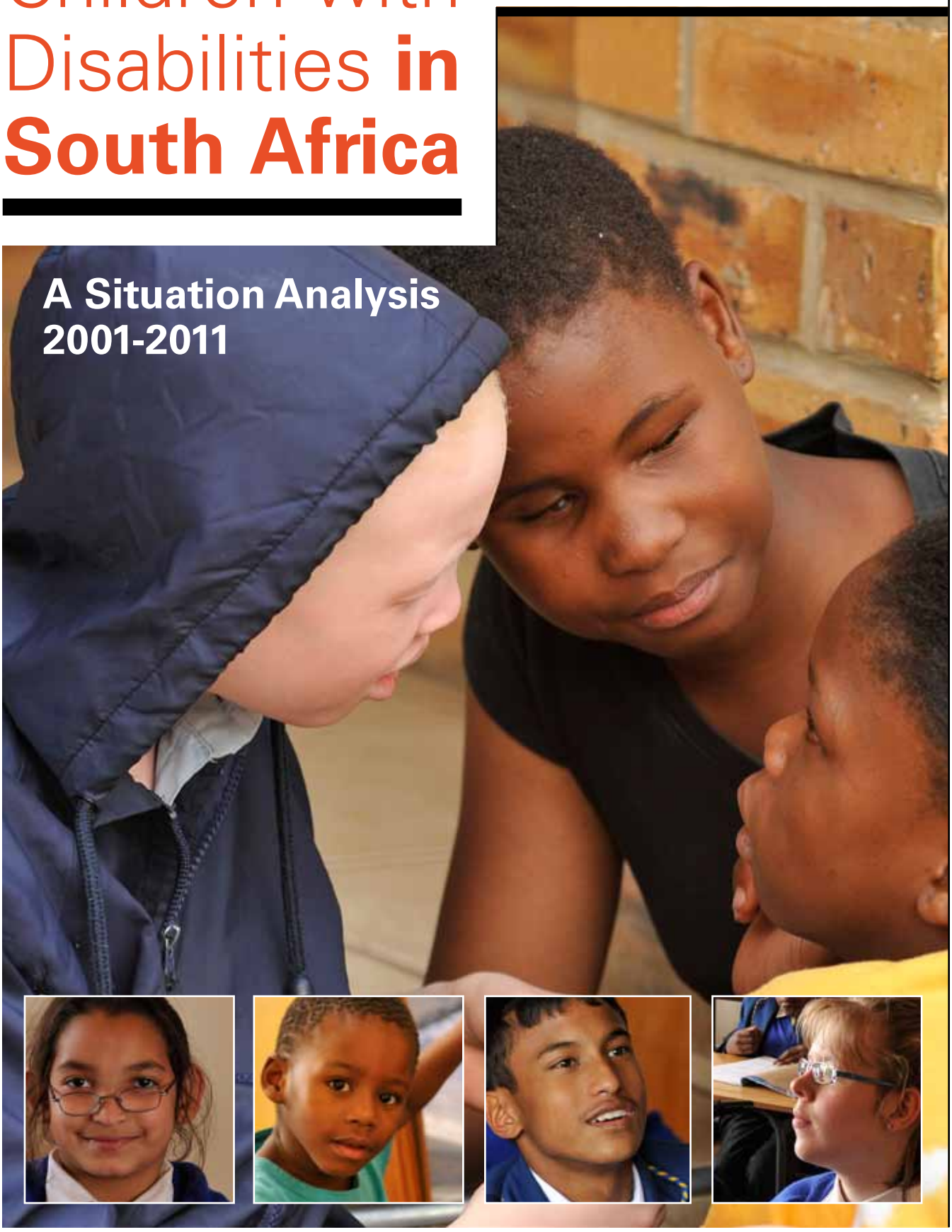
Children with Disabilities **in South Africa**

A Situation Analysis 2001-2011



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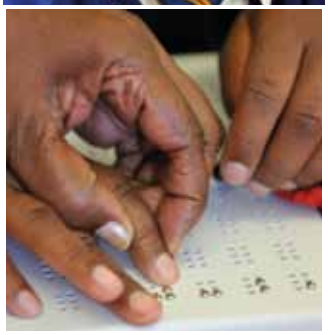
Children with Disabilities **in South Africa**

A Situation Analysis 2001-2011









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Acronyms

ACRWC	African Charter on the Rights and Welfare of the Child
CBR	Community Based Rehabilitation
CCG	Community Care Giver
CDG	Care Dependency Grant
CNS	Central Nervous System
CPI	Consumer Price Index
CRF	Community Rehabilitation Facilitator
CS	Community Service
CSIR	Council for Scientific & Industrial Research
CSTL	Care and Support in Teaching and Learning
DBE	Department of Basic Education
DHIS	District Health Information System
DICAG	Disabled Children's Action Group
DoE	Department of Education
DoH	Department of Health
DPME	Department of Performance Monitoring and Evaluation
DPO	Disabled People's Organisation
DPSA	Disabled People South Africa
DSD	Department of Social Development
DWCPD	Department of Women, Children and People with Disabilities
ECD	Early Childhood Development
FASD	Foetal Alcohol Spectrum Disorder
FSS	Full Service School
GHS	General Household Survey
HH	Households
HPCSA	Health Professionals Council of South Africa
ICF	International Classification of Functioning, Disability and Health
KZN	KwaZulu-Natal
MCWH	Maternal Child Women Health
NACCW	National Association of Child Care Workers
NGO	Non Governmental Organisation
NHI	National Health Insurance
NIDS	National Indicator Data Set
NPO	Non Profit Organisation
OSDP	Office on the Status of Disabled Persons
PHC	Primary Health Care
RtHB	Road to Health Booklet
SASL	South African Sign Language
SASSA	South African Social Security Agency
SIAS	Screening, Identification, Assessment and Support
SSRC	Special Schools as Resource Centres
UNCRC	UN Convention on the Rights of the Child
UNCRPD	UN Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

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Executive **Summary**



Learners at the Hope School, Johannesburg. The school follows the same curriculum as mainstream schools.

Purpose of study, methods and underlying framework (Chapter 1)

South Africa's ratification of the UN Convention on the Rights of the Child (UNCRC) in 1995 and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 has facilitated the implementation of programmes towards the fulfilment of the rights of children, and indeed people with disabilities in the country. However, significant knowledge gaps remain with regard to the situation of children with disabilities, their family and community environment, the underlying causes of their situations, and the adequacy of efforts by government and non-government actors to fulfil their rights.

This situation analysis seeks to fill these knowledge gaps. The study addresses the following questions:

- What is the extent of disability among children in South Africa?
- What is the extent of inequities and unfulfilled rights of children with disabilities?
- What factors have contributed to the adequacy (or inadequacy) of actions by the State and society at large?
- What are strategic opportunities for further progress towards the fulfilment of the rights of all children with disabilities?

The study is based on an analysis of both primary data and secondary data. Primary data was collected through focus group discussions, stakeholder consultations and key informant interviews. Secondary data comprised a desk review of available literature and research material on childhood disability. Sources included census and national household survey data from Stats SA, community-level studies, published material from local and international sources, academic dissertations, studies commissioned by various government departments, legislation, policies and strategies relating to services for children with disabilities, and recent strategic plans of relevant government departments.

The WHO International Classification of Functioning, Disability and Health (ICF) for Children and Youth served as the underlying framework for the study. Unlike previous analytical approaches that viewed disability through medical and welfare lenses, the ICF emphasises the use of a social model that is focused on removing the barriers that prevent people with disabilities from exercising their right to participate in society. The ICF emphasises that it is the collective responsibility of society to remove barriers to the equal participation of adults and children with disabilities. The ICF reflects a human rights approach to development – regarding people with disabilities as a group that experiences discrimination and whose rights are not respected and fulfilled.

The use of the ICF as the underlying framework for the study is underpinned by the South African Constitution, UN Convention on the Rights of the Child (UNCRC), African Charter on the Rights and Welfare of the Child (ACRWC or the African Charter) and UN Convention on the Rights of Persons with Disabilities (UNCRPD). The Bill of Rights in the South African Constitution specifies that everyone is equal before the law and has equal protection and benefit of the law. Discrimination on a number of grounds, including disability, is prohibited.

The UNCRC introduced specific rights for children with disabilities for the first time in international human rights law. Provisions prohibit discrimination on a number of grounds, including disability, while obliging State Parties to recognise and fulfil the rights of children with disabilities. The Committee on the Rights of the Child (responsible for monitoring compliance with the UNCRC) issued General Comment No. 9 in 2006 that deals with the rights of children with disabilities aiming "to provide guidance and assistance to States parties in their efforts to implement the rights of children with disabilities, in a comprehensive manner which covers all the provisions of the Convention".

The ACRWC requires that the child "should grow up in a family environment in an atmosphere of happiness, love and understanding". Specifically, the ACRWC makes provision for rights of children with mental and physical disabilities.

The UNCRPD emphasises respect, support and celebration of human diversity by creating conditions that allow meaningful participation by a wide range of people, including adults and children with disabilities. Promoting and protecting the rights of people with disabilities is not limited to the provision of disability-related services; it includes introducing measures to change attitudes and practices that stigmatise and marginalise



In the stimulation room at the Lebohang Centre.

people with disabilities. The provisions of the UNCRPD place an obligation on governments to remove the barriers that currently prevent the realisation of the rights of adults and children with disabilities.

The limitations of the study include difficulties with the use of different criteria by various surveys for determining the prevalence of disability, as well as the lack of comprehensive studies on children with disabilities. The study was completed before the 2011 Census which will provide most recent data on children with disabilities. Furthermore, the information presented in this report on services for children with disabilities, though comprehensive, is by no means exhaustive. Primary data collection also covered selected sites and provinces only (see Chapter 1 for details). Overall, the focus of the study does not include chronic illnesses, except where they are a cause of or present risks for childhood disability.

Prevalence of disability in children in South Africa (Chapter 2)

South Africa does not yet have a standard/nationally accepted measuring tool in line with the ICF. Estimates of child disability prevalence generated from various sources are therefore not directly comparable because of different definitions of disability and methods of data collection. Moreover, while the census and other national household surveys do include general questions about people with disabilities, these questions were not specifically designed to identify children with disabilities.

Measuring child disability is inherently much more difficult than measuring disability in adults. While adults have relatively stable characteristics, children go through a natural development process as they grow, learning how to talk, walk, read and write. Their evolving characteristics complicate the task of assessing function and distinguishing significant limitations from variations in normal developmental processes.

Since 2009, the Stats SA Annual General Household Survey (GHS) has used the Washington Group (WG) Short Set of Questions which asks survey respondents about difficulties experienced in seven domains of functioning, i.e. seeing, hearing, walking, remembering, concentrating, self-care and communicating. An individual is classified as disabled if they had "some difficulty" for two or more of the six categories, or had "a lot of difficulty" or were "unable to do so" for one or more categories. Following this approach, the GHS 2009 classified nearly 2.1 million children (11.2 percent of the total child population) as disabled. The prevalence of disability appears unusually high for young children: 28 percent of children in the age group 0-4 years and 10 percent in the age group 5-9 years were classified as disabled. Experience with the use of the WG Short

Set of Questions in South Africa suggests substantial challenges with measuring disability in young children because of problems inherent in differentiating real difficulties from normal developmental processes.

Nevertheless, the results from the GHS 2009 WG Short Set of Questions suggest that Census 2001 and Community Survey 2007 are likely to have underestimated the prevalence of children with disabilities in the country. Projections from Census 2001 indicate that there are some 474 000 children living with severe disabilities in South Africa today. The GHS 2009 thus points to more widespread mild to moderate disability among children than captured by Census 2001.

Disabilities related to sight and hearing are the most common, while approximately one in 10 children with disabilities was reported to have multiple disabilities. There are considerable disparities in the levels of reported child disability based on location, sex, age and other socioeconomic characteristics. The prevalence of reported disability is slightly higher among male than female children and increases steadily with age, and orphans and children living in institutions or on the streets appear to be at a higher risk of disability. Disparities in prevalence levels might reflect the general development or poverty level of an area, access to nutritious food, exposure to environmental or infectious agents, or social or other risk factors for disability.

Early detection of disabilities is crucial to ensure that children receive effective treatment and rehabilitation. Very often, however, disabilities are only detected quite late in the child's life. Research indicates that fewer than one in 10 public hospitals in the country provide some form of infant hearing screening and less than one percent provide universal screening.

There are, nonetheless, signs that efforts are being made to improve early detection of disability in children. In 2011, the Department of Health revised the *Road to Health* booklet (RtHB) to include a potential tool for the identification of children 'at risk' of disability. Screening for disability through school health programmes is also being strengthened as part of South Africa's efforts to 're-engineer' primary health care (PHC), and the Department of Basic Education is rolling out the screening, identification, assessment and support (SIAS) assessment tool which will assist educators in determining the nature of a child's disability and their educational support needs.

Inequities in access to services (Chapter 3)

The impact of inadequate living conditions is particularly negative for children with disabilities. According to Stats SA's Community Survey 2007, children with disabilities are less likely to have access to adequate housing, water and sanitation than their non-disabled peers. Children with disabilities are more likely to live in traditional dwellings and informal settlements than their non-disabled counterparts. Overcrowded living conditions and outside toilets place enormous stresses on children with disabilities and their families.

There is little national evidence available on access to early learning for pre-school children with disabilities. A 2006 study found that only a quarter of children aged 0-6 years, who were recipients of the Care Dependency Grant (CDG), attended a crèche or child-minding group.[1] Where children with disabilities do have access to early learning, it often takes place within informal community settings, with individuals (such as mothers of disabled children) running stimulation programmes.

