

# **Children with disabilities in South Africa: The hidden reality**



The African Child  
Policy Forum



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## The African Child Policy Forum (ACPF)

ACPF is an independent, pan-African institution of policy research and dialogue on the African child.

ACPF was established with the conviction that putting children first on the public agenda is fundamental for the realisation of their rights and wellbeing and for bringing about lasting social and economic progress in Africa.

ACPF's work is rights based, inspired by universal values and informed by global experiences and knowledge. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments. ACPF aims to specifically contribute to improved knowledge on children in Africa; monitor and report progress; identify policy options; provide a platform for dialogue; collaborate with governments, inter-governmental organisations and civil society in the development and implementation of effective pro-child policies and programmes and also promote a common voice for children in and out of Africa.



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## Acronyms

<b>ACPF</b>	The African Child Policy Forum
<b>CASE</b>	Community Agency for Social Enquiry
<b>CBR</b>	Community-Based Rehabilitation
<b>CDG</b>	Care Dependency Grant
<b>CREATE</b>	Community-based Rehabilitation Education and Training for Empowerment
<b>DART</b>	Disability Action Research Team
<b>DICAG</b>	Disabled Children's Action Group
<b>DPO</b>	Disabled People's Organisation
<b>DPSA</b>	Disabled People South Africa
<b>DSD</b>	Department of social development
<b>DG</b>	Disability Grant
<b>ECD</b>	Early Childhood Development
<b>HPCSA</b>	Health Professionals Council of South Africa
<b>IDASA</b>	Institute for Democracy in South Africa
<b>ILP</b>	Inclusive Learning Programmes
<b>INDS</b>	Integrated National Disability Strategy
<b>NGO</b>	Non-Governmental Organisation
<b>OSDP</b>	Office on the Status of Disabled Persons
<b>PHC</b>	Primary Healthcare
<b>RSA</b>	Republic of South Africa
<b>SADA</b>	South African Disability Alliance
<b>SAHRC</b>	South African Human Rights Commission
<b>SANAC</b>	South African National AIDS Council
<b>SASSA</b>	South African Social Security Agency
<b>SIAS</b>	Screening, Identification, Assessment and Support
<b>SIDA</b>	Swedish International Development Cooperation Agency
<b>SSA</b>	Statistics South Africa
<b>UN</b>	United Nations
<b>UNCRC</b>	United National Convention on the Rights of the Child
<b>UNCRPD</b>	United Nations Convention on the Rights of Persons with Disability





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## Preface

Children with disabilities in Africa are among the most neglected groups in the policy domain as well as in the private sphere. The majority of these children face enormous economic, political, and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing. Many of them do not have access to the most basic needs such as health services and education, experience multiple deprivations even within their family and are invisible in national policy agenda.

The African Child Policy Forum (ACPF) believes that revealing the realities and drawing attention to the life situation of children with disabilities is the first step to lay the foundation for the establishment of sound policies, strategic plans and effective services and support to children with disabilities in Africa. It is within this context that the ACPF took the initiative to document the reality of children with disabilities and their families in Africa through in-depth studies aimed at generating evidence about their situation and by so doing it hopes to encourage greater national commitment to children with disabilities.

The multiple-country study is an effort to make the situation of children with disabilities more visible, so that parents, community leaders, policy makers, as well as child rights activists and their organizations, commit themselves to better protecting and promoting the rights of children with disabilities. The study seeks to analyse how cultural, social, physical and other societal barriers prevent children with disabilities from enjoying their constitutional rights to equality, freedom and human dignity. It also seeks to establish opportunities and practices that could be used to address these barriers to enhance disabled children's participation in society.

*Children with disabilities in South Africa: The hidden reality* is therefore part of a multiple-country study conducted by ACPF. We hope that this report serves its purpose and contributes towards guaranteeing children with disabilities to equal opportunities, treatment and full participation in South Africa. It is our greatest hope that this research supports the formulation and implementation of national policies, programmes and legislations that promote the full participation, equality and empowerment of children with disabilities in South Africa.

David Mugawe  
Executive Director



## Executive summary

South Africa is a middle-income developing country and the seventh richest in Africa. Despite its relative wealth, however, there are huge disparities between rich and poor and the country has a low ranking (129 of 182) on the United Nations Human Development Index. South Africa has undergone radical transformation following the ousting of the apartheid regime and its replacement with a democratic government in 1994. Substantial resources are allocated to social services for children (in health, social development and education) but the impact of these is limited. The public health system – on which 85% of the population depends – is overburdened and understaffed, social development safety nets are overstretched and the education system is struggling to provide quality education for the majority of learners.

The African Child Policy Forum commissioned a desktop review of the realities of disabled children in South Africa to help improve understanding of the magnitude and needs of children with disabilities in Africa. The aim of this project is, therefore, to collect, summarise and synthesise relevant reports, researches and surveys from varied and reliable sources, in order to produce a report that clearly “assesses the life situation of children with disabilities in South Africa, including gaps in policy and practice, as well as good practice” (ACPF 2010b).

This study acknowledges the frequent blurring of lines between disability and

chronic illness, with the latter often resulting in functional limitations. However, the disability sector in South Africa is adamant about the need to maintain the distinction between the two. In addition, the study takes into account the many features of South African society that exclude disabled adults and children, recognising that the rights of disabled persons will be only realised if such barriers are removed.

This report refers to many researchers who cite the limitations of census data on the prevalence of disability. Nevertheless, in the absence of other data, we quote the most recent findings of Statistics South Africa (SSA) published in 2005: about 5% of children aged 0-19 have a reported disability – that is a total of approximately 496,000 children. The SSA study also found that visual, physical and hearing impairments account for 80% of disabilities.

The South African government has made significant progress towards protecting the rights of children with disabilities and promoting their wellbeing through legislative and policy reform. Building on the foundation of the constitution, the Bill of Rights and the integrated national disability strategy, the national disability policy framework (OSDP 2008) gives effect to the United Nations Convention on the Rights of Persons with Disability (UNCRPD). The departments of health, social development and education have developed sector-specific legislation and policies aimed at improving the

quality of, and access to, services for children with disabilities.

In addition, the government has established several bodies to monitor violations of rights, particularly those of vulnerable groups such as disabled children. These include the portfolio committee on women, children, youth and people with disabilities and the South African Human Rights Commission. However, to date, violations of rights have not been reported on a large scale.

Civil society has played an important role in advocacy for human rights in South Africa. The South African Disability Alliance (SADA) is comprised of 12 national organisations that represent disabled people. Their particular roles include raising awareness on disability issues, collaborating with government, and monitoring government implementation of services. However, their work is often compromised by lack of funding.

Despite policy and legislative reform, negative attitudes towards disability are still prevalent, and disabled adults and children continue to be excluded from mainstream provision. Services to children with disabilities are fragmented and not well coordinated and systems for early identification, referral and follow-up of these children are deficient. Research indicates that this lack of implementation is a result of several factors, including: the poor alignment of action programmes and policy; inadequate financial and human resources; and a lack of rigorous monitoring procedures.

Within the health sector, the systems

in place for the early identification of childhood impairments are inadequate. Furthermore, despite the provision of free health services for all children, other factors – such as the prohibitive cost of accessible transport – mean that disabled children continue to have limited access to healthcare. The South African government has recognised disability as one factor of vulnerability for HIV infection, but a great deal of work still remains to ensure that disabled children are protected from abuse and that they (and their parents and carers) are provided with the necessary information and support to ensure HIV prevention.

South Africa has acknowledged the importance of rehabilitation and assistive devices for disabled children. Community-based rehabilitation (CBR) in particular has been affirmed as an appropriate and affordable means of providing services. However, public health facilities are currently stretched to breaking point, and curative services often take priority over rehabilitation. This is compounded by the shortage of physiotherapists and occupational therapists in the public sector, as well as the lack of accessible health facilities.

One of the means of addressing the deepest levels of poverty has been the provision of a massive social grants system. Carers of children with severe disabilities are entitled to the care dependency grant, subject to an assessment by a medical practitioner. In 2008, close to 100,000 disabled children were benefiting from this grant.

Since the release of the white paper



on inclusive education in 2001, the South African government has implemented various pilot projects and field tested two key strategies: screening, identification, assessment and support (SIAS); and inclusive learning programmes. Human resource development has included training 5,000 personnel on inclusive education between 2006 and 2009. In addition, 30 designated schools have been upgraded with accessible facilities and the necessary assistive devices for learners. However, despite such achievements in designated schools, many challenges remain to ensure that all disabled children have access to quality education. Not least is the limited capacity of education officials, educators and support staff to implement inclusive education and limited funding for rollout. It has also been difficult to track the progress of implementation of the white paper, due to a lack of disaggregated data on disabled learners in mainstream schools.

Despite the gaps in research on disabled children in South Africa, this desktop study has identified a number of examples of good practice in terms of protecting their rights. These include strategies for promoting the inclusion of disabled children in legislation and service provision for vulnerable children. A range of resources have also been developed to support inclusion in HIV and education initiatives, while civil society organisations are also developing an innovative strategy to disseminate information about disability services to disabled adults and children, their families and service providers. The

implementation of inclusive education has become a vehicle for promoting universal access within the education sector. Finally, we also found several models for the implementation of accessible and appropriate services for disabled children.

The key recommendations to emerge from this desktop review are that the South African government, civil society and other stakeholders work together to:

- transform inclusive services at all levels;
- clarify the definition of disability and collect reliable data;
- improve monitoring and reporting on implementation;
- strengthen prevention and early intervention programmes;
- use available resources to develop and strengthen appropriate services;
- allocate adequate financial resources;
- use resources optimally through inter-sectoral collaboration;
- use research as an effective tool for change.

In conclusion, South Africa has many resources at its disposal to support children with disabilities. But the challenge remains to realise the vision of a *society for all children*. For this to become reality, government and civil society must work collaboratively to make inclusion a priority. Only this will ensure that the rights of disabled children in South Africa do not remain a theoretical concept, but are manifested through quality improvements to their lives.



## 1. The country context

The Republic of South Africa occupies 1.2 million square kilometres of the southern tip of Africa. The last census, carried out in 2001 found the total population to be 43.3 million, but a recent mid-year population estimate (SSA 2009) shows that the population now stands at close to 49.3 million. It is home to nearly 19 million children, many of whom are vulnerable (UNICEF 2009).

South Africa is a middle-income developing country and (according to the World Bank's world development indicators) had a GDP of US\$276 billion in 2008. On a per-head basis, it is the seventh richest country in Africa, and it has the world's 24<sup>th</sup> biggest economy. But these averages hide huge disparities, and South Africa ranks a dismal 129<sup>th</sup> out of 182 countries on the UN's Human Development Index,<sup>1</sup> with many ordinary citizens not benefitting from the country's development.

### 1.1 System of governance

Post-1994, after the apartheid regime was ousted, the South African government had to establish democratic systems as well as progressive legislation and policies on which to base equitable implementation and provision of services. This has led to the reconstruction of South African society – through political, social and

economic transformation. Given the huge backlog, particularly for the black majority of the population, providing services has led to competing demands on the country's budget – for example, having to divide available resources between the needs for housing and education (SIDA 2003).

South Africa has adopted a unitary system of governance, consisting of three spheres of government at national, provincial and local levels. There are nine provinces and 284 municipalities categorised as metropolitan, district and local structures. The national government consists of parliament, cabinet and 33 government departments. While the national government is primarily responsible for developing policy and monitoring its implementation, the provinces' mandate is to implement them. However, there are some instances – such as the provision of health, education and social services – where national and provincial government share responsibilities.

Each of the nine provinces has its own parliament and administration. The provinces are:

- Eastern Cape;
- Free State;
- Gauteng;
- KwaZulu Natal;
- Limpopo;

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1 The human development index is a comparative measure of life expectancy, literacy, education and standards of living for countries worldwide. It is a standard means of measuring wellbeing, and child welfare in particular, which are used to distinguish whether a country is developed, developing or under-developed. It also measures the impact of economic policies on quality of life. <http://hdr.undp.org/en/statistics/hdi> [retrieved June 2010].

- Mpumalanga;
- Northern Cape;
- North West;
- Western Cape.

Figure 1: Map of South Africa, showing provinces



Source: [www.afrilux.co.za/images/maps/south\\_africa\\_map.gif](http://www.afrilux.co.za/images/maps/south_africa_map.gif)

South Africa is often referred to as the 'rainbow nation', characterised by a diverse population in terms of race, culture and religion. However, it is also a country of extreme contrasts:

- Despite its considerable mineral wealth, 43% of the population lives on less than US\$2/day. The richest 20% earn two-thirds of the country's income.
- It has a very high rate of unemployment; yet suffers from crippling skills shortages.
- It was the first country to perform a heart transplant and some of its doctors are among the best in the world; yet mortality rates for children

under five have remained the same over the past two decades and one in 15 children die from preventable diseases.

- Outside of war zones, it is one of the world's most violent and crime-ridden countries; around 50,000 children are victims of violent crime each year (UNICEF 2009; Geddes 2010).

The new constitution adopted in 1996 signalled a move away from a racially based society: more black people have had access to opportunities such as education and employment, and the black middle class has increased substantially. However, a phenomenon

of 'economic apartheid' has developed, which is skewed towards black people, who continue to experience the highest levels of poverty and are disproportionately over-represented in indices such as unemployment and income poverty.

## 1.2 Government service provision

One of the challenges facing the country is the ineptness of civil servants, particularly at local government level. This is despite the major progressive public service reforms which national government has undertaken to enhance public service delivery. Since 2008 the country has witnessed a spate of (sometimes violent) service delivery protests, with communities calling for the government to fulfil its promises – to provide housing, electricity, employment opportunities, etc – and to address the nepotism and corruption of government officials.

### 1.2.1 Health

Health receives the second-highest slice of the country's budget after education, with 3.7% of GDP (more than R100 billion<sup>2</sup>) spent on the sector. While there are a few isolated incidences of high-quality healthcare, the general state of the public healthcare system is poor, characterised by dirty and over-crowded hospitals, long waiting periods, a lack of medicines and a shortage of medical staff.

***“Many thousands of public sector doctors, nurses and other medical***

***practitioners have left the country, fed up with the poor pay and appalling conditions. Others have gone into the rapidly expanding private sector. A study in 2007 found that one-third of public medical posts were unfilled. In some hospitals the vacancy rate for nurses is as high as 60%. The public sector now has just one doctor for every 4,570 inhabitants, against one for every 600 in private medicine”.***

***(Geddes 2010)***

According to UNICEF (2009), maternal mortality in South Africa is high and still rising, with the babies often dying or orphaned. It is estimated that one in 250 women dies during pregnancy or childbirth and AIDS-related diseases account for 23% of all maternal deaths. UNICEF holds that about 38% of these deaths could be avoided with better healthcare services.

In order to address these issues, the department of health has introduced a 10-point plan to improve the quality of healthcare for mothers and babies, which includes a strong community outreach programme. It has also introduced the expanded programme of immunisation to combat vaccine-preventable diseases. The programme is rolling out new vaccines to prevent the most common forms of pneumonia and diarrhoea. Recently the government announced a campaign to get 15 million people (one in three of the population) to undergo an HIV test, and is currently rolling out one of the world's largest antiretroviral programmes.

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2 This is equivalent to US\$ 12.5 billion.

***“By the end of July 2009, close to 800,000 adults and 76,000 children under the age of 15 were receiving free treatment. It is estimated that half of adults and two-thirds of children in need of antiretroviral medication are getting it”.***

**(UNICEF 2009:8)**

The department of health is working to ensure that available resources are not only used to improve quality of care, but also to increase the accessibility of services through outreach programmes.

