'The teacher told me I must just go and learn switchboard...and I said please, I can be a psychologist, I can be a lawyer. Why must I be a secretary typing somebody else's work all the time if I have brains. My not walking doesn't take my brains away'.(young girl with physical disabilities, Gauteng)

Gerison Lansdown

Rights for Disabled Children
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Disabled Children in South Africa
Progress in implementing the Convention on the Rights of the Child

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Background to the report
Despite the explicit inclusion of disability as a ground for protection against discrimination in the Convention on the Rights of the Child, and the provisions of Article 23, which specifically address the situation of disabled children, the reality of disabled children remains largely unchanged in most countries in the world. Widespread discrimination and abuse of their rights continues, and little international attention has yet focused on the need for governments to give a higher profile to the introduction of measures to end these abuses.

The international working group, Rights for Disabled Children, established in association with the Committee on the Rights of the Child in 1997 and funded by the Swedish International Development Agency, is seeking to gather and disseminate information on the situation of disabled children, in order to raise awareness and understanding both of the extent of violations of their rights and of the strategies that are needed to bring an end to those violations. In pursuit of this goal, it is undertaking a series of country visits to explore the situation of disabled children in different regions of the world. These visits will seek 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 DPOs 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

South Africa was selected as the first country to be visited, primarily because its Government has introduced a framework of progressive legislation and strategies designed to tackle historic discriminations against disabled people, but also because there has been significant action and involvement by Disabled People’s Organisations in the development of these initiatives. It therefore provides an interesting model from which to assess progress and possibilities for change. The visit took place over two weeks in October 2001 (see appendix 1 for details of organisations and individuals visited and interviewed).

Subsequent countries to be visited include:
• Nepal
• Rumania
• Ghana
• Central America – country to be determined
Section one - An overview of the situation of disabled children in South Africa

‘Most people do not expect disabled people to have any potential for success. They are just seen as a burden’ (parent)

The legacy of apartheid
One of the obvious legacies of apartheid is the gulf of difference in children’s experiences across the country. The Human Rights Commission describe the old South Africa as a ‘racially divided, traumatised, dehumanised and child welfare negligent society’¹. Because its philosophy was to segregate and divide, it is not possible to describe one South Africa. Whilst race determined social status, it also entrenched worlds of difference between those living in rural or urban communities, those with and without access to education, those with and without decent housing and sufficient food, those with and without opportunities for fulfilment of potential, those with and without recognition of respect for their dignity and humanity. For black disabled children, the commonly experienced difficulties of social exclusion and marginalisation, associated with their impairment, has been compounded by the oppression experienced as a result of their race. It is not possible to understand the situation of disabled children in South Africa without placing it in the context of that history.

Prevalence of disability
According to figures recorded in the 1996 Census, there are nearly 16.5 million children under 18 years, of whom 81% are African, 9% coloured, 8% white and 2% Indian. Data available on the prevalence of disability is inadequate, largely due to the historic failure to integrate disability into mainstream government statistical processes. In addition there are difficulties because:

- There is no consistently used definition of disability, nor clarity of distinctions between degrees of severity of impairment or need and assessment
- Different survey techniques are used to collect data
- Some surveys have excluded people living in institutions, thus inevitably producing inaccurate figures
- Lack of screening and early identification services lead to lack of awareness of disability amongst young children
- Negative attitudes towards disability leads to their exclusion from records
- Poor service infrastructure in some under-developed areas leads to lack of awareness of disabled people
- Violence in some areas has inhibited the collection of data

Accordingly, the statistics that are available vary widely and are frequently unreliable. For example, a survey undertaken by the Central Statistical Service in South Africa in

¹ First Supplementary Report, UN Convention on the Rights of the Child, South Africa, 1999
1995 reported a prevalence of 5%. Yet, the UN has estimated that around 10% of the population worldwide is disabled\(^2\).

Small geographical South African studies amongst children indicate a prevalence range from 3.3-6.4%. The 1996 Census found 4% of children to have disabilities. A Department of Health survey identified 5.9% of the total population to have a disability and 3.3% of children under 18 years. This survey also found that of the total disabled population, 9.4% are children, between 1-15 years old, that rural children are twice as likely to have three or more disabilities than their urban counterparts and that poorer provinces had significantly higher prevalence rates than the national average. Concerns have been expressed by some NGOs within the disability movement that the Department of Health survey contained significant methodological limitations, leading to an inadequate estimation of the numbers of disabled people. In particular, it was felt that the reluctance of many families to admit to having a disabled child, as a result of the associated stigma and prejudice, would have led to under-reporting.

The South African Federal Council on Disability (SAFCD) lobbied for more rigorous questions on disability to be included in the 2001 Census, in order to enhance the quality of data on prevalence. Their suggested questions were rejected on the grounds that they were too detailed, but the final Census form did include some additional questions which should provide better quality information than has been available to date.

Meanwhile, in the face of the conflicting and inadequate data available, the Children’s Institute, based within the University of Cape Town suggests that a working figure of 3-4% prevalence rate should be used plus a 1% prevalence of children infected with HIV/AIDS\(^3\). Using these figures, it is evident that there are well in excess of half a million children with disabilities in South Africa in need of appropriate services if they are to realise their rights.

Causes of disability
A significant proportion of impairments and consequent disabilities faced by children throughout the world arise from preventable factors. Nowhere is this more evident than in South Africa.

Poverty
The primary causes of disability amongst children in South Africa, as in other countries, have their roots in poverty. Poverty-related factors lead to many preventable impairments which in turn perpetuate poverty. The lowest socio-economic families are almost two and a half more likely to have a disabled child\(^4\). Illness, pre-and peri-natal problems, such as genetic disorders and birth trauma, injuries, accidents and violence are major contributory factors. Children living in rural

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\(^3\) Summary of literature; disability and chronic illness prevalence in children in South Africa, Child Health Policy Institute, June 2001

areas are disproportionately more likely to be disabled at birth than those in urban areas.

The ‘dop’ system
Some causes of disability have their roots in the apartheid regime. For example, many children were born on farms where their parents were poorly paid, lived in appalling housing and grew up in abject poverty. Common on these farms was the practice of the ‘dop’ system of payment whereby wages were paid in part with wine. This practice resulted in high levels of alcoholism with foetal alcohol syndrome (FAS) a major problem. Studies in the Western Cape, for example, have indicated an incidence of 5% of children suffering from FAS, the highest in the world, as contrasted with an average incidence of 0.4%\(^5\). The impact of FAS on the development of children is profound. Their intelligence is significantly affected, they have distinct facial features, exhibit life-long behavioural problems and remain very small in stature. Adolescents and adults exhibit high levels of mental illness including depression and anxiety. Although the ‘dop’ system has now been banned, there is evidence that it continues on many farms.

The combined effect of the ‘dop’ system and the poverty of farm workers continues to raise major barriers to the healthy development of farm children. A survey conducted in 1999, for example found that children on commercial farms had the highest prevalence of stunted growth at 30%. There is evidence that the wine used in payment is shared with children, thus perpetuating the risk of high levels of alcoholism. Inadequate nutrition, unhygienic living conditions, overcrowding, exposure to pesticide poisoning, accidents and violence all contribute to high levels of disability.

HIV/AIDS
The spread of HIV/AIDs in South Africa is a rapidly growing cause of disability amongst children. Current data indicates that 1 in 5 adults are infected with HIV and 1 in 9 of the population as a whole. It is estimated that a quarter of women attending public health facilities in 2000 were infected. Pregnant women in their late twenties show the highest infection rate at 30.6%\(^6\).

The risk of transmission of HIV infection at birth is the greatest risk faced by South African children at birth. Around one third of children born to infected mothers will be HIV positive, most of whom develop AIDS and die within a few years of birth. By the end of 1997, 80,000 children between the ages of 0-14 were infected and between 14-17 years, the numbers of children infected tripled. Current estimates indicate that upwards of one quarter of children in hospital are infected. The rates of infection amongst young people is growing, with 15-19 year old girls a particularly vulnerable group.

The infection rate amongst all age groups is still growing at a rate of 8% per annum, and is not under control. Recent projects on death rates published by the Medical Research Centre indicate that by 2010, one third of all deaths will be from HIV/AIDS and that by then, there will be 2 million AIDS orphans. Whilst devastating for any

\(^5\) Children on farms: Phillippi, the Western Cape, Child Health Policy Institute, May 2000

child, the impact of parental death is even greater for a disabled child, for whom relatives may be reluctant to take responsibility and whose opportunities for independent survival will be limited.