The country's inclusive education programme has enabled expansion of facilities for children with disabilities in public ordinary (mainstream) schools. The number of full-service schools (FSSs), i.e. schools that are equipped to support a range of disabilities, has grown from 30 in 2008/09 to 513 in 2010/11. Currently, some 110 300 learners with disabilities are attending ordinary public schools. In addition, 423 special needs schools nationwide are catering for approximately 105 000 learners. Nonetheless, evidence from surveys suggests that children with disabilities are substantially less likely to attend school than their non-disabled peers. Furthermore, among those children with disabilities who do get access to schooling, drop-out rates are higher than for those who are not disabled.

1 De Koker, C., de Waal, L. & Voster, J. (2006) *A profile of social security beneficiaries in South Africa*. Datadesk. Department of Sociology and Social Anthropology: Stellenbosch University.

Parents of children with disabilities are more likely to report that their children suffer from illnesses and poor health than parents of non-disabled children. Findings from the annual GHS between 2002 and 2008 consistently indicate that children with reported disabilities are 2.5 times more likely to be ill or injured than their non-disabled counterparts.

In 2009, an informal outreach programme conducted at five schools for the deaf in the Eastern Cape, the Free State and KZN found that deaf children are ignorant about HIV and AIDS, sex education, rape, abortion, abuse and harassment. In cases where they receive life skills programmes, deaf children are not always able to understand teachers, as often information is not given in South African Sign Language (SASL) and/or no deaf people are involved as trainers.

The difficulty with access to information on HIV for children with disabilities is compounded by the fact that a high number of youth with disabilities are out of school, and therefore they do not benefit from school-based HIV and child protection-related programmes.

Research co-ordinated by the Department of Social Development in Mpumalanga, in deep rural areas in Ehlanzeni, Nkangala and Gert Sibande districts,[2] found that only 42 percent of the children with disabilities identified were receiving rehabilitation and only 33 percent had the assistive devices they required. Some 59 percent reported that the caregiver did not know how to apply for an assistive device.

According to data from Stats SA's Community Survey 2007, children with disabilities are more likely to be orphaned than their non-disabled peers. One in four children with disabilities nationwide has lost one or both parents, compared to one in five among non-disabled children.

A 2010 survey by the Department of Social Development obtained information on more than 13 000 children staying in registered child and youth care centres across the country, such as children's homes, places of safety and shelter.[3] About 28 percent of these children were reported to have at least one type of disability. Yet, many centres are not well-equipped to cater for children with disabilities, or to facilitate their integration in mainstream society.

Children with certain disabilities are prone to particular types of abuse: mentally and physically disabled children are at an increased risk of sexual abuse whilst those with learning disabilities are especially vulnerable to neglect.[4]

A study by the Disabled Children's Action Group (DICAG)[5] found significant gaps in the child justice system in dealing with cases that involved children with disabilities. Witnesses were in many instances seen as incompetent when the level of language used in court proceedings was too complex and not understandable to the victims.

Adequacy of measures to fulfil the rights of children with disabilities (Chapter 4)

In the context of limited information, the study assessed the provision of key services that aim to enhance social participation of children with disabilities. These include the CDG, assistive devices, rehabilitation services, early childhood development (ECD) services, inclusive education and access to health facilities.

Overall, the CDG is found to be a positive tool for reaching large numbers of children with disabilities and their families with income support. Access to the grant continues to grow, from 86 917 beneficiaries in March 2005 to 116 786 beneficiaries in June 2012 (SASSA, 2012). However, concerns have been raised about the limitations of the CDG, including the use of eligibility assessment tools that are primarily based on determination of the severity of the health condition or impairment, without consistent and in-depth assessment of

2 Department of Social Services, Population and Development (2002/03) *Report on the Status of Children with Disabilities in the Province of Mpumalanga*. Department of Social Services, Population and Development: Population Unit, Province of Mpumalanga.
3 Community Agency for Social Enquiry (CASE) (2010) *Baseline Study on Registered Child and Youth Care Centres.* Study conducted for UNICEF & National Department of Social Development.
4 Deroukakis, M. (2010) *A retrospective analysis of children with and without disabilities attending the Teddy Bear Clinic, Johannesburg.* A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfillment of the requirements for the Degree of Master of Science in Medicine: Paediatric Neurodevelopment. http://wiredspace.wits.ac.za/bitstream/handle/10539/8845/Marilena_Deroukakis_Final%20_Msc%28Med%29%20Child%20Health.pdf?sequence=1
5 Quoted by Hesselink-Louw et al. (2003).

activity limitations and/or participation restrictions or environmental factors that may result in high levels of disability for the child.

It is difficult to report on the coverage of assistive devices as there is no database that systematically tracks the provision of these devices to children with disabilities in the country. Stakeholder consultations, as part of this study, revealed progress yet limited provision of assistive devices in the education sector. In particular, children with mobility impairments are not receiving what they need. In addition, training for educators on the specifications and use of assistive devices is limited.

Significant gaps remain in the provision of other services. The shortage of rehabilitation personnel in the public health sector persists, and the built environment poses severe risks for children with disabilities. Several policy documents have been prepared to guide the expansion of inclusive education and efforts have been made to implement various aspects (of inclusive education). Yet, huge access-related challenges remain, denying significant numbers of children with disabilities from participating in inclusive education.

The evidence also suggests that there are access constraints for children with disabilities who, due to increased risk of abuse and neglect or the severity of their condition, need institutionalised care. Special schools face peculiar challenges. The standard of curriculum delivery in these schools is poor, with a 'one size fits all' approach being used for children with intellectual disabilities. The choice of subjects offered at special schools is also very narrow, limiting options for learners in terms of opportunities after school.[6]

Underlying causes of the current state of service provision (Chapter 5)

There are factors, in addition to the historical legacy of apartheid, that constrain the provision of services for children with disabilities in South Africa. These include attitudes of society and service providers, gaps in legislation, policies and budgets.

Attitudes

South Africa does not yet have a standard/nationally accepted measuring tool in line with the ICF. Estimates of child disability prevalence generated from various sources are therefore not directly comparable because



Tshidiso Mutsweneng receiving his epilepsy medicine from Maureen Maepa, a student auxillary nurse being trained at the clinic in Matshediso LSEN School.

6 National Stakeholder workshop, 24 May 2011.



Learners in class at the Hope School, Johannesburg.

of different definitions of disability and methods of data collection. Moreover, while the Census and other national household surveys do include general questions about people with disabilities, these questions were not specifically designed to identify children with disabilities.

Although a shift has been made at policy level from an approach based on the medical/welfare model of disability to one based on the social model (which sees disability as a human rights issue),[7] this is often not reflected in the attitudes and approaches of service providers and society at large. Adults and children with disabilities are frequently viewed by society as objects of pity and deserving (only) of charity.[8]

Children who participated in the focus group discussions that formed part of the study reported that people's negative attitude towards them was one of the most difficult things for them to deal with. Their greatest dislikes were being laughed at, being called derogatory names and being teased about their disabilities.

Policies and plans

Inadequate alignment of policies to plans of Departments continues to undermine the pace of service provision. There are numerous policies in place that are intended to fulfil government's constitutional and legal obligations towards children with disabilities. However, these have not been consistently linked to national and provincial planning processes. For example, despite the clear statement of priorities in White Paper 6 on Inclusive Education, a review of strategic plans of the Department of Basic Education at the national and provincial levels reveals inadequate provisions to support children with disabilities. Again, although the National Rehabilitation Policy is in place, the Department of Health's strategic plans reviewed as part of this study (at the national and provincial levels) make little reference to this policy or to the Policy on Standardisation of Assistive Devices.[9] The Strategy for the Integration of Services for Children with Disabilities cites the Department of Social Development as one of the lead departments in the provision of habilitation and rehabilitation services for children with disabilities,[10] but neither national nor provincial strategic plans reviewed make clear provisions for implementation.[11]

7 This is reflected in policy documents such as the Office of the Deputy President (1997) Integrated National Disability Strategy and OSDP (2008) National disability policy framework and guidelines for the implementation of the national disability policy framework.
8 Nkeli, J. & Associates (2008) *Broad overview of the impact and an analysis of the effectiveness and efficiency of disability policy implementation in all spheres of government since 1994.*
9 Provinces were the Eastern Cape, KZN and the Western Cape. Indeed, the strategic plan of the Eastern Cape Department of Health 2009/10-2014/15 does not make any reference to rehabilitation (or provision of assistive devices) as part of the core functions of the department.
10 Department Social Development (2009) *Strategy for the Integration of Services for Children with Disabilities.* Interdepartmental Task Team.
11 Strategic Plan of the Department of Social Development 2010-2015.

Furthermore, although the South African government has ratified the UNCRPD, and the former Office on the Status of Disabled Persons (now part of the Department of Women, Children and People with Disabilities) has developed implementation guidelines,[12] these are not clearly reflected in the strategic plans of particularly the Department of Basic Education and the Department of Health. Only the Department of Social Development makes reference to the UNCRPD in its national strategic plan.

There are also difficulties related to monitoring of budgets for children with disabilities. The lack of specific information on service provision and related budget allocations appears to be a major barrier to the monitoring and protection of the rights of children with disabilities.

Difficulties around funding of NGOs

NGOs working in the disability sector have expressed grave concerns regarding accessing government funding.[13] Some organisations have reported that even where a service level agreement is in place, funding does not always come through as agreed,[14] and difficulties extend beyond the extent of funding and funding procedures, to a lack of understanding regarding the nature of services required for children with disabilities.

The Department of Social Development at national and provincial level,[15] on the other hand, is concerned about NGOs' lack of administrative capacity, skills for financial management and writing of business plans. The Department has plans to strengthen the capacity of NGOs.

Planning standards/access to a disability-friendly built environment

Despite increasing awareness of the need for environmental accessibility for adults and children with disabilities, many government services are not disability friendly, and severe challenges with the built environment exist. Some of the factors contributing to this are deficiencies in the regulatory framework and constraints faced by less-resourced hospitals. A review of the legislation related to environmental accessibility identified a number of deficiencies in the current regulatory framework, including a lack of consideration of the requirements of adults and children with different impairments.[16]

Lack of co-ordination and fragmentation of services

Challenges include lack of synergies between policies, limited consultations between government and NGOs, tendency to work in silos even within departments, weak mechanisms for co-ordination, disconnect between national and provincial levels, and the lack of adequate norms and standards for services.

Opportunities for fulfilling the rights of children with disabilities (Chapter 6)

There are several important opportunities in South Africa for accelerating the fulfilment of the rights of all children with disabilities. These include ongoing health sector reform, particularly efforts to introduce a National Health Insurance System, and the re-engineering of PHC.

Ongoing health sector reforms

Re-engineering of the PHC, in particular, is intended to lead to the provision of health agents at ward level (i.e. the lowest level of municipal administration) and in schools, thus providing potentially significant opportunities for prevention and early detection of disabilities. Furthermore, the new (extended) *Road to Health* booklet contains a table on developmental milestones, which should be used by PHC nurses for early identification and referral for children with developmental delays.

12 OSDP (2008) National disability policy framework and guidelines for the implementation of the national disability policy framework.
13 National Stakeholder workshop, 24 May 2011; KZN Stakeholder workshop, 12 May 2011.
14 For example, the Pietermaritzburg Cerebral Palsy Association reported that funding from DSD had come several months after it had been promised, and did not match the amount that the organisation had requested. KZN Stakeholder workshop, 12 May 2011.
15 Department Social Development (2010) p.54
16 For example, provision of tactile surfaces and cane detection areas may help persons with visual impairments, but building regulations primarily focus on the needs of wheelchair users.

The revitalisation of the PHC and the proposed Strategy for Integration of Services for Children with Disabilities provides an opportunity to re-visit the implementation of rehabilitation and community-based rehabilitation (CBR) and to assess the effectiveness of approaches currently being used in the country.

White Paper 6 on inclusive education

White Paper 6 on Special Needs Education[17] continues to provide an important framework to fulfil the right to quality education for children with disabilities. There is considerable room for new ordinary (mainstream) public schools to be built in compliance with the principles of universal design and environmental access specifications, thus avoiding the costly process of upgrading them at a later stage.[18] More ordinary schools should also be capacitated to become inclusive in their cultures, policies and practices. There is an urgent need for an action plan on the implementation of the SIAS tool (which is a key mechanism) to ensuring that schools will take all possible steps to support learners who experience barriers to learning. This must be accompanied by norms and standards for inclusive education, and the required funding must be secured.

Emphasis should also be placed on further training of (ordinary school) teachers in curriculum differentiation and how to adjust their classroom activities when teaching learners with disabilities such as visual and hearing impairments. The strengthening of district-based support teams provides an opportunity to improve referral and monitoring mechanisms between different levels of support (namely, ordinary schools, FSSs and special schools).

Children's Act (2007)

The expansion of ECD services creates the opportunity to mainstream measures to improve access for children with disabilities, and includes adequate training of ECD practitioners. In line with the Children's Act (2007), expansion of ECD must target those children most in need of early childhood stimulation and development – including children with disabilities and those from poor communities. This means that not only do facilities need to be accessible, but programmes also need to be appropriate and inclusive of children with disabilities.

Care Dependency Grant

Plans to introduce legislation for the implementation of a common tool to assess disability in the administration of the CDG,[19] provide an opportunity to move away from a purely medical model of disability to one that reflects the complex and dynamic nature of disability, as well as the contextual factors that shape it.