### **1.2.2 Social development**

Despite its status as a middle-income country, South Africa has a very high rate of child poverty. In 2007, 68% of children lived in households with a per capita income of less than R350 (approximately US\$ 50). The huge racial disparities in income poverty also need to be noted:

***“While three-quarters (75%) of Black children lived in poor households in 2007, only 5% of white children lived below the poverty line. Poverty rates for Coloured and Indian children are 43% and 14% respectively”.***

**(Meintjes and Hall 2008:77).**

UNAIDS estimates that within South Africa there are 1.4 million children aged 0-17 who have been orphaned as a result of AIDS-related diseases.<sup>3</sup> This not only puts huge strain on social development services (such as foster care, child and youth care centres); it

has also created a need for social and emotional support for a generation of children growing up without parents.

The South African government is addressing the worst poverty by means of a massive social grants system, which has been growing every year: the number of recipients has increased from 2.5 million in 1998 to 13 million in 2009. Much of this increase can be attributed to the introduction of the child support grant, which reached nine million children under 15 in 2009 (UNICEF 2009). The qualifying age for this grant has been increased to 18 years.

### **1.2.3 Education**

The South African education system has witnessed progressive reforms and the sector receives the country's highest budget – 6.1% of GDP. However, these levels of investment have not been matched by results: the average student's academic achievements are poor, and the country consistently scores low on international literacy, reading and numeracy assessments (UNICEF 2009).

Spending per pupil is now the same for black and white, but black children generally continue to fare worse than white children because they attend vastly inferior schools. Although public education was desegregated in 1994, most former black schools remain overwhelmingly black because they are generally in poor communities and/or rural areas. Former white schools

3 [www.unaids.org/en/CountryResponses/Countries/south\\_africa.asp](http://www.unaids.org/en/CountryResponses/Countries/south_africa.asp) [retrieved June 2010].

tend to have a good racial mix because middle-class blacks have moved into their catchment areas. Around 27% of public schools do not have running water, 78% are without libraries and 78% do not have computers (UNICEF 2009).

***“The poor quality of education undermines children’s ability and desire to learn. Many children experience a broken journey through school, interrupted by irregular attendance, absent teachers, teenage pregnancy and abuse and violence in and around schools. South Africa’s high levels of poverty continue to deny thousands of children access to quality education”.***

***(UNICEF 2009:7)***

The department of education exempts the poorest children from paying school fees, a policy that aims to increase enrolment and retention of children who would otherwise be early drop-outs. At tertiary level, numbers have been increasing and the racial profile steadily shifting – currently two-thirds of the 800,000 university students are black, while a quarter are white (Geddes 2010).

### **1.3 The challenges of the context**

It is within this context that the struggle to promote and protect the rights of children with disabilities needs to be understood. The public health system – on which 85% of the population depends – is overburdened and understaffed; social development safety nets are overstretched; and the education system is struggling to provide quality education for the majority of learners. Despite the investment of considerable resources, the country’s human development index is comparatively low, and indicators of child welfare suggest that “to be a child in South Africa is to walk a fragile path to adulthood” (UNICEF 2009:5). The call for a society for all (as articulated in the integrated national disability strategy) cannot be made without a call for equity and social justice, a call to use the country’s considerable resources to promote the survival, wellbeing and development of all children.





## 2. Background and purpose of the study

### 2.1 Purpose of the study

As a leading, independent pan-African policy and advocacy centre on child rights and wellbeing, the African Child Policy Forum (ACPF) recognises children with disabilities as among the most neglected groups in the policy domain as well as in the private sphere:

***“They [children with disabilities] are absent, or referred to only marginally, in public policy documents, sectoral (health, education, social) development plans or poverty reduction programs. National Plans of Action for Children in African countries sometimes make reference to children with disabilities, but suggest little action to meet their needs”.***

**(Ransom 2009)**

ACPF believes that the availability of data is essential in order to achieve greater national commitment to children with disabilities. Sound data provides the foundation for the establishment of sound policies, strategic plans and effective services and support; for knowledge has the potential to shape appropriate action in response.

***“Documenting the reality in terms of the nature, extent and magnitude of the problem is an essential and integral aspect of any effort aimed at ensuring the equality of opportunity and treatment of children with disability and ensuring their social inclusion”.***

**(ACPF 2010a)**

To this end, ACPF commissioned research to help improve our understanding of the magnitude and needs of disabled children in Africa. The research will support the formulation and implementation of national policies, programmes and legislation to promote the full participation, equality and empowerment of children with disabilities.

Primary data collection took place in three countries – Ethiopia, Uganda and Senegal – and, although data from South Africa will be included in the overall research findings, it is from a desktop review of completed research and other secondary data. This is because of the understanding that several similar studies documenting the realities of disabled children have already been conducted in South Africa. The aim of this project is, therefore, to collect, summarise and synthesise relevant reports, researches and surveys from varied and reliable sources, in order to produce a report that clearly *“assesses the life situation of children with disabilities in South Africa, including gaps in policy and practice, as well as documents good practice”* (ACPF 2010b).

### 2.2 Methodology

Several key recent research projects are used to identify data sources relating to the realities of disabled children in South Africa, including:

- A national study commissioned

by the department of social development (DSD) on the social needs of disabled people in South Africa which identifies social research on disability in the country conducted between 1995 and 2005 (DART 2006);

- An e-library of resources developed for the Network of African Women with Disabilities commissioned by the Secretariat of the African Decade of Persons with Disabilities which included information on children with disabilities in South Africa (2009);<sup>4</sup>
- A submission to the South African Human Rights Commission by the Disabled Children's Action Group (DICAG) on the extent to which the millennium development goals are being realised for children with disabilities (Philpott and Ambrose 2009).

As well as accessing the research emanating from these sources, a review of a number of key government policies that impact on children with disabilities was undertaken. Although the focus was on the most recent research, any relevant policies and legislation adopted before 2000 were included. Furthermore, research related specifically to disabled children, as distinct from research on children that makes reference to children with disabilities was sought.

### 2.3 Limitations

The data collection process and outcome has a number of limitations.

The lack of national database on disability research meant that the consultant had to make use of her own data identification and collection networks. The consultant is also aware of a number of examples of good practice which are not written up or published and can only be traced through word of mouth, informal contacts and networks. While several of these have been included in this report, many others (that have not been formally documented) were omitted.

Data for this study was based on the information that was available, rather than the information that was needed. This report is a collation of *existing* research and reports that relate to disabled children in South Africa, and while the principle of using existing resources is an important one, it also severely limited the study, compromising our objective of presenting an accurate and comprehensive picture of the realities of disabled children in South Africa. This was due to the following:

- It was not possible to obtain disability-specific information on access to health, education, or sports and recreation services, or child-specific information on access to assistive devices. This information is not collected through government information systems;
- It was not possible to obtain information on the views of children with disabilities or their parents, because this is not systematically documented and/or published;

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4 [www.africandecade.org.za](http://www.africandecade.org.za)

- Some of the key studies we drew on are out-dated (pre-2000), because more recent ones have not been conducted. It was not possible to assess the extent to which the data is still accurate;
- Government reports tend to focus on what has been achieved, minimising our access to information on difficulties and limitations of services.

As a result, these gaps in information and research are mirrored in this study.

It must be noted that, although there are wide variations between provinces with regard to various indices – such as HIV infection rate, number of special schools and number of therapists – provincial breakdowns are not included in this report, as the focus is on giving an overall national perspective of the realities of disabled children. This study found that some situational analyses on disabled children have been conducted in different provinces – for example, Department of social services, population and development (undated); Anderson and Phohole (2001); and Saloojee et al, (2003). While these are very positive, as they provide relevant local information on which to base planning for services, no common framework to assess the situation of disabled children has been developed on a national level. As a result, these reports cannot be used to build a comprehensive picture of what is happening nationally, nor can we compare progress and/or difficulties between provinces.

## 2.4 Disability and chronic illness

A chronic illness is understood as being an illness that cannot be cured and must therefore be managed as a lifelong commitment. Where such an illness is not managed well, it may lead to functional impairments, such as loss of vision or limitations in physical activity. At the point where the chronic illness results in functional limitations, it is seen as a disability (Graham et al 2010).

There is often a blurring of lines between disability and chronic illness in South Africa's policy landscape. Recent legislation, such as the Children's Act of 2005, has tried to be responsive to the growing number of children who are HIV-positive or suffer from AIDS-related illnesses (both chronic conditions), and thus makes separate references to children with chronic illness and children with disabilities. However, the distinction between the two is often not clearly perceived, particularly by grant applicants (Graham et al 2010).

This perceived association between disability and chronic illness needs to be seen within the broader context, as reflected in the calls from South Africa's disability rights movement for the demedicalisation of disability. Such calls have challenged the tendency of the medical profession to equate disability with illness, a practice that renders people with disabilities in need of 'care' or 'cure'. Instead, there are calls to clearly distinguish between disability and (chronic or other) illness. Organisations such as Disabled People South Africa (DPSA)

have recommended the institution of a chronic illness grant in addition to the disability grant, but the debate around this issue has yet to be resolved.

## **2.5 Key premise of the study**

Given that this study focuses on children with disabilities, it is important to clarify the view on disability within the South African context. The disability rights movement in South Africa has historically called for a shift away from understanding disability as a medical and welfare issue which aims to either cure or care 'tragic victims' towards seeing disabled people as citizens who have the same rights as all other citizens. This view sees disability not so much as being

about individuals with impairments that limit their functioning, but more as a barrier created by society's view of, and response to, disability and disabled people.

Taking this stance, this study explores the experiences of disabled children within the South African context. It seeks to determine how cultural, social, physical and other societal barriers prevent children with disabilities from enjoying their constitutional rights to equality, freedom and human dignity. The study does not only attempt to identify barriers but also seeks to establish opportunities and practices that could be used to address these barriers to enhance disabled children's participation in society.

### **3. Overview of the situation of disabled children in South Africa**

#### **3.1 Overcoming the legacy of apartheid**

Prior to 1994 – under the apartheid policies of the Nationalist government – the majority of disabled people were severely disadvantaged in terms of access to basic services. Not only were services skewed towards white disabled people, most were based in urban areas, and therefore inaccessible to those from rural communities. In addition, services were based on the medical or charity model, which views disabled people as sick and deficient or helpless and in need of care. As a result, many disabled people were denied opportunities and remained in the cycle of poverty and social exclusion (Office of the Deputy President 1997; Philpott 2004).

Since 1994, the challenge has been not only to address the backlog resulting from inequitable service provision, but also to change the medically based paradigm within which disability was viewed. There was a need to develop rights-based policies, address inequities in service provision and promote the inclusion of disabled children. Accordingly, the large-scale policy reforms of the late 1990s and early 2000s emphasised access and equity, and the focus has shifted towards a more rights-based and developmental framework, particularly within the social cluster.

However, the situation of children with disabilities “*continues to be characterised by neglect, ignorance, marginalisation and institutional failure*” (DSD 2009:5). The challenge remains to close the gap between policy and legislative developments and the implementation of services for disabled children; only this will make their rights to life, development and inclusion a reality.

#### **3.2 Prevalence of childhood disability**

Statistical data on the prevalence of age and gender-specific childhood disability in South Africa is inadequate, unreliable and at times conflicting. Historically, this is a result of:

- the lack of recent population-based childhood disability prevalence studies using a two-phase methodology (screening and confirmation of disability);
- the lack of comparable survey methodologies used in childhood disability prevalence studies;
- the fact that almost all existing childhood disability studies were undertaken before 2000, so data does not reflect the most recent situation;
- the lack of age-specific, population-

based childhood disability prevalence studies – only two studies specifically focused on children using the 10-question screen: Christianson et al (2000), which studied children aged 2-9 and Couper (2002), which studied children under 10 ;

- the lack of consistency and consensus regarding the definition of disability, particularly because disability is “culturally produced and socially constructed” (McLaren et al 2004:164);
- the different definitions of disability and confusion with impairment, which can lead to a lack of clarity about what is being measured;
- the fact that chronic illness and disease often go undiagnosed and resultant impairments unrecognised, particularly in areas with poor health and rehabilitation coverage;
- the different approaches used to record multiple disability or impairment and proxy versus self-reporting, which have all had an impact on prevalence rates;
- the lack of disaggregated data in terms of age and gender, which makes it impossible to estimate the number of disabled children in South Africa; because some impairments are age-dependent, it is impossible to interpret prevalence without age-specific rates in relation to impairment types.

The lack of reliable, comparable prevalence rates for children with disabilities is a major challenge to the development of targeted and

appropriate services, and thus negatively impacts on the rights of disabled children. This difficulty is compounded by poor (or absent) routine data collection systems on the number of disabled children who are receiving services – for example, the number of children with disabilities enrolled at special or mainstream schools across the country – and the difficulties of bringing statistical data together from various departments, because of different theoretical frameworks. In addition, the failure to mainstream disability into government statistical processes has contributed to the lack of prioritisation of the needs of disabled adults and children in social and economic planning (SAHRC 2002; McLaren et al 2004; OSDP 2008; DSD 2009).

### **3.2.1 Census figures on childhood disability**

Because the different sources of childhood disability prevalence rates use different methods and criteria to determine disability, it is impossible to give an accurate picture of the number and profile of disabled children in South Africa, or to track changes over a period of time.

Although we quote both census and general household survey findings in the report, these are problematic primarily because disability is self-reported and unconfirmed. The findings are therefore highly subjective and depend on a number of factors, including what is socially and culturally perceived to be a disability for a particular age group.

The second post-1994 census took place in 2001; the figures for the prevalence of disability in the table below were released in 2005 based on this census.

Table 1: Number of disabled children reported in the 2001 South African census by age and gender (SSA 2005)

Age group years	Number			Percentage		
	Male	Female	Total	Male	Female	Total
0-9	101,838	88,822	190,660	2.2	1.9	2.1
10-19	156,980	148,755	305,735	3.2	2.9	3.0
			496,395			5.1

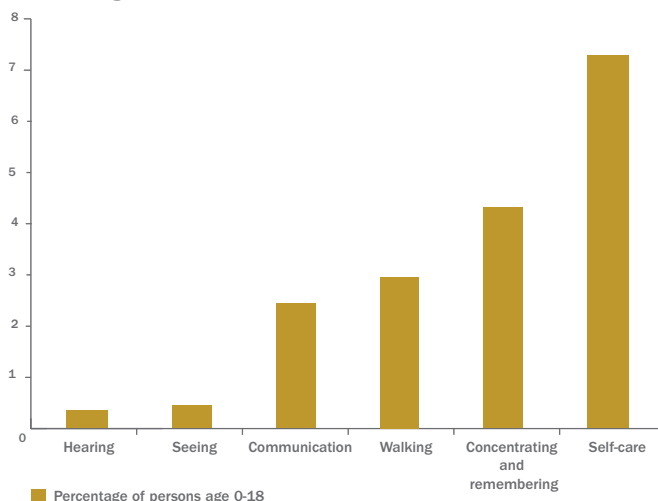
Source: SSA 2005

The table shows that about 5% of children aged 0-19 have a reported disability, giving a total of approximately 496,000 children.

The 2009 general household survey included a question on disability, which asked individuals to rate their ability level for a range of motor and cognitive activities. Those who said that they

had ‘some difficulty’ in two or more activities or ‘a lot of difficulty’ in one activity were rated as disabled. Using this system, 10.7% of children aged 0-18 years were classified as disabled (SSA 2010) – double those shown in the census (see Table 1). Figure 2 shows a breakdown of different activity limitations.

