What works?

Promoting the rights of disabled children
Guidelines for action

Gerison Lansdown
Rights for Disabled Children

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Disability Awareness in Action 2003

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Throughout this document , when we refer to 'disabled children' we include all children with sensory, physical and intellectual impairment or who have mental health difficulties - regardless of age and gender.

When we refer to 'inclusion' we mean the participation of disabled children through provision of fully accessible information, environments and support. This can include the provision of barrier-free environments, information in alternate media such as Braille or on tape, acknowledgement of sign as a language and the provision of personal assistant support and interpretation.

PREFACE

Street children, child soldiers, child prostitutes, trafficked children, child labourers all suffer violations of their rights. But the violations faced by disabled children are different. The discrimination and social exclusion they experience is akin to that of girls, indigenous or ethnic minority children who face widespread discrimination on the basis of their very being. A disabled child is viewed as other, lesser, a burden, a punishment or a curse. Disabled children will face rejection within the family, the community, their peers. They will face exclusion from education, cultural activities, festivals, sports and social events. And they will be disproportionately vulnerable to poverty, physical and sexual violence, lack of access to health care, emotional abuse and neglect. Disabled children will often be refused access to friendships, to recognition of their worth, even to life itself. Their isolation can be extreme. Their very existence is widely denied - too often, their births are not registered, they are not recorded in census data, they are hidden away in back rooms or abandoned in institutions.

So, for many millions of disabled children, life is bleak, lonely and harsh. Poverty, ignorance, superstition, culture and prejudice combine to deny the humanity of a disabled child and legitimate horrific rights abuses. They are defined by and judged according to their difference, and found wanting.

However, none of this is inevitable. It is possible to challenge and overcome the hostility to difference, to create environments which embrace diversity. It is not easy. It requires a commitment to overcoming resistance at every strata of society. It requires recognition of the extent to which societies place barriers in the way of disabled children's inclusion. But most of all it requires that we start to listen. We must listen to parents who are struggling to care for their child, hear the stories they have to tell, and respect the knowledge they have of their child. We must listen to disabled people who have experience and expertise in facing discrimination and social exclusion and the strategies for creating change. Most of all, we must start listening to disabled children themselves. By respecting their right to express their views and be taken seriously, a powerful source of energy is released - energy to enhance their own self-esteem, to act as peer advocates, to challenge adult prejudice, to demonstrate their own capacities, to press for improved rights. Only when the non-disabled world witnesses disabled children demonstrating their equal ability to participate as citizens, will the strength of the stigma, hostility and hatred begin to diminish.

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INTRODUCTION

The aim of the report

This report is based on a series of studies of the situation of disabled children in four very different countries, in different regions of the world, during 2001-2003. Through listening to their stories, and talking to politicians, officials, human rights institutions, parents, teachers, NGOs and disabled adults, it has been possible to develop a broad understanding of the range of experiences disabled children live with on a daily basis. It has also provided an opportunity to assess what is working best to overcome the discrimination and social exclusion. The report seeks to bring those findings together and present both what children say about their lives and the changes that are needed - in government, in civil society and in law, policy and practice - if the rights of disabled children are to be realised.1

Background to the report

In 1997, the UN Committee on the Rights of the Child, the international body responsible for monitoring governments' progress in implementing the Convention on the Rights of the Child, held a discussion day on the rights of disabled children. The aim of the day was to raise awareness and understanding of the situation of disabled children and the nature of rights violations they experience, and to identify strategies for more effective protection of their rights. Amongst the many recommendations arising from the day, was a decision to establish a working group to follow up the commitments made. This working group, Rights for Disabled Children was constituted in 1998. Chaired by Bengt Lindqvist, the former UN Special Rapporteur for Disability, the group comprises a membership representing Disabled People's International, World Blind Union, World Federation of the Deaf, Inclusion International and Save the Children Alliance. A member of the Committee on the Rights of the Child is nominated to attend the meetings as an observer. Disability Awareness in Action administers the work of the group, which has been funded for three years by SIDA.

Rights for Disabled Children undertook a series of country studies in different regions of the world in order to:

- identify the extent of continuing violations of their rights;
- examine the impact of the Convention on the Rights of the Child in addressing the situation of disabled children;
- examine strategies being developed to address those violations;
- examine the extent to which the voices of disabled children are being heard;
- explore the role being played by disabled people's organisations and their effectiveness in promoting change;
- highlight and disseminate examples of positive practice in respect of legislation, policy and implementation of the rights of disabled children.

Criteria for selection of countries

The criteria for selecting which countries were twofold. Firstly, we wanted to visit countries where there was a strong presence of disabled people's organisations, in order that we could assess and evaluate their role and impact. And secondly, we chose countries where there was clear evidence of some government action to address discrimination and social exclusion of disabled children. The aim of the studies was to find out what measures, processes and actions are working to improve the lives of disabled children. It was therefore important to focus on their countries where efforts are being made, in order to assess their effectiveness and learn and share the consequent lessons. We also wanted to visit countries with widely ranging social, political, cultural and economic environments, in order to explore the impact of those factors on realising the rights of disabled children. Accordingly, the countries visited were:

South Africa - Romania - Nepal - El Salvador

The country visits

An international consultant was appointed to undertake all four studies. Each study involved a two-week visit during which time meetings were held with:

- Government ministers and officials in relevant departments - health, education, social welfare, child protection
- NGOs working with disabled children
- Disabled people's organisations
- Projects for disabled children
- Schools - both special inclusive schools
- Hospitals and rehabilitation centres
- Human rights institutions or commissions

In each country, field visits were undertaken in order to view the lives of children in rural as well as urban environments.

In addition, central to gathering a picture of the situation in any country, was the need to listen to disabled children themselves. Accordingly, a consultation day was planned in each country, bringing together up to 25 disabled children and young people where we explored:

- What rights violations they experienced
- What were the priorities for change
- What was needed in order to create change

Highly successful consultation days took place in South Africa, Nepal and Romania. Unfortunately, it was not possible to organise a meeting with children in El Salvador. The management of the studies was undertaken within each country by the appointing a national co-ordinator. This person was either a disabled person representing a disabled persons' organisation or a parent of a disabled child working in an NGO promoting the rights of disabled children. In each case, the co-ordinator was responsible for:

- Setting up all the meetings
- Arranging the children's consultation day
- Gathering relevant documentation - legislation, government policies, reports, research
- Providing an overview and analysis of the country situation
- Organising the accommodation, transport and interpretation for the consultant
- Commenting on the draft report
- Translating and circulating the report once finalised

Production of the country reports

Following each visit, the consultant produced a draft report setting out:

- A brief background overview of the situation of disabled children including the historical context, data on prevalence of disability and any country specific causes of impairment
- The legal, political and social context - constitutional and legal rights, structures, strategies and policies to protect and promote the rights of disabled children, the role of NGOs and DPOs and the work of ombudsmen or human rights commissions
- The experiences of disabled children in respect of their rights - for example, experiences with regard to discrimination, family life, violence, social exclusion, participation, poverty, education or heath
- Lessons learned and future challenges

NGOs within each country were given the opportunity to comment on and correct these reports which were then published and available to be used as a tool for advocacy, to raise awareness of the lives of disabled children and lobby for greater compliance with the principles and standards of the Convention on the Rights of the Child.