**Cultural and social factors**

Disability in South Africa is still surrounded by stigma and prejudice. Having a disabled child is associated with punishment, curses and failure. Parents of disabled children often experience ostracism within their communities, and the birth of a disabled child doubles the likelihood of abandonment. In rural areas, it is commonplace for men to leave their wives after the birth of a disabled child. It is the wife who is seen to blame for the impairment. Furthermore, this abandonment is not frowned on, indeed, is largely condoned by local communities. In urban areas, where men also frequently leave their wives after a disabled child is born, it seems that men are seeking to escape the associated pressures of caring for the child rather than the stigma associated with the birth. However, the consequences for the abandoned mother are the same. The vast majority of disabled children are being brought up in single-parent households. For example, in one special school for 200 children only 20 had fathers.

The impact of these negative attitudes is that disabled children are frequently hidden from view, kept in back rooms, their existence and their human rights largely denied.

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7 Howell C, Presentation to the Community Law Centre Conference on the Rights of People with Disabilities, November 1996
Section two – The legal, political and social framework
The South African Government, since 1994, has given a high priority to issues of disability. Its commitment to challenging the profound social and economic injustices experienced by disabled people is evident in the range, nature and the status of measures introduced to achieve change. These measures include:

- Legislation giving disabled people equal rights
- The Integrated National Disability Strategy and National Plan of Action for Children to translate the legislation into a framework for action, backed up by powerful political structures designed to put the strategy into operation
- Systems for monitoring and evaluating progress.
- A provincial framework responsible for implementation
- The establishment of a statutory, independent Human Rights Commission

‘Adults categorise everybody – abilities here, disabilities there, religion, race…. Children don’t have that as yet. Preschool children are still free. People need to be educated to be more accepting. To accept that every child has the right to be educated and included in society as a member person, not as disabled or handicapped. There are too many labels, The very first step in any school situation is acceptance.’ (parent of a disabled child)

1 Constitutional and legal rights of disabled children
In 1994, the President pledged a commitment to put children first. The UN Convention on the Rights of the Child was ratified by the South African Government in 1995. In so doing, the Government made commitments under international law to recognise disability as a ground for protection against discrimination (Article 2) and to promote the fullest possible social integration of disabled children (Article 23). The Bill of Rights in the 1996 Constitution guarantees fundamental rights to all citizens. It includes an equality clause and the right to freedom from discrimination based on a number of criteria including disability. In addition, the Bill of Rights guarantees that ‘a child’s best interests are of paramount importance in every matter concerning the child’. The Promotion of Equality and Prevention of Unfair Discrimination Act 1999 translates the principle of equality into legislation stressing for example, the right to education and to supporting and enabling facilities such as Braille, sign language and hearing aids. The Employment Equity Act also places disability alongside gender and race as deserving of explicit attention in order to overcome discrimination.

These provisions mean that disabled people, including children, now have a constitutional right to be treated equally and enjoy the same rights as all other people.

2 The strategy for implementation
(i) The Integrated National Disability Strategy (INDS)
These legal rights were translated into a strategy for action with the publication, in 1997, of the Integrated National Disability Strategy. This strategy asserts disability as a human rights and development issue and promotes a social model of disability. It explicitly argues that the ‘collective disadvantage of disabled people is due to a complex form of discrimination’, and goes on to stress the need for reconstruction and development of South African society to address the developmental needs of disabled
people within a framework of inclusive development. It also recognises that the shift towards recognising the social rather than medical model of disability has been achieved largely through the lobbying of strong disabled people’s organisations.

A central principle embodied in the INDS is the right to self representation which it defines as meaning that the collective determination of disabled people must be used to inform the strategies of government. In addition, it commits to the introduction of integrated and sustainable policies.

The INDS is the responsibility of the Office on the Status of Disabled Persons which is now based in the President’s Office. An Inter-Departmental Co-ordinating Committee has been established to implement the strategy at departmental level. Each government department is required to establish a disability unit and undertake a disability audit to identify action needed to ensure implementation of the INDS.

(ii) National Plan of Action for Children (NPA)
The National Plan of Action was put into place in 1996 as a mechanism for implementing South Africa’s stated commitment to the ‘progressive realisation of children’s rights’. It provides a holistic framework for government policy across all departments and identifies 8 priority issue areas:
• Infrastructure
• Special protection measures
• Education
• Early childhood development
• Child and maternal health
• Nutrition
• Leisure and recreation
• Peace and non-violence

In addition, it addresses four cross-cutting themes – disability, HIV/AIDS, gender and peace and non-violence.

Co-ordination and implementation of the NPA is the responsibility of the Office on the Rights of the Child, which is based in the President’s Office. It aims to provide a vehicle for co-ordinated action between NGOs, government and child-related structures. An NPA steering committee, comprising representatives from national and provincial government and a wide range of interested institutions, including the SA Human Rights Commission, the Youth Commission and UNICEF introduced the idea of a report on the state of South Africa’s children. It is designed to draw together the most up-to-date information on the status of children’s rights and help identify gaps, encourage debate and assist in advocacy. The first such report was published in 2001 and contains a detailed section on the rights of disabled children and problems to date in realising those rights.

3 Monitoring structures
A Joint Monitoring Committee on the Improvement of Quality of Life and Status of Youth, Children and Disabled persons has been created comprising 17 Assembly members and 9 Council members. It is an all-party Committee with a remit to:
• Monitor and evaluate progress on the quality of life and status of children and disabled persons
• Make recommendations to Parliament on the basis of that work

In other words, a body has been established, independent of government, to monitor progress on the commitments the Government has made to both children and disabled people.

4 Provincial structures
The national structures are replicated at provincial level where the real task of translating policy into practice needs to take place. Each province has an Office on the Status of Disabled Persons and an Office on the Rights of the Child. They are also required to establish a Standing Committee which is responsible for implementing and monitoring national strategies at local level. Curiously, whilst the Joint Monitoring Committee has a remit in respect of youth, children and disabled people, the Standing Committees deal with youth, disability and gender. Consultation with local communities and NGOs is seen as an integral part of the process of implementation.

5 Establishment of a Human Rights Commission (HRC)
The Human Rights Commission was established through legislation in 1994. Its staffing of 11 commissioners includes both a commissioner with responsibility for disability and one for children. In respect of disabled children, the two commissioners collaborate. The Commission has a remit to tackle violations by taking up individual complaints, to promote awareness and understanding of rights and to monitor implementation of human rights by government, particularly in respect of social and economic rights. Each commissioner has established an advisory committee which serves both to advise and monitor the activities of the Commission. Accordingly, both a Disability and Child Rights Advisory Committee have been established. Both the disability and child rights commissioner sit on each. Disabled Children’s Action Group (DICAG) sit on the Child Rights Committee.

In 1998, the Child Rights Committee advised the Commission on a process for becoming an effective focal point for children. It devised a three stage project involving:
• a study tour of developing countries to learn about child rights programmes and how human rights institutions collaborate with child rights institutions
• an in-depth period of consultation with national NGOs working with children
• a consultative process with children in the nine provinces

A crucial component of this process was the inclusion of the perspective of disabled children alongside non-disabled children. Most, although not all of the consultative groups, included disabled children. The structure of the HRC, in bringing these issues together, enabled it to create an environment capable of recognising the common ground between all children in the exercise of rights whilst also creating space to address the specific concerns of disabled children. Disabled children were rendered visible, and their perspective, both on what rights they wanted respected and how the

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8 Towards a Focal Point for Children, South African Human Rights Commission, 2000
Human Rights Commission could contribute towards the realisation of those rights, was integrated with those of non-disabled children.

‘Since I’ve been in a wheel chair, people do not treat me the way they used to before. People do not respect me’. (young boy with physical disabilities, Western Cape)

The consultative process highlighted a number of important issues. For example:

- Consistent themes raised by all the consultative groups were the right to education, the need for better protection from violence and abuse and measures to tackle poverty.
- Some of the activities designed for the consultative process relied on physical movement. Where disabled children lacked wheelchairs, the solution was to exclude the child rather than change the activity.
- Some children who lacked wheelchairs were unable to attend.
- In one case, a child in a wheelchair was sexually harassed by another child. The question also arose as to how to deal with problems raised by children in the course of the activities, which necessitated intervention on the part of the facilitators. The need for child protection policies is evident.
- During the consultative process, the lack of assistive devices was identified as a major problem by the children. In response, the Commission then raised funding from donors to provide significant numbers of children with appropriate devices.