Figure 2: Percentage of children aged 0-18 with ‘a lot of difficulty’ or ‘unable to do’ a range of tasks



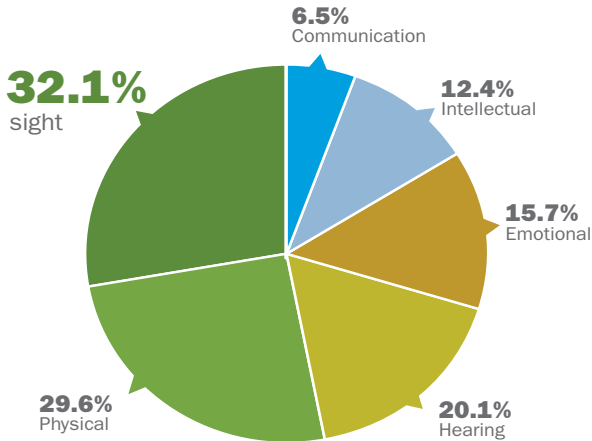
Source: SSA 2010

### 3.2.2 Prevalence of different impairment types

Different impairments – learning to walk or communicate and socialise with others – impact differently on a

child's ability to develop in a particular way. Figure 3 shows prevalence rates for impairments, based on the 2001 census information; these cannot be compared with the degree of difficulty given in Figure 2 as they are different measurements.

Figure 3: Prevalence rates for different impairment types



Source: SSA 2005

Figure 3 indicates that sight (32.1%), physical (29.6%) and hearing (20.1%) impairments constitute about 80% of impairments. These are followed by emotional (15.7%), intellectual (12.4%) and communication impairments (6.5%).

### 3.3 Risk factors and conditions contributing to, and associated with, impairment and disability in childhood

The study conducted by CASE – the Community Agency for Social Enquiry – (Department of health 1999) using a one-phase screen for reported disability,

found that the main contributors to childhood impairment and disability in South Africa were: illness; pre- and peri-natal problems such as genetic disorders and birth trauma; injuries; accidents; and violence. It also found that Africans living in rural areas are more likely to be reported disabled than those in urban areas. This may be due to the lack of physical and financial access to healthcare and antenatal services, lower education levels, poor nutrition and other features associated with poverty.

The OSDP (2008:8) cited the following as contributing factors to impairments and resultant disability:



- violence;
- poverty;
- unhealthy lifestyle;
- failure of medical services;
- environmental factors – epidemics, natural disasters, pollution and trauma.

Almost all of these factors are preventable. Indeed, the department for social development estimated that up to 40% of the causes of disability are preventable (DSD 2009). Children living in poverty are more vulnerable to disability, as poverty-related factors lead to much preventable impairment. Unfortunately, a lack of accurate information on the prevention and management of disability and the impact of targeted services compromises the ability of health and social services to address the factors that contribute to childhood disability (DSD 2009).

Although it is not possible to give a comprehensive breakdown of the overall prevalence of different impairment types in children, the existing research offered the following information on specific conditions associated with impairment and disability in childhood:

- *Developmental disability:* According to three population-based surveys conducted in South Africa between 1992 and 2002, the overall prevalence rates for all categories of developmental disability varied from 1.6 to 6.0% (McLaren et al 2004)<sup>5</sup>.
- *Cerebral palsy:* South Africa has a high prevalence of children with cerebral palsy (10 per 1,000). Birth-related trauma is one of the primary causes, and it is mainly manifested in intellectual impairment (Couper 2002).
- *Down syndrome:* Christianson and Kromberg (1997) found that down syndrome in South Africa was at least as common in the black population as in other population groups, with evidence suggesting that it occurs in one in every 600 births. The rate increases with maternal age, once the woman is over 35 years.
- *Neural tube defects:* Venter et al (1995) reported a birth prevalence of 3.35 per 1,000 children for neural tube defects, the most common of which are spina bifida and anencephaly. The intake of folic acid (type of vitamin B) before and during pregnancy can prevent most neural tube defects.
- *Hearing impairment:* A number of studies on hearing loss in South Africa have been school or hospital-based rather than population-based (van Rooy et al 1995; Prescott and Kibel 1991). The only prevalence study done on first year entry (Grade 1) school children, in the industrial areas of Witbank/KwaGuqa (Swart 1996) gave an overall crude prevalence rate for mild hearing impairment of 6% and for bilateral sensorineural deafness of 0.2%. According to Hear-it AISBL, an international non-profit

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5 The authors noted that the variation might have been due to poor methodologies that did not meet the criteria for two-phase surveys.

and non-commercial organisation, about 7.5% of school children in South Africa suffer from varying degrees of hearing loss<sup>6</sup>. Copley and Friderichs (2010:45) report a significantly higher prevalence of hearing impairment than any other birth defect; infant hearing loss is the most common congenital sensory birth defect, present in 4-6 per 1,000 live births: *“Preliminary reports in South Africa estimate that approximately 17 babies are born with or will develop hearing loss in South Africa every day, 85% of these being in the public health sector”*.

- *Intellectual impairment*: Research in different provinces found similar overall prevalence rates for children under 10 – for example, 15 per 1,000 in Bushbuckridge, Limpopo (Kromberg et al 1997); and 17 per 1,000 for mild intellectual impairment and 7 per 1,000 for severe intellectual impairment in Manguzi, KwaZulu Natal (Couper 2001).
- *Epilepsy*: A study of 6,692 rural children (Christianson et al 2000) found that 0.73% had epilepsy; lifetime prevalence was 7.3 per 1,000, while active prevalence was 6.7 per 1,000. Associated developmental disability was recorded in 71% of affected children, with 16% rated as moderate to severe. More than a half of the

children with epilepsy (57%) did not receive medication. This study concludes that the prevalence of epilepsy in the rural childhood population investigated is higher than that recorded in most similar studies from sub-Saharan Africa, and the poor utilisation of appropriate treatment is cause for concern.

- *Attention deficit hyperactivity disorder (ADHD)*: A small study by Oosthuysen (1995) found the prevalence of ADHD to be around 9% of a school sample. However, the possibility exists that the prevalence could be higher since teachers could not verify the period for which symptoms had been present.
- *HIV*: The most recent figures available from UNAIDS estimate that in South Africa there are 280,000 children aged 0-14 living with HIV<sup>7</sup>.

## Summary

In summary, there is a serious lack of age and gender-specific prevalence data on childhood impairment and disability, including risk and associated factors, and there is no disaggregated data on the extent to which disabled children benefit from service provision. These factors pose a major challenge to the development of targeted and effective prevention and intervention programmes for disabled children in South Africa.

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6 [www.hear-it.org/page.dsp?page=856](http://www.hear-it.org/page.dsp?page=856) [retrieved June 2010].

7 [www.unaids.org/en/CountryResponses/Countries/south\\_africa.asp](http://www.unaids.org/en/CountryResponses/Countries/south_africa.asp) [retrieved June 2010].

## 4. Action taken towards protecting the rights of children with disabilities

Post 1994, South Africa has made some progress towards ensuring the protection of all its citizens, including children with disabilities. Through its constitution and Bill of Rights, the country has created an inclusive, enabling legislative framework based on the values of freedom and equality for all. Furthermore, each government department has been required to develop policies and legislation which reflect these values. This section describes the key elements of these policies and legislative framework, as well as the two international rights conventions signed by South Africa. It also highlights the responsibilities of different government departments,

and the policies and legislation developed to ensure inclusion of disabled children.

The government has not been working alone in this process; South Africa's recent history is evidence of how civil society has played a critical role in exposing human rights violations and working towards justice and equity. This section also explores the contribution of NGOs in protecting the rights of children with disabilities.

### 4.1 The legislative context

Table 2 contains the government's key policies and legislation in protecting the rights of children with disabilities.

*Table 2: Summary of legislation and policies that shape the provision of services for children with disabilities*

<b>Legislation and policies that underlie the provision of disability services</b>	
<ul style="list-style-type: none"> <li>• Constitution;</li> <li>• Integrated national disability strategy;</li> <li>• Promotion of Equality and Prevention of Unfair Discrimination Act;</li> <li>• National disability policy framework;</li> <li>• Disability framework for local government.</li> </ul>	
<b>International conventions that place an obligation on the government to protect the rights of children with disabilities</b>	
<ul style="list-style-type: none"> <li>• UN Convention on the Rights of the Child (UNCRC);</li> <li>• UN Convention on the Rights of Persons with Disabilities (UNCRPD)</li> </ul>	
<b>Legislation and policies of key government departments</b>	
<b>Health</b>	<ul style="list-style-type: none"> <li>• White paper for the transformation of health services in South Africa;</li> <li>• National Health Act;</li> <li>• Mental Health Care Act;</li> <li>• Child and adolescent mental health policy guidelines;</li> <li>• Rehabilitation policy;</li> <li>• Free healthcare policy;</li> <li>• Guidelines for provision of assistive devices.</li> </ul>

*continued...*

Social development	<ul style="list-style-type: none"> <li>• White paper for social welfare;</li> <li>• Integrated national strategy on support services to children with disabilities;</li> <li>• Social Assistance Act;</li> <li>• Children's Act.</li> </ul>
Education	<ul style="list-style-type: none"> <li>• South African Schools Act;</li> <li>• Education white paper 5: Early childhood education: <i>Meeting the challenge of early childhood development in South Africa</i>;</li> <li>• Education white paper 6: Special needs education: <i>Building an inclusive education and training system</i>.</li> </ul>

**4.1.1 The constitution**

The South African constitution (RSA 1996a), as the supreme law of the country, embodies the government's commitment to protect the rights of all its citizens. Its intention is to: *"heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights... Improve the quality of life of all citizens and free the potential of each person"*.

While each of the rights itemised in the Bill of Rights contained in the constitution applies to every citizen of South Africa, the following three are especially pertinent to children with disabilities:

- the right to equality: *"Everyone is equal before the law and has equal protection and benefit of the law... The state may not unfairly discriminate against anyone on one or more grounds including disability"*;
- the rights of all children under the age of 18 to: basic nutrition; shelter; basic healthcare and social services; protection from maltreatment, neglect, abuse or

- degradation;
- the right to basic education.

**4.1.2 Integrated national disability strategy**

In 1997, the South African government adopted the white paper on an integrated national disability strategy (INDS), signalling a break with the past and a new approach to dealing with disability. The INDS was based on the constitution and the United Nations *Standard rules on the equalisation of opportunities for persons with disabilities* (UN 1993):

***"The rights of people with disabilities are protected by the constitution. Government departments and state bodies have a responsibility to ensure that, in each line function, concrete steps are taken to ensure that people with disabilities are able to access the same fundamental rights and responsibilities as any other South African"***

**(Office of the Deputy President 1997:v)**

The premise of the INDS is the social model of disability based on the understanding that most of the

barriers and difficulties faced by disabled people are not caused by their impairments, but rather by the barriers that exclude them from society. The INDS identifies a number of groups that experience particularly high levels of exclusion, including:

- children with disabilities, particularly black disabled children;
- children with severe intellectual or mental disabilities;
- disabled adults and children living in remote rural areas.

The vision of the INDS is a *society for all*, which encompasses human diversity and the development of all human potential. This can only become possible if disability issues are integrated into all government strategies, planning and programmes; it requires an integrated and coordinated management system for planning, implementing and monitoring at all spheres of government. The involvement of disabled people is central to the transformation process; thus the INDS recognises the need for capacity building and wide public education.

#### **4.1.3 Promotion of Equality and Prevention of Unfair Discrimination Act**

Another important piece of legislation for people with disabilities is the Promotion of Equality and Prevention of Unfair Discrimination Act (RSA 2000). This act identifies ways in which discrimination is manifested in South African society, and deals

with the prevention, prohibition and elimination of unfair discrimination, hate speech and harassment. The act also addresses issues around environmental accessibility and reasonable accommodation for disabled people in the workplace and prohibits the state nor any person from unfairly discriminate against any person on the grounds of disability. This includes:

- denying or removing any supporting or enabling facility necessary for their functioning in society;
- contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility;
- failing to eliminate obstacles that unfairly limit or restrict disabled people from enjoying equal opportunities, or failing to take steps to reasonably accommodate their needs.

## **4.2 International conventions that protect the rights of children with disabilities**

### **4.2.1 UN Convention on the Rights of the Child**

In 1996, South Africa signed the UNCRC thereby signalling its commitment to uphold and protect the rights of children in the country, in line with the principles of:

- non-discrimination;
- giving primary consideration to the best interests of the child;

- the right of children to survival, protection and development;
- the right of children to participate fully in family, cultural and social life.
- the principle of the best interest of the child will be upheld in all decisions concerning them;
- they have the right to participate in decisions which affect their lives.

#### **4.2.2 UN Convention on the Rights of Persons with Disability**

In 2007, South Africa ratified the UNCRPD, thereby indicating the government's commitment to protect the rights of its disabled citizens. The government also signed the optional protocol, allowing individuals whose rights have been violated to bring them to the attention of the committee on the rights of persons with disabilities and giving this committee authority to undertake inquiries of these violations.

The UNCRPD replaces the *Standard rules for the equalisation of opportunities for persons with disabilities* (UN 1993). In its preamble it recognises the family as the “*natural and fundamental group unit of society*”, which needs to be protected by both society and the state, and given assistance where necessary. The UNCRPD also emphasises the importance of mainstreaming disability issues, with signatories undertaking to “*take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes*” (Article 4.1c).

Although the UNCRPD applies to both adults and children, Article 7 specifically refers to children with disabilities, assuring them that:

- they have the same rights as other children;

The UNCRPD includes the right to education (Article 24), and obliges signatories to ensure that educational systems are appropriate for disabled children, enabling them to develop their potential and become involved in society. It stresses the importance of removing barriers that exclude children with disabilities from free compulsory education.

It also stresses the importance of habilitation and rehabilitation (Article 26), as these enable disabled children to enjoy maximum independence, develop their abilities to the full and be involved in all aspects of life. This requires the government to promote training programmes for rehabilitation personnel and promote the use of assistive devices.

Following ratification of the UNCRPD, the Office on the Status of Disabled Persons (OSDP) published the national disability policy framework and accompanying guidelines (OSDP 2008) which were intended to give a local interpretation of the UNCRPD, and to outline practical steps towards creating an inclusive society. The framework aims to ensure that all disability programmes and objectives are mainstreamed into government line function planning, implementation and budget allocations, and to promote an inter-sectoral approach.

The policy guidelines (OSDP 2008:20) identify a number of cross-cutting issues according to which all stakeholders will be monitored. These are:

- access to communication and information;
- prevention;
- public education and awareness;
- reasonable accommodation;
- universal access;
- monitoring and evaluation;
- budgeting;
- HIV and AIDS;
- mainstreaming;
- safety and security;
- human resource development.

Each of these cross-cutting issues has detailed policy objectives and targets for the period 2008-2019. The guidelines also specify the lead institutions responsible for implementation.

The disability policy framework for local government 2009-2014 (RSA 2009) aims to address the needs of disabled persons. It provides an enabling environment for municipalities, provincial and local government departments as well as other role players in local government, proposing implementation structures and mechanisms for coordinating and

monitoring disability services.

## **4.3 Legislation and policies of key government departments**

### **4.3.1 Health**

The government's vision is "an accessible, caring and high-quality health system" (Department of health 2007:11). Its legislative mandate derives from the constitution and several key pieces of legislation passed by parliament, which guide the provision of free healthcare to disabled people, enhanced accessibility of all health-related facilities and services and the adoption of a rights-based (rather than a medically-based) approach in the management of disability (OSDP 2008).

#### **a) Primary healthcare**

Central to the government's provision of health services has been the transformation of public healthcare into a district-based service providing primary healthcare. In working towards more equitable, accessible and appropriate health services, the white paper for the transformation of the health system in South Africa (Department of health 1997) provides a comprehensive policy on all the department's core service delivery areas. In 2001, a comprehensive primary healthcare package was drawn up – accompanied by a set of norms

and standards<sup>8</sup> – that encompassed the continuum of PHC services with regards to promotive, preventive, curative, rehabilitative and palliative care.

The National Health Act regulates health services and establishes a national health system which seeks to provide the best possible services within the available resources. While the Act aims to guarantee all South Africans access to healthcare services, it also specifies its aim to protect, respect, promote and fulfil the rights of basic nutrition and healthcare for vulnerable groups such as women, children, older persons and persons with disabilities (RSA 2003:2c).