SECTION ONE

What Disabled Children say about their Lives

Disabled children in all four countries face overwhelming barriers to the realisation of their rights. Despite differing cultural and religious attitudes toward disability, contrasting political histories and varying strengths of civil society and NGO communities, disabled children in South Africa, Romania, Nepal and El Salvador are marginalised from the mainstream. And despite efforts in all four countries to tackle many of these abuses, violations of their social, economic, cultural, civil and political rights remain commonplace. The reality is that they face difficulties in every arena of their lives. Their words and experiences, given to us on their consultation days, provide eloquent testimony to the barriers they face.

Article 2 - non-discrimination legislation designed to protect against discrimination frequently excludes disability as a ground for protection, and even when it exists, is rarely enforced effectively. Disabled children are commonly treated with hostility, contempt and rejection. Children themselves identify the need for changes in attitudes as vital, if their lives are to improve. They face:

- **Lack of legal protections**

'Sometimes it seems that the government is doing things for us as a favour rather than because it is our right'.

- **Inability to enforce rights**

'Even if our rights are violated, there is nothing we can do about it, nowhere to go'.

- **Discrimination within communities**

'Discrimination does not come from the government but from our families. Change needs to come from communities not just the government'.

'Since I've been in a wheel chair, people do not treat me the way they used to before. People do not respect me'.

'Traditional attitudes and beliefs have created the world we live in. We exist, we are here, but people just don't accept that'.

'If we are provided with opportunities and appropriate education, we can prove we are equal. Disablism is a mental problem - one of attitudes'.

Article 3 - the best interests of children are widely defined in terms of a requirement to conform to the non-disabled environment, and to adjust for the convenience of non-disabled people.

'Most people do not expect disabled people to have any potential for success. They are just seen as a burden'

'We will never make a nation out of people like you!'

A Romanian mother, when told that her child was autistic, was advised to place him in an institution, that he would never improve, would bring no joy and would destroy the family. She should therefore place him in an institution and forget his existence. Despite this recommendation, she chose to keep the child. In fact, part of the prediction was accurate. Her husband left her, unable to cope with the stress. Her extended family was reluctant to have anything to do with the child. His younger brother faced frequent bullying and taunts from friends about his 'stupid' older brother, and eventually resorted to denying his existence. On transferring to high school, he found that, on his educational notes, it stated that he had a brother with a severe learning disability. The mother, drawing on the experiences of others, was convinced that this would damage his chances of getting a university place.

Article 4 - duty to implement rights - lack of prevalence data on disability in all four countries inhibits any effective assessment of appropriate levels of expenditure in order to realise social and economic rights. Governments widely fail to take the necessary measures to implement social, economic and cultural rights to the maximum extent of available resources.

'There are laws to protect us from discrimination but no way of using those laws'.

'The government and society are not aware of our needs. They do not understand us. They fight for non-disabled children, not for us, so how can our potential be realised?'

A group of children in Romania acted out a role-play to illustrate the gulf between their 'paper' rights and their actual rights. The role-play consisted of a family visiting the doctor who recommended a course of physiotherapy for a child for two hours a week for a year. The cost would be £60 per month. The father, a policeman only earned $100 per month and his rent was $60. It was impossible to find the money, so the doctor refused to arrange the treatment. All health care for children is supposed to be free. But many doctors demand payment before offering services. It is widely acknowledged that many health professionals - doctors, physiotherapists, nurses - demand these 'backhanders', but little action is taken to address it.

Article 5 - respecting and promoting children's evolving capacities - both the potential and actual capacities of disabled children are routinely under-estimated and they are widely denied opportunities to fulfil their potential.

Jinu Agarwal was the only son of a well-to-do business family in Kathmandu. He was born blind and the family had kept him locked up in a room for 8 years. When a CBR worker heard about him, she intervened and encouraged the family to send him to a playgroup. He improved immensely and his parents realised that he was capable of progress.

Article 6 - right to life - disabled children can be allowed to die with relative impunity in many countries, as a lower value is attached to their lives or their death seen as 'merciful'.

Article 7 - right to name and identity -many disabled children are not registered at birth because parents deny their existence and are ashamed of the child.

Article 9 & 20 - right to family life or alternative quality care - many disabled children are living in institutions where little effort is made to promote opportunities for rehabilitation with their families and where the standards of care are extremely poor - inadequate food, health care, access to education, protection from violence or opportunities for social inclusion.

In Romania, despite progress in closing down the worst of the large institutions, the quality of life for children who are unable to return home remains grim. A home in the mountains containing 500 children was closed and 80 of the children were placed in a new home near Bucharest. When they arrived, most were unable to speak, unable to feed themselves using cutlery and lacked even the most basic knowledge of personal hygiene. This lack of skills bore no relationship to the potential capacities of the children concerned, but rather to the complete neglect of their care - a powerful illustration of the disabling impact of the institutional environment. They have now been taught these skills and some education is provided. But it is a grim place to have to call home. It smells of urine, the children share all clothing, even underwear, and they have no privacy. The physical environment is sparse, with virtually no facilities for play. Hardly any of the children had contact with their families. The centre is run by a doctor and all the children are on daily medication to control their behaviour. Most of the children have rarely been outside the four walls of an institution in their entire lives. And the future facing them was even grimmer. Once they become adults, unless their families can take them home, they will transfer into long-term hospitals and stay there until they die.

Article 12 & 13- right to express views - disabled children are excluded from many initiatives to promote children's participation. They are also widely silenced in families where they have a lower status than other children. Children in the study stressed the need for them to take a central role in challenging negative perceptions of disability.

'We need to believe in ourselves and challenge bad opinions by showing what we can do.'

'We need to be arguing for our own rights - not just rely on adults to do this on our behalf.'

'Disability is in the eyes of society. It is not in our eyes. If provided with opportunities, we can prove ourselves.'

Article 14 &15 - freedom of religion and association - it is extremely difficult for most disabled children to enjoy friendships and participate in social organisations because of either physical, social or cultural barriers. In Nepal, many disabled children are prohibited from participating in festivals or entering religious institutions.

'The inaccessibility of so many places means that our rights to meet with friends and families in everyday activities are practically non-existent'.

'Although a limited dial -a- ride services exists, it has to be booked in advance and is mostly used by older people. It means we have to organise our lives like a rota, whereas non-disabled children can act impulsively'.

Article 16 - right to privacy -many disabled children in institutions are denied any opportunity for privacy, personal attacks from adults and children in their community are commonplace

'My mother loves me but other people hate me. In the holidays, I am sad. I sit in a corner of the room and my parents just tell me I am lame, mad or dumb. Other children tell me to go away. They push and hit me'.