3 The role of NGOs
Focus on disabled children
There are many disability organisations in South Africa, the majority focusing on the provision of services to specific groups of disabled people. However, it has traditionally been focused almost exclusively on adult issues. Similarly, the children’s rights movement has neglected disabled children. Accordingly, the NGO community has replicated the wider society in rendering disabled children invisible. DICAG, an organisation of parents of disabled children set up in 1993 as a project within the NGO, Disabled People South Africa, has, to date, been the sole voice nationally speaking on behalf of disabled children. It became independent in 1997. Its strength has been its active and high profile commitment to advocacy through empowerment of parents. And it has achieved a remarkable profile in its short life, forcing government at national, provincial and local level to begin to take account of the rights of disabled children. Ironically, its success has resulted in many other DPOs taking no responsibility within their own organisations for promoting the rights of disabled children. Indeed, within the SAFCD, only two out of 14 organisations do so. This places a huge burden of responsibility on DICAG with its limited resources. (Most of the other disability specific members of the SAFCD will provide assistance and services to disabled children and their families if approached by the families or social workers.)

Funding for NGOs
Prior to 1994, most NGOs were independent of the government, with many receiving funding from international donors. Since then, many of these international donors have channelled their funding through the government, the rationale being that a
democratically elected government is best placed to determine priorities for NGO activity. This approach brings mixed blessings. On the one hand, a co-ordinated government strategy for funding NGOs has the potential for more consistency and coherence in the range of initiatives being supported. It is, at least in theory, more democratic and promotes the opportunity for locally, rather than internationally determined objectives to be pursued. Certainly, there are difficulties faced by some local NGOs in negotiating terms of grants to reflect the realities of disabled children at grass roots level. However, the price is that many formerly independent NGOs are now fully funded by government and are consequently less capable of providing an effective critique of government policy. Many such organisations are viewed by the Government as service providers, expected to deliver and not to challenge. Advocacy organisations, which do challenge government policy, are at risk of losing their funding. In general, NGOs struggle for funding and many have inadequate resources with few available options for accessing potential financial support.

**Collaboration with the Government**
The Government does make a consistent effort to engage with the NGO sector in the development of policy. It involves NGOs on many of its consultative bodies. It is receptive to lobbying. It does seek to create a relatively transparent policy-making process in which participation with civil society is welcomed. It formally recognises the South African Federal Council on Disability as a representative consultative structure of disabled people within South Africa for the government. There is, therefore, a relatively open dialogue between government and civil society. However, only a relatively small number of NGOs currently focus on advocacy as opposed to service provision in the disability sector. SAFCD is working to mobilise a greater breadth of work in the advocacy field. Certainly, effective lobbying with Government on behalf of disabled children would benefit from a broader coalition of active organisations.
Section three - The experience of disabled children

1 Right to life and to protection from violence
South Africa’s history of institutionalised violence against the majority of its population has left deep scars which are proving profoundly difficult to eradicate. The Government acknowledges that its children have been and still are exposed to ‘inordinately and traumatic levels of violence in its many forms – political, criminal, domestic and structural’. Some estimates suggest that as many as one in four girls and one in eight boys are raped before puberty. And these generalised high levels of physical and sexual violence throughout South African society inevitably impact even more significantly on disabled children, as among its most vulnerable members. Indeed, the Government, in the State of the Nation’s Children recognises that disabled children are particularly vulnerable to abuse of all kinds, including sexual abuse, although statistics are, currently, not reported to reflect the incidence of disabled victims.

Family violence
There are very high levels of violence within the family. Indeed, the children taking part in the consultation undertaken by the Human Rights Commission raise the extent of physical abuse as an issue of primary concern to them. A survey of organisations providing services to children affected by violence in 1994 found that a third of children had been the target of domestic violence. Unfortunately, it is likely, in South Africa, as in many other countries, that such abuse is even more prevalent against disabled children. They are more isolated, less able to defend themselves, more likely to spend considerable periods of time in the home and have lower status, all of which render them more vulnerable. NGOs working with disabled children indicated that abuse and rape, particularly in villages and townships is widespread. However, as no research has been undertaken to examine or address such abuse against disabled children, the evidence, as yet, remains anecdotal, inhibiting the capacity to take action to address it. It was generally felt that there was inadequate public debate on the issue of family violence towards children.

Institutional violence
NGOs working in the field of disability express deep concern over the scale of abuse perpetrated against disabled children in institutions. Whilst it was felt that progress had been made in rendering abuse of children more visible, and in creating mechanisms for investigating violations against children, the prevalence of violence continues to give real cause for concern. The Human Rights Commission is planning to conduct a snap survey of special schools in response to continuing complaints by both parents and NGOs about sexual abuse, particularly in respect of deaf children. There have been a number of high profile cases reported in the press concerning sexual abuse and rape of disabled children in special schools, but few ever reach the courts and achieve a successful prosecution. The difficulties in reporting, refusal to accept children as credible witnesses, the inaccessibility of the courts all inhibit any real means of redress. Furthermore, some parents, who have fought for years to get a

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child into school, are reluctant to take action when their child reports being abused for fear of losing the place. In other words, the right to protection from violence and abuse has to be sacrificed in order to retain the right to education. It is an invidious choice. In addition, there continue to be high levels of physical punishment used in schools, despite legislation banning such practices in 1996.

- Violence resulting from myths and taboos
  The belief that having a disabled child is the result of a curse persists in some provinces. There are still cases of mothers and other members of families being killed as the result of having a disabled child. The child is then isolated, evicted and sometimes killed\(^\text{11}\). Certainly, NGOs testify to examples of disabled children themselves being killed, possibly to protect the family members from such attacks but also in response to a belief that the child is cursed, brings bad luck, or is a punishment. There is also a widespread and deeply disturbing belief that having sex with a disabled child rids a man of HIV infection. This is leading to increasing levels of assault as the incidence and awareness of HIV rises.

**Government strategies to tackle violence**

The Government recognises the need to reduce the general levels of violence facing all children and has taken a range of measures to tackle it in line with Article 19 of the Convention on the Rights of the Child, the right to protection from all forms of violence, including:

- legislation to end the use of corporal punishment in schools and in all penal and child care institutions, although not, to date, in the home.
- major public education campaigns to tackle the high incidence of rape.
- development of an integrated National Strategy on Child Abuse and Neglect
- one-stop centres for abused children
- the creation of a child protection register

In addition, the Law Commission in its recent review of the Child Care Act 1983 has recommended the removal of the common law defence of ‘reasonable chastisement’ in any case involving a charge of assault against a child. If implemented, this would represent an important step forward in recognising the rights of all children to respect for their physical integrity and protection from violence. It also recommends the establishment of an Office of Children’s Protector to be based in the Department for Social Development with powers to investigate complaints under the revised statute and to ensure compliance with set minimum standards of treatment and care of children.

However, it is not clear in any of these measures, that the particular risks of violence faced by disabled children are explicitly addressed, nor that efforts will be made to develop strategies which ensure that they are enabled to seek the help and protection they need. For example, it is important that collection of data on violence and abuse is disaggregated. Child protection registers need to record disaggregated data if they are to be able to identify the incidence of abuse against disabled children and develop appropriate strategies for addressing it. The Law Commission Review of the Child Care Act recommends the development of a consolidated national child protection

register but, disappointingly, make no references to the need for disaggregation. The National Strategy on Child Abuse and Neglect needs to take evidence from those working with disabled children as well as disabled children themselves, and one-stop shops need to explore ways of ensuring accessibility to disabled children. The proposal for an Office of Children’s Protector, if implemented, would be a welcome development. However, it would need to ensure that the specific needs and rights of disabled children were explicitly addressed and that measures were taken to enable disabled children to access its services.

There is also a need for research into the experience of violence against disabled children looking at prevalence, causes and strategies for prevention. In October 2001, a conference held by SAPCAN, funded by Save the Children, identified major difficulties for disabled children in challenging sexual abuse – lack of access to the justice system, they are not believed, perpetrators are not punished, lack of facilities to help communication, lack of access to services. It recognised the importance of ending the exclusion of disabled children from programmes addressing child abuse and beginning to mainstream them into child protection measures.

2 Right to education
The education legacy
Article 28 of the Convention on the Rights of the Child asserts the equal right of every child to education. Article 23 stresses that disabled children must have access to education ‘in a manner conducive to the child’s achieving the fullest possible social integration’. Unfortunately, neither access to education nor inclusive provision is available to most disabled children in South Africa. The denial of this fundamental right has its roots in the apartheid system. Funding for education under this regime was strictly determined by race. On a pro rata basis, the formula for each child’s education was as follows:

- African 1$
- Coloured 1.5$
- Indian 2$
- White 10$

The segregation of children on the basis of race was compounded by a further segregation on the basis of disability. To be black and disabled condemned children, at best, to the poorest and least resourced sector of education and at worst, to no education at all. The legacy of this chronic under-funding and segregation still endures. Current statistics indicate that only about 64,200 students have places in 380 special schools. This represents approximately 20% of potentially eligible students, leaving as many as 280,000 unaccounted for\(^1\). Further inequalities exist on the basis of geographic location. For example, the Western Cape, a relatively affluent province, has 5.7% of the disabled population, but 21.58% of the schools and 0.96% of children enrolled, whereas the Eastern Cape, a much poorer province, has 17.39% of the disabled population but only 10.79% of the total number of schools and 0.28% of disabled children are enrolled. Expenditure per child also differs widely, ranging from 11,000R per child in Gauteng to over 28,000R per child in the Western Cape\(^2\).