Scalable projects

Efforts by NGOs have yielded several projects which have the potential for scaling up. Government agencies should consider these opportunities in planning for scale-up of service provision for children with disabilities.

Recommendations on how opportunities could be utilised (Chapter 7)

Disability Act and strengthening of existing legislation

In addition to considerations for a Disability Act, existing legislation needs to be strengthened to ensure compliance with the UNCRPD. The Education White Paper 6 (2001), for example, needs to be translated into tighter legal provisions in order to make Article 24 of the UNCRPD legally binding in South Africa.

Conditional grants

Opportunities exist around amending the regulations on current grants to prioritise children with disabilities. In addition, opportunities to design conditional grants for the specific needs of children with disabilities, such as for rehabilitation and the provision of assistive devices, should be explored.

17 Department of Education (2001) Education White Paper 6, Special Needs Education: Building an inclusive Education and Training System. Pretoria.
18 Department of Basic Education (2009) Report on the inclusive education field test 2004-2009. Presented to the Heads of Education Committee.
19 Strategic Plan of the Department of Social Development 2010-2015

Aligning policies to the UNCRPD

Some Departments have begun the process of aligning policies to the UNCRPD, as well as developing department-specific disability mainstreaming strategies, a training manual and an implementation plan. This is recognised as essential to ensuring that people with disabilities enjoy full and equal human rights and freedoms, and that there is respect for their inherent dignity. The process of aligning policies and plans of Departments should be accelerated.

Service delivery environment

There is a need to create a sustainable environment for service delivery partners (non-profit organisations or NPOs) through "capacity-building, collaboration and agency".[20] This requires the development of an effective service delivery model that ensures good planning, adequate funding, improved co-ordination and appropriate monitoring of implementation. Appropriate norms and standards should accompany this delivery model.

Partnerships and co-ordination

Partnerships between government and NGOs, different spheres of government and NGOs in the disability sector (disabled people's organisations) need to be strengthened in order to provide more effective and efficient services for children with disabilities.

Inter-sectoral collaboration is critical, especially at the planning and implementation levels (including the provincial sphere of governance) and requires networking between various departments (Health, Basic Education and Social Development), as well as NGOs who are providing services to children with disabilities. This is important to ensure early identification and appropriate referrals, and to promote the sharing of resources. A Directory of Services and/or a website, and joint planning and monitoring could be important starting points for co-ordination.[21] Furthermore, formal mechanisms for co-ordination are essential, and should be set out in provincial strategic plans. Strategic leadership is also needed at the national level to plan and implement appropriate services for children with disabilities.

Changing attitudes and providing community-based support

Changing attitudes towards children with disabilities is an ongoing challenge. An important part of this challenge is to provide the necessary support to parents, caregivers and community members who play a critical role in the lives of their children with disabilities. Such support should include tracking developmental milestones, teaching independence and caring for children.[22] Information must be disseminated in different formats and in ways that take cognisance of parents' and children's level of education.[23] Furthermore, disability and diversity awareness programmes need to be recognised as critical components of social cohesion, and as methods to reduce the vulnerability of children with disabilities to abuse and neglect.

Adopting a twin-track approach

Although catering for diversity needs to be a value that underlies all services, there is the danger that children with disabilities may be 'lost' in the effort to mainstream. International experience shows that even with mainstreaming, disability-specific programmes are still required. This has been termed the 'twin-track approach' and the Office of the High Commissioner on Human Rights[24] recommends this approach to monitoring the UNCRPD. It includes both a specific focus on the rights of people with disabilities, as well as the monitoring of the rights of people with disabilities, which is integrated into general human rights monitoring work.

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20 Department of Social Development Strategic Plan 2010-2015.
21 See for example *Cape Gateway,* a website which provides a single point of access to government information and services for residents of the Western Cape.
22 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
23 National Stakeholder workshop, 24 May 2011.
24 Office of the High Commissioner for Human Rights (2007) *From exclusion to equality: realizing the rights of persons with disabilities.* Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

Chapter 1



Break time at Sibonile School for the Visually Impaired.

1.1 Purpose of the situation analysis

South Africa's ratification of the UN Convention on the Rights of the Child (UNCRC) in 1995 and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 has facilitated the implementation of programmes towards the fulfilment of the rights of children, and indeed people with disabilities in the country. A Strategy for the Integration of Services to Children with Disabilities has, for example, been drafted.[25]

However, significant knowledge gaps remain with regard to the situation of children with disabilities, their family and community environment, the underlying causes of their situation, and the adequacy of efforts by government and non-government actors to fulfil their rights. Overall, there is a dearth of comprehensive research on childhood disability in South Africa. There are substantial information gaps on prevalence rates and the coverage and impact of available services, as well as policy constraints in increasing the coverage and quality of services for children with disabilities.

This situation analysis seeks to fill these knowledge gaps. The study addresses the following questions:

- What is the extent of disability among children in South Africa?
- What is the extent of inequities and unfulfilled rights of children with disabilities?
- What factors have contributed to the adequacy (or inadequacy) of actions by the State and society at large?
- What are strategic opportunities for further progress towards the fulfilment of the rights of all children with disabilities?

1.2 Methodology

The study is based on an analysis of both primary and secondary data. Primary data was collected through two processes. Firstly, qualitative information on the situation of service provision for children with disabilities was produced through focus group discussions, stakeholder consultations and key informant interviews.

Focus group discussions documented the experiences of children with disabilities and caregivers with regard to service delivery, as well as the stigma and discrimination that they encounter in their daily lives. Two of the focus group discussions were held directly with children with disabilities: one in a rural area in KwaZulu-Natal (KZN) and the other in an urban area in the Gauteng province. The third focus group discussion was held with caregivers of children with disabilities in a rural area in KZN.[26]

Stakeholder consultations were at the provincial and national levels. The provincial stakeholder consultation involved disability service providers from the NGO sector, academia, representatives of the provincial Departments of Education, Health and Social Development, and the Office of the Premier. National stakeholder consultations involved national disability service providers from the NGO sector and individual experts, as well as representatives of the Departments of Education, Health and Social Development at the national level, and of the Department of Women, Children and People with Disabilities.

Key informant interviews were conducted with representatives of the Departments of Education, Health and Social Development at the national and provincial levels in the Eastern Cape, KZN and the Western Cape.

Collection of secondary data comprised a desk review of available literature and research material on childhood disability. South African sources included census and national household survey data from Stats SA,[27] as well as community level studies. Published papers, books, chapters and a range of studies commissioned by different organisations were also consulted, along with academic dissertations relating to children with disabilities, and studies commissioned by various government departments.[28] Information on legislation, policies

25 Department of Social Development (2009) *Strategy for the Integration of Services to Children with Disabilities*. Revised draft. Pretoria: Department of Social Development.
26 The findings of these focus groups discussions have also been compiled in a separate publication.
27 These include the incorporation of descriptive analysis of the national household survey data from Community Survey 2007 and General Household Survey 2009.
28 Department of Social Development (2007) *Audit of Services Available to Children with Disabilities*. Pretoria.

and strategies relating to services for children with disabilities were reviewed, as were recent strategic plans of the three lead service delivery departments, i.e. Education, Health and Social Development, at the national and provincial levels in three provinces (the Eastern Cape, KZN and the Western Cape). International studies that formed part of the desk review provided the regional and global context, and included studies by UNICEF, the World Health Organisation (WHO), Save the Children and the UK Department for International Development, as well as publications from a range of international journals.

Various types of analyses were carried out to determine if the current system of service provision in South Africa is responding adequately to the rights of children with disabilities. These comprised three different elements:

- *Quantitative analysis*, including descriptive analysis of national household survey data on children with reported disabilities.
- *Qualitative analysis*, including analysis of information obtained through focus group discussions, stakeholder consultations and key informant interviews.
- *Institutional analysis*, including analysis of the national policy response as well as bottlenecks in the delivery of services for children with disabilities. Emphasis was placed on the three sectors responsible for most of the services required by children with disabilities: Education, Health and Social Development.

1.3 Underlying framework for the study

In the context of the UNCRPD, the WHO International Classification of Functioning, Disability and Health (ICF) for Children and Youth[29] served as the underlying framework for the study.

Historically, approaches to address the challenges faced by people with disabilities have been based on a *medical*, or *social* model of disability.

The medical model perceives disability as individual pathology or malfunction, a specialised health problem at the heart of which is an emphasis on clinical diagnosis.[30] Using this approach, the problems of people with disabilities are viewed as their own personal inadequacies or defects and the difficulties they experience are attributed to individual functional limitations. Medical personnel and therapists are regarded as the "experts", who "know best" the needs of adults and children with disabilities, and therefore have the power to make decisions on their behalf. State interventions aimed to provide treatment in order to "cure" the disability, failing which adults and children with disabilities were perceived to require "care".[31]

The welfare approach, which views individuals with disabilities as tragic victims or helpless individuals who are dependent on the charity of others, underlies the delivery of services. Services for people with disabilities are channelled through welfare institutions, with much of the responsibility of "caring" for adults and children with disabilities placed with civil society organisations.[32]

The perception of disability as a medical or welfare issue has led to the isolation of disabled adults and children and their families; they have been separated from their communities and excluded from participating in society, thus entrenching the cycle of dependency and helplessness. In South Africa, this approach has been compounded by "the legacy of the inequities of the apartheid system"[33] as well as persisting stereotypes of disability which continue to exclude adults and children with disabilities from mainstream society.

In contrast to the medical/welfare approach, the social model of disability recognises that the barriers that exclude adults and children with disabilities from participating in society are not created or caused primarily by their impairments, but arise from the way that society is organised to meet the needs of the non-disabled. As a result of a badly-designed built environment, inaccessible public transport, discriminatory

29 http://www.childinfo.org/disability.html The ICF was officially endorsed by all WHO Member States in 2001.
30 Philpott, S. & McLaren, P. (1997) 'Disability' in Barron, P. (ed) *South Africa Health Review*, Durban: Health Systems Trust.
31 Philpott, S. & McLaren, P. (1997) 'Disability' in Barron, P. (ed) *South Africa Health Review*, Durban: Health Systems Trust.
32 Office of the Deputy President (1997) White Paper on an Integrated National Disability Strategy.
33 Office on the Status of Disabled Persons (OSDP) (2008) *National Disability Policy Framework and Guidelines for the Implementation of the National Policy Framework*. Pretoria: OSDP.

attitudes and practices, and other barriers, people with disabilities are usually excluded from participating in mainstream society.

With the social model, intervention is focused not on the individual person with a disability, but on removing the barriers that prevent them from exercising their right to participate in society (as reflected in the UNCRPD). It is the collective responsibility of society to remove barriers to the equal participation of adults and children with disabilities.[34] The social model of disability reflects a human rights approach to development. Difficulties faced by adults and children with disabilities are regarded as a human rights issue, i.e. those with disabilities are seen as a group that experiences discrimination and whose rights are not respected and fulfilled (e.g. the refusal of a principal to accept a child with a disability constitutes a violation of the right to education for that child).

The medical and social models are frequently presented as being mutually exclusive. However, the World Report on Disability[35] argues that disability should not be viewed either as a solely medical issue or as a solely social issue, because persons with disabilities who face various forms of exclusion often also experience problems that arise directly from their health conditions. A balanced approach which acknowledges the impact of different aspects of disability is recommended by the ICF.[36] The ICF views disability as neither a biological nor a social phenomenon alone, but as the interaction between health conditions and contextual factors at the individual and environmental levels. Referred to also as the 'bio-psycho-social model', this approach embodies a compromise between the medical and social models of disability. The ICF classifies disability as having three dimensions, i.e. problems in bodily function or structure, problems related to activities and problems related to social participation. (Details of the ICF are provided in Box 1.1 and Figure 1.1.)

