chair ramps), revising the curriculum, providing health and welfare needs through intersectoral collaboration with social welfare, health, and so on. Yet the policy fails to engage the deep ideological underpinnings of the disability discourse and remains silent on the discourse of the marked body, even as we reshape the physical and material order.

Although it is commendable that as a society we are recognising difference through the ways that we are reshaping and rebuilding our physical and material worlds, these efforts are undermined and betrayed by the perpetuation of naming practices, of sorting and classifying, on which EWP6 is silent and, therefore, complicit. It might be argued that material change impacts on discourse change and, therefore, that the way we speak about and imagine disability will be appropriately modified as we rebuild our environments and change our practices. That material change impacts on how we speak about and imagine the world is undoubtedly true. However, if we accept the poststructuralist assertion that language constitutes reality and recognise that social practices regarding the body have been determined by a hegemonic discourse about marked and deficit bodies, and that in fact, such practices are themselves discursive formations, then it seems unlikely that changing social practices and built environments will disrupt the power of discourse, despite the extent of their moderating influence.

This policy acknowledges that 'some learners may require more intensive and specialised forms of support to be able to develop to their full potential' (EWP6, p. 16). It also says that it seeks to 'empower' learners by developing their individual strengths and enabling them to participate critically in the process of learning. But this participation is understood as an artefact that has been determined through its distance from the ideal. One's distance from the 'ideal' is set and measured against a range which, in the field of education, includes regulatory devices of assessment, entry to school tests, proficiency language tests, physical tests, etc. Again, who determines the tests, and how the tests are to be set, in other words, where the normative power lies, are not the subject of critical discussion.

Conclusion

The field of disability has been significantly advanced by recent developments, but has not engaged sufficiently with the ideologies that sustain the field. The essential thrust of the policy has been that of assimilating disabled people – through mainstreaming and integration – into a dominant order that itself is not set up for critique. The effect is to maintain disabled people in the kind of position that other subordinate groups have found themselves in, where their status as human beings is only understood in a derived and essentialised way.

As a way forward we argue for an analysis of the position of disabled people in education, but also in other fields, through what is variously called the non-synchronous route, the parallelist analysis or the joined-up approach. What these approaches do is attempt to understand the deep ontological integrity of the subject beyond the idealisations that govern and discipline dominant thinking. The objective, is to capture the complexity of interests, influences and factors in a school that give it a specific character. Such an approach requires a policy that recognises that many forces and influences coalesce, collide, fuse and interact to produce human beings, which can never be read through the dominant ascribed identities assumed to inhere in them. Policies are needed which are alert and responsive to this complexity and, more critically, can provide institutions such as schools with the guidelines that can deal with and support the complex identities their learners will bring.

Note

1 Personal communication to Crain Soudien from a Western Cape Education Departmental official, 2004.

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13 *Disabled students and higher education in South Africa*

Colleen Howell

Introduction

The higher education system inherited by the new democratic government in South Africa in 1994 was one that had been moulded and shaped by a colonial history and the ideology of apartheid. Taken the degree of racial inequality that existed in the higher education system prior to 1994, it is not surprising that within the overall equity framework, there has been a large focus on increasing the participation of black students in the higher education system (DoE, 1996, 1997, 2001a). This has resulted in a significant change in the racial profile of students at institutions (Cooper & Subotzky, 2001). Some attention has also been directed at increasing access for women (DoE, 2001a). Parallel to the access issues has been the government's restructuring of the 'institutional landscape' (DoE, 2001a, p. 12) so that all 36 public higher education institutions can be transformed where necessary in a manner which enables moving away from their racially skewed missions under the apartheid system (CHE, 2001).[1] Limited attention has been placed on addressing issues of access and participation for students categorised by the government's *National Plan for Higher Education* (NPHE) as 'non-traditional students' (DoE, 2001a: 28). Included within this category are disabled students, who are recognised in the policy framework as having been historically disadvantaged, and as an important target group to reach in broadening the social base of the higher education system.

As this chapter will show, disabled students in South Africa, particularly black disabled learners, have in the past been – and continue to be – especially vulnerable to exclusion from the education system, including the higher education system (DoE, 1998). These processes of exclusion are linked to broader practices which relate to the marketisation of higher education.

Access and participation for disabled students in South African higher education

For disabled students, inequalities in higher education begin with inequalities that have shaped the whole schooling system in South Africa. At this level, education provision was separated not only on the basis of race, but also on the identification and categorisation of learners into those who were regarded as 'normal' and those who were deemed to have special needs. This latter category included all those learners who were adjudged to be unable to fit in to the dominant, mainstream system. In practice, this group tended to encompass a wide range of students, and included learners with different disabilities, learners perceived to have learning difficulties or behavioural problems, and students in trouble with the law. The 'result was a dominant mainstream system for "normal" learners and a secondary system of specialised education for learners with "special needs"' (Howell, 2000, p. 112). This secondary system consisted mainly of a limited number of special schools or special classes in mainstream schools. Both systems of education were further divided along racial lines with very limited provision for black learners with 'special needs', including black disabled learners (DoE, 1998).

The limited provision that existed for disabled learners, especially black disabled learners, meant that among these learners there were very high levels of exclusion from the education system. Since these children were not in the system at all, it is difficult to accurately estimate the percentage of disabled children excluded from educational provision. However, in 1997 the government's *White Paper on an Integrated National Disability Strategy* (INDS) estimated that approximately 70 per cent of disabled learners of school-going age were outside the general education and training system (ODP, 1997). For the few more privileged disabled learners who were able to attend special schools, other problems inherent in a separate, peripheral system were evident. In some schools the curriculum was inappropriate for preparing learners for the world of work, with only some special schools offering tuition up to matriculation level (DoE, 1998), the minimum academic requirement for entry into higher education.

The lack of appropriate and adequate provision for disabled learners at the schooling level has profoundly affected access to higher education for disabled people. The INDS argued that although no reliable statistics existed in 1997, higher education largely remained out of reach for the majority of disabled people (ODP, 1997). However, census data indicates that the number of disabled children entering the schooling system has since improved (Stats SA, 2003). At the same time the implementation of a standard curriculum across the system means that, at least in theory, many more disabled children have the opportunity to obtain a matric.

Yet, although at the schooling level the education environment now has the potential to support greater participation by disabled people in higher education, many barriers still remain. For example, disabled learners in secondary education are still not always being appropriately advised or given the option to choose subjects that would facilitate their access into higher education. That is, even if they do complete their matric, they would not have completed the necessary subjects at the appropriate level for exemption to a higher education institution, especially at the university level. These problems are most often informed by attitudes within schools that reinforce the notion that disabled students do not have a future in higher education and thus it is not in their own interests or in the interests of the school to support that career path.

The effect of these perceptions and limitations in the schooling system limits the pool of potential disabled students for higher education. Furthermore, the inadequacy of the schooling system in South Africa is a key factor undermining increased access to and participation in higher education for all historically disadvantaged learners. The schooling system does not produce enough learners with the minimum entry requirements for higher education and, most importantly, does not provide learners with services of a sufficient quality to enable them to participate effectively and succeed in higher education (DoE, 2001a). Thus, while opportunities for greater participation in the schooling system by disabled learners have improved, the quality of the provision further intensifies their vulnerability to the forms of exclusion described earlier.

Shifting focus to the system of higher education in South Africa, barriers to access arising from the schooling system are exacerbated for disabled learners by inequalities inherent in the higher education system (in fact, to most higher education systems throughout the world). These barriers arise from the ways in which higher education institutions are structured and function, the dominant attitudes that inform and shape the practices of institutions, as well as the role that higher education plays within society as a whole.

It is important to recognise the interlinkage between these factors. For example, while eligibility for higher education is, in general, determined by fairly rigidly defined processes that are effective in filtering out the 'eligible few from the ineligible many' (Wolfendale, 1996, p. 1), for disabled students such processes are further informed by perceptions of their 'capabilities' as disabled people. Disabled students have reported being denied access to certain courses because they are believed to be unable – due to impairment – to meet the course requirements. Examples cited include courses involving fieldwork or practical professional development in off-campus facilities; courses that entail the studying of graphic material or the use of particular types of equipment; and courses which require extensive interaction with the public (Odendaal-Magwaza & Farman, 1997).

This supposed ineligibility can be directly linked to the dominant discourse of disability and special needs which, as has already been argued, provided the basis for a segregated and inadequate schooling system. So while higher education institutions have not been separated into 'special' and 'ordinary' institutions, the dominant medical discourse around disability (Fulcher, 1989) has placed the emphasis on the nature of the learner's impairment and the extent to which this impairment is perceived to limit particular capabilities, including academic pursuits.

Moreover, the criteria for ineligibility are seen to arise from the learner's own circumstances (e.g. the existence of an impairment such as Deafness or Blindness) rather than institutional practices. Barton and Oliver (1992) argue that the location of the 'problem' with the learner rather than with the institution, and the associated medical emphasis, serve to depoliticise this area and remove it from public debate and accountability.

This is very important in the South African context where a strong, rights based, anti-discrimination legal framework is in place to prevent unfair discrimination. Despite the South African Constitution's prohibition of discrimination on the basis of disability, which means that institutions cannot now refuse a student entry merely because of the existence of an impairment, institutions continue to influence the levels and scope of participation by disabled students, especially at the programme level – that is, what courses they can or cannot do. Although it is extremely difficult to provide solid evidence of discriminatory practices on the basis of disability, anecdotal evidence suggests that disabled students are often 'persuaded' that they would not be able to cope within a particular course. Similarly, on the basis of what is regarded as 'reasonable' for the institution, disabled students are still being told that the institution is not equipped to provide them with the support that they require, and that it would thus be in the student's interest to seek out alternatives. The student is therefore expected to take responsibility for the perceived limitations created by their impairment. Most importantly, their 'ineligibility' is not seen to arise from any form of discrimination on the part of the institution – a decision for which they would have to publicly account – but rather from a 'reasonable' assessment on the part of the institution of the perceived capabilities of a person with a particular 'kind' and 'degree' of impairment.

The eligibility of disabled students for higher education is also influenced by how this level of the education system is seen and the role that it plays within our society. Davies, Williams and Webb argue that understandings of eligibility in higher education are strongly defined, reproduced and legitimated through a dominant discourse which gives meaning to the 'purpose' of higher education in a society and the institutional practices which support this 'purpose' (Davies, Williams & Webb, 1997, p. 16). In the era of globalisation in particular, the emphasis on the development of skills and knowledge that are seen to be necessary for and dictated by the market, directs teaching and learning towards the attainment of these goals. Students who are regarded as being unable to compete successfully in this market are not seen as a priority in terms of curricula responsiveness, teaching and learning support, and the allocation of resources – with the former two, in particular, requiring changes in the organisation of and practices within institutions.

It is important to recognise that although, as already stated, the South African higher education policy framework has a strong equity agenda which includes disabled students, the policy also warns against institutions recruiting students 'who do not have the potential to pursue further study and that they do not retain students who have no chance of success' (DoE, 2001a, p. 25). For many people, their decisions about the potential of a disabled student and the associated likelihood of success are informed by perceptions of the degree to which the student is likely to 'cope' within the existing institutional environment. Thus, as Riddel argues, the onus is 'placed on individual students to fit into the university regime with little reciprocal adjustment' (Riddell, 1998, p. 213).

It has been suggested that the dominance of a medical discourse of disability that focuses attention on individual deficit has also influenced the way in which institutions have responded to disabled students already in the system, particularly in terms of addressing their learning needs within the teaching and learning process. Specifically, it has deflected attention away from the extent to which the methods and materials of teaching and learning used, the manner in which classes and learning have been managed and organised, and the nature of assessment practices may in fact act as a barrier to equitable participation for disabled students. This discourse obscures how barriers to equitable participation are inherent in the curriculum itself (DoE, 1998).

The problems experienced by disabled students in the classroom are often purely ascribed to a lack of necessary assistive devices or technical equipment. While such facilities may form an important part of the enabling conditions necessary to support the student in their studies, limited attention is paid to the teaching and learning process itself and the extent to which it may marginalise or exclude some learners, including disabled learners. An example of this is the situation where a blind learner is part of a class where the lecturer makes use of overhead projector slides without reading out or describing what is contained in the slides, on the assumption that all the students have access to the visual material.

While the lack of curriculum flexibility in higher education, or the lack of inclusive teaching and learning (McLean, Heagney & Gardner, 2003), remain a key barrier to the equitable participation of disabled students, barriers to curriculum access have also arisen through the way in which learning support services for disabled students, where they have existed, have been conceptualised and provided. It is difficult to provide an accurate and contemporary picture of what learning support systems are available across the higher education institutions in South Africa, as this area remains under-researched.[2] However, the available evidence suggests that the initiatives that are in place within institutions vary considerably in the work that they do and the services that they offer. In many cases they also experience resource constraints that limit the nature and extent of the services they are able to offer. Most importantly, however, most support services, where they do exist, tend to operate separately from, or have limited collaboration with, broader teaching and learning support initiatives within the institution. Where some link exists, the collaboration is mostly with student counselling services, rather than with those dealing directly with teaching and learning such as academic development programmes (CHE, 2001, p. 69).

This structural separation of learning support for disabled students from other teaching and learning support initiatives aimed at facilitating access to the curriculum is especially important in the South African context. Over the last 20 years, much attention has been placed on developing the capacity of the higher education system to respond to the challenges of inadequate and unequal schooling provision in relation to improving participation in higher education (SAAAD, 1995). It is not possible within the scope of this chapter to discuss the many rich and varied debates that have in the past, and until the present time, characterised what is generally referred to as academic development in South African higher education. However, for the purposes of this chapter, it is important to emphasise that these debates have focused attention on the nature of the teaching and learning process in institutions, and how to ensure that it is effective and responsive to the learning needs of those learners disadvantaged by the educational inequalities of the past. Similarly, these discussions have included considerations of how best to support students and staff so that the appropriate conditions are created and institutional practices introduced which will facilitate the active and equitable participation of all learners in the teaching and learning process.

However, despite the important focus of the debates, and thus developments in academic development initiatives, both the debates and associated institutional practices have largely failed to take cognisance of the learning needs of disabled students, or to consider their support needs as part of broader teaching and learning support processes. As already stated, learning support initiatives for disabled students have largely been discussed and addressed separately from these developments. While some disabled students will always require additional, and often more cost-intensive support to access the curriculum, such support should still be seen as part of academic development services and integrated into the general academic planning process. The lack of sustainable funding by the state for academic development in the past (SAAAD, 1995) has obviously affected the nature and scope of what such programmes have been able to achieve.[3] However, it is the ideological and structural distinction that is made between the learning support needs of disabled students and other students, especially other historically disadvantaged students, that reinforces divisions already set up at the schooling level between ‘normal’ students and those who are disabled.

In attempting to theorise teaching and learning support in higher education, Simpson argues that an important distinction exists between ‘learner services’ (counselling, health care, accommodation, career guidance, etc.) and those services orientated towards what he calls ‘learning development’ or support in accessing the curriculum (tutorial support, assessment support, or professional development) (Simpson, 1996, p. 25). He suggests that while both are important for effective learning, there needs to be a clear institutional distinction between the two. The latter must be delivered at the course and programme level, including ‘the additional support that some students will need' (1996, p. 24). Using this distinction, where support services for disabled students are present in South African institutions, they tend to be more closely linked to those categorised as 'learner services' rather than 'learning development' (1996, p. 25).

Riddell develops this argument further by suggesting that the dominant medical discourse of disability directs the provision of support in higher education to technical solutions. Support provision is thus based on the 'assumption that an individual student's problems could be remedied by a particular piece of equipment, the classic "technological fix"' (Riddell 1998, p. 217). While the provision of necessary assistive devices such as a Brailing machine may be necessary for some students, she emphasises that using technology without understanding 'the social context' will not bring about the changes that are needed (1998, p. 217).

The barriers for disabled students already described have been further exacerbated by higher education institutions whose campuses are partly or totally inaccessible to many disabled students, especially physically disabled and Blind students. For Blind and Deaf students, in particular, access to information has also been extremely limited.

These barriers have a profound and sustained effect on the psychosocial well-being and functioning of the student. Disabled people who have managed to attend higher education institutions argue that the energy, emotional resources and levels of stress involved in dealing with the overwhelming range of barriers that confront them are extremely undermining and place them at an ongoing disadvantage to other students. This in itself forces them to perform at a level not expected from other students, and if they are unable to do this, the prevailing attitudes and prejudices towards their abilities are reinforced. The barriers which disabled students experience in higher education institutions therefore contribute directly to negative attitudes among staff and students towards their participation in the institution. Lack of participation by disabled people in decision-making processes and structures within institutions has further marginalised these issues from debate and discussion in institutional planning and resource allocation (Howell & Lazarus, 2003).

Challenges for institutions and a new policy framework

The experience of disabled students in higher education up to now shows that the levels of inequality extend far beyond merely accessing existing provision within institutions. Although gaining access, especially to a career of the student's choice, is fundamental to the creation of equity for these students, being able to participate equitably in the process of teaching and learning, and having a fair chance to succeed, remains as important as the former imperative.

The challenges involved in the creation of equity for disabled learners in the higher education system are perhaps best captured in the joint report of two ministerial commissions set up in 1996. The report of the National Committee on Special Needs in Education and Training and the National Committee on Education Support Services states:

> The primary challenge to higher education institutions at present is to actively seek to admit learners with disabilities who have historically been marginalised at this level, providing them with opportunities to receive the education and training required to enter a variety of job markets. Alongside this is the challenge to develop the institution's capacity to address diverse needs and address barriers to learning and development. This includes not only learners with disabilities, but all learners. This requires that adequate enabling mechanisms be put in place to ensure that appropriate curriculum and institutional transformation occurs, and that additional support is provided where needed. (DoE, 1998, p. 126)

The government's policy framework now in place to address the concerns noted above draws primarily from three policy documents that have been published by the DoE since 1994. These are: *Education White Paper 3 on The Transformation of the Higher Education System* (DoE, 1997); the *National Plan for Higher Education* (DoE, 2001a), which is intended to operationalise the imperatives stated in White Paper 3; and *Education White Paper 6*: *Special Needs Education: Building an Inclusive Education and Training System* (EWP6) (DoE, 2001). It is not within the scope of this chapter to consider more carefully the strengths and weaknesses of this policy framework as a leverage mechanism for the kind of changes that are needed for disabled students. It is notable, though, that as Ball (1994) argues, policy texts are implemented into contexts which have their own histories and existing patterns of inequalities. These contexts both shape the process of policy implementation and are in turn changed by these processes.

Thus, like any policy process, the equity goals of the higher education policy framework in South Africa are being implemented into a specific context with its own unique characteristics. As stated at the beginning of this chapter, at a national level this is a social, political and economic context characterised by substantial inequalities from the past. Moreover, it is now strongly defined by a transformation agenda that aims to redress these inequalities through far reaching strategies for the reconstruction and development of the society. The higher education system is both affected by this volatile context, and expected to contribute to this process of reconstruction and development. A consideration of this 'context of practice' (Bowe, Ball & Gold, 1992), and its likely effects on the policy goals discussed in this chapter, is therefore equally important to the creation of equity for disabled students.

While recognising the importance of this deepened understanding of the policy framework and the change process, this chapter is concerned with merely describing the relevant features of these policy texts for disabled students.

White Paper 3 defines how student equity in higher education is understood and sets the parameters for taking forward this imperative. The policy states that one of the goals of the transformation process in South Africa is to build a higher education system that:

> promote[s] equity of access and fair chances of success to all who are seeking to realise their potential through higher education, while eradicating all forms of unfair discrimination and advancing redress for past inequalities. (DoE, 1997: 14)

The equity paradigm described in the policy is therefore one that recognises both the need to prevent unfair discrimination, and to implement strategies and practices which are designed to overcome inequalities generated in the past. This understanding of equity is especially important for disabled learners and sets a very important framework for how the needs of disabled students are responded to by the system as a whole, and by individual institutions.

A number of other principles and change strategies outlined in White Paper 3 take this principle further by suggesting that the equity agenda must involve, among other things, changes to the way in which institutions are organised and structured. Of particular importance is the recognition that disabled students form part of those sectors of the population who were especially disadvantaged in this past. The document therefore argues that the new higher education policy framework:

> Must overcome an historically determined pattern of fragmentation, inequity and inefficiency. It must increase access for black, women, disabled and mature students, and generate new curricula and flexible models of learning and teaching, including modes of delivery, to accommodate a larger and more diverse student population. (DoE, 1997: 10)

The government's commitment to increase access to higher education for disabled students is given more prominence in the *National Plan for Higher Education* (DoE, 2001a). The plan makes particular mention of what are sometimes called 'non-traditional students'. This category includes disabled students and other people who have not formed part of the 'traditional' student base – that is, mainly middle-class school leavers as opposed to mature learners, workers, women and disabled people. At an operational level the plan sets out what is expected from institutions in accounting for the progress they have made towards meeting these goals. The plan states:

> The Ministry therefore expects institutions to indicate in their institutional plans the strategies and steps they intend taking to increase the enrolment of these categories of learners, including clear targets and time-frames. (DoE, 2001: 28)

As discussed previously, while increasing enrolments is extremely important in the creation of equity, equal attention has to be given to issues of participation within institutions, and thus to the creation of opportunities for fair chances of success.

The plan also gives attention to the important connection between equity of access and equity of outcomes. It discusses at some length the importance of mechanisms such as academic development to ensure that all students are able to participate equitably in the process of teaching and learning, and thus have fair chances for success. In fact, the plan asserts that:

> higher education institutions have a moral and educational responsibility to ensure that they have effective programmes in place to meet the teaching and learning needs of the students they admit. This requires that institutions should integrate academic development programmes into their overall academic and financial planning. (DoE, 2001: 25)

While the plan emphasises broadly the importance of participation and fair chances of success in the creation of equity and, most importantly, the responsibilities of institutions to ensure equitable participation, these imperatives are not related directly to disabled students. The plan therefore puts in place the imperative to increase access to higher education for disabled students and emphasises the general importance of teaching and learning support in meeting the learning needs of all students. It does not, however, clearly and unambiguously emphasise the importance of an integrated and holistic approach to teaching and learning support in institutions, which would include the support needs of disabled students. What the policy does not do, therefore, is to challenge the historical divisions in teaching and learning support, discussed earlier in this chapter.

The higher education policy framework outlined above is further developed through the provisions of EWP6. This policy was published by the Ministry in July 2001. Its primary purpose is the creation of educational opportunities for learners who have not been able to access existing educational provision or have experienced learning difficulties, largely because the education system has failed to 'accommodate their learning needs' (DoE, 2001b: 6). Disabled learners are regarded as having been most vulnerable to these inequalities in the system. It is explained that particular learning needs may arise from external or internal factors such as socio-economic deprivation or impairments such as blindness. The education system should therefore have the capacity to provide for the 'broad range of learning needs (that exist) among the learner population at any point in time' (DoE, 2001b: 17). Where learning needs are not met, learners experience barriers that prevent them from being able to participate effectively in the learning process. So EWP6 argues for the creation of equal opportunities by addressing the barriers that restrict or limit equitable participation, and by ensuring that the education system is fully inclusive.

In all sectors of the education system, including higher education, addressing barriers to learning and providing for the full range of learning needs involves two main interventions. These are:

- Addressing the *barriers* within each sector, including the higher education sector, which limit access to educational provision and/or which prevent particular learners from being able to participate equitably in the process of teaching and learning;
- Putting in place strategies aimed at building the *capacity* of the sector to meet the full range of learning needs. Although there are a number of important things that have to happen for such capacity to be built, throughout EWP6, emphasis is placed on changing attitudes and overcoming prejudice; developing flexible teaching and learning programmes that respond to the diversity of learning needs (responsive curriculum); and putting in place mechanisms that can provide additional support to those learners who may require it.

While EWP6 mainly focuses on outlining the strategies and guidelines that will be used to bring about these changes in the schooling sector, some attention is also given to the higher education band. The policy makes reference to the National Plan's reporting requirement explained above and also states that the Ministry will make recommendations to higher education institutions 'regarding minimum levels of provision for learners with special needs'(DoE, 2001b, p. 31). In EWP6 it is also stated that while all higher education institutions will be expected to ensure that 'there is appropriate physical access for disabled learners', the provision of more specialised, cost-intensive support that may be needed by some disabled students will be organised on a regional basis (DoE, 2001, p. 31).

The latter assertion sets an important precedent for regional collaboration between institutions and is explained further in the document. EWP6 states:

> In higher education institutions access for disabled learners and other learners who experience barriers to learning and development can be achieved through properly co-ordinated learner support services, and the cost-effective provision of such support services can be made possible through regional collaboration. Institutional planning is now a critical part of national planning for higher education, and higher education institutions will be required to plan the provision of programmes for learners with disabilities and impairments through regional collaboration. This is now a requirement of the National Plan for Higher Education. (DoE, 2001b, p. 28)

To date, no further policy proposals have been developed which address in more detail how the imperative for regional collaboration in this area can be operationalised.

Conclusion

This chapter has attempted to sketch the historical, cultural and organisational challenges that face institutions of higher learning in South Africa, in terms of driving the process of transformation surrounding the fully equitable inclusion of disabled students. The South African socio-political backdrop of post-apartheid reconstruction, as well as the global marketisation of tertiary education, have contributed to a developmental climate which has often mitigated against the interrogation of barriers to learning faced by disabled students. In a country in which educational provision has been so drastically skewed along colour lines, the imperative toward redress in terms of race representation in higher education has been a central priority in the re-configuration of South Africa's institutional landscape. The need for close examination of teaching and learning discourses which present often invisible, yet profound, barriers to access and success for disabled students, has consequently not yet gathered adequate momentum.

In institutional (structural) terms, the response of higher education institutions has, largely, remained one rooted in a model of construing disability that serves to locate disabled students as an 'educational problem' outside the ambit of responsibility of the central teaching and learning structures. This tendency confounds the possibility of, and need for, teaching and learning methods and environments being interrogated and ultimately re-shaped, in terms of the requirements of inclusion of learners with diverse needs. Rather than being an 'add-on', it is imperative that adequate service provision for disabled students be viewed fully as the policy and budgetary responsibility of those structures which manage the entire curricular base.

The very substantial psychosocial stressors suffered by disabled students in institutions which fail to provide equitable service provision, should not be underestimated. These stressors may often cause such students to fail at their chosen courses. Alternately, students may succeed through engaging in self-injurious behaviour, such as working inordinately long hours, or going to enormous lengths to negotiate inaccessible physical environments. Of course, this is unacceptable, and a contravention of the basic human rights stipulated by the Constitution. Such possibilities also may serve to reinforce prejudices which remain in learning institutions; in the first case prejudices regarding the limited (individual) capability of persons with impairments, and in the second case the damaging stereotype of the impaired person who has 'overcome' his or her 'limitations' through hard work. In both cases, dominant discourses within the institution remain unchallenged and unaccountable.

Thus, the questions posed to South African higher education institutions by the disability movement – in conjunction with the Bill of Rights – are broad-based and searching ones; questions that will not be addressed by 'special' academic support programmes and the provision of assistive technology. Rather, it is the very ways of thinking about teaching and learning – from methods and materials to assessment instruments and physical environments – which demand examination.

Notes

1 In January 2004, the restructuring process led to the formal establishment of 24 public higher education institutions which reflect the merging and reorganisation of the previous 36 institutions. Further merger processes are presently underway so that by January 2005 the public higher education system in South Africa consisted of 21 higher education institutions, including both traditional type universities as well as those now called universities of technology (such institutions are the result of the merging of existing technikons and universities or reconstituted technikons).

2 In 2003, the Council for Higher Education commissioned the Centre for the Study of Higher Education (CSHE) at the University of the Western Cape to undertake an investigation into equity of access and opportunity for disabled learners in the public higher education system. This report entitled, *South African Higher Education: Responces to students with disabilities*, was published by the CHE in September 2005 and is available at http://www.che.ac.za.

3 In November 2003, the DoE issued a 'Notice on Funding of Public Higher Education' as an addendum to the Higher Education Act, No. 101 of 1997. This Notice outlined a new funding framework for higher education and made some provision for funding foundation programmes as part of academic development.

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14 *Developing a Disability Studies programme: engaging activism and academia*

Theresa Lorenzo, Mzolisi ka Toni and Mark Priestley

> The Disability Studies programme allows for the sharing of the wealth of knowledge that disabled people have…with nondisabled people. (Disability activist)
>
> Our success as the Disability Sector is in ensuring that the country and the continent would not lose such an investment…the programme has a lot to offer the African Decade on Disability. (Senior official, South African Federal Council on Disability)

March 2003 saw the launch of the first Disability Studies postgraduate programme in Africa at the University of Cape Town (UCT). The programme was developed through dialogue and collaboration between the academic communities of UCT and the Centre for Disability Studies at the University of Leeds, and the disability-rights movement in South Africa. This process has begun to demonstrate how authentic collaboration in educational programmes has huge potential to drive transformation and development. In this chapter, we outline the key features and implications of this programme for disability and social change.

Defining a discipline: Disability Studies and disability research

The first challenge in establishing Disability Studies on the African continent is to consider the nature of the discipline itself. As discussed elsewhere (see Chapter 3, of this volume) the study of disability has been dominated historically by understanding the experience of people with impairments through individual and biomedical models which focus on health conditions and differences of the body, typically within a discourse of personal loss. However, such approaches often marginalised disabled people from the curriculum and from opportunities for social, economic and political development.

Over the past three decades the discipline of Disability Studies has emerged as an independent academic field within health and social sciences. Disability Studies aims to build a new body of knowledge that sees disability as social oppression, where otherness, discrimination, systematic exclusion and oppression are the appropriate foci of critical analysis (Abberley, 1996; Barnes, 1990; Lunt & Thornton, 1994; Marks, 1999a; Oliver, 1996). A critical interrogation of the nature and origins of the marginalisation of disabled people in our country is therefore required. In addition, the introduction of a Disability Studies programme accords with the current transformation of higher education curricula to address the longstanding exclusion of disabled people from higher education institutions. Yet, within the South African context, raising the profile of disability issues and developing strategies to address them through partnerships between government, higher education and civil society is a process largely in its infancy.

To take forward this wider agenda, it is essential that prominent stakeholders and decision-makers from a variety of state and non-governmental institutions be afforded an opportunity to develop critical skills surrounding disability, in order that the needs of disabled people begin to be equitably integrated into broader social-transformation agendas.

The programme aims to develop and focus a research community comprising academics, activists, and field workers to foster action-oriented and collaborative research that will mobilise and inform disability transformation in our society.

It is also essential, if strategies for equity and inclusiveness are to be appropriate and effective, that uniquely South African and African models of disability oppression and disability development be constructed and elaborated. In so doing, UCT's Disability Studies programme aims to stimulate research in an area that has been largely neglected by academia. While the need for methodological care and vigilance concerning the political relationship of such research has been widely identified (Barnes, 1992, 1996; Morris, 1992; Shakespeare, 1996), disability activists have regarded much research as alienated from their experience, calling for approaches that engage more directly with their life worlds (Ferguson, Ferguson & Taylor, 1992; Finkelstein & French, 1993; Marks, 1999a; Morris, 1992) and that contribute to the emancipation of disabled people (Oliver, 1992; 1997; Stone & Priestley, 1996).

Potential areas of research in a South African context would focus on many of the key policy issues outlined in the *White Paper on an Integrated National Disability Strategy*, launched by the Office of the Deputy President in 1997 (ODP, 1997). For example, there is much need for research that will support inclusive education, implementation of the Employment Equity Act No. 55 of 1998, and access to the built environment and transport systems, as well as research that will develop outcomes measures to monitor progress on international instruments (such as the *Standard Rules for the Equalisation of Opportunities for Persons with Disabilities* [UN, 1993]).

Research will be important in informing debate on the contested interface between illness, disability and health, and in developing theoretical frameworks of disability from an Afro-centric perspective (since current theories and literature are based largely on Eurocentric perspectives). Research can help to develop and promote alternative disability lifestyles, cultures and support systems.

Partnership in developing a programme

It is our contention that the development of Disability Studies in this context requires the active engagement and leadership of the disabled people's movement (see Chapter 12, this volume). Disabled People South Africa (DPSA), the lead organisation in South Africa, has become a powerful mechanism for ensuring the protection and promotion of disabled people's rights and development. As a national, cross-disability, political organisation, it comprises nine provincial structures, with Disabled Children's Action Group (DICAG) recognised as a sister organisation that lobbies through parents for the rights of disabled children. DPSA had strong links with the African National Congress (ANC) prior to the 1994 elections and there was a strategic focus on integrating disability issues into the Reconstruction and Development Programme after the first democratic elections. DPSA has been instrumental in establishing an Office on the Status of Disabled People in the President's Office and each Premier's office across the nine provinces, as well as ensuring that disabled people count among the members of Parliament.

These mechanisms have provided a framework for the inclusion of disability issues into policy development and research, such as the *White Paper on an Integrated National Disability Strategy* (ODP, 1997), the Employment Equity Act and the White Paper on Inclusive Education (DoE, 2001). DPSA, together with disability organisations in South Africa and the African continent, has also been instrumental in initiating the African Decade on Disability (2000–2009) in recognition of the need to raise awareness on disability issues across the continent and create greater opportunities for disabled people (see Chapter 7 of this volume). The objectives of the decade identify a number of critical issues, based on the *Standard Rules for the Equalization of Opportunities for Disabled People* (UN, 1993) and the *World Programme of Action on Disability* (UN, 1981). These include poverty alleviation, education (with a specific focus on the inaccessibility of academic institutions), employment, rehabilitation and technology, and wider access issues. A Disability Studies programme carries the potential for a substantial contribution to the implementation of the ideals of the Africa Decade.

Development of the Disability Studies programme at UCT was undertaken through a process of extensive engagement, involving constructive dialogue and debate. Theresa Lorenzo was an active member of Rural Action Group on Disability (RURACT), a platform established by DPSA in the late 1980s to facilitate dialogue with rural practitioners and disabled people's organisations (Lorenzo & Cloete, 2004). Following the introduction of a Disability Studies module in the Occupational Therapy (OT) MSc programme at UCT in 1996, disabled people have been guest lecturers and advocates for more consistent involvement in the training of health professionals. There have also been a number of collaborative research initiatives between UCT's OT department and DPSA related to the social development and economic empowerment of disabled people, as well as a partnership with DICAG. There have been reciprocal gains for all stakeholders.

The disability rights movement has recognised the potential benefit of partnership with higher education institutions in creating academic platforms to develop an authoritative voice on disability issues from within the movement, integrating disability issues into teaching, research and policy development:

> We know what we need. There is a challenge in terms of how do you realise the knowledge. How do disabled people help government to use that knowledge to arrive at results that benefit the disabled? There is a realisation that disabled people lack that authority and have to use people outside the movement to tell us how to arrive at such results. (Senior official from a disability NGO)

Given South Africa's apartheid history and that rehabilitation services are dominated by professionals, a partnership between academia and the disability sector was initially viewed with some suspicion and scepticism; suspicion of the university and of academics' motives and philosophy, together with political dynamics within the disability sector itself, have led to strained relationships in the past. These experiences compelled leaders in the disability movement to look critically at ways of working with academic institutions, while supporting the opportunity for a pool of disabled people to pursue academic studies in order to develop their skills and knowledge and assume authority around disability issues. Effort was made to make early meetings frequent and to consistently involve the same people as far as possible. The adoption of an action learning approach (Hope & Timmel, 1995; Taylor et al., 1998) was found to be meaningful and productive and there was a growing mutual appreciation of the workings of each organisation. Disability activists gained an appreciation of the workings of UCT through debating and negotiating the form of the MPhil programme and its institutional location. The sharing of frustrations and difficulties fostered more open communication and understanding, leading to increased levels of trust. As one disability leader put it, 'we started to appreciate [the need to] learn to throw stones more constructively'.

The process of negotiation involved several stages. In April 2001, the School of Health and Rehabilitation Sciences at UCT secured a three-year grant from the British Council (under its Higher Education Link Programme) to work in collaboration with the Centre for Disability Studies at the University of Leeds. Leeds was chosen as a partner due to its internationally recognised Master's programme and its close historical links with the disabled people's movement in Britain (e.g. with the British Council of Disabled People). In July 2001, representatives of DPSA and UCT made a first visit to Leeds University to initiate the partnership, with a view to developing a similar programme in South Africa.

During the development period, there were reciprocal visits involving discussion and exchange on curriculum development, budgeting and finances, bursaries, strategies to support learning, and access to relevant literature and documentation. There were also opportunities for all parties to participate in relevant seminars and classes. In addition, the development of the programme was workshopped at the DPSA conference in Potgietersrus in October 2001, as part of a session on tertiary education, and presented at the 2003 UK Disability Studies Association conference in Lancaster by UCT academic staff members Theresa Lorenzo and Brian Watermeyer. A system for recognition of prior learning, supported by UCT's Centre for Higher Education Development, was adopted as a strategy for equity, allowing students disadvantaged by the apartheid education system a more substantial opportunity to gain access. Information regarding application to the programme was disseminated through the various organisations in the disability sector via the structures of DPSA and the South African Federal Council on Disability (SAFCD).

DPSA, in particular, had argued that the philosophy of Disability Studies, as a political and human rights issue, cuts across academic disciplines. Consequently, the new MPhil in Disability Studies at UCT was registered as an interdisciplinary and inter-faculty initiative. This decision was in line with the orientation of Disability Studies as an independent and critical discipline. It is pertinent to a range of academic fields, including education (from early childhood education through to tertiary education), health care (all disciplines), social development, public administration, social and political studies, law, engineering and architecture, economics, commerce, psychology and others. The development of the programme also involved meetings with the national Office on the Status of Disabled People (OSDP), international funders, and senior managers in the faculties and university. In September 2002, the Graduate School of Humanities approved the new programme for registration, with co-convenors from the Faculty of Health Science (Theresa Lorenzo, School of Health and Rehabilitation Sciences) and the Faculty of Humanities (Brian Watermeyer, Department of Psychology).

Learning lessons

In an independent review of the development process facilitated by the British Council's Link Programme, Haricharan (2003) found that there had been a strong sharing of ideas, experience and knowledge as well as skills development. The extensive dialogue provided encouragement to all the partners to see problems in a new light. Input from the disability movement provided leadership and guidance on critical areas that needed incorporation into the curriculum. Lessons were learned on all sides; staff from the University of Leeds learned about participatory approaches, democratic principles and transparency, while South African partners learned from the experiences of initiating and implementing Disability Studies programmes in Britain. Said one South African, 'the visit to Leeds was good exposure…[I] got to appreciate how Leeds went through their programme. I am much more mature in discussions and inputs after the visit.' Partners also came to recognise that the new programme had a lot to offer, both nationally and internationally, around developing expertise and experiences of disability in 'developing' contexts where poverty is an overriding disability concern.

As one might expect, however, there were many challenges posed by partnership. One of the most testing experiences was the attempt to establish an inclusive governance structure. Governance is ultimately about establishing structures of power related to decision-making and management control of resources. Such issues often raise emotive concerns about histories and hierarchies of power. In our case, these issues were made more complex by the need to directly involve the bureaucracies of higher education institutions and disabled people's organisations (including representation from UCT, DPSA and SAFCD). Much time was spent bringing people on board or trying to fill communication gaps. Although terms of reference were drawn up, the roles and responsibilities of the co-ordinating committee were sometimes unclear or misunderstood. For those most closely involved, commitment to ensuring representation and open communication proved testing, time-consuming and energy sapping.

The intention to constitute a programme committee (a UCT requirement for quality assurance) comprised of a multi-sector board of advisors was never fully implemented. It was difficult to adhere to the criteria developed to guide the nomination of individuals to participate in Link visits, because the unpredictable work commitments of individual participants meant that their availability was constantly changing. Administrative support was sorely lacking and there was no support to ensure the dissemination of meeting records, which contributed to mistrust and misunderstandings at times. With hindsight, a more developed memorandum of understanding between the leadership of the three partners, adequate secretarial resources, and knowledge management processes may have helped to avoid much of the confusion and misunderstandings that occurred.

Accessing funding and resources for the programme was one of the greatest challenges in a resource-constrained environment. DPSA was willing to fundraise for bursaries, while UCT focused on identifying funds for programme costs. Human resources were viewed as the richest resources however, and, with a combined commitment to managing differences constructively, much can be gained here through partnership arrangements of this kind. There was some concern that the Link grant might be viewed simply as a means to export Eurocentric approaches and expertise to South Africa, and British academics were sometimes reticent about their input as foreign 'experts':

> The funding model could be misinterpreted as a traditional colonialist model of British 'experts' travelling to countries in the South. Leeds saw the Link as a mutual and reciprocal initiative with potential benefits for both parties. (Academic, University of Leeds)

By contrast, teaching staff in South Africa often found themselves over-burdened with the demands of such a large undertaking and actively sought external input. In this context, a better strategy might involve committing resources to establishing and developing a pool of local disabled people to draw on as visiting lecturers.

Planning and funding are essentials for new programmes and the commitment of universities as host institutions is fundamental. The institutional partners seemed hesitant at times, with leadership emerging from amongst the co-ordinating committee. Although the Secretary General of DPSA and Director of SAFCD gave considerable time and expertise to the co-ordinating committee, direct engagement by senior Faculty and the University's leadership was less apparent. Institutional commitment to Disability Studies challenges universities beyond merely establishing new programmes. The challenge is to commit at the highest level to including disability as a key issue of diversity on the transformation agenda for higher education.

> There is enormous work to be done in the disability field…this is an important development initiative…developing a course and training people in Disability Studies and critical thinking about disability – a very important milestone in terms of development. (Academic, UCT)

Many lessons have been learnt that would strengthen similar initiatives in the future. It is acknowledged among participants that commitment to the goals was strong. Nevertheless, the process was not exempt from power struggles within and between partner organisations, often at a subtle level, but with high levels of emotion that disrupted effective communication. This may be inevitable, given that disability is fundamentally a social justice issue, dominated by historically unequal power relations between disabled and nondisabled people. Competition for scarce resources certainly fuelled these tensions. Establishing a critical Disability Studies in a traditionally disabling institution forced all those involved to confront these contradictions and challenges directly.

Thus, the goal of developing an entirely new interdisciplinary programme in a partnership between academics (in different continents) and the South African disability movement was an ambitious one. And yet, despite the administrative and other difficulties encountered, the key objective was met. The process was characterised by immensely positive energy and an authentic sense of trust, co-ownership and commitment fostered through action-learning and reflection.

Student recruitment and learning experiences

As mentioned earlier, implementing a 'recognition of prior learning' access route was viewed as critical to challenging historical patterns of disadvantage in access to higher education. In particular, there was a shared awareness that one of the biggest obstacles to social transformation in South Africa is the inequity in our education system. The barriers to access for the majority of disabled people have been doubly reinforced. Careful consideration was therefore given to admission requirements, which included either a bachelor's degree or equivalent (from any discipline, approved by the Senate of the University) or the recognition of prior learning. In the latter case, candidates were required to submit a personal profile of their competencies in order to qualify for admission on the basis of merit or expertise. In addition, candidates required a letter of support from their employer (if they were employed) granting leave for the study-week blocks, time for assignments and support in applying assigned tasks to their work context (where appropriate).

Using an additional internal application form, all potential applicants were requested to:

- Briefly describe their experience in the disability and development or service field;
- Write a page about how they saw the course as assisting them (i.e. why they wanted to do it);
- Identify the needs or problems they anticipated in participating in the programme;
- Elaborate on the kinds of contributions they felt they would make to the course;
- Give details of one reference able to comment on their ability to participate in the programme.

A selection committee consisting of representatives from the two university departments, one from DPSA and one from CHED (Centre for Higher Education Development at UCT) screened all of the applications. Five people who did not have undergraduate degrees or equivalents were invited for interviews (two face-to-face and three by telephone) to further assess their suitability.

The first cohort of nine students enrolled in 2003 and came from Cape Town, Eastern Cape, Limpopo and Gauteng. Their level of previous education ranged from Standard 10 (school-leaving qualification) to honours degrees and included diplomas in adult basic education and training, higher education, social development, and community organisation, bachelor's degrees in Occupational Therapy, Commerce, Advanced Marketing Management, Human Resource Management, English and Psychology, and honours degrees in Nursing and Communication Sciences and Disorders. Some of the students had also done various short courses in areas such as inclusive education, disability awareness, democracy and disability advocacy, organisational development and financial management. The variety in their backgrounds was also considerable: a disabled nursing sister who was also the deputy chairperson for DPSA in the Eastern Cape, an occupational therapist and speech and language therapist who worked in public and private health services, respectively, the Secretary General of DPSA, the national chairperson and national treasurer of DICAG, a disabled person who was a self-employed artist and disability consultant, the deputy director of the OSDP in the Office of the Premier of Eastern Cape, and an experienced disability consultant.

Whilst entry qualifications for postgraduate admission to university were often non-traditional, there was clearly a considerable depth of disability and development experience within the group. On a personal-experience level, one student had been physically disabled since childhood and three had acquired impairments in adulthood. There were three parents of disabled children and three health professionals. Considering professional, advocacy and activist experience, seven people in the group had experience as disability activists at local, provincial, national or international levels. The group's cumulative community experience included advocacy, rural development, policy development, capacity-building and parent mobilisation. Their experience of government departments included the Department of Finance, Department of Economic Affairs and the Department of Health. NGO experience within the group was also extensive and included health education at the South African National Tuberculosis Association (SANTA), focusing on rural and farming communities, project co-ordination for World Vision South Africa, leadership at DPSA and DICAG, policy co-ordination for the SAFCD, and co-ordination of the Masibambane Centre for Disabled Children in a rural area. Experience within higher education institutions included stints as guest lecturers in the Division of Occupational Therapy Master's programme at UCT, disability research assistant in the DoE, lecturing in community nursing, disability and health, and in discipleship training.

Collectively and individually these students brought a wealth of knowledge and expertise to the programme that would have remained largely untapped without a firm commitment to access for students with non-traditional entry level qualifications. The opportunity to involve students with high-level organisational and policy experience also greatly contributed to student-led curriculum development discussions during the course. The wide academic, professional, racial, disability and gender diversity within the group proved an enormous resource to student-centred learning, as well as a challenge for both students and teachers.

The MPhil programme involves part-time study over a period of two years. For the first year with this cohort of students it was offered in four one-week teaching blocks, with final examinations at the end of the year (this format may change in the future to make the programme more accessible to both external and university-based students). The first year of the programme consisted of five modules, convened across different departments as follows:

- Theories and issues of diversity (Department of Sociology);
- Introduction to disability issues (Department of Psychology, UCT, and Centre for Disability Studies, University of Leeds);
- Policy development, advocacy and disability politics (Centre for Higher Education Studies, University of the Western Cape);

- Disability lifestyles and support systems (School of Health and Rehabilitation Sciences, UCT).

The last day of each block was focused on researching disability and module evaluation. The second year comprised an elective module, a module on research methodology and a mini-thesis.

The students engaged enthusiastically during the study-block weeks and appeared to appreciate the space and opportunity for dialogue and debate on diverse current issues, although study presented practical challenges too. For example, there were problems to be resolved in ensuring accessible transport and teaching space for wheelchair users and people with other mobility impairments. There were difficulties in managing personal work commitments to attend the block weeks, and difficulty for some in financing tuition and travel (remembering that some students travelled to Cape Town from other provinces). However, the impairment-related needs of disabled students appeared to impact on the completion of academic tasks less than students' needs to balance study with work and family responsibilities. Intellectually, there was also the challenge of facing new and sometimes challenging attitudes towards disability in an intensive small-group environment.

In addition, it is important to note that recognising prior learning means more than just facilitated entry to a tertiary institution for previously disadvantaged students (and it is not only students who enter via recognition of prior learning who can benefit from academic skills development!). Linked to this is the need to look at how distance-learning support is provided to people from different provinces between blocks (although it is interesting to note that students who reside in Cape Town did not draw on any additional time from lecturers between blocks, due perhaps to their commitments in full-time employment). The first teaching block included an additional three-day orientation to adult learning and academic skills (such as critical thinking, reading and writing). Experience of the first year suggests that more time or preparation will need to be built into the programme for this kind of initial and ongoing academic skills development.

Despite considerable challenges, the first year of the MPhil was a great success and early feedback from the programme's first cohort of students suggests that learning is having a substantial impact on their understanding of disability issues, and that this impacts directly on the policy development, advocacy projects and poverty-alleviation initiatives with which many of them are involved. The way is now open to explore and evaluate the potential of the project to drive future activism, research and capacity-building.

Future directions

Many lessons have been learned from the establishment of the Disability Studies programme at UCT and the processes of partnership and development have raised many possibilities for the future. The key achievement thus far is the establishment of the programme itself, as one truly jointly owned by the academic and disability sectors. The partnership with DPSA provides a direct link with the southern African Federation of the Disabled (SAFOD) and the Pan African Federation of the Disabled (PAFOD). Since an intention of the Africa Decade on Disability is to encourage and build leadership within the five regions of PAFOD, DPSA has recognised the programme as a key resource for capacity-building towards this goal.

It is hoped that the programme will continue to attract students who are influential in government, industry, disabled people's organisations and higher education institutions. It is further hoped that the programme will act as a continental resource focus, attracting disabled people and key leaders from other countries in Africa – thereby contributing through policy and service development to the ultimate goal of more accessible opportunities for disabled people to create an inclusive African society.

An exploration of the substantial activism, research, development and capacity-building potentials of the project can now be undertaken. There is an urgent need to develop a vibrant community of disability development practitioners and researchers to create a platform for research and debate surrounding disability issues in South Africa, in order to drive and inform societal transformation. Most state-subsidised research organs such as the MRC and CSIR show a marked lack of disability-related research capacity or initiative (the HSRC has recently addressed this lack with the establishment of a Disability Studies research project). Programme staff have been approached with a view to providing in-service workshop tuition to the research staff of these organisations.

The administrative demands of supporting the growth and development of a Disability Studies programme are unusual and the rate of escalation of administrative requirements is likely to be rapid if we hope to realise the programme's full potential. It will be important to develop a pool of disabled people who become lecturers and researchers in academic departments. In the future this will enable the development of a foundational course in Disability Studies for all first year programmes at UCT.

Further development might also focus on collaboration with other universities in integrating Disability Studies into programmes for professionals across a variety of sectors. There will be issues here around funding, the availability of staff-mentoring expertise and a balancing of roles and responsibilities arising from new and existing course demands. Further, there will be a need to develop the skills of lecturers, researchers and supervisors for MPhil and PhD students in Disability Studies, which may necessitate buying in external expertise for tuition, research collaboration and supervision related to disability issues. Resources will also be required to maintain and strengthen liaison with civil society, and especially with the all-important disabled people's organisations. Towards this end, the establishment of a University

Chair in Disability Studies would help raise the academic profile of the discipline and establish a South African centre for Disability Studies.

The achievement of collaboration within the disability arena in South Africa to date has been remarkable. The struggle against apartheid left an 'activist' legacy, but also considerable community suspicion of the role and investments of the academic sector in development and transformation. Yet, without ongoing engagement and partnership, the goals of Disability Studies are unlikely to be achieved. The disability sector's extensive organisational networks and community development projects provide key research opportunities for data collection, as well as the piloting of innovative strategies, whilst the academic sector provides access to theoretical frameworks and the tools for critical interrogation of South African responses to disability at all levels.

Notes

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15 Developing literacy with Deaf adults

Meryl Glaser and Theresa Lorenzo

Introduction

This chapter describes the challenges, needs and strengths of the Deaf community[1] who use South African Sign Language (SASL) as their preferred language (for a discussion on the issue of sign language interpreting in South Africa, see Chapter 11 in this volume). It will focus specifically on a community adult literacy project which encompasses a bilingual–bicultural philosophy, capacity-building and skill-sharing. This initiative aims to achieve social change for a group which continues to be considerably marginalised.

This chapter starts by providing some background on the issue of literacy among Deaf people and the use of SASL as a medium of instruction. This leads into a section on the project that forms the basis of the research. The project is described in relation to various aspects such as the facilitators, learners, curriculum and methodology. The methodology section highlights specific approaches and techniques for reading, writing and editing that are used in the project. The chapter concludes with priorities for increasing Deaf people's literacy and summarises issues to be considered in scaling up this type of project and the specific factors to bear in mind, with reference to South Africa.[2]

Deaf people and literacy

Very little has been documented on the development of reading and writing in adult Deaf populations, both internationally and in South Africa. Additionally, not much has been researched nor published about the structure of South African Sign Language (SASL). This chapter draws on available material from research, experience and contact with South African Deaf adults over a period of many years, as well as with adult literacy projects serving Deaf users of SASL.

Development practitioners and service providers need to be aware of the importance of integrating the needs of the Deaf into any well-designed, locally appropriate programme rather than replicating what is already provided. However, Deaf learners have specific requirements in terms of presentational style, classroom interaction, curriculum content, learner-support materials and language of instruction. Because they cannot hear, Deaf people have little or no access to spoken language. Therefore, classes should be conducted in SASL with the aim of developing the written version of the target language, for example, written English.

Internationally, the average reading age of Deaf adults is said to be at fourth grade level (Conrad, 1979; Hyde & Muspratt, 1998; Paul & Quigley, 1994; Powers, Gregory & Thoutenhoofd, 1999; Watson, 1999). In South Africa, the situation is more complex. Indications are that the average reading age of Deaf adults who have attended schools for the Deaf is lower than the fourth grade level (Aarons & Akach, 2002; Aarons & Reynolds, 2003; Storbeck, 1999). Added to this, the racial inequities of educational provision in the past have resulted in varying literacy levels in Deaf people across different racial groups (Penn & Reagan, 1990; Reynolds, 1995). The project that will be described in this chapter works with adults who have completed their education at a Deaf school for coloured pupils, as well as learners from rural black schools for the Deaf.

Impact of educational practices

In order to understand why Deaf people have such low literacy levels, we need to examine past educational practices in schools for the Deaf in South Africa. Since the World Congress of Educators of the Deaf held in 1880 in Milan, schools for the Deaf worldwide have followed a policy of Oralism (Lane, 1992). This means that Deaf pupils have received their schooling through the medium of a spoken language, and have been taught to lip-read, and made to speak. In practice, this has meant that Deaf pupils spend much of their time at school developing (with differential levels of success) their lip-reading and speech skills, often at the cost of their general educational development, including the development of their reading and writing skills. Access to a spoken language is seriously hindered by lack of access to sound, and if the method for teaching reading is based on phonological awareness, many Deaf pupils simply never become literate (Johnson, Lidell & Erting, 1989).

From the 1970s onward, a philosophy known as Total Communication was introduced into many schools for the Deaf worldwide (Denton, 1976), eventually reaching South Africa. In this approach, pupils are taught using a combination of speech and manual signs. However, it has been shown that Total Communication, in practice, is simply speech with some simultaneous sign support, and that it is not sufficiently accessible to Deaf people (Johnson, Lidell & Erting, 1989). Schools for the Deaf have embraced a policy of using manually coded language, that is, a system in which an attempt is made to represent English (or any other spoken language) manually. The use of this system has proved unsuccessful in the education of Deaf people because it uses the lexemes (roughly, words) of one language (a signed language) with the inflections and word order of another (for example, English) (Johnson, Lidell & Erting, 1989). Learners are exposed neither to a full version of English nor to a full version of signed language because each language has its own grammatical structure. It is therefore not possible to produce both languages in their full form at the same time. Learners thus end up learning neither the signed language nor the written language, and only a small proportion achieves intelligible speech.