Article 18 - responsibility of both parents for a child - fathers commonly abandon a family when a disabled child is born. - a disproportionate number of disabled children live in single parent families, and it is all too common for mothers to abandon their child as well.

'Parental rejection is standing in our way. They act as a barrier to participation'.

'The family is the first school, and if families have a negative view of us, how can we have hope?'

Article 19 & 37-right to protection from violence and inhuman and degrading treatment - disabled children are 3-4 times more vulnerable to both physical and sexual violence and abuse and there are rarely any child protection procedures which take account of the particular difficulties a disabled child will experience in reporting abuse. The abusive treatment and neglect of many disabled children both in institutions and in family life includes denial of food, tying them to beds, physical assaults, refusing to let them out of the home. The DAA Human Rights Database has individual cases of violations affecting over 2.4 million disabled people of which 1.23 million are children although the actually cases are only 22% of the total. Over 37% of the cases against children are violations of degrading and inhuman treatment - more than the percentage against adults - and disabled children are 50% more likely to lose their right to life. There are very few avenues open to anyone to seek redress for these violations, either through national law or through the monitoring of international human rights instruments.

In Romania, when asked to rank the government's performance in protecting children's rights, disabled children gave the lowest score to its record in protecting them from violence. When asked to prioritise issues to be addressed by the government, the need for better protection from violence was their first demand.

Examples of violence the children described

- Deaf children being beaten for signing
- Many blind children being abused within their families
- Parents beating children who exhibit signs of mental illness, interpreting the behaviour as disobedience and wilfulness
- Significant abuse of children with learning disabilities
- Disabled children being rejected emotionally in families and abused because of their low status
- Children being hidden away in the family home, treated like animals, sometimes even locked in cages, particularly in rural areas
- Concerns over the widespread existence of sexual violence within families which is denied or covered up because families are not willing to expose the problem
- Examples of girls with learning disabilities being put on depo provera in order that they can be abused with relative impunity
- Difficulties for children in challenging abuse by teachers because of their high status in society
- Problems of abuse by older disabled men

Article 23 -right to social inclusion - disabled children are still widely excluded from many spheres of social, economic and cultural activity.

'It is difficult for us to get married. Parents discourage and ignore it. It is killing the our spirit'.

'Township roads are narrow and have no pavement. Speed bumps have been built to prevent speeding but they did not consult with us and these bumps create a barrier for wheelchairs. Our rights have been violated as we have been excluded as road users'.

'One of the consequences of being sent to a special school is that we are only able to socialise with other disabled children. Our segregation causes non-disabled children to look down on us and discriminate against us'.

Article 24 - right to best possible health and health care - without adequate data on the prevalence and nature of disabilities, many countries fail to provide adequate health assessment or care for disabled children. Physical barriers inhibit many disabled children from accessing health centres and surgeries and too many doctors lack the skills to communicate with disabled children.

A 5 year old child, living in a rural area in El Salvador, had a brain tumour. His mother needed to take him to hospital for an x-ray to see if it had grown. The overall costs of doing so would be approximately $200, including bus fares and overnight accommodation. A local CBR scheme had raised $120 for the family, but the remainder of the costs were still outstanding. Both parents were without work and had no means of finding the money. Meanwhile the child was receiving no treatment. The Ministry of Health responded to this story by arguing that the child was entitled to help with the costs. A means-tested system prevailed and poor families could get free health care, transport and accommodation. However, neither the family nor the local health centre appeared to be aware that such help was available.

Sunita, from Nepal, was born with severe bilateral clubfeet. When asked how far she had to travel to come to the hospital, she explained that she and her father had to walk three hours to reach the road after which they paid 80 rupees each for a bus ride. The price of the bus ticket was of greater concern to her, as a daughter of a poor farmer with not enough land to sustain the family, than the 12-hour bus ride itself .

Article 26 & 27 - right to an adequate standard of living - disability is both a cause and a consequence of poverty and disabled children in most countries in the world are disproportionately likely to be living in poverty. In South Africa it is estimated that more than 80% of black disabled children live in extreme poverty, often in inhospitable environments with poor access to health care . And 98% of mothers with disabled children in rural areas are unemployed, single and have had no education. 99% of disabled people are unemployed.

In Nepal, the vast majority of disabled people are unemployed. One survey found that less than 3% of the respondents over 14 years had received any skills training to enable them to obtain work . 76% were completely financially dependent on their families and a further 20% were only partially financially independent.

'We lack training. We cannot even think of independent living in the absence of skills. We need to fight for this'.

'I was born into a lower caste family. Life was a struggle. Both parents abandoned me. I started life with aspirations for myself. However, poverty and rejection by my family forced me to leave school at class 7. The local community did nothing to help me study. Now I cannot work because of my impairment and lack of education. People like me are discriminated against - in the family, in society, at national level. Life is a punishment for me with no-one to help or protect. We need love and equal opportunities not discrimination'.

Article 28 - right to education - the vast majority of disabled children in developing countries remain out of primary, let alone secondary or higher, education, and are often excluded from statistics compiled to demonstrate achievements in enrolment and attainment in primary education.

'Education for All does not include disabled children. The slogan remains a slogan'.

'I wanted to go to normal school but there were problems with the teachers. They neglected me and were very impatient. I had to make double the effort. Being included must involve getting appropriate support, and changing attitudes'.

'We need education for self respect, for employment, for establishing our position in society, for achieving acceptance, for being knowledgeable, and being independent. But this key component is missing from our society'.

'Appropriate education in the least restrictive environment is our right'.

'The right to education should apply to all disabled children and inclusion should really mean that - children should not be 'dumped' in mainstream schools without support, without teachers being trained, without the necessary resources and without the buildings being properly adapted'.

In one school in El Salvador, the 7th grade class was held on the upstairs floor. A child using a wheel chair was moving into that class and asked for the room to be changed to the ground floor. He was told that the 7th grade was always taught in that room and it was impossible to change it. Accordingly, he had to be lifted up at the beginning of the day and down again at the end. As the toilets were on the ground floor he was unable to use them throughout the day .

Article 31 - right to play - disabled children are routinely excluded from opportunities for play, sport and recreation through rejection by other children, or by physical barriers impeding access. Arts institutions also widely fail to provide access to enable disabled children to enjoy theatre, film, art or dance.

'As neighbours realised that my child was different and that disability was becoming visible, they prevented their children from visiting my home, as they were scared that their children would bring bad luck home' .

'My family said I was useless. I was never allowed to join in with other members of the family.'

Article 34 - right to protection from sexual exploitation - there is widespread denial of the sexual abuse of disabled children despite a growing body of evidence of its prevalence. The denial prevents children from being informed about their rights and seeking help. It also provides impunity for the abuser.

'If I remove my daughter from school, the abuse would stop, but she would be denied an education, and with it any hope of future independence. If I leave her there, she would get the education but would continue to suffer abuse. What do I do?'