Box 1.1: International classification of functioning, disability and health (ICF) for children and youth

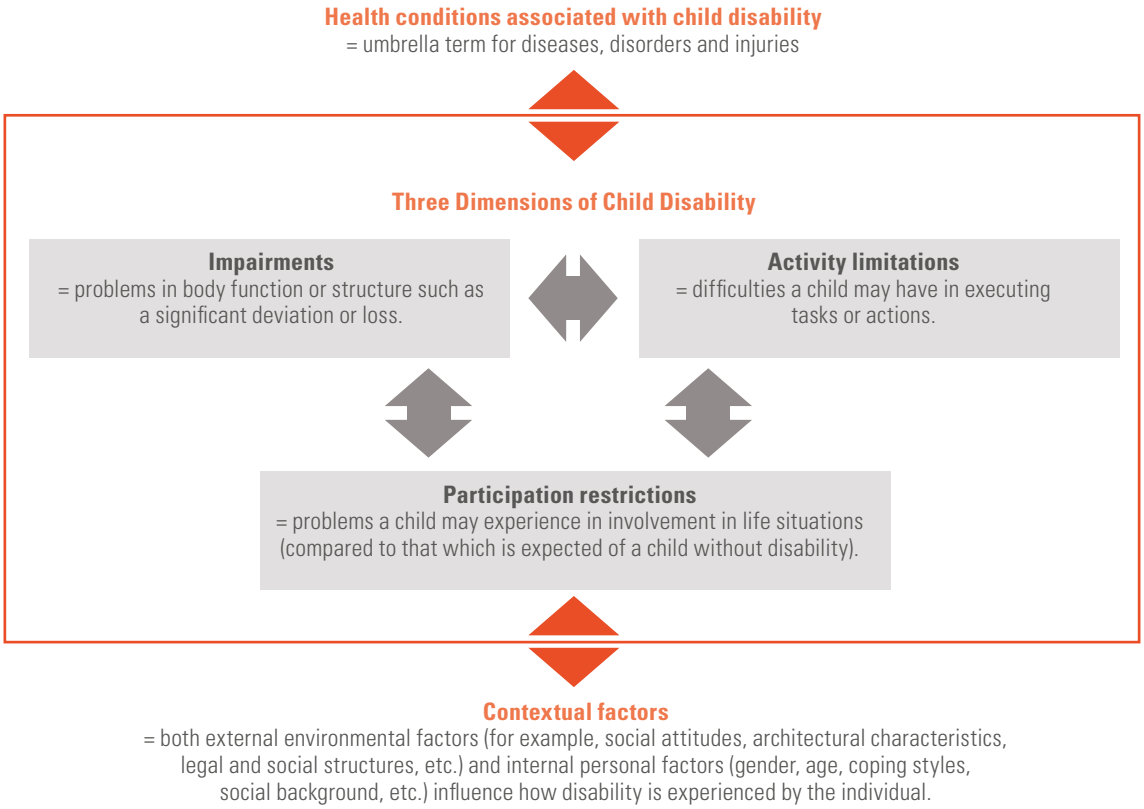
The ICF provides a classification of environmental factors that are acknowledged to have a significant impact on the extent of disability and how it is experienced. These factors may assist or *facilitate* participation (*facilitators*) or they may limit or prevent such participation (*barriers*). Contextual factors may be internal, personal characteristics, such as coping styles, which can influence the extent to which a child participates in society. They may also be external factors, relating to physical and information access, as well as to policies, service delivery systems and institutional arrangements. Knowledge and attitudes are also environmental factors that have a significant impact on service provision and levels of participation.[37]

Although it is not a measurement tool or survey instrument, the ICF provides a standard for health and disability statistics, particularly in terms of harmonising the different approaches to estimating disability prevalence, taking into account the complex and dynamic relationship between health conditions and contextual factors.[38] The ICF provides for a continuum of processes within which to assess/address the fulfilment of the rights of children with disabilities, especially at the point of limitation (whether at the impairment, activity or participation stages), as well as to identify both *facilitators* and *barriers* within the environment.

(Source: World Health Organisation & World Bank (2011) ***World Report on Disability****. Geneva: WHO & World Bank)*

34 CREATE & Office of the Premier, KZN (2011) *Human Rights for People with Disabilities in KwaZulu-Natal*. Foundation for Human Rights and Department of Justice and Constitutional Development.
35 World Health Organisation & World Bank (2011) *World Report on Disability*. Geneva: WHO & World Bank.
36 http://www.childinfo.org/disability.html The ICF was officially endorsed by all WHO Member States in 2001.
37 World Health Organisation & World Bank (2011) *World Report on Disability*. Geneva: WHO & World Bank.
38 World Health Organisation & World Bank (2011) *World Report on Disability*. Geneva: WHO & World Bank.

Figure 1.1: International classification of functioning, disability and health (ICF)



1.4 Legal context

1.4.1 South African Constitution

The South African Constitution provides the framework for democracy in the country; it has been central to the transformation of society, away from one of racial segregation towards one in which the human rights of all citizens are recognised and protected. The Preamble states that its intention is to "heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights … improve the quality of life of all citizens and free the potential of each person".[39]

The Bill of Rights in the Constitution sets out the rights of all citizens, as well as the specific additional rights of children.[40] The latter includes the right to family or parental care, or to alternative care when removed from the family environment, as well as to basic nutrition, health care services, social services and protection. According to the Bill of Rights, everyone has the right to basic education.

Significantly, the Bill of Rights specifies the right to dignity, freedom and equality.[41] It recognises that everyone is equal before the law and has equal protection and benefit of the law. Discrimination on a number of grounds, including disability, is prohibited under Section 9(3). Section 6(5)(a)(iii) also provides for the development and use of sign language.

Furthermore, the South African government has expressed its commitment to realising the rights of children with disabilities through ratification of international treaties, including the UN Convention on the Rights

39 Constitution of the Republic of South Africa (1996) Preamble.
40 Constitution of the Republic of South Africa (1996) Chapter 2, Section 28.
41 Constitution of the Republic of South Africa (1996) Chapter 2, Sections 9, 10 and 12.

of the Child (UNCRC), the African Charter on the Rights and Welfare of the Child (ACRWC or the African Charter), and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

1.4.2 UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child (1989) is a universally agreed-upon set of non-negotiable standards and obligations to protect the full range of human rights for all children, i.e. civil, cultural, economic, political and social rights.[42] The UNCRC acknowledges children as subjects of rights and participants in all matters affecting them. Although all the rights contained in the UNCRC apply to all children, the Convention also introduced specific rights for children with disabilities for the first time in international human rights law. Provisions included in Article 2 (non-discrimination) prohibit discrimination on a number of grounds including disability, while Article 23 specifically obliges State Parties to recognise and fulfil the rights of children with disabilities (see Box 1.2).

Box 1.2: Provisions of Article 23 of the UNCRC for children with disabilities

1. States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognising the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

The Committee on the Rights of the Child is responsible for monitoring compliance with the UNCRC.[43] The Committee on the Rights of the Child issued General Comment No. 9 in 2006 that deals with the rights of children with disabilities aiming "to provide guidance and assistance to States Parties in their efforts to implement the rights of children with disabilities, in a comprehensive manner which covers all the provisions of the Convention."[44]

42 http://www.unicef.org/crc/
43 Save the Children (2009) *See Me, Hear Me: A Guide to Using the UN Convention on the Rights of Persons with Disabilities to Promote the Rights of Children*. London: Save the Children.
44 UNCRC (2006) General Comment No. 9: The Rights of Children with Disabilities. Geneva: United Nations.

South Africa is obliged to submit in accordance with Article 44 of the UNCRC periodic State Party Reports that should focus on measures that the country has adopted that give effect to the rights recognised in the Convention and on the progress made in terms of the promotion, protection and fulfilments of the rights of children. South Africa submitted its Initial State Party Report in December 1997. The report was considered by the Committee on the Rights of the Child in January 2000.

The second and third periodic reports (due in 2002 and 2007 respectively) are yet to be submitted.[45] The Department of Women, Children and People with Disabilities is leading the preparation of a combined second, third and fourth periodic State Party Report for submission in 2013.

1.4.3 African Charter on the Rights and Welfare of the Child

The African Charter on the Rights and Welfare of the Child (ACRWC) sets out the rights that African states must ensure for children living in their jurisdiction.[46] The Charter provides a uniquely African framework for the protection and promotion of children's rights.[47] While acknowledging the dire situation of children on the continent, the Charter recognises the child as occupying "a unique and privileged position in the African society and that for the full and harmonious development of their personality, the child should grow up in a family environment in an atmosphere of happiness, love and understanding."[48]

In particular, Article 13 of the ACRWC makes provision for rights of children with mental and physical disabilities as follows:

> *1. Every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community.*
>
> *2. States Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, of assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development.*
>
> *3. The States Parties to the present Charter shall use their available resources with a view to achieving progressively the full convenience of the mentally and physically disabled person to movement and access to public highway buildings and other places to which the disabled may legitimately want to have access to.*

South Africa ratified the ACRWC in 2000, but its initial report (due in 2002) has not yet been submitted to the African Committee of Experts on the Rights and Welfare of the Child, which reports to the African Union.[49] The government is currently in the process of preparing the initial report for submission in 2013.[50]

1.4.4 UN Convention on the Rights of Persons with Disabilities

States party to the UNCRPD have undertaken "to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability".[51] The UNCRPD builds on previous conventions by placing emphasis on the specific forms of human rights violations that people with disabilities experience.[52]

Consistent with the ICF, the UNCRPD reflects a paradigm shift away from a medical or welfare response to disability, towards a human rights approach. The rights-based approach emphasises respect, support and

45 Chenwi, L. (2010*) South Africa: State of State Reporting under International Human Rights Law.* Reader compiled for the seminar on Promoting Constitutional Rights through International Human Rights Law. Community Law Centre, University of the Western Cape.
46 http://www.crin.org
47 Kaime, T. (2009) *The African Charter on the Rights and Welfare of the Child: A Socio-legal Perspective.* Pretoria: Pretoria University Law Press (PULP).
48 OAU (1990) African Charter on the Rights and Welfare of the African Child. Preamble.
49 Chenwi, L. (2010) *South Africa: State of State Reporting under International Human Rights Law.* Reader compiled for the seminar on Promoting Constitutional Rights through International Human Rights Law. Community Law Centre, University of the Western Cape.
50 Department of Women, Children and People with Disabilities (2012) Communiqué: South African Country Reports on International Commitments to the promotion, protection and fulfillment of Children's Rights. Pretoria: DWCPD.
51 UN (2008) The UN Convention on the Rights of Persons with Disabilities.
52 UN Office of the High Commissioner for Human Rights (2010) *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors.* Professional Training Series No. 17. New York & Geneva: UN.

celebration of such diversity by creating conditions that allow meaningful participation by a wide range of people, including adults and children with disabilities. Promoting and protecting the rights of people with disabilities is not limited to the provision of disability-related services; it includes introducing measures to change attitudes and practices that stigmatise and marginalise people with disabilities. It requires putting in place legislation and policies that remove barriers to the exercising of rights, providing programmes, awareness and social support to change the way society operates, and giving adults and children with disabilities opportunities to participate fully in society.[53]

The provisions of the UNCRPD place an obligation on governments to remove the barriers that currently prevent the realisation of the rights of adults and children with disabilities.

As with the UNCRC and the ACRWC, the committee overseeing the implementation of the UNCRPD has adopted guidelines regarding the form and content of the reports required to document the progress of implementation. State Parties are required to facilitate the involvement of NGOs (including organisations for persons with disabilities) in the preparation of reports, and the guidelines emphasise the inclusion of statistical data disaggregated for disability.[54,55]

The UNCRPD was adopted in 2006 and came into force in 2008. South Africa ratified the Convention in 2007, and the initial report on implementation was due in 2010. However, to date, no report has been submitted.[56,57] The government is working on a report for submission by December 2012.[58]

1.5 Limitations of the study

A number of limitations were experienced in conducting the study. Firstly, it was difficult to obtain accurate official data on children with disabilities. This was because of the different criteria used by various data sources for determining disability. In addition, although a large number of studies on childhood disability were identified, these were not altogether comprehensive. For example, no research was found on the access of children with disabilities to alternative care. The study was also completed before the 2011 Census which will provide most recent data on children with disabilities.

Secondly, the information presented in this report on services for children with disabilities, though comprehensive, is by no means exhaustive, as these services are provided by a wide range of government and non-government organisations.

Furthermore, focus group discussions were limited to three – two in rural areas and one in an urban setting. Key informant interviews, as well as analysis of the strategic plans of lead departments, were carried out in three of the country's nine provinces – the more resourced Western Cape, and the less resourced Eastern Cape and KZN.

Overall, the focus of the study does not include chronic illnesses, except where they are a cause of or present risks for childhood disability.

53 UN Office of the High Commissioner for Human Rights (2010).
54 Committee on the Rights of Persons with Disabilities (2009) *Guidelines on the Treaty-specific Document to be Submitted by States Parties under Article 35 of the Convention on the Rights of Persons with Disabilities*. UN doc. CRPD/C/2/3.
55 For example, reports should include statistical data on the realisation of each Convention right, disaggregated by age, sex, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories, on an annual comparative basis over the preceding four years (Para A3 [h]).
56 Chenwi, L. (2010) South Africa: State of State Reporting under International Human Rights Law. Reader compiled for the seminar on Promoting Constitutional rights through international human rights law. Community Law Centre, University of the Western Cape.
57 Chenwi, L. (2010) *South Africa: State of state reporting under international human rights law.* Reader compiled for the seminar on Promoting Constitutional rights through international human rights law. Community Law Centre.
58 Department of Women, Children and People with Disabilities (2012) Presentation to the Portfolio Committee on Women, Youth, Children and Persons with Disabilities: 30 May 2012. Cape Town: PMG.

Chapter 2



Sandile Mthembu, Grade 4, in his Art class at the HopeSchool.

2.1 Introduction

The demand for statistics on children and adults with disabilities has increased greatly over the past few decades. South Africa's Integrated National Disability Strategy White Paper (1997), for example, calls for "statistics on available services and programmes as well as on the different groups of people with disabilities". Likewise, Article 31 of the UNCRPD ratified by South Africa in 2007, places an obligation on governments to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention.

This chapter takes stock of available national statistics on the prevalence of disability in South African children. In the context of the ICF, such information is essential for monitoring the level of functioning in the child population and designing appropriate assistance and support services for children and their families. The chapter also presents the results of secondary data analysis of Stats SA's Census and national household surveys on child disability prevalence and the association with socioeconomic characteristics such as age, sex, location and parental education. Lastly, the chapter looks at the adequacy of early detection and early intervention measures. Very often, disabilities are detected quite late in the child's life, depriving them of effective treatment and rehabilitation.

2.2 Defining and measuring disability in children

There is no single, universally accepted definition of disability and therefore no single way of measuring it.[59] In the past, disability was seen as a purely medical condition. In this impairment-based model, measurement uses some variation of the question: "Do you have a disability?" This method tends to underestimate the true prevalence of disability as many people with disabilities may actually not identify themselves as disabled because of shame, stigma, or cultural standards of what is considered normal functioning.

The social model sees disability as the outcome of the interaction of a person's functional status with their environment. In other words, children and adults are not seen as inherently disabled, but as being disabled by external circumstances. With this approach, the focus of measurement shifts to monitoring levels of disadvantage and discrimination. Survey questions focus on identifying people with a condition that limits or prevents participation in activities such as education or work. Alternatively, the questions aim to identify people who have difficulty performing basic activities or major body functions, such as seeing or walking.