In working towards realising the right of access to healthcare, the department of health published its goals, objectives and indicators for the period 2001-2005. Those focusing specifically on

people with disabilities (children not specified) were included in the section *Chronic diseases, disabilities and geriatrics* which contains the following goals:

- prevent and control of non-communicable diseases;
- improve the quality of life of people with disabilities;
- eliminate avoidable blindness from cataracts by 2020.

The first and third are related to disability prevention and focus primarily on (elderly) adults. Indeed, most of the indicators for prevention and management of non-communicable diseases relate to persons between the ages of 18-75. The only one therefore that relates specifically to children with disabilities is the improvement of quality of life. The accompanying objective and indicators for this goal are contained in the table below.

Table 3: *National health goals, objectives and indicators relating to disabled children*

Goal	Objective	Indicators
Improve the quality of life of disabled people	Increase accessibility of health services to disabled people	<ul style="list-style-type: none"> <li>• % of people with disabilities who have accessed basic rehabilitation services</li> <li>• % of people with disabilities who have received assistive devices per province</li> </ul>

Source: Department of health 2001

<sup>8</sup> The package defined comprehensive primary healthcare services which would be common to the whole country within five years of implementation. It provided for rehabilitation at each level of care – from community through to tertiary level, and included child health and disability in its eight priority areas. The package was seen as tool to quantify staffing, infrastructure, equipment and financial resource requirements.



In 2000, the department of health published a policy document on the management and prevention of genetic disorders, birth defects and disabilities. However, its effectiveness is limited, as noted by the department of social development: *“The lack of coherent policy on prevention of disability demonstrates that the focus is more on curative than preventive services”*. (DSD 2009:28)

#### **b) Mental health**

Another important achievement of the department of health was the adoption of the Mental Health Care Act which aims to regulate mental healthcare services such that it *“makes the best possible mental healthcare, treatment and rehabilitation services available to the population equitably, efficiently and in the best interest of mental healthcare users within the limits of the available resources”*. (RSA 2002: clause 3a(i))

The Act provides for coordinated access to mental healthcare, treatment and rehabilitation services for mental healthcare users (including persons with intellectual disabilities) and integrates mental healthcare into general health services.

Accompanying the Act, the child and adolescent mental health policy guidelines (Department of health 2008) provide a framework for establishing mental healthcare services for children and adolescents at national, provincial and local levels of the health system. The guidelines are based on the premise of primary healthcare and emphasise the need for an inter-sectoral approach. They identify both risk and protective factors for mental

health of children and adolescents in South Africa.

#### **c) Rehabilitation and assistive devices**

The implementation guidelines of the national disability policy framework indicate that effective habilitation and rehabilitation *“promote independence and participation and are informed by the principles of development, empowerment and social integration of persons with disabilities”* (OSDP 2008:28). The guidelines propose community-based rehabilitation (CBR) to enable disabled people to achieve social integration, and stress the need to promote comprehensive rehabilitation, particularly in the areas of health, education and social services.

The goal of the national rehabilitation policy is: *“To improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen’s constitutional right to have access to health services... and to serve as a vehicle to bring about equalisation of opportunities and enhance human rights for people with disabilities”*. (Department of health 2000:2)

The policy affirms that rehabilitation services should be community-based, with accessible, affordable and appropriate services at all levels. A central tenet of CBR is the empowerment of disabled people, their carers and parents in the case of children. The policy identifies a number of different components of rehabilitation – including prevention of disability, identification and diagnosis of different conditions, medical and educational rehabilitation – which

involve collaborative working across government departments.

Rehabilitation includes the provision of assistive devices, which constitutes a key mechanism to ensuring that disabled people can participate as equals in society. In 2003, the department of health issued guidelines on the standardisation of provision of assistive devices to address the problem of the lack of uniformity across provinces in the provision of these devices, and to give directives for the assessment, issue and repair of various devices (Department of health 2003b).

#### d) Free healthcare

In working towards improved access to health services, the department of health issued a policy statement on free healthcare for disabled people at hospital level. In 1994 the government had prioritised free healthcare for pregnant women and children under the age of six; this statement extended access to disabled people.

***“Free healthcare is about all inpatient and outpatient hospital services such as diagnosis and treatment, specialised services, rehabilitation and provision of assistive devices”.***

***(Department of health 2003a:1)***

#### e) Addressing HIV and AIDS

The South African National AIDS Council (SANAC) was set up to coordinate the South African response to HIV and AIDS. It is a multi-sectoral partnership structure with representation from government departments and civil society. The

disability sector is represented under the umbrella of the South African Disability Alliance (SADA), which used the INDS to lobby the deputy president and minister of health for resources to plan for their response to HIV and AIDS (SANAC 2008). As a result, disabled people were involved in developing the national HIV, AIDS and STI strategic plan 2000-2005, and a number of disability organisations developed specific plans focusing on the following priority areas contained in the strategic plan:

- preventing new HIV infections;
- treatment, care and support;
- research, monitoring and surveillance;
- human and legal rights.

The cabinet adopted a new five-year national strategic plan for HIV, AIDS and STI in April 2007. Significantly, it recognises disabled people as a group vulnerable to HIV and AIDS, as well as the causal relationship between HIV and disability. This provides the basis for mobilising resources for disability and ensuring that disabled people are prioritised in the AIDS response (SANAC 2008).

### **4.3.2 Social development**

The vision of the department of social development is *“a caring and integrated system of social development services that facilitates human development and improves the quality of life”*. Like the department of health, its legislative mandate is based on the constitution, which provides for the right of access to social assistance for those who

cannot support themselves, as well as protection of the rights of children with regard to appropriate care, basic nutrition, shelter, healthcare and social services.

Comprehensive social development encompasses both social transfers and social services (DSD 2009). Prior to the adoption of the INDS, the department of social development used the medical or welfare approach to disability, which assumes that disabled people are unable to provide for themselves and need to be cared for and helped. Welfare provision therefore focused on curative care and charitable assistance. The white paper for social welfare marked a major shift away from this approach, articulating the vision of a system of welfare that *“facilitates the development of human capacity and self-reliance within a caring and enabling socio-economic environment”* (Department of welfare 1997:5). The white paper promotes an inclusive approach and seeks to correct past discriminatory practices, emphasising the importance of disabled people participating equally in initiatives that affect them: *“The aim and focus is therefore on enhancing independence, protecting the rights of and empowering persons with disabilities”* (OSDP 2008:38).

In 2009, the department of social development released the integrated national strategy on support services to children with disabilities (DSD 2009), which aims to improve the

quality of life of all children with disabilities in South Africa. The focus is creating an enabling environment where disabled children have equal and accessible services and thereby function independently and enjoy a full and decent quality of life in conditions that ensure dignity, promote self-reliance and actively participate in society. The five components of the strategy relate to international and national frameworks and areas of service delivery with regards to:

- survival and wellbeing;
- childhood development;
- protection;
- participation;
- mobilisation of resources.

#### a) Social assistance

The government recognises that children with severe disabilities need substantial care and attention, and that a parent may need to stay at home or employ a carer to attend to the child. Children with disabilities may need medication, assistive devices or frequent treatment such as physiotherapy. These extra costs can put strain on families that are already struggling to make ends meet (Hall 2009).

The Social Assistance Act provides for the care dependency grant, a non-contributory monthly cash transfer for parents, primary carers or foster parents of *“a child who requires and receives permanent care or support services due to his or her physical or*

*mental disability*<sup>9</sup> (RSA 2004 clause 7a). To qualify, the child is required to undergo a medical assessment and the parent or carer must pass an income or means test. In April 2009, the value of the care dependency grant was R1,010 (approximately US\$ 150) a month.<sup>10</sup>

It is significant that the grant can be paid to carers, not only parents and foster parents. This clause was introduced to accommodate people caring for children affected by HIV and AIDS, so that they can access financial support when the child is ill, without having to undergo a lengthy foster process. Any carer of a disabled child is eligible, including members of the extended family.

#### b) **Protecting children's rights and promoting their wellbeing**

The Children's Act (RSA 2005) outlines the government's obligation to protect the rights of children as embodied in the UNCRC. It identifies the role/s of provincial departments of social development around key areas of service provision for:

- partial care;
- early childhood development (ECD);
- prevention and early intervention;
- child protection services;
- child and youth care centres.

See Appendix 2 for the specific provisions made by the Children's Act and Children's Amendment Act for disabled children.

Early childhood development is critical for children with disabilities: as well as being a means of access to early identification and referral where necessary, it also provides opportunities for social, physical and emotional development. Indeed, the guidelines for the implementation of the national disability policy framework hold that *"ECD and stimulation within an inclusive environment is the cornerstone for the development of an integrated and equitable society"* (OSDP 2008:36). The Children's Amendment Act indicates that funding must be prioritised to make appropriate ECD programmes available to disabled children that cater for their needs (RSA 2007a clause 93:4b).

The guidelines for early childhood development services (DSD 2006) recognise that children with disabilities need to have access to services, and thus stipulate that premises and equipment must be 'disability friendly'. The guidelines include a list of rights of children with disabilities in an ECD setting. It also emphasises the fact that the parents of children with disabilities should receive information on local services and treatment from which the child would benefit. Practitioners must be trained in ECD and management of programmes and facilities for young children, including skills to accommodate children with disabilities:

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9 In April 2010 the social development portfolio committee invited comments on the Social Assistance Amendment Bill. A submission from key disability organisations consequently endorsed the recommendation to remove the words *mental* or *physical* from this clause, to include children with a range of impairments, including sensory loss.

10 [www.sassa.gov.za](http://www.sassa.gov.za)

***“If children with disabilities are admitted to ECD centres they must be helped to participate in or enjoy the activities provided. Support needs to be given to families to bring children with disabilities to ECD centres. They need to be informed that these centres have admission policies that welcome and accommodate their children”.***

**(DSD 2006:15)**

### **4.3.3 Education**

Section 29 of the South African constitution (RSA 1996a) indicates that all children are guaranteed the right to basic and further education, and the state must take reasonable measures to make these progressively available and accessible. The South African Schools Act (RSA 1996b) provides for compulsory basic education for all children aged 7 to 15 (Grades 1 to 9) and bans unfair admission policies<sup>11</sup> and discriminatory educational practices. The guidelines for implementing the national disability policy framework indicate that *“persons with disabilities should have equal access to education opportunities, irrespective of the severity of their disabilities”* (OSDP 2008:31).

The education white paper 6 (Department of education 2001) provides a framework for the government’s goal of an inclusive education and training system. Its intention is to investigate and address

barriers to learning, and to develop a system with which to recognise and accommodate the diversity of learners and their needs. The long-term goal is to build an open, lifelong and high-quality education and training system for all citizens, including children with disabilities. The short- and medium-term goals are to address the weakness and deficiencies of the current system and to expand access for children of compulsory age who are not accommodated in the present education system. The white paper embodies a significant conceptual shift from previous policy in that it is based on the following premises:

- All children, youth and adults have the potential to learn, given the necessary support.
- Many people experience barriers to learning primarily because of the system’s inability to recognise and accommodate the diverse range of learning needs. This is a major shift from the assumption that barriers to learning reside within the individual learner.
- The establishment of an inclusive education and training system will require changes to mainstream education, so that those experiencing barriers to learning can be identified early and given the support they need.

The white paper does not use the term ‘children with special needs’, but instead focuses on people who

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11. The admission policy for ordinary public schools was adopted in 1998 to make provision for learners with special needs to be admitted and supported in these schools.

experience barriers to learning. It does not abolish special schools, but instead seeks to strengthen them and enhance their expertise to ensure that children with severe disabilities are accommodated appropriately. It is envisaged that special schools will be converted into resource centres, which cater for learners who need high levels of support. Resource centres will also provide support for teachers and schools in the surrounding community/district to help them cater for learners with diverse needs.

Another key policy document impacting on children with disabilities is education white paper 5 on early childhood development (Department of education 2001). Taking into account the fact that nearly 40% of young children in South Africa grow up in conditions of severe poverty and neglect, it attempts to break the cycle of poverty by increasing access to ECD, particularly for poor children, and to ensure good quality programmes. To this end, it provides the basis for promoting extended service provision and better access to ECD facilities, through high-quality services and a comprehensive policy framework for coordinated service delivery.

#### **4.3.4 Sport and recreation**

The department of sport and recreation oversees the development and management of sports and recreation in South Africa. Through its national policies and guidelines, it aims to ensure that effective partnerships are in place with those implementing sports and recreation policies at

province and municipality level.

In its 2008 annual report, the department noted that: *“There is substantial evidence to show that sport has the ability to overcome social barriers and empower individuals. It can contribute to social cohesion and provide opportunities for engagement in community life”*. (Department of sports and recreation 2008)

The OSDP stresses that children with disabilities have a right to participate in sport, recreation, leisure and cultural activities, and sets the policy objective for the department of sports and recreation of ensuring that disabled children get equal access to these activities (OSDP 2008:52). It emphasises that both competitive and adventure sports are vital components in the habilitation, rehabilitation and social integration of disabled children:

***“It [sport] is critical for the development of holistic human beings and opportunities for participation should therefore be available from a young age, at school level and throughout adult life”.***

**(OSDP 2008:39)**

One of the objectives of the current disability policy framework for local government is *“providing sustainable, accessible and affordable community services to people with disabilities in municipalities”* (RSA 2009:48). While it does not specifically refer to children with disabilities in its objectives or indicators, it is anticipated that children would be potential primary beneficiaries among:

- people with disabilities actively

participating in sports, arts, cultural activities within a barrier-free environment;

- amateur and professional arts and cultural groups of people with disabilities formed, capacitated, promoted and funded through inter-departmental cooperation.

## 4.4 Monitoring bodies

### 4.4.1 Office on the Status of Disabled Persons

The OSDP was established in 1998 to coordinate and monitor the implementation of the INDS. The intention was that the OSDP would work together with various state bodies and departments, as well as NGOs, in order to promote the development of a disability-friendly environment. Its location in the Office of the President gave the OSDP a high profile, as well as a degree of political legitimacy.

Several new ministries were created following the national elections in 2009 and the OSDP was absorbed into the ministry of women, children and people with disabilities. Although it is not yet possible to assess the impact of this relocation, the joint association of disability with children, youth and women's issues may dilute the focus on disability. In addition, the location of the OSDP in a single ministry is likely to compromise its ability to monitor other departments in relation to implementation of the INDS. It faces the danger of losing its oversight role and becoming another government department, with its monitoring role taken over by the portfolio committee

### 4.4.2 Joint monitoring committee/ portfolio committee on women, children, youth and people with disabilities

The national disability policy framework indicates that the performance of all government departments should be accounted to the joint monitoring committee on the improvement of the quality of life and status of children, youth and persons with disabilities. The framework provides the systems according to which different departments are required to report (OSDP 2008). Since the 2009 elections, the joint monitoring committee has been restructured as the portfolio committee on women, children, youth and people with disabilities.

### 4.4.3 South African Human Rights Commission

Although the constitution prohibits discrimination on the basis of disability, this does not mean that such discrimination does not happen. Indeed, as McClain-Nhlapo et al (2006:101) pointed out: "*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*".