\(^2\) Education Management Information System, Department of Education
The impact of historical inequalities
The consequences of this failure to invest in an equitable education system compounds a vicious circle of deprivation and social exclusion. Disabled children, denied the right to education, are then trapped into continuing life-long poverty. It is estimated that 99% of disabled people are unemployed\(^\text{14}\). A key contributory factor rests in their low level of skills – an inevitable outcome of education exclusion.

Other barriers to education exist beyond the segregated nature and inadequacy of provision:
- In many areas, particularly in rural areas, there is no transport available to enable disabled children to reach schools. Even where it is available, it is inaccessible to many disabled children. Indeed, the Law Commission Review of the Child Care Act 1983 expressly recommends that the Department of Transport must budget for transportation of disabled children to school if the right to education is to be realised.
- Poverty and malnutrition inhibit the capacity to learn
- Deep seated prejudice and hostility to disabled children not only diminishes their self-esteem and confidence in learning but also leads to many parents underestimating their capacity to learn and benefit from education.
- Parents are not widely encouraged to be involved in their children’s learning, are marginalized and unsupported, thus inhibiting their capacity to serve as a resource to their children.
- Lack of appropriate teaching aids, poorly trained teachers and a rigid curriculum can lead to many disabled children being branded as incompetent or ineducable, irrespective of their real potential, and frequently leads to learning breakdown
- Many schools are physically inaccessible
- Whilst primary education is free, access to secondary education is dependent on the payment of fees, thus excluding most disabled children, who are almost all living in poverty.

In these circumstances, access to even the most inadequate schooling becomes a privilege not a right. Head teachers can and do refuse admission to children without having to give reasons and without any right of appeal. Parents often have to plead for years before getting a place, by which time the child is well past the age when they ought to be receiving primary education.

Children’s perspectives on education
Children, themselves, bear witness to the sustained and widespread prejudice and humiliations they face when they are at school. At a consultation day with young people held in Cape Town in October 2001, the participants highlighted the contempt in which many teachers held them. When one participant cited the remark often used by teachers ‘We will never make a nation out of people like you’, the others all affirmed that comments in the same spirit were regularly made to them. They also testified to the sense of social isolation associated with being at a special school, often far from their home and the desire to be accepted alongside non-disabled children. The children had a number of suggestions for improving life at school:
- School principals, teachers and children need to respect each other’s rights.

\(^{14}\) Integrated National Disability Strategy, 1997
Teachers need to have their awareness raised and have discussions around feelings and discrimination.

School settings should have non-disabled and disabled children together on one level instead of separating them within the school system.

Whilst the group acknowledge that there are some support systems in place, they feel that they are not active enough and therefore need to be strengthened

Representation of disabled students on school governing bodies is important for transformation and changing the situation at a school level.

To have an inclusion workshop that places the children, teachers and parents together to challenge existing thinking.

**Government strategies for change**

The Government is seeking to address these problems and is committed to respecting the rights of disabled children to education in an inclusive environment. The Schools Act 1996 introduces an equal right for all learners to access education without discrimination, bringing together the education of all children under one statute for the first time. It recognises sign language as an official language for the purposes of learning at a public school and makes the provision of support services mandatory. However, it has been subject to some criticism. The commitment it embodies to inclusive education stipulates that provision for students with special education needs must be made at ordinary schools ‘where reasonably practical’. Some commentators have argued that this wording places too much emphasis on safeguarding the system rather than protecting the rights of disabled children. Alternative forms of wording to strengthen the onus on providing inclusive schooling might be to substitute ‘unless this would constitute an unjustifiable hardship’ or ‘unless it cannot be made practicable’.

The legislation has been followed by the development of a policy both for moving towards transferring funding to schools on an equitable basis over a 15 year period and also creating an inclusive education environment. The policy distinguishes between mainstreaming or integration on the one hand and inclusion on the other. This distinction is worth documenting in full as it provides a useful analysis of the strengths of an inclusive model.

<table>
<thead>
<tr>
<th>Mainstreaming or integration</th>
<th>Inclusion</th>
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<tbody>
<tr>
<td>Getting learners to fit into a particular kind of system or integrating them into this existing system</td>
<td>Recognising and respecting the differences among all learners and building on the similarities</td>
</tr>
<tr>
<td>Giving some learners extra support so that they can fit in to the normal classroom routine. Learners are assessed by specialists who diagnose and prescribe technical interventions such as the placement of learners in programmes</td>
<td>Supporting all learners, educators and the system as a whole so that the full range of learning needs can be met. The focus is on teaching and learning actors, with the emphasis on the development of good teaching strategies that will be of benefit to all learners</td>
</tr>
</tbody>
</table>

15 Quality of Education for All: Overcoming barriers to learning and development, Report of the National Commission on Special Needs in Education and Training and the National Committee on Education Support Services, Department of Education, 1997

Focus on the changes that need to take place in learners so that they can fit in. Here the focus is on the learner

| Overcoming barriers in the system that prevent it from meeting the full range of learning needs. The focus is on the adaptation of and support systems available in the classroom |

In pursuit of its commitment to inclusion, six strategies are identified:

- Qualitative improvement of special schools and their conversion into resource centres integrated into district based support teams. There will be a continuing role for special schools for those children requiring intense levels of support. However, their role will be extended to serve as a resource to mainstream schools in providing training and professional support and they will be upgraded to help them fulfil this role.
- Mobilisation of the estimated 280,000 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
- Orientating 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

Summary
South Africa has had to face a unique set of barriers impeding the exercise of the right to education for all children. In the face of these barriers, it has introduced both legislation and a detailed and time-tabled strategy for achieving change. This is not only a principled approach but it makes clear social and economic sense: maintaining a significant minority population of uneducated and, therefore, economically unproductive people, serves as a drain rather than a boost to the economy in the longer term. Furthermore, it has made significant progress in equalising education expenditure both across and within provinces. However, although the intentions are good, it is likely that the implementation of the desired changes will be slowed down through lack of resources.

It is also worth noting that, to date, little work has been done to engage with disabled children directly in the development of proposals for change. Neither at national or provincial level, nor within individual schools is there any real dialogue with children, or even a recognition that a dialogue is necessary. The creation of more democratic structures within the education system would be of benefit in a number of ways:

- It would enable politicians, policy makers and professionals to learn from children themselves about the difficulties they face and improve the potential for effective outcomes
- It would enhance children’s self-esteem, confidence and create opportunities for learning skills of negotiation and communication

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17 Child Poverty and the Budget: Are children being put first?, S Cassiem, H Perry, M Sadan and J Streak, IDASA, 2001
It would enhance children’s understanding of democratic process of decision-making.

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

The extent of poverty

One legacy of apartheid is its creation of a society in which access to resources and services are deeply inequitable. Despite enormous wealth concentrated in the hands of the few, poverty is widespread, acute and entrenched. It has many different dimensions:

- Insufficient income and income-earning possibilities
- Lack of education, basic health and nutrition, ability to enjoy leisure and develop one’s talents
- Feelings of physical and economic insecurity and vulnerability
- Lack of ability to participate in family and community life and to influence one’s destiny

These dimensions are reflected in Article 27 of the Convention on the Rights of the Child which stresses the right to an adequate standard of living for ‘physical, mental, spiritual, moral and social development’. And in all these dimensions, disabled children are disproportionately at risk. Seven in every ten children live in poverty in South Africa. However, 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. It is also estimated that 98% of mothers with disabled children in rural areas are unemployed, functionally illiterate single women.

The causes are not difficult to find:

- Single parenthood The overwhelming majority of disabled children are being brought up in single parent households. As observed earlier, men tend to desert women who give birth to a disabled child, thus depriving the family of a key breadwinner
- Lack of work. Mothers on their own, with a disabled child, and too often with only limited education, find it difficult to get work. The lack of child care facilities means that, even where there is employment, mothers are left with a choice of leaving their children to go to work, or staying with them and remaining in acute poverty.
- Inadequate health care. Whilst there is free primary health available, it does not cover the tertiary needs of many disabled children for whom payment for treatment is out of the question. Where services do exist, they are centralised and children have to move away from home to access them. This is a particular problem for deaf children who learn a different dialect, and then cannot communicate with their families. Too often children are provided with care in hospital, but when they go home there are no local facilities available.