In one residential school for deaf children in a rural area in South Africa, a number of girls had been regularly raped by the head teacher, over a period of years. When they finally complained and were taken seriously, the head teacher was charged with assault and brought to court. However, he told the children that if they testified against him, their hands would fall off. The hands of deaf children, whose language is signing, are their link with the world. The children believed him and withdrew their charges. The case was dropped.

SECTION TWO

Making a Difference

If the formal commitments made to disabled children when governments ratified the Convention on the Rights of the Child are to be realised, major changes are needed in most countries in the approach taken to disability, the frameworks created for promoting and protecting disabled children's rights and the substantive legislation policy and practice impacting on their lives. Action needs to be taken at all levels of society and across a wide range of policy arenas.

AN AGENDA FOR ACTION

Creating effective government frameworks

Non-discrimination legislation

Implementation and enforcement

Collaboration across government departments

Responsibilities at local/regional level

Commitment of resources

Integration of disabled children into mainstream policy agenda and data

Training for staff

Dissemination of information

Parliamentary monitoring

Strengthening the role of civil society

Partnership with disabled people, parents and their organisations

Service providers è Including disabled children

Listening to children

Human rights institutions

Meeting children's demands

Ending discrimination

Being part of a family

An end to all forms of violence

Tackling poverty

Equal access to education

Being an ordinary child

Access to health care and rehabilitation

An equal right to life

1 Creating effective government frameworks

Many of the rights violations experienced by disabled children emanate from a failure on the part of governments to afford disabled children any priority. Even when governments do make commitments, the actual impact is far less than intended, because of a failure to put in place the necessary measures to create real change. The Committee on the Rights of the Child has consistently advocated the importance of what it has termed 'general measures of implementation' in order for governments to be able to give effective consideration to children's rights. Good intentions and legislation are not enough. Attention needs to be paid to how the government organises itself in order to meet the needs of children. Many of the measures needed for all children would benefit disabled children too. However, additional consideration must be given to the measures needed to address the profound exclusion and discrimination experienced on a daily basis by disabled children.

1.1 Non-discrimination legislation

'If society cannot cater for people with disabilities, it is society that must change'.

South African Integrated National Disability Strategy

What is needed

Legislative change in respect of disabled children's rights must be built on:

- Full consultation with disabled people's organisations;
- The introduction of legislation which both prohibits discrimination and which places explicit obligations on national and local government and public and private institutions to take the necessary action to end direct and indirect discrimination;
- Effective monitoring and enforcement mechanisms.

South Africa's Bill of Rights in the 1996 Constitution guarantees fundamental rights to all citizens and the rights to freedom from discrimination including on grounds of disability.

1.2 A Government strategy for implementation of rights

Without a plan of action or strategy for implementation, legislation alone will achieve little. It is a frequent complaint of the Committee on the Rights of the Child that governments document their legislation in their reports without providing any evidence as to whether it has been implemented, to what extent and with what impact.

What is needed

The strategy or action plan should:

- Be produced in collaboration with national disabled people's organisations and parent's organisations;
- Be given high political priority;
- promote the social model of disability and disability as a rights issue;
- Include responsibilities across all government departments;
- Be properly resourced;
- Be regularly monitored

South Africa has adopted a long-term approach to implementing the right to education. It has developed a six-pronged strategy to achieve inclusive educational environments over a 15 year period, focusing on building partnerships between key players in the education system. (Notably, children are missing from the dialogue about the introduction of these changes).

- **Conversion of special schools into resource centres serving as a resource to mainstream schools in providing training and professional support**
- **Mobilisation of all disabled children currently outside the education system**
- **Converting and redesigning 500 out of 20,000 primary schools to become 'full service' schools which are equipped and supported to provide for the full range of learning needs**
- **Familiarising governing bodies and professionals to the inclusion model**
- **Establishing district based teams to co-ordinate professional support services**
- **Implementing a national advocacy and information programme in support of inclusion.**

1.3 A dedicated unit responsible for implementation

Achieving the goals of the legislation and strategy is far more likely if a dedicated unit or agency is established by the government to take responsibility for implementation.

What is needed

A unit or agency for implementation should be established which is:

- Given a high level of government commitment;
- Has interdepartmental powers - in some countries, disabled children are the responsibility of the social welfare departments and are further isolated from key areas of policy development and rendered even more invisible;
- Properly resourced;
- Ensures that disabled people with the appropriate expertise are in the leadership of the unit.
- Works collaboratively with disabled people and parent's organisations, in order to ensure consistency and efficiency in achieving change.

South Africa has established the Office on the Status of Disabled Persons, responsible for implementation of the Integrated National Disability Strategy. It is sited in the President's Office, giving it a high profile and status, and sending out a powerful message to the wider society of the significance the government attaches to the issue. The pan-governmental approach is embedded in its strategy to promote the rights of disabled people. Each government department is required to establish a disability unit and to undertake a disability audit to identify action needed to ensure implementation of the strategy as well as reserving 10% of their budgets on disability issues. And the departments to whom recommendations are addressed in the strategy include health, education, welfare, labour, justice, arts, culture, science and technology, foreign affairs, welfare and population development, public works, transport. These recommendations spell out, not only the action required by the relevant government department but also the other bodies with whom they should collaborate

1.4 Responsibilities at local/provincial/district level

Many strategies fail because they are conceived at national level but fail to provide any effective mechanism through which the objectives can be translated into action at local level.

What is needed

- Delegation of responsibility from central government in order that the policy is 'owned' at local level;
- Dissemination of national policy or strategy to local/provincial/regional level in order that relevant staff fully

understand the nature of the policies, the underpinning legislation and consequent government obligations;

- Appointment of dedicated unit at local/provincial/regional level, with direct responsibility for implementation of the policy or strategy;
- An audit to assess what is needed at local level;
- Establishment of local forums of disability NGOs, disabled children, parents groups and other key partners;
- Development of a local strategy for implementation based on consultation with the local community and in accordance with local needs;
- Training of staff in the principles underpinning the policy and its practical implementation;
- Allocation of a dedicated and transparent budget for implementation.

Each of the nine provinces in South Africa has an Office on the Status of Disabled Persons, modelled on the National Office. And, as at national level, they are required to consult with local communities and NGOs in order to develop a provincial strategy for implementation. This structure seeks to provide the framework and staffing for ensuring that the strategy is translated into action, it delegates responsibility from central to provincial level and enables the process to be more democratic and accountable. However, in practice, significant problems impede implementation - lack of staff, exclusion of civil society, failure to develop a provincial strategy, inadequate funding, isolation from the provincial Premier, failure to establish a disability unit. These weaknesses in implementation provide valuable pointers to the structures needed in order to bring about effective change at local level.

1.6 Collection of disaggregated data

The Committee on the Rights of the Child explicitly request that governments provide data on disabled children addressing' the type of disability (impairment)……………..disaggregated inter alia by gender, age, rural/urban area and social and ethnic origin' .