One of the mandates of the South African Human Rights Commission (SAHRC) is to receive complaints from citizens whose rights have been violated, and take appropriate legal action on their behalf. However, the commission has received surprisingly few complaints relating to the violation



of rights on the basis of disability:

***“Despite the overwhelming prevalence of human rights abuses in South African society...experiences somehow do not become operationalised into formal complaints, thus restricting the commission’s potential for development of legislative prescriptions regarding disability rights”***

***(McLain-Nhlapo et al 2006:102).***

Although it does not disaggregate figures for disability, the SAHRC annual report for April 2009-March 2010 indicates that there were 233 complaints of human rights violations relating to children and 244 relating to education. Together, these constitute 5% of the violations reported to the commission for that period.<sup>12</sup>

## **4.5 The role played by NGOs**

The South African Disability Alliance (SADA) comprises representatives of the 12 national organisations that represent disability in the country. This structure, formerly known as the South African Federal Council on Disability, has been reconstituted as *“a body of consensus, and the voice of the disability sector in South Africa”* SADA represents approximately 8% of the country’s population.<sup>13</sup>

The 12 SADA national organisations are:

- Autism South Africa;
- Cheshire Homes;

- Deaf Federation of South Africa;
- Disabled People South Africa;
- Disabled Children’s Action Group (DICAG);
- Down Syndrome South Africa;
- Epilepsy South Africa;
- National Council for People with Physical Disabilities in South Africa;
- National Association for Persons with Cerebral Palsy;
- QuadPara Association of South Africa;
- South African Federation for Mental Health;
- South African National Council for the Blind.

A number of organisations working with disabled children fall under the umbrella of SADA, but most of these focus on specific impairment types such as autism, down syndrome or cerebral palsy. DICAG is the only organisation working with parents and children who have a range of different disabilities.

In addition to the members of SADA, there are numerous local and provincial NGOs working in the disability sector. These are usefully categorised as either disability service organisations – NGOs providing services in the disability sector – or disabled people’s organisations (DPOs), which are organisations of disabled people or parents of disabled children (Thomas 2005).

<sup>12</sup> Information kindly supplied on request from the SAHRC, June 2010.

<sup>13</sup> [www.ibility.org.za/public/Main/SADA.aspx](http://www.ibility.org.za/public/Main/SADA.aspx)



A review of available research reveals that NGOs have a number of key roles to play in promoting and protecting the rights of children with disabilities in South Africa, which are discussed in sections below.

#### **4.5.1 Raising awareness on the rights of people with disabilities**

Disability service organisations and DPOs both have a responsibility to raise public awareness of the rights of disabled people and to challenge stereotypes and misinformation about disability (SAHRC 2002). In this process it is critical that disabled people represent themselves in all matters that concern them, in accordance with the DPSA slogan “*Nothing about us without us*”.

The integrated national strategy on support services for children with disabilities envisages the role of DPOs as building the capacity of parents of disabled children and the children themselves with regards to legislation and advocacy:

***“DPOs also have the responsibility to provide capacity building to children with disabilities through leadership, mentorship and training programmes in schools, institutions of higher learning, protective workshops, residential and other facilities”.***

(DSD 2009:52)

#### **4.5.2 Collaboration with government**

The democratic principles of the South African government provides for civil society participation in the development

of policy, and as a result many NGOs, including SADA, are represented on consultative bodies. There is therefore potentially open dialogue between the government and civil society. However, the relatively small number of disability service organisations or DPOs focusing on advocacy as opposed to service provision means this opportunity is not exploited in full. SADA’s extremely limited capacity also undermines its potential for cohesive and coordinated advocacy work around issues of children with disabilities.

Indeed, Nkeli and Associates (2008:42) in their review of the effectiveness of disability policy implementation, found that the role of NGOs in the disability sector “*was seriously hampered by the lack of effective and efficient coordination amongst the sector. There was no platform to ensure that there is coordination and exchange of information and ideas between government and civil society... This has resulted in lack of effectiveness both by civil society and government in the implementation of disability programme[s] that would improve the quality of life of people with disabilities*”.

#### **4.5.3 Monitoring government implementation**

Despite the need to embrace opportunities for collaboration, it is essential that disability service organisations and DPOs maintain their independent voice. One of civil society’s most important roles is monitoring government implementation of relevant policies and legislation (DSD 2009). However, in order to do so, NGOs

need to be informed both of disabled children's rights and the obligations of government. An unpublished study by a member of DICAG found that parents have very little knowledge of legislation such as the Children's Act – for example, in relation to its provision for ECD – and of the means by which to take recourse should these obligations not be fulfilled (Meyiwa 2010). This points to the ongoing challenge for NGOs, not only to maintain their independence in order to critique the government, but also to educate members about their entitlements and opportunities for recourse if these are not fulfilled.

SAHRC is a resource that is available to the disability sector, providing a framework for holding the state accountable for complying with the Bill of Rights contained in the constitution. However, to make use of this resource, disability service organisations and DPOs must have *"an awareness of the universal entitlement, within our society, to the protection of human rights"* (McLain-Nhlapo et al 2006:106). For this to happen, organisations would need to present the SAHRC with cases of widespread, shared experiences of specific human rights abuses.

#### **4.5.4 Securing independent funding**

*"In general NGOs struggle for funding and many have inadequate resources with few available options for accessing*

*potential financial support"*. (Lansdown 2002:13)

NGOs in South Africa have found it increasingly difficult to access international funding. In the years immediately following the first democratic elections, international funders channelled financial aid to the government, rather than to the NGO sector (SIDA 2003). Since then the global recession has also contributed to major cutbacks in funding, resulting in huge strain on NGOs providing services to disabled children with disabilities<sup>14</sup>.

Nevertheless, there is growing awareness at international level of the need to include disabled children in programmes to achieve the millennium development goals (Thomas 2005).

In a report documenting the implementation of the UNCRC for disabled children in South Africa, Lansdown (2002) noted that some local NGOs have difficulties negotiating the terms of grants to reflect the realities of children with disabilities. Because many formerly independent NGOs which are now fully funded by government are less able to provide an effective critique of government policy. In fact, the government often views them as service providers, expecting them to deliver but not to challenge.

The DSD has been funding a number of national NGOs for many years, some – such as Epilepsy South Africa

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<sup>14</sup> To name just one, Hlanganani Nothando, an organisation that caters for severely disabled children in a rural area of KwaZulu Natal, has been threatened with closure due to a lack of financial support.

and the South African Federation for Mental Health – are working in the disability sector. The DSD's annual report for 2008/09 indicates that during this period, the department transferred R56 million (approximately US \$ 8.4 million) to NGOs. However, in a more recent report the department acknowledged that NGOs working with children with disabilities receive limited support from government and collaboration is poor (DSD 2009).

The national lottery contributes money to NGOs working in the disability sector; enabling civil society to contribute to NGOs working with disabled children. The government has also introduced tax breaks to individuals and companies donating to NGOs, including those working with disabled children.



## 5. The realities of children with disabilities

Despite the progress made in terms of legislative and policy reform, the realities for children with disabilities have not changed much. Indeed, the department of social development acknowledges that *“... services to children with disabilities still remain fragmented and unequal. Government departments still work in silos and services are not coordinated... Systems to identify children with disabilities at birth and track their progress through early childhood on to school-going age are sadly deficient”* (DSD 2009:9).

Why are children with disabilities not assured of the rights articulated in the constitution? Why are they not benefitting from the legislation and policies of government departments which should give effect to these rights? In their overview of the impact of disability policy implementation in South Africa, Nkeli and Associates (2008:26) found that *“the main obstacle[s] to the application of the Constitution... [were] negative attitudes towards disability, prejudice, misconception[s] about disability issues [and] stereotyping”*.

The authors partly attributed this lack of implementation to the poor alignment of programmes of action to policies, while SIDA's 2003 evaluation of the impact of OSDP activities observed that non-implementation of disability services is perpetuated when there are *“no or little sanctions when disability issues are not handled in accordance with the INDS”*. Other research indicates a lack

of coordination of services between government departments (which tend to work in silos) and between government and NGOs (Nkeli and Associates 2008; DSD 2009). This is further compounded by a lack of budgeting for services for children with disabilities – clearly documented by Wildeman and Nomdo (2007) as a key factor in the lack of implementation of inclusive education. The same applies to many other services such as rehabilitation and assistive devices (SIDA 2003).

Another key factor contributing to non-implementation is the lack of tools to monitor the implementation of policies and the fact that *“monitoring processes are not uniform, standardised and lack benchmarking”* (Nkeli and Associates 2008:87). The department of education (2009) found that inadequate data collection systems make it impossible to track real progress in terms of enrolment trends between special and mainstream schools. As a result, *“children with disabilities continue to experience discrimination at all levels of society. They are excluded from mainstream services that are relatively more resourced, less costly and within reach. These services are not accessible due to physical structures, communication barriers, negative attitudes and inexperienced service providers”*. (DSD 2009:11)

Despite all this evidence, little has been done to date to challenge the violations of the rights of disabled children through the channels currently available, such as the SAHRC.

## 5.1 Right to life and to protection from violence

Abuse of children with disabilities is a hidden, but frightening, problem in South Africa. Research indicates that disabled children are two-to-five times more likely to be abused than their non-disabled peers (Hesselink-Louw et al 2003), while those with intellectual disabilities are three-to-eight times more likely to be abused (Dhai 2003). A study by DICAG found that, in a sample of 36 cases of abuse of children with disabilities that came to trial, 14 were withdrawn; there were eight acquittals and 14 convictions. The prime reason given was that *"witnesses were seen as being incompetent"*, when in many cases the level of language used in court proceedings are too complex and many of the victims cannot understand it (Hesselink-Louw et al 2003).

The research points to the following factors that contribute to children with disabilities being particularly at risk of being abused or neglected (Anderson and Phohole 2001; Hesselink-Louw et al 2003; Naidu et al 2005):

- Disabilities can expose children to risk – for example, a child with a communication difficulty may be unable to refuse, call for help or report the incident; a child with an intellectual disability is likely to find it difficult to describe the abuse or to give evidence in court; a child with mobility impairments may be unable to physically escape the abuse.
- The extended enforced dependency of disabled children on carers often results in a deep level of trust, which can be abused.

- Society's intolerance of difference and lack of understanding about disability may lead to disabled children being considered less than human and not worthy of care. They may be seen as having no feelings, and therefore to suffer no emotional consequences of being abused or neglected.
- Parents who experience high levels of stress and frustration in caring for a child who requires extra assistance which is difficult to access may end up taking it out on the child.

Disabled children's vulnerability to sexual assault is increased when they live in institutions, with studies showing that 80-85% of criminal abuse of residents in institutions is never reported to the authorities (Hesselink-Louw et al 2003). This is compounded by the lack of general information about, and understanding of, sexuality, particularly for young people with intellectual disabilities (Dhai 2003). This is a great problem in adolescence, when increased interest in sexual activity is normal.

Participatory research conducted with disabled children by Clacherty et al (2004) found that a significant number of children who participated in the study had experienced both sexual abuse and neglect in the family and in the community. They found that this has significant impact on the children's wellbeing, and suggested that disabled children are more vulnerable to abuse because they cannot always understand or talk about it.

The tragedy is that while disabled children are at greater risk of abuse

and neglect, they also have less access to post-abuse support or service than other children in South Africa (Naidu et al 2005). Legal professionals are less likely to consider a disabled child as a reliable witness (DSD 2009); many courts are inaccessible in terms of physical structures and modes of communication; and in many provinces there are no safe places catering for children with disabilities, meaning that children often cannot be moved out of situations of abuse and/or neglect (Hesselink-Louw et al 2003).

## 5.2 Right to health

Access to healthcare is seen as *“the foremost catalyst to the equalisation of opportunities for persons with disabilities”* (Singh 2008). In this section we highlight the key findings of research in relation to the performance of the department of Health with regards to ensuring access to health services for disabled children.

### 5.2.1 Prevention of disability

The department of health’s annual report for 2007 reveals that the department has made some progress in programmes aimed at prevention of illness and disability among children, including:

- a reduction in incidence of polio to less than two cases per 100,000 children under 15;
- more than 90% full immunisation coverage in 84% of health districts;
- only confirmed 82 cases of measles in 2006/07, compared to 615 in 2005/06.

Copley and Friderichs (2010) report that only 7.5% of public hospitals provide infant hearing screening. Given that 85% of South Africans rely on the public health system for healthcare, this is a cause for concern in terms of early identification of hearing impairments among children.

### 5.2.2 Free healthcare

A review of the impact of the free healthcare policy (Leatt et al 2006) found that, while improving children’s access to healthcare is an appropriate and commendable policy objective, a number of barriers (other than tariffs at health facilities) result in limiting this access, including:

- the lack of accessible, convenient and affordable transport to and from healthcare facilities;
- a shortage of nursing staff and medicines.

Such barriers are likely to have particular impact on disabled children and their families, as they face additional challenges with transport (for example, by having to travel with their assistive devices) and long waiting periods resulting from staff shortages (for example, a child with cerebral palsy would find it difficult to spend many hours in a queue waiting for medication to control his or her spasms).

Leatt et al (2006) maintain that overcoming these barriers requires an improved understanding of what a child’s right to basic healthcare actually entails, and the responsibilities of different government departments to ensure children’s health and survival.

### 5.2.3 HIV and AIDS services

Despite the fact that the national HIV, AIDS and STI strategic plan 2007-2011 acknowledge disability as a vulnerability factor for HIV, disabled children still face many challenges in accessing HIV prevention programmes, as well as treatment, care and support. According to SANAC (2008), this is partly due to the isolation and discrimination faced by parents of disabled children within their own communities, where they are often seen as witches, sinners and having angered ancestors.

*“Parents of disabled children are often discriminated because of their children’s disability. Many are unemployed, as their disabled children require care and attention. There is extra pressure on the parents because of the increase in sexual abuse cases of disabled children in shelters, or in the care of relatives as a result of myths in societies that sleeping with a virgin cures HIV”.*

(SANAC 2008: 10)

The vulnerability of disabled children to HIV infection is further compounded by the lack of information they receive from their parents, as observed in the DPSA’s evaluation of HIV and AIDS programmes, single parents of children with disabilities are not empowered on how to teach their children with disabilities about HIV and AIDS. Children with disabilities are vulnerable to abuse by perpetrators.

DICAG parents emphasise the need

for basic information on HIV and AIDS, so that they can share this with their children<sup>15</sup>.

Among the reasons cited for the lack of attention given to HIV prevention for disabled adults and children (Swartz et al 2006) are:

- the lack of appropriate educational material;
- parental anxieties about raising sexuality issues with their disabled children, for fear of promoting their sexual behaviours;
- social isolation of disabled adolescents, which compounds their difficulties in terms of access to information and services.

Chappell and Radebe (2009) point out that schools have an important role to play in reducing the prevalence of HIV infection. However, the high number of disabled youth who are out of school means that they do not benefit from prevention and information programmes and are therefore at greater risk of HIV infection.

### 5.2.4 Habilitation and rehabilitation services, including assistive devices

The OSDP (2008) acknowledges that rehabilitation services in particular have been neglected, fragmented and uncoordinated due to the low priority given to such services, and the lack of an effective system to coordinate medical, vocational, psycho-social and education components.

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<sup>15</sup> The development of a booklet on HIV, AIDS and sexuality for parents of disabled children, developed by CREATE (2010) is included in Section 6, Examples of good practice (see 6.2.1).



A number of studies have recognised the impact of CBR on improving access to other services. For example Rule et al (2006:253) noted that *“Children are going to school and receiving formal rehabilitation for the first time... as a result of the CBR programme, an estimated 53 children in Kwa Zulu Natal Province that were outside the education system, have accessed education for the first time”*.

Documentation of the challenges of CBR stress that this is a multi-faceted approach and cannot be reduced to rehabilitation outreach (Rule et al 2006). The equalisation of opportunities, empowerment and social integration of disabled people, together with a focus on community development, are critical aspects of CBR.

There have been several CBR projects in different parts of South Africa. One of these, based on a partnership between the provincial department of health in Mpumalanga and DPSA, focused on providing support to DPOs with identification of children and adults with impairments and their consequent referral to relevant services. The project also provided information relating to disability, trained disabled consultants in peer counselling and facilitated access to assistive devices in order to enhance social rehabilitation and integration.

However, despite the government’s commitment to CBR through its national rehabilitation policy (Department of health 2000), there has been no

comprehensive strategy to implement CBR on a national level. Furthermore, assistive devices are often imported and prohibitively expensive, while consumables and maintenance services are rarely readily available or affordable (OSDP 2008).