Measuring child disability is also inherently much more difficult than measuring disability in adults.[60] As children grow, they go through a natural development process, learning how to talk, walk, read and write. In contrast to the relatively stable characteristics of adults, the evolving characteristics of children complicate the task of assessing function and distinguishing significant limitations from variations in normal developmental processes. Moreover, disability measurement often takes place through the filter of a parent or some other adult respondent in surveys – and not necessarily verified by a clinical diagnostic evaluation. Stigma or shame may also prevent people from identifying their children as disabled in surveys.

As is the case with many other countries, South Africa does not yet have a standard and nationally accepted measuring tool in line with the ICF outlined in Chapter 1. As a result, estimates of disability prevalence in children from different sources are not comparable because of differing definitions of disability and methods of data collection.

2.2.1 Census and national household surveys by Stats SA

Stats SA has applied various approaches to disability measurement in its censuses and national household surveys. Table 2.1 provides a summary of the different questions asked to determine disability and the reported prevalence of disability in children (under 18 years of age) by sex, age, population group and province.

The reported number of children with disabilities ranges from a low of 254 000 (1.4%) in the GHS 2008 to a high a 436 000 (2.5%) in Census 2001. Across the various sources, the patterns by sex and age group are simi-

59 World Bank (2007) *Measuring Disability Prevalence. Social Protection.* Discussion Paper No. 0706.
60 UNICEF (2008) *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys.*

lar: prevalence is higher among males than females and increases with age. The patterns by population group and province are, however, inconsistent.

Since 2009, the GHS has used the WG Short Set of Questions[61] which asks about difficulties experienced in seven domains of functioning – seeing, hearing, walking, remembering, concentrating, self-care and communicating. An individual is classified as disabled if they had 'some difficulty' for two or more of the six categories, or had 'a lot of difficulty', or were 'unable to do so' for one or more categories. Following this approach, the GHS 2009 classified nearly 2.1 million children (11.2% of the total child population) as disabled. The prevalence of disability appears unusually high for young children especially: 28 percent of children in the age group 0-4 years and 10 percent in the age group 5-9 years were classified as disabled. Experience with the use of the WG Short Set of Questions in South Africa suggests substantial challenges with measuring disability in young children because of problems inherent in differentiating real difficulties from normal developmental processes.[62] Nevertheless, the results from the WG Short Set of Questions suggest that the Census 2001 and the Community Survey 2007 are likely to have underestimated the prevalence of children with disabilities in the country. Projections from the Census 2001 indicate that there are some 474 000 children living with severe disabilities in South Africa today. The GHS thus indicates more widespread mild to moderate disability among children.

2.2.2 National Disability Survey by the Department of Health (1999)

The only dedicated, national population-based disability prevalence survey in South Africa was commissioned by the Department of Health and conducted by the Community Agency for Social Enquiry (CASE) in 1999.[63] The survey of nearly 9 300 households measured the extent of moderate to severe reported disability (without clinical confirmation) and attempted to capture the 'lived experience' of people with disabilities through in-depth interviews. The results of the survey showed a steady increase in reported prevalence of disability in children: from 1.6 percent among the children aged 1-5 years to 3.2 percent among 6-10 year olds, and 4.5 percent among 11-15 year olds. The study also found that neither the special nor the mainstream educational systems provided effective education for disabled children.

2.2.3 Small-scale child disability surveys

McLaren et al.[64] identify several childhood prevalence surveys conducted at the local level between 1992 and 2002 in South Africa. Examples include a survey on the prevalence of intellectual disability in Bushbuckridge, Limpopo; one on hearing loss and ear disease in schoolchildren in Witbank, Mpumalanga; and one on the causes of low vision and blindness in Mosvold, KZN. These surveys put prevalence of disability at between 1.1 and 6.3 percent, depending on the age group and type of disability. More recently, a study by Chhagan and Kauchali of children aged 2-9 years in the Valley of a Thousand Hills near Durban, KZN, found an overall disability prevalence of seven percent.[65] All these child disability surveys had very limited coverage with small samples and are too localised to permit generalisation at a national level.

61 Based on the Washington Group on Disability Statistics (WG) Short Set of Questions.
62 Stats SA (2010) *General Household Survey 2009*, Pretoria.
63 Community Agency for Social Enquiry (CASE) (1999) *We Also Count! The Extent of Moderate and Severe Reported Disability and the Nature of the Disability Experience in South Africa*. Pretoria: Department of Health.
64 McLaren, P., Solarsh, G. & Saloojee, G. (2004) 'Disability and Disablement', in A. Ijumba & C. Day (eds) *South African Health Review 2003/04*. Durban: Health Systems Trust. pp.163-171.
65 Chhagan, M.K. & Kauchali, S. (2011) Child Development and Developmental Disability. Presentation on behalf of the DDRC (Development Disabilities Research Collaboration between the University of KZN and the departments of Education, Health and Social Development). Available at http://www.ruralrehab.co.za/uploads/3/0/9/0/3090989/children_development_and_developmental_disabilities_ddrc_2011.pdf

Table 2.1: Number and percentage of children with disabilities by Stats SA data source

	Census 2001		Community Survey 2007		General Household Survey 2008		General Household Survey 2009	
Question to determine disability	Does (the person) have any serious disability that prevents his/her full participation in life activities (such as education, work, social life)?		Does (the person) have any kind of disability?		Is (the person) limited in his/her daily activities, at home, at work or at school, because of a long-term physical, sensory, hearing, intellectual, or psychological condition, lasting six months or more?		Does (the person) have difficulty in doing any of the following? Seeing (even when wearing glasses); hearing (even with a hearing aid); walking a kilometre or climbing stairs; remembering/concentrating; self-care such as washing or dressing; and communication in usual language incl. sign language. An individual is classified as disabled if he/she has 'some difficulty' for two or more of the six categories or 'a lot of difficulty' or 'unable to do so' for one or more categories.	
	Number	**%**	**Number**	**%**	**Number**	**%**	**Number**	**%**
Sex								
Male	226 692	2.6%	158 391	1.7%	154 521	1.6%	1 053 577	11.3%
Female	209 431	2.4%	123 970	1.4%	99 736	1.1%	1 031 123	11.3%
Age group								
0-4 years	71 326	1.6%	45 923	0.9%	29 651	0.6%	1 393 236	27.8%
5-9 years	119 430	2.5%	84 752	1.7%	75 320	1.5%	526 895	10.2%
10-14 years	149 863	3.0%	92 387	1.9%	93 033	1.8%	112 405	2.2%
15-17 years	95 503	3.2%	59 299	1.9%	56 252	1.8%	52 164	1.5%
Population group								
Black African	382 492	2.6%	246 433	1.6%	215 567	1.4%	1 794 691	11.4%
Coloured	27 080	1.8%	19 280	1.3%	17 398	1.2%	156 170	10.4%
Indian/Asian	5 135	1.6%	4 714	1.4%	3 993	1.1%	35 166	9.7%
White	21 415	2.1%	11 933	1.2%	17 299	1.7%	98 672	9.9%
Province								
Eastern Cape	62 192	2.2%	51 118	1.8%	29 767	1.1%	239 551	8.7%
Free State	35 212	3.5%	14 744	1.5%	15 144	1.4%	281 330	26.5%
Gauteng	51 545	2.0%	43 074	1.4%	58 974	1.8%	242 605	7.6%
KZN	108 552	2.7%	66 806	1.6%	59 485	1.4%	566 379	13.3%
Limpopo	68 384	2.7%	34 491	1.5%	26 834	1.2%	290 754	12.6%
Mpumalanga	41 344	3.1%	21 906	1.5%	16 590	1.1%	91 697	6.2%
North West	32 919	2.4%	20 174	1.7%	24 702	1.9%	104 930	8.3%
Northern Cape	5 855	1.9%	6 627	1.8%	6 574	1.5%	75 936	17.5%
Western Cape	30 120	2.0%	23 419	1.4%	16 187	0.9%	191 518	10.9%
Total	**436 123**	**2.5%**	**282 361**	**1.6%**	**254 257**	**1.4%**	**2 084 700**	**11.2%**

(Source: Analysis of Census, Community Survey and GHS data by UNICEF South Africa. Person weights provided by Stats SA were applied to obtain estimates representative for the entire child population)

2.3 Prevalence of disability in children: Levels and patterns from Census 2001

This section presents estimates of the prevalence of disability in children (0-17 years old) calculated from the Census 2001 dataset (10% sample) which is made available by Stats SA for public use. It is argued that the Census offers the most reliable national estimates of child disability to date for the following reasons:

Firstly, the Census covers the entire population in both private and institutional settings, while population coverage of other datasets is confined to private households. Many children with disabilities live in communal establishments such as residential or care homes and long-stay hospital wards. These types of institutions are not covered in household surveys.

Secondly, because the Census is an official count of every person in the country, it is possible to generate disability prevalence rates for small sub-national geographical areas (such as districts) and detailed disaggregations to analyse the association between children's socioeconomic characteristics and disability. Other datasets are typically not able to generate detailed cross-tabulations because of large statistical confidence intervals.

Thirdly, the question used to identify disability in the Census emphasises restrictions in participation in life activities as a result of disability. As such, it fits within the ICF framework outlined in Chapter 1.

To measure the extent of disability in South Africa, the Census 2001 questionnaire asked whether or not the referent person had "any serious disabilities that prevented his or her full participation in life activities such as education, work, and social ones". Disabilities included those affecting sight, hearing, communication, physical, intellectual and emotional functioning. Multiple disabilities were also identified.

Nationwide, 436 123 children, or 2.5 percent of the total child population, were reported to have some form of serious disability during Census 2001. Taking into account population growth over the last decade[66] and assuming disability prevalence has remained constant, this implies that there are some 474 000 children living with severe disabilities in South Africa today. In addition, many more children may have mild to moderate disabilities.

There are considerable disparities in the levels of reported child disability based on location, sex, age and other socioeconomic characteristics. These are discussed below.

2.3.1 Disparities in the prevalence of child disability

Location

The data suggests significant variation across provinces, ranging from 1.9 percent in the Northern Cape to 3.5 percent in the Free State (see Table 2.2). At district level, the prevalence of reported child disability ranged from 1.3 percent in Pixley ka Seme to 4.2 percent in Zululand (see Map 2.1). Children in rural areas were more likely to be reported to have some form of serious disability (2.7%) than children in urban areas (2.3%). These differences between areas in the country might reflect the general development or poverty level of an area, access to nutritious food, exposure to environmental or infectious agents, or social or other risk factors for disability.[67]

Sex, age and population group

Male children were more likely than their female peers to have a disability (2.6% versus 2.4%). Furthermore, prevalence increased steadily with age: from 1.6 percent among children aged 0-4 years, to 3.2 percent among children aged 15-17 years (see Table 2.3). Across population groups, prevalence was highest among Black African children (2.6%) and lowest among Indian/Asian children (1.6%).

66 The child population has grown by 9.2 percent from 17.3 million in 2001 to 18.9 million in 2011 (Stats SA (2011) *Mid-year Population Estimates*. Pretoria: Stats SA.)

67 UNICEF (2008) *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*. New York: UNICEF.

Parental education

Figure 2.1 shows that the prevalence of reported disability among children decreases as levels of parental education increase. Children whose mother or father had no or only some primary education were twice as likely to be reported as having some form of severe disability than children whose parents had completed higher education. The mechanisms by which parental education impacts child disabilities are, however, not well understood.[68] On the one hand, it may be that lower levels of parental education increase children's exposure to environmental, social or other risk factors for disability, such as toxins or lack of nutritious food. On the other hand, different levels of parental education may be associated with different levels of awareness regarding children's impairments or developmental delays.

Orphan status

Orphaned children appear to be more likely to have disabilities than non-orphaned children. Reported disability stood at 3.9 percent among children who had lost both parents and 3.2 percent among children who had lost one parent, compared to 2.4 percent among non-orphaned children (Figure 2.2). These disparities need further investigation. They could possibly be linked to the country's HIV epidemic and the fact that children whose disability was caused as a result of HIV and AIDS are more susceptible to losing their parents.

Children living in institutions or on the streets

Children living in institutions or on the streets are much more likely to be reported as having some form of serious disability than children living in households. Out of almost 109 000 children living in institutions at the time of Census 2001, one in five were reported to have some form of disability. While censuses are notorious for not adequately capturing the homeless population, Census 2001 indicated that 24 percent of the 3 000 children living on the streets had a reported disability (see Table 2.4).

Again, the causal relationship can run both ways. Children living on the streets are much more likely to be exposed to environmental, social or other risk factors for disability. At the same time, children with disabilities are more likely to be found in hospitals or to be sent off to specialised institutions for disabled children, or to boarding schools.