What is needed

In view of the complexity of the problem, a multi-faceted approach is needed which addresses not only the practical, logistical difficulties, but also the cultural and social barriers to data collection, including:

- Close collaboration and consultation with the disability community;
- Census questions to elicit the prevalence and nature of impairments and consequent disability, based on usage of the WHO International Classification of Functioning and Disability;
- Mapping exercises to identify all disabled people within local communities;
- Disaggregation with the total child population to render disabled children visible. This is necessary to assess, for example, the

respective access of disabled children to education - including enrolment, attendance and attainment data, or health care services, or to assess respective vulnerability to physical or sexual abuse;
- Disaggregation within the total numbers of disabled children - for example, differences in respect of gender, rural/urban environments, ethnicity, class or caste - in order to evaluate, for example, their relative access to education or their health status.

1.7 A commitment of resources

Nothing will change without a commitment of resources by governments to implement the policies developed to challenge discrimination and social exclusion. Inevitably, costs pose challenges for many countries. However, the long term cost-effectiveness will be recognised through this significant group of people becoming economically active and productive.

What is needed

- Greater priority given to disabled children and adults in poverty eradication programmes and policies;
- Budgetary analysis to assess the proportion of the budget devoted to social expenditures for children, and within that, disaggregated and preferably, ring-fenced, to identify expenditures on disabled children;
- Collaboration between the departments responsible for overall budgetary allocation and those responsible for policy and implementation for disabled children;
- Budgetary commitments attached to all polices and strategies for disabled children;
- Transparency in budgets allocated at both central and local government levels.

1.8 Integration into mainstream policy agenda

Whilst it is essential to develop a strategy dedicated to achieving greater social inclusion of disabled children, it is also necessary to include disabled children in mainstream policy agendas - a 'twin-track approach'. Too often disabled children are simply reduced to a category of children with 'special needs' and considered only in respect of those needs. The rights of disabled children must be addressed in all mainstream policies impacting on children's lives.

What is needed

- Creation of senior posts within national and local governments to monitor and evaluate the inclusion of disabled children, where appropriate, in all policies and programmes effecting them;

Inclusion of disabled children in all government literature promoting awareness of rights, information about services, public education;

Disaggregated data on all issues relevant to children, in order to assess and monitor the participation of disabled children;

Consultation with disabled children on their experiences, their aspirations, and the barriers impeding their realisation.

1.9 Training

Understanding that disability is a social construct and a human rights issue, necessitates a major shift for most people working with or for disabled children. Traditionally, the problem is located as being with the child, and the strategy adopted focuses either on adapting the child to 'normal' living, or 'special' provision is made in the form of education, institutional care or support services. The most obvious examples of this perspective are the traditions of segregating disabled children in special schools, or placing them in institutions. A rights-based approach necessitates identifying and removing the physical, economic, social and cultural barriers that disable children.

The children in Nepal identified the need for training or sensitisation programmes for their parents as well as others within their communities as the most important contribution needed if they were to be socially accepted and included. Their experience also demonstrated that some of the most effective sensitisation programmes were those delivered by disabled children themselves. It is rarely effective to exhort people to change their attitudes. However, evidence of articulate, educated and successful disabled children and young people exemplifying the very principles they are talking about, is a powerful mechanism for change.

What is needed

All the key people in disabled children's lives need to be sensitised to the rights of disabled children:

- Parents
- Teachers
- Health professionals
- Local and national government officials.

Community strategies for overcoming discrimination have been devised by disability NGOs in Nepal who have developed community awareness programmes in villages to enhance understanding about disability. Recently these initiatives are creating opportunities for disabled children themselves to advocate greater respect for their rights and serve as role models for other children.

1.10 Dissemination of information

Lack of access to information about rights and available services and how to access them, was endemic in all four countries. Confusion existed, for example, about eligibility for social security benefits, what aspects of health care were provided free of charge, the criteria for places in special schools or how to make complaints about poor treatment by government officials, teachers or doctors. Without proper information rights are meaningless.

What is needed

- Commitment on the part of government to ensuring that disabled people are aware of their rights and how to access them;
- Collaboration between DPOs and the government on developing a strategy for dissemination of information on rights;
- Multi-media approaches utilising a range of approaches to ensure that information is accessed by the widest possible audience. Both the content and the means of delivery need to be accessible.

In Nepal, one NGO has sought to fill the gap left by government by broadcasting a weekly programme on public service radio, which gives up-to-date news on the situation of disabled people and their rights. Disabled children are also invited to express their views on air. It is backed up by a monthly magazine giving information about the lives of disabled people and how they have overcome barriers to achieve their goals. The need for this dissemination, and the success of the initiative is evidenced by the fact that 68 listener clubs have been started all over the country to follow up the issues raised in the programmes. It is estimated that well over 50% of households in Nepal have access to radio, so it is a highly accessible medium of information for the majority of the population.

1.11 Parliamentary monitoring

Parliaments have an important role to play in holding governments to account on commitments they have made to disabled children.

What is needed

· The creation of all party parliamentary committees, with a remit to investigate progress on implementation of legislation.

2 Strengthening the role of civil society

Whilst governments have primary responsibility for the implementation of human rights standards for disabled children, the realisation of a culture in which human rights are respected is also highly dependent on the role played by NGOs, Disabled People's Organisations - both national and community-based organisations and groups and society as a whole.

2.1 Partnership with disabled people's and parent organisations

Unless and until governments begin to listen to disabled adults and children as well as parents of disabled children, and to respect them as partners, little will change. Challenging deep-seated discrimination and abuse can only be tackled through a multi-tiered approach in which disabled adults and children are viewed as central partners. Without their active participation, governments will get it wrong: they do not have the necessary knowledge and experience.

Disabled people's representative organisations and families need to be involved in both the development of legislation and policy at national level and implementation and design of programmes at regional, local or district level, whether this involves media campaigns, environmental accessibility, inclusive education, health care, training programmes or local information and advice services. They also have a key role to play in monitoring and evaluation of all these processes. Projects and programmes that are designed without reference to disabled people frequently result in ineffective outcomes and wastage of money.

What is needed

In order to ensure this partnership with disabled people

- Their organisations must be recognised and resourced (in line with the UN Standard Rule 18);
- Their views and experience given full recognition and priority;
- Parent's and disabled people's organisations should work together and support the voice of disabled children.

2.2 Service providers

In many countries, the primary providers of services for disabled children are NGOs. Clearly, civil society has an important role to play in promoting and protecting disabled children's rights. But governments too often offload responsibilities for service development onto NGOs, which is neither appropriate nor sustainable in the long term, nor indeed, desirable. And many of these NGOs have little or no collaboration with or influence from disabled children or adults. There is increasing concern that government funding inhibits the NGO from acting independently and silences any criticism of government. This allows governments to continue to abdicate responsibility instead of taking lead responsibility for service provision.

What is needed

NGOs need to acquire the competence and commitment to work with governments to:

- Work with disabled people's and parent's organisations in collaboration and to support their advocacy;
- Support campaigns for disabled children's rights;
- Provide models of good practice.

A disabled children's home in El Salvador, among other efforts to ensure that the children's families are involved as much as possible in

their lives, encourages parents to set up bank accounts for their children to save for the possibility that they might be able to return home.