The department of health acknowledges that a number of critical challenges currently limit access to health and rehabilitation services for disabled adults and children. These includes

**a) Scarcity of resources**

Singh (2008) noted that rehabilitation was important but has to compete with other programmes within the health sector. Other services – such as curative programmes and HIV testing and counselling – are often given priority over disability services (Philpott 2004).

**b) Lack of therapists**

In some areas there are simply no therapists available. Singh (2008) stressed the need to prioritise the recruitment of therapists; this issue is also critical in providing support to people experiencing barriers to learning – a central tenet of inclusive education (Department of education 2009).

The following tables compare the number of occupational and physiotherapists registered with the Health Professionals Council of South Africa (HPCSA) and those currently employed in the public sector<sup>16</sup>.

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<sup>16</sup> The data is from the Health Systems Trust. Unfortunately, no figures were available for speech and language therapists and audiologists. Note that figures are for those working in the health sector, and do not include therapists working in the education sector – for example, in schools.

Table 4: Physiotherapists registered with HPCSA and working in the public sector

Year	Number of physiotherapists	
	Registered with HPCSA	Working in the public sector
2007	5,059	850
2008	5,314	903
2009	5582	946
2010	5777	1009

Source: [www.hst.org.za/healthstats](http://www.hst.org.za/healthstats)

Table 5: Occupational therapists registered with HPCSA and working in the public sector

Year	Number of occupational therapists	
	Registered with HPCSA	Working in the public sector
2007	3,015	736
2008	3,174	785
2009	3325	806
2010	3508	838

Source: [www.hst.org.za/healthstats](http://www.hst.org.za/healthstats)

These figures show that in 2010 only 17.5% of registered physiotherapists and 24% of registered occupational therapists were working in the public sector. This shortage of rehabilitation personnel is part of the broader skills and personnel shortage within the public health sector as a whole but they impact most directly on disabled children. Using the recent figure of 2010,<sup>17</sup> it is estimated that there are:

- 2.44 physiotherapists per 100,000 population, or 1:41,000;
- 2.00 occupational therapists per 100,000 population, or 1:50,000.

These figures confirm South Africa's status as a middle-income country. Twible and Henley (2000) found that in English-speaking developed countries the average physiotherapist to population ratio is 1:1,400 (which is considered to fall well short of these countries' requirements). In developing countries the situation is critical with an estimated average therapist to population ratio of 1:550,000.

The situation for speech therapists and audiologists is even more shocking, since only four universities in the country offer training.

17 [www.hst.org.za/healthstats](http://www.hst.org.za/healthstats)

## c) Lack of staff training

The department of health acknowledges that service delivery within the sector is often a problem, with service providers needing further training on identification and referral options for disabled children (Singh 2008). Service delivery tends to focus on a medical model of disability, but should instead be approached within a human rights model: *“Service delivery is not about operating fancy equipment but about adopting a caring and compassionate attitude towards patients”*. (Singh 2008).

## d) Inaccessible facilities

Reporting on the 2003 national primary healthcare facilities survey, Reagon et al (2004) found that only 24% of facilities were wheelchair-accessible and only 28% had toilet facilities accessible to persons with disabilities. However, despite the huge challenges that remain, the report indicates that progress had been made since the previous survey of 2000, as indicated in Table 6.

Table 6: *Percentage of health facilities with accessible infrastructure for disabled people*

Feature of infrastructure	Year of survey	Percentage
Wheelchair accessible	2003	24
Accessible toilet facilities	2000	21
	2003	28

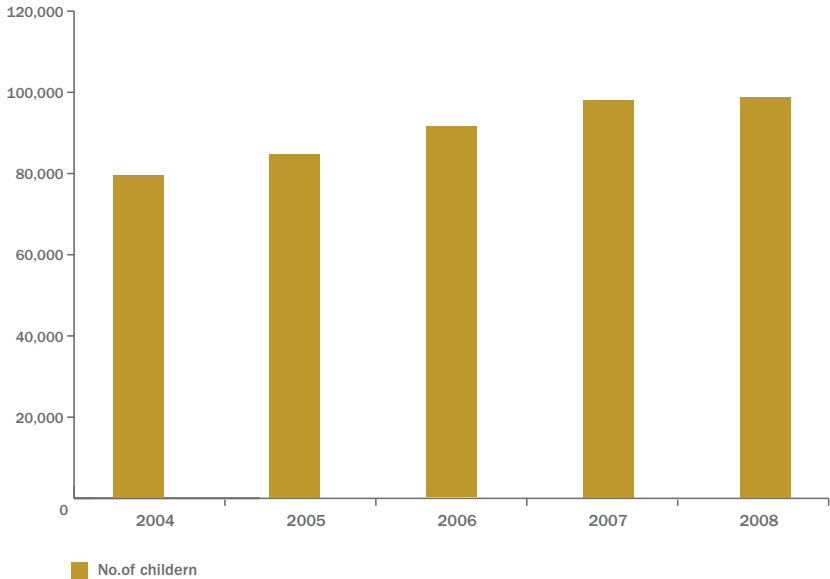
Source: Reagon et al 2004

### 5.3 Right to an adequate standard of living and to benefit from social security

Currently there is little data on the number of disabled children in South Africa, and it is therefore not possible to calculate a take-up rate for the

care dependency grant. However, data from the South African Social Security Agency (SASSA) indicates that the number of grant beneficiaries has consistently and gradually increased by about 20,000 over 4 years (Hall 2009). This data is illustrated in Figure 4.

Figure 4: The number of children receiving the care dependency grant 2004-2008



Source: SASSA data quoted in Hall 2009

A study investigating the increase in uptake of disability grants and care dependency grants between 2001 and 2004 largely attributed it to a growing awareness of the existence of the grant, combined with widespread poverty and unemployment which provided an additional incentive for carers to access the grants system (CASE 2005).

De Koker et al (2006) found that recipients of the care dependency grant were made up as follows:

- 26% intellectual impairments;
- 23% physical impairments
- 10% speech, intellectual and emotional impairments;

- 9% specific (chronic) illness – such as AIDS, cancer, TB.

The data collected in the Community Agency for Social Enquiry (CASE) study (2005) suggested that application criteria had varied in some provinces. The department of social development has recognised this and other difficulties associated with the lack of standardisation of assessment tools and processes for the grant and the system is currently under review. In 2008, the department commissioned the Children’s Institute of the University of Cape Town to pilot a new tool to assess the eligibility of children for the grant. The findings and recommendations of the study are yet to be released.

## 5.4 Right to education

### 5.4.1 Early childhood development

The OSDP (2008:36) acknowledges that the lack of an integrated ECD system poses a barrier to the development of disabled children. An analysis of the profile of beneficiaries of the care dependency grant found that only 24% of recipients aged 0-6 years attend a crèche or child-minding group (de Koker 2006).

Where early childhood development does take place, it is often in an informal community setting, where mothers of disabled children run stimulation programmes. Although this is better than nothing at all, children with disabilities would benefit more if they are accommodated in mainstream ECD centres, where effective individualised stimulation can promote independence and inclusion in mainstream society.

The department of social development (2006) identified a number of challenges facing the ECD sector, including poverty – as parents cannot afford to pay for ECD services – and HIV and AIDS, which affects children through direct illness (their own or of a carer), death and orphanhood. Another challenge is the discrimination against, and stigmatisation of, disabled children on the part of people who do not understand the nature of disability

or are frightened by it. They see the disability as limiting the child's ability to do anything, and thus view the child as a 'burden'.

### 5.4.2 Access to quality education for children with disabilities

The department of education has made some major strides in ensuring that disabled children access quality education, through their policy of inclusive education. Indeed, a study by Ferreira (2002) found that all learners benefited from the inclusion of a disabled learner at a mainstream school. The following sections outline the achievements and the challenges of ensuring quality education for disabled children.

#### a) Achievements

**Developing and field testing two national strategies:** In 2003 the department of education selected 30 districts across the country to field test two key strategies that form part of an inclusive education system: screening, identification, assessment and support (SIAS) and inclusive learning programmes (ILP).

The field test was carried out between 2003 and 2006; results have been used to revise the strategy documents and to assess and support people who experience barriers to learning (Department of education 2009).

Table 7: Districts selected for field testing strategies for inclusive education

Provinces	Districts	
Eastern Cape	Port Elizabeth Lusikisiki	East London Bizana
Free State	Motheo Lejweleputswa	Thabamofutsanyana
Gauteng	Tswane North D 3 Johannesburg East D9	Ekurhuleni West D6 Johannesburg South D11
Kwa-Zulu Natal	Empangeni Vryheid	Pinetown
Limpopo	Sekhukhune Mopani	Vhembe
Mpumalanga	Ehlanzeni Region Nkangala	Malelane Gert Sibande
Northen Cape	Frances Baard Pixley KaSeme	Siyanda
North West	Southern Bojanala	Bophirima
Western Cape	South Cape Karoo Metropole East	Metropole South

**Human resource development:** Between 2006 and 2009 more than 5,000 personnel – including teaching and support staff from mainstream and special schools and district officials – received training on all the main strategies of the inclusive education policy, in workshop and school-based formats. The training covered how to use the SIAS and ILP strategies to assess and support learners who experience barriers to learning and development. Teachers also received training on the use, management and maintenance of assistive devices (Department of education 2009).

**Physical upgrading of schools:** As part of the first stage of implementing

an inclusive education system, the department of education selected 30 mainstream schools across the country and is planning to convert these into full service schools<sup>18</sup>. Due to budgetary constraints, 10 were prioritised, with the other 20 left on hold. To date, eight schools have been converted and equipped to be environmentally accessible and serve the needs of all learners in their surrounding communities. The planning of the conversions was guided by an environmental access guide, and provincial physical planners were responsible for implementation (Department of education 2008 and 2009).

<sup>18</sup> Full service schools are schools that are developed in such a way that they have all the physical and human resources to cater for all learners.

**Supply of assistive devices and specialised technology:**

The department of education (2009) reported that many children with disabilities have received appropriate assistive devices, enabling them to access education and integrate into society.

*“In many cases children who had been carried by their parents and could not attend school, now have fitted wheelchairs that make them mobile and also provide postural support. Devices for learners with*

*visual impairment, communication disorders and hearing impairment substantially improve educational expectations for hundreds of learners who had previously been denied such opportunities”.*

*(Department of education 2009).*

The department also reported that, in addition to desktop computers, 30 special and full service schools received assistive devices and specialised equipment to aid learning, as shown in Table 8.

Table 8: Assistive devices provided by the department of education

Barriers to learning	Assistive devices provided
Physical disabilities	Customised wheelchairs. Standing and seating devices.
Visual impairments	IT equipment. Computer software. Desk-top magnifiers. Perkins Brailers, which are a sort of braille typewriter.
Hearing loss	Devices (like hearing aids). Therapy packs.
Communication disorders	Alternative and augmentative communication software

A fine and gross motor programme was provided for all foundation-phase learners with sensory integration delays. This intervention was supported with the draft manual that guides every step of the process including selection, procurement, management and maintenance of assistive technology (Department of education 2009).

While we acknowledge the importance of these achievements, we must not forget that disabled learners still face many challenges when it comes to accessing assistive devices. Learners often depend on rehabilitation

therapists and other support staff to assess them for appropriate devices, and train them in their use, repair and maintenance. The staff are often not available, even within special schools, and the effectiveness of such devices depends on both their appropriateness (in relation to the child’s disability type) and the provision of ongoing support.

**Advocacy campaigns:** The department of education developed a comprehensive strategy for public awareness and advocacy on inclusive education, and ran three campaigns in designated schools and

districts, together with a large-scale media campaign. The latter was in collaboration with the government's Communication and Information Service, which broadcast 13 episodes on inclusive education on primetime TV, reaching on average 1 million viewers per episode. A countrywide seminar series was arranged to inform people about the UNCRPD, and a DVD on best practice in inclusive schools was produced and distributed to schools in all provinces. A website, or inclusive education learning space, has also been developed to raise awareness of the public (Department of education 2008 and 2009).

According to the department of education (2008 and 2009), the outcomes of the advocacy campaigns include:

- at least 30 of the country's 80 districts are knowledgeable about the requirements of running an inclusive education system;
- more than 200 schools have embraced the ideals of inclusivity in their policies, cultures and practices without any additional resources or training;
- the broader public is aware of the inclusive approach to education and the rights of all children to attend their local neighbourhood schools and receive appropriate support;
- special schools understand the implications of their changing role within an inclusive education system.

An evaluation of a field test of the inclusive education policy noted that there had been remarkable progress, particularly in the creation of general and parental awareness to inclusive education, with the subsequent increase in the enrolment in mainstream schools of children with barriers to learning (Department of education 2009). Nkeli and Associates (2008) also found an increasing awareness and support for inclusive education on the part of educators and parents of disabled children. The authors see the integration of inclusive education philosophy and practice into pre-service and in-service teacher training as a major achievement.

Loebenstein (2002) explored the perceptions of inclusive education on the part of parents of children without disabilities. The findings indicated a generally favourable attitude, particularly the degree to which their children had been advantaged by exposure to difference in terms of developing a clear understanding of their disabilities, and consequently the extent to which more realistic representations of disability had been constructed by parents in terms of understanding the capacity of their children to live their full potentials. This research stressed the need for interactive discussion between parents and the school community as a means of mediating change, identifying solutions to educational challenges and establishing firmer partnerships between parents and schools.



**b) Challenges**

Despite the achievements above and the progress in developing legislation and policy to ensure that disabled children can access quality education, many remain excluded:

*“Children with disabilities and their parents often have few options when choosing whether to send their child to a mainstream or special school. This is especially problematic in rural areas. The limited capacity of special schools intersects with barriers in regular schools, resulting in the majority of learners with disabilities being excluded from education opportunities altogether. This results in illiteracy and low skills amongst adults”.*

(OSDP 2008:32)

A number of key challenges need to be addressed if disabled learners’ right to

education is to be assured. These are discussed below.

**Lack of progress in mobilising out-of-school youth:** Fleisch et al’s analysis of the data contained in Statistics South Africa’s 2007 community survey<sup>19</sup> found disability to be a significant barrier to education:

*“While only 167,000 children aged 7-15 years (1.9%) are reported in the survey as having some type of disability, children with disabilities account for nearly 10% of the total number of children who are out of school. The survey also indicates that children with disabilities have a much lower attendance rate than other children, as 38,000 children with disabilities (22.5%) were out of school”.*

(Fleisch et al 2008:43)

Table 9: Characteristics of children aged 7-15 years who were not in school in 2007

Characteristics	Number of children in school	Number of children out of school	Total number of children	% out of school	% of total number of children out of school
Total children aged 7-15	8,565,217	408,437	8,973,654	4.6	100
Disabled	129,567	37,510	167,077	22.5	9
Non-disabled	8,435,650	370,927	8,806,577	4.2	91

Source: Fleisch et al 2008, based on data from SSA Community survey 2007

The high percentage of disabled children who are out of school indicates that the education system currently fails to provide sufficient access to basic education for disabled learners.

Poor management and a lack of clarity on how to use the SIAS to place and support learners who experience barriers to learning both contribute to the exclusion of disabled learners

<sup>19</sup> This nationally representative survey collected data for 949,000 individuals and 247,000 households, and contains detailed information on educational attendance, employment, health, disability and access to grants.

(Department of education 2009). This represents a failure to fulfil the constitutional mandate to guarantee access to quality basic education for all children (DSD 2009).

**Limited capacity:** Limited human capacity within the sub-directorates for inclusive education and special needs at national, provincial and district levels undermines the implementation of inclusive education. This is compounded by high staff turnover and the general shortage of specialist professionals such as therapists (especially in rural schools), and often translates to poor support at delivery sites (Department of education 2008).