The use of signed language as a medium of instruction

It is sound educational practice for people to learn through the medium of their first language, rather than through a second language (Grosjean, 1992). In several other countries (Sweden, Norway, Denmark, Finland, parts of the USA, the UK and Australia) educators have begun using the natural signed language of the local Deaf community as the medium of instruction in schools for the Deaf and teach a written language as the second language (Pickersgill & Gregory, 1998; Prinz & Strong, 1998; Storbeck, 2000; Svartholm, 1994). In South African schools, despite policy changes which advocate for the use of SASL as a language of learning, there is still resistance to this approach, fuelled in large part by the fact that there are very few teachers of the Deaf in South Africa who are fluent users of SASL. Many educators of the Deaf are under the mistaken impression that a signed language is based on the local spoken language (Aarons & Akach, 2002). This leads to the incorrect assumption that there are eleven different signed languages in South Africa. In fact, there is one basic signed language in use in South Africa, despite a significant amount of lexical (vocabulary) variation. Additionally, many educators of the Deaf are not aware that SASL is an independent language with its own grammar, and linguistically quite as complex as any other natural language.

Deaf people see learning to read and write as being crucial in order for them to engage educationally, socially, politically and economically with the wider world. The challenge is to find a way to develop their reading and writing skills and to document how Deaf people do learn to read and write. Amongst themselves, Deaf people use SASL. They regard this as their first language. It is certainly the language in which they are most proficient, as it is difficult for pre-lingually Deaf people, people who are born deaf or lose their hearing before expressive language develops, to gain full access to a spoken language. Signed languages do not have a written form. Thus, Deaf people are required to learn one of the languages of South Africa as their language of literacy.

Since there are Deaf people who can read and write, we know that learning to read is not necessarily based on phonological awareness (a knowledge of sounds). We also know that in the case of the signing Deaf, learning to read and write is a matter of becoming bilingual, as well as literate.

Various research projects have been conducted in which Deaf children are taught through the medium of signed language to read and write the written form of a spoken language (Pickersgill & Gregory, 1998; Prinz & Strong, 1998; Storbeck, 2000; Svartholm, 1994). This approach towards the development of literacy in the Deaf is known as the 'Bilingual-Bicultural' approach (Grosjean, 1992). The two languages used are the signed language and the written form of a spoken language. The facilitator is expected to be fluent in both languages. As learners develop literacy in the written language, they become increasingly able to access written material. The first language, thus, is used as a route into the second. Signed language can be used to explain to the learners how the other language works and in what ways utterances in this language are different from their signed language equivalents. Research has shown that Deaf learners who use and are taught in Sign Language perform better in written language than learners who are not taught in this way (Prinz & Strong, 1998).

An approach that may go some way to redressing the low level of literacy in many Deaf adults is described here. Using an approach that uses the learners' existing knowledge of SASL and written English, and that highlights the differences between these languages, may facilitate the development of their second-language skills in written English.

It is necessary to examine the difference between what the learners know (their first language, or language of greatest proficiency) and the target language (here, written English). Firstly, because SASL is a face-to-face language and written English is not, there are obvious differences that the learners will need to recognise. Whilst spoken languages and signed languages are primary communication forms, written language is a secondary communication form. Learning literacy is a matter of moving from a primary to a secondary communication form. For Deaf people, however, learning literacy is about moving from a primary to a secondary communication form, as well as about moving from one language to another and about moving from one modality to another (visual-gestural to verbal, albeit written).

Secondly, there are many ways in which SASL differs grammatically from written English. They are different languages: it should be noted that the difference is more than simply a difference in the way that things, objects and processes are named. SASL and English are structurally different. The ways in which the phrase, sentence and discourse are structured in both languages has been found to be a source of confusion and difficulty. There is no possibility of translating SASL sign-for-word into English or for translating English word-for-sign into SASL. Thus, signed language is not a direct translation of any spoken language. The two languages have entirely different grammatical structures and processes.

It is extremely helpful for facilitators to understand the structure of both languages and to be aware of the differences between them. Learners can be assisted in acquiring a metalinguistic understanding (knowledge of how the language works) of the structure and processes of SASL in order to give them a bridge to becoming aware of the salient features of English.

An overview of an adult Deaf literacy project

Since 1996, an adult Deaf literacy project has been offered by the Deaf Community of Cape Town, a grassroots organisation run by Deaf people to serve the needs of the historically disadvantaged Deaf community. In 1995, a University of Cape Town (UCT) Social Work student identified the need for literacy development amongst Deaf adults in Cape Town. This sparked a community initiative in collaboration with staff of what is now the Communication Sciences & Disorders Division at UCT.

The training and research project is described in more detail below. It uses a bilingual–bicultural approach to address the particular needs of Deaf adults acquiring English literacy. A description of the facilitators, learners, the curriculum and the classroom organisation and techniques used follows.

Project facilitators

The literacy project is staffed by Deaf facilitators, paired with hearing support facilitators who are audiologists, linguists and their students from UCT.[3] The Deaf facilitators are not formally trained as teachers. However, two strengths that they bring are native fluency in SASL and a higher level of literacy than the learners. They are all respected leaders in the Deaf Community. The hearing support facilitators also use SASL in the classroom, but their contribution is to bring expertise in English to the classes. In addition, they provide ongoing informal *in situ* teacher training for their Deaf co-facilitators who run the classes. The pairing of educators facilitates the use of the bilingual–bicultural model of literacy acquisition, in this case enabling the accessing of written English through the medium of SASL. Both facilitators use SASL in the classroom. The facilitators work collaboratively. SASL and English are given equal status in the classroom.

Our model uses one Deaf and one hearing facilitator working as a pair. This is because there are fewer than ten trained teachers who are Deaf in South Africa. Even the most literate Deaf adults are second-language users of written language and even the most proficient hearing SASL users are second-language signers. This pairing ensures that both languages are modelled by proficient users and that at least one member of the facilitation pair is formally trained. The facilitators benefit from exposure to each other's language expertise and professional experience. The signing skills of the hearing facilitator are enhanced and the teaching skills of the Deaf facilitator are improved. This ongoing in-service training is the cornerstone of the model and has two major consequences: both facilitators' skills are developed and the learners benefit from their joint expertise. This is a classic opportunity for skill-sharing, capacity-building and redressing the power imbalance often found in educational contexts, as both facilitators and learners bring complementary strengths to the learning process.

As of 2001, the Deaf facilitators have been enrolled in an Education, Training and Development Practices Sector Education Training Authority (ETDP SETA) learnership programme, in partnership with a national NGO, Project Literacy. They will be accredited as ABET (Adult Basic Education and Training) facilitators at either National Qualifications Framework Level 4 or Level 5. As part of this learnership, the Deaf facilitators are officially mentored in the upgrading of their literacy and numeracy facilitation skills.

The success of the project depends on regular planning meetings attended by the co-ordinator and the hearing and Deaf co-facilitators. At these meetings, organisational and strategic decisions are made, in-service training and troubleshooting occurs and the practical aspects of implementation are discussed in SASL. A review of the previous week's lessons is shared with the group. Each pair of facilitators, in turn, recounts the activities of their class. This includes a report of the successes and difficulties experienced by the learners and a self-evaluation by the facilitators of techniques they used and their own performance. The group discusses these issues, makes suggestions and shares their expertise. This is followed by group planning for the following week's lessons. As in all adult literacy programmes, assessment is continuous and culminates in a final written assessment. Because of the dynamic nature of language in the visual modality, it is useful to incorporate the possibility of using video to record the learners' signed responses to an exercise, for example, their comprehension of a story that they have read. This allows the facilitators to assess the learners' understanding without the confounding aspect of their poor writing skills. In addition, video records of lessons are useful tools for self-evaluation by the facilitators.

Learners

The learners in the literacy project fall into two groups: those who have not attended school at all (schooling for the Deaf was only made compulsory in South Africa in 1996) and those who have attended schools for the deaf. They are almost all currently employed, albeit in menial jobs that require less of them than they are capable of. They grew up in hearing homes where the language used was English, Afrikaans or isiXhosa, but all prefer to use SASL as their primary language of communication. Reading levels are low, ranging between first and fourth grade, even though some of the learners have attended residential schools for the deaf for up to 12 years. Classes consist of between eight and ten learners.

At the beginning of each year the learners are grouped into classes using the Western Cape Education Department's ABET placement tools. This assessment material is designed to aid ABET facilitators in sorting the learners into ability groups. Although these tools are essentially reading and writing assessments, the instructions to the learners, as with all instructions in this framework, are given in SASL. The philosophy of bilingualism–biculturalism recognises that learners arrive with SASL as their primary language and thereafter learn written English as a second or third language, according to the general principles of teaching a second or foreign language. Although it is widely accepted that a successful way for learners to acquire a second language is through the medium of that language, in the case of the Deaf this is subject to a particular interpretation.

Given that Deaf people cannot adequately access spoken language and that English is both a spoken and a written language, for the Deaf, exposure to English means exposure to written English and learning English means learning written English. Classes are conducted entirely in SASL. All reading and writing activities are conducted in English, but face-to-face discussion and explanations happen in SASL. Thus, explanations of a particular word or grammatical structure in English is provided in SASL. The approach uses the learners' proficiency in SASL as a bridge to literacy in English.

The curriculum

The curriculum is learner driven. Learners select either general topics or specific tasks that are of interest and use to them in their daily lives while facilitators elicit from the group exactly what it is that they want to learn how to do. Learners' needs generally fall into three categories: topics of interest to them, for example, HIV/AIDS; specific literacy practices that they would like to learn, for example, reading the newspaper; and literacy tasks they need to perform, for example, filling in an Identity Document application form. Topics that frequently recur are banking, constitutional rights and voting, transport, time, payment arrangements and accounts, shopping, genetics and hearing loss, basic anatomy and physiology of the auditory system, and health issues, amongst others.

The curriculum is based on a variety of learning outcomes. Learners are required to manipulate different sorts of text and discourse types. These include: reading and completing passport application and other official forms, bank account and credit card applications; reading and responding to letters of invitation, other personal and business letters, job applications and faxes; reading sales advertisements, bus and train timetables, product prices and labels, instructions (for example, text telephone manuals), public health bulletins, announcements and pamphlets and newspapers; and writing life stories and other narratives, CVs and notes for communicating with people who do not use SASL. The learners themselves choose which of these genres they are interested in learning more about.

Specific literacy activities include learning the alphabet in relation to finger spelling, using a monolingual dictionary, acquiring the functional basic vocabulary for a topic or task and finding the way around texts using reading skills such as prediction, using captions, identifying names and places, decoding pictures and scanning and skimming for specific information.

Classroom organisation and teaching techniques

In each class of Deaf learners there is one hearing and one Deaf facilitator. Both facilitators use SASL and written language in the classroom. Because Deaf learners rely on visual input, the classroom is arranged to facilitate all their visual requirements. Learners must be able to see clearly the signed presentations of both of the facilitators, the signed contributions of all the other learners as well as any visual aids, such as blackboards, overhead projections, video material and flipcharts. Therefore, appropriate seating and lighting are essential. Facilitators need to check with learners that these arrangements are suitable and to ensure that they are regularly maintained. A U-shape arrangement of tables, with the facilitators at the open end, is one way of achieving these conditions, and the room must be well-lit.

Facilitators (both in educational or any other communicative context) need to be vigilant about the following when dealing with groups of Deaf learners or a group which includes a Deaf learner/ participant:

- It is essential to establish a protocol in which only one signer can make a contribution at any time.
- It is important that any person who begins signing first attracts the visual attention of all the participants. Attention-getting mechanisms may include appropriate arm waving, tapping of shoulders or flicking the lights.
- It is necessary to avoid situations that require dividing Deaf people's visual attention, for example, asking learners to read a flipchart whilst expecting them to watch someone signing, or continuing to sign whilst learners are busy writing.
- Lighting requirements vary for different visual tasks. For instance, reading overhead transparencies or watching a TV screen is easier when the room is darkened, whereas reading a flipchart or watching live signing requires good lighting. It may, therefore, be necessary to appoint someone to control the lighting during the lesson.
- Any activity that requires learners to move their attention back and forth from printed text to looking at signing or a flipchart/overhead projector can cause learners to lose their place repeatedly. This is easily overcome by ensuring that all texts that learners are given have printed line numbers in the left hand margin.
- Videotapes or CD-ROMs containing SASL examples provide an alternate form of training material, as the dynamic nature of a visual language is best shown using moving images. These Sign Language resources are also most easily accessed by learners, provided, of course, that the necessary technology is available to them.

The approach used in the adult literacy project entails collaborative reading, writing and editing of English, using SASL as a medium of communication. The Deaf facilitator usually initiates a discussion using SASL, while the hearing facilitator is responsible for seeing that learners are provided with the appropriate written English words or phrases when required.

Note that all explanations are conducted through the medium of SASL. However, since the content that is being focused on is the correct, precise written structure of an English utterance, it is necessary often to refer to that utterance. In order to refer to the precise written structure of an English utterance, a signer has two possibilities: they may indicate or write the utterance in English, or may make use of a particular convention, which is common in spoken language, when quoting one language while speaking another. This latter technique is called 'mentioning'. While using SASL, the signer may quote or 'mention' an English utterance, indicating every part of the English utterance in sign. The quoted utterance is embedded in a stream of grammatically correct SASL.

Adaptation and use of reading materials

The function of reading for adults is much more than simply the decoding of separate, individual words. Adults always read for a purpose, whether it is to get information or for their pleasure. For this reason, all the reading material used, even at the most basic level, is text that adults encounter in their daily lives. Texts, such as stories and topics of interest that are used in the classroom, may be adaptable in terms of level of difficulty. In the case of other texts, such as official forms, instruction manuals, and official letters and accounts, the level of difficulty is determined by the nature of the text. The level of difficulty itself, however, should not be a reason to avoid using a particular authentic text, because learners need and want to deal with these sorts of texts. A good example of this would be the comprehension exercises based on Identity Document applications or election-registration forms.

In the case of texts where the level of difficulty can be adjusted, facilitators should be wary of simplifying texts, as this can easily result in distortion of the message, tone and register. Ironically, simplification can result in the text, in fact, becoming more difficult to read. For example, redundancy sometimes makes texts easier to understand. Removing it can make comprehension more difficult as well as disturb textual cohesion. Also, making sentences shorter can lead to a loss of important connections, for example, conjunctions such as *because*, *but*, *if*, and important references, for example, pronouns such as *she*, *they*, *it*, *there*, *here*, *this*, *that*. Wherever possible, texts should be used as they are found.

For texts such as newspaper and magazine articles, stories, textbooks, catalogues, pamphlets and sales advertisements, a particular set of reading practices is recommended. Learners are given a piece of text relating to the current topic that they have chosen. The text may be one of many different types. The learners are asked to read silently.[4] They are asked what the text is and where it might have come from. In trying to identify the text, learners follow certain guidelines for reading any sort of text. They look for clues in the pictures, captions, headings, and layout or format, and on the basis of this and a few key words, they are asked to predict what they think the text is going to be about. Then the facilitators ask for specific information, for which the learners scan the text. Although not all the learners can find all the relevant information, working collaboratively, they can usually piece together the general idea and main points of the text.

Learners are encouraged to identify the words or phrases that they don't understand. Generally, the Deaf facilitator provides a signed explanation of the word or phrase and the hearing facilitator gives written examples of the use of the word or phrase in an utterance context. These written examples are then compiled into a handout, together with other expansions and explanations of parts of the text, and given to the learners the following week to reinforce the material covered the week before. The completed handouts form part of the learners' portfolios.

Learners are encouraged to answer one another's questions and to offer their own thoughts and life experiences related to what is being read. Periodically, learners are prompted to use their dictionaries to find the meaning of a word or phrase. These dictionaries are specifically designed for adult learners, to avoid relying on children's picture dictionaries or the far more complicated conventional dictionaries.

In the case of other texts, such as official forms, accounts, instruction manuals, official letters, recipes and instructions for cooking, certain conventions govern the structure of these texts so that neither the format nor the vocabulary used can be altered without changing the nature of the document. In the case of official forms, information is requested in a certain format. Not following the instructions results in failure. For example, if the facilitator simplifies a passport application form for the learners to complete and the learners submit these forms to the Department of Home Affairs, they are unlikely to be issued with passports. Therefore, a teaching strategy is used.

For reading texts that have a standard format, learners are given the text to examine. The text may be one of many different types. Using the same process as that outlined above, learners are asked what the text is, where it might have come from and what it is used for. They are given certain guidelines for reading these types of text, including paying attention to headings and subheadings, checking if there are any pictures and captions, and examining the layout or format. On the basis of this and a few key words, they are asked to predict what they think they are supposed to do having read the text. In order to do this accurately, learners need to be prompted to identify the particular vocabulary that provides the instruction about the task to be done. For example, a manual requires manipulation of equipment, forms require written information for completion, accounts require an action, notices require only comprehension and attention, official letters often require a response, recipes or instructions for cooking require attention to measures and sequences of actions. Certain vocabulary is generic to a particular type of text, such as requests for biographical information on most forms and bookkeeping terminology on accounts. Other vocabulary is more specific to the actual text. For example, an electricity account uses terms like 'kilowatts' and 'usage' and a computer manual will use terms like 'ports', 'software' and 'monitor'.

In the next part of the procedure, facilitators ask for specific information, for which the learners scan the text. Again, working collaboratively, learners can usually answer at least some of these questions. Once again, learners are encouraged to identify anything that they don't understand. Generally, the Deaf facilitator responds by providing a signed explanation of the word or phrase and the hearing facilitator writes down the explanations and supplies a common context for its usage. The written record is later compiled into a handout, which is given to the learners the following week to reinforce the material covered the week before. The completed handouts form part of the learners' portfolios.

Producing written work

The literacy project develops two learning strategies that help learners produce their own authentic written texts.

In the case of texts that have conventional formats that are new to learners, facilitators work with learners to jointly compose a model of the format, such as in the writing of CVs, business letters or addressing envelopes. This can also apply when helping learners to write dialogues or conversations as direct speech. Using the reading process described above, facilitators introduce learners to examples of the particular text type. Learners then piece together what should be contained in, for example, a CV. In the case where learners cannot find the information, the facilitators provide it in SASL. Any additional English vocabulary required is provided by the hearing support facilitator. Once learners understand the requirements of the format, they are asked to produce their own version of that particular text type. Learners then exchange papers with one another and collaboratively review one another's work.

With texts that do not have conventional formats, learners write their own stories and present them to the class for collaborative editing suggestions. This story writing can be embedded in conventional formats, such as letter or journal writing.

Learners begin by generating text in the second language using a number of different routes, such as self-generated stories or retelling of a signed story. Both these routes lead initially to a degraded form of the second language being produced. Through an editing process, facilitators provide some techniques for upgrading this degraded language or 'interlanguage' into English.

Once learners have written a 'best' version of their own or a signed story, it is presented to the group. The stories are signed by the author and the group confirms that they have understood the intended meaning through a signed discussion. The signed stories are then presented by the facilitators, another learner or on video. The stories are written either on a flipchart or overhead projector for presentation to the whole group. The stories are then edited by the group collectively.

In all cases, as part of the editing process, the written story is chunked into units of meaning with the help of facilitators, and the editing is done chunk by chunk using SASL. They identify what is appropriate and what isn't and then set about modifying the incorrect text, drawing on their collective knowledge of English. There is generally enough collective knowledge in the class as a whole for learners to jointly engage in these editing activities.

The support facilitator reminds learners how English sentences begin, prompts them by showing where additional words, such as prepositions and articles, are required, reminds them about tense and aspect (such as 'ran' vs. 'was running') in English, and points out where punctuation is needed. Learners are reminded of aspects of English grammar that have previously been taught. In the case where learners do not know the rule, the facilitator either explains it to them there and then or supplies the structure and delays the explanation of the rule until later.

This methodology does not focus on meaning and form at the same time. The Deaf facilitator checks that the class understands and agrees about the meaning of the story being told. This often involves a process of negotiation about both the content and the signed language. Grammatical explanations usually occur outside the context of collaborative writing activities, but the facilitators use the materials generated by the writing activities to illustrate the points being made. The facilitators begin by asking the group, in SASL, what they know about a particular English structure. The group collaborates to build up the rule prompted by the facilitators. Sometimes, facilitators remind learners of an analogous structure or equivalent way in which SASL expresses this meaning. What does not emerge is finally supplied by the facilitators.

Finally, the written form of a language has very strict conventions, which have to be learnt and used. Written language does not allow the same degree of variability as either spoken or signed languages do. Consequently, the demands on learners of written English are stringent in terms of acceptability. However, the written form also affords learners the luxury of an additional step in the process of learning to write, because working with the written form allows the learner to stop and think and edit the output. It provides an opportunity to learn and use its strict conventions. In this way, the use of editing in the writing process facilitates the movement from the primary language to the written secondary language.

Conclusion

This chapter has attempted to illustrate how the Deaf adult literacy project draws on the strengths of the Deaf community who use SASL to meet their own challenges and needs in communicating and living in a hearing world. Crucially, the nature of the bilingual–bicultural philosophy which informs this community project encompasses, amongst other features, capacity-building and skill-sharing, for both learners and facilitators. The project has shown how adult-literacy training can effectively redress marginalisation and sustain social change for members of the Deaf community.

But much work remains. Priorities in Deaf adult literacy for the future in South Africa include: further formal training for Deaf facilitators; development of learning support materials in SASL on video or CD formats; increased funding for literacy projects for Deaf adults; and provision of accessible transport and information on opportunities for development.

The scaling up of such a project is feasible, as it requires only a reasonable amount of resources. The key element is the involvement of Deaf adults as integral members of the facilitation team and the recognition of the role of SASL as the imperative language of learning.

Notes

1 The convention of writing Deaf with a capital 'D' is used to indicate the cultural identity of a Deaf person who uses SASL as a first language. In contrast, deaf with a small 'd' denotes a person with a hearing loss who uses spoken language as their first language and relies on lip-reading and amplification to communicate in that spoken language (Morgan, 2001).

2 This chapter has drawn significantly on a training manual which was compiled by Meryl Glaser and Debra Aarons (2002). The manual was funded by a research grant from the National Research Foundation: Social Sciences and Humanities, South Africa, and is entitled, *The acquisition of written English as a second language by Deaf adults who use South African Sign Language as a first language*.

3 When staffing a literacy project of this nature, it is not impossible to operate using hearing people whose SASL is initially not fully proficient. However, the hearing person must at all times defer to the Deaf facilitator on matters of SASL.

4 Deaf signers often sign to themselves when asked to read silently. This appears to be helpful to learners and should not be discouraged. It is, however, unclear what actual purpose this behaviour serves. Facilitators could observe this signing to see what the learner understands of the text. Learners tend to sign the words or phrases they know and to fingerspell those they do not.

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Section IV
Disability, poverty and social security

16 Disability, poverty, gender and race

Tony Emmett

In the last decade, the relationship between poverty and disability has been strongly established, and most of the major international development agencies such as the World Bank, the United Kingdom's Department for International Development (DFID) and the United States Agency for International Development (USAID) have placed disability on their development agendas. These developments have begun to point the way towards a more integrated approach to disability, and have prompted DFID, for example, to declare that 'eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account' (2000, p. 1).

However, less attention has been devoted to the ways in which disability and illness are intermediated by other inequalities, including gender and race. In general, disabled women experience higher levels of discrimination and disadvantage than disabled men (Abu-Habib, 1997; Elwan, 1999; Jans & Stoddard, 1999; Traustadottir, 1990). In the industrialised countries, for example, indicators of income, employment, education, social security and medical expenditure for disabled people show consistent gender inequalities (Jans & Stoddard, 1999). Moreover, the impact of disability on women is not only evident in relation to women who are themselves disabled, but also in relation to the role of women as mothers and caregivers. Being a woman implies an increased set of barriers to access and participation on various levels. Nowhere are these barriers more evident than in the case of women who have to cope with children who are disabled, or who have chronic illnesses. Especially within the context of women-headed households and early pregnancies, women face enormous challenges in raising disabled children, leading some commentators to talk about the 'feminisation of poverty' (Pokempner & Roberts, 2001; Corcoran & Chaudry, 1997).

Within industrialised countries such as the US, race also plays an important role, with both disability and mortality rates strongly reflecting racial inequalities (See, for example, Pokempner & Roberts, 2001; Sen, 2000). Within developing countries such as South Africa, data on disability rates are more fragmented and less reliable. However, data that do exist indicate that similar trends exist. In particular, in South Africa, with its history of colonial subjugation and racial oppression, racial inequalities, poverty and disability are intertwined in complex configurations that are difficult to unravel. Within the context of changing policies and attempts to redress the injustices of the past, understanding the complex relationships between disability, poverty, gender and race are vital for advancing the cause of disability and addressing poverty in South Africa.

This chapter therefore starts out by exploring what we know about the linkages between disability and poverty, and how disability has come to be seen as both a cause and a consequence of poverty. Following a brief discussion of the limitations of available data, the chapter first focuses on the risks that poverty and impoverished environments hold for the development of preventable impairments and debilitating diseases among poor people. It then goes on to consider how poverty can also arise as a consequence of disability.

Having laid a basis for understanding the relationship between poverty and disability, the chapter then moves on to consider how gender compounds and reinforces the linkages between disability and poverty. It reviews findings from the US which show that women with disabilities are more likely to be living in poverty than men with disabilities, and further argues that women are not only vulnerable because of gender inequalities, but also because of their roles as mothers and caregivers. Finally, this section of the chapter explores gender and disability in the context of developing countries.

The issue of disability and race (particularly within the context of the US) is briefly introduced before moving on to a more detailed discussion of disability, poverty, gender and race in South Africa.

Before proceeding, however, it is necessary to establish how the term ‘disability’ is used in this chapter, and in particular to distinguish between disabilities and impairments. The approach adopted in this chapter locates disability within the context of the social model, which sees disability mainly as a socially created problem rather than as an attribute of individuals. This approach is particularly helpful in focusing our attention on those aspects of disability that emphasise the commonality of disability with other forms of social disadvantage and marginalisation such as poverty, race and gender. Albert, McBride and Seddon (2002, p. 16) draw attention to these commonalities when they define disability as:

> A complex system of social restrictions imposed on people with impairments by a highly discriminatory society. Disability, therefore, is a concept distinct from any particular medical condition. It is a social construct that varies across culture and through time, in the same way as, for example, gender, class or caste…In this sense, disability as a policy issue becomes a cross-cutting social one, rather than something primarily associated with health and individual well-being.

Disability and poverty

Disability is both a cause and a consequence of poverty. Disability increases vulnerability to poverty, while poverty creates the conditions for increased risk of disability. For example, poverty increases vulnerability to disability through poor nutrition, lack of access to health care, greater exposure to violence and unintentional injuries, lack of knowledge of prevention, etc. Conversely, disability increases vulnerability to poverty because of the costs associated with disabilities, discrimination in the labour market, difficulties related to access to education and assistive devices, etc.

While the linkages between poverty and disability have often been noted, they have not been systematically examined (Elwan, 1999). This applies particularly to developing countries where information and research are limited, and rely heavily on anecdotal evidence and case studies. Rough estimates based on census, survey and registration data do exist for some countries, but these tend to be divergent, and there is little information about linkages with poverty (Elwan, 1999). Even data on disability prevalence rates within developing countries are subject to high levels of uncertainty and controversy. For example, the World Health Organization (WHO) has noted that it is not possible to estimate the number of disabled people in the world more accurately than at 10 per cent of the total population (WHO, cited in Elwan, 1999, p. 5).

In this regard, South Africa is no exception, as the *White Paper on an Integrated National Disability Strategy* (INDS) noted (ODP, 1997). While a number of surveys have attempted to address the issue of disability in South Africa, there is little agreement between their findings, even on national prevalence rates, as Table 16.1 illustrates. It should be borne in mind, however, that the definitions of disability and the methods used to identify people with disabilities were not consistent through these surveys. For example, the 1996 National Health and Population Survey included chronic illnesses as well as disabilities, accounting perhaps for the considerably higher prevalence rate produced by this survey. Furthermore, the 1996 and 2001 Censuses used different questions to identify people with disabilities.

Table 16.1 Estimates of national disability prevalence rates 1995–1999

Survey	Year	Prevalence rate (%)
CASE Survey for Department of Health	1998	5.9
National Health and Population Survey	1996	12.8
1996 Census (Stats SA)	1996	6.6
October Household Survey (Stats SA)	1995	5.2
October Household Survey (Stats SA)	1999	3.7
Census 2001 (Stats SA)	2001	5.0

Sources: Taylor 2001; Stats SA, various

Poverty and the risk of disability

The relationship between poverty and disability has been more clearly demonstrated for industrialised countries than for the developing countries. Demographic studies in the US, for example, have found a growing relationship between poverty and risk for disability. For example, longitudinal estimates indicate 'a significant increase in the rate of childhood disability over the past 14 years among constituencies defined by poverty and single-parent headed families' (Park, Turnbull and Turnbull, 2002, p. 152). On the basis of their review of recent findings, Park, Turnbull & Turnbull concluded that 'poverty is not a secondary topic in the field of special education services and disability policy anymore'.

While knowledge of the prevalence, incidence or epidemiology of disabling diseases in developing countries is limited, it is clear that disability in impoverished contexts is strongly associated with *preventable* impairments arising from communicable, maternal and peri-natal disease and injury. Among the conditions that are frequently associated with disability in developing countries are malnutrition (including vitamin deficiencies), lack of basic sanitation, limited access to preventive health and maternity care, limited knowledge of health practices, diseases and disability, inadequate housing, dangerous work conditions, and injuries resulting from political and criminal violence, civil conflict and natural disasters (DFID, 2000; Elwan, 1999).

WHO has estimated that as many as 20 million women a year suffer impairments and long-term complications as a result of pregnancy and childbirth (DFID, 2000). Malnutrition can either directly cause impairment or increase susceptibility to debilitating diseases. Malnourished mothers are at risk of bearing low birth-weight babies, who in turn are at risk of contracting disabling diseases. Adverse environmental conditions, including inadequate shelter, the lack of clean water and poor or no sanitation facilities, compound the risk of infection. Failure to provide adequate and timely health care (whether due to lack of parental knowledge or poor and inaccessible health facilities) can intensify disease outcomes so that remediable impairments become permanent. According to one estimate, only two per cent of disabled people in developing countries have access to rehabilitation and appropriate basic services (Despouy, cited in DFID, 2000).[1]

WHO also estimated that up to 70 per cent of blindness in children in developing countries is either preventable or treatable, and that about 50 per cent of disabling hearing impairments are preventable (DFID, 2000). It has been found that maternal education, access to information, dietary and food preparation practices, and the level and coverage of primary health care play a greater role in prevention than more specific interventions (Elwan, 1999). As much of the disability in developing countries stems from preventable impairments, a large part of this disability could therefore be eliminated through treatment or alleviated through rehabilitation (DFID, 2000; Elwan, 1999).

The complex interactions of risk factors in impoverished environments are vividly depicted in the following passage:

> The child in a poor family who is malnourished and living in an unheated apartment is more susceptible to ear infection; once the ear infection takes hold, inaccessible or inattentive health-care may mean that it will not be properly treated; hearing loss in the midst of economic stress may go undetected at home, in day care, and by the health system; undetected hearing loss will do long-term damage to a child who needs all the help he can get to cope with a world more complicated than the world of most middle-class children. When this child enters school, his chances of being in an overcrowded classroom with an overwhelmed teacher further compromise his chances of successful learning. Thus, risk factors join to shorten the odds of favourable long-term outcomes. (Schorr & Schorr, cited in Pokempner & Roberts, 2001, p. 8)

In developing countries and particularly in sub-Saharan Africa, the relationship between disease and disability has been compounded by HIV/AIDS. Of the 40 million people estimated to be living with HIV/AIDS, 38 million (95%) live in developing countries, and of these 28 million are in sub-Saharan Africa. Although Africa is home to only 10 per cent of the world's population, it accounts for 90 per cent of all new cases of HIV infection and 83 per cent of all AIDS deaths (SARPN, 2002). Life expectancy in South Africa fell from 62 years in 1990 to 48 years in 1999, largely as a consequence of AIDS (Woolard, 2002).

Accidents and conflict are also important causes of disability, especially in developing countries, where levels of conflict and violence are often high (DFID, 2000; Harriss-White, 2003). In conflicts, both active combatants as well as civilians are at risk both during active conflict and after such conflicts, due to unexploded ordnance and land mines. In particular, disabled persons are especially vulnerable to deteriorating health (including psychological problems) under the conditions caused by war and political violence. Health care and social welfare systems are often disrupted or break down completely, and some conditions that might have been treatable under more normal circumstances, can become disabling. Poverty has also been associated with demanding and risk-prone work environments, where impairments can result from accidents or contamination by toxic substances.

Poverty as a consequence of disability

In her extensive review of the literature on disability and poverty, Elwan (1999) finds that, in general, disabled people and their families are poorer than the rest of the population. In many industrialised countries, disability has been shown to be associated with lower levels of income and an increased likelihood of poverty. Employment rates for disabled persons are usually lower, and both employment and income appear to be negatively associated with the severity of the disability.

Disabled people are also likely to have lower educational and literacy levels than the rest of the population; when disabled people are employed, they are likely to be under-employed relative to their levels of training. They are also less likely to have savings and other assets than the nondisabled population.

These findings apply to both developing and developed countries. In industrialised countries, the incomes of disabled persons do not match those of their nondisabled peers even when compensatory benefits are taken into account, and in spite of substantial transfer and employment programmes, disabled people continue to face higher risks of poverty. In some developing countries, higher disability rates have been shown to be associated with higher illiteracy, poor nutritional status, lower inoculation and immunisation coverage, lower birth weight, higher unemployment and underemployment rates, and lower occupational mobility (Burchardt, 2003; Elwan, 1999; Yeo, 2001).

The International Labour Office estimated in 1984 that the unemployment rate for disabled people in industrialised countries was two to three times that of nondisabled white people; surveys conducted in Australia, Canada, the UK and the US showed similar trends (Elwan, 1999). While there is little data on relative employment rates in the developing countries, data from Mauritius and Botswana suggest that similar trends exist in developing countries. Data from Namibia show that in 2002, 8.1 per cent of disabled respondents were employed as against 20.8 per cent of nondisabled (Eide, Van Rooy & Loeb, 2003, p. 63). Existing data also suggest that disabled people work longer hours than nondisabled people, are paid at lower rates, are more likely to work in poor working environments, have poor promotion prospects, and are at greater risk of becoming unemployed (Elwan, 1999).

Studies conducted in industrialised countries show that disabled people generally have lower incomes than nondisabled people. For example, surveys carried out in the US between the 1950s and the 1970s showed substantial disparities between disabled and nondisabled incomes, with the average wage rates of disabled people amounting to about 60 per cent of those of people without disabilities. A survey conducted in the US and Germany in 1987, found that on average disabled men earned half of what nondisabled men earned. Studies in the UK also showed that home ownership was lower among disabled than nondisabled people, and that disabled people had fewer substantial assets, and fewer rights to pensions and other welfare benefits. Furthermore, many of these disabled people had a need for higher incomes than those without disabilities. The lower incomes observed during their working years continued into old age and disabled people were less likely to have the kind of pension or the level of provision that would adequately protect them from poverty in old age (Burchardt, 2003; Elwan, 1999).

On average, disabled people receive less education, and have lower literacy rates and educational qualifications than the nondisabled population. Recent studies suggest that about 2 per cent of children with disabilities in developing countries receive an education. Boys with disabilities attend school more frequently than girls with disabilities, and disabled women, who suffer discrimination both on the basis of their impairments and their gender, generally have even lower literacy rates than disabled men. It has also been shown that women with disabilities are two to three times more likely to be victims of physical and sexual abuse than women without disabilities (Elwan, 1999; DFID, 2000).

Using longitudinal data from the British Household Panel Surveys in conjunction with other studies conducted in the UK and Germany, Burchardt (2003) systematically demonstrates the relationship between disability, poverty and social exclusion. In Britain it was shown that those people in the lowest quintile of the income distribution were two-and-a-half times more likely to become disabled than those in the highest quintile. Similarly, the risk of disablement was nearly four times higher for those people with no educational qualifications as for those who held a degree. Burchardt was also able to show that this association between the risk of disablement and educational levels was not simply a product of the higher risk of disability associated with aging together with the generally lower levels of education of older generations in relation to younger generations. Rather she found that the risk of disablement was higher for young people without qualifications than for their older counterparts.

Secondly, in addition to higher rates of poverty among disabled people as a result of the risk factors discussed above, it was also found that the onset of disability was associated with an added risk of entering poverty, as well as 'a decrease in the proportion of people leaving poverty' (Burchardt, 2003, p. 63). In other words, becoming disabled increased the risk of those who were not poor before the onset of disability becoming poor, and diminished the odds of those who were already poor for escaping poverty. In spite of Britain's highly evolved social security system, social security benefits were only able to compensate for the loss of income of a small minority of those who became disabled. As Burchardt (2003, p. 64) observes: 'contrary to the popular myth that the onset of disability is a random occurrence, it is strongly patterned by social and economic circumstances'.

Disability impacts not only on individuals, but also on households that have disabled members. This has meant that a larger proportion of the population is affected by disability than the percentage of individual disabled people. In the US in 1990, for example, the proportion of families with a member with a disability was 29.2 per cent, while the proportion of individuals with a disability was 13.7 per cent (Elwan, 1999). Very similar trends were found in Scotland where 13.7 per cent of the population had a long-term health problem or disability, whereas 29 per cent of households contained one or more persons with a long-term illness (Scottish Poverty Information Unit, 1998). According to Statistics South Africa's (Stats SA) 1999 October Household Survey data, while only 3.7 per cent of the South African population had disabilities, at least 16 per cent of households had a disabled member (Taylor, 2001, p. 358).

Analysis of Tanzanian survey data showed that households with disabled members had mean consumption levels of less than 60 per cent of the average, and headcounts 20 per cent higher than the average. On the basis of these results, the author concluded that disability was 'a hidden face of African poverty'. (DFID, 2000, p. 4)

In addition to their lower income and consumption rates, disabled persons and their families are often burdened by additional costs resulting from disability. Such costs include special medical care, rehabilitative and restorative equipment and services, providing for special education needs, and costs incurred for or by care providers, including opportunity costs of foregone income. In the US, for example, data collected in 1987 and updated in 1993 showed that the medical expenditure of disabled people was four times greater than expenditure of people with no disabilities (Jans & Stoddard, 1999).[2]

In developing countries where income maintenance and other social security programmes are uncommon, disabled persons are usually the responsibility of their families, and even in industrialised countries, families play an important role in providing care and financial support to the elderly. There are also various costs associated with marginalisation or exclusion of disabled persons from services and social and community activities. Such exclusion and marginalisation, which often reduce the opportunities that disabled people have to contribute to their households and communities, includes negative attitudes to disabled persons, lack of adequate or appropriate transportation, physical inaccessibility and lack of learning opportunities. Such barriers can affect access to education and employment, as well as reducing opportunities for social participation (Elwan, 1999).

Lukemeyer, Meyers and Smeeding (2000), who studied the impact of caring for children with disabilities and chronic illnesses on poor families in the US, found that both out-of-pocket expenses and foregone earnings represented a substantial burden for many of the families studied. Using a sample of low-income families in California, the study found that almost half of those families with special needs children had incurred some direct, out-of-pocket expenses in the preceding month, and about 20 per cent incurred costs of more than $100. Half of the mothers with disabled children indicated that care for the child made it difficult for them to work and 19 per cent reported that special care responsibilities prevented them from working at all.

Based on their data, the writers estimated an average loss of about $80.52 per month in mothers' foregone income for each household with a severely disabled child. They conclude that families with disabled children are at 'exceptional risk for economic hardship, due to heightened demands on family resources and to reduced availability for employment' (Lukemeyer, Meyers & Smeeding, 2000, p. 412).

Disability and gender

There is a dearth of information on disability and gender in South Africa. For this reason, this section will focus rather heavily on data from the US which, though not directly applicable to South Africa, provides an important conceptual basis for local work.

Disability and gender in the US

In industrialised countries, data show that disabled women are, in general, more disadvantaged than their male counterparts, with indicators for income, education, employment and social assistance showing consistent, although not always large, gender differences. Data from the early 1980s, for example, showed that disabled men were almost twice as likely to be employed as disabled women, while disabled women who had full time employment earned only 56 per cent as much as disabled men in full-time jobs (Elwan, 1999, p. 28).

More recent data also show that disabled women face a double disadvantage in the workplace, based on both their gender and their disability status. Disabled women are not only less likely to be employed than men, but also earn less than men. It is also clear that, especially in relation to severe disabilities, the impacts of gender and disability are cumulative (Jans & Stoddard, 1999).

Similar trends exist in relation to income. Firstly, working women between the ages of 21 and 64 years earn less than working men, whether or not they have a disability. Disabled women also earn less than nondisabled women, as well as earning less than disabled men. In 1994–1995, for example, nondisabled men earned 49 per cent more than nondisabled women. Among people with a non-severe (or mild) disability, men earned 55 per cent more than women. In the case of severe disability, the gender gap was smaller, with men earning 26 per cent more than women, although for both men and women the gap between those with mild and severe disabilities was substantial. However, in spite of this large gap, the median earnings of men with severe impairments were still slightly above those of women with mild impairments (Jans & Stoddard, 1999).

Gender inequalities were also evident in relation to education for disabled children. While males and females were equally represented in the school-age population, this was not the case in relation to special education. Boys made up about two-thirds of students in special education, with the greatest discrepancies occurring in learning disabilities (74%) and emotional disturbances (76%). A further point of interest is that girls in special education tended to do better academically than their male counterparts. However, upon completing their education, girls were less likely to be employed, earned lower wages and were also less likely to enrol for post secondary education (Jans & Stoddard, 1999).

Gender inequalities also exist in relation to social assistance in the US. As the primary programme of federal benefits for children with disabilities and their families, Supplemental Security Income (SSI) is biased in favour of boys. In 1998, for example, 63.5 per cent of children awarded SSI grants were boys; while 36.5 per cent were girls. Between 1988 and 1998, boys were consistently awarded more SSI grants than girls. While the number of grants awarded had increased during this period, the gap between male and female beneficiaries of the grant also increased. Although it is necessary to take into account that boys in the US have higher rates of disability than girls, as Jans and Stoddard (1999, p. 16) point out, 'this alone does not account for the gap in SSI benefits between boys and girls'.

Welfare benefits also differ among adults. In 1995, for example, 25.6 per cent of women and 30.6 per cent of men with work disabilities received Social Security benefits. On the other hand, women received higher percentages of need-based benefits such as food stamps (29.1% of women, 19.8% of men), Medicaid benefits, (36.2% of women, 27.2% of men), public housing (6.8% of women, 4.4% of men) and subsidised housing (4.6% of women, 2.7% of men). Gender differences were also apparent in social security benefits for workers with a disability, with more men than women receiving OASDI (Old Age, Survivors and Disability Insurance) benefits, as well as the average grant for men being higher than that for women. In 1997, for example, 59 per cent of those receiving benefits were men. At the same time, the average monthly benefit for men in 1997 was $810, while for women it was only $595. Perhaps most disturbing is that benefits have been consistently higher for men over four decades, and that the gap between average monthly grants to men and women has grown since the 1970s (Jans & Stoddard, 1999, p. 16).

Data collected in the US in 1987 and updated in 1993 showed that medical expenditure on disabled people was four times greater than the expenditure of nondisabled people.[3] The study also showed that disabled males had higher per capita expenditure than disabled females in all age groups, except children. These differences were particularly pronounced for the 45 to 64 age group, where per capita expenditure on men ($6,100) was 40 per cent higher than on women ($4,365) (Jans & Stoddard, 1999).

Against this background, it is not surprising that women are more likely to be living in poverty than men, and that people with a work disability are more likely to be living below the poverty line than those with no work disability. In 1992, it was estimated that for people with work disabilities in the 16 to 64 age group, 33.8 per cent of women, as against 24.2 per cent of men, were living in poverty.[4] For those classified as having a severe work disability (a condition that prevents them from working), 40.5 per cent of women, compared to 31.2 per cent of men, were poor (Jans & Stoddard, 1999).

To sum up, the data from the US show that disability has had a consistent and in some cases severe impact on the lives of both men and women. However, the negative impact of disability is unevenly spread among the genders. While in some cases the differences between men and women might be relatively small, especially when considered against the background of the overall impact of disability, it is clear that women bear a heavier burden than men, and that these inequalities are systematic.

Disability, gender and family structure

Pokempner and Roberts (2001) argue that the overlap of disability, poverty and race in the US is significantly affected by family structure and gender inequalities. Women are especially vulnerable not only because of their weak positions within labour markets, but also because most of the responsibility for parenting and care-giving falls on them. This vulnerability is intensified when women have to care for one or more disabled children:

> Their return in the waged labor market is rarely sufficient to support a family and the work done to care for their family is not valued or compensated. The devaluation of both types of work creates additional costs for the mother attempting to care for a disabled child. These additional costs highlight the gender inequalities which continue to pervade the labor market in terms of wage structures, the devaluation of care giving work inside and outside the home and the ill-fit between family care giving and work within the market. (Pokempner & Roberts, 2001, p. 7)

As demonstrated earlier, people with disabilities and their families are often burdened by additional costs resulting from disability, which include special medical care, rehabilitative and restorative equipment and services, providing for special education needs, costs incurred for or by care providers, as well as costs associated with marginalisation or exclusion from services and social and community activities. For example, public transport often does not cater for the needs of disabled people, restricting their mobility and compelling them to use more expensive alternatives such as taxis or private transport.

The problem of costs associated with disability is compounded by family structure, particularly among the more impoverished sections of the community where single-parent families and women-headed households predominate. Since the 1960s, the US, in common with many other parts of the world, has witnessed a dramatic increase in female-headed households. For example, between 1960 and 1990 the percentage of all children who were living in mother-only families grew from 8 to 20 per cent (Corcoran & Chaudry, 1997, p. 42). This trend and the strong association between female-headed households and poverty (for example, between 1959 and 1988, the percentage of poor children living in mother-only families rose from 20 per cent to 57 per cent) have prompted social commentators to talk about the ‘feminisation of poverty’ (Corcoran & Chaudry, 1997; Pokempner & Roberts, 2001).

Racial differences in family structure follow similar patterns. In the US in 1992, for example, 59 per cent of African-American children lived in female-headed families in contrast with only 17 per cent of white children. In South Africa, Stats SA's 1999 October Household Survey showed that 42 per cent of all African households (2.7 million) were female-headed (Aliber, 2003, p. 480).

Because women disproportionately head poor families, they are at greater risk of suffering illness and disability than members of the general population, while at the same time enduring the negative consequences of disability. Furthermore, the problems of female-headed households are often linked to early or teenage pregnancies, which carry with them a range of other disadvantages such as:

- Dropping out of school in order to give birth to or care for a child;
- Obstacles to continuing education after the birth of the child;
- More limited prospects of marriage;
- Where marriage does take place at a young age, the limited experience of the couple and the additional demands of parenthood often lead to the dissolution of the marriage;
- Greater probability of low birth weight and giving birth to a disabled child.

Gender and disability in developing countries

Very little hard data exists on disability trends in developing countries. The evidence that does exist is, for the most part, fragmented and often anecdotal. Existing information does, however, suggest that, in general, very similar trends to those in industrialised countries exist also in developing countries, except that conditions in the developing countries are likely to be worse and considerably more prejudicial to disabled people, and especially disabled women. This is likely to be the case for a variety of reasons, including higher rates of poverty and unemployment, pervasive deficits in services and social security, environmental and social conditions that are not conducive to health, and political and cultural limitations relating to human (and especially, women's) rights.

In general, survey results show higher rates of disability for women in industrialised countries, but lower rates in the developing countries.[5] Lower female rates in the developing countries may indicate that severe impairments may be male-dominated, while disabled females may be under-reported or may receive less care and die sooner. For example, estimates from India and Pakistan indicate that male disability rates are higher than female rates. This 'could indicate that girls and women with disabilities receive less care and support, and die earlier. Another possibility is that the gender division of labour is such that disabled women contributing to household activity are not identified as disabled, whereas the visibility of disabled men is greater' (Elwan, 1999, p. 9). Studies conducted in Yemen and Egypt showed similar trends, with higher prevalence of disability among boys, which researchers attribute to higher mortality rates among girls with disabilities (Abu-Habib, 1997, pp. 1–2). The limited information available on disabled women and girls seems to bear this out. In some communities, for example, disabled girls receive less care and food, have less access to health care and rehabilitation services, and may have reduced access to education and employment opportunities. Disabled women sometimes also have fewer marriage prospects than disabled men, and can be at risk of being physically and sexually abused. Abuse from persons outside the family often goes unreported because of the shame that some families feel in having a daughter with a disability (DFID, 2000: 3; Elwan, 1999;). Shah (1992, p. 20) also argues that especially in the rural areas of the East, a woman who loses her sight also loses her 'status, privileges and rights both in society and in the family'.

Having a disabled person in the family is sometimes thought to damage the marriage prospects of other members of the family. It is also suggested that disabled men are more likely to marry than their female counterparts. Abu-Habib (cited by Elwan, 1999, p. 29–30) maintains that:

> discrimination starts at home, in the early years of the life of a disabled woman. This discrimination brings with it a reluctance on the part of families, or rather decision makers within the families, to make tangible and intangible resources available to disabled women, thus further undermining their life chances…their social isolation as women is deepened by their disabled status.

Abu-Habib also cites a UNDP study that shows that disabled women were twice as prone to divorce, separation and violence than nondisabled women (Elwan 1999). In some areas, mothers are blamed and stigmatised for giving birth to a child with an impairment, while in others disabled women are kept hidden and thus socially isolated. (See also Boylan, 1991; Owusu, 1992).

While women have to bear the greater burden of caring for others, their own access to care and treatment appears to be limited in both the industrial and the developing countries. For example, the Economic and Social Commission for Asia and the Pacific (ESCAP) reports that commuting to rehabilitation centres poses serious difficulties for women and girls with impairments, and is expensive for their families. The report maintains that access problems are more severe in rural areas, where high rates of illiteracy and longer distances compound the difficulties experienced by disabled women. Higher rates of blindness among rural women in India has also been attributed to the limited access that women and girls have to transport to areas where they can receive the necessary medical care for eye diseases. As Harriss-White (2003, p. 9) observes, the process of care for disabled people in India is 'socially constructed and extremely male-biased'. In a study of disability in three villages in India, for example, it was found that the percentages of adult males receiving treatment ranged between 53–56 per cent, while for adult females the corresponding percentages ranged between 11–39 per cent (See also Boylan, 1991).

In a study of 200 graduates of special education institutions in Lebanon, Thomas and Lakkis (2003) found that while women graduates had higher educational levels than men, only 35 per cent of the women graduates were employed as opposed to 52 per cent of the men graduates.

Disability and race

For both children and adults, interactions between poverty, gender, race and disability produce complex patterns of social inequality and debilitation. For example, in the US, poverty and disability have been consistently related to race. According to the 1994–1995 Survey of Income Participation, for example, the proportion of persons with a severe disability between the ages of 22 to 44 years was 11.8 per cent for African Americans, 5.6 per cent for whites, and 6.7 per cent for Hispanics. For individuals aged 45 to 54 years, the percentages were, 18.4, 10.5 and 15.7 respectively. African American children, who are twice as likely as white children to be poor, also disproportionately experience illness and disability. Similar trends exist in relation to HIV/AIDS in the US. In 1991, for example, African Americans were 3.5 times more likely to contract AIDS than white Americans. The risk was even higher among African American women, who were 13.8 times more likely to contract AIDS than white women. Infant mortality rates for African American children in the US are also twice as high as those for white children. Between 1950 and 1991, the racial gap in the infant mortality rate actually increased from 1.6 to 2.2 (American Medical Association, 2003; Pokempner & Roberts, 2001).

In part, the association between race on the one hand and ill-health or disability on the other, can be attributed to the lower incomes of African Americans, but it has been shown that even when controlling for socio-economic status, at every level of income, African Americans experience shorter life expectancy and poorer health outcomes:

> Blacks have a higher mortality rate than whites for eight out of ten leading causes of death, and the gap has been widening. A recent review of data and research indicates the persistence of racial disparities in the incidence of illness and disease, and the likelihood that disease will lead to death. (Pokempner & Roberts, 2001, p. 5)

African Americans are not only disadvantaged in relation to American whites, but as a group also suffer considerably higher rates of mortality than do the populations of nations that have much lower levels of income, such as China, Sri Lanka, Jamaica, Costa Rica and the Indian state of Kerala. As Amartya Sen (2000, pp. 23–24) points out,

> Bangladeshi men have a better chance of living to ages beyond forty years than African American men from the Harlem district of the

> prosperous city of New York. All of this in spite of the fact that African Americans in the US are very many times richer than the people of comparison groups in the third world.

Disability in South Africa

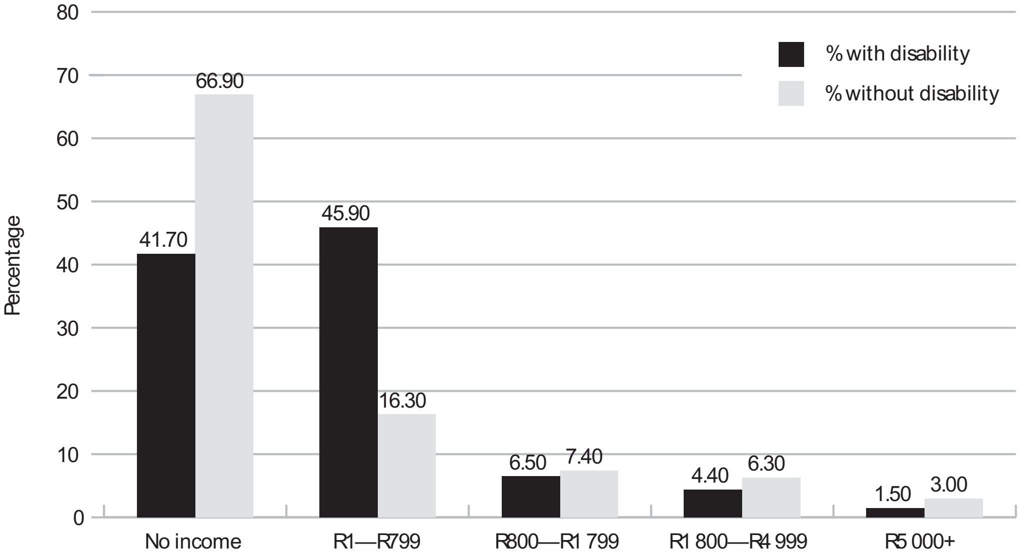
How do these trends manifest themselves, if at all, in South Africa? Earlier in this chapter it was noted that there is a lack of reliable statistical information on disability in South Africa and other developing countries, and it was illustrated how the existing South African data diverge in relation to prevalence rates for disability in South Africa.