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18 as above
19 Using a definition of poverty as a child having less than 319R (32US$) per month, used by D Haarman, The Living Conditions of South Africa’s Children, University of Cape Town,1999
20 Children with disabilities at risk due to age and disability, L Pretorius, in Making the Link, A report from the International Seminar on Macroeconomics and Children’s Rights, Save the Children, Midrand, 1998
21 Poverty submission to the Speak Out On Poverty hearings, Disabled People South Africa, 1998
Depressingly, because so many disabled children die early, local health services are poorly equipped to address the needs of those that do survive.

- **Lack of maintenance** Despite the overwhelming number of mothers bringing up disabled children alone, and their crippling poverty, virtually none apply for maintenance from the fathers. An investigation into maintenance undertaken by the Joint Monitoring Committee on the Improvement of Quality of Life and Status of Children, Youth and Disabled Persons in 2001 found that, although there was comprehensive legislation to pursue absent fathers, its implementation was extremely weak. In particular, mothers of disabled children were not using it because of lack of information, lack of transport, inefficient administration by the courts and fear of losing their Care Dependency Grant.

- **Lack of education** opportunities available to disabled children leads to unemployment and then condemns them to an adulthood as well as a childhood spent in poverty.

**Government strategies for tackling poverty**

The Government is committed to tackling child poverty. When it ratified the Convention on the Rights of the Child, it made a commitment to ‘A First Call for Children’ and has adopted two key strategies for poverty alleviation.

- In the National Plan of Action for Children, putting children first in budget allocation is identified as the primary mechanism to ensure that children’s rights are realised.

- **GEAR** – Growth, Employment and Redistribution is an economic policy framework which aims to reduce child poverty by creating employment opportunities for parents and for children leaving school, to create informal markets and thereby increase government revenue available for spending on social services for children.

However, what is clear, in the absence of any detailed research into their situation, is that despite the National Plan of Action, GEAR and the INDS, there are still major gaps in the provision of comprehensive strategies to address poverty alleviation of disabled children. NGOs have argued for a range of approaches necessary to tackle poverty including:

- Free health services until the child is 18 years of age, including both primary and secondary services
- Assistive devices
- Nutritional schemes for day centres
- Government subsidy for day care centres
- Vouchers – transport, food, nappies and medicine
- Education subsidies
- Counselling

The Law Commission Review of the Child Care Act 1983, too, recommended the need for genuinely free access to primary and basic health care and education.

There is, currently, social security provision available for disabled children. A care dependency grant of 570R per month (around 57US$) can be awarded to parents.

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providing permanent home care to a child with a severe mental or physical disability. Given the high levels of poverty, it represents a substantial income to poor families and is a powerful poverty-alleviating mechanism, but is, nevertheless, characterised by significant problems.

Eligibility
- **Means testing**
The grant is means tested which means that its focus is purely poverty alleviation. It is not designed to meet the additional costs associated with illness or disability. Whilst means testing is a method of targeting the most needy, it is often applied incorrectly, is administratively demanding and costly and is experienced as demeaning for the recipient.

- **Nature of impairment**
The grant is only available for children needing permanent home care and who are permanently severely disabled. There is no clear definition of severity which means that it is wide open to different interpretations and inconsistencies in its award. There is also a lack of clarity of definition between non-disabling or intermittent chronic illnesses and those that lead to disablement. Furthermore, it is defined exclusively in ‘medical’ rather than ‘social’ terms. Eligibility is determined by the nature of the impairment rather than the need resultant from the particular functionality. No provision exists for children with chronic illnesses, including HIV/AIDS, many of whom have significant additional needs and consequent costs for the family.

Service delivery
- **Take up**
There is a lack of awareness of the availability of the grant and the mechanisms for applying. The take up rate is increasing – from 17,721 beneficiaries in 1999 to 30,737 in 2001. However, the take up rates amongst eligible children still remain low and vary widely between provinces. For example, whereas in Kwazulu-Natal and the Western Cape, take up is around 20%, in some provinces it is less than 10%23. Overall it is estimated that 14% of severely disabled children are receiving the grant.

- **Assessment**
The assessment is undertaken by a medical officer and is highly subjective and open to personal interpretation. It is done purely on medical grounds without taking into account factors such as the costs of treatment, level of care needed, costs of assistive devices or transport costs. Some children are refused because they have a place in school, and are thereby deemed not to need permanent care, whilst others in the same situation are awarded the grant. In other words, mothers are forced to ‘choose’ between a grant, which may be their only source of income, and education for their child. This lack of consistency increases the stress associated with applying, creates injustices and almost certainly will act a deterrent to take-up.

- **Administration**
The system is fraught with delays and inefficiencies. Applications invariably take 4-5 months to process. Indeed, SAFCD report some families waiting for up to four years...
for the grant to be processed. Attitudes of welfare officials are often disrespectful and inconsiderate, and there is a lack of awareness of the processing requirements and eligibility grounds on the part of too many officials.

**Budget**
The funding for the Care Dependency Grant derives from an allocation to provincial governments from the national government. However, the funding is not ring-fenced and there was widespread concern voiced by DPOs that insufficient money was made available at provincial level to meet the needs of all eligible children. Indeed, the view was expressed that the administrative hurdles placed in the way of obtaining the grant were, in effect, a strategy for reducing applications. Certainly, there is no incentive to promote take-up campaigns when the money needed to meet the consequent demand is not available.

In summary, the grant is targeted at a very small proportion of those in need, is difficult to access, inefficiently and unfairly administered and inconsistently awarded. The Government is currently reviewing the provision of social security benefits and has set up a Committee of Inquiry into a Comprehensive Social Security System. It is due to report in January 2002. However, it has been criticised for failing to include any specific disabled child representatives. In addition, the Law Commission Review of the Child Care Act 1983 has made recommendations designed to tackle poverty and strengthen the social security benefits for children. For example, it recommends that the existing Child Support Grant, currently a means-tested benefit for the poorest children, should be transformed into a universal non-means-tested grant for all children, which is annually adjusted in line with inflation, and that the Care Dependency Grant should be paid on top. Whilst it takes the view that the Care Dependency Grant should continue to be means-tested, it makes a number of suggestions for improving access and take-up, including:

- amending the definition of a ‘care-dependent child’ to remove the reference to permanent (24-hour) care;
- clarification of the criteria for eligibility in line with the needs of the child and the costs associated with his or her care,
- simplification of the procedures for accessing the grant

**NGO actions to address poverty amongst disabled children**
There is considerable NGO activity seeking both to press the government to fulfil the commitments it has already made to tackle child poverty and to extend the scope of existing commitments to include disabled children more directly. In addition, there are many initiatives to empower parents, particularly mothers, to provide mutual self-help and support to overcome the impact of poverty. Many of these initiatives are directed at strategies which contribute towards development rather than dependency.

**For example:**

- **Research**
The Children’s Budget

IDASA, a research-focused NGO, has undertaken an analysis of government policies and expenditure across the fields of government budgets, health and nutrition, justice, welfare and education to assess the extent to which children are being put first in tackling poverty alleviation. This analysis, the Children’s Budget, was published in
2000. Disappointingly, it has not disaggregated its data to evaluate the situation of disabled children. They are invisible as a distinct group within the report, despite their very significant vulnerability to poverty. However, it is now recognised that the failure to analyse the situation of disabled children represented an important omission and IDASA are currently undertaking a study on disabled children and poverty in the provinces of the Western and Eastern Cape.

- **Advocacy**

**ACESS**

In response to the Government review on social security, a civil society movement, the Alliance for Children’s Entitlement to Social Security (ACESS) has been established\(^\text{24}\). It is calling for a number of measures designed to remedy the structural weaknesses in the provision of the Care Dependency Grant, including:

- a system that addresses the holistic needs of children
- an extension of the Care Dependency Grant to children with moderate disabilities, and chronic health conditions
- removal of the criteria of ‘permanent home care’
- provision of free health care to disabled children
- provision of food and transport vouchers, and subsidised education and training

It also wants the assessment to be undertaken by a panel which includes representatives of DPOs. On the issue of whether the grant should continue to be means-tested, the NGOs are unresolved.

- **Empowerment**

**DICAG**

DICAG 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 from not only from poverty but also 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 therapy. It was targeted at 400 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 needing 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 mothers, for whom correspondingly, the process was significantly empowering.