Collair (2001) investigates the indicators of successful inclusion of a deaf learner in a mainstream class focused on a child with a hearing aid, which enabled her to access the curriculum via verbal communication with some compensatory behaviours and learning support. The research found that positive attitudes on the part of the school, the capacity and willingness to support her and good social integration were the school-related factors that facilitated successful inclusion. However, such levels of support (as required by deaf learners in mainstream classes) are extremely difficult to provide if teachers are not trained and/or schools are understaffed.

Eloff et al (2002) focused on the role of teachers in inclusive education. The qualitative results indicated low or non-existent levels of stress in teachers who have to cope with a child with a physical disability, while the results

also reveal some concerns about the communication processes between parents and teachers and a perceived lack of pre-service training. Again, this points to the need to increase support for teachers – in this case through reassurance (that perhaps their concerns will not be realised), pre-service training and strengthening communications with parents.

**Limited knowledge and skills:**

Although more than 5,000 education personnel have received training to date, provincial and district officials, educators and other support staff do not have the necessary skills and knowledge to provide education support to disabled learners. According to research conducted by Sisonke (Department of education 2008), the training focused on raising awareness rather than teaching specific skills, and has not been sustained or supported at district level. The department of education (2009) notes that:

- in some schools for the deaf, teachers cannot use sign language;
- a large number of teachers in special schools have been trained to teach mainstream learners and do not have the skills to differentiate and adapt the regular curriculum for children experiencing barriers to learning;
- in many instances district officials are reluctant to support teachers in special schools as they fear that the teachers' knowledge is greater than theirs.

Special schools have expressed the need for support from district officials

on a regular basis, specifically in terms of mainstream curriculum advisory services, indicating that school staff need to master the mainstream curriculum before they can be trained on differentiation and adaptation. Despite this request, many special schools throughout the country have not received any training on the regular mainstream curriculum (Department of education 2008).

**Limited advocacy campaigns targeting provincial education departments:** Despite the department of education's reports on the positive outcomes of their advocacy campaign, Wildeman and Nomdo (2007) found little evidence of well directed and active advocacy and information campaigns aimed at informing education officials about inclusive education and the implications of its implementation. Instead, they hold that there is no consensus on the interventions required to remove barriers to learning at institutional level, and as a result there is little common understanding on inclusive education between key players at provincial level. Furthermore, the limited advocacy campaigns have not targeted the parents of children with disabilities. As a result, many parents and families of disabled children remain unaware of their rights in relation to access to education and education support.

**Difficulties faced during conversion of primary and special schools into full service schools and resource centres:** Wildeman and Nomdo found that upgrading and improving the facilities of schools in order to provide

for learners requiring moderate to high levels of support has been hampered by *"conditions of neglect, poverty and lack of service provisioning... This situation is exacerbated by the time it took to complete protracted infrastructure tender processes when the conversion of schools was finally initiated"*. (2007:3)

There were also difficulties the way in which the department of public works, which was initially responsible for the infrastructural upgrading, managed the process. Since the selected schools were not included in infrastructure projects and priorities of the provincial physical resource planning units, they could not be incorporated in the infrastructure priorities of the department of public works, and were dealt with instead as 'side projects'. This situation has now been addressed, with the conversion of full service schools managed by infrastructure directorates at national and provincial levels, with the inclusive education directorate acting as a watchdog (Department of education 2009).

**Limited government funding:** Although intended to improve access to education and support for people who experience barriers to learning (including disabled children) and to address fragmentation in the provision of education services in South Africa, the lack of government funding has severely restricted the implementation of inclusive education. For example, Wildeman and Nomdo (2007:2) found that *"poor funding of the inclusive education and training initiative is an*

*important reason for the delay and non-implementation of policies”.*

Nkeli and Associates (2008) confirmed that the lack of physical infrastructure to ensure accessibility and the lack of material resources required to remove barriers to learning have hampered the effective implementation of education white paper 6.

The inclusive education policy has only been recently made a national priority and the national treasury has stepped in to provide funding for its expansion in 2008/10 and 2009/12. Before 2008 funding from Denmark, Finland and Sweden has been used to implement most of the programmes.

**Lack of data:** Although this research identified a number of studies on education and disabled children,<sup>20</sup> most were conducted before 2001, when the inclusive education policy was released. Since then, several academic theses have dealt with the issue, two of which we have cited in the discussion (Collair 2001 and Ferreira 2002).

The most recent figures available from the department of education (2010) indicate that of the 14.1 million learners enrolled in all sectors of the education system in 2008, 96,500 (0.7%) were in special schools. However, although the report gives the breakdown of pass and failure rates at mainstream public schools, it does not do so for special schools. Nor is there any indication of the number of disabled learners attending mainstream schools.

The inclusive education directorate did provide information on the number of learners in special schools who passed the school-leaving examination (matriculation) in 2005, but these figures are not easy to interpret and do not provide a comprehensive picture. The number of pupils entered for the examination does not always match the number who actually took it, nor are the number of pupils eligible to sit the exam always given – for example, the data states that six pupils from Efata School for the Blind were entered for the exam and all passed; a 100% pass rate is given, but there is no indication of the total number of pupils in Grade 12 and therefore eligible to sit the exam. No statistics could be found on the number of disabled learners entering and completing tertiary education.

The department of education (2009) reports that of a total enrolment of 8,629 learners in the 10 designated full service schools, 569 (6.6%) experience various barriers to learning<sup>21</sup>.

## 5.5 Right to social inclusion, including sport and recreation

As well as facing the personal challenge of their own impairment, the experiences of disabled children in South Africa are coloured by the social and cultural norms which view them as being a burden on society. Such a view creates and perpetuates a context within which disabled children

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20 [For example,?] the DART Consortium (2006) mentions 43 articles on education and disabled children in its annotated bibliography.

21 It must be noted that similar figures are not available for public mainstream schools across the country.

are rendered vulnerable to abuse and violence:

***“Children with disabilities remain mostly marginalised and particularly vulnerable to negative social attitudes.***

***Rejection in formative years for young children has a significant role to play in the exclusion from normal development of a child and participation in family and community life. Children with disabilities are excluded from mainstream services and cannot function optimally, not only because of their disabilities, but also due to inaccessible buildings, attitudes of service providers and the community”.***

***(DSD 2009:16)***

The department of social development acknowledges that the participation of disabled children in leisure, arts, culture and sports activities is “a grossly neglected area of service delivery... and deserves to be given individual attention. It is an expansion of the section on integration and reintegration, where the activities into community life are further defined”. (DSD 2009:44).

Despite this assertion, any detailed research or review on the participation of disabled children in sports and recreation in South Africa, could not be identified.



## 6. Examples of good practice

This section discusses examples of good practice in the inclusion of disabled children in South Africa that are identified in the review of existing research.

### 6.1 Effective strategies to promote the inclusion of children with disabilities

There are many organisations in South Africa working to promote and protect the rights of children. The following are two examples of good practice that illustrate how disabled children have benefited from inclusion within the broader children's sector.

#### 6.1.1 Advocating for inclusion of children with disabilities in legislation

Jamieson and Proudlock (2009) document the work of the disability task team of the Children's Bill working group. Working under the auspices of DICAG, the team engaged in a variety of advocacy strategies to promote the inclusion of disabled children in particular in legislation to promote the wellbeing and protection of children in general.

An evaluation of the impact of the task team's advocacy "...shows that the campaign was very successful. Not only were the views of the disability sector represented throughout the debate, but the majority of legislative

*solutions proposed by the Task Team were incorporated into the final text of the Children's Bill*"<sup>22</sup> (Jamieson and Proudlock 2009). The study attributes the success of the advocacy campaign to the following factors:

- widespread consultation with disability organisations;
- engagement with members of parliament, through formal presentations and informal contacts;
- drawing on the media to support the call for reform;
- conducting research (in the form of issue-specific factsheets) to support arguments;
- having the support of a central organising body – the Children's Bill working group – which drew together many different civil society organisations from the children's sector.

#### 6.1.2 Inclusion of children with disabilities in programmes targeting vulnerable children

Children's rights organisations have included children with disabilities in their programmes and service provision in a number of initiatives, such as:

- The Children's Rights Centre's recent publication 'A chance to play' (Prest Talbot and Thornton 2009), which recognises the need to specifically include disabled children in and through play activities.

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<sup>22</sup> The provisions of the Act are contained in Appendix 2.

- The Isibindi Project – the National Association of Child Care Workers’ programme to support children in child-headed households; this project now incorporates a component that focuses on identifying and supporting disabled children within such households<sup>23</sup>.

Such initiatives are underpinned by the provisions for disabled children in the Children’s Act (RSA 2005 and 2007a), which provides for services aimed at preventing child abuse and neglect as well as focusing on ECD and child and youth care centres.

## 6.2 Resources for inclusion

Government departments, disability service organisations and DPOs in South Africa have all contributed to the development of resources aimed at providing specific information to support disabled children and their families. Some of those resources are discussed here.

### 6.2.1 Resources on HIV and AIDS and disability

DPSA has compiled the *Resource manual for disability and HIV/AIDS training for peer educators*<sup>24</sup>. Community-based Education and Training for Empowerment (CREATE) has developed a sex and HIV education leaflet for parents and carers entitled *Start talking... Keep talking... Growing up and my child or teenager with a disability* (Chappell and Johns 2009)<sup>25</sup>.

### 6.2.2 Resource box for inclusion

DART has developed a mini-library of information and resources on disability, which is catalogued according to different barriers – for example, poverty, HIV and AIDS – and housed in a cardboard box. DART has supplied this *Resource box for inclusion* to every education district in KwaZulu Natal province, to Isibindi sites and to NGOs across the country.

### 6.2.3 Resources for inclusive education

The implementation of inclusive education in South Africa has generated many resources, offering new knowledge on how to implement an inclusive education system in a developing context (Department of education 2008 and 2009). They can be used for training educators, and planning and monitoring within the education sector. There has been progress in developing resources for screening and assessing learners, which focus on early intervention and the provision of appropriate support within inclusive settings.

The following documents can be downloaded from the Thutong education portal for inclusive education:<sup>26</sup>

- *Management plan for the transition to an inclusive education system* (2005).
- A short summary of white paper 6 (for schools, parents and communities) in the form of a pamphlet: *Building*

23 Key features of the Isibindi model and more information on the project can be found at [www.naccw.org.za/isibindi](http://www.naccw.org.za/isibindi)

24 [www.dccdd.nl/data/1236081286323\\_Resource\\_Manual\\_for\\_Disability\\_and\\_HIV-AIDS\\_Training.pdf](http://www.dccdd.nl/data/1236081286323_Resource_Manual_for_Disability_and_HIV-AIDS_Training.pdf)

25 [www.heard.org.za/downloads/disability-handout-english.pdf](http://www.heard.org.za/downloads/disability-handout-english.pdf)

26 [www.thutong.doe.gov.za](http://www.thutong.doe.gov.za)



- an inclusive education and training system: understanding education white paper 6* (2005).
- *National strategy on screening, identification, assessment and support* (2008).
  - *Operational guidelines to the national strategy on screening, identification, assessment and support guides planners and DBSTs on the implementation of the SIAS* (2008).
  - *Guidelines to ensure quality education and support in special schools and special school resource centres* (2008).
  - *Guidelines for full service and inclusive schools* (2009).
  - *Guidelines for inclusive learning programmes* (2005).
  - *Conceptual and operational guidelines for district-based support teams* (2005).
  - *Conceptual and operational guidelines for full service schools* (2005).
  - *Conceptual and operational guidelines for special schools as resource centres* (2005).

The following reports and documents are available from the department of education:<sup>27</sup>

- *National audit on special education provision in South Africa* (2002).
- *Interim funding principles for inclusive education* (10 April 2007).

- *The environmental access guide for full service schools* (2007).
- *Report on the quality of education and support in special schools for learners with visual impairment* (2010).

### 6.3 Effective dissemination of information

The Sponge Project<sup>28</sup> was set up in response to the recognition that disabled people, and parents of disabled children (especially those living in rural parts of South Africa), often find it difficult to get information about rehabilitation services that are available from government departments and NGOs in their area. The project seeks to advocate for more comprehensive and integrated rehabilitation for disabled adults and children, and works towards improving access to government services such as health, education, social security, housing and transport.

The Sponge is a privately funded initiative that offers a free SMS information service for disabled people and their families to help them locate their nearest rehabilitation resource. Those needing information must SMS their name, town, disability and the service needed to a central number<sup>29</sup>. The reply is by SMS and aims to help them contact local organisations.

The project holds a database which currently has more than 3,000 contacts. An electronic newsletter is

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<sup>27</sup> [www.education.gov.za](http://www.education.gov.za)

<sup>28</sup> <http://thespongeproject.yolasite.com>

<sup>29</sup> The number is 072-172 2623

sent out to everyone on the database to improve their awareness of disability issues and inform them of available resources. A registration form for service providers is available on the website.

Analysis of 100 SMS calls made. The Sponge project in May 2010<sup>30</sup> reveals the following:

*Table 10: Disability profile of people requiring services via, The Sponge project:*

Disability	
Physical	60
Blind	19
Deaf	10
Intellectual	11
TOTAL	100

*Table 11: Types of service requested via, The Sponge Project*

Types of service required	
Therapy	50
Assistive devices	15
Education	12
Employment	12
Social security (disability grants)	7
Care	3
Housing	1
TOTAL	100

## 6.4 Promotion of universal access through inclusive education

Through the implementation of inclusive education, a number of mainstream schools have been converted into full service schools, which comply with the principles of universal design. The involvement of planners and personnel from the department of public works in this process has had a tremendous impact on provincial physical infrastructure in general, positively influencing their understanding of the need to ensure that all public buildings are accessible for all people.

Lessons were also learnt on the best ways of converting existing schools, and ensuring that plans for new schools are inclusive from the start (Department of education 2009).

## 6.5 Developing models of implementation

NGOs in South Africa have played an important role in the protection of the rights of disabled children through innovative strategies and programmes, and developing small-scale models of implementation. There are many examples that could be cited here – the list in this section is only a small sample of what is being done by disability service organisations and DPOs in South Africa.

<sup>30</sup> As reported in The Sponge newsletter, May 2010.

### 6.5.1 Community-based rehabilitation

Previously CBR projects were initiated by NGOs such as the South African Christian Leadership Assembly in Khayalitsha in the Cape, and community-level personnel were trained by organisations such as CREATE. More recently, DPSA has worked in partnership with the department of health in the provinces of KwaZulu Natal and Mpumalanga to provide community-level services by deploying disabled people as community workers.

These NGOs have all been responsive to the huge need to provide accessible services for disabled adults and children, and have developed models of training and implementation that can be up-scaled and adopted by government.

### 6.5.2 Inclusive education

NGOs conducted some early inclusive education pilot projects in collaboration with academic institutions, which enabled the department of education to 'test' some of the strategies contained in the white paper on inclusive education (Department of education 2001). The KwaZulu Natal inclusive education project was a consortium of NGOs working together to assist with the rollout of inclusive education in that province. A number of other organisations have also supported disabled children and their

families to ensure that they have access to quality education; these include: Inclusive Education Western Cape (IEWC); Down Syndrome South Africa (DSSA); Epilepsy South Africa; and the South African National Council for the Blind (SANCB).

### 6.5.3 The Chaeli campaign

The Chaeli campaign was founded in 2004 by five girls between the ages of six and 12 – Chaeli Mycroft, her sister and three friends – who started the campaign to raise R20,000 (approximately US\$ 3000) for Chaeli's motorised wheelchair. They reached their target in seven weeks by selling cards they had designed and miniature plant pots.