Against this background, some caution has to be exercised in interpreting survey findings, and particularly in terms of teasing out the complexities of the relationship between disability, poverty, gender and race. As the Taylor Committee points out, 'in general, quantitative data cannot do justice to the experience of disability, and a more nuanced reading of the data is required for decision making'. But while the available data may be limited in various ways, it can nevertheless 'provide some useful insights'. (Taylor, 2001, pp. 357–359)

In common with other countries, existing data also suggest that disabled people in South Africa are disproportionately represented among the poor. As Woolard (2002, p. 5), for example, observes, Stats SA's 1999 October Household Survey (OHS) data show that while fewer than two per cent of individuals living in households with monthly incomes above R10 000 were categorised as disabled, the disability rate was more than twice as high for individuals living in households with monthly incomes below R800 per month.

These figures do not, however, provide a complete picture of income distribution among South Africans with and without disabilities, as Figure 16.1 attests. The most striking feature of this distribution is that there were considerably fewer disabled people without income than nondisabled people without income. The obvious explanation for this finding is that disabled people are more likely to receive social security grants, especially disability grants, than nondisabled people. The finding should also be seen against the background of the very high levels of poverty and unemployment in South Africa. Some support for this explanation is provided by the large percentage (46%) of disabled people who had incomes of below R800. Proportionately, nearly three times as many disabled people fell into this income category than nondisabled people. Further support is provided by Table 16.2, which sets out the percentages of disabled versus nondisabled people receiving grants. The remaining data are consistent with the assumption that disabled people have lower incomes than those without disabilities, as proportionately fewer people with disabilities are represented in all income categories above R800.

Figure 16.1: Monthly income of people with and without disabilities, 1999



Source: Calculated from Stats SA, 1999.

Therefore, while the data do provide some support for the assumption that disabled people are poorer, it also underlines the importance of the role social security, and particularly disability grants and old age pensions, play in alleviating poverty. However, the impact of social security on poverty alleviation for disabled people needs to be qualified.

Firstly, a slightly larger percentage of disabled people (87.6%) than nondisabled people (83.2%) had incomes of less than R800 when the two categories are combined. Together with the other categories, which show consistent disadvantage of disabled people, therefore, disabled people may be seen as more disadvantaged, particularly when one takes into consideration that the majority of people with incomes below R800 could be classified as poor.

Secondly, as social security grants are on public record, respondents are less likely to conceal information on this source of income than are respondents receiving other (particularly illegal) sources of income.

Thirdly, as personal income is involved, it is not possible to know what the income situation is of the household as a whole, nor how many persons without incomes or with very small incomes are dependent on the income derived from grants. Then there is also the issue of the additional costs associated with disability (caregiving, assistive technology, transport, etc.) which means that low levels of income have to cover more costs.

Table 16.2: Percentages of people with and without disabilities receiving grants

Type of grant	**Percentage of people *with* disability receiving grant**	**Percentage of people *without* disability receiving grant**
Old age pensions	16.47	4.02
Disability grants	14.93	0.28
Retirement benefits	2.46	0.78
Support from outside household	5.03	3.09

Source: Calculated from Stats SA, 1999.

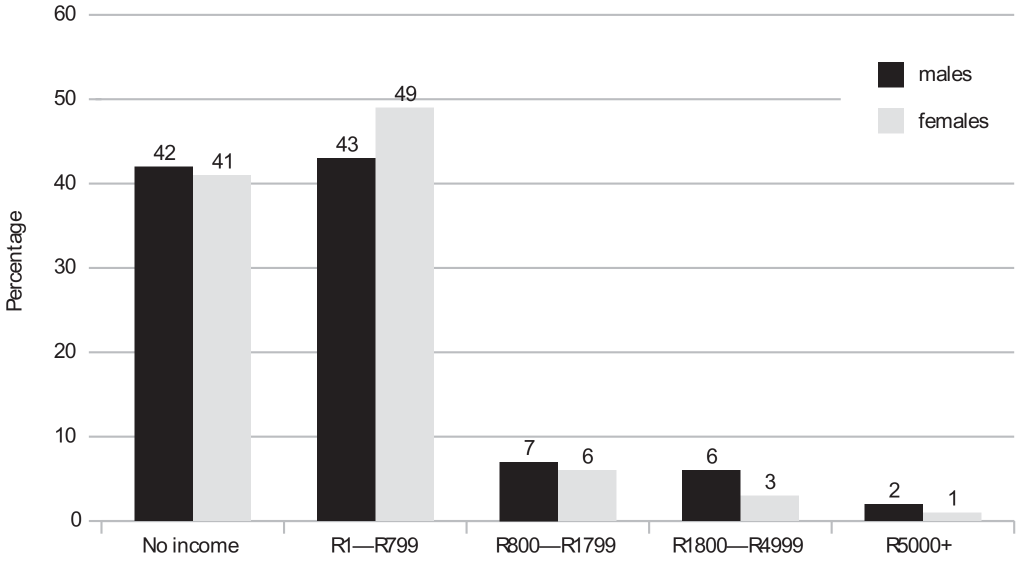
The most important sources of income from social security grants and other sources (excluding wage income and other earnings), as captured in the OHS of 1999, are presented in Table 16.2.[6] This shows that while about 15 per cent of disabled people received disability grants, the percentage of disabled people receiving old age pensions was slightly higher at 16.5 per cent. Proportionately, disabled people received more than four times as many pensions as nondisabled people. Three times as many disabled people also received retirement benefits than nondisabled people, as well as receiving proportionately more support from outside the household than nondisabled people.

The CASE Report for the Department of Health (Schneider et al., 1999: 30–31) also found racial and gender inequalities in the distribution of grants. For example, coloured respondents (53%) were most likely to receive grants or private insurance pensions, while African respondents (29%) were least likely to have access to grants or private insurance pensions. The data also showed that males with a single disability were more likely than their female counterparts to receive grants

Further support for the association between poverty and disability is implicit within the provincial prevalence rates for disability, as obtained by the CASE survey. The survey showed that the three South African provinces with the highest concentrations of poverty, the Eastern Cape, KwaZulu-Natal and Limpopo, also had the highest prevalence rates for disability. The prevalence rates for these provinces were 8.9 per cent, 6.7 per cent and 6.3 per cent respectively, while other provinces had prevalence rates ranging between 5.8 per cent in the Free State and 3.1 per cent in the North West.

In Figure 16.2, the personal incomes of disabled people are disaggregated by gender. While the differences between males and females are relatively small, relatively clear disadvantages are apparent for women, particularly in relation to incomes of R800 and more. In particular, twice as many men as women earned incomes of R1 800 and above. For those at the bottom of the income scale, the proportions of males and females without income are similar, but slightly more disabled women earn incomes under R800 than men.

Figure 16.2: Personal income of disabled people, by gender



Source: Calculated from Stats SA, 1999.

Given the association between poverty and disability, and the extreme racial inequalities in the distribution of income in South Africa, one would expect higher rates of disability in South Africa among Africans and coloured people than among white people and Indians. The available data provides some support for this, but not in all cases. In Table 16.3, the distribution of disability among the major population groups in South Africa of three datasets, Stats SA's 1996 Census and 1999 OHS, and the CASE disability survey of 1998, are presented. Both the 1996 Census and the CASE survey indicate relatively higher rates of disability among Africans, with the Census data producing a prevalence rate for Africans that is more than twice as high as the rate for white people. For the OHS of 1999, however, the highest prevalence rate was for coloured people (4.5%) followed by Africans (3.4%). While in general the results of these surveys do suggest that the distribution of disability is racially biased, and that Africans are likely to have higher prevalence rates, various other discrepancies in the data (for example, the relatively high prevalence rate among white people in the CASE survey) raise questions about the reliability of the data. The Census 2001 proportions (roughly calculated) are Africans 5.23 per cent, white people 4.46 per cent, coloured people 4.22 per cent and Indian 3.69 per cent. The reasons for different proportions could be related to the concepts being measured in each survey, and the high white rate for the CASE survey can be explained as being similar to the rates obtained for developed countries, which are generally higher than for developing countries – one important reason for this being longer lifespan and better access to services.

Table 16.3: Distribution of disability among the major population groups, by percentage

	1996 Census	1998 CASE survey	1999 OHS
African	7.6	6.1	3.4
Coloured	3.7	4.5	4.5
Indian	4.2	4.8	2.2
White	3.5	5.3	3.2

Sources: Schneider et al., 1999; Stats SA 1996; 1999

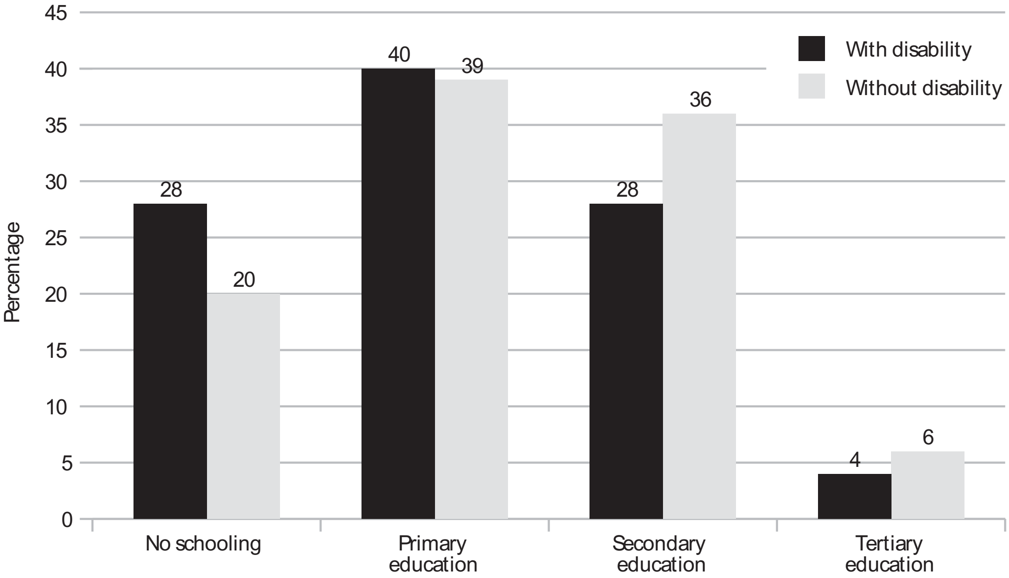
Using data from the 1996 census, Aliber (2003: 481) found only small differences in the unemployment rates of disabled versus nondisabled people. For example, for disabled Africans, 45.3 per cent were unemployed (according to the broad definition), as against 42.5 per cent of Africans without disabilities. Similarly, 26.7 per cent of disabled coloured people were unemployed as against an unemployment rate of 20.9 per cent for all coloured people. Aliber attributes these small differences to the very high rates of unemployment in South Africa in general, but the definitions and methods used to identify people as disabled in the 1996 Census may also have played a role.

In contrast to the 1996 Census, the 1998 CASE survey of disability, which used a more sophisticated methodology to identify disabled people (although accessing a relatively small sample), found significant differences in employment rates relating to race, gender, the number of disabilities and age of onset. More importantly, the CASE study found an overall employment rate of 12 per cent for disabled people. This represented about a third of the employment rate for the general population at that time. However, these findings also need to be treated with a degree of caution. Besides the relatively small sample,[7] the CASE report does not differentiate between people who were economically inactive and those who were unemployed. It differentiates between 'unemployed – looking for work' and 'unemployed – not looking for work'. Nor do the figures make provision for the proportionately larger number of people beyond retirement age represented within the population of disabled people.

In terms of racial issues, the CASE study found that white people were more likely to be employed, with 19 per cent of white disabled people employed in full-time positions compared to 6 per cent of Africans, 4 per cent of coloured people and 9 per cent of Indians. Disabled women were also less likely to be employed, with 11 per cent of disabled women included in the sample indicating that they were employed, as against 15 per cent of disabled males. This difference was statistically significant. The study also shows that age of onset played a role in the employment of disabled people in that only 7 per cent of those who had acquired impairments before 2 years of age were employed, as against 17 per cent of those with age of onset between 19 and 65 years.

One of the ways in which early onset of disability may impact on employment is through education. For example, Stats SA's 1999 OHS showed that nearly 30 per cent of disabled school-age children were not attending school or not attending full time, compared with 10 per cent of nondisabled children (Taylor, 2001, p. 358). Inequalities in the levels of education attained by people with or without disabilities are also reflected in Figure 16.3, which shows that more disabled people had no schooling and fewer had secondary or tertiary education. In relation to primary school education, however, there was very little difference between those with or without disabilities.

Figure 16.3: Percentages of population with and without disabilities, by level of education



Source: Calculated from Stats SA, 1999, OHS

The CASE study also found that attendance of primary school by disabled children was relatively high, with 79 per cent of respondents attending mainstream primary schools and a further 12 per cent at special schools. Only 5 per cent of the qualifying respondents were not attending primary school. In contrast, 44 per cent of respondents were attending mainstream high schools and a further 9 per cent were attending special secondary schools. CASE attributes the relatively low attendance of secondary schools by disabled children to the lack of attention to their special educational needs in primary schools, resulting in these children being unable to reach high school.

The CASE data also clearly show that the educational disadvantages of disabled people are compounded by racial inequalities. At the secondary school level, 51 per cent of African disabled children were out of school, in contrast with only 11 per cent of disabled white children. Furthermore, white children were more likely to attend special schools than African children, with 32 per cent of white children in special schools at the primary level and 33 per cent at the secondary level. In contrast, only 8 per cent and 5 per cent of African children attended special schools at the primary and secondary levels, respectively. Far more disabled African children (85%) were therefore in mainstream primary schools than their white counterparts (56%).

These results need to be seen against the background that special schools 'have traditionally captured most of the budget for special needs' (Schneider et al., 1999, p. 24) and that only limited provision is made for catering for the special educational needs of children with disabilities in mainstream schools. For example, the CASE data showed that children attending special schools were more likely to have access to and to be using assistive devices than those attending mainstream schools (Schneider et al., 1999). In general, disabled Indians and white people were more likely to be using assistive devices than Africans and coloured people. Furthermore, the majority of assistive device users lived in urban areas (Schneider et al., 1999).

In turn, access to assistive devices and personal assistance were shown to 'have a highly significant impact on how respondents rated their disability or activity limitation' (Schneider et al., 1999, p. 20). Whereas 58 per cent of those with no personal assistance or assistive devices rated their disabilities as severe, only 5 per cent of these rated their disabilities as severe with access to an assistive device, and 12 per cent of these rated their disabilities as severe with personal assistance. Similar situations applied also to diagnostic and assessment services, with more privileged and urbanised populations having access to specialised services (Schneider et al., 1999). Lack of access to effective identification and assessment of disabilities in turn were associated with 'ad hoc placement within mainstream schools with no real consideration of the child's needs' (Schneider et al., 1999, p. 25).

As in the case of assistive devices, the complex interrelationships between disability, poverty, gender and race in South Africa appeared to be intertwined with issues of locality, and in particular, location in rural and urban areas. This is particularly relevant to South Africa where, under apartheid, the former (largely rural) homeland areas were severely under-funded and deprived of social and economic services. As pointed out in the INDS, the location of people in disadvantaged areas like the former homelands has 'had a particularly severe impact on people with disabilities who found themselves in an inhospitable environment, facing poor living conditions and unable to access the help they needed':

> The Disabled Children Action Group (DICAG) estimates that 98 per cent of mothers of children with disabilities living in rural areas are

> unemployed, semi-literate or functionally illiterate single women. Deserted by husbands and lovers, often socially ostracised by their communities, and banished into isolation by their extended families, they tend to withdraw into a world of their own. (ODP, 1997)

While the CASE report comes to the overall conclusion that there 'do not seem to be significant differences in the access to services between urban and rural areas for Africans with disabilities' (Schneider et al., 1999, p. 36), this appears to be contradicted by more detailed findings in other parts of the text. For example, the report states that

> rural respondents between the ages of 0 and 10 (59%) were more than twice as likely to have three or more disabilities than their urban counterparts (24%). This suggests that people in rural areas do not have access to services which could prevent a relatively minor disability or impairment develop[ing] in to a major one. (Schneider et al., 1999, p. 16)

Furthermore, it maintains that rural Africans were more likely to be disabled at birth than their urban counterparts and suggests that this 'could be linked to the lack of adequate pre- and peri-natal services for Africans in rural areas' (Schneider et al., 1999, p. 19).

The questions on access to services asked what services were needed and were in fact received. Nothing was asked about the nature of the services. So, clearly, few people who needed rehabilitation services received them (39%). While a higher proportion of people who needed health care in fact received it (76%), this does not give us an indication of whether the health services were adequate or not. There is a substantial likelihood that a large proportion of this provision was of a poor standard.

Conclusions

Overall, existing data on disability in South Africa suggest that disability, poverty, gender and race are intimately associated with one another, and that the cumulative impact of disability, poverty and other social disadvantages such as gender, race, age and physical location can therefore create extreme vulnerability and exclusion for those sections of the population who suffer multiple and overlapping disadvantages.

A major difficulty, however, exists in relation to the consistency – and therefore reliability – of South African data on disability. As we have seen, major differences exist in the findings of the different surveys. Such discrepancies are not unique to South Africa, but are present in much of the data on disability in developing countries.

Various reasons have been advanced for the discrepancies in existing data, including the use of different definitions and methods of measuring disability in the various surveys. However, while problems of definition and measurement are important, the matter goes further than this. Given the strong association that has been established between disability and poverty in industrialised countries, one would expect that disability rates would be higher in developing countries where conditions of poverty and ill-health are more pervasive. Existing data do not support this assumption. Instead, estimates of the percentages of the population with impairments tend to range between 10 and 15 per cent in industrialised countries, while in the developing countries the figures tend to be significantly lower, usually below 6 per cent of the total population. Demography of the population, access to services (e.g. emergency services), industrialisation and related illnesses and injuries, all contribute to higher rates in developed countries, as well as the methodologies used for measurement.

While definitional and measurement issues are important in understanding these differences (for example, surveys in industrialised countries have generally been more sophisticated and more comprehensive than in developing countries), other reasons, such as 'the premature death of disabled people (mainly infants, female children and women), failure to record disabled people in censuses and surveys, and higher "thresholds" for the identification of impairment and disability' (Albert, McBride & Seddon, 2002: 4), have probably also played a role. In addition to differences in the quality of, and resources available for, research in low and high income countries, conditions in developing countries also present difficulties for research on disability, including poor infrastructure in the more remote areas, problems associated with reaching poor households, and difficulties relating to the identification and awareness of disabilities, particularly in children. The stigma that is often associated with disability may also play a role, in that some people may conceal their disability status or that of members of their households. This is most likely to occur in those households and communities that are poorer and located in rural and less accessible areas, that is, in contexts in which one would expect disability rates to be higher (Taylor Committee, 2001: 357).

A number of issues and questions arise from this brief discussion and the data presented in the previous section. Firstly, if for any of the possible reasons discussed above, disability rates are indeed lower in developing countries than in industrialised countries, then one would expect it to be more difficult within developing contexts to identify associations between disability and other disadvantages such as poverty, gender and race, because one is dealing with a smaller segment of the population. More accurate information on disability would therefore require larger samples as well as more sophisticated techniques for the identification of people with disability.

Secondly, the picture is further complicated by the possibility that lower prevalence rates in developing countries may largely, or in part, be a product of higher mortality rates among people with disabilities. If this is the case, then it is likely that those segments of the population that are most vulnerable to disability would also be most vulnerable to premature mortality. This in turn would have the effect of lowering disability rates among those parts of the population that one would expect to be most vulnerable to disability. In order to obtain a more comprehensive understanding of disability within developing contexts, it may therefore be necessary to locate disability trends within the context of mortality trends. As Hulme and Shepherd (2003: 409) point out, how to deal with 'those who die preventable deaths' is a key conceptual challenge for the study of poverty, and 'these need to be incorporated in our analysis as they experience the most acute form of deprivation (i.e. deprivation of all capabilities) for all of the "lost" years of the life they would have had'.

Thirdly, the picture of disability within a developing context like South Africa is further complicated by the pervasiveness of poverty and unemployment. As Aliber (2003) argues, differences in unemployment rates might be more discernible within tighter labour markets. South Africa also has a relatively well-developed social security system for a developing country, and within a context of pervasive poverty, access to disability grants and other social security benefits have a greater impact on income distribution among people with and without disabilities, than they would in a context with lower rates of poverty and unemployment.

Fourthly, in common with most (if not all) other countries, in South Africa disability rates rise exponentially with age (see, for example, Stats SA 2001, p. 34; Schneider et al., 1999, p. 16). Larger proportions of the population with disabilities are therefore eligible for old-age pensions than in the population as a whole. This, as we have seen, has an impact on the distribution of income between disabled and nondisabled citizens. But because of the younger demographics of developed country populations, the absolute numbers of older people contributing to the number of disabled people is not huge.

Lastly, a related issue is that the age of onset of disability appears to play an important role in determining employment opportunities, in that those who become disabled at earlier ages are less likely to be employed than those who become disabled at an older age. The CASE data showed that fewer than half of those who had acquired impairments before two years of age were employed in comparison with those with age of onset between 19 and 65 years. One possible contributory factor is education, because schools (whether special or mainstream) often do not make sufficient provision for the special educational needs of children with disabilities. Longer exposure to negative social attitudes and social isolation may also contribute. This suggests that in addition to the cumulative impact of different disadvantages such as gender and race, time of exposure to disabilities may be cumulative as well.

At the basis of the issues raised here is how we conceptualise disability and poverty, and the relationship between them. As Burchardt (2003, p. 64) points out, the onset of disability is not a random occurrence, but is 'strongly patterned by social and economic circumstances':

> Those who are already disadvantaged are at significantly greater risk of becoming disabled. There are strong associations between being poor, being out of work, having low educational qualifications and the risk of developing a long-term health problem or impairment. Many of these risk factors are amenable to policy intervention. The onset of ill health or impairment often entrenches and deepens pre-existing disadvantage, and this too is preventable. For these reasons the prevalence and distribution of ill health and impairment in society should be regarded as more akin to a phenomenon which we have chosen to fail to prevent, than to a natural disaster.

Notes

1 The CASE survey (Schneider et al., 1999, pp. 159–60) indicated access to medical rehabilitation by 17 per cent of respondents who said they needed rehabilitation. Studies conducted in Namibia and Zimbabwe showed that access to rehabilitation services by those needing them was 26 per cent for Namibia and 55 per cent for Zimbabwe (Eide, Van Rooy & Loeb 2003, p. 85; Eide, Nhiwathiwa, Muderedzi & Loeb, 2003, p. 92).

2 In this case, disability was defined as an *activity limitation* in a major life area such as work, school or housework, due to a chronic health condition or impairment.

3 In this case, disability was defined as an *activity limitation* in a major life area such as work, school or housework, due to a chronic health condition or impairment.

4 Work disabilities were determined by survey questions that asked respondents whether they had a condition that limited the kind or amount of work they could do. In 1998, for example, 17.2 million people, or 9.9 per cent of the working age U.S. population (16–64 years) had a work disability.

5 For example, in 1995 in the US it was estimated that women and girls with disabilities made up 21.3 per cent of the total non-institutionalised population, as against 19.8 per cent for boys and men. This higher disability rate for women has been attributed to the higher average longevity of women (Jans & Stoddard, 1999).

6 Only those grants and sources of income in which proportionately one per cent or more of either of the two categories of respondents received benefits were included in Table 16.2. It should also be noted that in 1999/2000 old-age pensions and disability grants accounted for R15.3 billion (or 86 per cent) of total state expenditure on grants in contrast with only R1.6 billion for all other grants (Taylor, 2001: 373).

7 While information was obtained on 42 947 people, 2 435 were identified as having a disability. Of these, 1 703 constituted the sample of the detailed study on the experience of disability.

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17

Tough choices: disability and social security in South Africa

Leslie Swartz and Marguerite Schneider

The social model of disability

Introducing the *White Paper on an Integrated National Disability Strategy* (INDS) in November 1997, President Thabo Mbeki wrote:

> Among the yardsticks by which to measure a society's respect for human rights, to evaluate the level of its maturity and its generosity of spirit, by looking at the status that it accords to those members of society who are most vunerable, disabled people, the senior citizens and its children. The concept of a caring society is strengthened and deepened when we recognise that disabled people enjoy the same rights as we do and that we have a responsibility towards the promotion of their quality of life. (ODP, 1997, p. 1)

The INDS is an ambitious and progressive document, which was designed to provide the basis for delivery, on the part of both government and society as a whole, in terms of disability. In line with international thinking on disability, the INDS aligns itself with what is known as the 'social model' of disability, framing disability as a human rights issue, and pointing out that barriers in society (including attitudinal and physical barriers) can be disabling to people. People may be excluded from education and employment, for example, not because they are unable to participate in these spheres, but because others assume they can't. They may be unable to get work, furthermore, not because of any incapacity of their own, but because of the lack of safe, accessible and affordable transport. The South African Human Rights Commission's report, *Towards a barrier-free society*, similarly to the INDS, places great emphasis on attitudinal barriers preventing the full participation of disabled people in South African society, concluding that 'prejudice remains the greatest disability' (SAHRC, 2000, p. 62).

This understanding of disability is important for developing a human rights culture and for helping South Africans learn more about creating an accessible society which enables fullest participation by all citizens, including citizens with disability, in all aspects of life (see Chapters 1 and 8, this volume). A key feature of progressive thinking on disability is that there are no neat divisions between 'the disabled' and 'the nondisabled'; disability is a fluid and changing category, and what causes disability is an interaction between the person and the environment (see Chapter 2, this volume). In the social model promoted by the INDS we can, in fact, decrease the prevalence of disability by changing the environment – physical and/or attitudinal.

This has very important implications: the same person may be classified as disabled in one context and not disabled in another. An accessible, caring society strives to create environments across the country such that disability is minimised. This includes promulgating legislation so that people with disabilities have fair access to work opportunities (employment equity legislation), and ensuring that physical barriers do not keep disabled people out of work. Though we have legislation on the design of the built environment, many buildings remain inaccessible and transport remains a huge problem for people with disabilities (see Chapters 23 and 25, this volume). Where the social and physical environment cannot be made fully accessible, special social security benefits for disabled people in the form of grants and free health care should be provided.

Barriers in South Africa

The reality is that the INDS, appropriately enough, is an aspirational document, and the ideals that we may have for a barrier-free society, to use the term used by the Human Rights Commission, are far from being realised. The reasons for this are diverse and not the main concern of this chapter, but they include attitudinal issues in society as a whole, and, crucially, resource challenges. Though universal design, for example, is not necessarily especially expensive in the creation of an environment accessible to all, retro-fitting existing buildings and access routes to accommodate all South Africans can be technically and aesthetically challenging, not to mention expensive. The ideal of safe and accessible transport, furthermore, cannot be seen outside of the context of a situation in which most South Africans are confronted with a transport system which is inadequate. A barrier-free society requires access to high quality, adequately resourced, mainstreamed education – a very difficult goal to reach where there are problems of access to adequate education for many South Africans who do not have disabilities. Schools, for example, with very poor facilities, inadequately qualified teachers and large classes cannot reasonably hope to provide optimal learning opportunities for disabled learners. This being the case, the problem of disabled people being inadequately skilled for the labour market continues to grow. Employment equity in its best sense can be achieved only when all people have the best possible opportunity to develop their skills for the labour market. People must ideally be employed on the basis of their skills and abilities – on the basis of what they have to offer – rather than simply on the basis of meeting quotas. If, in order to fill quotas, people with less than adequate skills are employed, this can lead to long-term damage to inclusivity in society as a whole, and in fact to the reinforcement of an erroneous view that impairments inevitably create workers who are not able to play their full role in the economy.

South Africa, as is well known, is a very unequal society, with high rates of unemployment and poverty, and with differential access to resources on the basis of race, income and place of residence, to name but a few. Progressive provisioning for disability cannot optimally take place where there are such huge inequalities in society as a whole. The social model of disability has a bedrock assumption that society be as equal as possible for all. Implementing the social model properly in a society which is as divided and unequal as South Africa is, becomes an almost super-human task. Able-bodied South Africans struggle daily to gain fair access to skills, to work opportunities, to education, to recreational and cultural pursuits, to education. These struggles are magnified for people with disabilities. Where jobs are scarce and unemployment high, where do disabled people, often with the legacy of inferior education or of no education at all in many cases, stand in the long queues for jobs in South Africa?

Inevitably, the broader context of a society struggling to meet the needs of all its citizens, impedes the growth of optimal participation of disabled South Africans (and, most especially, the vast majority of disabled South Africans who are poor and have not had adequate opportunity to develop adequate skills) in society at large. There can be no doubt that enormous progress has been made in the participation of disabled people in society, and in the power that disabled people now wield in a number of areas, not least in government, where the Office on the Status of Disabled Persons is located in the Presidency itself. But the reality is that most disabled people continue to be marginalised and poor – a situation shared by very many other South Africans.

Disability grants

This reality places a serious burden on those trying, in accordance with government policy (and with progressive thinking internationally), to implement the social model of disability. This is a challenge worldwide and not just for South Africa (Honeycutt & Mitra, 2004; Szymendera & Swartz, 2004). Within the social model, changes to society as a whole are emphasised with the broader goal of creating an environment which maximises participation. Social grants and what are disparagingly termed 'hand-outs' for disabled people, are seen as being associated with attitudes towards disabled people which are patronising and 'welfarist'. Rather provide skills and jobs than disability grants, the social model would argue (a view which would be echoed by very many disabled people). Where jobs are scarce in the country as a whole, however, where access is a general problem, where there is inadequate provision of basic assistive devices needed by some disabled people, it is inevitable that, invidious though this situation may be, the emphasis time and again comes down to the appropriate provision of social security in the form of grants. In South Africa, the grant for adults, who in terms of legislation are unable to sustain themselves economically by reason of disability, is known as the disability grant; for children who require extra care and attention there is the care-dependency grant. Both grants are administered by the Department of Social Development (DoSD), but require participation by other departments, notably the Department of Health in assessments for grants in some cases, and the Treasury, of course, for provision of funds.

Rise of beneficiaries

There has been an astronomical rise in the number of those accessing disability grants over the past few years (see Tables 17.1 and 17.2).

Table 17.1: Number of beneficiaries of disability grants by province

Province	**April 1997**	**April 1998**	**April 1999**	**April 2000**	**April 2001**	**April 2002**	**April 2003**	**April 2004**
EC	167 090	149 485	128 942	132 732	139 417	163 099	218 273	301 415
FS	43 182	47 582	40 140	31 384	36 402	45 790	76 392	108 869
G	81 929	67 701	60 005	63 615	63 632	73 265	116 706	156 457
KZN	167 618	171 120	148 165	133 847	135 480	146 932	183 086	284 163
L	68 040	17 838	46 203	51 693	58 237	68 010	76 297	89 589
M	31 558	32 153	30 703	32 533	34 764	38 454	47 123	65 603
NC	31 276	31 418	37 509	27 874	26 994	33 315	38 545	42 659
NW	51 900	50 301	52 839	48 987	55 812	58 501	72 363	98 402
WC	89 729	92 930	89 272	89 947	90 721	105 562	125 180	123 807
Total	732 322	660 528	633 778	612 614	641 459	732 928	953 965	1 270 964

Source: Treasury figures supplied to authors on request

Note: EC = Eastern Cape, FS = Free State, G = Gauteng, KZN = KwaZulu-Natal, L = Limpopo, M = Mpumalanga, NC = Northern Cape, NW = North West, WC = Western Cape

Research commissioned by the Treasury was investigating reasons for disability grant growth at the time this book was being written, and once the results of the study are available, it will be possible to discuss the reasons for growth with some confidence. It is useful however to consider in some detail what some of the challenges are which face those trying to apply the grants legislation fairly, as well as various attempts which have been made to improve the situation with regard to grants.

Table 17.2: Annual growth in disability grant beneficiary numbers, by percentage

Province	April 1998	April 1999	April 2000	April 2001	April 2002	April 2003	April 2004
EC	–10.5	–13.7	2.9	5.0	17.0	33.8	38.1
FS	10.2	–15.6	–21.8	16.0	25.8	66.8	42.5
G	–17.4	–11.4	6.0	0.0	15.1	59.3	34.1
KZN	2.1	–13.4	–9.7	1.2	8.5	24.6	55.2
L	–73.8	159.0	11.9	12.7	16.8	12.2	17.4
M	1.9	–4.5	6.0	6.9	10.6	22.5	39.2
NC	0.5	19.4	–25.7	–3.2	23.4	15.7	10.7
NW	–3.1	5.0	–7.3	13.9	4.8	23.7	36.0
WC	3.6	–3.9	0.8	0.9	16.4	18.6	–1.1
Total	–9.8	–4.0	–3.3	4.7	14.3	30.2	33.2

Source: Supplied to authors by National Treasury on request.

Note: EC = Eastern Cape, FS = Free State, G = Gauteng, KZN = KwaZulu-Natal, L = Limpopo, M = Mpumalanga, NC = Northern Cape, NW = North West, WC = Western Cape

Assessment panels

Historically, and in terms of the Social Assistance Act (No.59 of 1992), assessments for disability grants were in the main conducted by medical practitioners. Medical practitioners receive little or no training in the process of making assessments for disability and care-dependency grants. With shortages in such practitioners, in rural areas in particular, in the context of an enormous (and rising) health-care burden in South Africa, it has become an increasing challenge to the health system to provide assessments. Where health resources are few, furthermore, medical practitioners may resent and try to avoid work which they see as administrative – such as assessments for grants – rather than the clinical work for which they were trained.

Partly because of these issues, and mindful of the challenges in realising equitable and efficient access to disability and care-dependency grants, the Department of Social Development promulgated regulations in 2001, enabling assessment panels to make the assessments for grants. The panelists may, but are not required to, have medical practitioners as part of their composition. The panels are required to comply with Regulation 24 (a) of Social Assistance Act (No.59 of 1992) as amended with effect from 1 December 2001. In terms of the Act as amended, panelists should 'evaluate information and determine disability' for both disability and care-dependency grants. Panels themselves may have flexible membership, but the following may, according to regulations, be represented on the panels:

- A senior social security official;
- A rehabilitation therapist (nurse, social worker, occupational [sic], psychotherapist, audio visual therapist [sic] etc.);
- A representative from the disability sector or a reputable member of the community namely a priest, the chief, magistrate, or a person who is familiar with the community and its circumstances;
- Any additional member/s, if necessary, as may be relevant to a particular application namely a doctor or specialist doctor, psychiatrist, paramedical personnel, traditional healer to name but a few. (DoSD, 2001, p. 1)

There are three requirements for appointment to the panels:

- Members should have some familiarity with disability or care dependency.
- Members must be familiar or familiarise themselves with the socio-economic conditions of the area or community for which the panel is appointed.
- Members must be willing to undergo training developed by the department. (DoSD, 2001, p. 3)

To date, assessment panels have been implemented formally in three provinces: Free State, KwaZulu-Natal and North West. Apart from the issue of equitable access to assessment, there was also hope that panels would assist in other ways. Some disabilities may not be obvious on cursory examination (e.g. those 'invisible' disabilities which may be consequent on deafness, epilepsy and certain forms of brain damage in which the impairment is not immediately detectable). Practitioners other than medical practitioners, and community members who have had the opportunity to observe applicants over a long period of time, may, it was hoped, be better placed to detect 'invisible' disabilities' than would a medical practitioner forced to undertake a quick assessment, with limited resources.

The enormous strength of the assessment panel model is that it allows great flexibility and local appropriateness in the panels' constitution and functioning. In keeping with the social model, furthermore, it allows for a panel to have rich contextual understanding of both the applicant and of the environmental facilitators and barriers to optimal participation. The chief difficulty of the assessment panel approach is that it is difficult to achieve equity in assessment processes when assessments are context-rich and conducted by panels that are constructed differently in different areas. This issue leads to another challenge that the assessment process faces.

The assessment process

Some general issues related to assessment in the context of disability discussed in Chapter 18 (this volume), will not be repeated here in any detail. It is important to note, though, that the social model brings with it something of a tension when the issue of assessment for grants is considered. The social model emphasises the transpersonal aspects of disability – patterns of oppression in society, and facilitators and barriers to participation. Assessment for a grant requires an emphasis on the individual with an impairment. The question an assessment has to answer is individual and categorical: 'Does this person qualify for a grant or not?'. This flies in the face of arguments which correctly point out that there is no neat distinction between the 'disabled' and the 'nondisabled', and also that disability is contextual and fluctuating according to social and environmental conditions. Ideally, therefore, disablement should be seen not as a static condition inherent to a person, but as a contextually dependent process in which impairment, functioning and the environment interact and change in potentially unpredictable directions over time (Verbrugge & Jette, 1994). Assessment of eligibility for a grant, then, should not be simply the assessment of a state of being, but rather of a complex and changing environment.

A number of countries, including Canada, the United Kingdom and Australia, have attempted to translate these complexities into usable and user-friendly processes. In 2002, the United States Committee to Review the Social Security Administration's Disability Decision Process Research, the Board on Health-care Services of the Institute of Medicine, and the Committee on National Statistics, Division of Behavioral and Social Sciences and Education of the National Research Council, published *The dynamics of disability: Measuring and monitoring disability for social security programs* (Wunderlich, Rice, & Amodo, 2002).[1] Fundamental to the assessment of disability in the Committee's approach is the distinction between the assessment of *attributes* as opposed to *relational concepts*. The following passage discusses work-disability specifically but applies equally to other forms of disability:

> *Relational concepts*, in contrast to attributes, cannot be accounted for solely among the characteristics of a body system or the individual. Relational concepts include elements of the situation other than the individual's attributes. In the disablement model, the concept of *disability* is a relational concept. Therefore, to assess work disability directly, an indicator must assess the individual's capacities in relation to work role expectations as well as the social and physical environmental conditions in which they are to be performed. To understand the reasons why a person has a work-related disability, one has to consider not only the person's own functional capacities, but also the person's capacities in relation to relevant physical and social environmental expectations and the individual's response to his or her limitations in capacity. (Jette, 1999: 3)

What is central to note from this quotation is that even when there is not an explicit commitment to the social model of disability, and even where it could be argued that there is insufficient emphasis on the disabling role of the environment, there remains, in contemporary thinking, a fundamental shift in how disability is thought about and assessed for social security purposes. This shift is from an attributional model towards a model which is far more contextual and, indeed, relational. Even if, therefore, one may have a range of reservations about the social model and its potential to deliver an appropriate assessment framework, the key contribution of viewing disability relationally is retained in an exceptionally well-researched system. The social model, the INDS, and even the *International Classification of Functioning, Disability and Health* (WHO, 2001), were not specifically designed to assess disability for social security purposes. It may be argued that there is something of a jump from these models to what has to be a categorical assessment decision-making process, at any given time. But even in the absence of these, the key issue of contextual, relational assessments remains.

Jette (1999) goes on to offer a sobering analysis of what is and what is not possible in disability assessment:

> This assessment has to be sensitive and specific, so it can deal with false positives as well as with false negatives…In addition, it has to be practical, safe, and ideally, inexpensive to administer. That is no easy task. In fact, anyone who has done work on assessment knows that attaining this goal is like searching for the 'holy grail'. It cannot be done; it is extremely challenging to try to meet all of these criteria. A major challenge…in trying to measure disability is to balance the scientific concerns (like reliability and validity) with the practical and pragmatic concerns requiring real-world trade-offs. One has to give up some reliability and validity, sensitivity and specificity if, in fact, the goal also is to come up with something really practical and inexpensive to administer. It is not possible to achieve all of these. (Jette, 1999, p. 4)

There are two key points which are essential to mention here. First, every assessment process must be able to accurately *include* in the system people who have disabilities (known technically as 'sensitivity'). It must also accurately *exclude* from the system people who do not have disabilities (known technically as 'specificity').

In other words, the imperative to improve equity and access does not mean that every person who applies should be given a grant. This would defeat the need for an assessment process at all. Equitable access means that the *appropriate* people should be awarded grants after all people have had an equal chance to *access the assessment process* – not to get a grant, necessarily. The assessment process is as much about deciding who should *not* receive a grant as it is about deciding who should receive a grant.

The second key point made here by Jette (1999) is that there has to be a trade-off between ease of use and administration and validity concerns. This trade-off may be painful but, as Jette says, it is inevitable, especially at the early stages of development of new assessment approaches. It is also the case that any assessment process cannot be checked for validity outside of the real-world context within which that process is applied. There has to be certainty that those administering any assessment device are fully competent to use that device – a very tall order given the wide range of persons involved in making assessments. Clearly, uniform training of assessment personnel is key, but it can never be assumed, even under ideal circumstances, that perfect administration occurs. But what, in the social model, is 'perfect administration'? The social model requires that context is taken in to account, and it is therefore possible that the same person, with the same impairment, could legitimately be seen as disabled in one context (e.g. a very inaccessible environment) and not disabled in another (e.g. a very enabling environment). This may lead to difficulties with people claiming to live in more inaccessible areas in order to receive grants.

The issues of assessment difficulties are not unique to South Africa, nor is it impossible to make compromises about these. What is essential, though, is that these choices are made explicitly and in a real-world context, backed by good research. It is a disservice to good assessment for grants to work from the assumption (explicit or otherwise) that a perfect system is possible.

The complex ethics of assessment

Much has been made of the issue of corruption in the process of assessment for disability and care-dependency grants in South Africa, and this is a serious issue needing attention. There are however more subtle issues at work which complicate the assessment process. People who apply for grants are usually poor, and the grant will often provide a livelihood for many people, and not just the disabled grantee. The disability and care-dependency grants are not designed to be poverty-relief measures, but in reality, this is how they often operate. The case study below tells the story of the role of the grant in the economic and emotional life of a South African family.

> *The story of Gift, and the abuse of the grant system*
>
> Gift has just turned 18. He has a serious mobility impairment but is able to maintain his one-roomed house, to look after his two young nieces who live with him, and also to catch public transport to school where he is completing Grade 12. Two years ago his mother died of AIDS, and shortly thereafter his aunt (the mother of the two girls whom he cares for) also died of AIDS. His grandmother lives some way away, with his only surviving aunt and her six children, all under the age of 12. Gift does not get on well with his aunt and prefers not to live with her. Gift has been receiving a care-dependency grant and his grandmother an old age pension; these are the two only sources of income for the two households. His grandmother has been trying to access grants for looking after the grandchildren, but with no effect thus far. Gift is now concerned that, as he is 18 and no longer eligible for a care-dependency grant, he will be assessed for a disability grant and not be granted one. He does not know how the two households will survive.

Comment

In terms of the requirements for a care-dependency grant, it is clear that Gift should not have been receiving the grant at all. Far from being a child requiring permanent care, he has in fact been running a household and caring for others. He should also not, strictly speaking, qualify for a disability grant as he has sufficient skills to be able to provide for himself. But in the context of huge unemployment where he lives, he will be unlikely to find work and he would also like to continue at school.

Any person conducting an assessment, whether this person is a medical practitioner or not, has to weigh up the reality of the law against the situation of people like Gift. It is exceedingly difficult to apply the principle of distributive justice to assessments when as a practitioner one is faced with the reality of poverty. If (and we have heard of many cases of this) practitioners recommend grants, when according to the law they should not be recommended, this may be unethical in an abstract sense; but it may reflect the application of a personal and individual ethic of assisting a very poor family.

Conclusion

Assessment for and provision of social security in the context of disability is challenging everywhere. South Africa is a leader in relation to other middle-income countries in providing for social security for disability, but faces enormous challenges. With very high unemployment rates in South Africa, the context in which grants are awarded is vastly different from that in which the idea of grants was conceived. The concept of grants being available for people who, by reason of disability, are unable to support themselves financially, is a good one. However, many people with disabilities, like many without disabilities, are unable to support themselves because of broader macroeconomic factors – there are not enough jobs for South Africans. This reality places the disability grant system under enormous pressure, especially in the context of the HIV epidemic (see Chapter 9, this volume), and raises questions about poverty relief and social security in South Africa, questions which go far beyond issues of disability.

Note

1 This volume represents the culmination of six years of investigation by a large team, and this and earlier volumes documenting the process are available from the National Academy Press Website at http://www.nap.edu.

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18 *Issues in disability assessment*

Joan Andrews, Marion Fourie and Ruth Watson

This chapter deals with three related topics. Firstly, matters pertaining to disability and assessment are briefly introduced. Next, reasons for the performance of assessments are presented, and various issues that impact on the way that assessments are done are discussed. The last section of the chapter deals with the development of a South African assessment tool, and includes a summary of assessment principles and an overview of the components of a comprehensive assessment, both for children and adults.

Issues around the assessment of disability

The assessment of disability is a topic fraught with difficulty for a range of reasons. How should disability be understood? What is ability as opposed to disability? What should be assessed, and if assessment is necessary, what code of practice is available to guide the task? The word disability suggests a lack of or decrease in ability, and is based on the common assumption that anyone who is not the same as others, is lacking in ability in some way.

However, the UK based Union of the Physically Impaired Against Segregation (UPIAS) formulated a definition of disability in 1975, that for the first time shifted the issue of causality away from a focus on something being wrong with an individual, to the difficulties created by society. The disability movement's current concept of disability 'locates the causes of disability squarely on society and social organisation' (Oliver & Barnes, 1998, p. 17), as opposed to any lack or shortcoming of the person. The so-called social model (Oliver, 1990) has sought to change public awareness by defining disability as the result of society's unwillingness or inability to accommodate the needs of all citizens, irrespective of bodily difference or impairment. As Chapters 2 and 16 in this volume show, the social positioning of disabled people in society is crucial. This creates certain challenges for assessment, as this chapter will show.

The orientation to understanding disability in this chapter is aligned with the *International Classification of Functioning, Disability and Health*, known as the ICF (WHO, 2001). The ICF classifies disability as problems in bodily function or structure, problems related to activities, and problems related to social participation. The ICF is not entirely endorsed by the international disability movement, but it incorporates many of the principles which the movement regards as critical. In the ICF, disability is presented as an expression of difficulties that arise as the result of a combination of personal, health related, functional and environmental factors. Each person's experience of disability is viewed as unique, and problem severity fluctuates depending on the nature and interaction of all the factors. Age, gender, place and type of residence, family support and duration of the problems, are just a few examples of possible variables. The ICF is used as a tool for the assessment of disability internationally and, in our view, is particularly useful in providing a common language for those involved in such assessments.

The philosophical and technical nature of disability assessment has undergone a number of key alterations during the course of the last century. The prevailing approach to disability assessment during the 1950s and 1960s, primarily involved rehabilitation professionals concentrating on physical, behavioural and vocational limitations as the main difficulties preventing people from participating fully in society (Jongbloed & Chrichton, 1990). It was generally accepted that it was the role of health professionals to attempt to reverse, modify and measure disability, in the form of such 'individual limitations'. The practice of allocating a percentage disability was common as an estimate of incapacity and/or functional loss. This practice still persists, particularly for compensation assessment (such as that relating to industrial-injury benefits) (Spiker, 2003).

However, as mentioned earlier, 'in the 1970s the individualistic conception of disability was challenged by a socio-political definition' (Jongbloed & Chrichton, 1990, p. 32). The new paradigm that emerged revolutionised practice by placing emphasis on the failure of society to adjust the social environment to match and meet the needs of disabled people. This has impacted on the emphasis and method of assessment, embodying a movement away from the measurement of personal and individual problems to the consideration of external influences and limitations that prevent people from providing for their own needs, and for the needs of their families. As a result, comprehensive assessments now include both quantitative and qualitative methods.

The environment

Using the social model as a frame of reference, the investigation of a disabled person's environment is a very important aspect of the assessment procedure. The notion of environment here incorporates the person's living space and the people that share it, the neighbourhood and immediate community of which the person is a member, and the broader social sphere beyond these confines. Each aspect of the environment may offer access, opportunities, positive challenges and choices, or may present constraints and restrictions.

The extent to which the environment supports (or hinders) a person's needs, aspirations and functioning is the question at issue here. Often, many, if not most, of these environmental factors are beyond an individual's control, yet have a considerable impact on his or her personal freedom. For example, barriers which prevent functioning (understood here as meaningful and purposeful action), or make it difficult for an individual to do what they need or want to do, must be explored. Professionals performing an assessment of disability need to ask what changes might be effective in facilitating the person's participation and inclusion in the space, activities and responsibilities of their surroundings, and then decide if such changes are possible.

Poverty

According to the Office on the Status of Disabled Persons (OSDP), 'the largest concentrations of people with disabilities are in the lowest income-earning households with the lowest educational levels' (OSDP, 2003: 89). Disabled people are especially vulnerable to poverty through alienation from opportunities for work and the generation of income. It is hard to reach consensus about disability statistics because figures tend to be estimates based on incomparable information, but the information indicates that a disproportionate number of disabled people are chronically poor (Yeo, 2001a). Unlike assessment for legal and personal purposes, the assessment of a disabled person and the determination of their eligibility for a social security grant must take the general circumstances of poverty into consideration, as well as environmental difficulties that contribute to the person's experience of disability.

By way of contextualising the predicaments of persons with disabilities, Naidoo asserts that 'mass poverty is a reality in South Africa, and this reality has not receded meaningfully in the past eight years'; that is, since democratisation (Naidoo, 2003). Chronic poverty (of at least five years duration) affects 18–24 per cent of the South African population (*Chronic Poverty Update*, 9.12.2002). People living in poverty are vulnerable to a variety of difficulties and hardships. The bare impact of poverty, thus, may be compounded by associated risks, such as its adverse influence on early child development, increased vulnerability to HIV/AIDS infection (Heywood, 2003), and a heightened risk of exposure to violent crime. Extra costs incurred of necessity by disabled lifestyles may further exacerbate the predicament of poverty.

Destitute people tend, of necessity, to explore a wide variety of means of survival. One course of action may be an application for a social security grant. Aliber (2001, p. 2) asserts that 'the South African government's social security system is by far the largest anti-poverty instrument in the country'. Only very poor people are eligible, and a substantial proportion of disabled South Africans fall into this category (Yeo, 2001b). The competition for grants is a factor that demands careful consideration in the assessment process, requiring assessors to compare relative degrees of economic impoverishment between applicants. Apart from a financial means test, information regarding assets and resources must be collected.

Why assessments are necessary

Assessment for legal and insurance purposes

Various types of insurance products providing protection against loss of employment or loss of the ability to earn a living are available within the insurance industry. All of these require an assessment to be completed before any decisions regarding compensation can be made.[1]

Personal/private insurance – disability benefits

Various types of disability benefit products are on the market, with the scope of a disability evaluation being largely determined by the particular policy requirements, reflecting what the industry terms a 'legal definition' of disability. According to Spavins (2003), insurers assess a disability claim by evaluating the following four categories of information:

- The applicant's personal profile;[1]
- Work related information: job description and information on work experience;
- Disability definitions and rules of the specific fund to which the claimant belongs;
- The applicant's medical condition and its impact on functioning.

Whilst precise disability-clause wording is likely to differ from one insurer to another, disability cover most commonly considers two broad areas. Firstly, the extent and duration of disability, ranging from total to partial; and permanent to temporary. Secondly, the ability to work is assessed in relation to the applicant's ability to perform:

- The particular job he/she was doing immediately prior to becoming disabled;
- His/her own occupation or a similar occupation that the claimant can reasonably be expected to follow, taking into account his/her education, training, experience and knowledge;
- Work of any kind.

Compensation / injury on duty

Employers and employees jointly fund this type of insurance. The Compensation and Occupational Injuries Act, No. 130 of 1993, makes provision for workers who suffer occupational injuries or diseases. The cost of treatment is covered, and in instances where disability prevents a return to work, the monthly pension and associated expenses may also be covered before the final settlement is made. The extent of disability is determined by delegated assessors, commonly medical practitioners, and is based on a disability percentage associated with the degree of impairment (rather than on a comprehensive assessment of functional difficulties). Compensation is calculated according to this disability percentage.

Motor vehicle accidents

Section 3 of the Road Accident Fund Act of 1996 provided for the establishment of the Road Accident Fund, which has as its objective monetary compensation for loss or damage wrongfully caused by the drivers of motor vehicles.

In determining compensation, a relatively complex, multidisciplinary assessment system is utilised to quantify the extent of disability as it relates to:

- General damages (i.e. intangible 'losses', such as pain and suffering, loss of health, disfigurement and loss of amenities and enjoyment of life);
- Medical expenses (i.e. 'reasonable' medical and hospital costs attributed to bodily injury, as well as expenditure reasonably required to remedy or ameliorate a condition – including assistive devices, prostheses, specialised accommodation requirements and transport costs);
- Loss of earnings;
- Loss of earning capacity (i.e. losses related to residual inability to work).

Assessment for social security grants

The South African Constitution (1996) makes provision for the social security of citizens – both adults and children – who are in need of care, or unable to support themselves and their dependants. According to the Social Assistance Act, No.13 of 2004, a disabled person is defined as 'any person who has attained the prescribed age [18 years] and is, owing to his or her physical or mental disability, unfit to obtain, by virtue of any service employment or profession, the means needed to enable him or her to provide for his or her maintenance'. Parents or legal guardians of minors requiring care due to disability may apply for a care-dependency grant, rather than a disability grant. Anybody who applies for a social security grant must undergo an assessment to determine eligibility.

One of the issues requiring attention in the process of assessment for a social security grant is poverty. The grant is intended to provide individuals with the means to disrupt forces which maintain their predicament of chronic impoverishment. Haarmann (2000) evaluated the impact of social assistance on various social, economic and development factors. She found that the support (in terms of both coverage and quality) was so little, and the needs of grant applicants (including disabled people) so various, that grant holders had little hope of ever becoming economically active.

A key question pertains as to whether the purpose of the grant is to provide disposable income to destitute people, or to assist such persons in reaching a position of being able to provide for their own needs. In these two cases, the assessment process would serve quite divergent purposes. In South Africa at present, the care-dependency grant is awarded to eligible individuals under the age of 18 years. The adult disability grant may be awarded on a temporary basis where there is an expectation that the applicant will be able to resume a productive life, or permanently, if no change in the person's functional abilities can be expected. Even in the latter instance, assessment is required both initially and for the purpose of review within a five-year period.

The South African Department of Social Development (DoSD) undertook to formulate and pilot a new social security assessment tool by September 2003 (OSDP, 2003). As part of the process aimed at developing such an instrument, the Department embarked upon an examination of a range of key related concerns, including the following:

- The lack of uniformity of approaches to assessment across the provinces;
- The current poor uptake of the care-dependency grant across South Africa;
- The lack of clarity regarding social grant eligibility criteria (particularly for children);
- The subjective nature of assessment;
- The need for training of assessors;
- The lack of awareness regarding availability of grants in rural areas; and
- Corruption within the administration of grants. (OSDP, 2003)

Prior to the development of the new assessment tool, the Department had implemented a number of changes in the existing assessment procedure. In December 2001, the Social Security Act, No. of 1992, was amended to introduce assessment panels, rather than individual assessors. This change was implemented for a range of reasons. Firstly, grant uptake in rural areas is lower than it is in urban areas. This is probably due to a lack of awareness regarding the availability of support, but also to a shortage of professional people being available to perform assessments. Accordingly, the new model makes provision for assessment panels of six people, including reliable and responsible members of the local community, as well as professionals where possible. The earlier policy of permitting one person to recommend a disability grant, without consultation, fostered corruption in some provinces. Panels, by contrast, operate as a team, and must reach agreement before recommending that a grant be awarded. A further advantage of the panel process is that a panel assessment is able to benefit from the diverse experience and insights of the different professional and community backgrounds of panel members. Arguably, this method offers applicants a fairer and more reliable service. Specifically, the introduction of panels has facilitated participation in the assessment process by professionals other than medical practitioners, thus beginning to redress the prior dominance of medical approaches to the assessment.