**Summary**

Poverty, in its broadest definition, continues to blight the lives of the vast majority of disabled children in South Africa. Inadequate levels of income, lack of access to health care or education, inability to afford transport, and social exclusion are defining characteristics of their day-to-day lives. The Government is taking action to overcome many of these difficulties and to overcome the structural disadvantage faced by so many children. However, the Children’s Budget analysis of government expenditure indicates that whereas there has been a large increase in defence spending over the

\(^{24}\) The Right of Children with Disabilities to Social Security- The Implementation of the INDs in South Africa, T Guthrie, Children’s Institute, University of Cape Town, 2001
medium term, allocations for welfare and community development are set to decline in real terms\textsuperscript{25}. The difficulties facing disabled children are compounded by the huge provincial inequalities in welfare spending and take up of the Care Dependency Grant, the limited scope of the grant and the lack of any strategy for children affected by HIV/AIDS.

4 Right to social inclusion

Prevailing attitudes
The ultimate goal of a strategy for disabled children must be inclusion and acceptance. It is a goal embedded in the Convention on the Rights of the Child, articulated through the right to non-discrimination, to participate in all matters affecting the child, to a name and to have a birth registered, to the fullest possible social integration, to equality of access to education, to participate in cultural life. Not surprisingly, however, in South Africa, as in most countries of the world, the experience for most disabled children continues to be one of social, economic, physical, cultural and institutional exclusion, despite the Government’s commitment to change. In reality, the process of challenging the deeply entrenched negative attitudes and injustices will take many years.

To give birth to a disabled child is still a matter of disgrace, a curse, a punishment, a failure to which blame is attached. Once born, many children are hidden away in back rooms, effectively invisible. Concern has been expressed by some NGOs, for example, that the prevalence data on disability under-estimates the numbers, because families deny the existence of a disabled child. They are denied stimulation and attention, and what money is available to the family tends to be invested in non-disabled children. There is also anecdotal evidence that some babies are killed. Other family members are often ostracised by their communities.

As neighbours realised that my child was different and that a disability was becoming visible, they prevented their children from visiting my home, as they were scared that their children would bring bad luck home\textsuperscript{26}.

This early rejection, which impacts profoundly on the child’s self esteem, is then affirmed by the wider society which denies equal access to education, to work, to friendships. Children grow up believing themselves to be worthless, an economic burden, ‘lesser’ than other children. These harmful and discriminatory attitudes are major barriers to children’s survival and development\textsuperscript{27}.

Barriers to inclusion
The INDS recognises disabled children as a group particularly vulnerable to exclusion. Some of the barriers are the result of indirect, unintended factors such as poverty, inaccessible buildings and transport, lack of opportunities for play or

\textsuperscript{25} Child Poverty and the Budget: Are children being put first?, IDASA, 2001
visibility within the media. Others arise as a consequence of explicit policy such as special schooling and segregated residential care. Children participating in a workshop in Cape Town identified being included in all aspects of life - access to employment, physical access and the opportunity to fulfil your ambitions - as the rights most important to them. And they provided eloquent testimony to the scale of the barriers they face in their daily lives which inhibit such inclusion28:

- **Inaccessibility of buildings** – despite legislation since 1986 requiring all new building be accessible, it is widely felt that these laws are flouted and there are no enforcement mechanisms to challenge violations. The children described the humiliation and indignity of being carried where no ramps exist. For many, the alternative of remaining outside or not going out at all were preferable options. The consequence is that access to public facilities is often denied to them, and they cannot meet with friends to share in everyday activities.

  ‘The inaccessibility of so many places means that our rights to meet with friends and families in everyday activities are practically non-existent’. Young disabled person, Cape Town

  ‘Going to a building with no lift and having to be carried is undignified and the most embarrassing thing ever’. (Young disabled person, Cape Town)

- **Transport** – very little public transport exists which can be used by disabled children. A Dial-a-Ride exists in Cape Town, but it is very limited in availability, it has to be booked a week in advance and is mostly used by elderly people. And the service excludes them from their peers. They want to travel with their friends. One participant observed that it requires disabled children to organise their lives like a rota, whereas non-disabled children could organise their social lives impulsively. There are two pilot buses which are accessible and the Government does intend to transform the services but, to date, their general feeling was that policies existed on paper and not in practice. However, in most of South Africa, even this limited provision is lacking. Many children have to rely on taxis and commented on the intolerant attitude of many taxi drivers. Not only do the children have to pay double – once for themselves and once for their wheelchair - but some drivers refuse to take them and make it clear that disabled people are seen as a nuisance.

  ‘Taxi drivers are often, impatient, intolerant and rude, and treat us as a burden’. (Young disabled person, Cape Town)

- **Inaccessibility of roads** – Township roads are narrow and have no pavement. In order to prevent speeding, speed bumps have been placed in the roads but these create a barrier for wheel chairs. No consultation took place with disabled people before introducing these changes. The participants felt that this was a violation of their rights as they have now been excluded as road-users. Parking bays for disabled people have been created, but they are frequently used by non-disabled people.

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28 Youth Workshop report, organised by DICAG, Cape Town, 6 October, 2001
- **Special schools** – one of the consequences of being required to attend special schools is that disabled children are only really able to socialise with other disabled children. Their segregation causes non-disabled children to look down on them and discriminate against them.

- **Impunity for violations** – the children stressed the fact that, although there were laws in place to protect their rights to non-discrimination, there were no mechanisms through which those rights could be enforced. None of them considered that using the courts was an option. The lack of funding for legal aid, the difficulties of getting the evidence, the difficulties of being believed, all serve as a barrier to obtaining justice.

Interestingly, when discussing action that needed to be taken to overcome these barriers, they located themselves as central to the process of change:
- The need to become a self-advocate in order to change people’s mindset
- The need to be assertive in order to be able to achieve
- The need to keep themselves informed about their rights in order to challenge violations
- The need to recognise their own strengths, talents and their capacity to utilise those talents

**Empowering mothers to promote inclusion**
The marginalisation, disempowerment and poverty facing mothers of disabled children significantly weakens their capacity to advocate effectively for their child’s right to inclusion. Yet mothers are the key to change, because ultimately, it is their commitment, love and dedication which will influence whether or not a disabled child survives and develops, and their right to social inclusion is respected. The Law Commission Review of the Child Care Act 1983 recognises the importance of empowering parents to care for their children at home and suggests that this requires improved health care services, accessible schools, free or affordable assistive devices and support programmes for parents. It also stressed the need for a more integrated approach to the delivery of services in order that parents can find their way through the system more effectively and receive more coherent and effective provision.

The Disabled Children’s Action Group (DICAG) has focused its energies on working with mothers to build their confidence in accessing services, dealing with professionals, understanding the nature of disability, recognising that it is a social issue requiring action on the part of the whole community and that disabled children have equal rights with non-disabled children. It argues that there are five elements needed for parent empowerment:
- 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, for example by involving parents as contributors in professional training, participation in conferences and in local, provincial and national policy making committees
• Supporting the development of economic independence of mothers through early childhood development facilities, basic adult education and training and skills development in self-employment

A major illustration of its work to promote empowerment has been in the support of mothers of disabled children in establishing day care centres. It has established over 300 day care centres reaching 12-15,000 children who would otherwise have been left unsupported at home. These centres provide both mutual support for mothers and social environments for children. They create opportunities to acquire confidence in their own skills, share experiences and advocate for better services. Indeed, so successful have they been that they are now attracting non-disabled children who also lack services. Thus the potential for promoting inclusion is strengthened.

**Listening to children themselves**

South Africa remains a culture in which children are not encouraged to speak in front of adults. There is considerable resistance to any recognition that children have a unique expertise and perspective drawn from direct experience. This exclusion of children is reflected throughout society. The Government has made few, if any, efforts to include disabled children in any of its consultation mechanisms. The NGO sector in the disability field remains predominantly an adult one. Even where they are working in the field of children’s policy, there is little attempt to communicate directly with children. Certainly schools have created no opportunities for children to be heard in the development of policy, content of the curriculum, teaching methods or school rules.

The silence of children is exemplified in the following experience of a disabled woman:

*She had polio as a child, leaving her with one leg much shorter than the other. In consequence, she had always experienced difficulties carrying her school bag and coat around at school. The struggles she faced, combined with criticisms by teachers when she was late, caused her to drop out of school. She observed that children with similar disabilities would undoubtedly still be facing the same difficulties. When asked whether she had ever raised it with the school to consider what could be done to address the problem, she expressed astonishment. No child could tackle such a problem - there were no avenues for doing so and no possibility of being taken seriously.*

The children taking part in the Cape Town consultation expressed similar views. When asked what action they would take if they were abused or discriminated against at school, the answer was none. They universally felt that in a dispute between a teacher and a child, the teacher would always be believed. Furthermore, lodging a complaint would only lead to further persecution and punishment.