The organisation's mission is to *"mobilise the minds and bodies of children with disabilities and to normalise society through advocacy and education programmes and events"*. It runs several different programmes including: custom-made assistive devices; therapies (physiotherapy, occupational therapy and communication facilitation); and support to disabled children in mainstream schools. The theme that runs through all its programmes and events is the importance of inclusion and diversity in society, based on understanding that *"disability is created by the way in which society responds to the impairment"*.<sup>31</sup>

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31 [www.samesamebutdifferent.co.za](http://www.samesamebutdifferent.co.za)

#### 6.5.4 Shonaquip

Shonaquip is a company that produces wheelchairs and other assistive devices for children with disabilities. Shona, the founder, began the company when she undertook to make a new wheelchair for her daughter, Michelle – one that would fit her better and improve her development. The factory

has expanded rapidly and now also employs a number of therapists and disabled people who work with clients either in the office or in clinics and day care centres throughout the Western Cape. In addition to wheelchairs, Shonaquip makes standing frames, sleeping forms, and specially designed wheelchairs which are designed to improve the posture and quality of life of disabled children<sup>32</sup>.

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32 [www.marquette.edu/safrica/shonaquip.shtml](http://www.marquette.edu/safrica/shonaquip.shtml)

## 7. Conclusion and Recommendations

### 7.1 Conclusion

The South African government has sought to redress the injustices of the past, and shape a society characterised by human rights, equality and dignity for all, as embodied in the constitution and Bill of Rights. It has made numerous legislative and policy provisions in support of this, based on the vision of the integrated national disability strategy: *a society for all*. In addition, the government has indicated its commitment to realise the rights of children and disabled people by ratifying the UNCRC and the UNCRPD.

Although these achievements have altered the legislative landscape in South Africa, they have not resulted in an overwhelming change to the realities of disabled children. Yes, there is greater access to healthcare services; yes, there are more disabled children in mainstream schools and more are receiving care dependency grants. But monitoring systems can neither assess disabled children's access to general services such as ECD and school nutrition programmes, nor track the quality of services provided for them. They do not reflect the continued barriers of access to health, social development, education, sports and recreation services, nor do they effectively document the impact of resource and personnel shortages.

It needs to be recognised that South Africa has many resources at its disposal to support disabled children.

This study has identified a number of them, including training manuals, resource materials for parents and educators, and guidelines to promote integrated service delivery. The country has a vast field of academics and research institutions from which to draw research and analysis skills. These are critical resources which have the potential to inform service conceptualisation, planning, monitoring and evaluation. The role of disability service organisations and DPOs working with disabled people and the parents of disabled children is critical at this stage. They also need to familiarise themselves with the law and hold the government to account when it does not fulfil its obligations.

The challenge remains to retain the vision of *a society for all children*, to work collaboratively to keep this as a priority and ensure that it does not remain a theoretical concept but results in quality improvements to the lives of disabled children in South Africa.

### 7.2 Recommendations

On the basis of the findings of the study, the following recommendations have been suggested for action to improve the life situations of children with disabilities.

### ***Transform inclusive services at all levels***

South Africa has very progressive and inclusive legislation and policies, which are aimed at ensuring that the rights of children are upheld. Indeed, important gains have been made in terms of legislative provisions to protect the rights of children with disabilities. However, removing barriers of access for disabled children requires more than a supportive legislative context: it requires the transformation of institutions, practices, facilities and environments at every level of society, to make them accessible for everyone.

This transformation entails a fundamental shift away from a welfare-based approach (providing help for what are perceived as ‘tragic and unfortunate’ children), towards a rights-based approach. This requires re-conceptualising services so that they cater for the diversity of children, ensuring that all children have equal access and opportunities (Philpott 2008). It requires that disabled children are anticipated, planned for, welcomed and accommodated with appropriate services. It means adopting the principles of universal access, so that provisions for disabled users’ access are incorporated into buildings and public facilities – including sports fields and playgrounds for children – from the inception stage, through to design, planning and building (SAHRC 2002). It means ensuring that disabled children stop being an ‘after thought’ and are included from the very start when conceptualising, planning and implementing programmes targeted

at children. Such transformation can happen in the context of a supportive legislative environment, but it requires serious political will.

### ***Define disability and collect reliable data***

Although the South African government has adopted a very progressive definition of disability, different researchers and government departments do not use it as a basis for data collection. This results in variation in collected data, which makes it difficult to make comparisons. There is a need for government departments – such as health, education and social development – to reach consensus on the definition(s) of disability, to ensure consistency in collected data and the development of indicators that will measure the impact of intervention programmes.

The current lack of reliable data on disabled children makes it difficult to determine the extent to which different rights of children with disabilities are being realised in South Africa. For example, the general household survey (SSA 2010) contains data on the number of children attending ECD facilities, but does not include information on the number of children with disabilities attending or not attending. We therefore recommend that national statistics data collection should collect specific data on children with disabilities. This should include population-based studies measuring the prevalence of childhood disability, as well as the type and severity of disability. Furthermore, all government departments that deal with disabled

children – health, social development and education – should include data on children with disabilities in their information systems. For example, the department of education should include information specific to disabled children in their education management information system – this will ensure the visibility of disabled children on the national database.

### ***Improve monitoring and reporting on implementation***

This desktop review found that there is very limited research in the country which documents the experiences of disabled children. We therefore recommend that intervention programmes are developed with measurable indicators that can be used by decision makers to evaluate policies, programmes and services. This will also help direct the allocation of resources (DSD 2009). According to Schneider and Saloojee (2007), core indicators should include:

- child status (health, functional limitations...etc);
- family and household environment;
- neighbourhood and surrounding environment;
- service access;
- service quality.

This recommendation is further articulated by Nkeli and Associates (2008) who argue that comprehensive disability-related reporting, and

indicators should be an integral part of government information systems<sup>33</sup>. To ensure that monitoring is effective, DPOs and disability service organisations will need to build their members' capacity in legislative literacy so that they can play an active role in the monitoring process (Philpott 2008; Meyiwa 2010). In other words, people need to know what their rights are, when they are violated, and where and how to seek appropriate services (Naidu et al 2005).

### ***Strengthen prevention and early intervention programmes***

South Africa is a relatively well resourced country and the high level of preventable disability among (poor) children is disturbing. The country has a predominantly young population and many are at risk of illness and/or injury which could lead to permanent disability. A range of tools for infant screening and early detection and intervention of childhood disability have been developed by various stakeholders<sup>34</sup>.

It is critical that government and civil society work together to strengthen prevention and early intervention programmes to:

- promote disability awareness, particularly of 'invisible' disabilities such as hearing loss;
- make qualitative improvements in the public health system, particularly at primary care level;

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33 For example, the education management information system and national education infrastructure management system.

34 For example, the Carel du Toit parent guidance programme and HI HOPES, a home-based intervention programme offering hearing and language services to families of hearing impaired children (Copley and Friderichs 2010)

- draw up a strategy for securing and retaining medical and rehabilitation personnel;
- improve collaboration between different stakeholders, including parents, NGOs, therapists, teachers and health personnel.

### **Use available resources to develop and strengthen appropriate services**

In a society with extreme levels of disparity between rich and poor, one of the key challenges is to work towards equity. It is often tempting for a middle-income country such as South Africa to strive to replicate the service models of developed countries. However, the government needs to be responsible in using available resources to the maximum benefit, in order to achieve optimum outcomes for all its citizens, including disabled children. This requires creative and innovative approaches, which are responsive to the country's unique challenges and available resources. This important lesson that has already been learnt in other developing countries facing similar constraints is also applicable in South Africa:

***“Because of the lack of rehabilitation health personnel, it is contingent upon the educators and policy makers to support alternative models of healthcare delivery... The traditional institutional-based medical model approach to rehabilitation is expensive, often inappropriate, inefficient and does not meet the needs of most people with disabilities. The escalating cost of healthcare, the increasing***

***economic constraints, and the shortfalls in service provision have all contributed to the urgent need to develop innovative ways to utilise therapists in the community”.***

***(Twible and Henley 2000)***

### **Allocate adequate financial resources**

As a middle-income developing country, South Africa is relatively well resourced, and the government has made efforts to allocate the necessary resources to match policy directives. However, there are often competing priorities, and pressure to cut costs and make short-term savings on ‘soft services’ such as rehabilitation. In the long term this will have devastating consequences for disabled children and their families.

As with any other intervention, services for disabled children need financial resources. Funding limitations as reported by Wildeman and Nondo (2007), Singh (2008) and Nkeli and Associates (2008) must be addressed if the country is to meet the constitutional imperative of providing equitable services to disabled children. In their review of the implementation of inclusive education in South Africa, Wildeman and Nomdo (2007) particularly emphasised the need for:

- human resources;
- physical and learning infrastructure
- transport;
- funding to mobilise out-of-school youth.

Human resources are also required for the health sector to address the acute shortage of rehabilitation personnel



(Singh 2008; Nkeli and Associates 2008), and for the social development sector to provide the specific services outlined in the Children's Act, including disability prevention and early intervention, ECD and protection services (Philpott 2008). Funds are also needed to ensure physical access of health and social development facilities.

### **Use resources optimally through inter-sectoral collaboration**

If the rights of children with disabilities are to be effectively protected, it is critical that the different sectors that provide them with services and support work together. The existing research specifically calls for collaboration between government and civil society organisations in terms of:

- government recognition and support for disability service organisations and DPOs that currently provide services for disabled children (Philpott 2008; Singh 2008; Copley and Friderichs 2010);
- adopting a multi-disciplinary approach in promoting the protection of disabled children and providing support for children who have been abused, as well as their families and carers (Hesselink-Louw et al 2003; Naidu et al 2005);
- establishing an integrated strategy for community habilitation and rehabilitation, one of the policy objectives of the national disability policy framework (OSDP 2008).

Although the integrated national strategy for support services for children with disabilities (DSD 2009) already offers the necessary framework for providing such integrated services, for it to happen effectively, implementation mechanisms need to be developed that contribute to growing a common understanding of CBR as a community development strategy to alleviate poverty (Rule et al 2006). There also needs to be an interdepartmental policy framework for CBR with clear mandates and roles for different stakeholders (Rule et al 2006) and a focus on local/primary levels of service delivery (DSD 2009).

Strengthening the link between government and DPOs is particularly important to fostering sustainable development. According to Nkeli and Associates (2008), the following elements are needed for this to happen effectively:

- the government needs to develop a clear programme of action on disability, supported with a budget;
- DPOs must be involved in all planning and discussions;
- 'disability champions' should be appointed at focal points and senior manager level within each government department;
- a capacity development programme must be put in place to train DPO managers in leadership, financial management and governance to ensure sustainability.

### **Use research as an effective a tool for change**

This review has identified that comprehensive national research on disabled children is limited, making it difficult to plan, implement and monitor specific interventions. The following studies included in this review call for additional research on key issues:

- *Nkeli and Associates (2008)* stress the need for more research on the impact of policy, legislation and programmes on and for disabled people;
- *The department of social development (2009)* recommends that research be done on the prevalence and causes of childhood disabilities, in order to inform prevention programmes;
- *Rule et al (2006)* highlight the need to increase awareness of the

value of CBR at national, provincial, district and local levels, through research and documentation of CBR programmes. The authors stress the importance of linking such studies with mechanisms to continually monitor and evaluate CBR and of training practitioners to ensure continuity of service delivery.

Fleisch et al (2009) caution that even where research establishes a need, it does not necessarily lead to effective action in response. A number of different factors – including political will, capacity and commitment of personnel, and adequate budgets – have to be addressed if research findings are to shape the development of services. In such cases, research processes and outcomes have the potential to play a critical role in contributing to the protection of the rights of children with disabilities.

## **Appendices**

### **Appendix 1: Definitions**

#### **Child**

'Child' means a person under the age of 18 years (RSA 2005).

#### **Disability**

Persons with a disability are those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (UN 2006).

#### **Universal design**

Universal design is the design of products, environments, programmes and services to be usable by all persons, to the greatest extent possible, without the need for adaptation or specialised design, including assistive devices and technologies for particular groups of disabled people where these are needed (UN 2006).

#### **Universal access**

Universal access means the removal of cultural, physical, social and other barriers that prevent disabled people from entering, using or benefiting from the various systems of society that are available to other citizens. Universal access is the only way disabled people can enjoy equal opportunities and benefits, and to fully integrate with their families and friends into society. It is the key to exercising civil, political, economic, social, religious and cultural rights in society (SAHRC 2002:9).

## Appendix 2: Overview of the Children’s Act and Children’s Amendment Act as they apply to disability

### A) Children’s Act

#### **Chapter 1: Interpretation and objects**

1. (1) **Interpretation** of ‘care’: in relation to a child, the term includes, where appropriate:
  - (h) maintaining a sound relationship with the child;
  - (i) accommodating any special needs that the child may have.
2. The **objects** of the Act are:
  - (h) to recognise the special needs that children with disability may have.

#### **Chapter 2: General principles**

6. (2) All proceedings, actions or decisions in a matter concerning a child must:
  - (d) protect the child from unfair discrimination on any ground, including health status or disability of the child or a family member;
  - (f) recognise a child’s disability and create an enabling environment to respond to the special needs that the child has.

#### **Children with a disability or chronic illness**

11. (1) In any matter concerning a child with a disability, due consideration must be given to:
  - (a) providing the child with parental care, family care or special care as and when appropriate;
  - (b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
  - (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community;
  - (d) providing the child and the child’s carer with the necessary support services.
11. (2) In any matter concerning a child with chronic illness, due consideration must be given to:
  - (a) providing the child with parental care, family care or special care as and when appropriate;
  - (b) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community;
  - (c) providing the child with the necessary support services.

11. (3) A child with a disability or chronic illness has the right not to be subjected to medical, social, cultural or religious practices that are detrimental to his or her health, wellbeing or dignity.

#### **Chapter 4: Children's courts**

##### **Children's courts and presiding officers:**

42. (9) The children's courts hearings must, as far as is practicable, be held in a room which:
- (d) is accessible to disabled persons and persons with special needs.

##### **Participation of children:**

61. (1) The presiding officer in a matter before a children's court must:
- (a) allow a child involved in the matter to express a view and preference in the matter if the court finds that the child, given the child's age, maturity and stage of development and any special needs that the child may have, is able to participate meaningfully in the proceedings and the child chooses to do so.

#### **Chapter 7: Protection of children**

114. (2) (a)(b)(c)) Part A of the National child protection register must reflect:
- (iii) whether the child has a disability and if so, the nature of the disability;
  - (iv) whether the child has a chronic illness and if so, the nature of the chronic illness.

### **B) Children's Amendment Act**

This section lists the significant provisions made for disabled children in the Children's Amendment Act, by service provision area.

#### **Chapter 5: Partial care**

77. (1) Includes consultation with the department of transport and makes reference to clause 11<sup>35</sup>.
78. (4b) Indicates that funding should be prioritised to ensure that partial care facilities are accessible to children with disabilities.
79. (3) Provides for facilities for children with disability or chronic illness.

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<sup>35</sup> Clause 11 recognizes the state's obligation to provide care and protection for children with disability

### **Chapter 6: Early childhood development**

- 91. (1) Definition includes communication development.
- 92. (1) Includes consultation with the department of transport and makes reference to clause 11.
- 93. (4b) Indicates that funding must be prioritised to make ECD programmes available to children with disabilities.
- 94. (3) Stresses the programmes must be appropriate to the children for whom they are provided, including disabled children.

### **Chapter 8: Prevention and early intervention**

- 144. (1c) Purpose of prevention and early intervention is to develop appropriate parenting skills and the capacity of parents and carers to safeguard the best interests of disabled children.

### **Chapter 13: Child and youth care centres**

- 191. (3a) In addition to residential care, child and youth care centres may offer provision of appropriate care and development for disabled children.
- 192. (1) Makes reference to clause 11.

### **Chapter 14: Drop-in centres**

- 214. (1) Makes reference to clause 11.
- 215. (4b) Indicates that funding of drop-in centres should be prioritised to make them accessible to disabled children.

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