At the time of writing, the ever-increasing demand for assessment of grant applications well exceeds the DoSD’s capacity. Applicants are required to endure long delays and waiting lists for appointments with assessment panels. According to the OSDP, the system of administration requires substantial improvement, notably a reduction in the number of steps comprising the overall process (OSDP, 2003).

Principles for assessment

A number of key principles guide the assessment of disability. These are gathered and described in relation to core themes.

Firstly, the applicant’s needs should occupy a position of prime importance in the assessment. Thus, they should be afforded the opportunity to express experiences and opinions before the assessment panel, as well as to pose questions. Correspondingly, panel members should endeavour to gain close insight into the applicant's experiences, their reasons for applying for a grant, and their perception of functional difficulties. Therefore, an awareness of disability issues and an empathic approach are essential qualities for all who have contact with the applicant throughout the assessment process. At the same time, efficient management of the assessment process is a necessity, so that applicants do not suffer as a result of bureaucratic barriers.

It is imperative that the assessment method and process be uniform across all regions. It is recommended that the same systems be applied nationally, embracing the reduction of bureaucratic obstacles and delays that may contribute to the perpetuation of economic marginality and dependency. The principle of uniformity raises the importance of establishing reliability and validity. For a uniform assessment to be reliable, quality control and training is needed both to maintain uniformity and to establish national consistency in disability assessment. These should be both initial and ongoing. Training is required in order to ensure internal and mutual consistency within and between each section of the assessment tool.

Validity ensures conformity and fairness. Content validity requires that items of the tool relate logically to the concept of disability assessment and represent all possible associated domains. Over time, the extent to which the assessment tool carries empirical validity (in terms of quantitative measures) will become increasingly evident. (Note, thus, that the DoSD's assessment tool, completed in October 2003 and discussed earlier in this chapter, has not yet been validated). However, given that disability assessment involves a variety of components and modes of evaluation, it should be noted that demonstrable empirical validity is difficult to achieve.

Regarding access to information about applications and awards, it is crucial that communities be informed about the different types of grants, to whom the grants pertain, and how interested parties can apply. Public education is crucial. The assistance of a local community member well acquainted with the application process (such as a professional, or a disabled person who has applied previously for a grant) may be an extremely useful resource. In the absence of such an individual, alternative support should be found.

Placing the applicant at the centre of the process as well as ensuring that information about their application is available to the applicant, requires co-operation and support between public services. To this end, the needs of applicants will be served best by integration and co-ordination between services such as health, education, labour and social development.

Methodology

Over recent decades, social scientists have undertaken a move away from the (historically) dominant quantitative approach to representing societal processes, and increasingly incorporate qualitative dimensions in data collection and analysis. This accommodation has also found an echo in the assessment of disability. A multi-method approach to data collection offers the advantage of examining a range of related areas comprising the complex shape of disability, from several angles and in various dimensions.

Firstly, it is of central importance to ensure direct involvement of the person being assessed. The aim here is to provide the individual with the opportunity to tell their own story, and furnish subjectively relevant information. The individual's opinions, perceptions and experiences must be elicited and respected if a thorough and accurate picture of his or her life circumstances, attributes and difficulties is to be obtained. Such an exploration is essential, notwithstanding the often severe time constraints under which the work takes place. Much depends in these circumstances on the skill of the interviewer.

Secondly, facts and measurements (i.e. quantitative data) need to be established and recorded. Aspects of the health assessment are an obvious example here (muscle testing to determine the level of a spinal cord injury). However, certain abilities, such as self-care activities, may also be quantitatively evaluated.

Thirdly, data pertaining to the particular living circumstances of the individual must be captured. This data should relate to domestic as well as local environments, support systems, facilities and services available, and prevalent attitudes within the community concerned.

Once assembled, all aspects of the data must be merged to provide a comprehensive and coherent assessment. Multiple methods provide the flexibility required to cover a wide range of problems, while assessing each by the most suitable means (Hulme & Shepherd, 2003).

The assessment panel

Co-operation between public services that requires macro-management needs to be matched with attention to the composition of the assessment team. Members should be selected to complement the knowledge and skills of their colleagues. Team members should be drawn from diverse backgrounds that represent the disability and public sectors, the local community and professional experts. In order for the panel to function effectively, teamwork skills may need to be developed.

In performing the assessment, a number of key areas of information stand out. It is important to note that many of these areas are interdependent. These relate to the applicants:

- Personal details and reasons for applying for a grant;
- Social environment;
- Health status;

- Functioning and participation in a range of activities, and the degree of difficulty that the applicant experiences;
- Productivity history (where productivity refers to the ability to work, meet requirements and apply effort towards the achievement of some outcome, which may not necessarily be a concrete product);
- Available resources;
- The ability to maintain him/herself financially;

If an assessment of a child is required, the first three points would be included, plus an evaluation of the child's need for special care.

The assessment process will uncover information that can be used for the applicant's benefit other than in the grant application. Panels should be familiar with support services and be able to use sector networks. Referral is therefore made if further information is required from an expert (e.g. auditory testing), or if the panel is in a position to recommend resources or interventions to the applicant's benefit (such as schooling, training, assistive devices).

The assessment panel's task is to decide whether or not the applicant qualifies for a grant. Current legislation makes provision for children 'that are severely disabled and permanently at home' (OSDP, 2003, p. 80), but does not provide for children whose needs extend to additional care, or expenses for special medicines, equipment, and so forth. The grant for adults may be awarded if assessment shows that the applicant is unable to provide for their own needs; a further discussion of such eligibility is provided below.

It is an applicant's constitutional right to appeal against an unfavourable grant decision. Should a re-application be made, the assessment process will need to be repeated.

Components of a comprehensive assessment

As mentioned earlier, the ICF (WHO, 2001) provides a new strategy for approaching issues of disability assessment, offering a comprehensive view of interrelated and interacting factors that have an impact on the health, well-being and functioning of people who have a health condition or impairment. These factors are described as influencing people's environmental context, either making their functioning possible, or impeding their free engagement in the world around them and the activities they may wish to pursue. Specially trained people administer the ICF; it is long and therefore costly. Given the issues raised earlier, a tool for use in South Africa needs to be shorter, simpler and adapted for use by a variety of people.

A tool that takes a holistic view of an applicant's abilities and difficulties, and includes different domains for assessment, is strongly recommended. An assessment of a health condition and/or impairment does not define functional abilities, nor is there a correlation between a particular condition and a person's ability to meet their own basic needs. For example, a person with a visual impairment is not (as often assumed) necessarily unable to perform everyday tasks for him/herself. In short, impairment does not equal incapacity. Rather, impairment may lead to exclusion, discrimination and prejudice, and it is these factors which, in turn, may well create very substantial problems regarding full participation in home, work and community life.

As already indicated, there are a number of domains that need to be covered in a comprehensive assessment. While some aspects require distinct measurement variables (e.g. obtained via standard clinical tests), others are of a more descriptive nature (such as social circumstances and the environment). The components of a comprehensive assessment should include the environment, personal details and circumstances, the health condition or impairment, the activities tasks and roles of daily life, and work and work-related activities.

Personal details

Apart from the usual identifying details, information about the applicant and general background information personalises the assessment. This should include a brief summary of major past events, educational history, particular abilities and training, work skills and work history.

Environmental assessment

There are two aspects to an environmental assessment. The first concerns what the assessor knows about the environment, and how these factors might impact on the life of the applicant. This includes the nature of regional, provincial and national structures, policies and resources. The second part covers detail regarding the applicant's immediate living space. This includes the following:

- Facilities present within the living space (e.g. running water; walking-aid if needed), and the other people that share the space, including the impact that they have on the applicant's daily life;
- The nature of the neighbourhood, immediate community and district where the applicant resides (e.g. attitudes of community members towards the applicant, and local resources and services available, such as a training centre for school leavers or a community health centre);

Information from both aspects must be integrated in order to gain an appreciation of the positive and/or negative effect that these environmental factors may have on the applicant's life and functioning.

Health assessment

An assessment of the applicant's health condition and/or impairment is the most familiar aspect of disability assessment, and in some systems still exists as the only requirement for a disability assessment. A medical doctor traditionally performs the assessment, but any health professional competent to complete the necessary requirements could also do this. The assessment procedures for children and adults are different because of the prevalent conditions at different ages. What is required includes:

- A diagnosis of the primary and any associated conditions, a description of any problems and a prognosis for the primary and any other conditions;
- A description of management of the health condition/impairment (e.g. medication or surgery, including the person's response), as well as the level of co-operation with treatment;
- A record of where treatment was given and any future management required, as well as referral for further special investigations, testing or treatment if this is considered necessary.

The emphasis in this section of the assessment is not on the 'medical facts' alone, but rather on a description of the severity of the health problem (prognosis, complications, complexity of management) and on the anticipated duration (temporary or permanent) of the condition.

Assessment of activities and functioning

An assessment of activities and functioning includes the well-known assessment of the activities of daily living, including basic and instrumental activities (that is, within the immediate and broader environments). Crucial to this assessment is noting what the applicant needs or wants to do, things that make performance easier or more difficult, and the degree of difficulty that the person experiences in performing these activities. If a child is being assessed, all activities will be related to the appropriate age and stage of the child's development.

Questioning should be structured according to the social roles which the applicant fills, in terms of the activities which these roles inform. Examples of social roles include that of a mother, embodying all of the tasks of child care, from feeding and dressing, to bathing and soothing. Also of note is how much help the applicant may need, and any associated costs (for example, the need for a lifting hoist, or adapted transport).

Productivity assessment

Considering productivity and work-related activities, most disability assessment procedures set out to establish if an adult can work and support him/herself. Open labour-market employment has been seen as the benchmark with regard to competition, wages, skills, job standards and labour practices. This does not, however, exclude consideration of other means of earning an income, such as informal work, self-employment, or protective and sheltered work situations.

The South African context requires a somewhat different approach. Given high levels of unemployment and the established link between disabled people and the historical lack of access to training and job opportunities, a consideration of paid employment only, is insufficient and inappropriate. It is necessary to think more broadly about what people do to survive, and what their associated skills and abilities are. Consider, for example, a woman who supports her family in a remote rural area where no formal work is available, or a man in an urban area who receives food and shelter in exchange for odd jobs.

To make the distinction between different people's ways of providing for their everyday needs, four categories were created. These are set out and described in Table 18.1. Each category requires certain knowledge, skills and abilities, and would be assessed accordingly. The list of requirements provided is not exhaustive, but is intended to give an indication of what reasonable expectations around productivity might be.

Conducting assessments

It is important that assessors know *how* to assess applicants. Obviously, the outcome of an assessment will differ depending on its purpose (e.g. personal insurance or social-grant application), as well as the age of the applicant. But the assessor's knowledge of the environment (which may need to be acquired for this purpose) is also important to consider the extent to which it creates barriers and limitations beyond the applicant's control. A key question is whether the applicant is further disabled as a result, and if so, whether this can be reversed or not.

In line with the principle of placing the applicant at the centre of the assessment process, the person being assessed should have the opportunity to tell their story. Apart from the insight that this can offer, it is also a good way of confirming certain information supplied from other sources and to fill in gaps. For example, one way of capturing the essence of a person's story is to record actual words spoken, if these are particularly striking.

It is common practice to assess problems of bodily function, structure or impairments according to a rating scale for the purpose of compensation assessments (e.g. absolute deafness = 100 per cent loss of hearing capacity). 'The "percentage" in this scale represents judgments of value, rather than any precise statement of functionality or capacity' (Spiker, 2003, p. 32). The preferred approach for all purposes is presented above. This method provides much more useful information in a way that makes it possible to evaluate this aspect of the assessment together with all others.

Table 18.1: Categories of productivity

Category	Requirement	What needs to be assessed
Work: open labour market employment	• Engaged by an organisation or individual and receiving regular payment (hourly, daily, weekly or monthly); • Job governed by some controlling body or authority; • Pre-determined wages/salary are negotiated, and, depending on skills level, additional benefits may be offered; • Written contract; • Varied job descriptions: levels of training, complexity, responsibility and job demands; for example, physical or sedentary, skills levels (e.g. semi-skilled); • Regular working hours (e.g. 8 working hours per day or 40 hours per week shift work of up to 12 hours, day or night).	• Personal independence in self-care mobility, use of public or private transport; • Adequate communication and social skills; • Appropriate behaviour; • Endurance and stability of health condition; • Quality and quantity of work & work speed; • Basic work abilities, for example, work habits; • Work capacity and skills level; • Insight into own abilities and appropriate job choices; • Job seeking abilities.
Self-employment	• Working for own account, either in the formal or informal labour market; • May employ others; • May work on a contract basis; • Usually a provisional tax payer, depending on income; • Offers a service or skill;	As above plus: • Business skills; • Knowledge of suppliers and services; • Support systems; • Entrepreneurial flair; • Experience; • Marketable service/product or skill; • Available funding; • Self-discipline; • Perseverance.
Work-related activities	• Self-initiated activities that provide a product which can be used or traded to meet the basic necessities of life; • These activities may be done alone, or with others who share the same purpose for example, growing vegetables, caring for animals, doing chores in exchange for something needed (e.g. clothing access to water food etc.).	Some of the above plus: • Self-motivation; • A positive attitude; • Satisfaction from being productive; • Ability to serve and/or take instructions; • Self-safety; • Social, communication and networking skills.
Protected/ sheltered employment	• Organised workshop under the auspices of a controlling body (e.g. Mental Health Society Department of Labour); • Employment offered by a sympathetic employer, who provides reduced job requirements (e.g. type of work, working hours, productivity); • Token remuneration; • Workers assisted and supervised and work may be adapted to match worker abilities.	• Personal independence transport may be provided; • Need for supervision/assistance; • Physical or mental impairment and/ or a chronic health condition; • Manual skills; • At least 50–70 per cent productivity; • Eligibility for a disability grant if not yet receiving one.

In order to avoid unnecessary wasting of time, as well as expense and inconvenience, a person with a known health condition ought to be able to carry a record of any previous health assessment they have undergone so that they do not have to undergo the same sort of examination repeatedly.

While the purpose of each assessment makes the method required clear, the issue of referral for services that would assist an individual in functioning more independently, remains a central outcome (e.g. use of assistive or adaptive equipment, or special services that may improve functional status). At each stage of the assessment process, therefore, the assessor must ask whether there are any alternatives that would benefit this person, and if so, what they are, and how they can be realised.

Having completed the different aspects of the assessment, it remains for the information to be collated and integrated. An assessment of disability is complex, always unique and typically taxing for the assessor, who must think carefully about a range of information sets, many of which are mutually influential. There is no quick and simple method of performing the task, and no summative or formulaic process that will provide a reliable and valid answer. Unfortunately, when an assessment is done there is usually insufficient time for reflection. Experience therefore often plays an important part. It is essential that assessors be afforded the opportunity to learn over time and through repeated exposure. Given the method and components for assessment suggested here, applicants will receive a fair, complete and helpful (if not necessarily favourable) result.

Notes

1 Throughout this chapter the person being assessed has been referred to as an applicant; the term 'client' may be preferred.

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Section V
Disability and service provision

19 Physically disabled women and discrimination in reproductive health care: psychoanalytic reflections

Victoria Nokwanele Mgwili and Brian Watermeyer

Introduction

This chapter aims to begin a critical discussion regarding discriminatory attitudes and practices surrounding the reproductive rights of persons with impairments in South Africa. Making use of interview data gathered from physically disabled women, experiences of disablist attitudes surrounding sexuality and reproduction within state reproductive-health clinics were examined. Within a critical psychoanalytic framework, the possible intra-psychic underpinnings of forms of discrimination were considered in an attempt to illuminate the – often unconscious – motives behind observed responses. It should be noted, for readers not acquainted with a critical psychoanalytic approach to interrogating disablism (e.g. Marks, 1999), that in Chapter 4, of this volume, Brian Watermeyer provides an introduction to this framework.

Background

Victoria Mgwili (VM) is the chairperson of the Disabled Women's Development Programme within Disabled People South Africa (DPSA). The Women's Programme is located in the Eastern Cape province of South Africa. Over the course of many conversations during meetings of the organisation, it became apparent that physically disabled women were enduring experiences of discrimination at local reproductive-health clinics within state hospitals. Consequently, VM decided to formalise this anecdotal data by documenting interview evidence of the women's experiences as health-care consumers within these clinics. According to Section 27(1)(a) of the South African Constitution (1996), every citizen has the right of access to adequate health care services, including reproductive health care. As shall become evident from the experiences of the women who participated in this small study, these constitutional prescriptions are not being met.

Data was gathered regarding the experiences of disabled women in three types of physical settings within the reproductive health system – that is, family planning clinics, antenatal clinics, and delivery rooms. For each of these settings, responses of health-care staff is described, followed by a concise, critical analysis and interpretation of the personal and ideological disablist underpinnings which may be at play. Thereafter, a brief discussion will attempt to extract broader trends from the data. In interrogating the experiential data, VM, a nurse with extensive professional experience in settings very similar to those under scrutiny, has drawn on her personal knowledge in speculating on likely organisational dynamics perpetuating the observed treatment of disabled clients. She has also drawn on her experience as a user of the reproductive health service.

It should be noted that the data drawn upon in this study in no way represents an adequate or scientifically randomised sample of the experiences of physically disabled women across South Africa. Rather, the intention is to provide a snapshot of some of the dynamics that emerge between health-care professionals and disabled women in these settings, in order, essentially, to motivate and inform a more systematic research programme. It should be clear from the evidence already recorded here that reproductive-health settings are a site of struggle for disabled women attempting to reclaim basic rights to human dignity, appropriate health care, and the definitive voice in decisions regarding their own bodies.

The analysis of some of the responses of clinic staff members to disabled women is interpretive and tentative. Without the insights which would be garnered by an opportunity to question clinic staff individually, regarding the underpinnings of their actions, the interpretation presented here, analytically and experientially informed as it is, can only be preliminary. As such, we wish to acknowledge that at times the picture may be a somewhat caricatured or skewed one, due to methodological limitations. However, it is important to bear in mind that the presentation of a complete picture of disablist discourses in reproductive health care is neither possible nor our intention. Rather, our aim here is to highlight the pressing issues with a view to motivating for their further investigation.

Family planning clinics

The setting

Family planning clinics (FPCs) are settings which function primarily as a dispensary for various forms of contraception, including oral and injected contraceptives, and contraceptive loops. Before a service user is given contraceptives, a thorough medical examination is performed, including an examination of the reproductive organs. This examination includes a cervical smear to test for cervical cancer or the presence of abnormal cells. During this procedure, a woman lies on her back, with legs raised and supported by poles and stirrups. The same position is used for the insertion of a contraceptive loop.

Responses to physically disabled users

Amongst the disabled women interviewed, the experience of being treated as asexual was a familiar one, applying in a number of life contexts, including FPCs. The tacit message received was one of the women being positioned as somehow not part of, or privy to, the 'normal' human experience of desiring and deserving intimate and fulfilling sexual contact. This assumption was evident in a range of comments, both direct and indirect, passed by clinic staff members. A class of these comments communicated various feelings of surprise or confusion at the women's very presence at the clinics. That is, the tacit or overt question posed by staff members was 'why are you here?' or 'what could you possibly need from us?', as it was assumed that the women were sexually inactive. An associated assumption, communicated casually, was that a disabled woman seeking contraception must be afraid that she may be raped.

Interestingly, these assumptions regarding disabled women being sexually inactive were mixed at times with invasive, even hostile, questions surrounding their relationships. Incredulous questions like 'do you have a boyfriend?' may be understood as relating to unconscious resonances surrounding a form of punitive disentitlement projected onto the service user. What may be at play here is the experience of needing to construct the disabled women as incapable of, or excluded from, relationships, in a manner which affirms the 'in-group identity' of staff members in this domain. In other words, this hostility may in fact reflect an 'acting out' of undeserving feelings within the staff member, involving hostility directed at parts of herself which resonate with the image of physical disability.

The oppression and punishment of disabled people in a myriad of ways across our society may be (partially) understood as a compromising alternative to punishing ourselves for our own, internal 'disabled' parts. A punitive response thus emerges from the health-care professional, directed at the disabled woman before her, which may express her own need to identify herself as deserving, as included, in opposition to the 'damaged' and 'shameful' person before her (for more on this, see Hollway, 1996; Wendell, 1996). Clearly evident is a distinct discomfort with disabled people 'not fitting in' with stereotyped assumptions held regarding 'their' nature and place. An ironic paradox is present here. While simultaneously expressing an awkward difficulty in engaging with the (assumed) experience of disabled women, staff members also powerfully position the women within these meanings.

The subtle hostility described above was also reflected in the experience many women had of feeling like 'an imposition' or 'a problem' at the clinics. Due to physical impairment, it was difficult or impossible for some women to assume the usual position for examination. In these instances, women were confronted with questions such as 'now…how am I going to examine you?' These and similar utterances left women feeling as though they were expected to 'make up for' or ‘apologise for’ their bodies. Thus, the message that ‘this is not a place for you’ was recapitulated in many ways.

It should be noted, in terms of this and many other types of problematic response described by the service users, that staff members at the clinics are likely to have had little exposure to emancipatory, inclusive or critical social ideas surrounding disability. It is likely that during their training, disability was framed as a medical condition requiring a medical ‘cure’ (see White, 1995: 267). A consequent difficulty may arise when an impairment viewed as a medical condition does not have the possibility of cure, rendering an experience of helplessness or impotence within the health-care worker. Such a subjective situation is extremely well suited to the emergence of internal, personal and often problematic emotional responses to disability, which have the power to skew and disrupt the potential for open and equitable admission of the patient’s voice into the consulting relationship (see, for example, Good & Delvecchio-Good, 1980; Kleinman 1986,1987).

Marks describes what she terms the ‘curative zeal’ of biomedicine; an approach which prizes cure above all else, and consequently equips professionals in a manner which leads to difference being constructed as a form of medical failure (Marks, 1999a). Similarly, Sinason (1992) writes of how professionals may ‘shut their eyes and go stupid’ when confronted with disability, ‘not just because it is painful, but because it is unbearable to see damage and not be able to repair it, not be able to put it right’ (Sinason, 1992, p. 58). She continues: ‘health-care is pursued with such moral zeal that ill health and disability become difficult to integrate within conceptions of community and humanity’ (Sinason, 1992, p. 78).

In light of the foregoing, it is our position that to simplistically blame or vilify health professionals for the inequitable treatment of disabled people would be both unfair and illogical. Disablist ideology has a particular significance and impact within the medical establishment, due to disability having been historically situated as a medical responsibility. But such ideology is not, by any means, peculiar to mainstream medicine. Rather, it is a society-wide phenomenon, which resides in, and is perpetuated by, all of us – disabled and nondisabled alike. Health-care professionals who have never been given the opportunity to explore and interrogate their own assumptions and fears surrounding disability cannot be expected to consistently respond in a manner which deals equitably and calmly with what is, in fact, the unknown.

All who are familiar with Disability Studies will probably acknowledge the extraordinary shift in perceptions which occurs as one begins to grasp the immense and far-reaching implications of the social model of disability. Individuals who have not had the opportunity to engage with an emancipatory model of disability typically remain in the individualising mode of thinking, which all or most of us have internalised all of our lives. Besides being allocated the unreasonable – and often misapplied – responsibility for supplying cures, health-care workers are, perhaps ironically, as much products of disablist segregation as any other members of society. It is thus the structures of medical training which, primarily, require our attention in terms of accountability and redress of the status quo described in this chapter.

A number of respondents reported having witnessed, or received anecdotal evidence of, parents of intellectually disabled girls or young women being urged by staff members to bring their daughters to the clinics for contraceptive treatment. This phenomenon was well known to VM. In some accounts, these conversations were held in the presence of the daughter concerned. The prejudicial assumptions surrounding intellectual impairment are multiple here, ranging from infantilising ideas regarding sexual decision-making capacity, to the dangerous and unethical assumption that an intellectually impaired woman necessarily cannot understand the nature of a conversation held about her sexuality. Given the high prevalence of sexual abuse and rape amongst intellectually impaired persons in South Africa, concern and awareness regarding these issues is necessary and fully justified. However, such concern must be operationalised within a mode of clinical practice which foregrounds transparency, dignity and the right to individual freedom.

The spectre of fearful fantasies surrounding intellectually impaired persons and sexuality (see Sinason, 1992) is evident here in the marked resistance to exploring the individual experience of sexuality of intellectually impaired women, as the FPC staff members would explore the sexuality of any other service user. One intellectually impaired woman who had undergone this experience of discrimination commented that it left her feeling falsely accused of promiscuity, whilst simultaneously conveying to her the message that any form of sexual contact she may have would, by definition, be somehow illicit. As in the case of the physically disabled women, the message surrounding sexuality here can seemingly be pared down to ‘it’s not for you’.

Antenatal clinics

The setting

At the antenatal clinics (ANCs), pregnant women are examined in order to ensure that each mother is physically well, and that her baby is in a good position for the delivery. A further, more complex examination may also be performed in order to establish whether the woman is physically able to give birth without surgical or instrumental assistance. For this procedure, the woman is expected to assume the same position as for a cervical smear.

Responses to physically disabled service users

At ANCs, forms of discrimination were experienced similar to those described in the FPCs. Respondents apprehended a mixture of confusion, disapproval, surprise and intrusiveness from staff members at the fact that they had become pregnant, and were about to give birth to a child. In the words of VM, ‘a disabled woman is not meant to become pregnant, as she is not expected to make love to a man’. The respondent continues:

> Immediately after becoming disabled I started to put on weight. Because of this, some people assumed that I had become pregnant. One service provider asked me whether I was pregnant, and I said ‘no’. She said, in a joking tone, ‘I was going to inform the police, because the man that can make you pregnant needs to be arrested’.

One respondent related how, upon seeing her in the antenatal room, a staff member commented in passing that ‘men have low morals’. Seemingly, the implication here was either that the woman had been raped, or, yet more disturbing, that a man would have to be of low moral fibre to engage in sexual activity with her. It was the latter interpretation which seemed most plausible to her. A stereotype associated with this asexual, or dys-sexual, view of disabled women, was the idea that physically disabled people live with constant pain. This, in the minds of some staff members, fitted with the idea of the ‘low morals’ of men who would engage in sex with physically disabled women, who were regarded as too frail or vulnerable to withstand or manage – let alone enjoy – sexual contact.

The body position prescribed for examinations performed in the ANCs are typically very difficult – and often inappropriate – for women with impairments of the lower body or legs. Alternative, medically appropriate positions are possible, but seemingly were often not utilised – an analogue of the broad principle seemingly at work here, in which it is the impaired person who is required to ‘accommodate’ to the system, rather than the health-care system being held responsible for the provision of an appropriate service (Sinason, 1992: 75). The simple, inverting lens of the social model radically alters this construction of needs and responsibilities (see Abberley, 1996; Lunt & Thornton, 1994; Stone, 1999). It was at these times, too, that questions such as ‘how am I going to examine you?’ tended to arise. The humiliation of being required to assume a posture which is extremely difficult, even impossible, and perhaps painful, led some respondents to consider ceasing attendance at the ANCs. Of course, this state of affairs presents the very real risk that antenatal complications may arise and remain undiagnosed and untreated.

Delivery rooms

The setting

As the name implies, the delivery room is where woman give birth to their babies, under the care of health-care professionals. During labour, several examinations of the cervix are performed. For giving birth, the same physical position is assumed as for the cervical smear.

Responses to physically disabled users

VM narrates the story of a close friend's delivery room experience:

> One Sunday afternoon I received a phone call from my friend who has paraplegia. She was nine months pregnant – the time when the baby is full term and ready for birth. She told me that she felt severe pains around her waist and the way she was describing the frequency of pain convinced me that she was in labour. She was also worried by the fact that it was Sunday and not a working day. I told her to go straight to the hospital. She called me after having her baby and told me what had happened…She had arrived at the nearest hospital labour ward and told the midwife that she was feeling severe pains around her waist. The midwife seemed to acknowledge her pain, but then left the room, and did not return for some time. After a long while, and a lot of distress and uncertainty, she was transferred from her wheelchair to the examination table. Various staff members then asked her intrusive questions, such as 'how are you going to give birth?' and 'how are you going to hold your baby?' This was very traumatic for her, especially at this time. She needed support, like any other woman giving birth would. There were also a lot of indirect comments and insinuations which left her feeling very unsafe and exposed. She was then left alone for a second, extended time. The labour pains were becoming severe, and her anxiety continued to get higher. In desperation, she decided to phone her parents and tell them what was going on. They came and took her to another hospital, where she was examined. The labour was advancing. She was taken to the operating theatre and a caesarean section was performed. She had a baby girl, who is now three years old. My friend has vowed not to have another child because of the traumatic experience she had. She feels that both herself and her baby were at great risk because of the negligence and discrimination of service providers in that hospital.

Of course, it is unclear whether the staff negligence experienced by this woman was necessarily related to her impairment. State health-care services in most parts of South Africa are inadequately resourced, creating a situation in which many health-care professionals work under extreme stress and inordinately high patient loads. Yet, the impact of this story lies in the manner in which discriminatory and denigrating responses imbue the experience of that inadequate resourcing with a personal malignancy.

The experience of childbirth is often a highly anxiety-provoking one, besides being extremely physically and emotionally challenging. Women in these circumstances require an environment which is both supportive and (subjectively) trustworthy. What this woman was met with was an experience of her personal dignity and legitimacy as a mother being threatened and compromised, even in the midst of this difficult and vulnerable time. The meaning of the experience of being left alone within the context of these communications, may have been especially hurtful.

A subtle punitive element is identified in the questions staff members directed at her; questions which dispute both her right and her ability to bear and raise a child. Again, one may interpret these messages in terms of an unconscious need to dissociate and disidentify oneself from persons culturally identified as the custodians of damage and inability (Shakespeare, 1994) – in this case, inability and illegitimacy in the realm of sexuality and reproduction. By constructing this woman as not entitled to, or capable of, child-rearing, staff members may be reaffirming their identities as entitled and adequate in these domains, whilst simultaneously managing feelings of helplessness in the face of 'incurable difference'. Questions such as 'how are you going to hold your baby?' may be (unconsciously) aimed at finding reassuring confirmations of the 'defectiveness' of the impaired woman, such that she remains available as an object for the disowning and projection of unwanted characteristics. Furthermore, successfully attributing blame for whatever difficulties arise in the service delivery to the user and her impairment may provide staff members with the means to exculpate themselves from an anxiety-provoking sense of responsibility.

As noted earlier, the lack of training of most health-care professionals in emancipatory, socially critical models of disability is centrally relevant here. In addition, it is a truism that, in times when one is confronted with an anxiety-provoking unknown, such as that experienced by staff dealing with a disabled service user, there is reassurance in establishing any sense of knowing who and what one is dealing with. Put another way, it may be easier to decide what the experience, capabilities and difficulties of the disabled women are in advance, rather than remaining in the anxious, uncertain position of seeing and feeling something anxiety-provoking, but not knowing what it means. Thus, stereotypes may be understood, at times, as procuring a sense of control in the observer – control in the face of the tentativeness and threat of what Goffman termed 'sticky interactions' between 'normals' and 'the stigmatised' (Goffman, 1963).

Discussion

Implicit throughout the material is evidence of physically impaired women in these health-care settings being used, in psychoanalytic terms, as 'receptacles' for the unmanaged feelings of staff members (Marks, 1999a). Manifestly, this is present in the form of subtle and overt blaming experienced by the service users. In a variety of ways, users felt that it was communicated to them that any problems they had with the services provided, were due to some lacking or defect within themselves (see Barnes, 1990).

During this process, individual staff members, as well as the reproductive health system as a whole, may be understood as defining themselves – or itself – in opposition to the disabled Other, who carries 'the burden of difference, the excess, the surplus that will not fit' (Burman, 1996, p. 138). The message, received by disabled users, was that the service was shaped around, and identified with, nondisabled users, and a nondisabled identity. It was clear that some of the overt or subtle denigration was believed, or accepted, by some of the respondents. These service users spoke of how the familiarity of the messages meant that it was that much more difficult not to be affected or destabilised by them. They described having waged internal battles surrounding the legitimacy of their bodies, their motherhood and themselves, which left them vulnerable to the attacks experienced in the reproductive clinics. The words of Mason aptly describe the predicament the women spoke of:

> Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self images and low expectations, turning them into weapons with which we re-injure ourselves every day of our lives. (Mason, cited in Marks, 1999, p. 24)

Managing anxieties regarding one's sexual attractiveness is never easy. These concerns are universal, and arise within all of us, especially during those times of our lives when we have experiences that leave us feeling inadequate, unloved or unwanted. Denigrating messages regarding bodily impairment can evoke and enliven in disabled people those parts of internal experience. In other words, whilst we all carry these uncertainties, disablist ideology selectively directs attention to such fears in the lives of persons with impairments. Relentless negative messages regarding one's legitimacy and adequacy as a participant in the social interchange surrounding sexuality would, over time, provide increasing momentum to the capacity for self-denigration we all have.

Common amongst the respondents was an experience of sexual relationships being short-lived. This was attributed to the impact of perceptions such as those demonstrated by the clinic staff, which served to maintain suspicions regarding the motives of men, thus often disrupting the potential for stable relationships. In addition, disabled women whose experience of reproductive health services at the clinics had been traumatic, demonstrated a tendency to stay away from the services, in a manner which supported, confirmed and compounded a sense of exclusion from sexual relating. The personal and ideological impact of the discriminatory messages which the respondents received at the clinics thus stretched some way beyond the practicalities of basic assistance in reproductive health.

Along with blame, a common overarching response received by the disabled women was pity, expressed in a variety of forms. All women using the service are in need of care – however, the expression of pity, based on the observer's fantasies and assumptions about life with an impairment, positions disabled women very differently in relation to the need for, and access to, care. As noted by French (1993), our human need for care – our mutual dependence – is an ubiquitous part of our lives. However, disablist ideology selectively (yet arbitrarily) positions some dependencies or needs as illegitimate. Pity and blame expressed at the sight of impaired bodies in the reproductive clinics may serve to position disabled women outside of the realm of 'normal' entitlement to care. Instead, the needs of these women are positioned as 'additional', as 'special', ushering in a discourse related more to charity and altruism than to universal citizenship rights.

Psychoanalytic thinkers such as Jacques Lacan associate pity with disavowed aggressive or sadistic impulses. The experiencing or expression of pity by staff members upon first contact with a physically disabled service user necessarily involves the projection of personal feelings evoked by disability. In other words, if one feels pity for an individual one has never previously met, then, logically, the assumptions underpinning and justifying that pity must come from oneself. In short, positioning another as worthy of pity always involves making quite substantial assumptions regarding their experience of the world and the self. Where do these originate?

In psychoanalytic terms, this pity may be understood as a form of reaction formation; that is, an unconscious strategy of 'going to the other extreme' in order to manage difficult feelings evoked by disability. If, as Shakespeare (1994) suggests, disabled people do function as the psychic 'dustbins' of our societies, it is logical that we, as observers, would feel fear, distaste or even revulsion for visibly disabled people. Such feelings relate, in Shakespeare's words, to our struggle with being reminded of parts of our own human experience of which we are ashamed. Pity may arise as a defensive inversion of this revulsion, or need to dissociate ourselves, as these aggressive feelings – especially when directed at persons culturally constructed as vulnerable – are likely to be experienced by ourselves as unacceptable. Lacan, though, goes substantially further. He would suggest that the conscious pity commonly felt in response to images of disability is, in fact, an inversion of quite primitive murderous impulses. Disabled people may resonate with parts of ourselves of which we are so ashamed, that we would rather that those parts – and the disabled people who bring them to our consciousness – would simply cease to exist. Policies of eugenic extermination of disabled people, and the extensive and long-standing phenomenon of the involuntary sterilisation of intellectually disabled persons, may be dramatically, and disturbingly, illuminated by these ideas (see, for example, Sinason, 1992).

Touching closely on this phenomenon, many respondents described having been urged by reproductive health-care professionals to choose sterilisation as a means of contraception. At a conscious, manifest level, the reason provided for this recommendation relates to an assumption that physically disabled women will not be able to care adequately for a child, and still less adequately for more than one child. However, in VM's experience and opinion, a more important latent motivation underpins this position. The emotional difficulties, anxiety and awkwardness experienced by staff in dealing with disabled women, she believes, renders a wish to eradicate their presence at the clinics. Simultaneously, this would symbolically mean the eradication of all that the women represent, and call to mind, about the internal lives of the health professionals dealing with them.

Marks would understand the moderation of this basic impulse – of wanting disabled women out of sight – into the more acceptable idea of recommending sterilisation as 'what these women need', as an example of the defence of rationalisation. In the case of rationalisation, guilt-evoking impulses of unconscious origin are managed through the construction of conscious, coherent justifications for the actions they inform (Marks, 1999). In this case, then, it may simply be more comfortable to frame the exclusion within the legitimacy of medical terms, than to acknowledge discomfort of a more personal origin. Needless to say, the fact that in the current ideological milieu surrounding disability, it is felt to be acceptable and reasonable to advise physically disabled women to be sterilised, on the assumption that adequate child care will not be possible, is in itself disturbing, and worthy of interrogation.

Conclusion

The domain of sexuality and reproduction, in the lives of persons with impairments, is a site of oppression which attacks the most fundamental of human and personal rights. To be shown, overtly or insidiously, that the society seeks to prevent one's reproducing – to prevent one's self from some form of continued expression and existence – is to have one's very legitimacy as a human citizen assaulted. As asserted by Sinason (1992) in her landmark work surrounding the unconscious meanings of intellectual impairment, to be told that one should not reproduce, is to be told that one's own existence is invalidated.

The experiences of the women in this small study certainly were that of being told that they did not have a place – a place in the reproductive health system, a place in the realm of sex and sexual reproduction, or a place in the world. We have sought to begin to suggest some possible underpinnings for the ubiquitous and robust nature of this type of discriminatory response to the sexuality of persons with impairments in settings such as those explored above, but the need for more systematic investigation is clear. What is striking, quite simply, is the degree to which staff members in the study, although working at a reproductive health setting, were not ready to engage with the sexuality of physically disabled women. Instead, an anxiously fervent, denying, invalidating, critical, patronising, pitying or shaming set of responses was in evidence, underscoring an experience, within the users, of their participation in reproduction being regarded as illegitimate.

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20 Community-based rehabilitation: new challenges

Sarah Rule, Theresa Lorenzo and Milani Wolmarans

Introduction

Community-based rehabilitation (CBR) has been piloted in different parts of rural and urban South Africa since the 1980s. This chapter reports on the implementation of CBR within two contexts in South Africa – in Pietermaritzburg by the CBR Education and Training for Empowerment (CREATE) programme and in Mpumalanga, a CBR partnership programme between Disabled People South Africa (DPSA) and the provincial Department of Health.

The chapter explores:

- Different ways of implementing CBR as a strategy for community development, including rehabilitation, equalisation of opportunities and social integration;
- Two approaches to development of grassroots workers, namely community rehabilitation facilitators (CRFs) and CBR consultants;
- The challenges facing CBR based on the use of mid-level workers and the challenges faced in developing the CBR programme in Mpumalanga, as well as the framework used and the implementation of the CBR partnership programme.

The chapter provides an initial section on the background to CBR, followed by the two case studies. Specific issues highlighted are: the importance of intersectoral collaboration; the nature of grassroots workers; the nature of partnership between Disabled People South Africa (DPSA) and government departments; integration with other formal development and rehabilitation programmes; and the need for monitoring and evaluation of programmes.

CBR developments

In the late 1980s, a number of disabled people and therapists in South Africa became interested in finding an alternative to traditional or conventional rehabilitation services. Traditional rehabilitation services were provided in hospitals, mostly in urban areas, and focused on the deficits of the person with a disability. This medical-model approach to rehabilitation, failed to meet the needs of many disabled South Africans in terms of availability, and appropriateness. As Werner writes:

> conventional rehabilitation tries to change or normalise disabled persons to fit into society as it exists, rather than trying to change society so that it accepts and accommodates to a wider range of human differences. (Werner, 1993, p. viii)

CBR was an alternative that brought the issues of the participation of disabled people, community development and social integration to the fore. Internationally, CBR projects had been initiated in various countries by the early 1980s. In South Africa, three pilot training programmes were set up for CBR workers in the early 1990s. One training project was started in Khayelitsha, Cape Town, at SACLA clinic, another at Tintswalo Hospital, Acornhoek, under the auspices of the University of Witwatersrand, and the third at the Alexandra Health Centre in Alexandra township, Johannesburg.

International context

CBR has been implemented in many different ways throughout the world. The World Health Organization (WHO) published a manual to train local supervisors and family members of disabled people to become involved with CBR (Helander, et al., 1989). The WHO model of CBR has placed a strong emphasis on medical rehabilitation. The International Labour Organisation (ILO) has placed more emphasis on vocational rehabilitation and community integration. In 1994, the ILO, the United Nations Education, Scientific and Cultural Organisation (UNESCO) and WHO came together and drew up a joint position paper on CBR based on their similarities of approach. Their joint paper defines CBR as:

> a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of people with disabilities. It is achieved through the combined efforts of people with disabilities, their families, and communities and the appropriate health, education, vocational and social services. (ILO, UNESCO, WHO, 1994, p. 1)

This definition of CBR, now widely accepted in South Africa, advocates a broader concept of rehabilitation, wider than purely medical rehabilitation. By incorporating social integration, the equalisation of opportunities and community development into the definition of CBR, the three UN organisations indicate an approach to CBR that is more in line with the social model of disability. In addition, the participation of disabled people and their families is seen as an integral part of CBR, rather than an optional extra, as often happens in conventional rehabilitation.

In spite of the support for this definition of CBR, Disabled Peoples International (2003) argue that CBR is still medically oriented in some regions and, in some cases, disabled people's ideas and concerns are not given equal weight to those of professionals. Lang (1999) concurs and indicates that many CBR projects are managed without much input from disabled people or local people. Miles

(1996) points out that in a number of cases there has been a divide between CBR programmes and disabled people's organisations (DPOs) and that some CBR workers have dismissed the value of working with the disability rights movement.

According to Miles (1996), the goal of CBR programmes should be to empower disabled people to control their own lives and play a key role in services for themselves. An international review of CBR in 2003 indicated that there has indeed been a marked shift in emphasis in CBR programmes towards the empowerment of disabled people (WHO, 2003). The definition of CBR has been reviewed to shift the focus to the equalisation of opportunities, poverty reduction and social inclusion of disabled people (WHO, 2003). The question of ownership of CBR programmes by disabled people's organisations (DPOs) has received more attention and is receiving more serious deliberation. The promotion of disabled people's rights is seen together with the promotion of their responsibilities to contribute maximally. The dissemination of information as a resource has been highlighted. The concept of interdependence of the different stakeholders and DPOs to achieve the goals of CBR programmes is gaining more recognition, though more research that focuses on the nature of local resources and participation in CBR programmes is needed (Finkelflugel, 2004). With the shift from focusing on individual need to seeing disability as a universal right and part of community development, research is beginning to show how CBR is making a difference in significant ways. More people have started to participate and gain access to resources. Coleridge (2004) encourages us to keep faith and hope alive.

Internationally, there is a range of options in terms of personnel to carry out and run CBR programmes. A number of CBR projects use the WHO model in which local supervisors (who may or may not be volunteers) work with family members of the person with a disability (Jaffer & Jaffer, 1994; Valdez & Mitchell, 1999). A number of other projects use volunteers who are given several weeks of training and become grassroots CBR workers (Thorburn, 1994). In some countries, including South Africa, mid-level rehabilitation workers may be employed in CBR programmes. There are also likely to be managers of CBR programmes who may come from a variety of professional or other backgrounds. Depending on the project, some personnel may be disabled people or family members of disabled people.

Case study 1: implementing CBR through mid-level workers in South Africa

One of the pilot CBR training programmes in South Africa was set up in 1990 at Alexandra Health Centre by the Institute of Urban Primary Health-Care (IUPHC). The IUPHC training programme trained mid-level CBR workers, known as community rehabilitation facilitators (CRFs), in community development as well as social and physical rehabilitation, for two years. The CBR projects that developed around the country using CRFs thus represent a model of CBR that uses mid-level CBR workers who are employed to provide services that include community development, physical rehabilitation, social integration and the equalisation of opportunities.

The CBR training, started at Alexandra, was then continued in Pietermaritzburg by CBR Education and Training for Empowerment (CREATE). The training consists of modules that integrate skills in community development and aspects of physiotherapy, occupational therapy, speech therapy and social work. This multi-skilling of CRFs has played a crucial role in offering an integrated service to disabled people and their communities. CRFs are encouraged to bring disability issues into any development projects in their areas and to work with disabled people to overcome negative attitudes and other barriers to inclusion. The CBR training programme enables CRFs to work individually with children or adults with disabilities to improve their ability to function independently. CRFs are also taught to set up and work with support groups, and to work with disabled people's organisations if they exist.

Since 1990, approximately a quarter of all trained CRFs have been disabled people or family members of disabled people. Although the IUPHC and subsequently CREATE have recommended that students selected for the course should have experience of disability, many of the organisations that send students to the course do not adhere to this recommendation. In CBR projects where the CRF is disabled, we have noticed that there is greater commitment from the CRF to the project. Disabled CRFs also often have greater empathy with their clients. Greater ownership of the CBR project by disabled people is also possible when a local disabled person is chosen and trained as a CRF. In the Drakensberg area of KwaZulu-Natal, all the CRFs are disabled and the CBR programme has been monitored by a local organisation that includes disabled people. Three of the CRFs worked for several years as volunteers before becoming employed to do CBR. This is quite remarkable, given the usually high turnover of volunteers in CBR projects (Crishna, 1999).

Since the mid- to late-1990s, CRFs have been able to register with the Occupational Therapy Board of the Health Professions Council of South Africa. This has enabled CRFs to be employed in posts as therapy assistants within the Department of Health. However, this also means that the Occupational Therapy Board has to accredit the CBR training, and when the policies of the Occupational Therapy Board change, this affects the CBR training. Currently, the CBR course run by CREATE in Pietermaritzburg is accredited until the end of 2006. At this point, the changing policy of the Occupational Therapy Board dictates that, if it is to be accredited, CREATE will have to train occupational therapy technicians rather than CRFs. Eighty per cent of the course will need to be concerned with occupational therapy knowledge and skills while only 10 per cent of the course will be allowed to focus on community development, and another 10 per cent will focus on skills from physiotherapy and speech therapy. In essence, the very nature of the CBR course would have to change. This illustrates the danger that can befall CBR and CBR training if it becomes too focused on one sector (in this case, health). As the ILO, UNESCO, WHO (1994) definition suggests, CBR should at least be involved with health, education, welfare and labour sectors.

The model of CBR based on the employment of mid-level CBR workers (CRFs and community rehabilitation workers) has meant that communities and disabled people receive services broader than therapy alone. Another achievement of this model has been that over 100 disadvantaged urban and rural communities now receive rehabilitation and disability services through the employment of CRFs and community rehabilitation workers (the latter trained in Bushbuckridge). Many of these disadvantaged communities now have active DPOs or support groups where none existed previously. In these communities, the CRFs work with the support groups or DPOs, although, as in other international CBR programmes, there may not be full ownership and participation by disabled people. Two examples follow to illustrate what CBR can be like if implemented with the help of CRFs.

One of the concerns of CBR is the equalisation of opportunities for disabled people. In a small town and rural area in KwaZulu-Natal, the CRF decided to tackle the difficulties that disabled people experienced with public transport. In particular, it wanted wheelchair users to have equal access to taxis. At that time the local taxi association had a practice of charging double fares for wheelchair users. The CRF ran a disability awareness workshop with the taxi owners. The taxi owners then requested that similar workshops be run for the taxi drivers. The CRF, together with her supervisor, ran these workshops. The result of these workshops was a change in attitude by the taxi association, and consequently, they stopped the practice of charging double for wheelchair users. In addition, at the time of Yellow Ribbon Day, the taxi association made nine taxis available free of charge to transport disabled people from the rural areas to an event in Pietermaritzburg. The intervention of the CRF with regard to public transport in this area has had an impact on the equalisation of various opportunities for disabled people. Not only do disabled people now have equal access to public transport, they also now have easier access to health care, potential employment and other services offered in the town.

The ILO, UNESCO, WHO definition of CBR (1994) states that CBR is part of community development. Community development encompasses many activities that may uplift a community. A CRF working in a peri-urban area near Durban has been involved in a water and sanitation project in his community. The *nkosi* (chief) of the area approached the CRF and requested his involvement in a project to bring running water and sanitation to the homesteads of this area. The CRF participated in the meeting between the *nkosi* and the local eThekwini municipality and was able to advise the municipality of what adaptations would need to be made to meet the needs of disabled people. At the request of the municipality, the CRF was then involved in a project to map all the homesteads of disabled people where adaptations would need to be made to the planned water and sanitation system. Now, those disabled people who have needed it, have had toilets installed with ramps and the water tanks are supplied with taps and a locking mechanism that are at a suitable height for wheelchair users.

The involvement of a CRF in this water and sanitation project is a good illustration of what can be achieved when CBR is implemented in a comprehensive way. Community development no longer only benefits nondisabled people; disabled people are also beneficiaries of any development. In this example, CBR is so much more than rehabilitation or therapy at a community level. Yet in the current set-up, CRFs are the only employed grouping that would provide such services. As illustrated in this case study, CBR should not be restricted to rehabilitation or therapy, as it can reach so many more people through the emphasis on community development.

Where there is a focus on the removal of barriers experienced by disabled people in a CBR project, social action may result. One CBR student studying at CREATE formed a CBR committee in his community to oversee and guide the implementation of CBR. The committee was made up of disabled people, the CRFs, a youth representative and representatives from local non-government organisations. The local councillor was invited to join the committee, but he did not attend any of the meetings. One of the first priorities identified by the CBR committee was the removal of barriers to community participation experienced by disabled people. The barriers the committee identified included a lack of sign-language interpreters at community services, negative attitudes of community members and the councillor, and physical barriers such as steps. The committee decided that it would be appropriate to hold a march of disabled people who would present a memorandum of their demands to the local councillor. The march would make disabled people visible in the community and hopefully this would help to change attitudes. The march took place on a Saturday between the community hall and the local taxi rank. Representatives of the municipality did not arrive, but the memorandum was read out to all those present. Community members and taxi drivers listened as disabled people and some of their family members spoke to the gathering about their experiences of disability and the barriers they encounter in that community. The memorandum was later delivered to the municipality. This event not only served to make the community aware of disability, it also encouraged and empowered disabled people to speak for themselves.

Social integration of disabled people is another key component of CBR, as defined by ILO, UNESCO, WHO (1994) and WHO (2003). Social integration can happen in a number of ways and CRFs have approached this aspect of their work from an individual and family level, as well as from a community level. One CRF working with a disabled person in a wheelchair in Gauteng recognised that the disabled man was socially isolated and found that one of the causes of this isolation was that there was no ramp at his front door. The CRF discussed the need for a ramp with the man's family. On her next visit, the CRF found that the family had built a ramp at the front door and they had improved access at the gate. The disabled man was not at home, as he had gone to visit his friends!

Another CRF approached social integration from a different angle. She had heard that at a local church disabled people were being made to sit behind the door of the church during services because they were 'sinners'. A disabled person herself, she approached the priest and discussed the rights of disabled people. Although it was difficult to change the priest's ideas, her intervention meant disabled people were then allowed to join the rest of the congregation in the main section of the church. In the same area, at another church, the priest himself was disabled. Many members of this congregation were refusing to take communion from this priest because of his disability. Again the CRF was involved in raising awareness of disability, this time with members of the congregation. The outcome of this work was that the congregation became more accepting of their priest.

These examples illustrate that CBR is certainly more than a health concern, although in South Africa it is generally the Department of Health in different provinces or health-related non-government organisations that have taken CBR on board. Most CRFs incorporate aspects of social services (such as helping disabled people access disability grants) in their work, as well as health-related activities and sometimes working with education authorities.

This intersectoral nature of CBR is also illustrated in the work of one CRF employed at a special school in KwaZulu-Natal. The 2001 Education Department's White Paper 6: *Building an Inclusive Education and Training System* (EWP6), sets out government's strategy for making the education system responsive to and inclusive of learners who experience barriers to learning (which includes disabled learners). One part of the strategy is to identify and include youth and children who are out of school. The national Department of Education piloted a study of the implementation of EWP6 and inclusive education. One of the research sites of this pilot study was a special school that already employed a CRF. The CRF became involved with the pilot project, specifically with identifying and locating youth and children who were out of school. She managed to find a number of these children and youth in the area, and through the pilot project, some of these learners were placed at schools. The national Department of Education commended this research site as being the most effective of all the sites of the pilot project in finding out-of-school youth and children. In addition to this work, the CRF is also involved in activities with staff from the district Department of Health. She works with therapists to bring rehabilitation to children in a local day-care centre for severely disabled children. This CRF has also worked with a group of disabled adults who started an income-generating project. If the CRF was to restrict her work to one sector only, for example education, her service to the community would be incomplete and would probably not meet the needs of disabled people in the area.

This case study illustrates that CBR is multifaceted and cannot be reduced purely to rehabilitation. The equalisation of opportunities and social integration of disabled people are equally important aspects of CBR and are promoted by CRFs. Although not all CRFs are involved in projects and activities such as those mentioned above, the studies illustrate what is possible when a CRF is included in the implementation of CBR.

Case study 2: the Mpumalanga CBR Disability Support Programme

Most debates about CBR have contributed little to the empowerment of disabled adults and parents of disabled children, and this is a matter of great concern. Since 1998, the Mpumalanga Department of Health has had a formal service partnership with two provincial DPOs for the delivery of CBR, of which one is an agreement with DPSA Mpumalanga for the implementation of community-based disability-support services.[1]

The majority of the disabled children and adults living in Mpumalanga Province live in conditions of abject poverty and isolation. Rehabilitation professionals have found it very difficult to provide effective rehabilitation services, including community support services, due to the wide gap between professionals and disabled people. This gap is due to low literacy and empowerment levels among people with disabilities and cultural and language barriers. At the same time, however, DPOs strive to give their membership the greatest possible measure of social and economic participation and independence, irrespective of the nature and origin of their impairment.

In 1994, the Mpumalanga Department of Health's rehabilitation services were limited to 4 out of 27 provincial hospitals. These services reached about 500 people per annum out of a total of 3.1 million people in the province. However, there were numerous CBR activities through the efforts of DPOs in the province. All of these activities were community-initiated. Thus, the challenge for the Rehabilitation Programme of the Mpumalanga Provincial Department of Health was how to build on what was already there. Services in the province needed to be developed to make them accessible to everyone, but the challenge lay in how to develop these services. It was recognised that there was a need to develop a plan of action involving all stakeholders.

The process of developing a model

Certain principles underpinned the framework used to develop CBR as an appropriate model of service provision in Mpumalanga. The process took two years of negotiation (1996–1997) to reach agreement on the model for implementation.