There are limited individual examples of children’s participation. For example, an initiative by Save the Child involved children in a democratic process of hearings in which they linked with local politicians. An arts and culture project, Project Phakama, works with disadvantaged children through theatre in raising awareness of their rights. Molo Songololo works to empower children in situations of commercial exploitation. However, they are fragmented initiatives, none of which work directly with disabled children.
DICAG have begun to try and challenge the traditional assumptions of incompetence and render children themselves more visible. At their 2001 annual conference, they invited young people to participate for the first time. One of the most potent messages they contributed was that it was not sufficient to rely on adults to speak on their behalf, however well intended. Children had their own perspectives which needed to be heard. DICAG is also developing a pilot project in three provinces to empower disabled children to speak for themselves. Other NGOs are also slowly beginning to recognise the importance of listening to children. Down’s Syndrome SA is running workshops with both parents and children providing education on human rights and accessing services. Cheshire Homes are also seeking to shift their traditional focus on residential provision toward community-based rehabilitation, with a particular focus on children’s self-representation. SAFCD has recently undertaken to coordinate and facilitate a research project on children with a Swedish Higher Education Institute and Swedish DPO in collaboration with South African Higher Education Institute and South African DPOs, in order to ascertain their experiences of respect for their rights. The National Children’s Forum held a seminar for children with HIV/AIDS and other chronic illnesses, and hope to develop it as an on-going process. However, progress remains slow. It is not yet an issue being taken sufficiently seriously by any sector of society.
Section Four - Lessons learned

The strengths of existing frameworks
On paper, the framework for the realisation of the rights of disabled children is well developed:
• Legal rights to equality and non-discrimination are in place
• A strategy for their implementation has been created
• Bodies directly responsible for their implementation exist in the powerful location of the President’s Office
• All government departments are charged with the responsibility of ensuring the realisation of the rights of disabled children
• A provincial framework for implementation has been established
• An independent parliamentary committee has powers to monitor implementation, report on progress and make recommendations
• A Human Rights Commission has been established
• NGOs are consulted and involved in the development of policy

It is an excellent framework which recognises the importance of moving beyond legislation, if real change is to take place in removing the barriers impeding the realisation of rights. Its strengths lie in:

- A preparedness not only to make commitments but also to introduce the mechanisms for being held to account on those commitments – the policies acknowledge that whilst legislation affirming rights is important, it is insufficient on its own to achieve the necessary changes.

- A recognition that, in order to bring an end to the violations of rights against disabled people, changes are needed throughout society – in attitudes, in removing physical barriers, in promoting an inclusive environment. An understanding of the extent to which societies disable people with impairments is embedded in the policies.

For example, in the Mpumalanga Province
• The Department of Health set up a project to acquire assistive devices. It arranged a meeting with politicians and 350 disabled people who all arrived in wheelbarrows or being carried. The impact was such that 1 million Rand was made available to provide 1,161 wheelchairs, 150 for children.

• The Department of Education developed a campaign, which involved visiting all schools to sensitise them on issues of disability. The outcome has been an increasing enrolment of disabled children in mainstream schools

- A commitment to involving all government departments in contributing to the changes needed.

For example, in seeking to promote barrier-free access, the INDS recommends:
• the development of guidelines to be drawn up by the Department of Public Works
that legislation is drawn up in consultation with the Departments of Public Works, Justice, and Constitutional development and Provincial Affairs, as well as the National Environmental Accessibility Programme and the South African Bureau of Standards.

- collaboration with the professional bodies in the design and construction industries, universities and other tertiary institutions to develop appropriate curricula and handbooks on accessible and integrated design for professional training of architects engineers and town planners.

- the Office on the Status of Disabled Persons in consultation with the National Environmental Accessibility Programme to review building regulations.

- the Department of Environmental Affairs and Tourism and the South African Tourist Organisation develop norms and standards in the tourist industry.

- A recognition that the real work of implementing policy needs to take place at the local level and therefore national structures need to be reflected throughout the provincial and district system.

- An understanding of the importance of utilising the strengths and experiences of NGOs and DPOs in the development of policy and practice – that they need to be involved as partners.

- A willingness to consult widely with civil society in order to seek consensus for change.

It therefore establishes a model that could usefully be emulated by other governments. However, to date, there are limitations and difficulties with the implementation of the process.

**Weaknesses in implementation**

**(i) Challenging violations**

‘Even if our rights are violated, there is nothing we can do about it, nowhere to go.’ (young disabled person, Cape Town)

Whilst legal rights have been established, there are few mechanisms available for children to use the law to challenge violations of those rights. It was very clear from the consultative exercise carried out by the Human Rights Commission in 1999-2000 that few children were aware of their rights and even fewer felt sufficiently empowered to access help if those rights were abused. No legal aid is available and given that almost all disabled children are poor, this lack serves as a major barrier to access to the courts. The Human Rights Commission can take up cases but is clearly limited in its scope for action. Without access to information or advocacy, rights have little meaning in the day-to-day lives of children.

**(ii) Self representation**

The Integrated National Disability Strategy emphasises the importance of self-representation of disabled people. However, it is silent on the issue of how this principle could be extended to children. Traditionally, the voices of children, their experiences, views and concerns have been rendered invisible by the adult world. The
invisibility of disabled children is even more profound. It is not sufficient to assume that their rights can be adequately represented by those adults speaking on their behalf. To date, debate on the importance of giving expression to the voices of children, and empowering them to participate in the development of strategies for change, is relatively poorly developed. Neither the government nor the majority of NGOs have begun to explore these issues sufficiently. And none of the recommendations included in the Strategy involve creating opportunities for consulting with disabled children themselves.

(iii) Scope of the Integrated National Disability Strategy (INDS)
The INDS does address the situation of children. It specifically identifies disabled children, particularly black disabled children as a group experiencing high levels of exclusion. However, there is little emphasis on children in the strategy itself. Indeed, the guiding documents for implementing the Strategy are the Standard rules, the World Programme of Action Concerning Disabled Persons and the Disability Rights Charters. The Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child are conspicuous by their absence.

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. The invisibility of children in public policy making is common, but until they are included as participants with an important perspective to contribute, policy will continue to be adult-focused and excluding. 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.

As currently drafted, the Strategy does not tackle, for example, the physical and sexual violence that is a major area of concern to disabled children. It does not deal with support for parents of disabled children. The only recommendation which proposes consultation with DICAG relates to early childhood development, yet there are important children’s perspectives which need to be addressed in many of the recommendations, for example on education, transport, assistive devices, barrier-free environments. In its strategy for improving residential services, it focuses on the needs of adult disabled people. Accordingly, it does not address the issue of segregating residential care for disabled and non-disabled children. This issue, however, has been picked up by the Law Commission Review of the Child Care Act 1983 which recommends the need to introduce special subsidies to residential care facilities to help them become accessible and to provide training for staff in to enable to run inclusive services.

(iv) Barriers at national level

'Sometimes it seems that the government is doing things for us as a favour rather than because it is our right'. (young disabled person, Cape Town)

The paper commitments embodied in the INDS are not yet being fully taken on board by government departments. The Inter-Departmental Co-ordinating Committee undertook a review in 2001 on departmental progress on its implementation. It found that there was considerable hostility to the strategy, and indeed to disabled people, in
some quarters. It would seem that government policy and thinking in this field is still considerably ahead of the staff charged with responsibility for its implementation. It also found that in undertaking the required disability audit, the focus had been almost exclusively on employment of disabled people within government departments rather than on policy developments.

(v) **Provincial capacity for implementation**

There is widespread concern that the capacity for implementation of the INDS at provincial level is very limited. Many of the officials responsible for the Strategy lack any training or experience in the field of disability. Many have little or no understanding of the concept or implications of the social model of disability. Few have a history of experience in establishing consultative mechanisms for developing local policy.

These problems are exemplified in the report of a field visit by the Joint Monitoring Committee on the Improvement of Quality of Life and Status of Children, Youth and Disabled Persons to the Eastern Cape in 2001. The findings of the Committee indicate:

- lack of staff to co-ordinate and monitor polices
- lack of a provincial strategy for implementing the INDS
- failure to establish a disability unit
- no audit undertaken within government departments
- no effective interaction with the provincial Premier
- the Department of Welfare leading on all projects and programmes not the Provincial Plan of Action (PPA) thus marginalizing them and limiting the potential for change
- exclusion of civil society from the PPA
- the ineffectiveness of the PPA in consequence of its isolation

Feedback from many NGOs indicate that these problems are not restricted to the Eastern Cape. Indeed, they are typical of the pattern across the country, with the possible exception of the Western Cape and Gauteng, traditionally much better resourced provinces. For example, in one province, efforts were made to develop an early childhood programme, but it proved impossible to get funding because there were no inter-sectoral budgets. There is a lack of mandate between departments with parents being sent from one to the other, often giving up in despair.