2.3 Including disabled children

In all four countries in the studies, there were many NGOs working with children and many others working in the disability field. However, relatively few exist with an explicit remit to advocate on behalf of disabled children, or to facilitate disabled children to advocate for themselves. And without such organisations, they tend to get sidelined by both.

It is imperative that the rights of disabled children are addressed, both by organisations dedicated to their interests but also within the mainstream children's NGOs. The issues of direct concern to children are not necessarily the same as those of adults. It is relatively rare for the more mainstream children's NGOs to systematically include disabled children within their programmes.

What is needed

- Children's NGOs need to review their programmes thoroughly to ensure that they do not directly or indirectly exclude disabled children;
- Children's NGOs need to give a higher priority to the rights of disabled children as a minority group who experience extreme violations of their rights;
- Disabled people's and parent's organisations need to focus more on the rights of children, and in particular to create opportunities for the participation of children within their organisations.

The Defensorias - The Council for the Human Rights of Adolescents in El Salvador is a group of 150 young people aged between 16-22 years who work as 'defensorias' of children's rights. The group comprises both disabled and non-disabled young people and their work involves promoting their rights, monitoring compliance and advocacy individual cases. They teach both children and adults about the concept of children's rights and encourage children to exercise those rights. They also advocate in the public policy field to achieve greater compliance with the principles and standards of the Convention on the Rights of the Child. Initially they had to overcome a deep mistrust amongst adults who lacked confidence in them because of their youth. They reported how, when they spoke at schools' parent committees the reaction was often one of anger or contempt. However, gradually that is beginning to change. People do now come to them to report cases of abuse and they advise on where to get legal help and what rights exist under the law.

2.4 Taking children seriously

Children have a different perspective and a unique contribution to make to the development of law, policy and practice affecting their lives. Their views and experience cannot be adequately represented by either their parents or by disabled adults. Adults forget about being a child very quickly! Life now, and its pressures and concerns, are not necessarily the same as when those adults were young. Children must be given an opportunity to participate directly in forums designed to hear their views, and their views must be respected, valued and taken seriously. Whilst disabled children face many of the same difficulties as disabled adults, it is not possible to subsume their experience within that of adults and assume that they are thereby sufficiently catered for. Of course, children themselves are not themselves a homogenous group, but they do share a particular set of experiences, views and knowledge associated with the status of childhood which can only be accessed by consulting with them directly.

What is needed

- Children's NGOs need to develop programmes in collaboration with disabled children designed to provide them with opportunities for self-advocacy;
- Children's NGOs need to commit to including disabled children in mainstream participatory programmes;
- Disability NGOs need to work with children as well as adults in developing their programmes and to encourage children to act as spokespeople for the organisation
- Governments need to develop fora for listening to disabled children, both as part of the whole constituency of children but also in respect of their specific experiences as disabled children.

During a training course for teachers provided by the Ministry in a school in Timisoara, Romania, ten children were noticed outside the head teacher's office during a break. They had come to see him because they were concerned about one disabled child who was not coping well with the transfer to mainstream. They were worried that he would be sent back and wanted to know what they could do to help support him, to prevent his being returned.

2.5 Human rights institutions

While parliaments have a role to play in monitoring governments' adherence to specific legislation and policy commitments, it is also necessary to create independent human rights institutions that can play a broader role in both promoting and protecting disabled children's rights. It is imperative that rights violations do not continue with impunity. Many different models of human rights institutions for children exist: there is no one ideal structure. In Europe, the preferred approach has been to create dedicated children's rights commissioners or ombudspeople, who have a remit in respect of all children under 18 years including disabled children. In addition, many countries also have disability rights commissions. In other regions, children are more likely to be included in generic institutions.

For children, including disabled children, many of the abuses they experience are perpetrated by those individuals with authority over them in their day to day lives. Their low status in most societies is reflected in the low status afforded to abuses of their rights in human rights institutions in many parts of the world.

What is needed

If human rights institutions are to be effective in monitoring, promoting and protecting the rights of children, including disabled children, they need:

- Dedicated children's and disability posts;
- Independence from government;
- Partnership with disabled people's organisations
- Clear and comprehensive powers, for example to investigate violations of children's rights, issue reports, be consulted by government on proposed legislation;
- Accessibility for all children, including disabled children. The institution itself must be physically accessible. In addition, it must disseminate information about its role and how children can approach and use it. They also need to be involved in the institution through advisory groups or other consultative mechanisms in order that its priorities reflect those of children themselves.

The South African Human Rights Commission, which has both a disability and a children's commissioner. It undertook a wide-ranging consultation in 2000, with both disabled and non-disabled children, to ascertain their priorities for the Commission's work . At the time of the study, it was also giving consideration to undertaking an investigation into the sexual abuse of disabled children in residential schools.

3 Meeting children's demands

In addition to changing the structures and processes within government and civil society in order to promote the rights of disabled children, substantive changes are also needed to law, policy and practice affecting their day-to-day lives. During the course of the country studies, children were asked to identify the priority actions needed for change. A consistent pattern emerged. They wanted an end to discrimination in order that the following rights could be fulfilled:

- To be part of a family
- An end to all violence
- Action to tackle poverty
- Equal access to education
- To be allowed to be an ordinary child
- Access to health care and rehabilitation
- An equal right to life

The following section sets out suggested actions that could be taken to meet these demands. The detailed implementation would necessarily have to reflect the social, economic and cultural context of the individual country, but the recommendations provide a broad overview of what is needed to achieve real respect for disabled children's rights.

3.1 An end to discrimination

The previous section has outlined the legislative requirements for ending discrimination. However, in order for legislation to be effective, sustained measures for its implementation are needed.

What is needed

- Disabled children's rights and respect for the equal rights of all children as part of the school curriculum, backed up by school policies to introduce the principles into practice;
- Opportunities for disabled children to talk to the media and appear on television and radio to talk about their experiences and concerns;
- Help for parents to enable them to play a stronger role in building their child's confidence;
- Opportunities for disabled children to meet with non-disabled children;
- Opportunities for disabled children to meet together to give each other support and build alliances;
- Research with children to learn about the nature of the discrimination they face and their ideas for addressing it.

Many CBR and other NGO programmes have endeavoured to transform family attitudes through education, information and support to parents. Save the Children UK, for example, has undertaken mapping exercises of numbers of disabled children in villages in Nepal. They found that, although initially many parents denied the existence of a disabled child, once the family were supported and encouraged to recognise the equal value of a child, whether or not she or he was disabled, they were genuinely pleased to be able to do so. In an environment of superstition and cultural beliefs which assert the blameworthiness of disability, parents often need 'permission' to love and accept their child.

3.2 Being part of a family

The Preamble to the Convention on the Rights of the Child identifies the family as the fundamental group of society, which should be afforded protection and assistance in order to provide a happy, loving and understanding atmosphere for children to grow up in. The children, too, stressed the importance of a loving family where they feel valued and wanted.