The first component focused on the need to establish meaningful and equal partnerships between all stakeholders. Regular meetings created a space for debate and dialogue so as to reach consensus and mutual understanding about the definitions of disability and the meaning of CBR, as well as to build trust within the partnership. It was important to develop an understanding of disability as a human rights and development issue, and link that with rehabilitation services. In this way, the partnership was achieved.

The process also enabled a review of current practice and an appreciation of the strengths of the model and aspects that should be changed. Arising from this was a common understanding of service delivery, and a package of required services was developed. The CBR Disability Support Service was designed to provide disabled people with the tools of self-empowerment. The programme's long-term objective is to facilitate social re-integration, development and poverty alleviation of and for disabled people, which corresponds to the key outputs of the Provincial Rehabilitation Programme of the Mpumalanga Department of Health. Addressing disability issues requires the active participation of disabled people themselves. It was imperative that the outcomes of interventions should be empowerment-orientated. The programme was initially piloted in 1998, with DPSA as the service provider.

Principles for service delivery

Implementation followed principles identified by the stakeholders. Disabled people would participate equally in decision-making and not just as passive recipients of services. Services would be based on needs identified by people with disabilities themselves. Family involvement formed a key aspect of the rehabilitation process. As such, partnerships between the client, their family and rehabilitation personnel formed the basis of rehabilitation service delivery. Peer support is seen as a central part of the rehabilitation programme and the development of peer counselling services receives priority. Rehabilitation services should be provided as close to home as possible.

Implementation

The implementation takes place through disabled people contracted by DPSA to render the following services at community level: the identification of disabled people; the provision of information about their rights and available services to disabled people; peer support and counselling as well as family counselling; raising awareness on disability rights in order to reduce discriminatory attitudes; and referring disabled people to relevant health, rehabilitation, education, social and employment services.

The CBR consultants sign an annual performance agreement with, and are accountable to, DPSA through their community-based organisations or self-help groups. They are paid on an hourly rate based on performance. Initial training focuses on disability rights, government service-delivery mechanisms and systems, basic counselling and communication skills and advocacy and awareness. Follow-up training is needs based. The pilot project was implemented in Ehlanzeni District, then known as the lowveld region, as rehabilitation services in general were under-developed in the rest of the province. DPSA's administrative capacity at the time was also weak. The results of the pilot were overwhelming, with over 400 people with disabilities accessing the service in a six-month period. In 1999, CBR, implemented in partnership with disabled people, became part of formal rehabilitation service delivery, but was still only implemented in the lowveld region to ensure sustainability. The project was extended to all 17 municipalities on 1 November 2000.

Some successes to date

The programme provides support to DPOs, while identification and referral of adults and children with impairments to relevant services increased. Dissemination of information relating to disability was made a priority, and disabled consultants were trained in peer counselling as well as facilitating access to assistive devices in order to enhance social rehabilitation and integration.

- Thirty-one unemployed activists with different disabilities were contracted as CBR consultants. They have been trained by DPSA Mpumalanga to render a service in all 17 municipalities in Mpumalanga.
- More than 35 000 people with disabilities and their families were reached between 1997 and 2004. They have been provided with information about their rights and disability services. People with disabilities have been referred to different social services and as a result disabled people have had access to assistive devices such as wheelchairs and hearing aids (many for the first time). Also, children are going to school and are receiving formal rehabilitation services for the first time;
- A wide network including district education authorities, welfare authorities, paralegal advice centres, non-government organisations and the South African Human Rights Commission has been established with the aim of improving access to opportunities for people with disabilities.
- People with disabilities now have access to peer support and information whilst still in hospital immediately after the onset of disability – this directly impacts on the success of formal rehabilitation services

- Community-based organisations of disabled people are experiencing a tremendous growth as a result of the increased advocacy within communities.
- People with disabilities are accessing appropriate HIV/AIDS information for the first time.

More specifically, from 2003 to 2004, the successes of the Mpumalanga CBR Disability Support Programme include:

- 12 061 new clients with disabilities were identified and received information on services and available opportunities for people with disabilities.
- 29 unemployed disabled activists with different disabilities, including parents of disabled children, were contracted as CBR consultants for the implementation of services. Economically, this has liberated them from abject poverty, as they all earn between R 1 500–R 2500 per month.
- A total of 9192 clients were referred to therapy and orthotic prosthetic services provided at public hospitals, community health centres and clinics, and to local schools and special schools via the education district office, pension officers and social workers, and home affairs officials.
- An estimated 53 children with disabilities that were outside the education system as a result of the programme have accessed education for the first time.
- An estimated 882 people with disabilities accessed assistive devices that enabled them to move around more freely, leave their homes, participate in community activities, look for jobs, and communicate more easily.
- Nine new self-help groups of disabled people have been established as a direct result of the CBR Project.
- Three CBR consultants and a provincial administrator accessed permanent employment through their involvement with the project.

To date, the programme has had a direct impact on the quality of life of people with disabilities, and contributes significantly to the accessibility of services, especially in rural areas. It costs only R125 per individual, per annum to access the service.

The programme forms a vital component in maximising the impact of community service therapists, as it ensures sustainability and continuity of services within an identified community-based knowledge system.

The CBR project has significantly contributed to the expansion of formal rehabilitation services. There are a total of 120 rehabilitation professionals working in the province with formal rehabilitation services in 24 of the 27 provincial hospitals, and monthly outreach rehabilitation to 154 clinics and community health centres and to 109 pension pay points.

Key lessons learnt from the Mpumalanga programme

The programme managers and stakeholders have identified various issues arising from reflecting on and monitoring the programme on a continuous basis.

Partnership

One of the key challenges was to understand and work out answers to the question, 'what does an equal partnership with disabled people really mean?' It is crucial to understand that building partnerships is an ongoing process, not a once-off activity, we have to keep on committing ourselves to this as people come and go. This might sound obvious today with the benefit of all the knowledge developed and accumulated over the past seven years. Yet it is my firm belief that it is as difficult today, if not more so, as it was nine years ago, to really commit ourselves to meaningful and equal partnerships that are devoid of suspicion, paternalism, pretence, anger and rubber-stamping.

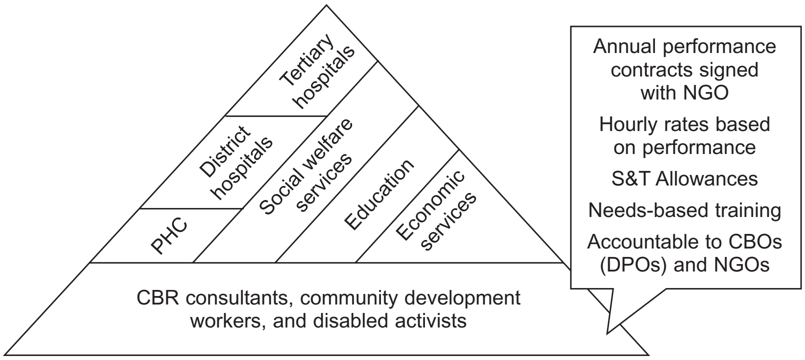
Professionals and DPOs in Mpumalanga had to learn by listening to one another. A fundamental principle underlying our partnership is the principle of consensus building – it is a relationship of give-and-take between the different stakeholders involved. The *Integrated National Disability Strategy* (ODP, 1997) provided indicators of successful partnerships, noting that they require the full participation of DPOs and parents' organisations, and the recognition that DPOs play a key role in CBR.

There was a need to recognise that rehabilitation is a means to an end, and not an end in itself. Therefore, there is a critical need for rehabilitation personnel to link with other disability services and programmes (for example, around education, social services, employment, housing, transport, etc.).

There was a need to distinguish between different levels of service and to identify a clear role for each – namely, CBR, outreach services (understood to comprise services rendered by professionals based at centres outside the community, for example, hospitals and clinics), and hospital-based services.

It is recognised that there is currently a gap in terms of specialised services for people with disabilities. CBR provides the framework and philosophy of the rehabilitation package. We have learned together the importance of localising the model – to start small and learn together in partnership. Expansion then follows rapidly.

Figure 20.1: CBR partnership programme: an implementation model



Intersectoral collaboration

For the CBR programme to be successful, it has to have formal links with the Departments of Education, Social Services, Health, Labour and Housing as shown in Figure 20.1. It also needs to have formal links with programmes focusing on economic empowerment of people with disabilities. In reality, effective interdepartmental co-operation and planning of service delivery at provincial, district and community level is minimal and is a major challenge in the implementation of the programme. Over the years, some intersectoral collaboration has been achieved at a community level, although this is happening on an ad hoc basis and not within formalised systems. One of the reasons for this could be the lack of an intersectoral policy framework and therefore no intersectoral budgeting for activities of this nature.

Disability-specific focus

Sometimes people ask why there is a need for services to specifically focus on disabled people. Disability is a complex multi-faceted issue. There are numerous opportunities for disabled people, but few people are able to access them as a result of attitudinal, physical and communication barriers. There is a need to facilitate the process whereby disabled people can access resources and services to which they are entitled. This programme helps to bring people up to the 'starting line', as previously they have been disadvantaged, and so they are starting at a level that is below that of other people. There is a need to create opportunities for disabled people to be providers of services, not always being only recipients of services. Lastly, CBR consultants become disability resource persons, and this contributes to community development in the areas where they work. Access to enabling services for disabled people opens up participation opportunities for people with disabilities to contribute meaningfully to community development processes.

Integration

One of the factors contributing to the success of the CBR programme is that it has been integrated into the formal rehabilitation programme of the Mpumalanga provincial Department of Health. The CBR disability support programme is integrated into the rehabilitation referral network, thus enabling identified people with disabilities to access appropriate formal rehabilitation services. However, it is important to localise the model as well as to harness resources in the community. The overall co-ordinator of rehabilitation services has an excellent grasp of how to work with the political structures and different levels of government.

The role of the Office on the Status of Disabled People

This case study would not be complete without giving recognition to the important role of the Office on the Status of Disabled People (OSDP) in the Office of the provincial Premier. The OSDP has been a major force in promoting a perspective of disability as a human right and development issue as well as bringing together stakeholders.

Being able to use the OSDP as a sounding board and support structure, as well as being part of broader disability equity processes through the OSDP, enabled the rehabilitation programme to develop a broad vision and context within which to work, adapt, negotiate and advocate for more enabling and sustainable rehabilitation services and partnerships. It has therefore also served as a tool to reassure us in challenging times and to give us the energy to remain focused and persevere.

'Nothing about us without us'

In concluding this case study, the joy and fulfilment of working with children and adults with disabilities lies in the slogan of DPSA and Disabled Children's Action Group: 'Nothing about us without us'. Seeing people who previously were downtrodden, depressed and unable to assert themselves suddenly have the courage and skills to challenge bad practices in government services and non-government institutions should not threaten us. Rather, it should give us courage to go on, as we are achieving the ultimate aim of CBR – empowering people to take control over their own lives.

The Mpumalanga CBR programme has shown that real partnerships with communities are essential for sustainable socio-economic development. Also that affirmation of disabled people contributes to them playing active and leading roles in society.

Priority challenges for the way forward for CBR in South Africa

The work in Mpumalanga and KwaZulu-Natal illustrates the value of CBR together with the need for consensus-building on the future of CBR within the South African context. The liveliness of the debates amongst the three authors in the writing of this chapter was evidence of what is needed on a larger scale. The key challenges faced by stakeholders and practitioners in implementing CBR in South Africa have been debated in an attempt to identify priorities for the way forward (Philpott, 2004).

There is a need to broaden our understanding of disability. A broader understanding must recognise rehabilitation as an enabling process to promote poverty alleviation, community participation, economic empowerment and development, and survival of people with disabilities. Is the concept of independent living relevant in a South African, or indeed any social context? Conflict between the different stakeholders involved in CBR needs to be channelled constructively into developing new knowledge related to effective strategies for implementation, and the training of future service providers. The *Integrated National Disability Strategy* (ODP, 1997) and *National Rehabilitation Policy* (DoH, 2000) need to develop implementation mechanisms that could contribute to growing a common understanding of CBR as a strategy in community development to alleviate poverty. In this way, sustainability of CBR initiatives would be fostered.

In a number of situations the implementers of CBR programmes have to account for their work in terms of health-related activities, rather than considering the broad outcomes of CBR, including equalisation of opportunities and social inclusion. For this reason, a challenge facing South Africa is to gain a broader understanding of the outcomes of CBR. A key challenge lies in the principle of recognising rehabilitation as a means to an end and not as an end in itself. As a strategy within community development, CBR could contribute to the service delivery agendas of different government departments such as primary health care, inclusive education, social development and poverty alleviation. There is a need for the development of an interdepartmental policy framework for CBR with clear mandates and role clarification for different stakeholders. The plan would include a budgeting framework that would allow for contributions from all stakeholders. It is important that CBR programmes build alliances and facilitate collaboration among a wide range of stakeholders.

The challenge facing people involved in CBR is to bring the issue of CBR to the provincial and local levels of government and to encourage support and resources from the various government departments that could be involved. There is a need for strong formal partnerships (an underlying principle of CBR) between DPOs and professionals employed by government or non-government organisations. This challenge extends to those involved in CBR to form closer ties with DPOs. Cornielje (1993) and Miles (1996) write about urban based CBR projects in Alexandra township in Johannesburg and Amaoti informal settlement in KwaZulu-Natal that have been closely linked with DPOs. Another challenge lies in recognising the role that DPOs play in the implementation of CBR. In a number of cases the formation of community-based DPOs are the result of CBR projects that empower and motivate disabled people to come together. However, it is necessary that the contribution these initiatives make to the outcomes of CBR be formally recognised. The challenge, therefore, lies in including DPOs in the accountability chain and governance of CBR programmes. At a district and provincial level CBR will benefit from close partnerships with DPSA and other DPOs. If CBR projects become accountable to disability organisations and not only to the employer, this will enable CBR to be implemented with and not for disabled people. In situations where disabled people become CRFs or CBR consultants, the disability sector has a direct stake in CBR.

The need to develop an accredited training for mid-level workers in order that they can be registered and employed in South Africa remains a contentious issue. With the impending change in the accreditation of mid-level CBR training by the Occupational Therapy Board of the Health Professions Council of South Africa, it is important to evaluate what skills personnel working in CBR need. The proposed change in course outline is likely to produce Occupational Therapy Technicians who have a health bias and who do not have in-depth community development understanding and skills. Personnel trained on such a course are likely to focus on rehabilitation, with less consideration for equal opportunities and social integration.

Increased collaboration between professional therapists, mid-level workers, CBR consultants and stakeholder sectors has yet to be achieved throughout the different provinces. Institutions of higher education involved in training health-care professionals and social workers bear responsibility for ensuring that these challenges are addressed in the curriculum. The challenge is to locate the training of CRFs within a community development framework. The Department of Public Service and Administration and the Department of Provincial and Local Government are in the process of training community development worker cadres through a learnership programme which will implement community development programmes. The challenge for existing CBR programmes is where and how the interface with these programmes will happen.

There is ample evidence of the urgency to raise the profile of CBR in South Africa. This can be achieved by increasing awareness of the value of CBR at national, provincial, district and local government levels, but requires documentation and publishing of CBR programmes in South Africa. Many stakeholders and donor agencies have voiced concern related to the lack of published documentation and research in South Africa. Such publications could present evidence of the value and impact of CBR in particular communities. It seems the time has come to revive networks such as the Rural Action Group on Disability, which was very active prior to the 1994 democratic elections in South Africa. Such a structure is needed to advocate and lobby nationally, provincially and at local government level for changed attitudes towards, and a better understanding of, CBR.

Delegates involved in international consultations on CBR need to give feedback to the grassroots structures such as DPOs and community development and health forums, higher education institutions and centres. To establish a system to continually monitor and evaluate CBR and the training of practitioners and grassroots workers at different levels of governance, is to ensure continuity along the continuum of service delivery. Linked to such a structure is the need to establish funding channels. The revival of CBR networks and gatherings to discuss the value and impact of CBR in South Africa would provide a means to co-ordinate information on CBR, together with the benefits of identifying a CBR research agenda.

The two case studies in Mpumalanga and KwaZulu-Natal demonstrate the challenges involved in ensuring these projects are sustainable, as well as showing the urgency of integrating different approaches into policies, alongside rigorous monitoring and evaluation. The two approaches complement each other to provide the means to disseminate information and the means for early intervention with sustained follow-up and development. The vision of equal opportunities, poverty reduction and social inclusion of disabled people and their families can then become a reality!

Note

1 This case study is adapted from a paper presented by Milani Wolmarans, Rehabilitation Programme Manager in the Department of Health, Mpumalanga, at the CBR workshop held at Valley Trust, 28 June 2004.

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21 Psychiatric disability and social change: an insider perspective

Siyabulela K and Madeleine Duncan

Introduction

This chapter provides an insider perspective on psychiatric disability, a perspective which is central to the national objective of improving the quality of life of all citizens and accessing the potential of every person, including those marginalised and excluded from full participation in society (cf. Makgoba, 1999). The project of South African nation building requires that the voices of all people need to be heard. People with psychiatric disabilities face numerous environmental, access, legal, institutional and attitudinal barriers in obtaining equal opportunities for the advancement of their human potential. As other chapters in this book show, initiatives around social change in South Africa must address the human and economic costs associated with the stigmatisation of disabled people (including those with psychiatric disability) and their families.

What are the perspectives of persons living with enduring mental health problems on our society's objectives for social change? The purpose of this chapter is to experiment in developing alternative approaches to promoting awareness around psychiatric disability issues. Our respective contributions to this chapter are clearly distinguished in the acknowledgement that we have different contributions to offer. Siyabulela K's[1] contribution describes the difficulties, challenges, strategies and triumphs he experiences negotiating life with a psychiatric disability in Cape Town. His experience is not the story of all psychiatrically disabled people, not even some. Inevitably themes will recur, as they do across whatever cleavages one uses to distinguish some kinds of people from others, but Siyabulela's experience is not held up as 'typical', or even emblematic; it is simply and uniquely his own.

But as important as the emphasis on ownership is here, so too is it necessary to be alert to the problems of appropriation that so often distort and undermine collaborations between nondisabled academics and 'their' disabled informants. Conscious of academia's privileged position as the producer of knowledge about 'Others', the collaboration in this chapter is an experimental attempt to weaken, if not restructure, that power dynamic. Conventionally, the most scientifically acceptable way for disabled people and professionals to 'collaborate' in qualitative research is for the former to become research data or for their 'voices' to be represented in themes and corresponding quotes. Irrespective of the so-called 'trustworthiness' of the themes and quotes, the power still lies with the professional to decide what will and will not be published and how data will be presented. This dynamic raises important questions: is the researcher exploiting the research subject even though they are a voluntary participant? Can a 'research subject' also be an author? How may a book on disability and social change create spaces for ordinary people, especially those who are marginalised, not only by their health condition, but also by poverty, poor education and historical oppression, to participate equally in the project? As the academic professional in this collaboration, I (Madeleine) grappled with the problem of how we (academics) produce a book about disability and social change that actually demonstrates exactly what it means to be inclusive and committed to equal opportunities when it is quite possible that 'they'– the 'disabled' – don't write as 'fancy' or 'scientific' as we do, or possibly, as is the case with this collaboration, don't use English as their first language.

At the base of this dilemma is the question: how do academic professionals give expression to values of inclusion and equal opportunities while simultaneously insisting on retaining ownership and control of academic paradigms and methodologies, the criteria and assessment of 'academic rigour' as a condition of participation, and the production and dissemination of research and 'findings'? There are no easy answers and the questions multiply, but a crucial part of this debate must address who it is academics imagine their audience is. For if that audience includes non-academics – as it surely must, if our work hopes to contribute toward the improvement of society – then academics need to come down from the rarefied and reified air of the academy. Such a climb down, as it were, involves a willingness to break with the hegemony of scientific convention and professional prejudice.

These are big questions and beyond the scope of this chapter. But it is the backdrop and the context of this collaboration between a non-academic psychiatrically disabled person and a nondisabled academic professional. While the chapter is an experiment in a particular kind of collaboration, it emerges from a larger research project into the dynamic relationships between psychiatric disability, chronic poverty and occupation. Understanding more about the ordinary things that people with mental illness and their households do everyday and the way they expend their time, energy, interests and skills in meeting their needs under circumstances of chronic poverty, will shed further light on the costs of disability and the potential of disabled people.

The chapter begins with Siyabulela's reflections on living with mental health problems. It is a verbatim transcript of a written journal he kept over a period of a month. Because of the difficulties of his impairment and English not being his first language, he requested questions or headings to use as triggers for journalling. These have been retained in the text to provide context. Thereafter follows Madeleine's more general comments and reflections on psychiatric disability in South Africa. Finally, a concluding discussion ends the chapter.

Siyabulela has a ten-year history of mental health problems. He first became ill during his matric year, but persevered with his studies to successfully complete a Bachelor of Technology degree. He has not been able to secure employment due to repeated relapses and a lack of opportunities for supported employment. He survives through creative use of a disability grant and collaborative efforts by members of his household to make ends meet. Siyabulela shares a house with eight people in an informal settlement in the Cape metropole. Madeleine is a mental health professional with more than 30 years of experience as an occupational therapist. She is interested in negotiations of power in the interpretive research process as well as in exchanges between mental-health service users and service providers, especially where gender, race and cultural differences exist (Cohn & Lyons, 2003; Swartz, 1998).

> *My mental illness is about…..*
>
> Becoming so lonely, worried, anxious, being upset and being uncertain about the future. I also think that it is that time in your life when you became unconfident and unsure of yourself. It is that time when you forget how to look after yourself and not being in control of your life, for example, forgetting to comb your hair, forgetting to wash as if you are instructed to kill somebody or forgetting to zip your trousers or being not totally sure of whether you look perfect or imperfect. Sometimes you see someone wiping his/her mouth and you also do likewise.
>
> I also think it is about that time in your life when you mistrust some of your relatives which I think may be caused by living apart. You don't realise that they are doing the best to take care of you, but to you, you think about them killing yourself. I also think it is about you thinking the worst about yourself or your family or relatives like what could cause death which result to you having constant headaches. It is about being impatient to wait for a long period of time in queues when seconds became minutes, minutes turn into hours and hours turn into days. Every time the end of the treatment taking (medication) comes you start experiencing problems concerning your health.
>
> I also think that it is that time in your life when you don't trust your judgement and when you don't love yourself like before. Where you always need an approval from an elder person with necessary experience. It is also about being high or as if you're miscarried. It is when you feel inertia especially towards the coming of the weekend. You feel powerless or weak at that time and not prepared to start something new as it can lead to regret later, especially if you can't succeed in doing it perfectly. I can't keep my relationship well with people I already know except new faces. I do experience difficulties with being a coward as according to Proverbs there are many traps for a coward and other cultures/beliefs believe that you die many times than your actual death if you are a coward. I think that it is difficult to stay real because I feel less better when I consider how far others have progressed and much is expected of me in the household as a person with

the highest standard who is supposed to make more difference at my home and I cannot because of my illness.

Reasons for mental illness

Most people's mental illness is caused by growing up under too much hardship and failure to keep promises by people you trust too much. I also think was the cause was a long history of hunger and poverty which the family has. Other mental illnesses are caused by constant use of drugs which can change the way you view life and people around you. I think for others it is caused by high divorce rate which leave children being lost with not enough guidance from the single parent as a result of separation from the other parent. If we live with mother we are going to miss father as our role model/father figure as it is believed that girls grow towards the direction of their mother and boys towards the direction of a father and girls answerable to their mother and boys answerable to their father vice-versa.

Some people think it was caused by over concentration in studies for my matric when I was always giving too much attention to school work. I think it could be partly the cause because I am a person who is not clever but who is a hard worker. I can end up that way but not totally that way as I have learnt from the Technikon that we under-use our thinking capacity as the researchers believe that we are using only 10 per cent of our brain. Another cause of this illness may be the genetic reasons from the elders to children as also my father was suffering from mental illness long ago and misusing of money and alcohol. Some people believe that this is caused by me not being active or giving attention and interest in relationships and sex life. They believe that if you are not active in sex life, sperms block your backbone which could lead to brain damage.

Being hospitalised

I was very sad and not knowing exactly what to expect as it was the first time for me to be a patient. I was afraid of being left alone by the people who escorted me. I was afraid of other patients who were violent and became very afraid to get lost in the hospital which is big as…Hospital [emergency psychiatric admissions ward at a general hospital] and I was better relieved when I was sent to…Hospital [psychiatric institution] as it is not that complicated, unlike the one before. I was unhappy most of the time as a person who likes staying at home, so I became home-sick even when I was still a student. I could not concentrate better while studying in the library which means maybe finding work at home would be better.

Health professionals and clinic staff

They were very considerate and helpful. They were doing the best they can to help us, to see to it that we all eat before being given treatment, to see to it that from time to time our hospital clothes are washed and we keep on changing them. They tried the best they can to see to it that everyday we get a bath. They also made sure that we eat better kind of food which could assist in us getting well sooner and ensure that in between main meals we get bread and tea and also ensure that all those who smoke are given few cigarettes to smoke, which is good as without it the patients who smoke cannot think properly. They made sure that sometimes we are given time to be on the playing field to help ourselves get fit and to prevent stiffness which may be caused by taking treatment or injection. What I also liked was the way they allowed visitors to come and see their relatives in private rooms for enough time. What I didn't like was only one thing of our parcels which our relatives leave them to be given to us getting lost without reaching us. For example my relatives left towels, underwear, comb and a Vaseline which I didn't receive.

Advice to helpers

They should keep on doing the good job that they are doing and try by all means to work hand-in-hand with traditional healers and Christians in finding the common solutions to these diseases and always remember that for every effort and time wasted, there is a reward in return. Therefore even if they are underpaid, God will bless them especially for their care, kindness, dedication and commitment to their work, and it will be their favour if with all these illnesses, it is a test they will overcome.

Taking medication

The medication makes me to feel better and also makes me to think straight and easy. It made me to sleep at night as a person who can take more than an hour before falling asleep. It also made me to be able to cope at school as two years after I returned to school and managed to pass which means that it was the right combination of tablets. Later it made me to become stiff and to sweat a lot. The medication also made me to become drowsy especially if I take many kinds of tablets during the day. Sometimes it make me to be always tired and needing rest. Sometimes it makes me to become constipated and more hungry and lose control of myself especially if I miss a meal time. It also sometimes makes me feel black, become sick and tired quickly.

Impact of culture

According to our culture, they believe that living in hunger and poverty could lead to revolting, being uncontent and being rebellious against one another due to hardship with no-one taking a stand for each other and also defying authority. I think mental illness it could lead to more bad things and misfortunes in your life, living without doing your customs and traditions. The doing of customs and traditions could make me much better with enough recognition and without any doubt about myself. According to our culture we are encouraged to have a better hope for tomorrow as they say if it was bad yesterday, it may be good tomorrow. In every cloud there is a silver lining. There is a light at the end of the tunnel. If the road is up, it could be going down the other side and we are also given hope that all is created for other things not to be in abundance as that could level or mean more death to us.

Being poor

Being poor affects me because I cannot always get what I need at the time I want it but somehow it helps as it forces us to prioritise. Start with important things first and end with those least important. It is a little better since the Rand regained strength and by Government taking a watchful eye on prices as before you can't afford to buy anything else other than food with my Disability Grant which is much better than before.

It does affect me because I cannot be able to go back to my home to see my father (other parent) who is in Transkei. It affects me because I cannot afford to do what I am supposed to do concerning customs and traditions which according to our culture would mean not being given the right recognition and which could affect the kind of man I will be/I will become as it is believed that without doing traditions you can have bad luck and ancestors would guard or protect you as they will not get to knowing you well as a member of the family. Poverty stops us from doing all the necessary customs and traditions for us all in the family. We have a back-log in customs and traditions. I also hope to pay back my NSFAS Loan.

Poverty has also caused almost all family members to care and be more considerate to one another. It has caused us to face life and its challenges together and to remind each other to take treatment especially if he/she sees something wrong/funny with each other in terms of behaviour or response. We by all means encourage each other to excel at what he/she does especially if it is good.

Finding employment would help me survive poverty. I will keep on entering competitions until such a time I may win a great prize like a car/house where I could sell it and buy a second hand car like a family car which could be helpful like in fetching water and wood in time of need, do shopping, transporting sheep/goat and taking the family to holiday destinations and investing in the renovating my home in the Eastern Cape.

Getting a disability grant

It helps me to buy food and clothing and to pay for life-insurance policies which cover me and my family against death. It also help me to buy additives of treatment which could help keep me fit, healthy and have stamina like, multivitamins and anti-stress tablets, etc. It also helps me to be able to buy stamps so that I can post competition letters as a person who likes to enter for them from time to time. I also use it to pay for the services of a traditional healer. I also use it to buy electricity and more especially gospel and reggae cassettes because I like music with beautiful vibrations, revitalisation sounds and with messages all the time. I also buy empty cassettes to record important speeches like the Budget speech. The disability grant goes much further after the government's intervention in price control, thanks to our government.

Making ends meet

We look for specials when we buy and we (different earners in the household) take turns in buying food. We bake bread for breakfast and dinner and avoid depending on bread from the shop. We only eat a full meal at night and we try by all means to alternate main meals: today – pap, tomorrow – rice; the day after: samp, etc. We try to eat food which is healthy and also try other meals which are recommended by dieticians and researched like Lucky Star which they say cures nerves because it is rich in carbohydrates and has fatty acids that replace chemicals which can be short of in people living with…[diagnosis].

We avoid buying small items as usually they cost more for example, we buy large products like 12, 5 kg and 10 kgs, or assemble 5 kg X 2 or 2,5 kg X 4. We divide dishwashing liquid and mix with water to last longer. We re-use old tea/coffee bags and we mix cat food for our animals with porridge for it to last for a while. Family members also buy products with competitions for me to enter either on my behalf or for themselves as long as it can benefit all of us at home. We buy clothing and electric appliances only when there is a sale. We try to rely on family members with an experience in repairing/maintaining and do not hire someone especially if one of us can do it . We use a land-line rather than a mobile phone and we make sure that during emergencies we nominate one of us to represent us and we all contribute money which can be used when needed.

Attitudes of others

The family of mine is very supportive in terms of finding a solution to my problem as a person who always need approval. They are very considerate as I usually make matters worse which is influenced by my negativity. They calm me and try to make me understand as if I am disappointed or sad it will all be written on my face or my posture which you could see without asking. They are also even prepared to fetch tablets from the clinic on my behalf if I have other important things to do. What has not changed is the way they treat and respect me irrespective of mood changes, they stay real and always true to themselves and myself. As a person who looks better with short hair and no moustache, they always cut my hair or give me money to cut it at a nearby barbershop. When someone greets and makes small talk with me I become more crazy with more mistakes or react strangely which leave me ashamed of myself. They always make sure that they advise me mostly in things which need experience of an adult.

The community is also very supportive and considerate except those who are not aware of you being a patient who is living with mental problems. They can doubt you and sometimes question you what is it you are doing and why are you doing it or talking on your back. They sometimes tend to call you a CEYLON if you sometimes seem as if you will burst by being boiling mad. They also tend to call you a *moffie* [slang for gay person] or as somebody who is very jealous of others if you show interest in being a friend to somebody who has the same sex as you especially if he/she is young. They can call you a gay or a lesbian or call you a coward especially you can't solve any conflict due to your indecisiveness which is caused by the illness. Even for my father who was also suffering they tend to call him '*maniphela*' which is a word which means that sometimes your brain doesn't work or call you '*bokili*' which is a word referring to a person who works hard for others although he/she doesn't get paid or somebody who sometimes don't think straight.

We find difficulties in getting a job due to fears of us not coping well or needing too much assistance. Another problem for us is finding it difficult to have friends as some may get lost with time. I think the current way is alright where you are hospitalised after your first sickness and discharged and then allowed to take treatment at your nearby clinic, then after a number of years being sent to the rehabilitation centre. I think that those who show potential should be helped to further their studies and helped with job-finding skills.

Coping strategies

I read scriptures from the Bible because with constant reading you get contact and guidance from the Lord. After reading a few other booklets I became empowered which is true that knowledge is power. I became sure of myself. I also remind myself of RSA's achievement after ten years of freedom by reading CNA Calender. I also use my diary to remind me of important future dates/appointments and budgeting for every month where I prioritise. I also sometimes fetch the medicine from the clinic and from the traditional healer. I used to visit friends and relatives who are around the town until such a time when I don't feel like it especially after death pass of someone in that home. I also try to keep myself occupied reading local free newspapers and entering different product competitions. I try my best to keep my family out of the poverty line. I also listen to kinds of advice which are usually given over the media like in radio programmes and magazine articles which give advice on how to cope with stress, developing a healthy living style and about nutrition like the buying of cheapest body building food like fish mince.

Disability rights

I think our human rights are that we have the right to be treated fairly, free from discrimination from all grounds as stated in the new constitution and the right to choose. I think we have the right to free basic education from Grade 1 to Grade 9 as recommended by the United Nations to all free nations that are under democracy and the right not to be separated from other children and the right to primary health-care and the right to be considered in building buildings that are user-friendly to people with disabilities like less upstairs and less complicated and unsafe buildings which could lead to suicide promotion. Lastly I think we need to be free from discrimination against unfair judgement due to our un-aired views which may be caused by mental illness. I think our needs mostly is to get employed or else, being kept busy and focused as staying in our townships could lead us get involved in all conflicts because of the number of the differences we might have of which some may be caused by our illness which could change your views and perception. I think concerning our abilities is that in many things we do to make our future better is to be given enough time and assistance which could help us succeed like other people.

Suggestions for social change

I think more emphasis should be on first time patients and more freedom to those with many years of living under treatment. I would also suggest for staff going back to the basics in how to handle relationship with patients. I also think the number of staff should be increased. The hospital card should clearly state when to fetch medicine and when to see a doctor so as to be able to send someone to fetch on your behalf and staff must be strict in honouring the appointments they make with patients.

They should raise more awareness to everybody as what I have found out is at the present moment Alzheimer and schizophrenia covers a small percentage of the population but estimates about the future say it will be everybody's problem in 10–15 years period of time because of poverty and globalisation. I also think that they should tend the basics in doing their job and encourage equipping their clinic with more staff to overcome mania which is caused by stress and depression. I also like the way concerning treatment taking (medication and clinic visits) being allowed for only one month as that could save the Hospital in terms of replacing lost and careless placed treatment. I also encourage giving more medication in a time during December as most of us go to holidays. My ideal world would be in

> a way where everybody does only what he/she would like to be done to him/her and where every body lives life to the fullest with all rights that are enshrined in the constitution.
>
> I would advise for the allowance of dagga to be used for medicinal purposes as there are many diseases out there they say it can cure like cancer and many more and even God could punish us for not making better use of available resources. I think it must not be allowed to be used for drug smoking purposes. Interested people must be forming a club with regulations on how to use it, for example, I think we can make better use of it in making clothes. Hemp plant could lead to employment to many South Africans.
>
> I would also suggest better use of Bible role models to encourage and guide youth of what they hope for the future as today few present leaders are prepared to be role models.

Defining psychiatric disability

In an effort to reduce the perceived hegemony of the medical model, proponents of the social model of disability have exposed the ways in which language can be used to oppress (Barnes & Mercer, 2004; Coleridge, 1993). Our attitudes are influenced by the labels we use to describe the humanity of those we perceive as different. Drawing attention to the language used to describe or define psychiatric disability is therefore an important way of challenging the unquestioned assumptions upon which most people operate. For example, the terms 'mental' and 'psychiatric' refer to phenomena of the mind in health and in distress but are often used colloquially to stigmatise unusual behaviour. Terms such as 'mental health problems', 'mental illness', 'psychiatric impairment', 'psychiatric disorder' and 'psychiatric disability' are appropriate in different contexts, depending on whether a medical, functional or political perspective is adopted (APA, 2000; Barnes & Mercer, 2004; WHO, 2001).

Mental health problems refer to experiences of mental and emotional distress that arise from time to time in everyone's life due to personal circumstances. These problems may require medical attention, counselling or some form of culturally appropriate intervention for a period of time in order to facilitate adaptive functioning. The terms 'mental illness' and 'psychiatric disorder' are often used interchangeably and refer to a 'clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (for example, a painful symptom) or disability (impairment in one or more important areas of functioning) or with significantly increased risk of suffering death, pain, disability, or an important loss of freedom' (APA, 2000, p. xxxi). In an attempt to move beyond a purely organic interpretation of mental illness, the 'biopsychosocial approach' in the form of a multi-axial diagnostic system was introduced in the third *Diagnostic and Statistical Manual of Mental Disorders* (DSM III) (American Psychiatric Association, 1980). This approach implies that 'the etiology of a disease or disorder has biological, psychological, and sociological determinants such as genetic, developmental and environmental factors' (Stein & Cutler, 2002, p. 616). The biopsychosocial approach is helpful in defining, categorising and assessing clinically significant behaviours and in providing a common language amongst mental-health service providers for directing therapeutic and rehabilitative measures. The interpretation of psychological, social and occupational (as in work) 'functioning' on Axis V, of the Global Assessment of Functioning (GAF) scale of the DSM-IV (APA, 1994, p. 32) is, however, strongly linked to the presence or absence of the symptoms of mental illness. The GAF Scale therefore medicalises the concept of 'functioning' and reinforces a reductionistic approach to intervention; it focuses on the 'curing' or 'overcoming' of distressing symptoms (for example, hallucinations, thought disorder and depression) and uses these, by inference, as indicators of levels of adaptive functioning. The medical perspective has value in tertiary health-care contexts, but is inappropriate when it sees the human mind and behaviour as alterable and the social environment as unalterable. That is, the implication is that if the person does not fit the social environment then that person – and not the environment – must change.

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) introduces a functional perspective on disability. 'Functioning' in the ICF is an umbrella term encompassing all body functions, activities and participation. It describes and categorises the situation of each person within an array of health or health related domains, and like the DSM, runs the risk of becoming another disabling barrier because it reduces the experiences of disabled persons to descriptions of impaired body functions and structures, activity limitations and participation restrictions. Similarly to the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (UN, 1994), the ICF is a 'conceptual framework for information that is applicable to personal health-care, including prevention, health promotion, and the improvement of participation by removing or mitigating societal hindrances and encouraging the provision of social supports and facilitators' (WHO, 2001, p. 7). It provides users with a common, universal language for mapping the process, degree and quality of functioning and disability of individuals and populations.

The ICF, however, does not classify personal factors such as the particular background of the individual, such as his or her gender, race, lifestyle, habits, values, interests, education, past and current life experiences and a range of other idiosyncratic features. It is therefore not person centred, nor does it take into account the purpose and meaning that individuals derive from functioning in the world; it is not attuned to humans as meaning-making beings. This is of particular significance to people who have to negotiate life with serious mental health problems. According to the ICF, the activity limitations that occur as a result of a body structure or body-function impairment are just that – an inability to do something or to perform an action (the person can or cannot brush their teeth or catch a bus, etc.). There is no appreciation of the profoundly personal dimensions of being, doing, becoming and belonging that the doer of the activity attaches to his or her participation in the life they are living (Wilcock, 1998; Yerxa, 1998). In other words, activity for the doer may be more than the ability to perform a skill or a function; it may be a communication process whereby thoughts and feelings are expressed non-verbally and the means whereby human potential is accessed. Interaction with objects and people in their environment enables humans to respond to an innate need to be meaningfully and purposefully engaged in the process of exploring and mastering their environment. According to Miller and Walker, it is 'through action-orientated experiences that humans test skills, clarify relationships; integrate and develop sensory, motor, cognitive and psychological functions; become socialised to cultural norms and roles and gain competence as social beings' (Miller & Walker, 1993, pp. 266–267). The dynamic between mental impairments and the ensuing activity limitations and participation restrictions is ultimately about the quest for identity and meaning. Without this perspective, the terminology and constructs emanating from the ICF may be as oppressive as those emanating from the medical model.

The medical perspective defines psychiatric disability as impairment in one or more areas of psychological, social and occupational functioning (i.e. the problem is the person), whereas the political perspective defines it in relation to the sociopolitical barriers, negative attitudes, marginalisation and oppression that people face as a result of their mental illness (i.e. the problem is society) (Barnes & Mercer, 2004). The functional perspective tries to bridge the gap by referring to 'disability' as an umbrella term for impairments, activity limitations and participation restrictions. Some radical activists against the dominance of the medical model, and psychiatry in particular, prefer the term 'psychiatric survivor', referring to their survival of mental-health services rather than their mental illness. They are unwilling to see impairment as a part of their condition and call for adjustments to the social model of disability which they feel is too accommodating of medical perspectives (Beresford, 2004). Irrespective of the perspective adopted, the challenge is always to use terms with a clear appreciation of the ideology from which they originate or which they support.

Implications of psychiatric disability

People with psychiatric disabilities are discriminated against more overtly than those with other disabilities (Beresford, 2004; Herman, 2001). As Johnstone demonstrates, marginalisation occurs in many guises and at many levels:

> [M]ental ill-health – and its profound stigmatisation – carries with it a burden of human suffering that at times is not only incalculable, but incomprehensible to non-afflicted onlookers. This, in turn, can perpetuate a most cruel injustice, notably, the denial of the mentally ill's moral entitlements to things that other people take for granted:

> function, a sense of place in an intersubjective world, empathic connection with reciprocating others, peace of mind, happiness and participatory citizenship. (Johnstone, 2001, p. 200)

The incalculable suffering of people with psychiatric impairments occurs because the intensity of their impairments, experienced subjectively, is concealed (as opposed to invisible). They conceal their impairments in order to manage their stigmatised illness identities (Fitzgerald & Paterson, 1995). The accompanying distress may lead to a range of functional limitations and behavioural difficulties that restrict their participation in valued life roles. Psychiatrically impaired people may also have limited appreciation of the impact of their different behaviour on significant others and society in general.

Consequently, the task of care may be a particularly difficult one in households that are increasingly held responsible for monitoring the welfare of a psychiatrically impaired member, due to the policy of brief hospitalisation and rapid de-institutionalisation. The slow implementation of community-based psychosocial rehabilitation services, in accordance with the national rehabilitation policy, has compounded the incidence and prevalence of psychiatric disability (DoH, 2003). The fact that mentally ill people may look or act in 'odd' ways contributes to their stigmatisation; in other words, the assumptions of what 'madness' means and the realities of different (and at times downright difficult and obnoxious) behaviour compounds their exclusion. Media images also compound stigmatisation by linking mental illness with aggression and danger (Brown & Bradley, 2002; van Niekerk, 2005). Some may argue that psychiatrically disabled people therefore have a responsibility to manage their impairment, if possible, in ways that do not unduly perpetuate negative stereotypes.

While attitudinal barriers to mental illness may be – at least partially – understandable, they remain the most difficult to overcome. Ignorance, fear and misunderstanding prevent society from appreciating the full potential of people living with mental-health challenges. Given socio-political rights, including equal opportunities and a supportive infrastructure, psychiatrically impaired people can experience optimal quality of life and contribute substantially to social development. The realities of poverty, unemployment and structural violence, however, confound the implementation of these objectives. According to Higson-Smith, Richter and Altman (2004), unemployment in South Africa rose from 17 per cent in 1994 to nearly 30 per cent in 2001, using the expanded definition of unemployment. In March 2004, also using the expanded definition, the unemployment rate stood at more than 40 per cent.[2] It stands to reason that many of the problems experienced by people with psychiatric disability both contribute to and result from chronic unemployment and enduring poverty (Draine, Salzer, Culhane & Hadley, 2002; Polak & Warner, 1996). Concluding her study of the ways in which adults negotiate mental distress in Khayelitsha, MacGregor states:

> [T]he narratives of the ‘nerves of suffering’ continue to be told in Khayelitsha: to kin, to neighbours, to community health workers and to health-care professionals. But they are too common to attract attention. For professionals they do not have the currency of those that speak of social disruption, a recognised biomedical diagnosis, or of trauma related to a particular event. Marginalisation in an environment like Khayelitsha takes many forms. To be poor is to be marginalised. To be mentally disturbed and poor is to be doubly marginalised. ‘When is life going to be easy?’ people ask. (MacGregor, 2002, p. 253)

The double marginalisation of psychiatric disability is evident not only in the lives of ordinary people but also in research and policy development. There is, for example, limited literature on the topic in current disability journals. Psychiatric disability is neglected in poverty research; this despite the fact that one member in every four families in the world is living with a psychiatric disorder and that disability is recognised as a factor contributing to why poor people stay poor (Saracenoe & Barbui, 1997). Psychiatrically disabled people, or disabled people in general, tend to be poorer not because of lack of action on their part. Though their agency may be severely constrained by a host of structural and organic factors, disabled people tend to be constantly seeking out ways to improve their situation (Hulme 2003). Among psychiatrically disabled people, their decline may be traced to social exclusion resulting in part from their stigmatisation, but also from major health ‘shocks’ such as repeated relapses, under-resourced mental-health services and poorly regulated private and civic action.

One of the main political drivers of the current South African government is redress and equitable distribution of mental-health services across all provinces and for all citizens. Freeman (1998) sees the provision of accessible, affordable, adequate and appropriate mental-health services not only as a political imperative but also as a moral right. However, the reality is that implementation of these objectives is limited by severe constraints on financial resources. According to Freeman, the Department of Health is ‘called upon to provide comprehensive mental-health services using essentially the same budget that was available to the old dispensation, from a base where the majority of South Africans received either no or extremely poor mental-health services’ (1998, p. 742).

When society is unable to reduce the impact of impairments and the person experiences barriers, the impairment becomes disabling and psychiatric disability follows (van Niekerk, 2005). However, the past five years have seen substantial improvements, including the devolution of mental health services to primary levels of care. People with psychiatric impairments are increasingly experiencing their rights to full participation in society through the equalisation of opportunities across a number of public sectors. Van Niekerk believes that further gains will be made through greater intersectoral collaboration. She suggests that ‘the labour sector is extremely well positioned to make a far bigger contribution than the health sector, particularly with regards to the incorporation of disabled (*both physical and psychiatric*) people into the world of work' (emphasis added, 2005, p. 26). According to her, the Skills Development Levy Act of 1999 makes particular provision for the inclusion of disabled people, firstly through tax benefits and secondly, through making the training of disabled people an imperative for all Sector Education Training Authorities. Critical indicators of social change include evidence of significantly higher numbers of disabled people being meaningfully productive through full participation in community development initiatives or gainfully employed in the open labour market, in supported employment positions or running their own businesses (Harnois & Gabriel, 2000; Watson & Swartz, 2004).

Psychiatric disability and social change

A common thread throughout the critical issues raised here is the matter of attitude towards difference in all its forms and towards psychiatric impairment in particular. It is easy to lose sight of what really matters in achieving social change: the willingness for change to start with each one of us personally by confronting the content of our own hearts (Coleridge, 1993; Ndungane, 2003; Zola, 1982). As policy makers, professionals, change advocates and ordinary citizens, we are all disabled to a greater or lesser degree. In his seminal work on disability, liberation and development, Coleridge (1993) suggests that having a disability is not a fixed state, but rather a continually changing and evolving interactive process. It is not something one is or is not, but rather a set of characteristics everyone shares to varying degrees and in varying forms and combinations. Ultimately the quest for meaning and social change must be 'deeply spiritual and profoundly political' (Coleridge, 1993, p. 213). Coleridge challenges the notion that the social model of disability is sufficient to deal with prejudice. In essence he argues, as does Zola (1982), that social action ought to derive its purpose and power from the human heart, and therefore that the heart – that is, the spiritual quest for meaning – is the basic institution of society.

Of course, in positing the human heart as a social institution, Coleridge is invoking the qualities of honour, trust, freedom and courage that are sometimes symbolised by the virtuous heart. But the crucial point is that, for Coleridge, the issue rests within the individual and not primarily between the disabled person and society (Coleridge, 1993, p. 212). Direct experience of disability, such as living with an impairment, caring for a disabled person, providing professional services to mentally ill persons, or developing disability policy, does not necessarily produce disability consciousness and acceptance of differentness. This can only occur through sensitising one heart at a time to the equality and worthiness of all people, irrespective of differences in abilities, appearances, behaviours, beliefs and values. Coleridge suggests:

> (W)e can start by accepting that disability exists. It is part of human life, part of the way things are. Let us engage with it, enquire into it, make friends with it. Disabled people do this from the inside, people who are not yet disabled need to do it from the outside. One way or another we cannot ignore it: if we ignore it, we place ourselves outside the human condition in some kind of unreal aseptic world that cuts us off from our very humanity. (1993, p. 216)

This kind of sensitivity is so crucial because the heart without it cannot motivate appropriate action, which in disabling social environments, equates with appropriate political interventions. Put another way, it is disingenuous to argue that disability is located in social environments, as the social model suggests, because social environments are an abstraction, a concept. If social environments have no intrinsic agency, how can they be disabling?

There are two thrusts to Coleridge's analysis. By focusing attention on the hearts of disabled and nondisabled people, Coleridge draws attention to individual action that can both create and perpetuate disability as well as stimulate appropriate political action. But Coleridge's focus also conveys strong criticism of the social model for displacing the culpable agency of individuals onto abstractions such as 'society' and 'social environments'.

Pityana also thinks that individual effort is central to managing and changing social environments. Addressing himself to a call for a renewal of African values, Pityana refers to the importance, in a multicultural society, of citizens being encouraged to understand the life world of others:

> To understand the life world of another, one has to get into the soul of the people, to discover the hidden body of meanings, values and assumptions of that community: to know the 'unknowable'. The way in which societies negotiate this realm of the 'unknowable' is through communicative action, dialogue and recognition of difference. (Pityana, 1999, p. 143)

Pityana goes on to remind his audience that the moral values implied in the South African Constitution set a basic or minimum standard for behaviour, so that all can share basic expectations and entitlements. Crucially, he notes that 'these standards, however, would be meaningless if they were not accompanied by a sense of obligation about practice and action'(1999, p. 147).

Echoing Pityana, Teffo (1999) presents a compelling argument for the potential of '*ubuntu*', the primary organising principle of African morality, to shape and guide social change. *Ubuntu* encapsulates a view of the world wherein one's own 'humanness' or humanity is affirmed through the recognition of the humanness of others. As with many worldviews, respect for human nature is fundamental. But what makes *ubuntu* a powerful resource for social change is that it pivots on reciprocity. Amongst other values such as the duty of care, devotion to duty and solidarity inherent in this form of African humanism, Teffo highlights 'compassion with and sensitivity to the aged, *the handicapped* and the less privileged' (emphasis added, 1999, p. 154). It is a fine line between compassion and paternalism. The latter, but also sometimes the former, usually sits at the crux of prejudice and stereotyping. However, Teffo qualifies compassion by linking it with reciprocity and cohesiveness promised by *ubuntu*:

> I am attracted to an existence in which people treat each other as human beings and not simply as instruments or tools, where people become committed to one another without necessarily having to declare such commitment. When the chips are down it is compassion which makes it possible for others to rise to the occasion. Compassion integrates and binds people together'. (1999, p. 155)

Psychiatry as a discipline in South Africa remains steeped in biomedical approaches to psychiatric impairment, and still has a considerable way to go to include more recent debates and shifts in thinking surrounding disability. While the medical model has a significant role to play in the diagnosis and alleviation of biopsychosocial distress, its attitudinal limitations are not yet fully appreciated by lay and professional role players alike. Therefore, despite the adoption of the primary health-care philosophy, it is likely to remain the preferred approach in addressing mental-health issues in South Africa. The emphasis at present (and appropriately so in acute care settings) is still primarily placed on understanding, diagnosing and 'fixing' the impairment (person) rather than also considering the advantages of promoting socially inclusive environments through comprehensive (promotive, preventive, curative and rehabilitative) mental health care and community development initiatives that emphasise individual and collective agency. It is instructive as well as deeply disconcerting that recent publications in psychiatry do not address psychiatric disability and include only cursory reference to preventative mental-health programmes, mental-health promotion strategies and psychosocial rehabilitation (Sardut, 1998). Advancing the psychiatric disability agenda in South Africa will depend, in part, on vigorous consumer activism and substantial transformation of lay and professional education within a rights-based framework (Chapman & Rubenstein, 1998). *Ubuntu* and other indigenous knowledge systems can and should play a central role in transforming the practice of psychiatry as well as advancing the disability agenda in South Africa.

Conclusion

Social transformation is evidenced by the extent to which the most marginalised people in our society are afforded dignity and equal access to opportunities for personal development, and for contributing to the production of culture. While a substantially strengthened legislative and policy framework (for example, the

Integrated National Disability Strategy (ODP, 1997) and the Employment Equity Act of 1998 has paved the way for disabled people to experience participatory citizenship, social and professional attitudes continue to perpetuate stereotypes of them as dependent and less competent (DoL, 1997; 1998).

> I [Siyabulela] acknowledge the limitations imposed by my impairments on my functioning and participation in valued life roles. These do not however limit my dreams or potential for a full and productive life. I strive, with the support of significant others, to overcome the numerous barriers imposed by my life world. It is my basic human right to be treated with dignity by professionals and service providers who focus on my strengths and potential rather than my diagnosis, impairments and activity limitations. I also have the right to freedom from stigmatisation by the community, a more efficient health system, cultural inclusion and access to supported employment or meaningful, productive daily occupation. Until these are readily available we cannot speak of significant social change. Psychiatric disability can be minimised by creating opportunities for disabled people to become agents of their own histories and masters of their own destiny in the mainstream of society.

Notes

1 For confidentiality reasons, Siyabulela prefers to not give his full name.

2 Unlike the official definition of unemployment, the expanded definition includes those unemployed who have not actively sought work in the previous four weeks and therefore includes those who have given up looking for work (see Stats SA, 2004).

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22

Parents and therapists: dilemmas in partnership

Judy McKenzie and Bronwen Müller

Introduction

Some disabled children may undergo therapeutic intervention throughout their lives, and this makes the relationship between parents and therapists vitally important. Parents can offer important contributions to debates around disability because their engagement with disability involves unique imbrications of medical discourses with kinship ties, as well as the negotiating of social discourses around inclusion and exclusion and the unequal power relationships that define what is 'normal'. Based on their experiences, conversations and sharing with parents, therapists are in a unique position to bring these contributions to the health-care sector. That said, it is important to recognise that therapists cannot claim to represent parents, and that parents' perspectives and contributions are not homogenous. The discussion presented here is intended to stimulate debate and does not attempt to answer the many questions that it will raise.

Both contributors to this chapter are parents of children with severe disabilities, both physical and intellectual. The chapter is structured in a manner which aims to examine and put into context our own experiences and those of other parents of disabled children. We then turn to the concept of partnership and question, firstly, whether it exists and, secondly, whether it is in fact a desirable way of configuring the relationship between parents and therapists. We conclude with some avenues to be explored in increasing the effectiveness of service providers in meeting the needs of children with disabilities and their families in South Africa.

Affordability and accessibility

In the private sector in South Africa, therapeutic intervention is expensive – 30 minutes of speech therapy generally cost about R130 in Cape Town in 2005, and an hour of physiotherapy can cost R380. Medical aids that cover unlimited treatment can cost close to R4 000 a month for a family of two adults and two children.

With this in mind, it is only the privileged few who will be able to afford to sustain a long-term relationship with one or several therapists. As a proportion of disabled children may benefit from a variety of therapies, parents need to choose which to focus on at which time and determine the number of therapy sessions they can afford. It is a given that the continuance of the therapy depends on continued payment, and some therapists are more accommodating than others in structuring their services around the number of sessions parents are able to afford.