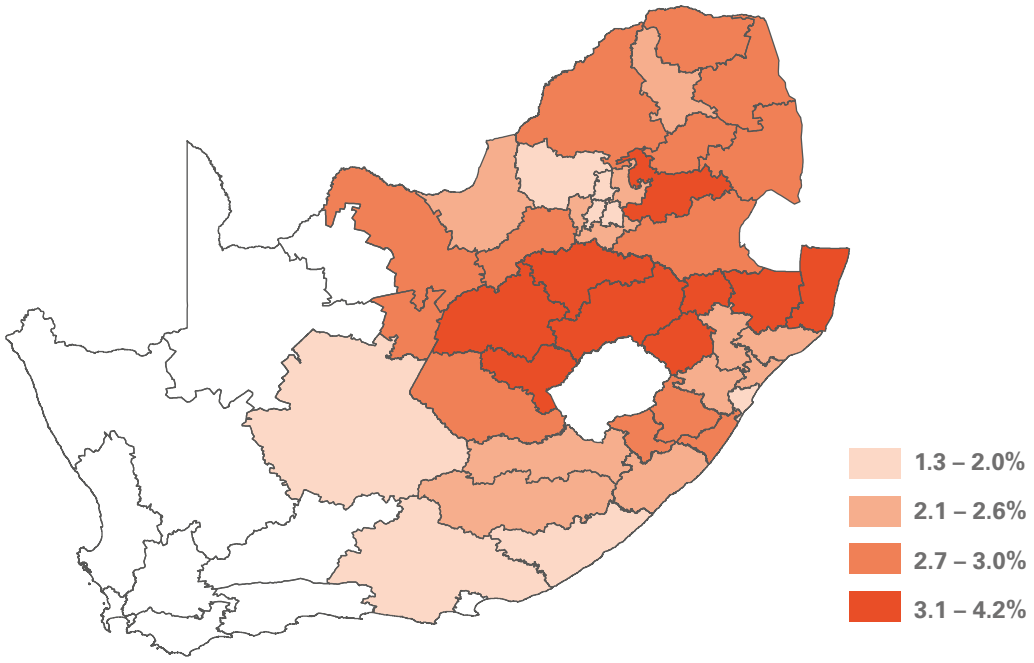
Table 2.2: Children reported to have any severe disability by location (2001)

	Total child population	Children with reported serious disability	Prevalence of severe disability (%)
Province			
Free State	1 017 836	35 212	3.5
Mpumalanga	1 321 960	41 344	3.1
KZN	3 950 330	108 552	2.7
Limpopo	2 498 123	68 384	2.7
North West	1 376 546	32 919	2.4
Eastern Cape	2 864 529	62 192	2.2
Gauteng	2 515 999	51 545	2.0
Western Cape	1 500 182	30 120	2.0
Northern Cape	304 223	5 855	1.9
Rural/Urban			
Rural	9 559 252	259 134	2.7
Urban	7 790 476	176 989	2.3
South Africa	**17 349 728**	**436 123**	**2.5**

(Source: UNICEF South Africa computation based on Census 2001)

68 UNICEF (2008) *Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys*. New York: UNICEF.

Map 2.1: Percentage of children reported to have any severe disability by district (2001)



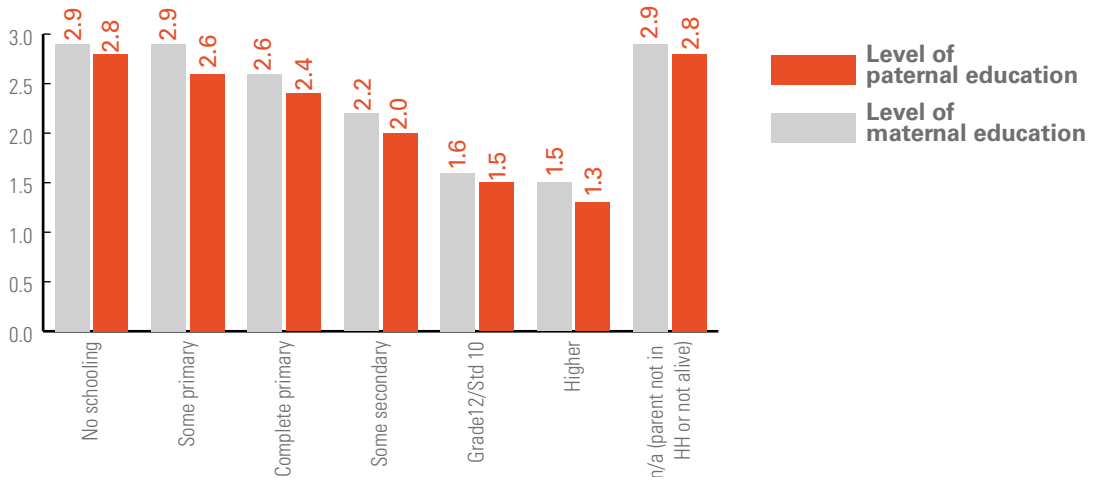
(Source: UNICEF South Africa computation based on Census 2001)

Table 2.3: Children reported to have any severe disability by sex, age and population group (2001)

	Total child population	Children with reported serious disability	Prevalence of severe disability (%)
Sex			
Male	8 641 196	226 692	2.6
Female	8 708 532	209 431	2.4
Age group			
0-4 years	4 429 376	71 326	1.6
5-9 years	4 849 900	119 430	2.5
10-14 years	5 052 172	149 863	3.0
15-17 years	3 018 279	95 503	3.2
Population group			
Black African	14 498 824	382 492	2.6
Coloured	1 488 499	27 080	1.8
Indian/Asian	328 229	5 135	1.6
White	1 034 175	21 415	2.1
South Africa	**17 349 728**	**436 123**	**2.5**

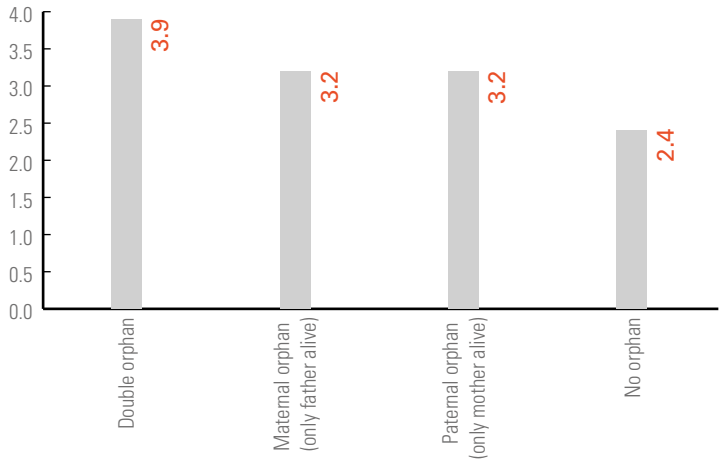
(Source: UNICEF South Africa computation based on Census 2001)

Figure 2.1: Percentage of children reported to have any severe disability by level of parental education (2001)



(Source: UNICEF South Africa computation based on Census 2001)

Figure 2.2: Percentage of children reported to have any severe disability by orphan status (2001)



(Source: UNICEF South Africa computation based on Census 2001)

Table 2.4: Children reported to have any severe disability by whereabouts (2001)

	Total child population	Children with reported serious disability	Prevalence of severe disability (%)
Living in households	17 237 958	413 773	2.4
Living in institutions	108 800	21 630	19.9
Homeless	2 970	720	24.2
South Africa	**17 349 728**	**436 123**	**2.5**

Note: 'Households' refers to children living in housing units and non-institutional collective living quarters (e.g. hotels or workers' hostels). 'Institutions' comprise hospitals, childcare institutions, boarding school hostels, homes for the disabled, initiation schools, convents, defence force barracks, prisons, community and church halls, and refugee camps. 'Homeless' refers to children with no form of shelter on census night and no known residential address.
(Source: UNICEF South Africa computation based on Census 2001)

2.3.2 Types of disabilities in children

Overall, among the six types of disabilities included in Census 2001, disabilities related to sight and hearing were most commonly reported: over 100 000 children (23% of all disabled children) were reported to be blind or to have a severe visual limitation, while another 92 500 children (21% of all disabled children) were reported to be deaf or profoundly hard of hearing (Table 2.5).

The two least prevalent types of disabilities reported were emotional and communication disabilities: 43 000 children (10% of all disabled children) were reported to have behavioural or psychological disabilities, while another 22 000 children (5% of all disabled children) were reported to have speech impairment. In addition, one in 10 children were reported to have multiple disabilities, with seven percent reporting two disabilities, and just three percent reporting three or more. Overall, the average number of disabilities reported was 1.17 per child with disability.

Census 2001 also found significant disparities in the prevalence of specific types of disabilities across provinces (Table 2.6 and Table 2.7). For example, compared to the national average, children in the Free State were twice as likely to be blind or severely visually limited. Children in Limpopo and Mpumalanga were more than twice as likely to be deaf or hard of hearing than children in the Western Cape. As noted above, these provincial differences might reflect varying exposure to specific risk factors associated with specific types of disability.

Table 2.5: Children reported to have any severe disability by type of disability (2001)

Type of disability	Number of children affected	Prevalence (%) in child population	Distribution (%) among children with disabilities
Sight (blind/severe visual limitation)	100 345	0.6	23.0
Hearing (deaf, profoundly hard of hearing)	92 549	0.5	21.2
Intellectual (serious difficulties in learning)	68 550	0.4	15.7
Physical (e.g. needs wheelchair, crutches or prosthesis)	64 911	0.4	14.9
Multiple (combination of two or more)	44 790	0.3	10.3
Emotional (behavioural, psychological)	42 830	0.2	9.8
Communication (speech impairment)	22 148	0.1	5.1
At least one disability	436 123	2.5	100.0

(Source: UNICEF South Africa computation based on Census 2001)

Table 2.6: Children reported to have any severe disability (2001)

	Sight (blind/ severe visual limitation)	Hearing (deaf, profoundly hard of hearing)	Communication (speech impairment)	Physical (e.g. needs wheelchair/ crutches/ prosthesis)	Intellectual (serious difficulties in learning)	Emotional (behavioural, psychological)	Multiple (combination of two or more)
Sex							
Male	50 498	44 987	12 766	35 405	36 491	23 146	23 399
Female	49 847	47 562	9 382	29 506	32 058	19 684	21 390
Age group							
0-4 years	15 577	15 705	3 814	11 993	9 494	7 166	7 577
5-9 years	26 002	27 552	7 068	17 861	17 708	11 063	12 176
10-14 years	34 715	31 981	6 805	21 183	25 434	14 763	14 982
15-17 years	24 051	17 312	4 461	13 874	15 914	9 838	10 055
Population group							
Black African	92 418	84 963	19 707	56 491	56 124	38 297	34 493
Coloured	4 081	3 765	1 227	5 086	5 741	2 939	4 241
Indian/Asian	1 049	1 086	155	792	999	468	586
White	2 797	2 735	1 059	2 541	5 685	1 126	5 471
Province							
Western Cape	4 726	4 776	1 589	5 209	5 999	3 240	4 583
Eastern Cape	10 396	14 029	3 970	11 106	10 679	6 994	5 018
Northern Cape	1 444	716	140	1 339	1 087	486	644
Free State	11 480	6 230	1 274	3 752	4 682	2 792	5 001
KZN	21 812	26 346	5 730	18 103	16 550	10 402	9 609
North West	9 819	5 474	1 651	5 137	4 900	3 308	2 630
Gauteng	14 240	7 784	2 669	7 070	9 620	4 489	5 674
Mpumalanga	10 778	9 539	1 526	5 522	4 870	4 391	4 719
Limpopo	15 650	17 655	3 600	7 674	10 164	6 728	6 913
South Africa	**100 345**	**92 549**	**22 148**	**64 911**	**68 550**	**42 830**	**44 790**

(Source: UNICEF South Africa computation based on Census 2001)

Table 2.7: Prevalence (%) of different types of disabilities among children by province (2001)

	Sight	Hearing	Communi-cation	Physical	Intellectual	Emotional	Multiple
Western Cape	0.32	0.32	0.11	0.35	0.40	0.22	0.31
Eastern Cape	0.36	0.49	0.14	0.39	0.37	0.24	0.18
Northern Cape	0.47	0.24	0.05	0.44	0.36	0.16	0.21
Free State	1.13	0.61	0.13	0.37	0.46	0.27	0.49
KZN	0.55	0.67	0.15	0.46	0.42	0.26	0.24
North West	0.71	0.40	0.12	0.37	0.36	0.24	0.19
Gauteng	0.57	0.31	0.11	0.28	0.38	0.18	0.23
Mpumalanga	0.82	0.72	0.12	0.42	0.37	0.33	0.36
Limpopo	0.63	0.71	0.14	0.31	0.41	0.27	0.28
South Africa	0.58	0.53	0.13	0.37	0.40	0.25	0.26

(Source: UNICEF South Africa computation based on Census 2001)

2.4 Health conditions associated with child disability

As noted in the *2011 World Report on Disability*, there are three broad health conditions associated with disability: (1) infectious diseases such as HIV and AIDS, TB, encephalitis, meningitis, measles, mumps and poliomyelitis, malaria; (2) non-communicable chronic diseases such as diabetes, mental disorders, cancer, respiratory illnesses; and (3) injuries caused by, for example, road traffic accidents, violence or humanitarian crises.

However, the relationship between health conditions and disabilities is complicated and determined by inter-related factors. Health conditions are strongly influenced by a child's exposure to environmental factors such as malnutrition, or access to sanitation or health care. Table 2.8 describes risk factors and resultant health conditions associated with childhood disability in a framework of five periods during the life cycle of young children, occurring: before birth (during pregnancy, antenatal, prenatal); at birth (neonatal); after birth (peri-natal); during infancy (under one year); and/or during early childhood (1-5 years).