(vi) **Lack of resources available**

Repeated concerns were raised about the lack of funding at provincial level available to implement both the INDS and the National Plan of Action for Children. The budgetary allocations from national government are insufficient to allow the recruitment of adequate numbers of staff and to develop effective programmes. Furthermore, the funding allocation for neither the INDS nor NPA are ring-fenced and can, and do get allocated to different areas of provincial spending. Similar problems arise in respect of the provincial expenditure on the care dependency grant, funding for which is also not ring-fenced, and accordingly does get siphoned into different budgets. The Children’s Budget indicates that whilst the Government’s

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29 Eastern Cape Visit Report 2-4 May 2001, Joint Monitoring Committee on the Improvement of Quality of Life and Status of Children, Youth and Disabled Persons
declared commitment to prioritise spending on children has been fulfilled to some extent, there are still insensitivities to poor children within the equitable share formula used to divide revenue amongst provinces. Other negative trends affecting disabled children include the decline in spending on the Integrated Nutrition Programme, stagnation or decline in health spending and reductions in Early Childhood Development budgets.

This chronic failure at national level to provide sufficient funding, compounded by a failure to prioritise spending on disabled children at provincial level are seriously hindering any effective potential for implementation of these two important strategies. These problems of budgets and administration are compounded by the lack of adequate prevalence data on disabled children. Without this data, it is not possible to develop or cost programmes effectively

(vii) Consultation with NGOS

Although there is representation of NGOs in many of the consultative mechanisms established by the Government, there remains a view that NGOs are often consulted but not heard. Policies are often developed without adequate initial input from Disabled People’s Organisations (DPOs) with the result that mistakes are made, and belated consultation with DPOs is undertaken to achieve damage limitation. Projects and programmes, too, are designed without reference to disabled people, frequently resulting in ineffective outcomes and wastage of money. The following initiatives identified in the Eastern Cape exemplify the problem.

- A toilet was renovated at the Department of Welfare to render it accessible. Instead of putting in a sliding door, all that was done was to change the door to open outwards instead of inwards. The result is to make it more difficult to open the door by a wheelchair user.

- At a primary school, ramps have been built, but the entrance to the class remains too narrow to be accessed by a wheelchair user. Accordingly, a child can get into the school, but not his or her class.

- A day hospital had a ramp used for stretchers brought in by ambulances. Walls were built to make the ramp longer to enable wheelchair users to go up the ramp independently. However, in so doing, the ramp was rendered too narrow for stretchers. In other words, in making it accessible for one group, it has excluded access for severely ill patients. Neither doctors nor nurses on the wards were informed or consulted on the proposed changes.
Conclusion

As in every country in the world, the lives of disabled children in South Africa are characterised by discrimination. The evidence presented in this report provides powerful testimony to the fact that, whilst all children experience discrimination in the exercise of many rights, there is a double jeopardy facing disabled children, a jeopardy compounded still further for non-white disabled children. Disabled children are more likely to be poor, to be denied access to education, to experience violence, to be denied the right to life. They have less opportunity to make friends, to fulfil their aspirations, to participate in all those ordinary day-to-day activities that non-disabled children take for granted and that make life meaningful. It is hard for disabled children to have fun. It is hard for them to play. Most fundamentally, it is hard for them to be seen and recognised as people.

Many governments have begun to recognise that disabled children experience abuse of their rights. However, all too often, the concerns articulated by politicians are not accompanied by the concrete action necessary to create real change. Without it, these expressions of concern remain little more than hand-wringing - pious aspirations which achieve nothing on the ground. The South African Government is not guilty of hand-wringing. The very deep suffering that its people experienced through the years of apartheid has sharpened understanding of the need to give explicit priority to promoting, protecting and fulfilling human rights. And this is reflected in the vigour of the actions taken by the Government in the disability field. It has not only acknowledged the scale of the barriers facing disabled people in seeking to exercise their rights, but it has made explicit commitments to removing those barriers. Furthermore, it has translated those commitments into statutory entitlements, policies and strategies for implementation and mechanisms for monitoring progress. In so doing, it has gone further than most governments around the world. Its methodology in tackling discrimination against disabled people provides invaluable lessons for others to learn from and follow.

However, it takes time to convert commitments into a culture of rights, and, not surprisingly, South Africa still has a long way to go. It will take many years to redress the profound inequalities experienced by the disabled community. It will take a great deal of change before disabled children grow up believing that they are valued equally alongside their non-disabled peers. The adult world is not yet sufficiently willing to accept that children, including disabled children, have a right to be heard and that they have perspectives, views and experiences which must inform legislation, policy-making and service delivery. The framework put in place by the Government needs not only to be actively sustained, but it needs to be evaluated by children themselves, and amended and developed accordingly. The NGO community obviously has a vital and continuing role to play in this process. It needs to continue to hold the Government to account on its commitments and it, too, needs to work more openly and collaboratively with children as partners. The work done to date has offered disabled children hope for a better future. It is incumbent on all those in positions of power and influence, within and outside government, to ensure that they do not now betray the promises made to South Africa’s disabled children.
**APPENDIX 1**

**Programme of visits**

1 – 12\(^{th}\) October 2001

<table>
<thead>
<tr>
<th>DATE 1(^{st}) – 12(^{th}) October</th>
<th>ORGANISATION</th>
<th>LOCATION</th>
<th>CONTACT PERSON</th>
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<tbody>
<tr>
<td>Monday 1(^{st}) October</td>
<td>SAFCD Secretariat</td>
<td>Rosebank Cape Town</td>
<td>Washeila Sait</td>
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<td></td>
<td>Erica Special care Centre</td>
<td>Rocklands Mitchell’s Plain</td>
<td>Gwen Rosen</td>
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<tr>
<td>Tuesday 2(^{nd}) October</td>
<td>DEAFSA</td>
<td>The Bastion Claremont</td>
<td>Steven Lombaard</td>
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<td>JMC on children, youth and disabled</td>
<td>Parliament Cape Town</td>
<td>Hendrietta Bogopane</td>
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<td>Wednesday 3(^{rd}) October</td>
<td>IDASA</td>
<td>Cape Town</td>
<td>Mastoera Sadan</td>
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<td></td>
<td>Child Health Policy Institute</td>
<td>Rosebank</td>
<td>Teresa Guthrie</td>
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<tr>
<td>Thursday 4(^{th}) October</td>
<td>Disabled People South Africa</td>
<td>Cape Town</td>
<td>Gillian Burrows</td>
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<td></td>
<td>DPSA Self-help Group</td>
<td>Cape Town</td>
<td>Gillian Burrows</td>
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<tr>
<td>Friday 5(^{th}) October</td>
<td>Policy Project HIV/AIDS and Disability</td>
<td>Cape Town</td>
<td>Sylvia Abrahams and Caroline Wills</td>
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<td>Saturday 6(^{th}) October</td>
<td>DICAG Youth</td>
<td>Days Inn Cape Town</td>
<td>Sandra Ambrose</td>
</tr>
<tr>
<td>Monday 8(^{th}) October</td>
<td>SAFCD consultative meeting with: Deaf Blind SA Cheshire Homes Children’s Institute DICAG Down’s Syndrome SA Mpumalanga Province DH SAFCD</td>
<td>Holiday Inn Airport Johannesburg</td>
<td>Washeila Sait</td>
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<td>Tuesday 9(^{th}) October</td>
<td>Human Rights Commission</td>
<td>Johannesburg</td>
<td>Commissioner Jerry Nkeli</td>
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<tr>
<td>Wednesday 10(^{th}) October</td>
<td>Save the Children Sweden</td>
<td>Pretoria</td>
<td>Nomakwezi Malahleha</td>
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<tr>
<td></td>
<td>UNICEF</td>
<td>Pretoria</td>
<td>Jesper Morch</td>
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<tr>
<td>Thursday 11(^{th}) October</td>
<td>Mitchell’s Plain District Education Development Programme</td>
<td>Cape Town</td>
<td>Berenice Daniels</td>
</tr>
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</table>
APPENDIX 2

Abbreviations used in this report

**ACCESS**  Alliance for Children’s Entitlement to Social Security

**DICAG**  Disabled Children’s Action Group

**DPO**  Disabled People’s Organisation

**FAS**  Foetal Alcohol Syndrome

**GEAR**  Growth, Employment and Redistribution

**IDASA**  Institute for Democracy in South Africa

**INDS**  Integrated National Disability Strategy

**NGO**  Non-Governmental Organisation

**NPA**  National Plan of Action

**PPA**  Provincial Plan of Action

**SAFCD**  South African Federal Council on Disability

**SAPCAN**  South African Association for the Prevention of Childhood Abuse and Neglect

**UNICEF**  United Nations Children’s Fund