Geographical accessibility in the private sector in the major centres is usually not a problem. However, a problem may arise when a child requires the input of several therapists. There is no formalised co-ordination of services and consequently overall goals for the child are typically not set. Mothers find themselves overstretched by taking their child from one therapist to the next, reducing time available for engaging their child in social activities. Further, this may involve a restriction in attention paid to other children in the family, as well as an impact on the mother's capacity to work. This situation can be accommodated where the problem is a short-term one, but in our cases, this is potentially a lifelong commitment. In the smaller centres, where choice is limited and therapists do not have the opportunity to specialise, if one is unhappy with the service provided, there is nowhere else to go.

The situation in the public sector makes the question of partnership laughable. While in the major centres, therapists at tertiary-level hospitals provide a degree of support, in more rural areas of the country, there is little or no provision. Here, the majority of clients draw on public sector health care, and the majority of therapists are located in the private sector. Table 22.1 presents data on the public/private divide as of 1999.

Table 22.1: The public / private divide in South African health care, mid-1999

Description	**Total**	**Public sector 1999**	**Private sector 1999**	**Public:private Ratio**
Physiotherapists	3406	463 13.6%	2943 86.4%	1:6.36
Occupational therapists	1986	388 19.5%	1598 80,5%	1:4.12
Speech therapists & audiologists	1388	119 8.6%	1269 91.4%	1:10.66

Source: Van Rensburg & Van Rensburg (1999)

Accessibility is clearly a problem. One response is to train mid-level rehabilitation workers within a community-based rehabilitation framework. Such workers have undergone integrated training across the rehabilitation professions, which enables them to provide an integrated service, so avoiding some of the problems of the fragmentation of services in the private sector. An additional consideration is that while services in the public sector might be affordable, the costs of getting the child to the service site can be prohibitive.

Models of service delivery

In our experience, the mode of service delivery remains firmly rooted in the medical model. By way of exemplification, the following advice to parents is offered by the Baby Therapy Centre in Pretoria:

- Get an interdisciplinary assessment from a team of baby therapists. Here an evaluation can be made of your child's strengths and needs.
- Specialised therapists will help you learn the skills to handle your child correctly.
- The physiotherapist will help your child develop the correct movement patterns in order to develop more normally.
- The occupational therapist will work on the fine-motor and sensory impairments.
- The speech therapist will address feeding problems and communication disorders.
- Other therapies such as hydrotherapy and music can be of great benefit to your child as well.
- It is of utmost importance to start therapy (especially correct handling of the child) as soon as possible, to utilise the stage of maximum brain growth in the first few years of life. Early intervention programmes should be followed.[1]

The most striking feature of this advice is how the child's needs are carved up into the different developmental areas according to the therapist that addresses that area. For children with pervasive developmental delays like ours, it makes no sense that therapy be divided up in this way. Why does this division exist and who does it actually serve? Why should one person be concerned with movement, another with talking and a third with social skills? As parents, we are concerned with the quality of life, socialisation and maximal functioning and independence of our children. The narrow focus of each therapist might ensure that they are specialised in that particular area of development, but it also means that they may be blinkered to other areas. Where is the whole child in all of this and who will co-ordinate the different therapists to ensure maximum benefit for the child?

In considering the development of our nondisabled children, we tend to look at them in a holistic manner, recognising that one area of development can be in advance of another at any stage. We strive to facilitate their development in such a way as to prepare them and support them in their integration into the family and the community. However, the development of disabled children is pathologised in a manner that may exclude them from the family and the community. Mothers must be taught how to handle their child 'correctly', 'impairments' must be worked on and 'disorders' addressed. All of this requires specialised help in specialised settings, and so begins the process of segregation of people with disabilities. This sends a strong message to the child and the family, and ultimately to society as a whole – that to have a disability is to be somehow incomplete and perpetually in need of help.

Dovey and Graffam (1983) identify a learnt helplessness in parents that limits their effectiveness and their ability to make good decisions for their children. In a similar vein, Creal (1998) describes the effect on her brother, Norman:

> He describes how segregated physical activities led to an absence of friendships and their therapeutic focus overrode a sense of fun and play – swimming became aquatic therapy, play became recreational therapy, art became art therapy, having a pet became touch therapy, and music became play therapy. Every activity was seen as a way to make Norm 'better' and supported the premise that he was not good enough, not adequate, not normal. (Creal, 1998, pp. 2–3)

A consequence of pathologising the development of the child with a disability is that it puts the theoretical framework for therapy within a medical model of diagnosis and cure. By contrast, it is our experience that the purpose of therapy in the case of developmental delay is learning new skills, rather than achieving a cure. It is therefore necessary that therapeutic strategies be based on sound models of learning theory. Therapy as it is currently constructed often assumes a behaviourist model, drawing on concepts of shaping, reinforcement, generalisation and operational goals, with reward systems being used to motivate the child. While these approaches can be valuable in teaching new skills, there is a risk of decreasing the intrinsic motivation of the child to learn through spontaneous interaction with their environment. Theories of education have long since shifted toward a constructivist approach to learning, based on the principle that people construct their own understanding and knowledge through engagement in real life contexts with the guidance of a more capable facilitator of learning. In so doing, learners become active participants in their own learning (Murphy, 1997). There is an assumption that for the disabled child, learning takes place differently. To us this assumption is invalid.

The following case example illustrates a child with an intellectual disability constructing his own learning in a real life context:

> J. attended physiotherapy. One of the goals was to get him to take weight on his arms and the activity was crawling on all fours. The physiotherapist devised games and used toys to get him to do this but it was hard going, as he soon wanted to handle the toys and would then move out of the crawling position. A few days later he was observed at school with his friends crawling through a tunnel constructed of blankets hung over chairs with his playmates. He crawled on all fours for thirty minutes in this way.

However, there are cases where the same effect is gained in a therapy situation:

> My three-year-old loved constructing a house out of large, soft blocks with other children, walking along its walls, climbing its steps and crawling through its tunnels. A few physiotherapists work in a large sunny house and, while each child is seen by one therapist for an hour, they often spontaneously join up in their

> activities for a while. There will be children standing in basins in the bathroom drawing exotic shapes on the mirrors with shaving cream, while others are doing guided playing with the colourful balls that fill the bath. The children's choices of activities are respected and encouraged and their 'rewards' are the sense of satisfaction they get from developing their own potential.

In our experience, therapy is still firmly placed within a medical model of disability. Therapists tend to diagnose the problem in relation to what they are able to offer. This means that the focus is firmly on the child with the problem, and the social barriers to development are not carefully considered, as most therapists lack expertise in addressing these. As such, the construction of rehabilitation places the problem squarely within the child and the family. While community-based rehabilitation may begin to explore some of the social constraints that operate, in reality the focus is often on making the same services accessible rather than a fundamental change in the type of service delivered. This is to be expected, given the medical bias of the therapists' training and their need to do what they were trained to do.

The casting of rehabilitation within a medical model presents an obstacle to parents, as well as to the efforts of therapists, in that it fails to take into account the complex social interactions in which the child must engage. And yet it is these social interactions that facilitate the child's integration into society – an issue that is of essential importance to parents. The likely outcome of such an approach is described in the *Integrated National Disability Strategy*:

> Disability tends to be couched within a medical and welfare framework, identifying people with disabilities as ill, different from their peers and in need of care. Because the emphasis is on the medical needs of people with disabilities, there is a corresponding neglect of their social needs. This has resulted in severe isolation for people with disabilities and their families.(ODP, 1997, p. v)

A key implication of the medical model of service delivery is that the child is rarely observed functioning in his or her own context. The following case example illustrates a therapist's reluctance to move into her patient's everyday world:

> In a class where the child with Down syndrome was the only pupil with a diagnosed disability, the teacher asked the parent to arrange for her to meet the speech therapist so that she could have a better understanding of the methods the therapist was using and try to incorporate some of them into the child's school day. The therapist said it would not be possible for her to go to the school but that the teacher was welcome to sit in on the child's therapy session. The teacher and her assistant travelled some distance out of their way and sat in on the session in their private time.

The therapist here has lost an opportunity to observe and map the skills that her client needs in the real world in order to develop as a person. Additionally, the therapist has missed a chance to maximise the impact of the one hour per week that she works with her client, by ensuring that it is built on by people who are in contact with the child every day. Maximising the benefit to the client should be the central concern of the way in which the service is provided.

This issue becomes even more relevant with the introduction in South Africa of *Education White Paper 6: Building an Inclusive Education and Training System* (EWP6) (DoE, 2001). EWP6 calls on therapists, whether in the public sector or the private sector, to structure their service delivery in such a way that they are able to act as consultants to educators rather than as clinicians. Instead of working within the confines of special schools and clinics, therapists become a part of the District Support Team, which provides support to educators in schools by consulting with them around specific barriers to learning that educators observe in their classrooms. By the same token, employment equity legislation, which makes provision for people with disabilities in the open labour market, will also place demands on therapists to work within the real life context of the disabled person. In the health sector, the adoption of primary health care and community-based rehabilitation will also require a move away from clinical settings into the community (see also Chapter 20, this volume).

Unequal power relationships

> If you think about it, from the age of three until the age of twelve, three times a week, women who were older than I was, who were more powerful than I was, who had more authority than I had, brought me in to their room, their space, their turf. They took off some of my clothes. They invaded my personal space. They gripped me and touched me, manipulating my body in ways that were painful – it hurt. Some of the exercises that were done in physical therapy were very painful, others were threatening. (Kunc, cited in Giangreco, 1995, p. 6)

This quotation illustrates the power that the therapist exerts over the body of the child in rehabilitation. While parents do not experience this power directly, they are in a position to decide whether to subject their child to this kind of control or not. Given that most parents will be persuaded that it is in their child's best interests, most would probably not question the need to put their children through exercises as described above. This is the influence over the mind that the health-care industry has come to possess. Kunc describes how the treatment he received at the hands of rehabilitation therapists was instrumental in establishing in him the firm belief that disability is an undesirable and unacceptable human condition:

> And what I learned at that moment in life was that it was not a good thing to be disabled and that the more I could reduce or minimize my disability the better off I would be…The implicit message that

> permeated all my therapy experiences was that if I wanted to live as a valued person, wanted a quality life, to have a good job, everything could be mine. All I had to do was overcome my disability. (Kunc, cited in Giangreco, 1995, p. 2)

We would suggest that a disempowerment of disabled people is implicit in the message that parents take home with them from their interaction with therapists. Any behaviour can become part of the pathology and there is a huge drive to normalise the child. However, we simultaneously know that we cannot make the child 'normal' because he or she has a severe disability. What we learn is that our child will never be good enough because he or she will never be normal. Such learnings contribute to the exclusion of the child from society.

The power dynamics that structure the relationship between parents and therapists are usually established during the first assessment of the child. Two people (usually women) face each other. The one conducting the meeting and taking notes is experienced at this and asks the stranger a list of personal questions, including how she reacted to the news that her child is not 'normal'. To the stranger, most of this questioning often seems unnecessarily intrusive.

This structured gathering of profoundly personal information by the therapist introduces a power dynamic into the relationship that usually remains unacknowledged. Writing down the answers to this list of questions and filing them away adds weight to them and can add anxiety to a parent already worried about whether she is doing enough to meet her child's needs. The purpose of ascertaining whether the family needs additional support loses its relevance when, as is frequently the case in South Africa, such supports are not available to parents.

Based on this first assessment and with some consultation with parents (usually only the mother), therapy goals are developed. Parents are then expected to carry out activities in the home that support these goals. However, these goals are often not experienced as meaningful by parents. This is particularly true of less educated parents. An observer describes a therapy session:

> The therapist handled the child showing the mother how to feed her child and talking all the while. The speech therapist explained that it was important to feed the child foods of the correct texture and to use special feeding aids so that the child would learn to chew and swallow in the correct way. The mother was looking on with a very depressed face and it was clear that she did not understand how these exercises were going to address the problems that she was currently having with her child. Subsequently the therapist realised that the mother was concerned about getting food, any food for her child to eat, living as they did in conditions of extreme poverty.

Relationships between parents and therapists

Parents' emotional vulnerability at the initial consultation with a therapist tends to be higher the shorter the time which has elapsed since the diagnosis of their child. At this first meeting, the therapist will often make a judgement on whether the parents have 'accepted' the child's disability. Dovey and Graffam analyse this notion of acceptance in terms of a pathological and a normative model:

> The pathology model really views the entire experience as a process of moving from shock/trauma to healing/acceptance (note the medical connotation). Hence initial discovery has been associated with shock, ego-damage, guilt, frustration and disappointment. Others have characterized this as a profound tragedy and the beginning of chronic and unresolvable sorrow. Those holding the normative view point out that such reactions do occur, but are quite normal, and that families are falsely treated as though they had no life prior to or other than that ordered by the disabled member…In fact the normative model describes the parent experience as one of periods of intense stress associated with day-to-day living. In short the implications are that the relative impact of disability fluctuates over time, the nature of parental concerns change over time, and this process is not that different from what all parents and families experience. (Dovey & Graffam, 1983: 54)

This certainty that there are specific 'normal' stages of grief attached to the diagnosis of a child with a disability assumes that parents reach an end point in their reaction to the event. Cynics may suggest that therapists are invested in the stages of grief because failure to achieve developmental progress in therapy could be attributed to parents' inability to move through the stages of acceptance. However, the parenting of a child with a disability, as with any child, is a dynamic process that requires flexibility and changing responses within an understanding of how their child manages different environments. The lack of recognition of the normality of crisis periods also means that these are not accommodated within the therapy plan. There is a need to adapt therapy goals toward transition times such as going to school and vocational training.

In our experience, the professionalisation of assistance to parents of disabled children is a disempowering experience for parents, in much the same way that disabled adults have experienced disempowerment through the professionalisation of their support services. In our experience, the general expectation of society is that parents will do what is in the best interests of their children and this assumption need not fall away where the child is disabled.

Parents know better than anyone that raising a disabled child involves extra challenges, and that parents consequently need support. Our concern, though, is that parents are not deciding what form this support should take – professionals are. It is as though the responsibility for the disabled child belongs less to parents, and more to professional helpers. This is often seen in rural communities where, as a result of years of a medical and welfare approach to disability, disabled children are seen to be the 'government's child'. The paradox here is that while medical and welfare professionals undermine parents' confidence in their ability to do what is right for their child, they depend almost entirely on parents or caregivers to implement what those same professionals perceive to be the correct approach. Exclusion from society begins at home in these circumstances, where the disabled child is constructed as being so different from other children that parents are not trusted to do what is best for him or her.

There is another dimension to this relationship between parents and therapists. Rehabilitation therapists tend to rely on mothers – rather than both parents – to have an impact on their child. When a home programme is developed, it is the mother who is typically expected to implement it. A study by the Joseph Rowntree Foundation (Kagan, Lewis & Heaton, 1998) in the UK found that hospitals and other health-care providers, social services and schools did not take account of parents' work hours. There was a widespread assumption that mothers of disabled children did not work outside the home and were available at any time. Constructed in this way, caring for a child with a severe disability can be a full-time occupation for the mother, which can have severe economic and emotional consequences. Coleridge (1993) points out that the implementation of community-based rehabilitation relies heavily on the family in achieving its impact. He argues that this is precisely what has been happening all along and that more thought should be given to creating space and respite for mothers, rather than imposing additional burdens.

Questioning the notion of partnership

In the light of the above discussion, we would like to ask the question: does a partnership exist between parents and therapists? We do not deny that it may develop in certain cases, but in light of the issues discussed above, it is unlikely to be the norm.

This brings us to a second, more difficult question: is a partnership the kind of relationship that we should aspire to in conceptualising the intersection between parents and therapists? Within the current model of service delivery, we think not. The medical model within which therapists operate limits their understanding of the needs of our children. With partnership comes a sharing of control and decision-making which we sense many parents are reluctant to relinquish to therapists. Further, given that the 'partnership' is dependent on the payment of fees, the notion of a partnership is dishonest. It is a consumer-client relationship, not a partnership. Where payment is not an issue (such as in the public sector), parents are even more vulnerable as they can demand only limited accountability from the therapist.

Schoeman and Schoeman (2002) portray the helping professions as tools of societal control ever in search of new markets, which can only be found through the further labelling and manufacturing of deficiency. They argue for a community vision in which clients become citizens. In such a community, difference from the norm is not identified with fallibility but rather all forms of diversity are embraced as enriching the society. In this view, the question of partnership is not between helper and helped, but between equal citizens. Clearly, in the current context of professionalisation of 'support services', this form of partnership cannot exist.

The relationship is therefore best understood as a collaboration, rather than a partnership. The vision here is one of collaboration in achieving goals jointly developed between parent, child and therapist, utilising the specific skills of the therapist to best effect. Parents should be empowered in their own decision-making to the extent that therapists become positioned as a resource to be called upon to reach certain goals. This can only be achieved through the sharing of experience by parents, and the development of strong parents' movements that can provide support and information regarding the available options and resources. Therapists are called to ask themselves whether they do in fact have appropriate skills to support their clients and their clients' families, and how they can share these skills through an empowering relationship.

A step toward achieving this new kind of relationship is being made at REHAB, a disability NGO in East London, which runs a pre-school programme for severely disabled children to prepare them for admission into mainstream education. Parents participate in a process based on 'choosing accommodations and outcomes for children' (COACH) devised by Giangreco (Giangreco et al., 2000). The purpose of this process is to identify parents' priorities for their children's progress. These priorities form the basis from which the child's educational goals are developed. The therapist's role within this context is to apply his or her skills to the achievement of outcomes that have been identified by the parents. The following case example illustrates the process:

> Aphiwe is an intelligent child of four years old who has cerebral palsy which makes his gait very unstable and limits the use of his hands. He has a strong will and an engaging personality. His mother identifies the following priorities for him: developing the use of hands and legs; dressing and undressing; washing hands and face; combing his hair; drawing; working independently; participating in group work.
>
> The educators and therapists at the school and the parents undertake to work on these priority areas in the coming year with a review in six months time. The physiotherapist advises the school and the home on methods for increasing his control over his limbs and examines ways in which positioning can help him to achieve the other goals, for example, drawing and washing his hands and face. Therapy is integrated into the overall goals for the child and is delivered in the school setting.

In this situation, the therapist becomes positioned as a resource to the parents and school. Parents are given a strong decision-making role through the COACH process, and will be given the opportunity to evaluate the effectiveness of the programme. The consultative method and the delivery of therapy services within the school are also mechanisms that ensure therapy is more accessible to parents who work, and therefore cannot access individual therapy.

Looking to the future

A negative picture of the relationship between therapists and parents has emerged from this discussion. Therapists may respond by saying: 'What do parents want us to do? Are they saying that their children don't need help?' Therapists certainly have an important role to play. But that role, as well as parents' roles and the relationship between them, needs to be re-examined. These issues raise an important debate that must be opened and continued.

The trainers of rehabilitation professionals must undertake a critical examination of the impact of the medical model on their service delivery. It is not enough to attach a course in Disability Studies to their training programmes, or to invite a few speakers from the disability rights movement to give a lecture. A much deeper examination of their own understanding of disability, and how this is reflected in their training, is needed. Crucial to this debate is that the majority of therapists work in the private sector, where payment for services occurs through medical aids based on clinical services provided within a medical model. While this may be appropriate to the treatment of a sports injury, it is not necessarily appropriate for a child with a severe disability. It also does not assist with community-based rehabilitation provision. A key question is whether the training institutions will continue to prioritise training for the private sector, which is dependent on medical aids, or develop new programmes that reflect a broader understanding of disability issues.

The provision of a holistic service requires that careful thought be given to how the skills of different rehabilitation professionals can be integrated. Community-based rehabilitation programmes have produced rehabilitation professionals with a broad knowledge base who can meet a wide range of developmental needs. Is specialisation in different areas of development the most useful way of doing things? Is there a possibility that specialisation could be organised around transition times, such as schooling or employment?

Issues of equity and affordability of rehabilitation services must to be included in the ongoing processes of health sector reform. Professional bodies, government and training institutions need to examine why there is a preponderance of rehabilitation professionals in the private sector. Is it through lack of planning for their role in the district health and education systems? Does the problem lie in their training? These and other questions need to be asked. The preceding discussion argues that rehabilitation services be reconceptualised as a resource to parents that supports them. This requires the development and application of new skills in facilitation of community process. Whether therapists will develop these skills or work with community facilitators is an open question.

Therapists are called to move their practices into communities and the real life situations of their clients. These practitioners must ensure that they are aware of policy changes that affect their clients' expectations. At the same time, parents must be made aware of their rights and responsibilities with respect to inclusive education and potential employment for their children. Parents need to empower themselves by establishing support groups and sharing information so as to facilitate their disabled children's development – in the same way they do for their nondisabled children. As part of this process parents' experiences and views need to be documented in a systematic way. Research into the needs of parents with disabled children is thus a necessity.

In conclusion, parents acknowledge the need for additional support for their disabled children. The dilemma for parents and therapists is how much intervention is useful and what kind of intervention? A child with a severe disability needs help. But to what extent should this help take the form of trying to correct the disability, or working harder to integrate the child within society? These are not mutually exclusive and both should be happening simultaneously; the difficulty is in striking the balance. It is only through continued debate and sharing of experiences that we will make progress here.

Note

1 See www.babytherapy.org.za/cerebral.html

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Section VI
Disability and human spaces

23 Disability and universal access: observations on housing from the spatial and social periphery

Justine Coulson, Mark Napier and Gertrude Matsebe

Basis for the study

This chapter is based on work undertaken for an international comparative study on 'enabled environments' which included case studies in Pretoria (South Africa) and New Delhi (India).[1] We focus here on four South African case studies. Both the Indian and South African national governments have adopted disability rights measures and made attempts to move away from the medical model of disability to a social model. The challenge facing both countries is to realise those rights through policy and practice. Both countries present an opportunity to study the translation of rights into practice at the micro-level (UN, 1999).

The research set out to understand the processes by which people with disabilities in urban settlements are prevented from fully participating in the socio-economic development of their community and the wider society, and to suggest ways in which greater inclusion could be achieved in the future. By gaining new insights into the nature of the interaction between people with disabilities and their environment, we wished to achieve a greater understanding of the environmental and attitudinal barriers that hinder their entry into education, employment, training, the full use of services and access to appropriate shelter and public buildings.[2] Having identified these barriers, the research explored practical means to overcome them through consultation with people with disabilities, their families, their communities and the service providers.

This chapter focuses on the findings from the broader research project that relate more directly to access to appropriate shelter (and shelter-related benefits), mobility around settlements and access to public facilities in those settlements. The Habitat Agenda, of which both South Africa and India are signatories, requires that governments provide laws and policies that create inclusive environments so that people with disabilities enjoy full access to new public buildings and facilities, public housing and public transport systems.

The United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) guidelines argue that there are six key elements to achieving barrier-free environments:

- A complete legal system (from law to standards);
- A full set of instruments (for example, master plan, town plan, detailed plans);

- Administrative effectiveness (from permission to control);
- Professional undertakings (from guidelines to expertise);
- Political transparency (openness of information, public attendance and involvement);
- Democratic control (from awareness to participation)(ESCAP, 1995, p.7).

The current study examined the success of local and national efforts in translating accessibility policies into practice for people living in low-income informal and formal settlements. It considered the six elements of the ESCAP guidelines from the perspective of people with disabilities. The project looked at the extent to which the physical environment in low-income neighbourhoods limits the mobility, and thus, the social integration of people with disabilities and asked what measures could be taken to make this environment a more inclusive one.

The shaping and reshaping of South African urban settlements is the shared responsibility of residents, design professionals, municipal officials, local and national politicians, financiers and developers, yet in South Africa the concept of 'universal access' is rarely discussed. Universal access means that individuals should be able to move from home to community to public buildings without barriers in their way, 'to use space in a continuous process – to be able to move around without restriction' (ESCAP, 1995: 1).[3] Rule 5 of the United Nations Standard Rules[4] also draws on the idea of space as a continuous process and understands the 'physical environment' to include 'housing, buildings, public transport and other means of transportation, streets and other outdoor environments' (UN, 1994).[5] Yet there is little currency to the idea that the removal of physical barriers within the built environment is very much the domain of private and public designers and developers of human settlements. Instead, it is often assumed that it is the responsibility of people with disabilities to adapt to the way the environment is designed.

This chapter is about the nature of the interface between the physical environment and people with disabilities in four, predominantly poor settlements in the Tshwane Municipality in and around Pretoria (now Tshwane). It is overlaid by a description of elements within the socio-legal environment which attempt to moderate the physical and non-physical barriers that disabled people face when trying to access better housing and living environments. Living in shacks in informal settlements, in older township houses, or in recently constructed government subsidised 'RDP housing', presents its own set of challenges of limited space and access to social and economic opportunities, compounded by conditions of relative poverty and spatial marginalisation.

Formal low-income housing neighbourhoods are the settings in which the built environment form has been created and recreated with scant attention to achieving universal access and ease of movement. Successive state manifestations (colonial, apartheid, and democratic) share the burden of this scant attention, with the current challenge being to address widespread poverty, inequality and large housing backlogs in a context of extreme spatial dislocation and the ongoing prevalence of significant social and physical barriers. It is demonstrated that these urban dysfunctionalities are experienced most acutely and practically by people living both in poverty and with disabilities. As Imrie (1996) has observed, despite the increased awareness resulting from global programmes focusing on disability issues (mirrored in the South African policy discourse), people with disabilities continue to be disproportionately represented amongst the poor, the unemployed and the uneducated. In South Africa, being poor and historically marginalised often means having to live on the distant fringes of cities and towns (see Lemon, 1991), which further exacerbates the difficulty of mobility along with profound feelings of dislocation for other people who live with disabilities.

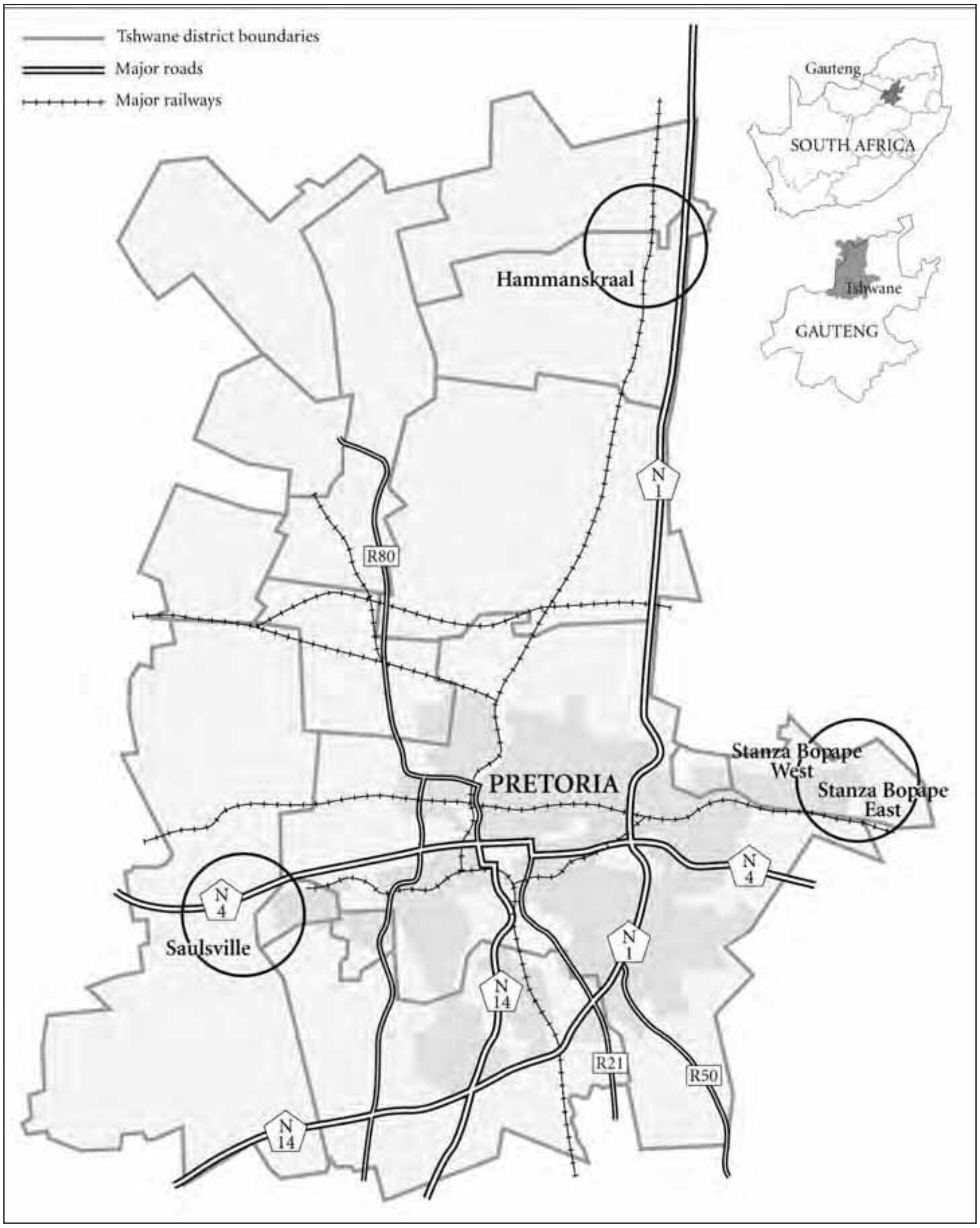
Methodology

Adopting the social definition of disability meant that we studied the quality of the linkages between people with disabilities and their physical, social and economic environment. The term 'impairment' is used to refer to an individual's condition, which can include physical, sensory, intellectual or behavioural impairment. The project adopted the World Health Organization (WHO) definition of impairments, which are defined as 'problems in body function or structure such as significant deviation or loss', and activity limitations, which are defined as 'difficulties an individual may have in executing activities' (WHO, 2001, short version, p. 12). The majority of the participants in the research project have either a sight, hearing, physical or intellectual impairment (or illness)(i.e. the impairments causing disability as listed in the Disability Rights Acts in both South Africa and India). However, the emphasis was placed not on identifying people through their type of disability, but on including those people who identify themselves as experiencing the WHO concept of a 'restriction or lack of ability' in doing various activities.

The project, which spanned two years, worked as far as possible with a participatory action research (PAR) approach to explore the nature of the relationships that people with disabilities living in low-income urban settlements maintain with their families, their communities, service providers, employers and their physical environment. A PAR approach is important, as many people with disabilities complain that services and other measures are put in place by well-meaning organisations, without consulting disabled people themselves. A failure to use local knowledge of disability that only people with disabilities themselves can provide, often leads to inappropriate provision and measures (Metts, 2000).

Four settlements were selected around the city of Pretoria (see Figure 23.1). They were selected to represent settlements informal in nature (i.e. temporary building materials, not full property title to the land, not fully serviced) and where poverty was a dominant part of life, but where government interventions through the national housing programme were also evident.

Figure 23.1: Map of the Tshwane Metropolitan Area showing the location of the four settlements included in the study.



Other important factors in the selection of these settlements were that community-based service providers were active in offering general services to people with disabilities and that researchers had some previous experience with these communities. The four areas selected were Stanza Bopape East and Stanza Bopape West (east of the city beyond the township of Mamelodi), Saulsville (west of the city beyond Atteridgeville) and Hammanskraal (far north of the city).

The last was the most distant settlement and was similarly located to one of the four Indian case studies (named Bhatti Mines) on the distant fringes of Delhi. The other three South African settlements were more typically located on the far sides of older, traditional township areas where informal settlements and new government greenfields projects are common. The settlements are typical of freestanding informal settlements which comprised 12.3 per cent of the national housing stock during the 2001 Census (Stats SA, 2002), and formal government subsidised housing which comprised 10 per cent of housing stock at the time.

Table 23.1: Case study area characteristics: communities at a glance

Area characteristics	**Stanza Bopape East & West**	**Saulsville**	**Hammanskraal**
Distance from central Pretoria (approx)	30 km (east)	15 km (west)	50 km (north)
Origin	Land invasion 1990 by township & rural homeless	Land invasion 1990 by township homeless	Land invasion by rural migrants managed by traditional leaders
Settlement types	RDP* and informal	RDP and informal	In-situ upgrading and informal
Number of households	14 229	7 309	1 325
Average household size	3.66	6.16	4.99
Households living in shacks (%)	50	60	80
Population unemployed (%)	49	41	41
Households with monthly income under R12 000 (%)	42	26	46.5

Source: Municipal Demarcation Board, (2002–2006)

Note:* New formal settlements constructed as part of the original Reconstruction and Development Programme (RDP) and now as part of the subsidy programme of the Department of Housing.

In each community, the project identified key community members who had experience of disability issues as community facilitators for the research. The community facilitators were responsible for identifying potential participants for the study, inviting people to key events, assisting with or carrying out the reconnaissance and main surveys, and serving as information contact points and resource persons for other participants on the study from their own and other communities. They became integral to the research, actively directing the focus and making and maintaining contact with the participants.

In constructing our sample, a key concern as a project that set out to be participatory was to identify a size of sample that was large enough to allow us to highlight patterns of experience and small enough that it was manageable for a single full-time researcher.[6] We decided to work towards a sample of 50 people in each of the four research sites; in the end 186 people participated (see Table 23.2).

It was important that our sample included people willing to participate in workshops and site visits, representing amongst them a range of types of disability, all age groups, both genders, those linked and not linked to service providers, employed and unemployed, having different levels of mobility within the plot, the community and the city and beyond, and those who could be reached by the community facilitators.

Table 23.2: Types of first impairment compared to national average

Project				**National**	
Classification	**N**	**%**	**%**	**%**	**Classification**
Blind	6	3.2	9.1	26	Sight (Blind and low vision)
Low vision	11	5.9			
Deaf	8	4.3	6.5	14	Hearing (Deaf and hard of hearing)
Hard of hearing	4	2.2			
Physical/locomotor disability	70	37.6	37.6	25	Physical/locomotor
Intellectual disability/ mental retardation*	36	19.4	40.4	21	Intellectual/emotional
Mental illness	39	21.0			
Speech problem	4	2.2	2.2	3.3	Communication
Epilepsy	8	4.3	4.3	n/a	
				11	Multiple/not specified
Total	186	100.0	100.0	100.0	

Source: National percentages from Stats SA, 2002

Note: 'Mental retardation' was a term that the research team felt was not appropriate. However, it continues to be a widely used and understood term and remains here only for the sake of clarity.

There were a series of elements to the study: the reconnaissance survey, which was a short survey used to identify participants through door-to-door visits, community workshops for the identification of themes important to the participants, informal focus groups on issues raised, interviews with service providers, field visits by participants to make observations of certain environments, the sketching of mobility maps, and a detailed household survey.

General characteristics of the sample

The sample was equally divided across the four research sites – Hammanskraal (25.3%); Saulsville (25.3%); Stanza Bopape East (23.1%); Stanza Bopape West (26.3%).

Gender

Of the sample, 42 per cent were female and 58 per cent male. The UN estimates that worldwide 51 per cent of people with disabilities are women (DAA, 1995). The 2001 South African census reports 52 per cent of people with disabilities in South Africa are female and 48 per cent are male.

Age

Of the people with disabilities, 32 per cent were children (18 years and below), 52 per cent of the people with disabilities were adults aged between 19 and 64, and 16 per cent were elderly adults aged 65 plus.

Household composition

Of households included in the study, 41per cent were headed by women. Only 3.8 per cent of people with disabilities lived alone; 2.7 per cent of males with disabilities lived in male-only households compared to 7 per cent of females with disabilities living in female-only households

In presenting brief examples of the evidence gathered, the following sections move from experiences of the home environment, into experiences of the broader environment of the settlement and city, and conclude with a discussion of people's experiences of the legislative environment, related to the way in which government housing benefits are accessed, and how built environment regulations support or hinder the achievement of universal access.

The home environment

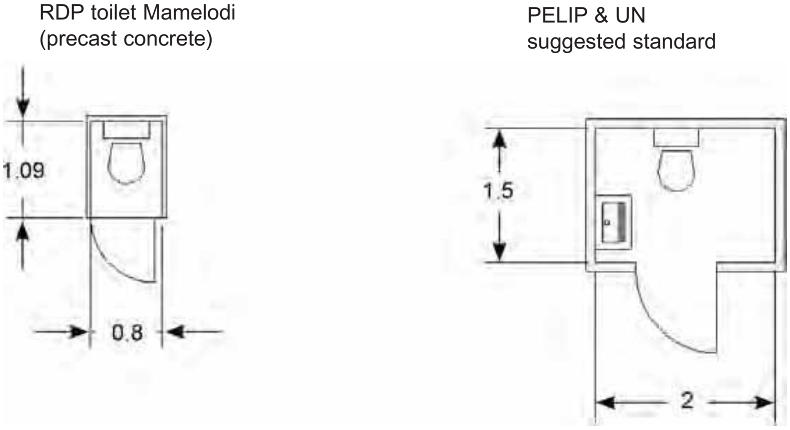
Any discussion on physical accessibility around homes should reflect the fact that homes are being built both by designers and constructors of government housing as well as being designed and constructed by the actual owners themselves, usually as informal housing arising out of a situation of poverty. The level of awareness of both these groups around accessibility needs to be considered. In addition, the Department of Housing recently introduced measures to fund the modification of houses to make them more accessible to people with a limited range of disabilities (DOH, 2000). However, the take up is very small at this stage. By September 2003, only 222 variation subsidies had been approved (DOH, 2003). This is discussed in more detail below in connection with accessing the housing subsidy.

In the workshops, participants in the study outlined a range of issues that related to their homes and the plots on which they lived. The most common issue revolved around inability to use the toilets that had been built on their plots, or lack of access to sanitation. Pit latrines are difficult to use for people with physical or visual impairments, and flush toilets in RDP houses are often inaccessible (Figure 23.2). Others mentioned the need for grab rails to assist mobility, difficulties in making houses secure to keep out intruders (especially for visually impaired people), and problems with incomplete structures and water shortages.

Figure 23.2: Inaccessible toilets in RDP houses

More than half the people in the project sample (51.6%) used a pit latrine as their main form of sanitation. Nationally 30 per cent of the population rely on pit latrines – according to Statistics South Africa (Stats SA, 2002). A further 67 per cent had access to a water tap on the plot, and the remaining 33 per cent used communal taps or water tanks. New government housing is serviced with toilets, either as a separate structure outside the main house, or built within the house.

Figure 23.3: RDP and ESCAP toilet plans


RDP toilet Mamelodi (precast concrete)

PELIP & UN suggested standard

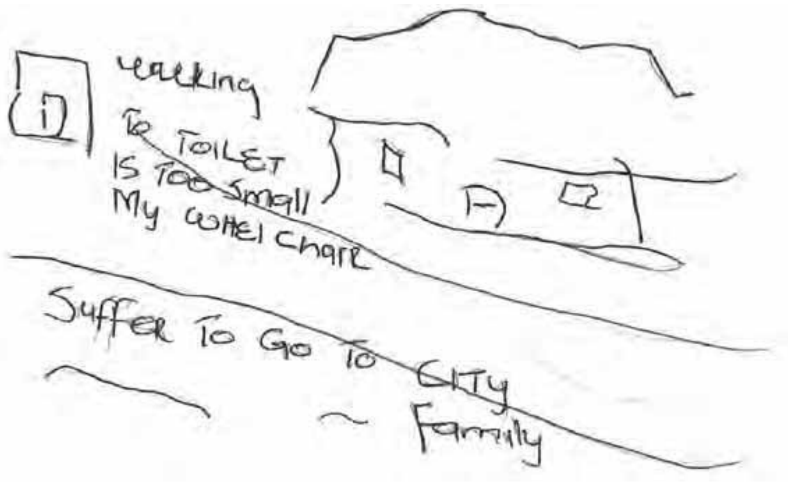
Simply put, the dimensions and layout of typical toilets on plots do not allow people with mobility limitations (including many elderly people) to use them. Figure 23.3 compares a typical RDP toilet with an adequate toilet, according to publications such as ESCAP (1995). The toilet units that have been constructed in Stanza Bopape and Saulsville are made of pre-cast concrete. This makes it more difficult for those households who wish to install grab rails to do so. Sometimes toilets built outside the house are hazardous to use at night because of high levels of crime. At other times, people told us they felt uncomfortable using inside toilets where the extremely small houses allow for little real privacy (Figure 23.4 shows a house plan with an internal toilet).

Figure 23.4: Lack of privacy: toilet in small house

In the informal settlement case study areas, there were no formal toilet facilities, either private or communal. In these cases, households either construct an informal pit toilet or simply dig holes at random over the plot. This lack of toilet facilities is problematic for people with disabilities.

Elias Mahoro[7] is blind and lives in a one-room wooden shack on a small plot with his girlfriend in the Stanza Bopape area. At the workshop, he spoke with some embarrassment about having to dig a hole on his plot in order to defecate. He mentioned the lack of privacy and also the fact that he was dependent on his girlfriend or someone else guiding him to an appropriate spot. Those with limited mobility due to paralysis, muscular weakness or pain similarly face problems when required to use informal squat toilets (see Figure 23.5).

Figure 23.5: Drawing by Elias Mahoro showing informal squat toilets – the only option



On the issue of accessibility in slums, the UN guidelines offer nothing explicit and simply stress that any improvement, rehabilitation and relocation programmes for slum dwellers must address the needs of people with disabilities and the elderly (ESCAP, 1995, p. 19).

Although access to toilet facilities was the main issue raised in workshops, other issues came to the fore during the household surveys. Few participants had either planned to modify their houses and plots to make them more accessible, or had the resources or the position of influence within the household in which they were living, to achieve those changes. Of note is that, when answering questions about difficulty with tasks around the house, most people referred to their own limitations rather than to limitations in the environment in which they were living.

We interviewed 186 people with disabilities and only 34 (18%) responded to a question relating to the problems they faced trying to carry out everyday chores and activities around the house. Given the sample profile, many more people are likely to have experienced physical challenges and the low response rate indicates fairly low levels of consciousness of the relationship between impairment and the physical environment. Many of the people who did respond identified more than one problem.

Seven people discussed problems related to objects being too high for them to reach: not being able to hang out the washing because the line is too high; not being able to get to a storage box because it is on the top of the wardrobe and being unable to use a chair to climb up; not being able to reach things on shelves. Eight people referred to problems moving in and out of the house due to narrow doorways and/or steps. There were five respondents who mentioned uneven, stony or steep surfaces that were preventing them from moving around their plot or from getting off the plot. Four people mentioned the fact they were unable to carry heavy things; this is a particular problem for people living on their own with water taps outside the house. Within a traditional gender-based division of labour, men will often take responsibility for maintaining the physical structure of the house. Three male respondents felt the problems they faced were related to this sphere of responsibility. Whilst not being able to climb a ladder, mend a roof or use a hammer may not seem like a problem that one would experience on a regular basis, it was clearly of concern for these men. One respondent mentioned not being able to cook because she only has the use of one hand and another woman referred to not being able to mend clothes due to her impaired vision.

In light of the problems experienced, it is instructive to review the kinds of home modifications that are catered for by government housing subsidies. Disabled people who are eligible to apply for the housing subsidy (i.e. live in a household with a monthly income of R3 500 or less), are also eligible to apply for an increase in the subsidy amount to cover housing modifications that would adapt their home to their specific needs. Depending on the nature and severity of a beneficiary's disability, the following additional provision may be granted:

- R720 to provide 12 square metres of paving and a ramp at the entrance to a home;
- R300 to provide kick plates to doors;
- R1 100 to provide grab rails and lever action taps in bathroom; and
- R700 to provide visual doorbell indicators. (Department of Housing, 2000, pp. 183–184)

More recently, other modifications have been allowed for. However, our study found that *none of* the people living on RDP sites had applied for this subsidy or had heard of it. The problem would seem to be one of poor advertising. Information regarding the housing modification grant could be disseminated along with information regarding the subsidy variation. Applications for the modification grant are submitted at the same time as the application for the housing subsidy. It is important to note that individuals who acquire a disability after moving onto a RDP plot are still eligible to apply for the modification grant. This should be made clear in order that low-income families avoid spending money unnecessarily – the family of one participant had spent money on building a ramp into their RDP house when they could have applied for a grant.

House and plot modifications which would assist people with partial and total sight impairment (for example, tactile surfaces, the use of colour and lighting) are not catered for adequately in the current subsidy provisions. Low cost, universal-access design solutions, such as not having many level changes between inside and outside spaces, have also not been mainstreamed in design circles.

This briefly describes the home environment. We shall return shortly to individuals' experiences of trying to access the housing subsidy.

The settlement environment

This section looks at the disabled people's environment beyond their home, and considers how broader settlement design and types of servicing affect the lives of people who participated in the investigation.

Formal low-income housing under the current government housing programme is designed to be adapted by people once they occupy that housing. Although the architects and draughtspeople responsible for the design of the housing could make it easier and less costly to modify such housing, there is a great deal that households could do to adapt their housing to their own needs (Napier, 1998). In this sense, attaining freedom from barriers is a relatively surmountable task at the house and plot level, although unnecessary costs do arise because of lack of foresight and awareness on the part of the original designers. It is at the level of settlements that engineers, architects and planners leave a direct legacy which is much more difficult and costly to modify in order to remove physical barriers that obstruct individuals and the community. The creation of formal human settlements represents large infrastructural investment, as does the upgrading of informal settlements. Despite policy (but not legislated) which calls for barrier-free design (ODP, 1997) and many instruments which should guide design at the settlement level (e.g. *Guidelines for Human Settlement Planning and Design* (CSIR, 2000); *National Building Regulations*, Section S (SABS, 1990) and its associated Code 0246 (SABS, 1993)), it is exceedingly rare to see barrier-free design principles applied in South African low income settlements.

When asked about the public realm, there were three areas of concern that were raised by the research participants: roads and pavements, access to public buildings, and access to public and privately owned transport.

Roads and pavements

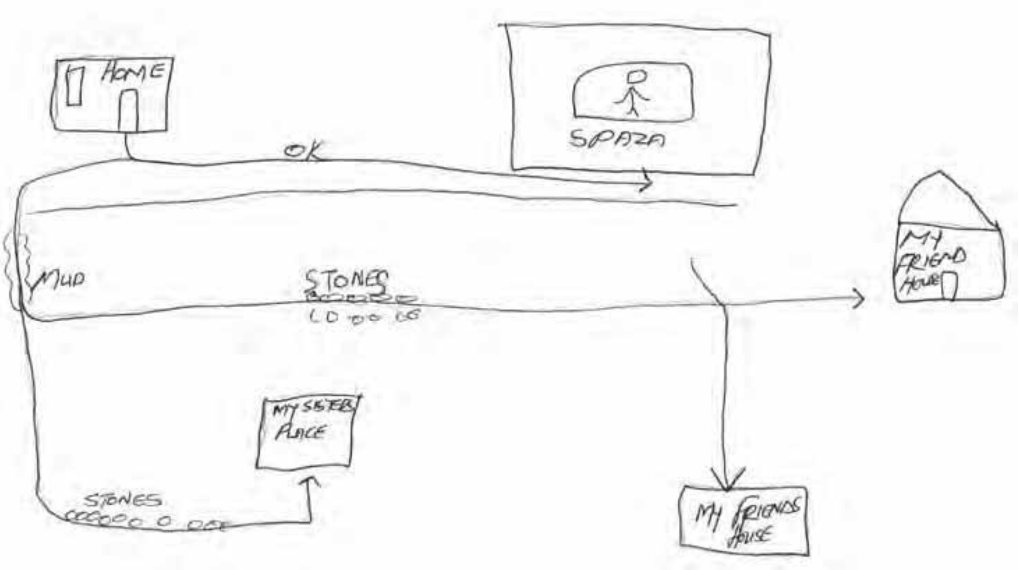
The workshop participants discussed both formally designed environments and informally designed environments. People with locomotor and visual impairments raised the problem of uneven, muddy, rocky and unsurfaced roads, particularly in informal settlements (Figure 23.6). Participants pointed to the difficulties they experienced crossing busy roads, no matter what their disability. The lack of pavements meant that people with locomotor, visual and hearing disabilities were in danger from drivers. High kerbs in more formal areas meant people with locomotor and visual impairment struggled to move on and off roads.

Figure 23.6: Poor roads are a barrier

Whilst one might expect there to be muddy, uneven roads running through informal settlements, what was clear from the workshop findings was that even in new formal developments, insufficient attention is given to integrating barrier-free design features. For example, Mandela Village in Hammanskraal was upgraded in 1995. Yet, despite the development being so recent, the high kerbs (built to prevent flooding during the rain) have no kerb ramps built into them. Workshop participants further mentioned the fact that the roadsides are often uneven or there may be rubbish blocking their route. For someone with limited mobility, veering out into the busy road to avoid an uneven surface or obstacle is particularly dangerous and those with visual or hearing disabilities may be unaware of oncoming traffic. UN guidelines stress that 'pedestrian walkways should be as far as possible from vehicular traffic' (ESCAP, 1995: 64). At a national level, the *Guidelines for Human Settlement Planning and Design* (CSIR, 2000) similarly stress the need for planning to take into account pedestrian movement through a settlement.

Amos Baloyi is a 32-year-old wheelchair user who lives with his two adult brothers and two teenage cousins. He previously lived with his uncle in a formal area, but the family decided to move to an informal settlement to relieve overcrowding and in the hope of qualifying for a government housing subsidy. Their three-room shack is now located in an informal settlement in the Saulsville area. Whilst living at his uncle's house, the surfaced roads and more spacious plot meant that he was more able to move around independently both on the plot and in the wider community. In the informal settlement, the muddy, uneven paths that run between the plots mean that he is unable to leave the plot without assistance. This has severely reduced his independence and the scope of his social life (Figure 23.7).

Figure 23.7: Drawing by Amos Baloyi showing how muddy uneven paths prevent independent movement



Road and pavement design can be altered given the necessary design expertise and without great cost. City-centre areas tend to be designed for greater accessibility (although many of the subtleties and now common in many other countries are ignored). Outlying townships are rarely designed for ease of movement and safety however, reflecting the unequal allocation of resources of the city government to the centre and the peripheries.

Public and commercial buildings

Public and commercial buildings also provide an opportunity to create conditions for universal access. Participants highlighted problems with accessing public toilets in many public buildings, with no provision for places to sit, even at pension offices which were specifically meant to cater to the elderly. The access to many buildings only by stairs (e.g. banks, schools, clinics, railway stations) adversely affected people with locomotor disabilities, and public phones and automatic teller machines were placed too high for wheelchair users.

In commercial premises such as shops, the degree to which property owners catered to the needs of people with disabilities depended very much on the attitude of the owners and managers of the shops, instead of being dependent in any way on formal regulations which might ensure some level of universal access. Research participants visited various public buildings as part of the study.

Peter visited his local general store to assess accessibility. He found that it was difficult to turn corners due to stock being kept in the aisles, and the shop owner agreed to move the stock. Products on the top shelves were difficult to reach and he could not reach products that were at the bottom of the freezer.

During a visit to Saulsville railway station it was found that ticket counters were too high for wheelchair users, toilets were inaccessible, staircases limited access to platforms (Figure 23.10), and the gap between platform and carriage made it difficult to board trains. In contrast, the Saulsville police station, although not yet fully accessible, had been adapted with ramps, accessible toilets and lower counters as a result of the direct lobbying of one of the project's community facilitators a number of years before the research project took place.

Figure 23.8: Saulsville railway station: no access

Public and private transport

After releasing some of the research findings in a public forum targeted at decision-makers and including community-facilitator representation, the comment was made that attention to the 'micro-architecture' of public spaces and buildings was all very well, but if a person could not get from their homes to such facilities in the first place, because of inappropriate public or private transport, then changes in these other environments would be of little value. Although this investigation did not focus on transport issues (in that another DFID funded project was already treating this in detail), some of the greatest barriers reported by participants were in the area of public and private transport.

For people with disabilities living in the four communities studied, the main form of transport was taxis or the public bus system. Overtrading on some taxi routes had led to violent conflicts between drivers' groups, and taxi drivers continued to have a reputation for being aggressive. Public buses are subsidised and mainly run between centres of employment and peri-urban residential areas. Access to road transport was an issue that was raised in all workshops held. The main concerns expressed by participants can be summarised as:

- Inability to afford regular taxi use;
- Negative attitudes of taxi drivers to disabled people;
- Long distances between bus/taxi stands and home or destination;
- Difficulty in getting on and off transport.

Illustrating the combination of these factors is the story of Emily Radebe who is 78 and lives with her 34-year-old daughter and three grandchildren (ages 1, 9 and 14 years) in a one-room shack in an informal settlement in the Hammanskraal area. One place that Emily does like to go is the luncheon club for pensioners that is held at the local community centre every week. Getting from her house to the main road is difficult because of steep, rocky and muddy conditions. Once she gets to the main road to hail a taxi, she faces other problems. The taxis are not designed to be accessible to disabled people and she finds it difficult to get in and out of the taxi and find space to put her walking frame. The drivers are sometimes impatient. A further barrier for Emily is limited finances. Some weeks there simply is not enough money to cover the R10 return fare. Once Emily gets to the community centre, she faces another barrier. Although she can get into the centre itself, the toilet at the centre has a set of stairs at the entrance, making it difficult for her to use. It is clear that Emily faces financial, social and physical barriers when she tries to make a simple trip to her local community centre.

Participants also reported that many drivers do not stop to pick up people with disabilities. After discussion with a taxi owners association, it became clear that the drivers' negative attitude towards disabled people might be attributable to various reasons. For instance, it takes a long time to pick up a person with a disability – particularly those with a locomotor disability – as they are slow to get into the taxi, and folding up a wheelchair is time consuming. This additional time makes it difficult for drivers to reach their expected targets for the day.

Public transport is little better. At the time of the study, there was only one accessible commuter bus in Gauteng Province.[8] PUTCO (Public Transport Company) recently invested its own money in developing an accessible bus as a part of its social responsibility policy. The bus has a wheelchair lift and space for four passengers in wheelchairs. Drivers were well trained in accommodating the needs of people with disabilities. However, the coverage by such transport is woefully limited, and efforts should be made to move quickly beyond pilot projects based mainly on goodwill towards policy and legislative imperatives.

The built environment is designed and created by different actors, from the self-made shacks built by squatters to city-wide transport systems shaped by national and municipal policies. People should be able to move continuously and without difficulty through the built environment. However, it is clear that there are a host of existing barriers, both physical and attitudinal, to this notional freedom of movement.

The institutional and legislative environment

Behind the physical picture that has been sketched above is the policy environment which seeks to develop funding and institutional instruments to improve the built environment. National legislation, housing subsidy provisions and public statements indicate a willingness to create a barrier-free environment. Are the existing regulations and institutions sufficient to create these conditions? This section reports on findings from the study in relation to this question.

Accessing housing benefits

The government housing benefit that is available to people with disabilities includes a housing subsidy, which allows the construction of a typical 30m^2 concrete block house and an additional amount to fund certain modifications to the house, according to the needs of the person with the disability who is applying for the subsidy or is part of the household applying. The uptake of this form of subsidy has been slow. This investigation found convincing evidence that, apart from the physical barriers of reaching municipal and provincial offices to apply for or follow up progress on applications for housing subsidies, there were a range of other less visible barriers to entry.