Table 2.8: Summary of risk factors for child disability

Risk factor	Predisposing factors	Resultant health conditions	Impairment/disability
1. Risk factors occurring before birth (during pregnancy, antenatal, prenatal)			
Birth defects[69] and congenital disorders[70]	Genetics/hereditary	Congenital heart disease Congenital cataract Congenital deafness Down Syndrome Neural tube defects Hydrocephalus	Mobility Cognitive Seeing Hearing
Environmental (infections, nutritional, toxic, traumatic)	Viral infections	Congenital rubella/syphilis	Mobility Cognitive Seeing Hearing
	Intake by mother (alcohol, smoking, medication)	FASD Attention Deficit Disorder	Cognitive
Multifactorial		Asthma, Insulin-dependent diabetes Renal disease	
2. Risk factors at birth (neonatal)			
Prematurity Birth Complications	Low birth weight Birth asphyxia Hypothyroidism Jaundice Meningitis	Developmental delay Epilepsy Intellectual disability Retinopathy of prematurity	Physical Intellectual disability (Psychopathology is high in children, boys having more behavioural problems than girls[71]) Visual impairment
Infections	HIV mother-to-child transmission	HIV encephalopathy	Neurodevelopmental disability[72] Those who survive (prevalence 2.1%) without early treatment have a high prevalence of cognitive, visual spatial and motor deficits[73] and neurological impairment Neurodevelopmental delay – severe motor, language, cognitive
	Cerebral malformations Seizure disorders Severe birth asphyxia Stroke Central Nervous System (CNS) infections Meningitis TB meningitis	Cerebral palsy	Mobility Cognitive

69 Birth defect is an abnormality of body structure or function present at birth.
70 Congenital disorder is any potentially disabling condition arising before birth.
71 Molteno, G. et al. (2001) 'Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town', South Africa, in *Journal of Intellectual Disability Research,* December, 45(6):515-520.
72 Neurodevelopment Disability is a functional limitation due to a neurological disorder with an onset early in life and occurring across a range of domains: cognition, movement, seizure disorders, vision, hearing and behaviour. Causes may be genetic, congenital, infectious, nutritional, toxic or traumatic.
73 Abubakar, A. et al. (2008) 'Paediatric HIV and neurodevelopment in sub-Saharan Africa: a systematic review', in *Tropical Medicine and International Health*, July, 13(7): 1-8.

Risk factor	Predisposing factors	Resultant health conditions	Impairment/disability
3. Risk factors after birth (perinatal)			
Infections Injuries	CNS infections	Cerebral palsy, epilepsy, HIV, ID, rheumatic heart disease	Mobility Cognitive
4. Risk factors during infancy (under one year)			
Infections	High fevers Febrile convulsions Dehydration	Encephalitis Bacterial meningitis	Cognitive Hearing – deafness Visual – blindness
5. Risk factors during early childhood (1-5 years)			
Infections	Lack of Vitamin A	Measles results in corneal scarring	Visual
	Unhygienic conditions	Polio	Mobility
	Upper respiratory tract infections (URTI) and neglected ear care	Otitis media	Mild to moderate hearing loss
	Mosquitoes and lack of nets	Malaria (especially cerebral malaria)	Cognitive Mobility
	Unhygienic conditions	Encephalitis, meningitis	
Parasites			
Ingestion of eggs of the pork tapeworm	Parasitic disease of CNS – neurocycicercosis	Acquired epilepsy	Intellectual Cognitive Motor deficits
Intestinal worms	Unhygienic conditions around the house, e.g. worm eggs in the ground; lack of water to wash hands before eating	Anaemia	Intellectual Cognitive
Bilharzia	Bathing and using water from contaminated rivers		
Risk factor	Predisposing factors	Resultant health conditions	Impairment/disability
Child injury			
1. Child injury – Non-intentional (accidental)	Falls, burns and thermal injuries due to: Failure of care by parents/ caregivers Environmental hazards Poor or absent safety standards Unattended or defective paraffin appliances Unattended poisons, etc.	Head injury Traumatic brain injury Spinal cord injury Amputation of limbs Burns	Mobility Psychological Aggressive behaviour Cognitive
2. Child injury – Intentional (non-accidental)	Trauma Violence	Anxiety Depression Post-traumatic stress disorder, etc.	
3. Child abuse – Physical, emotional, sexual, child neglect			

Risk factor	Predisposing factors	Resultant health conditions	Impairment/disability
Malnutrition			
In South Africa 1 in 3 children nationwide experience hunger or are at risk for hunger[74, 75]			
Child undernutrition	Protein energy malnutrition	Underweight for age[76] Stunting[77] – sign of chronic malnutrition Wasting – sign of acute malnutrition, lack essential nutrients, strong predictor of mortality	Developmental delays Mobility Psychological Impaired cognitive function
Micronutritient deficiencies	Mineral deficiencies (e.g. iodine, iron, foliate) Vitamin deficiencies (e.g. Vitamin A)[78] Iron deficiency – linked to insufficient iron intake, worm infestations	Delayed physical and mental growth Decreased resistance to infections (e.g. measles) Iron deficiency anaemia[79] Attention Deficit Hyperactivity Disorder	Mobility Cognitive deficits Mild intellectual disability Learning disabilities Behavioural disabilities (aggressive behaviour) Psychiatric (mental) disability
Environmental			
Unclean water Lack of sanitation	Compromised immunity to infections Linked to malnutrition	Diarrhoeal diseases Intestinal worms Eye ailments Skin ailments (eczema, impetigo)	Visual Cognitive – learning
Toxins: Pollution			
Air pollution: Inside Outside	Smoke Smog	Lower respiratory tract infections Asthma Respiratory diseases, e.g. pneumonia, chronic cough Eye problems Cancer Leukaemia	Mobility Visual Cognitive
Lead	High levels of lead in the blood	Long-term health problems, potentially irreversible Anaemia and abnormal growth of almost all organs Permanent muscle paralysis Brain damage – lowered IQ Hyperactivity and difficulty concentrating, reading and learning, difficulties at school	Mobility Visual Cognitive

74 SAHRC & UNICEF (2011) South Africa's Children: A Review of Child Rights and Equity.
75 UNICEF (2010) 'Inequities in the Fulfilment of Children's Rights in South Africa: A Statistical Review'. Background document for UNICEF's Strategic Moment of Reflection. October.
76 UWFA is associated with apathy, less positive affects, lower levels of play and more insecure attachment. (Walker et al. 2007)
77 Stunting is associated with reduced years in school and poor academic performance.
78 Vitamin A is essential for eye health and optimal functioning of the immune system.
79 Iron deficiency anaemia inhibits cognitive development, increases vulnerability to infections and cardiac failure.

2.5 Early intervention and detection of children with disabilities

Early detection of disabilities is crucial to ensuring that children receive effective treatment and rehabilitation. Many underlying health conditions and impairments of young children can be remedied in a cost-effective manner, but in the absence of early intervention they may lead to long-term disadvantage. The UN Committee on the Rights of the Child therefore recommends that

> *… governments establish systems of early identification and early intervention as part of their health services, together with birth registration and procedures for following the progress of children identified with disabilities at an early age. Services should be both community- and home-based, and easy to access. Furthermore, links should be established between early intervention services, pre-schools and schools to facilitate the smooth transition of the child.*[80]

2.5.1 Early detection and intervention measures in the health system

Developmental screening involves the detection of disability in children within the primary health care (PHC) setting, often during immunisation visits. The purpose of screening is to ensure that children 'at risk' are identified and referred for further assessment and intervention as necessary. Screening involves assessing children's progress against developmental milestones (sitting, crawling, standing, walking, talking and handling objects) as well as examining vision and hearing. As a child's development is exponential during the first three years of life, developmental screening is a particularly effective measure for early identification of potential problems, and thus for early intervention.[81]

However, to date, early detection does not appear to be foremost among the health care priorities for children in South Africa and there is currently no national screening programme being implemented.[82,83] Although the last decade has seen initiatives on developmental screening in the Western Cape, PHC facilities in the other provinces have not been able to support such a programme.[84] Moreover, even in the Western Cape delivery was found to be limited. A formal evaluation conducted in 2003 revealed a number of difficulties with implementation: almost one in four facilities did not deliver any developmental screening; only one in nine facilities conducted screening according to protocol; and no register of children identified as being at risk was kept.[85]

Swanepoel et al. (2009) reported significant delays in diagnosis and intervention for infants who are born with, or acquire in the first few weeks of life, permanent bilateral hearing loss. While the critical intervention period is before 6-9 months of age, studies in the Western Cape and Gauteng provinces found that the average ages were about two years for diagnosis; three years for initial hearing aid fitting; and three and a half years for enrolment in early intervention. Swanepoel et al. estimate that fewer than one in 10 public hospitals provide some form of infant hearing screening and less than one percent provide universal screening.[86]

Stakeholder consultations conducted as part of this situation analysis of children with disabilities identified a lack of training with regard to identification of disabilities in the health sector and insufficient trained therapist capacity at the clinic level as key barriers preventing effective early detection.[87] This was confirmed during focus group discussions with caregivers of children with disabilities, where several accounts were given of doctors giving false assurances to parents that their children 'would be fine'.[88] Medical personnel who are often unaware of what services or referral options are available further compound problems with early detection, and as a result children may be referred inappropriately, or not referred at all.

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80 UNCRC (2006) General Comment No. 9: The rights of children with disabilities. p.16
81 Baez, C. (2000) 'Developmental Screening in Children: News from the Districts' in Health Systems Trust *Update*, 52:19-20.
82 National Stakeholder workshop, 24 May 2011. Burgers Park Hotel, Pretoria: Health Group.
83 Yezingane Network (2011) *Children's HIV and AIDS Scorecard 2011: Monitoring South Africa's response to children and HIV and AIDS*. Children's Rights Centre.
84 Saloojee, H. & Bamford, L. (2006) 'Key childhood health promotion and disease prevention programmes' in *South African Health Review 2006*. Durban: Health Systems Trust. pp. 181-202.
85 Children's Institute UCT (2003) *Evaluation of the Western Cape Province Screening Programme for Development Disabilities in Pre-School Children: Full research report*. Children's Institute: University of Cape Town. Available: http://web.uct.ac.za/depts/ ci/pubs/pdf/health/poldraft/wcdsp.pdf
86 Swanepoel, D.W., Storbeck, C. & Friedland, P. (2009) 'Early hearing detection and intervention in South Africa' in *Int. J. Pediatr. Otorhinolaryngol*. June, 73(6):783-786.
87 National Stakeholder workshop, 24 May 2011.
88 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.

In 2011, the Department of Health revised the Road to Health booklet (RtHB) to include a potential tool for the identification of children 'at risk' of disability. The RtHB is a parent-held record distributed to all newborns at state and private facilities, and designed to assist health workers in monitoring the growth and development of a child. In the revised booklet, health practitioners are required to indicate if there is 'any disability present' under the 'details of child and family' section. The booklet also contains a developmental screening chart with the domains of: (a) Vision and adaptive [behaviour]; (b) Hearing and communication; and (c) Motor development. Milestones are shown for 14 weeks, six months, nine months, 18 months, three years and 5-6 years. A child is to be referred to a therapist if they have not achieved a particular milestone.

2.5.2 Detection of disability in the education system

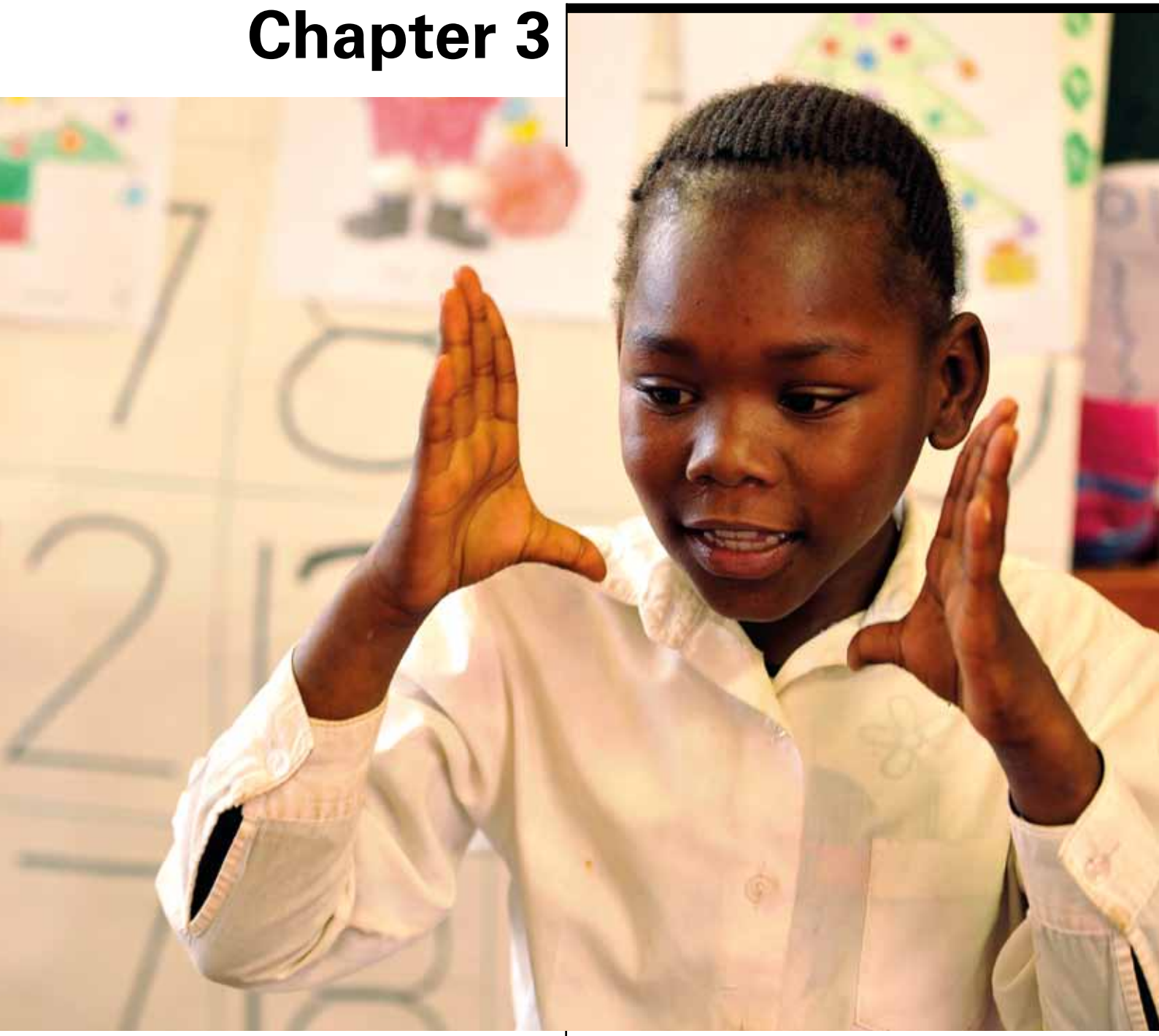
If not already determined before entering school, identification of a child's disability in mainstream schools often occurs late or not at all. Many educators lack adequate assessment skills and are unable to determine the level of a child's impairment and the type of support required. A lack of provision of timely support results in learners not being able to achieve to their maximum academic potential.