What is needed

- Education, counselling and support for parents to reduce the risks of abandonment;
- Provision of respite and day care services to provide parents with necessary breaks which enable them to get rest or find employment;
- Commitment to working with families for rehabilitation.

Where children do have to live in institutions, there is a need for:

- Clear and accessible policy, regulations and guidance on provision of care in residential institutions needs to be issued by the government, covering, for example, child protection, staffing levels, standards of care, access to education and health care, rehabilitation, reviews, complaints mechanisms, confidentiality policy, respect for the views of children;
- Training all staff in residential institutions on children's rights in order that their practice is consistent with the principles and standards of the Convention on the Rights of the Child;
- Regular reviews should be held on every child in an institution, as required by article 25 of the Convention on the Rights of the Child. These reviews should always ensure that the child's views, as far as possible, are listened to and taken seriously;
- Developing fostering, adoption or parenting schemes - where return to the child's own family is not possible, fostering or adoption should be considered;
- Commitment to encouraging disabled children's participation in local communities;
- Attendance at local schools wherever possible;
- Independent inspection systems, including meetings with children, will need to be established in order to monitor the standards being maintained in all institutions in which children live whether run by the state, the church, NGOs or private bodies;
- Clear accessible complaints procedures which children can use in the event of any abuse, discrimination or other ill-treatment or injustice;
- Democratic structures which allow children to contribute towards the policy of the institution.

In South Africa, DICAG, an NGO working with parents of disabled children argues that there are five elements needed for parent empowerment so that they, in turn, can fight for the rights of their children.

- **Mutual respect between parents and professionals which accepts that parents, like professionals have qualities and skills.**
- **Acknowledging and recognising families' needs and strengths**
- **Providing information as an essential foundation for making rational and informed choices**
- **Creating opportunities for exposure and social contacts**

- **Supporting the development of economic independence of mothers through early childhood development facilities, basic adult education, training and skills development for self-employment.**

3.3 An end to all violence against disabled children

Physical and sexual violence against disabled children is widespread, but largely disregarded and denied in most countries.

What is needed

- Legislation to prohibit all forms of physical and sexual violence, including corporal punishment, against children in the home, in school, in child-care institutions, in hospitals or in penal institutions, whether run by the state or privately;
- Review of child protection legislation to ensure that it addresses the particular forms of violence experienced by disabled children, provides adequate visibility of their abuse and is effective in protecting disabled children;
- Public information campaigns to challenge cultural norms, raise awareness and promote the unacceptability of all forms of violence against all children, particularly disabled children. Research into the prevalence, nature and causes of violence against children, disaggregated to provide a clear picture of the situation of disabled children. This data is vital in developing effective strategies for addressing the problem;
- Training for all relevant professionals on the rights of disabled children, and skills in detecting symptoms and assessing the possibility of ill-treatment, taking into consideration the child's impairment. Teachers, for example, need help in finding alternatives to physical punishment, as a disciplinary tool;
- Child protection policies, including disabled children, to be introduced in all institutions, setting out the behaviours expected from teachers, carers or other staff and what action to take in the event of any child being abused;
- Codes of conduct in all institutions and schools which establish principles of non-violence, strategies for reducing levels of violence and mechanisms for tackling abuses of this principle;
- Safe and accessible reporting systems for children, including disabled children, making complaints about violence or abuse;
- Information to all children on their right to protection from all forms of violence and where to go for help if this right is violated, ensuring that this help is fully accessible;
- Codes of conduct in all institutions and schools which establish principles of non-violence, strategies for reducing levels of violence and mechanisms for tackling abuses of this principle;
- Children themselves, including disabled children, must be consulted within any programmes of research, public education, child

protection, media campaigns or the development of non-violence policies or codes of conduct.

In El Salvador, Save the Children Sweden has sought to end the silence surrounding the sexual abuse of children and published a shocking account of the extent and severity of the problem.

3.4 Tackling poverty

Strategies to address poverty need to focus on the goal of promoting both the social integration of and opportunities for independence of disabled people.

What is needed

- Disabled adults and children to be included in all poverty alleviation policies and schemes;
- Disabled adults to be included and supported in all training and employment opportunities;
- A system of benefits or grants that reflect the real extra costs of disability;
- Parent support services to help parents provide adequate care for their child.

DICAG (South Africa) has worked with the Department of Health in the Province of Mpumalunga to implement a nutrition programme. It was argued that children could learn and achieve more if they were better fed and that the problems of poor nutrition derived, not only from poverty but also from a lack of knowledge and difficulties in physically feeding children. Accordingly, a pilot programme of feeding therapy was designed to provide help with diets and feeding. It was targeted at 400 disabled children. The programme experienced considerable initial difficulties. Apart from some administrative problems, many parents felt angered by being told by professionals that their feeding practices need changing. In response, the project held a series of workshops with food therapists and parents in which they did role-play reversals. The outcome was a major learning experience for the professionals who understood the need to be more sensitive to the knowledge and experience of the mothers, for whom, correspondingly, the process was significantly empowering.

3.5 Equal access to education

The right to education is realised for only a small proportion of disabled children in the developing world. Even where disabled children have access to schools, it is often in segregated environments or in mainstream schools without any of the necessary support, teaching or equipment.

What is needed

- Legislation establishing the right of all disabled children to education, irrespective of the nature of their impairment;
- If there is free education for non-disabled children, then disabled children should also have access to free education;
- A national strategy for inclusive education based on consultation with all key stakeholders- children, parents, teachers in mainstream and special schools, disability NGOs;
- School policies on inclusion need to be drawn up with the children, parents and teachers in order to promote a culture of acceptance and non-discrimination;
- Preparation for teaching staff. One of the problems faced in many schools, deemed to be inclusive, is that the teachers lack any training or preparation for working in an inclusive environment. The consequent lack of confidence often expresses itself in hostility to the disabled children and their presence in the school;
- Preparation for children to help them adapt to inclusive environments;

· Preparation for parents of both disabled and non-disabled children. It is important that parents of existing pupils are informed about the process of inclusion, its rationale and the potential positive benefits that will accrue for their child;

- Appropriate planning and preparation within the school to ensure effective inclusion.
- Creating democratic schools in which children, including disabled children, are given the right to express their views and have them taken seriously in all aspects of the school environment;

A school in Nepal enrolled ten blind children for the first time in 2000. Initially they were placed in a resource class where they were taught Braille with a specially trained teacher. Once they were competent in Braille, they transferred into the mainstream classes. The special teachers are available to explain, support and address any problems that arise. The experience is widely agreed to have been successful. Many of the blind children are leaders in their class. The children are all friendly with each other and the sighted children are positive about working collaboratively with their blind friends.

A children's club in the Bhaktapur district of Nepal has a number of disabled children taking a lead role. They recently decided to undertake a house-to-house survey in their village to find out how many disabled children were not enrolled. Once they had identified the children, they counselled the parents to persuade them of the value of their children receiving education. In some cases, the problem was primarily one of poverty, and where this was the case, the children undertook fundraising to help the family cover the costs of getting the child to school.