As none of the participants in the current study lived in households with a monthly income of more than R3 500, all would have been eligible for the housing subsidy. In summary, 39 per cent of our sample lived in households that had already been allocated a formal plot. Of this group, 65 per cent lived in households that moved onto ‘site and service’ plots (i.e. without the initial provision of a formal house), whilst 35 per cent had moved onto a plot with some form of formal shelter provided. Of the total sample, 24 per cent lived in settlements that had been upgraded, with services being installed. Most of this group came from the Hammanskraal research area, where the development of Mandela Village was an atypical case of in-situ upgrading. Of the total sample, 37 per cent lived in unrecognised, informal settlements, in households that were waiting to be invited to apply for the subsidy, in the process of applying, or waiting to be allocated a site.

Moving from the settlement type to the house type, Table 23.3 outlines the frequencies of different types of shelter occupied by people with disabilities in the sample.

Table 23.3: Dwelling types occupied by sample

Type of dwelling	Frequency	%
Backyard shack	16	8.6
Backyard room	3	1.6
Main shack	128	68.8
Main house – formal complete	11	5.9
Main house – roof house*	1	0.5
Self-built house	27	14.5
Total	186	100.0

Note: – ‘Roof houses’ in Mamelodi are special variations of the RDP starter house. A corrugated iron roof on an iron frame is constructed with only the toilet being enclosed. Residents are expected to add the main walls, windows and doors.

Rather than dealing with random individual applications, participants in informal settlements were asked to wait until their ward representative was advised by the local councillor that they could put in a group application for all the residents in the ward. Residents may live in the informal settlement for a number of years before being invited to apply. Some of the research participants complained of waiting five years or more before being invited to apply. From the time of application, residents may have to wait for up to another five years.

In the application process, evidence was gathered of discrimination in the subsidy application that related specifically to the participants’ disabled status. A number of single adult men mentioned the difficulty they faced in accessing the housing subsidy. The Housing Code states that someone is eligible for the housing subsidy, if ‘he or she is married or co-habiting’ or if ‘he or she is single and has dependants’. As most one-parent households in South Africa are headed by women, there is a popular understanding that in order to be allocated a house, a man must have a female partner or dependents. This is in fact not the case, and the Housing Code waives these conditions for people who have a disability.[9] However, this waiver has not been widely publicised and many officials and residents are unaware of it. In fact, none of the 186 participants, nor the social workers who specialise in disability issues, were aware that there was a waiver on the standard qualification criteria nor that there was an additional variation subsidy that would allow people to improve accessibility in and around their houses.

In general, discussion in the workshops picked up on the fact that many men with disabilities are unmarried, and there was a suggestion that it was more difficult for them to find partners. The groups also discussed the fact that as a disabled person, a man had less likelihood of finding employment and therefore had only the disability grant as income. The grant of R620 a month (at the time of the study) was insufficient to allow a man to save enough for '*lobola*' (bride price), and to cover the cost of maintaining a family.

Although no female participants brought up the issue of applying for their own plot or house, this should not be taken as an indication that independent home ownership was not equally important for women with disabilities. It may be that women are confident that once they start a family, they will be able to apply for a plot. However, this obviously means that those women who discover they are infertile or fail to find a partner will be forced to continue to live as adult dependants. As 57.4 per cent of the women in our study aged 18 years and above lived with their children, it may be a problem that fewer women have had to confront. Of all the adult women living in government-subsidised housing, 36 per cent were household heads, which suggests that over a third of adult women with disabilities have not experienced difficulties accessing the housing subsidy under the criteria of a 'single person with co-dependants', regardless of their disabled status.

The situation is very different for adult men with disabilities. No male with a disability aged over 18 years who lived with his own children lived in a household of more than five. In contrast, men without children lived in households with up to 10 members. In stark contrast to over 50 per cent of adult women with disabilities living with their own children, only 5.7 per cent of all adult men with disabilities aged 18 and over lived with their children. For the men in the workshops who raised this issue, their experiences of being unsuccessful in applying for a housing subsidy meant that they were forced to continue living as an adult dependant within an extended family, or remain in a shack. The problems that participants mentioned in relation to living as a dependant included overcrowding, lack of privacy, misuse of the disability grant by other members of the household, and a lack of independence.

Some single men with disabilities reported having responded to the problem of not being able to apply for a disability grant by entering into 'false' relationships, either by entering into an 'arrangement' with a female friend or by setting up a relationship that they finish once the subsidy has been approved. For example, a friend of Johannes Dambuza, who is sight impaired, set up a relationship for him in order to meet the selection criteria to qualify for the housing subsidy. Once he had secured the tenure, he ended the relationship, as it was not a genuine one. Morris Baloyi also has a sight impairment and currently lives in an informal settlement in the Stanza Bopape area. He has encountered problems in securing a permanent site, because as a single man without children, he does not fulfil the requirements commonly believed to be stipulated in the criteria. He has been involved in numerous relationships with the intention of enjoying the benefit of owning a house/site, but each time the site is allocated, the relationship has ended. From these examples, it would appear that the criteria or, in this case, mistaken perceptions about the criteria that apply to people with disabilities, have serious social impacts as people manoeuvre to qualify for benefits that, ironically, they do already qualify for. Several test cases were taken on as part of the PAR process, and participants emerged from the project with a better grasp of the potential benefits available to them. The education of service providers (government and non-government) would be a more wide-ranging exercise.

A representative of Gauteng Provincial Government admitted that there had been little action taken in the past to raise awareness of the disability variation or the criteria which apply. The Gauteng Provincial Government is beginning to tackle the problem. In order to increase the number of applications for the variation subsidy, the government has set up a sub-directorate to assess the effectiveness of the municipal governments' current handling of the disability variation in the subsidy application procedure. A task team has been formed to ensure that the information on the subsidy is widely disseminated. However, an interview with a training officer linked to the task force in August 2002 revealed that, so far, training has only been offered to housing officials at the municipal level.

Whilst this awareness raising is welcome, it is a vertical, top-down model of dissemination and as such fails to address the issue of awareness at the community level. This study has shown that, for the individual person with a disability, the housing subsidy application process is experienced as a complex and somewhat fraught relationship between applicant, councillor and ward representative. The applicant is essentially passive in the process, waiting to be invited to put in an application. For the participants in the study, their understanding of the housing subsidy is shaped by the incomplete knowledge of the ward representative, whose understanding of the subsidy in turn comes from the councillor and his representatives.

There is a clear need for widespread awareness-raising amongst officials and politicians responsible for allocating subsidies and other benefits, both to address their knowledge of the regulations which they are charged to implement, and to address attitudinal barriers that they place in the way of people who approach government in good faith. At the same time, to increase informed demand for the subsidy and variations, a targeted communications campaign is essential. If people with disabilities, and the wide range of lobby groups that represent specific interest groups, are to mobilise to access the benefits that have been designed to meet real needs, then a more active pursuance of the rights of disabled people in the housing arena is warranted. The degree to which people became networked and begin to achieve greater access to services through this limited research project is evidence that higher levels of organisation, coupled with sound information about benefits, is a potentially empowering combination.

Building regulations and guidelines

Given the evidence about the barriers that exist to accessing both benefits and moving through the physical environment, one might think that the regulatory environment is non-existent when it comes to universal access. However, a great deal of work has been done around the regulatory environment. The *National Building Regulations* of 1986, Section S, refers specifically to the design of more accessible buildings (SABS, 1990). There is a more detailed, associated Code of Practice (SABS, 1993). However, the regulations provide themselves with what appears to be a 'let-out clause', as they state that 'economic considerations may make it difficult to provide facilities in all buildings'. Furthermore, the guidance in Section S of the building regulations does not apply to dwellings and therefore there is no requirement that designers and builders involved in constructing dwellings take note of Section S. Similarly, the status of the Code of Practice is ambiguous, it not being clear whether it is afforded the same force in law as the original *National Building Regulations*.

Section S of the *National Building Regulations,* fails to consider the obstacles and inconvenience caused by reflective and otherwise misleading surfaces, or the use of tonal colour and contrast, which affect people with sight impairments and people with intellectual disabilities. In fact, many of the more recent innovations which address a wider set of types of disability are ignored.

The South African Human Rights Commission's (SAHRC, 2002, p. 28) review of built environment legislation and disability also highlighted the point that there is currently insufficient enforcement of Section S by building control officers, which has resulted in the majority of public buildings in South Africa being inaccessible.

The *Guidelines for Human Settlement Planning and Design* (CSIR, 2000) stresses the importance of designing settlements with the pedestrian in mind. However, consideration of the disabled pedestrian is limited to references to ramps and access for paraplegics (CSIR, 2000, Ch.5.3), consideration of wheelchair users (CSIR, 2000, Ch.5.4), and 'sloped openings in kerbs' (CSIR, 2000, Ch.8). Wheelchair users are not the only disabled people whose needs must be integrated into planning. In a country where the most common disability is sight impairment, there should be a greater consideration of people with sight and hearing impairments, and forms of locomotor disability that result in the use of assistive devices other than wheelchairs (Gibberd, 2001).

The Less Formal Township Establishment Act of 1991 was brought in to facilitate the rapid construction of low-income settlements in order to encourage development and stimulate the economy. The Act allows the local authority to give permission to the developer to bypass legislation relating to town planning and building and thus provides a means of bypassing any legislation relating to barrier-free environments for people with disabilities (Gibberd, 2001).

Conclusion and challenges facing South Africa

It is clear from the issues outlined above that planning legislation and guidelines in South Africa fail to fully integrate the needs of people with disabilities through barrier-free design requirements. National design guidelines need to be rewritten so that they include correct, up-to-date technical information, consider the comprehensive needs of all people with disabilities, and take into account the affordability of the measures suggested with an emphasis on low-cost and 'no-cost' interventions. In order to achieve barrier-free environments, guidelines relating to access should be integrated into general guidelines under appropriate headings, rather than being set apart. The legal requirement to comply with accessibility guidelines needs to be made much clearer. The SAHRC report (2002) recommends that legislation must be regularly updated, strictly monitored and imposed, and the repercussions of non-compliance made much clearer.

At the same time, people with disabilities and organisations which represent disability rights can take a greater role in improving mobility, by becoming more aware of the physical adjustments that can be made in the home and settlement environment. Although awareness of the physical environment as barrier can and should be heightened, the fundamental issues of affordability and empowerment, especially of people living in poverty and with disabilities, remain key challenges.

Until the changes outlined above take place, housing settlements that fail to include barrier-free design elements will continue to be developed and disabled people living on low incomes will continue to find themselves unable to move about the communities, towns and the cities in which they live. The earlier discussion about seemingly progressive housing benefits and building regulations, when juxtaposed with the realities of the disabled people living in low-income settlements in our sample, illustrates that in a country where the rights to freedom of movement and non-discrimination are constitutionally enshrined, there remains an immense gap between intention and reality.

The emphasis in the housing field has been on mass delivery to cater for the needs of a very broadly defined notion of demand for housing (see Smit, 1999; Bond, 2000). This is partly justifiable given the magnitude of the housing backlogs that existed in

1994, but has meant that the more specific needs of certain sectors of society have been passed over in the drive towards large numbers of houses. Where provision has been made, we have seen that attitudinal barriers have often frustrated progressive legislation.

In a country where over 16 per cent of the housing stock is informal (Stats SA, 2002) and another 10 per cent is new formal government subsidised housing,[10] it is clear from this investigation that people with disabilities living in these situations continue to confront many physical barriers to full participation in society.

Policies and guidelines exist, but need updating and enforcement. The institutional wherewithal is often not present to deliver on policies, and attitudinal barriers exacerbate the difficulty of accessing benefits. Key to improving the situation is the need to continue to raise awareness of accessibility issues amongst low-income disabled people in order that the fight for these changes can be located where it can be meaningfully articulated.

Notes

1 The project was funded by the Department for International Development (DFID) of the British Government, managed by Dr Justine Coulson through the University of Newcastle upon Tyne, and with case studies co-ordinated by Concerned Action Now, an NGO based in Delhi that specialises in research and advocacy on disability, and the Council for Scientific and Industrial Research (CSIR), a parastatal based in Tshwane.

2 People with disabilities all over the world identify the attitudinal behaviour of the nondisabled as a massive problem they face throughout their lives. This negative social process is often described as 'disabilism' and occurs as a combined and cumulative effect of prejudice, humiliation and discrimination.

3 This document is also available online at: http://www.unescap.org/esid/psis/disability/decade/publications/z15009gl/z1500901.htm

4 These refer to the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Four of the eight standard rules were addressed in this project, namely: accessibility; education; employment; income maintenance and social security.

5 This is Rule 5, Part (a)1 downloaded from http://www.unescap.org/esid/psis/disability/decade/st-rule2.asp#tar.

6 In the South African case, the full time researcher was Gertrude Matsebe.

7 All names have been changed to protect confidentiality.

8 The Johannesburg Metropolitan Area has purchased 15 access buses (double deckers) to integrate both people with disabilities and able-bodied people. Although they started operating late in 2002, they operate from the city centre to the surrounding suburbs and therefore do not go to the townships where the majority of people with disabilities live. These buses were also used in 2003 to help with transport on the International Day for People with Disabilities in areas around Gauteng (including Tshwane).

9 'In situations where the subsidy is being awarded to a household where a member of that household is disabled, a number of exceptions apply: 1. Disabled subsidy applicants need neither be married or cohabiting, nor have financial dependants.' (DOH, 2000, p. 178).

10 This information is based on DoH 2001 delivery figures (http://housing.gov.za). Barriers are also likely to be significant in traditional rural housing stock, accounting for another 15 per cent of housing stock, and an unknown percentage of old township stock.

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24 Disability and homelessness: a personal journey from the margins to the centre and back

Gubela Mji

There are many reasons why I have been drawn to an intersection between disability and homelessness, but perhaps the most significant has to do with where I come from and how I was raised. I was born in a rural village that by today's standards one would describe as impoverished, though that is not how we thought of ourselves. Sharing was the norm and was not questioned. There was no sense of competition between us. I should also add that there were no people without homes in our village. There were disabled people in our village and they lived with their families. Among disabled children, those who did not have severe impairments attended the local school. Unfortunately, as in the rest of the country, disabled people in our village were stigmatised and some people in our community deliberately marginalised them. Disabled children were called *umntwana karulumente*, a child that belongs to the government, because it was seen as the government's responsibility to care for disabled children.

I was particularly close to my grandmother who I like to remember as a human-rights activist. She was a teacher by profession but was incapacitated because of asthma. She was an ardent reader and listened to the news on her little battery-operated radio every day. Many people used to come to her for advice. She never openly told us to feel passionate about issues of social justice and social development, but she was an important influence on our beliefs and attitudes.

How did I come to be a physiotherapist? My grandmother drummed it into me again and again that to succeed in life you need a professional training of some kind. I wanted to help injured people get back on their feet again and since it was my understanding that physiotherapy was a helping profession, that was the direction I chose. Today I am an educator in the field of physiotherapy and rehabilitation living and working in Cape Town. I have always thought that professions shape individuals, and as I have grown in my profession, my grandmother's nurturing has stayed and grown with me. I feel I chose physiotherapy as my profession because I knew it would allow me the room to promote social justice, a desire already planted deep inside me by my grandmother. Consequently, I also feel that I was ready for a topic concerning homelessness and disability to emerge, as I was also emerging and turning to face myself. What I didn't realise was how this topic was going to affect my life.[1]

Drawing lines between biases, facts and hearsay

I was approached by fourth year physiotherapy students to help them with their mini research project. The topic, the impact of disability on homeless people, excited me very much as I saw in it a new line of enquiry for physiotherapists. At that time, I was still very much caught up in the medical model of rehabilitation and research. I had not yet been exposed to the methods of qualitative research and the importance of examining the relations between people and contexts and considering these relations as producing meaning (Gubrium & Holstein, 1997). Mine was a far more clinical approach. My training had focused on describing the pathology and treatment of a great variety of impairments brought about by medically defined conditions, including strokes, cerebral palsy, and head and spinal cord injuries. Not only was I unwittingly disadvantaged by my clinical training, but my many assumptions about homeless people would also soon be challenged. Most of the homeless people I had previously been exposed to irritated and disturbed me by knocking at my door asking for something. My stock response to these 'intrusions' into my life was detached tolerance. Having committed myself to supporting the fourth year students, I thought about the seemingly insurmountable problems faced by disabled people, whose homes I had observed. I couldn't imagine how a disabled *and* homeless person could meet their needs on a daily basis, let alone make their voice heard.

I started reading about homeless people. I discovered that homelessness resulted from a combination of factors such as loss of job, family and health problems (Clarke, et al., 1995). The draft summary paper from the Conference for Homeless Persons held in 1995 (*The Haven News,* July 1995) identified increasing unemployment, lack of affordable housing, social disintegration and social and economic policies as contributing factors to homelessness in South Africa. *The Haven News* (April, 1996) mentions many other reasons that drive people onto the streets, including alcoholism, divorce, abuse and mental-health problems. In a recent study (Mji, 2001) a majority of homeless disabled people identified disability as the main contributor to their poverty and homelessness. Some complained that after their discharge from hospital following an accident or other incident, they had neither work nor place to stay. Their employers were not prepared to re-employ a disabled person and their landlords evicted them for overdue rent. These complaints are supported by Plumb, who notes the snowballing effect that underlines the vulnerability of society's poor:

> The working poor live on a precipice that can tumble them into homelessness any time. An illness, or an unexpected layoff, brings missed pay checks which lead to skipped utility or rent payments, which snowballs into penalties, which ends in shutoffs or eviction. That leaves a Hobson's choice between no place at all or city-run homeless shelters, which often are dirty, noisy and unsafe. (Plumb, 1997, p.973)

I knew that in South Africa, our constitution guarantees certain basic rights for all citizens, including rights to access health services, housing, water and sanitation, employment opportunities and education. Yet as I read more, I asked myself whether homeless people with disabilities were able to gain access to these fundamental rights? I wondered whether homeless disabled people were utilising social rights like disability grants? And if not, what does this suggest about the constitution's power to guarantee fundamental rights? What does it mean to be a South African citizen, if access to fundamental rights is unequally distributed between the citizenry? Social networks connect people and can be a powerful resource for collectively organising around shared concerns. Social networks can empower individuals (Friedemann, 1992). I wondered what kind of social networks connect homeless people with disabilities? I wondered with Murray when s/he asks, 'Who speaks for homeless persons during health-care reforms? What are the needs and resources of the homeless persons?' (Murray, 1996, p. 18) Homeless people are still widely perceived as being dirty, dumb, wanting in skills, drugged, irresponsible and prone to violence. In Cape Town, they are associated with stolen supermarket trolleys that are overloaded with mouldy possessions. Society regards them with suspicion and sees them as needing to be controlled, institutionalised and managed (Friedemann, 1992).

After the physiotherapy students completed their study, we had a reflective session. The students were sad. They wanted reassurances from me that I would take their research further and actually begin to address the needs of homeless disabled people. I wanted to explore this topic further, but was struck that, despite also feeling sad, I did not feel the depth of the students' sadness. I realised that I had yet to spend time with homeless disabled people and had yet to experience their lives beyond my own irritations and prejudices. I realised that I had to listen to homeless people themselves.

In December 2000, I lived for a week in a homeless people's shelter. At this shelter, 20 per cent of residents had impaired mobility and 25 per cent had mental disabilities of various kinds. During my stay, I assisted with the daily functioning of the shelter and assisted where needed. In the afternoons, I spent time with some of the disabled residents, speaking with them and listening to their experiences. A suitable private environment was created where I could conduct interviews and record their life stories undisturbed.

I found the experience as profound as any in my life. Try as I might to be open minded, when I began my 'internship', I found I could neither compensate for my ignorance nor overcome my prejudices. At the first few one-on-one interviews, I noticed my fear and a sense of danger at being in a personal and intimate space with a kind of person I had always taken to be rude, violent and drunk. And yet when I listened to someone's life story, their problems, fantasies and struggles, something began to change. I was faced with the dilemma of wanting to hold on to something to distinguish 'this kind of person' from the kind of person that I am. At the same time, I found myself recognising myself in their problems, fantasies and struggles. These biographies did not fit stereotypes of homeless people; they spanned the continuum of real life. I had difficulty containing my emotions and feelings. I felt angry at what I saw as exploitation of homeless disabled people and discomfort at recognising my complicity with it; sadness at what I saw as lost opportunities; agitation because I could not find a quick solution to both the social and rehabilitation problems experienced by the people with whom I was living. And I felt a deep concern at how far I had travelled from my rural childhood into the abstract violence of Cape Town's urbanity, a social violence underpinning and underpinned by the abstract violence of my professional training and its attendant medical-scientific categorisations, codifications and pathologies. I was rediscovering in conversations with homeless disabled people a capacity that I recalled from my childhood to recognise myself in others, a capacity that had been slowly eroded by the rationality and instrumentalism of my medical training and the bureaucracy and alienation of urban living.

The life stories and experiences of the people I interviewed and with whom I spoke tended to revolve around the barriers that impeded what they saw as their 'progress' or their ability to participate in the shelter-community and the world beyond. Interestingly, health services were not seen as a priority in their hierarchy of needs, a finding supported by Murray (1996). The most frequently reported needs were more shelter, more contact with friendly and responsive people, speeding up the processing of disability grants, food and clothing and discounts for homeless disabled people. The majority of the people I spoke to did not consider themselves to be any different from abled homeless people and suggested that lacking a limb was insufficient reason to set them apart. They argued that concentrating on what they can do gives them a positive outlook on life. Some of the salient themes are discussed below.

Some homeless disabled people with whom I spoke saw their impairment as a burden. One person said, 'I feel like I am being ignored by people who work in the hospital because I have got more needs and require assistance'. Another said the fact that he is homeless drew attention away from his needs and that he was treated poorly because he was homeless. He wonders which is the greater issue, 'Am I disabled or homeless or both? I cannot tell'.

One participant complained that her leg hurt more in the cold and exposure of sleeping on the street, 'When you are outside its not like being here, here you are sheltered'. Impaired mobility increases the need for accessible transport and homeless disabled people become reliant on a van that the shelter provides irregularly. Mobility impairments, often following an accident or after many years of manual labour, further curtail already very limited opportunities to earn income.

One respondent complained, ‘I have been a worker all my life. Now I cannot work except doing odd jobs and household chores’.

Sweeney (1993) says that homeless people are likely to receive poorer quality health care than others and are subject to greater risk of disease due to their life style. Furthermore, it is difficult for homeless people to ask for help because prejudices against them mean that attracting a supportive or concerned response is next to impossible. Plumb (1997, p.974) supports this view, ‘as health-care policy continues to encourage the transfer of the medical care of the poor (including homeless people) into managed health-care systems…gatekeeping mechanisms designed to ration care may lead homeless adults to further avoid seeking care in the early stages of illness if the care-seeking process becomes more arduous or time-consuming’.

Each homeless community will have different demographics and health needs. The common denominators are the obstacles encountered in trying to access resources and health-care facilities; bureaucracy, transportation, accessibility, time and limited resources all lead to frustration, anxiety and avoidance.

Many participants experienced the shelter as a hostile, unstable and demeaning environment that discouraged residents from asking for help. As one person put it, ‘If you ask people why they insult other people, this makes me not like to ask people for something’. Life at the shelter was also reported to be overly regulated and restricted and the staff were said to lack sympathy for one’s specific impairments. One respondent complained, ‘…you are kept here and you are given work…this leg is very painful, but I don’t say anything because of fear of being chased out’. Participants experienced the strict regimen and perceived lack of empathy as demeaning, ‘I have to stay in like a child, and I must stay here like a convict’. Ultimately, the most sustained complaint against the shelter’s social environment is that there is little respect for the humanity of homeless disabled people. After a tirade of complaints against the management and social environment of the shelter, a respondent ended with a plea, ‘I want dignity, care and respect’.

Homeless people struggle to adjust to the environment of the shelter. When adjustment fails, the increases in stress can cause or exacerbate physiological/psychological disorders and violence. As stress increases, more energy is needed to meet life’s necessities, coping with the behaviour of others and defending one’s physical, material and psychological space. This can lead to more stress and so a vicious circle is set in motion.

The issue of family support was a particularly sore area for many participants. South Africa’s post-apartheid government has implemented a policy of reintegrating disabled people with their families, especially those with mental health problems. Though this policy has important merits, many of the participants in my study recounted stories of abuse, neglect and deprivation by some members of their families. Poverty and unemployment is an important factor here and the monthly disability grant is often the only regular source of income for the entire household.

Spending the grant, barely sufficient to meet the needs of the disabled person for whom it is intended, is seldom controlled by the disabled person whose needs are often relegated down a list of priorities that favours the wider household. Inevitably, the disabled person begins to identify the family as an oppressor and ultimately sees the streets as a viable solution, 'My family doesn't treat me nicely; they don't treat me like a brother, they treat me like a stranger'. This was echoed by others, 'I used to stay with my daughter, and she married a man who doesn't work. When he is in the house and I am out, he steals my money. I couldn't take it anymore.'

Perhaps not surprisingly, some participants felt hopeless about their life and thought of suicide. 'My heart is sore. When I tell people about my life story it makes me very upset. That is why I like to keep it behind me. Not all people are good for me here, homeless people are not good and I am very lonely. Sometimes I think to kill myself, and it is the only time then I won't have any problems'.

The fact that homeless disabled people desire interpersonal contact, in addition to satisfying their material needs, cannot be underestimated. Rejection and isolation are so crucial to the plight of homeless disabled people, because personal relationships are fundamental and essential to our humanness and sense of belonging. As Tryssener, Jones and Lee (1999) have observed, the needs of homeless people, whether disabled or not, are no different to anyone else. But there is a significant difference in the extent of deprivation. This is where disability does become an issue, because the isolation, rejection and marginalisation that comes with being homeless is compounded by disability. Most of the homeless disabled people in the shelter expressed a desire to form a disability group, 'we all have an ailment and being one, suffering as a team, we will overcome this'. The value attached to interpersonal contact and support between homeless disabled people was matched with the importance accorded interpersonal contact and connection with able-bodied people who may or may not be homeless. This importance pivoted on a desire to be treated with respect and dignity, 'I mix well with other people because they like me, they respect me, and I like that'.

Family was also valued because it was seen to be a stabilising force in life as well as an important source of support. Some participants wanted to be reunited or reconciled with their families: 'I wish I could have my parents back; I could stay under their roof'. Another said, 'I see, look at married couples and I think I should have got married, my life would be better'.

Isolated and deprived of interpersonal contact or supportive family structures, some homeless disabled people I spoke with developed alternative relationships and found support structures in the spiritual resources of religion, 'Oh yes! I believe in God. I ask Jesus to help me, guide me, and give me strength, and keep me safe in the hands of man'. Another said, 'But then I think again that I must thank God that he is still looking after me in spite of all the problems I have'. Other homeless disabled people I spoke with chose to accept and be satisfied with their present situation, 'The good thing about this place is that you have your bed and food, I am prepared to stick out in the shelter whatever conditions are'. Another said, 'You see there is nothing we are complaining about here, but it's not a home'.

Despite broadly similar concerns and basic needs, the people I spoke with did not all share the same problems and concerns and did not all respond to these in the same way. I was beginning to realise that through my assumptions and prejudices, I had gathered a diverse group of people together around the criteria of homelessness and disability. By being neither homogenous nor abstract categories, the group's heterogeneity was erased and their difference from myself as drunken, rude, violent, etc. was essentialised. By essentialising their difference, I had failed to recognise their essential humanity and once again I was reminded how far I had travelled from my childhood.

All of this was brought home to me towards the end of my stay at the shelter. As I came to know my participants better, I began engaging them about their individual strengths and weaknesses, and they engaged me about what my interest in their problems meant to them. One person had this to say:

> I see myself as a good person. I believe that if you use your common sense and work hard, then you will live better. Another thing I am grateful about is my mentality. I am still all right, as we are talking. I am in a position to question you, as you are in a position to question me and we can conduct a dialogue. If my mentality was affected, that would not be possible.

Other participants were concerned about negative qualities they recognised in themselves. These included 'bad moods', 'hot tempers' and aggression. Most participants mentioned alcohol abuse and identified alcohol as a significant contributor to violence and fighting.

Finally the homeless disabled people appreciated that I sat down and listened to them:

> I don't want to ask questions, but want to respond and say, as far as I am concerned, you talking to us makes me feel very proud. As we discuss these problems, I feel that there are people who are interested in us, who feel we need help and time. Coming together as a group helps us get this straightened out.

At the end of my stay and having completed my interviews and focus group discussions, I interviewed the manager of the shelter. I was shocked at her lack of understanding of the plight of homeless disabled people. I wanted to see other shelters, meet more homeless disabled people and the people who work with them. I also wanted to talk with people in the disability movement about the interconnections between disability, homelessness and poverty. I wanted to know what is being done to support disabled people within the homeless population.

I began interviewing managers at other shelters with homeless disabled people and it quickly became apparent that the shelter I had stayed at was not unique in its lack of support for disabled residents. Research I conducted at ten shelters around the Cape Peninsula found that 13.7 per cent of residents in these shelters suffered impairments of one kind of another. In December 2000 at one shelter included in my study, 20 per cent of residents suffered from impaired movement and 25 per cent from intellectual disabilities (Mji, 2001). At groups for disabled people that I visited there was great concern about poverty within the disability sector, and efforts were focused on trying to create opportunities for disabled people to participate in the job market. Yet they had not thought about interconnections between disability, poverty and homelessness. Increasingly, I felt that this was a crucial area in need of research and advocacy.

The *White Paper on an Integrated National Disability Strategy* (INDS) notes the strong relationship between disability and poverty; poverty makes people more vulnerable to disability, and disability reinforces and deepens poverty (ODP, 1997). To be homeless and disabled would appear to be a double burden.

That homeless people make up an increasing, vulnerable population is beyond doubt. As Plumb observes, homeless people are at higher risk of contracting preventable diseases leading to progressive morbidity and premature death than people with homes (Plumb, 1997). Yet while Plumb is correct, the persistence of medical discourses of disability and the entrenchment of welfare and care-based approaches to responding to this vulnerability, have established the view that disabled people are different from abled people and are in need of care because they are ill. Emphasis on the medical needs of disabled people obscures their broader social needs, and perhaps more importantly, diverts critical scrutiny away from the systems and relations of power that contribute to perpetuating their vulnerability.

As a social group, homeless disabled people are so marginalised from the economic, political, social and cultural forces that reproduce society as well as generate society's social concerns that it is barely accurate to speak of homeless disabled people as peripheral. While it is important to recognise that this group is not homogenous and that there are sectors of the disabled community that experience greater discrimination and marginalisation than others, it is still true to say that disabled homeless people as a group lack both political influence and social power to improve the condition of their members' lives. Although it bodes well that over the past 15 years, disabled people's organisations all over the world have worked to reposition disability as a human rights and development issue, the benefits of these intellectual shifts in activism still need to be realised for disabled people on the streets of Cape Town and other urban centres in South Africa.

That said, the question remains; how does one bring the issue of homeless disabled people to the centre of discussions? The shift to positioning disability as a human-rights and development issue is a useful beginning. But new intellectual, analytical and critical resources for thinking through the issues and positioning the debates can only be the beginning. For although interventions must proceed from an appropriate concept of the issues, we must ensure that intellectual labour informs action rather than takes the place of action.

The promotion and protection of the human rights of homeless disabled people is a cornerstone of the INDS. In this effort, the INDS takes its lead from South Africa's Constitution that guarantees certain fundamental rights for every citizen. But as Sheila Riddell (1996) shows, some rights and duties that accrue automatically to the abled population are granted only conditionally to disabled people. And again, poverty and access to financial resources play a significant role in determining who can access their basic rights. An example cited by Plumb (1997) demonstrates what is at stake here. It has already been suggested that homeless people are a population especially at risk of medical ailments. Lifestyle and exposure result in a higher incidence of chronic illnesses, and lack of access to medical care causes preventable illnesses to remain undiagnosed and untreated until late in their course. Yet despite the new rights discourse and development paradigm, there has been a marked lack of action either at the level of political leadership within the national and provincial health departments or at the level of the public health-care infrastructure. Quite simply, hospitals and health-care institutions have been reluctant to provide quality care to homeless people and other clients who lack financial resources, despite the fact that that Article 27 of the Bill of Rights guarantees the right to health care, food, water and social security for everyone. The example of the health sector is drawn from Plumb's discussion of the difficulties facing homeless people in general, but his example is equally applicable to disabled homeless people.

Of course, the lesson has long been appreciated that the legislating of human rights is not worth much if these are neither accessible nor monitored. Recent debates around the appropriateness of a notion of human rights rooted in a western liberal tradition, in which the individual is the basic unit of political agency, has also complicated the rights-based approach to empowering those on the margins (Lang, 1998). Such an individualised notion of empowerment as espoused by the international disability movement runs contrary to social customs and practices that are found in many developing countries, where collective action is valued (Hellander, 1992; Lang, 1998).

That some kind of collective responses might be a more appropriate strategy through which to address disability, homelessness and poverty in South Africa, is intimated in Lang's argument that an appropriate intervention into disability should begin with altering the environment (Lang, 1998). After all, if it is the systems and relations of social power that disempower and marginalise homeless disabled people, then it is these social relations that require reform.[2] From this point of view, increasing access to rights will mitigate the impact and, to a certain extent, defend marginalised groups against the constellations and alliances of power that disempower them. But how appropriate is it to place the burden of responsibility of promoting social justice on marginalised groups, rather than seeking to promote social justice through dismantling those constellations and alliances that threaten it? Altering the environment does not mean building more ramps and widening doors (although that too), it means changing the social relations that determine the kind of society in which we want to live.

As I reflected on what kind of society I would like to live in, my thoughts returned to my childhood and I wondered whether the village I grew up in might be a model for the kind of collective action that could alter Cape Town's social environment. I have already mentioned that in my village there were no homeless people, although there were people with disabilities. I wondered what attitudes and beliefs were at work in producing and reproducing a community that accommodated impairments at the same time as it promoted an enabling environment – that is, a community where people with disabilities were not reduced to and defined by their disability. And I wondered whether there are any lessons to be learnt here and how they might be transposed.

I will not try to provide a blueprint for how things should be, but my journey as a researcher, as a professional and, more importantly, as a person, has helped me see that two so-called 'marginal' issues like disability and homelessness raise questions about the kind of society we want to live in. And these are the very same questions raised by my grandmother in a rural village many years ago.

Notes

1 Gubela Mji is a physiotherapist working in Cape Town. In 2000, she was asked by fourth year physiotherapy students to mentor them through their mini-research project on the impact of disability on homeless people. Thus began a journey of self-reflection and self-discovery that took Gubela from the relative comforts of her profession to homeless shelters, memories of her youth, and the poor rural village where she grew up. Her journey led her to the central question at the crux of the issue: how to integrate debates around homelessness into debates around disability. The editors have decided to preserve the autobiographical tone of Gubela's contribution and therefore retained the first person narration.

2 For an excellent analysis of how the interests of tourism and capital have systematically sought to erase marginalised youth and homeless people from Cape Town's 'city bowl', see Klopper 2003, pp. 227–241.

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25 Entrepreneurship, employment and skills development: Ari Seirlis in conversation

Ari Seirlis and Leslie Swartz

Who is Ari Seirlis?

Ari Seirlis is the National Director of the QuadPara Association of South Africa, and many of his entrepreneurial activities have been designed to empower and secure rights for persons with disabilities. The diversity of what he does is astounding. From helping to ensure that people with mobility impairments gain access to watching top rugby matches, to slugging it out about the rights of persons with disabilities in terms of employment equity; from supporting 'flyball' in South Africa (a fast-paced relay race played by quadriplegics!), to advising the South African Sexual Health Association about sexuality and disability; from fighting the continuing fight to allow mobility impaired people to use assistive devices to go on to beaches, to training persons with disabilities to develop their own businesses; Ari has done and does do it all. When we were putting this book together we could think of no better person from the disability sector to give an insider's view on entrepreneurship. Ari's sheer energy, and his range of activities, including running a successful signage business for 15 years, and, currently, being central to the Amasondo Esibindi project (discussed later in the chapter), mark him as a successful entrepreneur.[1]

Leslie Swartz (LS): Thank you for agreeing to contribute to our book, Ari. Please can we begin by getting a sense of how you understand what an entrepreneur is?

Ari Seirlis (AS): Well, that's an interesting question! The Concise Oxford Dictionary describes an entrepreneur as a 'person in effective control of commercial undertaking'. This definition is a good example of what I think is a basic misunderstanding. There is a big difference between somebody who is an entrepreneur and somebody who owns their own business. Only some people who own businesses are entrepreneurs – there are those who have had their business passed down to them through the family and I don't think that they should necessarily qualify as entrepreneurs. There are also those who raise capital and buy a popular franchise – can they be defined as entrepreneurs? They are business owners, yes, but they have not started something new. Even a person who has an extraordinary skill and immediately trades the skill in the market is not necessarily an entrepreneur.

There's another way in which entrepreneurship can be misunderstood. I was brought up to understand that an entrepreneur was someone who came up with a clever idea, somehow managed to raise the finance to manufacture or sell this idea or product or service, made some profit, sold the business or the idea, and then started again. In this definition, entrepreneurs are seen as selfish people after a fast buck, people who take the profits and run on to the next profitable business or deal. This image of entrepreneurs is really unfair, especially if you consider the power of small business in this country and how they have empowered many people who might not necessarily have found work. Entrepreneurs have created and continue to create sustainable job opportunities in this country. For many people, entrepreneurship represents their best hope of finding a job.

LS: It's clear you feel really passionate about this. How did you come to be so interested in entrepreneurship, and, in fact, become an entrepreneur?

AS: Well, it's not something I always thought of getting into. Fresh out of school, a private one too, I went straight to University in Cape Town to study the traditional B.Com degree. The only books I'd ever read were those which we had to read as part of the school syllabus and therefore books like *Rich Dad, Poor Dad* (Kiyosaki & Letcher, 1988) were not on my bookshelf and I had certainly not heard about them.

In those days, the image of entrepreneurship was not good. An entrepreneur was seen as somebody who had not made the grade at school and could not get into university or technikon, someone who went off and did this entrepreneur thing, more out of necessity than anything else. Well, I'm not sure where they went, but I can tell you, many of those learners are now some of the richest, most successful and influential South Africans today.

They say that necessity is the mother of invention, and that's probably the case with me too, having had the opportunity myself to investigate entrepreneurship soon after my accident which rendered me quadriplegic. My disability has given me the insight to know that, had I not had my accident, I might not have explored this opportunity. I would have missed out on the many achievements, deals and experiences I have had as an entrepreneur. In fact, I have earned well as an entrepreneur, well enough to have given the last few years of my life to serving the disability sector as a volunteer and administrator. It was my disability that led me on the path to entrepreneurship.

LS: It is clear, though, that you are a very particular kind of person. Is entrepreneurship a realistic option for most people with disabilities?

AS: What alternatives are there? There is no doubt in my mind that for someone with a disability, entrepreneurship is an opportunity to consider. One might think that the Employment Equity Act has now taken its place in order to ensure more opportunities for persons with disabilities in the workplace, but this has not been the case. Yes, there are quite a few more persons with disabilities in the open labour market, but who and where are they? The Employment Equity Act and derivatives have seldom worked in any country in the world and I don't think it is a solution in this country either. In fact, since the inception of the Act in 1999, there are less persons with disabilities employed!

LS: I'm surprised you say this – are you against employment equity legislation, which has been fought for so hard?

AS: I'm not saying I'm against employment equity, but you have to understand that legislation cannot create the ideal situation. Employers should want to employ people's skills – as soon as they are forced to employ persons with disabilities, problems arise. As soon as somebody is branded an 'equity' employee – just as has happened on occasion with the employment of black people and women – the person is in a very particular box. This may be very disempowering, and contribute further to the marginalisation that the legislation is designed to combat. I have witnessed on many occasions the same person with disabilities being traded from company to company for a better wage. This is not the purpose of the act.

LS: OK, I understand the unintended negative consequences of equity legislation, but what is the alternative?

AS: This country definitely needs an Employment Equity Act, and there will be some impact, but the Act cannot work without support from other changes in society. Let me give you three examples. First, without the full application of the Skills Development Act it is naïve to think that, given our history, there will be enough skilled persons with disabilities to be employed in all sectors of the economy. Second, without an adjustment to the nature of public transport, it is simply impossible for some people even to get to their place of work. This is most obvious in the case of people with mobility impairments, but the issue of safe and accessible public transport is important to people with a range of other disabilities too. The third example concerns the correct application of the National Building Regulations. It is always difficult to estimate the costs of 'reasonable accommodation' for people with disabilities, and there is in fact no set cost to the reasonable accommodation of a wheelchair user, for example, or to that of someone with sight impairment. This we understand. Unfortunately, though, what makes matters worse is that 'reasonable accommodation' has also been interpreted as referring to major structural changes to buildings. These changes should actually have been dealt with by the building owner or landlord in the context of building regulations. The need for all buildings to be accessible should not be confused with the particular accommodation needs that arise with employing a particular person with disabilities – but the confusion occurs time and again.

There are also limits as to how far employers will go in terms of enabling equity. There is no doubt that some employers are interested in complying with legislation, but they draw the line when it comes to brave moves like cancelling the lease if the building is not accessible or spending their own money on making the building accessible for persons with mobility impairments.

Behind all of this, though (and this goes back to the negative consequences of thinking that equity legislation will solve all our problems), in many cases, the reasonable accommodation issue does not lie with satisfying a physical requirement that the person with a disability needs. Accommodation lies rather with sensitising existing employees to honour and respect the skills of the person with a disability and to understand the nature of the disability in order to develop a team spirit that is conducive to the deployment of those very skills that were employed. It is this attitude in the workplace that commands the success or failure of introducing a person with a disability to the workplace – and these attitudinal factors, I boldly state, are far more important than obeying the letter of any law. Persons with disabilities (along with many black people and women) have had far too many experiences of being tolerated as a 'requirement' or of being cynically used as 'window dressing', for us to underestimate the importance of attitudes.

LS: Given what you say about attitudes (and I think you're right), can you give me a sense of how these might play out in other contexts – like those of transport, for example?

AS: As I have said, the biggest problem facing persons with disabilities and in particular those with mobility impairments is that there is no public transport system that caters for persons with mobility impairments. You cannot catch a train, bus, taxi or any public transport system if you use a wheelchair or have any assistive device for your mobility. The same applies for many sight impaired people. The issue also affects persons hard of hearing. Safe, accessible transport which people can travel on without an assistant is, practically speaking, out of reach for those with intellectual disabilities.

This is the tragedy facing many persons with disabilities in South Africa, and unfortunately the problem of public transport is going to exist for many years to come. Interestingly enough, the notorious taxi system in South Africa which is so effective in transporting people into the cities, took interest in the plight of the disabled, especially those with wheelchairs. But what were the motives? Here was an opportunity to charge an extra fare, and this was probably the basis of their willingness to transport persons with disabilities. So do we from the disability sector shout 'viva taxi owners viva' or do we shout '*phantsi*!' (down with taxi owners!). What do you do when people start to do the right thing for the wrong reasons? One can argue this for ages and your stand on this issue will depend on whether you own a taxi or not.

Not that there aren't solutions. An immediate solution would be to offer taxi operators a subsidy for transporting persons with disabilities, which would allow them to pay the same fare as others do, and this would be fair. But who is going to pay for the subsidy, who can finance this? Government? Corporates?

I must mention that there is debate and consultation going on to change the type of taxi used. The new taxi will accommodate persons with disabilities and at some stage these vehicles will be introduced onto the roads. This process has been labeled the taxi recapitalisation initiative. I fear this will take some time.

The voice of the disabled community does not demand free transport, but rather accessible and affordable transport appropriate to its needs. This is not a request. It is a demand and also a human right, which is supported by the Constitution and a number of other acts. Unfortunately, this very voice is still too fragmented to be heard. Many of the previous doyens and comrades of disability are now in government and it is often not popular within that structure to continue the very same demand. Some of the key activists are now 'government puppies'. Unfortunately, this was bound to happen.

LS: I haven't heard the term 'government puppies' before – it sounds quite rude! Can you explain what you mean?

AS: I am talking about people who are now in the employ of government and who have to toe the government line, as one would have to with any employer. It stands to reason that people who were part of a pressure group in the community would be in a different position and say different things when they are in government.

LS: Thanks for explaining that! To keep on this topic of transport, it seems to me, though, that you see transport as the most fundamental issue. This might surprise some people…

AS: I do see it as fundamental. If we draw up a hierarchy of what persons with disabilities need in order to get into the workplace or to become entrepreneurs, I see it like Maslow's hierarchy of needs. Firstly, accessible transport. Secondly, accessible buildings. Thirdly, skills-development opportunities. Lastly, employment opportunities.

If people can't get to work, and can't do the kinds of work that the economy needs, then it becomes a bit silly to talk about employment equity – everything else has to be in place. Employment equity legislation sounds wonderful, and it is important, but if people can't even get to work, then there's not much point, really. Think about skills development – it's a word bandied around persons with disabilities and almost everyone with a disability has sore ears from hearing those words so often. There is no doubt that the empowerment of persons with disabilities depends on skills development, but skills development opportunities are as far away from people with disabilities as the transport infrastructure.

There is a funny upside to this though. Because both jobs and skills training are not accessible to people with disabilities, the opportunity to become an entrepreneur is almost forced upon those with disabilities, and especially on those with mobility impairments. Entrepreneurship is often not a choice, but forced upon someone who has a dream and has the will to make it come true. What wonderful opportunity, but generated from such a desperate situation.

Not that the picture is all rosy. There are some very successful entrepreneurs who have disabilities, yet these are clearly in the minority. Being an entrepreneur doesn't mean that you don't need transport anymore – you still need that very same transport to meet, negotiate, tender, investigate opposition and look for new markets. As a result, quite often the type of business selected by persons with disabilities and budding new entrepreneurs is determined by their agility and mobility and not by what the market needs, the market niche available or, most importantly, the entrepreneur's dreams.

LS: What successes have you seen in turning this situation around?

AS: In order to understand the situation now, you have to think a bit about the background history. In the past, the open labour market, corporates, parastatals and even government rarely considered the plight of persons with disabilities. If they did, they dealt with these people as if they were in need of charity rather than as people who have skills which could be developed. It was easier to give charity than to develop skills. But this very attitude has created a situation in which there is now huge competition to attract skilled people with disabilities. The corporate market has definitely been influenced by the success of a few very skilled and intelligent persons with disabilities. They have also realised that there are indeed some skills within the sector, and that these skills, if used wisely, can attract the right customer in the right market. An interesting corporate strategy is to profile your disabled staff in order to attract the attention of a better customer or a better tender opportunity, and this is now common in the market. So having an employee who has disabilities can be a real asset in a competitive market.

As far as skills development is concerned, there are now the SETAs (Sector Education and Training Authority) and the challenge put forward by the National Skills Development strategy is to earmark 4 per cent of all learnerships for people with disabilities. So there is now the opportunity for skills development in entrepreneurship or new venture creation where little existed before.

Already, the Quadriplegic Association of South Africa has launched through the Services SETA a new venture creation project for persons with mobility impairments, branded Amasondo Esibindi, meaning 'wheels of courage'. This project was piloted in KwaZulu-Natal and is now being rolled out in Cape Town and Johannesburg. Soon there will be a whole lot of new businesses piloted by our Amasondo Esibindi graduates. The double whammy is that they will become employers and surely also, SETA members. The Services SETA has, in this particular project, taken the bold step of contracting the Quadriplegic Association as the lead employer, and this has proved successful.

If you consider that most members of all the SETAs are small businesses and SMMEs (Small, Medium and Micro Enterprises), then new venture creation not only provides income generation, revenue generation and financial independence for people with disabilities, but also brings new members to the SETAs, new levy payers and tax payers. What a wonderful transition for government.

Remember that even though the term 'entrepreneur' is often taken to mean a one-man band, keep in mind that most of these small businesses employ people. So the very group of people so disadvantaged by lack of transport, ignored by the corporates, and hand-picked by a few conscientious businesses, are now employers themselves!

LS: We've established by now that you are a great fan of entrepreneurship for persons with disabilities, but are there any pitfalls apart from those you've already mentioned which people should look out for?

AS: Let me emphasise the positive again first! Entrepreneurship is a viable and profitable concept, it allows flexibility for persons with disabilities – especially those with severe disabilities – and offers growth opportunities. The only concern an entrepreneur should have, besides the well-being of his or her own staff, is how much to grow the income stream without sacrificing quality or service. What a wonderful concern to have. I believe that entrepreneurship is an important solution for persons with disabilities to get into business and earn a living.

Now let's look at the one huge disadvantage to budding entrepreneurs and especially those with disabilities. The commercial banks and lending houses do not lend money to entrepreneurs who cannot support their idea or dream with collateral or security, should they need to borrow money in order to set up their business. Now, this seems like normal business practice as many people battle to get loans from banks. But banks have been reluctant to take any risks to promote new entrepreneurs. Even those banks who market themselves as the ones who promote empowerment in this new dispensation of ours have been slow to put their money where their marketing mouth is. Though I don't have figures to prove it, I have no doubt that banks are nervous to lend money to persons with disabilities. I've even heard one banker say that the fear is what the bankers will be able to repossess should the borrower not pay back. Could the banks be seen to be repossessing a wheelchair or an artificial limb, for example? These items often have high values, but you can imagine how it would look if the bank were to insist on repossessing them? So the banks see the disability only – it doesn't matter what skills you have, it doesn't matter how ambitious your dream is. The fact is, banks are not geared up to support entrepreneurs, especially entrepreneurs with disabilities. The disability element does not seem to add any confidence to the banker's mind.

LS: Can this situation be put right?

AS: There is a solution, but it's very expensive. Venture capitalists are always on the lookout for ideas to invest in and sometimes take the risks necessary to float a business. This comes at a price, as venture capitalists command equity and a big return on investment. Fair enough – they also want an exit strategy and this does allow the business owner to eventually acquire the equity back again, but not after huge profits surrendered to the venture capitalist.

This dampener on entrepreneurship opportunities is not as dire as it seems. Most persons with disabilities who have ventured into entrepreneurship have businesses which are small, or at least start small, and do not need vast sums of capital to start. Lending houses on street corners do lend money in small amounts, but unfortunately at huge interest rates. There's been much debate over the legitimacy and opportunity that these lending houses offer to persons who are desperate for money, and especially those with disabilities. The high interest rate means that once you have borrowed the first rand you never seem to get out of their reach. Such is the risk of becoming an entrepreneur or starting a new venture.

What would be an ideal situation would be to have a facility at all banks whereby they gave value to skills and measured the potential of a new business. This potential should weigh against the provision of financial security and collateral. Unfortunately, this will only happen if you created legislation to support this. This probably won't happen, given the way our capitalist economy works.

Perhaps the SETAs that support a new venture creation should consider offering seed capital within the learnerships in order to give entrepreneurship a chance. This solution sounds great. I must add though that I have seen few people who have been given money for free to start their own business, succeed, and I have seen many who have had to borrow money at a cost, being successful.

But all these things are part of the creation of an environment which is friendly to entrepreneurship. The schooling system should allow opportunity for entrepreneurship to be understood and taught. This should encourage learners to dream from a young age of owning their own business, instead of thinking only of the open labour market and turning to entrepreneurship as a last resort, which is so often the case. Entrepreneurship is a career, not a 'get out of jail' last resort!

LS: What about the skills needed to become a successful entrepreneur? Can you have a dream about a business idea and develop it and start and succeed without skills?

AS: I don't think so. Skills development and entrepreneurship are partners. It's been proven over and over again that a good idea has to be matched with some business acumen, market knowledge, market research, business skills and communication, in order for the idea to turn into profit.

I mentioned earlier the new venture creation project driven by the Services SETA – Amasondo Esibindi. The secret of this project is that it combines skills development and on-the-ground experience. The first half of the learnership is theoretical – skills are learnt and studied. Thereafter, a mix of developing the business on the ground together with further skills training is implemented in order to guarantee the success of the business.

I must mention also that the qualifying criteria for the persons with disabilities to participate in the Amasondo Esibindi learnership were that the learner had to have mathematics at a Grade 11 level and a fair command of the English language. This does seem a hindrance to those who are already disadvantaged. However, research showed that these qualifications are needed to get through the course and for a business to be successful. An opportunity to do a bridging course has now been offered so that more people can qualify for this programme. In summary, then, new and good ideas on their own don't make money. Throw some skill and acumen at this good idea and it has a fair chance of generating income.

LS: Are there any special advantages to being an entrepreneur with disabilities?

AS: An interesting advantage that an entrepreneur who has a disability has is that many other businesses think that they are satisfying some sort of equity strategy by employing or contracting the services of an entrepreneur with a disability. This is not so and there are no points or credits for having a disabled entrepreneur as your subcontractor. But it looks good, and your customers will surely be proud of you as they witness a contractor with a disability on your premises.

Entrepreneurs should take advantage of this perception and market the services as those provided by somebody with a disability. There will be a group of people with disabilities who would resent doing this. My thoughts are that you can either see the disadvantage of having a disability in business or use your disability to attract new customers, better customers and better contracts. I'm not saying that you should prostitute your disability in order to do business, but rather promote your ability to have overcome adversity as a skill you have developed. This skill adds value to your business.

The concept of entrepreneurship offers the opportunity to level the playing fields within the different disability generic groups, meaning that your business opportunity or interest is not dependent on the type of disability you have. For years, the open labour market has always categorised persons with disabilities into different types of workforces or bundles of skills, depending on their type of disability. For example, people who are blind or sight impaired are considered switchboard operators, wheelchair users are categorised as call centre operators and those hard of hearing or deaf are considered good storemen or overseers. And so in the open labour market, your disability often constituted the type of job you could get. Very few employers considered matching your skills against a job. Instead, they focused only on your disability. This translated even into how people got paid – instead of matching your experience against the job or responsibility when considering your remuneration, your remuneration was tabulated according to your disability. A crude example goes as follows: a wheelchair user should get R1 400 per month, and a blind person – R1 100 per month. I know this may seem ridiculous, but this practice has taken place in many businesses all over South Africa. Interestingly enough, employers using this system are not shy to say that they are way ahead of the employment equity system!

Entrepreneurship does not focus on the disability but on the person's abilities. It allows for any goods or services to be traded or manufactured, provided the recipe is correct. The price tag does not alter according to disability, but according to what the person can offer.

LS: Ari, do you have any final comments and tips for potential entrepreneurs who have disabilities?

AS: Entrepreneurship doesn't guarantee success, nor does disability guarantee you a job in the open labour market, Employment Equity Act or not. For a business to be successful, the business plan needs to be well researched, needed by the market, unique, have some capital and then add some passion. To retain a job in the market, you need skills, you need to perform and reach your targets. Disability does not guarantee that your business will be successful and disability does not guarantee you will keep your job.

The open labour market must employ skills, and not disability. If we all respect this simple rule, we will ensure the successful placement of people with disabilities in business. Too often, persons with disabilities think that they have a right to employment just because they have a disability, and forget that they need a skill as well.