3.6 Being an ordinary child

More than anything, the children wanted to lead ordinary lives - hanging out with friends, going to the cinema, having a boyfriend/girlfriend, playing sport, going to school, helping their parents in the home or fields, going shopping, going to parks and playgrounds, imagining what they would be when they grew up. But these everyday activities are denied to most disabled children. Barriers impede their participation at every level, denying them opportunities for an ordinary life.

What is needed

Enforceable and well publicised legislation to remove barriers in the built environment. While cost is often cited as the main reason for failing to provide a barrier free environment, it has been estimated that when accessibility is incorporated into the original design of a building, the additional cost rarely exceeds 0.2%;

- Accessible transport services are vital to any opportunities for integration in society;
- Accessible housing - many disabled children live in accommodation that effectively imprisons them at home unless they are accompanied by a non-disabled person;
- Opportunities for sport and recreation are key to children's physical health, self-esteem, enjoyment, exploration and engagement with the world;
- Access to art and cultural life is as important for disabled as for non-disabled children.

Voice for Education is a project initiated by Save the Children UK in Nepal using role models of disabled children who had successfully overcome discrimination, poverty and immense physical and social barriers to become high academic achievers. Initially the project identified key individuals in villages to mobilise support for encouraging parents to send their disabled children to school. Once some were in school, they began to serve as role models for other families. The project now works by using community motivators to bring forward children as role models to share their stories and advise other communities. These children talk to other children, to government officials, to parents and the media. The scheme is now operating in 32 villages in 3 districts.

3.7 Access to health care and rehabilitation

Lack of access to appropriate and adequate health care was a recurring theme throughout the study. The problems identified ranged from inability to pay for the necessary care, lack of availability of community-based provision, attitudes of medical professionals, physical inaccessibility of many health services, lack of information about what was available, lack of appropriate assistive devices, lack of knowledge on the part of parents in how to protect the health of children and the medicalisation of disability.

What is needed

- Access to comprehensive free health care should be the goal for all children, including help with the costs of transport, and also accommodation when they need to stay overnight with their child;
- Training for health professionals on disabled children's rights, and the principle of equal treatment, non-discrimination and disability as a social construct;
- Greater recognition of disabled children as individuals entitled to be consulted about their own health care and whose views should be taken seriously, in accordance with their level of understanding and capacity;
- Community-based services providing information, advice and training to parents of disabled children in order that they can help promote their child's health and well-being;
- Mobile surgical camps to provide services in rural areas.
- Improved provision of assistive devices, such as prosthetics.

In Nepal,the hospital providing reconstructive and rehabilitative care cannot afford to import expensive prosthetics from abroad and they are not manufactured domestically. Accordingly, they have established a workshop which has applied the technology from models made abroad using cheaper materials which can then be made available more widely.

3.8 An equal right to life

In all the countries studied, it was claimed that all lives were equally protected in law. However, in practice, contempt for the life of a disabled child meant that, too often, less efforts were made to protect it. Many of the suggested actions relating to ending discrimination, providing better health care, supporting families, and tackling poverty will contribute towards affording respect for the equal right to life of a disabled child.

But additional measures are needed.

What is needed

- Explicit legislation providing equal right to life for all people, irrespective of impairments;
- Birth registration programmes which seek to ensure that disabled children are registered alongside non-disabled children. It is not uncommon for the existence of a disabled child to be denied and neither registered nor entered in a government census. Not only does this failure create difficulties for the child in the future in accessing certain services, but it does expose them to greater risks of infanticide or neglect;
- Training for medical staff in children's rights to raise their awareness of the equal right to life of all children. Examples exist from around the world of doctors making 'quality of life' judgements

to determine the withholding of life-saving treatments or interventions. Professional policies on this issue need to be developed in collaboration with disabled people;

- Ending relative impunity for killing a disabled child - the lower sentences often imposed on people who kill a disabled child imply a lesser value on the life that has been taken. Such an approach is in violation of the Convention on the Rights of the Child which insists on the equal right to life without discrimination on any grounds, including disability.

CONCLUSION

Despite the profoundly different social, economic, political and cultural contexts of the four countries in this study, the struggles faced by disabled children on a daily basis are remarkably similar. Their common impassioned plea is for changes in attitudes in order that they can be accepted and included as 'ordinary' children. It is a straightforward demand, but far from easy to achieve. Poverty, cultural traditions, ignorance, fear and social isolation all contribute towards their rejection. All of which need to be addressed if real change is to be achieved. However, what also emerges is that there is a great deal that governments and civil society can do to overcome discrimination and social exclusion. Four basic ingredients are essential:

- Willingness to listen - disabled people, including importantly, disabled children, must be central to the development of change. It is they who have the expertise, the experience and the understanding that are vital to the realisation of their own human rights. Progress will never be achieved without their direct involvement. Governments need to have humility in recognising their need to learn from the disability community.
- Political will - even the poorest governments can achieve significant changes in the lives of disabled children if they are prepared to commit time and resources.
- Recognition of disability as a social construct - central to the creation of change is the need to understand the physical, social and cultural barriers which impede the social inclusion of disabled children. As long as the problem continues to be perceived as within the child him or herself - and the consequent strategies focused on the child not the environment - no real change is possible.
- A multi-tiered approach - tackling the deep-seated discrimination faced by disabled people requires changes in many areas and at all levels - through legislation, explicit policies, enforcement mechanisms, the establishment of consultative mechanisms, dedicated staff and budgets, community programmes, transparent and democratic decision-making processes, educational reform, public awareness campaigns. An integrated, comprehensive and enforceable approach is essential.

In all four countries in the study, it is possible to see real progress. Educational inclusion is on the agenda. All have some form of institutionalised dialogue with disabled people's organisations. All are introducing legislation and policies to promote non-discrimination and have created some form of unit within government to take lead responsibility for disability issues. The role of the disability community has been effective in raising awareness and influencing the political agenda. However, progress is still slow and it remains fragile. Most significantly, there is little awareness or understanding of the importance of listening to disabled children, themselves. Yet as this report and the four country studies show, they have a great deal to say, they have a profound understanding of the changes that are needed and are anxious to have a place at the table. Indeed, the most effective advocacy for change comes through disabled children themselves articulating their demands. In so doing they demonstrate, in the most potent means possible, the absurdity of the prejudices held against them.

It is important to listen to the messages they have contributed to this study and learn from them. What they tell us is that they are part of the solution. The most effective and respectful response must be to create processes for working with them to give effect to the changes they are seeking, and which are documented in this report, to enable them to lead 'ordinary' lives.

For copies of the four country reports and Its Our World Too, a report on the international status of disabled children apply to DAA, 11 Belgrave Road, London SW1V 1RB, UK,e.mail:info@daa.org.uk

The organisations that undertook this role were: DICAG in South Africa, Trebuie! In Romania, Nepal Disabled Human Rights Centre in Nepal, and ACOGIPRI in El Salvador

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