Entrepreneurship is potentially profitable, and employment opportunities are out there. But, entrepreneurship takes hard work and capital, and to be employed, you need skills. I can't say this strongly enough – beware if you think that disability generates income, beware if you think that disability gives you the right to employment. Skills, as I have said, are what are traded to employers for income. If you are an entrepreneur, it will be the markets that will command your price and demand your product or service, not your disability. There are many persons with disabilities who would argue that they have a right to income and employment. Whilst it is appreciated that disability comes with a huge cost to your pocket and your family, in practice this right can never be entrenched – all people who work must have something to offer. This is how the world works.

On the other hand, you can use your disability to your advantage. Your disability does give you an opportunity to attract attention. Disability does not earn a living, but used correctly – it can get you into the market. After that it is sheer hard work – sweat is what earns a living.

As I've said before, the Employment Equity Act has not had the impact the government thought it would, but it has created the awareness in business of employing persons with disabilities or engaging with persons with disabilities. This is where entrepreneurs who have disabilities should strike gold. Entrepreneurs must take advantage of empowerment opportunities within tender procedures and use this to procure work and contracts. Entrepreneurs should develop partnerships and alliances with companies in order to assist those very companies to acquire contracts to mutually benefit the relationship.

You can't buy entrepreneurship. You have to add skills, as well as dreams, mentors, capital, research and many more elements within a recipe to become a successful entrepreneur and trade for a profit.

Think about this: if you're blind or have a sight impairment, make sure you've got vision. If you are deaf or hard of hearing, make sure you listen. If you can't walk and use a wheelchair or assistant device, make sure you learn how to walk the walk.

Skills are your tools; entrepreneurship is your vehicle. Disability is often a state of mind.

Notes

1 Like a number of other chapters in this book, this chapter is somewhat unusual in its construction. Working from notes provided to us by Ari, by talking with him, and by accessing other materials which Ari has written or co-written, Leslie Swartz put together

this chapter and Ari checked over it and made the necessary changes. The chapter has been structured as a conversation.

Reference

Kiyosaki, R., with Lechter, S. (1998). *Rich dad, poor dad: What the rich teach their kids about money –that the poor and middle class do not!* New York: Time Warner Books.

26 *Media and disability*

Jane Stadler

> The modern day media plays an important role not only in reflecting public attitudes and values regarding disability, but also in shaping them. (Gold & Auslander, 1999, p. 709)

The media affect us in many ways: as a major socialising influence, a carrier of culture, a source of information, education and entertainment, an important factor in political communication and participation in a democracy, and a communicator of ideological values and norms, attitudes and beliefs. Thus the media can be seen to exert an influence on identity formation and associated issues around stigma, self-esteem, social relations, economic and political positions.

When considering the relationship between the media and disability, a number of aspects need to be examined, among them: media content (representations, stereotypes, absences), media technologies (issues of access and technological determinism) and media policies (which address language, technology, content and scheduling). Significantly, media content, technologies and policies all convey discourses about disability that frame the way disability is constructed and viewed in society.

The term discourse refers to the way in which a subject or issue is conceptualised in society. The discourse, or body of ideas, circulating in society about a particular topic or social group can influence people's attitudes towards others and ways of interacting with them. There are various discourses of disability disseminated through the media and other channels of communication. These include the medical model, the social model, the cultural model, charitable discourse and many variations on these themes. In an attempt to give an overview of the complex relationships between media and disability outlined above, this chapter will also consider the importance of self-representation and 'mainstreaming' by means of examples drawn from The South African Broadcasting Corporation's (SABC) programming and public service announcements.

Discourses of disability in the media

The language used in the media to describe disability is significant: many terms used in news reports involving disabled persons reveal a perception of disability as an abnormality, an impairment, an illness or a tragic loss of 'normal, healthy' functioning (Gold & Auslander, 1999). Such terminology arises from the medical and charitable models of disability, which contribute to a discourse of disability that is disabling and disempowering of disabled people, because it naturalises perceptions of disabled people as victims who require help, treatment and rehabilitation. This perspective does not recognise the individuality, agency and abilities of disabled people. The idea that disabled people require pity or remedial treatment is often unintentionally conveyed by media programmes such as documentaries about modern medicine and by public service announcements and appeals that ask the public to support charities offering services to disabled people.

Categorising people as either able-bodied or disabled is problematic as it creates an illusory binary opposition between 'us' and 'them'. Media messages, representations and ways of using language that naturalise and reinforce this opposition, convey a distorted picture of disability by failing to acknowledge that disabilities are situated on a continuum of impairments and forms of disadvantage. In this way they can contribute to stigma and misunderstanding. Chapter Four in this volume on disability and psychoanalysis, discusses in some detail how simplified binary distinctions between ability and disability function to protect individuals from a range of anxieties about weakness, infirmity and damage. The important point for this chapter is that everyone experiences some form of impairment and disadvantage at some time in their life, so such conditions should not be represented in the media as abnormal.

Better communication with, and input from, disability communities, could enable media practitioners and policy makers to assist in creating very different perceptions and understandings of disability. For example, the social model as a discourse of disability perceives discrimination and prejudice to be the real causes of disability, rather than physical or mental deviations from what is considered to be 'normal'(for example, Oliver, 1990). This approach to disability locates 'the problem' in the social construction of disability, suggesting that members of society are disenabled by representations, social perceptions and elements of the built environment. Together these form a disabling social context. The way society responds to disability compounds the difficulties faced by disabled people; obstacles and prejudices are often more challenging than sensory impairment or limited mobility. Researchers John Swain and Sally French point out that understanding disability as a social construct enables us to see that a disabled person's problems are not necessarily the result of impairment, but often arise 'from the failure of society to meet that person's needs in terms of appropriate human help and accessibility' (2000, p. 573).

Swain and French also present another discourse of disability, one that they call the affirmative model. Rather than locating the 'problem' of disability in impaired bodies or in a disabling society, the affirmative discourse of disability focuses on the benefits of living with disability and on positive identities rather than personal tragedies. For instance, Swain and French note that the experience of disability can help disabled people to 'transcend the constraints of nondisabled norms, roles and identity and affirm their experiences, values and identity' (2000, p. 576). In particular, some disabled people have explained that living with disability enables them to escape restrictive social expectations about what men and women are supposed to look like and do. For proponents of this view, this experience is liberating because they avoid feeling defined by unrealistic social ideals of 'the body beautiful' and associated superficial values (Swain & French, 2000, p. 578). The experience of being disabled can provide a space to challenge the values of mainstream society and the definitions of 'normality' and success that often constrain people's ambitions and sense of self-worth.

Theorists who work with what might be called a cultural model of disability emphasise the benefits that many disabled people experience from a sense of belonging to a disability community with a shared language, shared experiences and shared values (French, Gilson & Depoy, 2000, p. I209). Jean Hall's interesting research explores how disabled people benefit from what she terms the 'core values' of disability culture, which include attitudes towards helping others and accepting help, understandings of interdependence, and a farsighted, responsible orientation to planning ahead (Hall, 2002). Hall is suggesting that a distinct disability culture has a great deal to offer disabled people, to help them cope with life, accept themselves, and relate socially.

The social, affirmative and cultural aspects of disability are not given adequate representation in the media. An important step towards a more positive media role in the way disabled people are represented, and in the way that disabled readers, viewers and listeners are addressed, is to raise awareness of these different discourses of disability amongst media practitioners, policy makers and members of the public. There is often a lack of awareness that attitudes towards, and ways of talking about, an issue or a social group might be problematic, or even that there might be alternative understandings. This is partly because the media tends to naturalise dominant discourses, ideologies and ideas. When we see the same kinds of images and views represented in the media over and over, without having access to alternative discourses, it is easy to accept them as natural and legitimate. James Valentine, whose work analyses media portrayals of disability, foregrounds the problems that arise when the media only publicises one discourse of disability:

> If messages of the same kind are put out by other programmes and in other media then cultural assumptions are likely to be reinforced, rather than challenged. It is worth emphasising that deaf and disabled portrayals are used to reinforce predominant virtues and fears. Furthermore, in relation to the representation of a particular marginal group, alternative sources of information may not be readily available. If your only images of certain people come from the media (if you have no direct interaction with them) and these representations tell consistent stories, then you are likely to have your view of these groups framed by media accounts. (Valentine, 2001, p. 722)

This shows how damaging stereotypes can be and how easily they can contribute to or reinforce assumptions and prejudices. It also suggests that it is very important for the media to represent diverse images, identities and viewpoints.

Media theorists Huntemann and Morgan (2001) make the point that the absence of representation is also a form of prejudice that can have harmful effects. They point out that members of society who do not see representations of people 'like themselves' in the media learn 'a fundamental lesson about their group's importance in society. Daily, they are being sent a loud and clear message that they do not count for very much in society' (Huntemann & Morgan, 2001, p. 316). In this way the media functions to define what counts as 'normal', 'central' and 'valuable', and to make under-represented or misrepresented groups feel that they have little worth. Prejudicial representations in the media can also cause a sense of alienation and resentment where disabled viewers feel that in order to be proud of their identity they must reject the values and norms of mainstream society (Huntemann & Morgan, 2001, p. 317).

In the next section of this chapter, I want to explore a few specific issues and examples related to representation of disability, using SABC programming as a case study. Here I will also look at how the media addresses disabled members of the audience, particularly deaf people. After analysing media content, I will go on to look at the implications for media policy, giving arguments for and against mainstreaming and foregrounding the importance of self-representation, using a public service announcement made by a deaf director as an example. The chapter will conclude with an overview of media technologies such as the internet, and captioning for TV and cinema, raising considerations for the future of the media and disability.

South African media disability initiatives

In South Africa, the SABC is investigating ways to address and include disabled and deaf audience members in its special programming, educational programming and mainstream programming. Prime-time news is accompanied by sign language in a limited slot, and a few educational programmes aimed at school children such as *Let's Meet*, *Fundani Nathi* and *Star Maths* incorporate sign language to varying extents. *DTV*, one of the only programmes specifically aimed at deaf and disabled audience members, provides a valuable service but is scheduled well outside of prime time. The Sunday morning slot makes it inconvenient for those who have family or religious obligations at this time.

Let's Meet, a short educational show for primary school children, is an interesting example of the efforts of South African media to engage with disability. The ten-minute show introduces the audience to prominent South Africans, giving a sense of history and national identity. *Let's Meet* begins with a cartoon character named Elliot holding a screen on which we can see a sign language presenter. Elliot is the host of the show, and the role of the sign language presenter is to ask questions as he delivers information about various South African celebrities, and to sign the voice-over narration that accompanies archival footage about the lives of celebrities. Elliot introduces the signer (different signers work in different episodes) and asks her to guess the name of the celebrity being showcased. The sign presenter only communicates using sign language, while a third party provides voice-over narration and subtitles appear at the bottom of the screen. Throughout most of the show we see archival footage, maps and photos in the top left corner of the screen, with the signer in the bottom right corner, shown from the waist up. This framing enables viewers to distinguish facial expressions as well as hand gestures.

Let's Meet has some very positive elements. It functions to incorporate sign language into the mainstream SABC educational television curriculum and rather than addressing deaf children as a 'special' audience, it meets their language requirements in the same way that SABC programming meets the language needs of Zulu or Xhosa audience members. Furthermore, in *Let's Meet,* the sign language presenter is addressed by name and plays an active (if limited) role. In other programmes such as *Fundani Nathi*, the sign language presenter is anonymous and plays a secondary role to Nandi, the vocal presenter, and to puppets on the show. In one *Let's Meet* episode about Oliver Tambo's life, the signer asks the question 'do you know how to sign "hero"?', demonstrating the classic body-builder pose of flexed biceps, with raised fists. In the 'Baby Jake' episode she explains that we all need someone to believe in us if we are to succeed. She says 'I am deaf, someone believed in me, and here I am presenting this programme to you. It's hard work…' This is positive because it individuates the sign presenter as a person with a job and as a legitimate character on the show, rather than just a substitute for subtitles. It also addresses the experiences of deaf people and gives an uplifting message about self-esteem and success. These isolated examples represent a move in the right direction, but *Let's Meet* and other South African programmes need to include much more of this sort of material.

Despite its strong points, *Let's Meet* does have some limitations. The provision of multiple ways to access the same information (speech, sign, text and image) is a good initiative and one that recognises that deaf audience members tend to be visual learners (Luckner, Bowen & Carter, 2001). However, where possible the sign language presenter's own voice should be used in the interests of self-representation and sound-image fidelity, and to give the sign presenter a more central role in the show. The content of *Let's Meet* also needs to be tailored to represent different identities as successful, as well as to explore different notions of success. For instance, there are no prominent disabled South Africans showcased on *Let's Meet*. The effort to teach the hearing audience some sign language that occurred in the 'Oliver Tambo' episode should form part of every show. Teaching the audience at least one sign per episode would be a positive, inclusive gesture, empowering for deaf and hearing audience members. Such an initiative would make it clear that deaf people have things to teach others and would recognise sign language as one of the many languages used in South Africa. Indeed, sign should be treated as the twelvth official South African language, as this constitutes recognition of citizenship. The representation of disabled people, cultures and languages on TV and in other media has far-reaching implications for cultural citizenship, and hence for the rights and opportunities for citizens to actively participate in the cultural life of a society (see Goggin & Newell, 2003). The principal limitation of *Let's Meet* is that it is not located within an approach to programming and scheduling that addresses the needs and interests of disabled people in a consolidated, inclusive manner. If other educational programmes regularly included deaf and visibly disabled children, and if disabled people were centrally involved in mainstream media production and presentation, then *Let's Meet*'s imperfections would be unimportant. Stated bluntly, what *Let's Meet* does not do in terms of representing and addressing deaf and disabled people is likely not to be done at all in South African media.

Mainstreaming and 'special programming'

In addition to special media programmes, and technologies and policies designed to meet the needs of disabled people, disability also needs to be integrated into mainstream media offerings as a matter of course. In the words of Barbara Kolucki, a leading writer in the field of media and disability, 'the natural inclusion where no one says anything about a disability is necessary for our children (and adults) to see diversity and disability as natural, acceptable and part of the landscape of everyday media'.[1] In response to policy directives, the media's approach to disability has often taken the form of providing limited programming that targets disability issues and addresses disabled audience members in a tokenistic way or as a minority group. Most of these programmes about deafness and disability are marginalised in terms of being placed on educational channels and scheduled outside of prime time. This raises the concern that 'special programming' that targets disabled audience members, caters to their needs and focuses on disability-related issues, functions to reinforce a sense that disabled people are separate from 'mainstream' society, and are not a part of it. Brian Watermeyer's research at the University of Cape Town suggests that marginalisation and exclusion from the media and other aspects of everyday life presents a serious difficulty for many disabled citizens:

> Disabled people do not need our charity; they simply require inclusion and participation in the processes of society. In terms of media, this translates into policies which aim to simply include and reflect the experiences of the approximately 10 per cent of our population considered disabled, as the full and equivalent citizens that they are. What is primarily required, thus, is not a 'disabled corner' of the media, but rather a situation in which disability is normatively visible in all areas of broadcasting. The principle of proportional representation of

> members of various race groups in the media is well established, and the same logic applies in the case of disabled people. The questions which mass media should seek to ask regarding the needs of disabled South Africans do not pertain primarily to special programming for the development of disabled people. Rather, the issues are much broader, pertaining to the ways in which disabled people may become more visible throughout the broadcast arena. (Watermeyer, 2003)

Kolucki's and Watermeyer's work suggests avenues for the development of media policies and representational strategies that will transform the ways in which the media addresses and represents disabled people. For instance, if South Africa's media landscape were to be shaped by the viewpoints articulated above, a representative proportion of programming would be directed to the needs of disabled people. More importantly, locally produced advertisements and programmes would regularly include disabled characters and presenters, irrespective of whether the programmes focused on disability as an 'issue'. This is important because mainstream serial dramas, with their longer format, leave a deeper impression than educational documentaries or 'special programming', due to wider publicity, regular repeated broadcasts and enduring viewer identification with complex, developing characters (Valentine, 2001). Integrating representations of disability into the mainstream media would help to ensure that diverse discourses and images of disability circulate in the media, and that more opportunities exist for identifying with and relating to disabled screen characters.

Other researchers argue that mainstreaming is not the answer, and that programming that specifically addresses disabled members of the audience should take priority over increasing the visibility of disabled people in the mainstream media. They argue that a 'mainstreaming' approach tends to represent disabled people from the perspective of nondisabled people and for the benefit of mainstream audience members, and that it assumes that integration into the mainstream is what disabled people need and desire. For instance, Valentine critiques hearing accounts of deafness, 'In considering the fashionable use of deaf characters as heroes or heroines in film and television drama, it is important to note that these characters are constructed for a mass audience: they are mainstream representations of marginality' (2001, p. 707). Valentine claims that because the difficulties and 'virtues' associated with deaf screen characters are presented from a hearing perspective, they are laden with gendered cultural values from the hearing community about silence, stoic endurance, vulnerability, martyrdom, rudeness, modesty, etc. Such mainstream representations tend to reinforce an 'us versus them' binary opposition (Valentine, 2001).

Articulating yet another point of view, some theorists emphasise the benefits of shared experiences in a shared culture, as opposed to mainstreaming (e.g. French Gilson & Depoy, 2000; Hall, 2002). This has relevance to media policy, because the suggestion here is that disabled people do not necessarily perceive special programming that is aimed at disabled audiences to be a form of marginalisation. These specifically targeted programmes help to build a sense of disability culture, and they foster the possibility for disabled people to share common concerns and unite as a community or lobby group. The feeling of group identity with other disabled people often transcends class, race and gender identifications, and creates a tension between the impulse to integrate with the mainstream and to preserve a distinct identity (Hall, 2002).

Media policy makers need to negotiate a solution to the tension between supporters of mainstreaming, and those who seek to preserve the identity of the disability community and to foster group identity with special programming. Policy must, therefore, aim to ensure that South African broadcasting meets the need for mainstream representations of disability and provides a representative proportion of programming that caters to the language requirements of the Deaf community and the needs and interests of other disability communities. Mainstreaming remains an important goal – not as part of an effort to assimilate disabled people within mainstream society and to erase social differences, but rather as an acknowledgment that disability cultures form an integral part of the diversity, multiculturalism and multilingualism that constitute South African society.

Public service announcements and self-representation:

Special programming and mainstream media are not the only avenues for using the media to represent and communicate about disability; the media can also be used to educate and raise awareness by means of public information campaigns. In an overview of research on media and disability, Kolucki (2001) writes that media messages can indeed produce positive effects on attitude. She cites a study of communication strategies used in public service announcements (PSAs) dealing with disability related issues which claims that the most successful PSAs consist of positive messages delivered by disabled people speaking on their own behalf. Kolucki states that the most effective media messages were those in which 'people with disabilities spoke for themselves, they did not act in a previously stereotypic helpless or hopeless manner, (and) they presented interesting and factual information about their disability'.

The slogan 'nothing about us without us' (Goggin & Newell, 2003, p. 20) expresses the principle of self-representation in the media. This applies to representations of disability in mainstream programming and in special programming, as well as in PSAs and information campaigns designed to raise awareness about issues related to disability. Valentine (2001) notes that there are huge differences between media representations of disability that involve self-representation, and those that are constructed for a mass audience by nondisabled media professionals. For example, when deaf actors and deaf directors are involved in media production, the richness of the deaf community is represented and deaf characters are no longer represented as being alone or silent (or as being spoken for by hearing characters, or using subjective voice-over narration that expresses private thoughts).

A PSA about deaf and disabled South Africans directed by a deaf man called Donovan Mulligan is a local example that illustrates the importance and effectiveness of self-representation in the media. In conjunction with Disabled People South Africa and Channel 5 Film and TV Production, Mulligan entered a competition hosted by MultiChoice Africa for PSAs called the Vuka Awards. He created an advertisement that was screened on DSTV throughout southern Africa, raising awareness about deafness and disablism. The advertisement competed successfully with other PSAs made by film students and professional advertising companies, and communicated its simple, powerful message clearly and effectively. The PSA is entitled 'Give us a Break' and it consists of a long take of Donovan Mulligan wearing casual clothes, framed in a medium shot standing against a blue stage curtain under studio lights. Mulligan addresses the camera and the audience directly, using sign language and captioned speech. He says:

> My name is Donovan and I am deaf. Because I wanted to communicate more effectively, I learned to speak. Now because I sound a little strange, some people think I am stupid. But I'm not! That's the problem for most disabled South Africans. People judge us before they know us. Take the trouble to find out more about what we're able to do. Even offer us employment. So my appeal to you: Please give us a break. Know us before you judge us. And so to prove my point, I thought you might be interested to know that I directed this Vuka entry myself.

The PSA made by Mulligan was judged to be among the top 30 per cent of entries in the Vuka competition. The content, and also the fact that it was self-directed, situates it somewhere between the social and affirmative models of disability, by focusing on the abilities of deaf and disabled South Africans and by pointing out, in a non-punitive manner, how society's prejudices are typically more disabling and disadvantaging than physical impairments. This television advertisement is a very good example of the way in which the media can play an important and positive role in social change by raising awareness about disability, educating and informing the public, and providing opportunities for self-representation.

The issues raised above suggest that while disability programming plays an important role and meets the special needs of a particular audience, it needs to be a part of broader changes in the way disability is represented in the media, and in the way disabled people are addressed by the media. Self-representation is an important part of the process of empowerment and inclusion. Involving disabled people in the process of media production can go a long way towards changing misconceptions and countering misrepresentations. However, disabled people cannot change the media alone; it is also necessary to facilitate workshops and educate existing media practitioners about these issues and to launch public education campaigns.

These suggestions are in line with the policy objectives set by the *Integrated National Disability Strategy* (ODP, 1997, pp. 23–4), which advocates the following strategies:

- Media awareness: the development of disability awareness projects aimed at journalists and the public broadcaster;
- Media visibility: increased visibility of people with disabilities in the media;
- Self-representation: people with disabilities are best equipped to change perceptions and attitudes towards disability, and should therefore play a central role in the development of strategies and projects;
- Public media: the public media plays a central role in the way society constructs images and beliefs and should therefore be utilised as a key mechanism in changing attitudes.

Through adopting these strategies, the power of the media could be harnessed to empower and embrace disabled members of the public rather than serving to reinforce marginalisation or stigmatisation.

Media technologies

The content, production and scheduling of media texts and the kinds of messages that are (or are not) being circulated in society by the media about disability, constitute central aspects of the relationship between media and disability, but they do not provide the whole picture. Media and communication technologies also play important roles in enabling or disabling members of the public and in constructing one's place in society.

The internet, for example, has allowed people to communicate swiftly across great distances, participate in political discourse and publicise their points of view, form relationships independent of the physical markers of age, race, gender and ability, and create online communities that are not bounded by geographical location. Computer Mediated Communication (CMC) enables people to separate their physical bodies from their social identities to a certain extent, communicating with others in an online environment in which mobility, appearance and the functionality of limbs and organs are rendered invisible and/or irrelevant (Goggin & Newell, 2003). For many disabled people, such media technologies are liberating and enabling, because communicating in an online environment avoids the prejudices that are often triggered by the visible signs of disability. Information and Communication Technologies (ICTs) offer a sense of community and interconnectedness as well as access to information and entertainment independent of physical mobility. This in turn enables participation in governmental decision-making and independent access to information (e.g. health-care information). CMC helps 'home-bound' disabled people to extend the range and reach of their experiences and social interactions, at the same time enabling people with mobility impairments to work from home or residential care settings, and generally facilitating access to relevant information about health, technological innovations, policies and advocacy groups (Goggin &

Newell, 2003). ICTs also offer the disability arts movement an online exhibition space and in this sense the 'use of new media and communication technologies is actually constituting a new cultural space for people with disabilities' (Goggin & Newell, 2003, p. 134). In these ways, media and communication technologies can enhance the sense of agency and citizenship that disabled people and other members of the public experience in everyday life.

While ICTs clearly offer enabling benefits, technological developments are themselves shaped by socially bounded perceptions of the needs, interests and purposes that technology serves, 'Technology is always a form of social knowledge, practices and products. It is the result of conflicts and compromises, the outcomes of which depend primarily on the distribution of power and resources between different groups in society' (Wacjman, cited in Goggin & Newell, 2003, p. 3). This perspective helps us to view the relationships between media, disability and society from a different angle: it is not just media content that is significant, but also media technologies, since new developments in media technologies reflect social structures and mechanisms of exclusion and inclusion. For instance, it is considered exclusionary that the technological capacity exists to meet the needs of blind web users without great expense, and yet the majority of websites are set up to cater to the needs of sighted people. In order to be profitable, research into new technologies is directed into projects that serve the interests of the majority, and disabled people represent a small and fragmented market. The development of new media technologies follows market forces and reproduces existing power relations instead of transforming them. In addition, access to new media technologies is dependent on money and education, and (particularly in Africa) disabled people are often on the wrong side of the digital divide in these respects. For these reasons, media policy must play an important role in regulating new technological developments and the manner in which they are made accessible to various sectors of the population – not just to the majority of people or to those with the most purchasing power.

While media and communication technologies may reflect social biases, they can make a positive difference to the lives of disabled people. Most media technologies are designed to address the needs of nondisabled users, but there are a number of technological innovations that render the media more accessible to disabled people. South Africa must embrace these technologies and ensure that they are affordable and accessible to those who will benefit from them. Technologies that make mainstream media accessible to disabled audience members often take the form of 'special services' available at additional effort and cost but, increasingly, the World Wide Web Accessibility Initiative and regulatory bodies are working to change this by setting standards for online accessibility and by ensuring that, for example, new televisions are manufactured with built-in teletext or captioning decoders.

Captioning is an inexpensive media innovation that serves deaf audience members. Captioning, which is not used extensively in South Africa, involves colour coded subtitles with descriptions of sounds effects, laughter and music, positioned to indicate who is speaking. These captions, which enable literate deaf people to understand television shows, can be 'open' so everyone can see them at the bottom of the television screen, or 'closed', in which case a special teletext television or decoder is required. In many countries such as Australia and New Zealand, media policy requires closed captioning for all prime-time and news programmes, and for all government sponsored public service announcements. With the introduction of digital television, captioning will be required for virtually all programmes.[2] Similar media policies exist in developed countries worldwide, with America boasting the most extensive captioning legislation in the world. New media technologies and policies, and the fact that digital media like DVDs come with the function to display subtitles in a range of languages, are increasingly rendering popular culture, current affairs and other media offerings more accessible to people who are deaf or hearing impaired. Video description is a service that is similar to captioning and is designed to make television more accessible to the visually impaired (Goggin & Newell, 2003). As mentioned above, the technology is also available to give blind people access to the web. However, to access speech, Braille and large-print functions requires additional skills and web structure; directories and links might not serve blind people well due to the complexity and variety of options (Goggin & Newell, 2003).

The range of different disabilities makes universal media-access legislation and accessibility regulations difficult to specify and enforce. Access issues for CMC differ from other media such as television, radio and print media. Not all forms of disability impede access to the media, and not all forms of disability can be 'overcome' by technologies that facilitate access. For example, websites may need to be modified in several different ways to meet the needs of the blind and the deaf, while some people with mobility impairments may need special keyboards or other technologies on their home computers to facilitate access, and others may not face any obstacles to access at all. Meanwhile, the internet and CMC have little to offer those with intellectual disabilities, and to date no serious efforts have been made to make media technologies accessible to this group (Goggin & Newell, 2003).

Conclusion

This overview of the relationship between disability and media texts, technologies, policies and modes of production offers some indication of the media's capacity to play a positive or negative role in society. The media has the potential to foster understanding, tolerance and respect for difference and diversity. However, negative portrayals in film and television of people with different abilities can undermine this process. The INDS frames the problem of media-related prejudice in the following terms:

> One of the greatest hurdles disabled people face when trying to access mainstream programmes are negative attitudes. It is these attitudes

> that lead to the social exclusion and marginalisation of people with disabilities. Negative attitudes are continually reinforced. Disability is portrayed as a 'problem'. People with disabilities are viewed as helpless and dependent; as ill and in constant need of care and medical treatment, or as tragic victims. (ODP, 1997, p. 23)

Traces of charitable discourse and the medical model of disability that were discussed in the beginning of this chapter and alluded to in the quotation above, are present in every area of media and disability analysed here. When disability is theorised as deficiency (following the medical model), it is not aligned with other categories of identity (such as race, class, gender and sexuality). Some media-disability theorists argue that a shift towards thinking about disability in terms of identity and locating it within the established framework of identity politics will work to reshape the media's engagement with disability (Goggin & Newell, 2003).

Beyond issues of self-representation, media content and its impact on identity and social relations, we have seen that media technologies and media policies also play a central role in enabling or disabling members of society. Lyn Jongbloed's work on disability policy studies shows that policy results from social negotiations around definitions of impairment, disability and handicap and conceptions of the rights and responsibilities of individuals and groups (Jongbloed, 2003). Different models, perceptions and discourses inform thought, representations and policies. In other words, when disabled people are seen as a medical problem, policies focus on health care; when understood as an economic problem, policies focus on integration, sheltered employment and productivity. When disabled people are seen as a socially disadvantaged group (like women, poor people and people of colour), policies shift towards social welfare, human rights and freedoms, self-representation and empowerment. The disability movement and associated community organisations and NGOs should not be relegated to the margins of government and corporate decision-making: 'commitment to embracing disability requires innovative policy making processes that are open, transparent and accountable. Citizens and their organisations should be involved at every level of decision making' (Goggin & Newell, 2003).

Each aspect of the relationship between disability and the media can be harnessed to alter and diversify existing discourses of disability, once the limitations of current modes of deploying technology, communicating representations and constructing media policies are recognised. The future of disability and the media can be reshaped by proactive media policies, enabling media technologies, and by raising awareness amongst media practitioners, presenters and the public about the different discourses of disability that are communicated to us and by us in everyday life.

Notes

1 For all Kolucki references in this chapter, please see www.disabilityworld.org/06-08-03/arts/currentresearch.shtml

2 See www.auscap.com.au

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27 'Ag shame' and superheroes: stereotype and the signification of disability

Kathleen McDougall

In a recent Human Sciences Research Council and South African Broadcasting Commission (SABC) Education study of disability and media in South Africa, respondents from the South African disability sector were asked what stereotypes of disability they were aware of. That they responded with lists and lists of prejudiced perceptions is not particularly surprising. What is perhaps more interesting is that the lists contained both positive and negative stereotypes. One respondent, a wheelchair user, connected the positive and negative stereotypes of disabled people in an expression of her exasperation at being reduced either to a sign of tragedy – what she calls the 'Ag shame' syndrome – or of heroism.

> R: [P]eople with disabilities are portrayed as superheroes or as an 'ag shame' kind of attitude.
>
> Q: 'Ag shame'?
>
> R: Ja, that's a South African idiom. You know, it's seeing people not for what they can contribute, but how are they going to be looked after. It's this old welfare type of role model as to how people see us. For me, we are just ordinary people really, just getting on with our lives…We have one sense or another that doesn't work in a way that yours do…[and so just because of that] one tends to make superheroes of them, and for me, that is a problem…

The question of a dichotomy between being seen as pitiable or as 'superheroic' is a point to which she returns many times in the interview. Later she goes on to explain why she thinks it is a problem that disabled people are perceived as superheroes:

> And yes, some of the things that are achieved are…I mean, look at Jeff Hilton-Barber who climbed Kilimanjaro as a blind person; it's an incredible feat! But we need to take the incredible feats, and have again, a balance of just ordinary, everyday things that are happening that people are not aware of…

For this respondent, narrating disability exclusively in terms of the pitiable or the heroic is to disregard smaller achievements, but powerful achievements nonetheless:

> There are many of the people who are looked up to in this country, like Dr William Roland from the South African National Council for the Blind. I'm not saying that it's wrong, but what I'm saying is that there are many, everyday people living in rural areas who get forgotten. For me, even the smallest achievement from someone in a rural area is a great achievement because of the lack of facilities that they have, as opposed to what we have here.

Later she replaces the phrase 'ag shame' with 'non-entity', 'it's either superheroes or non-entities'. This shift in vocabulary lays bare what is really at stake. Being regarded either as tragic and pitiable or as heroic in the face of that tragedy is a kind of disregard. To be perceived in mythic proportions is not really to be perceived. There is a sense in which all the different stereotypes and stereotypical narratives of disabled people and disability in general show fundamentally the same profound disregard for what is really there (see Chapter 4 in this volume for a psychoanalytic explication). This chapter is a discussion of how disability stereotypes may be understood in terms of how disability comes to be an empty signifier, a kind of catch-all signifier of a range of meanings.

My discussion of stereotype and signification draws on the narratives of respondents in a recent Human Sciences Research Council study of disability and the mass media in the South African context (McDougall et al., 2004). Most respondents were representatives of national disabled people's organisations, and some respondents were disabled media professionals and Sign Language interpreters. This discussion also draws on a review of literature related to the representation of disability in the mass media and to narrative tropes of disability.

The 'Ag shame' syndrome

A number of respondents noted the tendency for disabled people to be perceived as pitiable, for instance:

> The stereotype [is] that disability is always pathetic, that disability is dependent. It's presented as disabled people are very innocent, and very much deserving of one's sympathy. Yes, there is a strong stereotyping that disability doesn't play a major role in society because they're not capable of it. They are disabled, and unfortunately, it is seen as a very big umbrella…this great umbrella of dependency.

This is a very common perception among respondents. As another puts it:

> [W]e are being portrayed as poor and in constant need of care. We are sick or ill and illiterate. In the media, the impression that is given through to society is that when you are a disabled person, you need handouts… Ninety per cent of all the coverage is where an able-bodied person is standing up for example, and a person in a wheelchair is

> sitting, obviously in his wheelchair, the poor and tragic victim, receiving a handout.

Many respondents complain that being perceived as the poor and tragic victim in need of assistance reduces their identity to this single distortion of dependency. They are seen as not quite whole human beings, even as less than human. One respondent expresses this frustration:

> Blind people are depicted as people in need and as people who are experiencing problems – and all those things. You will rarely find them talking about blind people as human beings.

In these representations, the 'umbrella of dependency' is so big that it masks the humanity – as well as the individuality – of the person who is disabled.

The idea that disabled people are in need of handouts is a feature of what Clogston (1990) terms the social pathology narrative model. In this model, disabled people are economically disadvantaged and in need of support either from society or from the state. However, they are not entitled to this support – it is a gift, not a right. Because their disability reduces their identity to 'unfortunate' and 'disadvantaged', they are entitled only to pity.

Although disability is sometimes portrayed as a punishment (as in the movie *Hook* (Norden, 1994) where the villain's hook is both his punishment for being villainous and the sign of his evil, grasping nature), it is more common in contemporary depictions of disability to signify innocent damage. One example among many is the movie *Nell,* in which the main character's inability to communicate is both the result and the sign of the isolation of which she is a victim (Norden, 1994). Similarly, in *Rainman,* the autistic character's charm is his innocence of the dishonest use to which his unscrupulous brother puts him (Norden, 1994).

The idea of disabled people as innocent and deserving of sympathy is at the very heart of the 'ag shame' syndrome. However, as one respondent points out, the goodwill suggested here is a lie:

> This is the way I see the disabled get portrayed. [T]he moment they bring somebody up, they will always discuss…look at some of the talk shows…they bring a disabled guy in and they will talk about the problems he's got with his bladder. Or, how do you cope emotionally with this. But they don't take disabled people and talk real issues with them. Talk about their work and why…There are so many other things that they can do apart from being 'ag shamed'. 'You are so good. I'm so happy that I could have met you because you are such a good example,' and when he turns around…you can see that this guy is lying about it. And that is what's frustrating and it frustrates me.

It is not just the respect that is a lie, but that this is how disability should be understood – that disabled people *must* be 'ag shamed'. The respondent's use of language here is telling. 'Ag shame' is an attitude and a disposition toward disabled people. But it is also a verb – disabled people are 'ag shamed' on talk shows. This is a discourse that may be employed as much by disabled people as by nondisabled people. The following respondent alludes to this problem of complicity:

> You know, as I've said, the only one that can teach anybody about disability, is the disabled person himself – and not somebody that thinks he knows how disabled people operate. And obviously, sometimes the disabled person that gets involved in this or gets used as a source, he himself might create this 'ag shame' image around himself. I think that might be to the detriment of the disabled.

Herein lies one possibility of recovering agency. If the implication here is that to be 'ag shamed' is to be attached to, and defined by, a disabling narrative of innocent damage, the corollary is that one can choose to participate in authoring that narrative, or choose not to, or write the narrative differently, as this respondent is doing. For this respondent, 'ag shame' is the ultimate failure:

> Well, e.tv did a little thing a while ago on spinal cord injuries and sexuality. There was a huge hype. And it was okay, but I was disappointed when I saw it. The programme flippin' annoyed me; I didn't want to finish watching it because I think it was portrayed wrong … you know, they made a huge hype of: disabled people, can they have sex? Which is nice – it's an interesting topic – but I think the way that they handled it was totally wrong…the message came over, but my curiosity wasn't satisfied afterwards. I think if I were an able-bodied viewer, I would think: Gee! Shame! And immediately, if you get that reaction, the programme was a disaster…

One response to the negative portrayal of disability as being synonymous with dependency and pity is to insist on representing the positive – as one respondent does:

> A lot of it is also done in a way that it is pitiful, which we don't really like. We don't want people feeling sorry for our people. If it does come across in that way, we'd rather then do it in a positive light.

However, as has already been indicated, instituting a complete reversal does not necessarily mean the production of accurate and empowering portrayals of disability. How Christopher Reeve is portrayed perhaps represents the purest form of the superheroic disabled person. The poignancy of his career as heroic disabled spokesperson lies in the difference between his movie persona as Superman and his real-life paralysis. His depiction on the website for the Christopher Reeve Paralysis Foundation in 2005 illustrated this. The image of Superman, standing with his arms behind his back, was placed between images of Reeve in his wheelchair following his spinal cord injury. On the left he was shown receiving an honorary degree, seated in his wheelchair facing and looking up at the leader of the convocation. On the right, he was depicted alongside his wife, in a portrait shot where they both faced the camera. She was slightly above him leaning her head against his. This pose alluded to the wheelchair that was out of the frame, and Reeve's disability was further suggested by the plastic pipe leading to his throat. It was significant that the only depiction in colour in this montage was an image of Superman, a fiction. This image played an ambiguous role in the montage. On the one hand, Superman seemed to haunt the more recent real-life representations of Reeve. On the other hand this image seemsed more real than the others – it is, after all, how we remember him best.

In this way, the image of Superman challenged the veracity and potency of the subsequent pictures that displayed signs of Reeve's disability. More simply, though, the web page provoked perhaps the quintessential 'ag shame' reaction – 'ag shame, look how he used to be'. The very attempt to lionise Reeve reduced him to what was left behind when Superman went back to planet Krypton: forever a diminished Clark Kent. This fostered the illusion that if it were not for the horse-riding accident, Reeves would still be Superman, forever young and 'perfect'.

Greg Walloch, provocative and disabled stand-up comedian, challenged Reeve to a duel in his show *F**k the Disabled* (2001), by saying 'I want to be the best beloved disabled person in the United States, no, the *world*. I want to kick that Christopher Reeve's butt!' Every aspect of Walloch's show explodes stereotype, whether of disability or of being gay. As he says in the opening line, he likes 'keeping it real'. Yet his provocative challenge to Superman is merely his vehicle to challenge the idea of the disabled superhero. Walloch tells of how he finds being described as heroic demeaning:

> You know a lot of people come up to me and they say 'I think you're really brave, I think you are really courageous just for being who you are'. But they're not saying that about who I am or what I've accomplished in my life. They're just saying that based on how I look when they walk by.

Walloch vociferously rejects the idea of disabled people as 'nicer' than everyone else – as 'beyond reproach'. He comments, for instance, on the idea that specific disabilities are associated with specific beatific destinies:

> 'Cerebral palsy: brought to this earth to heal the family with one sweeping gesture of love'? The words totally glared off the page at me and I thought, you know, I don't really want that job!

In rejecting the notion of disability as angelic, Walloch also rejects the role of the superhero.

Superheroes

The idea of 'being positive' about disability, as it features in the responses discussed here, is a problematic one. In the response quoted earlier, being positive would be the antidote to pity. However, it is more often the case that 'being positive' can also arouse pity, as in the example below:

> This poor girl who sits there and she wants to become a motivational speaker because they think she is special, and personally, I think that she's going to waste her flippin' time – because it's not going to work for whatever reason. You know, it's that 'ag shame' type of image that hangs around the disabled. And the moment they feature in the media or get exposure in the media, it's immediately the 'ag shame' reaction. And if you take any rugby player and put him on the set and say, 'this guy is doing so well', nobody will think: 'ag shame, another rugby player'.

For this respondent, as for the earlier respondent, the idea of canonising some disabled people for their ability to 'overcome' their disability is as problematic as the 'ag shame' syndrome. Being positive for this respondent involves more than simply parading disabled people who have achieved 'against the odds':

> [Media coverage of disability] is not enough, definitely, but that's my personal opinion. And it should be more positive and it should be more upbeat. You know, it gives you sometimes the impression if you read it, they don't say it, and I'm generalising, I know, and I shouldn't. But often if you read a disability story, it's 'ag shame', '*ag fooi tog*', or 'this poor person has managed eventually to get somewhere' kind of slant to it, and it's horrible. Ja. It's a person and they just happen to have a condition on the side, so what?! Don't always make it 'ag, shame' and '*ag fooi tog*', and 'how wonderful it is, you know, that one out of the thousands has reached something'. Meantime there's so many living a normal life...

The perception that 'positive' portrayals of disability are denigrating is not unusual among respondents. Another respondent points out that being 'positive' in this way implies that those who do not fit the 'superhero' success mould are failures:

> And if you find them talking about a blind person, they are talking about a person who is the exception – a person who has succeeded in spite of all odds. There are exceptions with blind people, yet that is not always true. Many blind people do not have basic services, and therefore they cannot succeed. It's not their fault that they can't succeed…So the person who has succeeded, it's fine; he or she has succeeded, but those who didn't, it's not because they are lazy. It's not because of anything to do with them, but it's just because there aren't services.

The superhero narrative is really the same narrative as the 'ag shame' narrative: disability is located in the body of the disabled person. The consequence of both is that there is neither social responsibility for the lack of access to social services, nor for the ways in which bodily and intellectual perfection are defined. But recognising the fundamental lie that narratives of 'superhero' disabled people are identical with 'ag shame' narratives is like spotting that the Emperor has no clothes. Clogston (1990) describes the superhero or 'supercrip' narrative as one in which the disabled persons' deviancy is not their lack of fortune (as in the social pathology model discussed in the previous section) but the 'superhuman' feat of living a normal life 'despite' their disability. Both narratives are founded on the idea that disability is deviant.

Marks (1999) suggests a number of explanations for the extreme reactions that people sometimes have towards disability. She describes the ways in which people without disabilities often disregard, express pity or even fixate on people with disabilities. She suggests that these reactions are sometimes projections onto disabled people of fears of being dependent and isolated, which are generated during infancy. She also suggests that the extreme reactions people have to disability have their roots in a particular medical model of disability, also described in relation to narrative practices in Haller (2000) and Clogston (1990).

Disability is defined in the medical model as a disease, despite the fact that many disabled people are not ill (Marks, 1999). Defining disability in this way has a number of severe consequences for how disability is understood and how it is experienced both by people with, and without disabilities. One of the most important consequences is that the ways in which social practices themselves make the experience of being disabled more extreme, are hidden. For instance, the fact that most South African classrooms are not accessible to learners in wheelchairs (ODP, 1997) contributes significantly to those learners' mobility impairment. These learners might not experience themselves as mobility impaired, or not as severely mobility impaired, if classrooms were physically different. If the problem is assumed to be located in the learner, as it is in the medical model, the importance of classroom accessibility would not be recognised. Similarly, and even more pertinent to this research, Deaf people have restricted access to television programming not because they are Deaf, but because television programmes do not have captions. One of the respondents in the HSRC/SABC Education study tells a story of how the Deaf South African Olympic medallist Terence Parkin was silenced through the inadequacy of a television interviewer.

> Again, with the Olympics, I saw some horrific interviews with Terence Parkin after the 2000 Olympics. Terence didn't have an interpreter with him. So his coach was interpreting. He's a coach – he's not a sign language interpreter! And even they don't have a very deep communication level. They communicate really well when it comes to

> swimming, but now the media is asking: 'how are you feeling? How are you feeling?' And you could just see he got very uncomfortable, not knowing what to do. This coach is just answering for him…Rather interview him in the proper way or don't interview him at all. Don't make him look stupid. They made him look deaf and dumb on television because they *put the barrier in place*.

In another example, a Deaf respondent connects the way in which Deaf people are often made to look 'dumb' with a belief that Deaf people have, as she puts it, 'small minds'.

Disability and the body

The medical model relies on understanding the body as split from the mind and the body as the location of the 'disease' of disability. This understanding ignores the ways in which a person's experience can shape organic constitution, internalised oppression and the phenomenon of 'secondary handicap' (Marks, 1999; Sinason, 1992). A corollary of understanding the body and the mind as fundamentally split off from each other is the tendency in the medical model approach to regard people with disabilities in terms of their bodies alone. Marks describes how this has led to children's needs to form emotional bonds or to develop intellectually being ignored in favour of treating their bodies in medical institutions. One of the less obvious ways in which this attitude impacts is that issues that relate to disabilities, but are not visibly written onto the body, are often disregarded. One respondent draws a tacit link between the invisibility of disabilities like epilepsy and bipolar disorder and the way in which people with intellectual disabilities – a different kind of invisibility – are removed from society and so are rendered invisible:

> [D]isability in most cases is associated with the physical – something that you can see. But someone with epilepsy or a bipolar mood would not be regarded as disabled because these things are not spoken about and they are not made visible so that people can know, a person with bipolar is a person like this. But mostly with regard to intellectual and mental disabilities – that's an area that's extremely critical, in that you have a lot of these people dumped in institutions.

There is a sense in which being invisible is congruent with being silenced, a congruency that stems from the limitations and distortions of the medical model, with its exclusive fixation on deficit bodies, that cannot understand disability as situated in complex relations ranging from the personal to the political and including socio-economic, psychological, historical and physical factors. The tendency to conceive of disability as an exclusively physical rather than a social problem is, of course, a great way to skirt the issue of disabling environments and the medical paradigm's complicity in creating and perpetuating those environments.

It is also a great way to carve out a field of expert knowledge that silences, with authority, input from disabled people themselves. Reduced to the status of malfunctioning bodies, disabled people are represented as lacking capacity to put forward their point of view. In the medical model, the person with a disability is not qualified, like the doctor is, to pronounce judgement on physical conditions. Consequently, the disabled person's experience of being disabled is easily silenced in favour of the official, 'qualified' and therefore authoritative opinion of the doctor. The idea that disabled people are not qualified to represent their own experience, or that their experience is not relevant, is a pervasive one. It is certainly echoed in how people with disabilities are not represented or are misrepresented in the mass media throughout the world, and in how seldom people with disabilities are instrumental in representing their experiences in the media (see for example, Auslander & Gold, 1999; De Cumberlatch & Negrine, 1992; Haller, 2000; Hevey, 1992; Marks, 1999; Rapp & Ginsburg, 2001; Valentine, 2001; Wolfson & Norden, 2000).

The institutionalisation of people with disabilities, and the fact that they lack access to many mainstream public spaces may be an important factor in how easily people with disabilities are stigmatised. Oliver and Fonash (2002) summarise stereotyping processes in the context of the mass media and disability. They suggest that stereotype is related to how people define themselves as part of a group. One is more likely to stereotype those who are not perceived to be part of one's own social group. The respondents in the HSRC/SABC Education study support this idea in that they commonly attribute negative discrimination to ignorance. For Bradford, one of the producers of *How's Your News?* (Stone & Bradford, 2004) in which five physically and intellectually disabled reporters cross the United States interviewing passersby, the display of disability in the show helps to foster a more active acceptance of disability and of disabled people:

> The traditional view of disabled people is they're on a bus, and you put 'em on a bus, and you go take them somewhere, and you just kind of shuttle them into the museum or the zoo, and then take them out, and they don't interact with the public. And so *How's Your News?* was about getting out there and getting in everyone's face and saying 'Hi, what's up?' (Stone & Bradford, 2004).

Most challenging for those being interviewed were Robert Bird and Larry Perry, as both do not speak. The show features long scenes where Robert and Larry attempt (and sometimes succeed) to communicate. Bradford defends the no-holds-barred way in which the disabled reporters are portrayed in *How's Your News?*:

> I think that to say that *How's Your News?* is offensive, that it shouldn't be shown, is to say that the people, the reporters, on *How's Your News?* should not be on television – or that they are not aware of what they're doing and they *are* and they're proud. (Stone & Bradford 2004)

For Bradford, the way in which these two reporters' experiences are not censored from the show is a way of introducing viewers to their reality: an insistence on their presence as an act of respect for their physical and intellectual difference.

Disability as homogenous

Research suggests that people are more likely to perceive 'out-group members' as homogenous' (Oliver & Fonash, 2002) – the essence of stereotype. Disability is commonly understood (and portrayed) as homogenous. For instance, the whole spectrum of disability is often signified by the wheelchair user. As one respondent puts it:

> This is a personal thing, but my biggest problem with stereotypes is that the world out there thinks that a disabled person is a person in a wheelchair – or a deaf or a blind person that you can see. That is the worst kind of stereotyping that there is.

She goes on to bemoan the common perception that physical disability automatically implies intellectual disability: 'And of course, the fact that when someone is deaf or blind or whatever, they think that they're also mentally retarded.' The way in which physical disability is assumed to signify intellectual disability resonates with the conflation of all disability into the symbol of the wheelchair.

Another respondent comments on how the wheelchair stands both for disability in general and for illness:

> It's sort of every time they want to demonstrate a disability they throw in someone in a wheelchair. To give you an example, every time there's a hospital scene in any production – local or not – there's always someone being pushed around in a wheelchair almost to sort of reaffirm that this is a hospital scene. You know, so then the stereotyping comes in when people who use wheelchairs are seen as sort of medical cases. You know, it's not a mobility thing – it's a medical thing. Whereas the wheelchair is just a tool of mobility.

The issue of homogeneity is relevant both to disability in general and to the way in which particular disabilities are understood. One respondent makes this especially clear in her discussion of epilepsy, where she points out that the extent of a disability may be judged by its impact on the actual person rather than by an objective standard:

> [E]very person's epilepsy is different. As I say, one person might have a seizure once a year, but it might be awful to that person just having one a year, where another might have three a day and they're coping fine and living a normal life. So it depends on the person, it depends on the types of seizures, it depends on how the person's coping with their seizures.

Similarly, another respondent discusses mobility and hearing disabilities:

> They don't understand the diversity within the disability groups. Let me explain. Accommodation needs in general, of quadriplegics, paraplegics and any plegics…People that are hard of hearing – extremely hard of hearing – became deaf later; completely, profoundly deaf. The different diversity within those groups is not being understood, and it's being portrayed in the wrong way. People, for example, treat and deal with a hemiplegic in the same way as a quadriplegic because they don't understand the different accommodational needs.

A common stereotype mentioned by respondents related to a common assumption among nondisabled people that disabled people cannot speak for themselves. A number of respondents commented on how nondisabled people would resist addressing them directly:

> They see the wheelchair, and as a result of being in a wheelchair, they then don't speak to you as a person. If you happen to be with nondisabled people, they then talk to them and use them as your mouthpiece…we thought you were the exhibit for the lecture, and we were waiting for the lecturer! So that is in a nutshell how we are perceived. And why is that? It's because again, not many people with disabilities are empowered to talk for themselves.

In the above case, the respondent describes her being in a wheelchair as the reason for her being disregarded. For a blind respondent, the reason is his blindness:

> And the other stereotype is that being blind means maybe being unable to think; being unable to do things on your own. And that's why you'll find that if I go with someone assisting me or even my companion who happens to be sighted, they will ask him or her what I would like to have – or something about me – rather than talking to me directly. That is something that we always teach. You will find that if the owner of a car or who is responsible for the car... I don't drive... now, they'll rather talk to someone who is driving me. If I insist that they should talk to me because the driver is not going to pay for the [repairs], they'll insist: you are not driving. Let me talk to the driver. Which to me is not right.

In both of these cases the respondents describe the challenge of understanding the inappropriate response. Both frame the way they are disregarded within a rational framework. For the first respondent, the problem is basically that people with disabilities do not regularly speak for themselves – that she is unusual in this. For the second respondent, who is less forgiving, the disregard he suffers, while intolerable, is rooted in the belief that it is the person who is *driving* the car who is responsible for the car – not an entirely unreasonable idea. However, in both narratives it is overwhelmingly clear that the disabled protagonists are relegated by the prejudiced nondisabled people with whom they are conversing, to the position of bystander in their own story. This is fundamentally unreasonable. The unreasonable and unreasoning reaction that these two highly empowered disabled people describe may be explained as the nondisabled people's insistence on narratives in which disabled people are always objects. Disability is sometimes less a signifier of disability, and more a signifier of various bogeys. Or, more directly, as Cheryl Marie Wade, a disabled playwright, puts it in an interview for the documentary *Talking Back,* 'mine are the hands of your bad dreams – booga, booga – from behind the black curtain' (Mitchell & Snyder, 2000). What the 'ag shame', 'supercrip' and medical model narratives have in common is that at their centre there is still a kind of pulsating fascination with what is defined in the narrative as the horror of disability – what Hevey (1992) refers to as the 'enfreakment' of disability.

In semiotic terms, in all the narratives described above the signifier 'disability' continues to signify to a greater or lesser extent negatively as a lack – whether as a physical lack, a lack of life chances, a lack of opportunity, or, more broadly, simply as a lack of humanity. The tendency in this way of making meaning, is for a disabled person to signify predominantly as 'disabled', rather than as a person with a specific and unique history and outlook. Barthes (1993) describes this semiotic process as mythologising. He uses the example of a photograph of a black French soldier saluting the French flag. The photograph is not so much of the actual soldier – he is not the subject of the picture. The picture is a statement about French imperialism, and the soldier comes to stand for acquiescence to that imperialism, for the power of French imperialism. The sign of the soldier is emptied of denotative meaning and comes to have only connotative meaning. One respondent in the HSRC/SABC Education study describes a similar mythologising process in relation to disability:

> I think the media doesn't address disability in a mainstream way. You know, to treat a disability issue or…a disabled person, who achieved something, as a person first and then focus on his disability. But now, it's big news because this guy who is in a wheelchair managed to get a diploma. 'Wow! This guy got a diploma!' So what! He's in a wheelchair, so what! So I think it's very much them not looking at it as a mainstream issue. But you know, dealing with it very much in isolation. And then, not dealing with it properly at all, even when they do.

Narratives about disability are often predictable, and disability is often portrayed in a homogeneous way. Disabled people all too easily come to stand for abstract concepts such as dependency or isolation. Another respondent describes how stereotype works in the following way:

> They say blind people are arrogant. That is one of the stereotypes. But of course, I told him, you'll find that the blind people that you are talking about, who are so-called arrogant, are not necessarily arrogant. They are just assertive. They are telling something that is unusual to the hearer,

> and the hearer may think it is arrogant at its best – or at its worst! This is one of the stereotypes.

At the heart of stereotype is the refusal to understand anything unscripted about the stereotyped person. The refusal is at the level of language as much as it is political: the refusal to believe that disability is not deviant is also the refusal to understand a disabled person as anything other than that monolithic sign 'disability'.

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