Efforts to implement a standardised assessment protocol in South Africa's education system are ongoing. In 2008, the Department of Education launched the National Strategy on screening, identification, assessment and support (SIAS). It serves as an assessment tool that assists educators in determining the nature of a child's disability in terms of educational support needs. SIAS builds on the international ICF framework and focuses on barriers to learning and development, rather than health conditions or impairments. Training of educators in the use of the SIAS assessment tool started in 2007, and to date over 28 000 educators have been trained. SIAS is presently being legalised through publication in the Government Gazette, after which it will be rolled out and implemented nationwide.[89]

Screening for disability through school health programmes is being strengthened as are South Africa's efforts to 're-engineer' PHC in the country.[90] School health programmes are considered an essential element of a comprehensive package of PHC services that must be delivered to every school in the country, targeting all children attending learning sites, including children with special needs. The envisaged school health service package includes a health assessment of all new learners. All children entering Grade 1 are to undergo an assessment of hearing, vision, speech and gross motor function. When delays or difficulties are identified, children should be referred for further assessment, treatment or remediation.

89 Key informant interviews. National Department of Basic Education. Inclusive Education Directorate.
90 Rispel, L. et al. (2010) *Revitalising Primary Health Care in South Africa. Review of Primary Health Care package, norms and standards.* Johannesburg: Centre for Health Policy, School of Public Health, University of Witwatersrand. November. p.86.

Chapter 3



Story telling time at MC Kharbai School for the Deaf. The children are taught how to sign, and on Saturdays parents can come to the school to learn sign language for free.

3.1 Inequities in access to services

3.1.1 Poverty and access to an adequate standard of living

The right of every child with a disability to an adequate standard of living is recognised in the South African Constitution, UNCRC, ACRWC and the UNCRPD. While parents have primary responsibility for their children, the State has an obligation to support them in the role of protecting and promoting the wellbeing of their children, particularly in situations of poverty.

According to the *World Report on Disability,*[91] data in developing countries on whether having a disability increases the probability of being poor are mixed. A World Bank analysis of 14 household surveys in developing countries, including Stats SA's GHS 2005, found that children with disabilities do not live in systematically wealthier or poorer households than their non-disabled counterparts. Adults with disabilities, however, do typically live in poorer than average households – a reflection of lower educational attainment compared to non-disabled adults.[92]

The impact of inadequate living conditions is particularly negative for children with disabilities. According to Stats SA's Community Survey 2007, children with disabilities are less likely to have access to adequate housing, water and sanitation than their non-disabled peers, although the differences between disabled and non-disabled children are relatively small. About 57 percent of children with disabilities live in permanent houses (house or brick structure) compared with 62 percent of non-disabled children (Table 3.1). Children with disabilities are more likely to live in traditional dwellings and informal settlements than their non-disabled counterparts. The latter fact probably explains why children with disabilities have somewhat lower access to adequate water and sanitation (Table 3.2 and Table 3.3).

In a focus group discussion[93] with children living in a rural area of KZN, a boy with a physical disability described how he had to walk a long distance to fetch water for his family, using a wheelbarrow, because water tanks are far from the homesteads and accessible only on gravel roads or paths. Overcrowded living conditions and outside toilets place enormous stresses on children with disabilities and their families. Clacherty et al.[94] found poor and cramped housing to be a significant barrier to the increasing independence and abilities of the children with disabilities.

Table 3.1: Percentage distribution of children by type of dwelling (2007)

	Non-disabled children (%)	Disabled children (%)
House or brick structure on a separate stand or yard	61.7	56.8
Traditional dwelling/hut/structure made of traditional matter	19.8	23.5
Informal dwelling/shack NOT in backyard, e.g. an informal/squatter settlement	7.9	9.7
Informal dwelling/shack in backyard	3.4	3.1
House/flat/room in backyard	1.9	2.1
Flat in block of flats	2.7	2.0
Town/cluster/semi-detached house (simplex, duplex, triplex)	1.6	1.6
Other	1.0	1.2
Total	**100.0**	**100.0**

(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

91 World Health Organisation & World Bank (2011) *World Report on Disability*. Geneva: WHO & World Bank.
92 Filmer, D (2008) 'Disability, Poverty, and Schooling in Developing Countries: Results from 14 Household Surveys' in *World Bank Economic Review.*January, 22(1):141-163.
93 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
94 Clacherty, G., Matshai, K. & Sait, W. (2004) *How Do Children with Disabilities Experience Poverty, Disability and Service Delivery? A Report on Participatory Workshops*. IDASA: Cape Town.

Table 3.2: Percentage distribution of children by main source of water in the household (2007)

	Non-disabled children (%)	Disabled children (%)
Piped water inside the dwelling or yard	59.6	54.3
Piped water from access point outside the yard	22.3	24.0
Borehole	3.5	3.9
Spring	1.8	2.1
Dam/pool	0.8	1.0
River/stream	9.3	12.0
Water vendor	1.1	1.1
Rainwater tank	0.8	0.7
Other	0.8	0.9
Total	**100.0**	**100.0**

(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

Table 3.3: Percentage distribution of children by main type of toilet facility available to the household (2007)

	Non-disabled children (%)	Disabled children (%)
Flush toilet (sewerage system or septic tank)	44.2	39.1
Dry toilet facility	5.5	5.0
Pit toilet with ventilation	9.0	10.5
Pit toilet without ventilation	27.0	27.9
Chemical toilet	0.4	0.3
Bucket toilet system	2.1	2.3
None	11.8	14.9
Total	**100.0**	**100.0**

(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

3.1.2 Early learning and education

Section 29 of the South African Constitution indicates that all children are guaranteed the right to a basic education and to further education which the State, through reasonable measures, must make progressively available and accessible. Likewise, according to the UN Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD), children with disabilities have the same right to education as all other children, and shall enjoy this right without any discrimination and on the basis of equal opportunity.

Early learning

There is little national evidence available on access to early learning for pre-school children with disabilities. One small-scale study of disabled children living in a peri-urban township of Orange Farm in Gauteng found that only 35 percent of children aged three years and over were attending pre-school.[95] Another study found that only a quarter of children aged 0-6 years and who were recipients of the CDG, attended a crèche or child-

95 Saloojee, G., Phohole, M., Saloojee, H., & IJsselmuiden, C. (2007) 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township' in *Child: care, health and development*. 33(3):230-235.

minding group.[96] Where children with disabilities do have access to early learning, it often takes place within informal community settings, with individuals (such as mothers of disabled children) running stimulation programmes.

Access to education

The Department of Basic Education has made progress towards ensuring that children with disabilities can access basic education, based on the policy of inclusive education (Table 3.4). Currently, some 110 300 learners with disabilities are attending ordinary public schools. In addition, 423 special needs schools nationwide are catering for approximately 105 000 learners. The number of full-service schools (FSSs) – schools that are equipped to support a range of disabilities – has grown from 30 in 2008/09 to 513 in 2010/11.[97]

Table 3.4: Indicators on inclusive education for special schools, full-service schools and ordinary schools

	2008/09	2009/10	2010/11
Special schools			
Number of special schools	413	418	423
Number of learners in special schools	96 535	100 717	104 633
Number of teaching staff	8 057	8 618	8 781
Number of support staff at special schools	5 381	6 108	4 988
Number of special schools with hostel facilities	219	260	261
Number of special schools converted to resource centres	30	60	120
Number of special schools with Grade R	112	121	134
Full-service schools			
Number of full-service schools	30	91	513
Ordinary public schools			
Number of schools	25 875	25 906	25 850
Number of learners with disability in ordinary public schools	96 653	82 211	110 273

(Source: Department of Basic Education, EMIS data from annual schools surveys 2011)

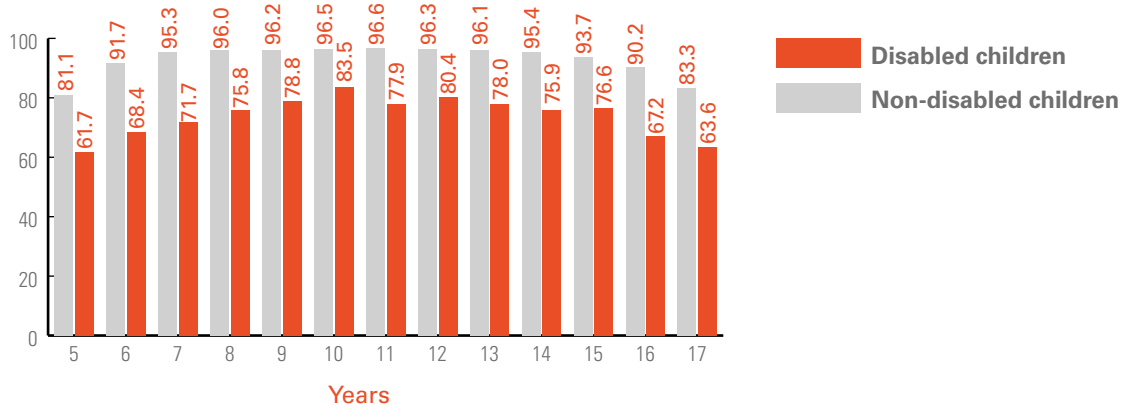
Nonetheless, evidence from surveys suggests that children with disabilities are substantially less likely to attend school than their non-disabled peers. According to the 2007 Community Survey, school attendance among non-disabled children of compulsory school age (7-15 years) was 96 percent, compared with only 78 percent among children with reported disabilities – nearly 20 percentage points lower (Figure 3.1). At provincial level, school attendance among children with disabilities is lowest in North West (70%), while those living in Gauteng and Mpumalanga are substantially more likely to attend school (82%) (Figure 3.2). Trend analysis on the basis of GHS data suggests that access to education for children with disabilities has not improved between 2002 and 2008 (Figure 3.3).

Communication disabilities appear to be the biggest barrier to access education; school attendance among children with speech impairment is only 64 percent. School attendance among children who are blind or have a severe visual limitation is substantially higher at 91 percent (Figure 3.4).

96 De Koker, C., de Waal, L. & Voster, J. (2006) *A profile of social security beneficiaries in South Africa.* Datadesk. Department of Sociology and Social Anthropology: Stellenbosch University.

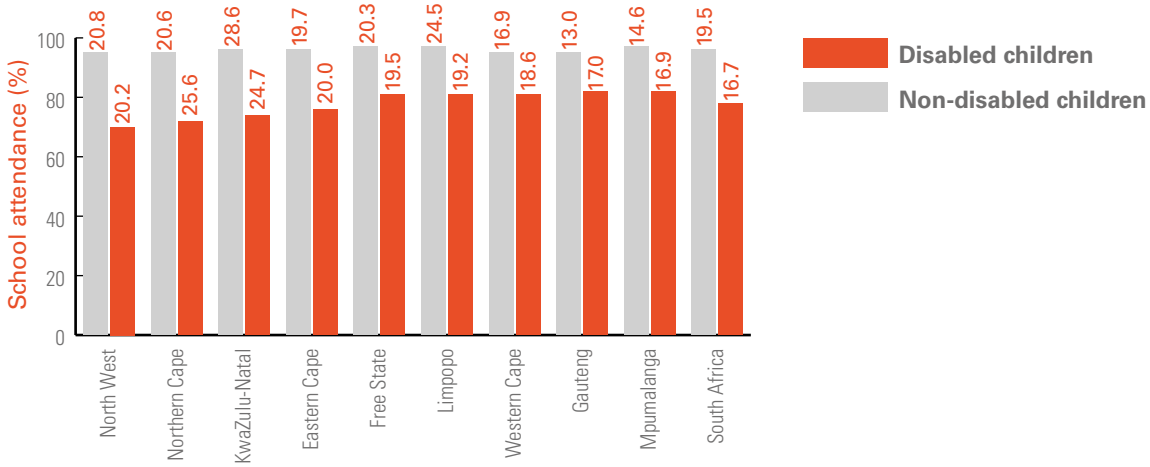
97 Department of Basic Education (2010) *Report on the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in Education.*

Figure 3.1: Percentage of children attending an educational institution by age and disability status (2007)



(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

Figure 3.2: Percentage of children of compulsory school age (7-15 years) attending an educational institution by province and disability status (2007)



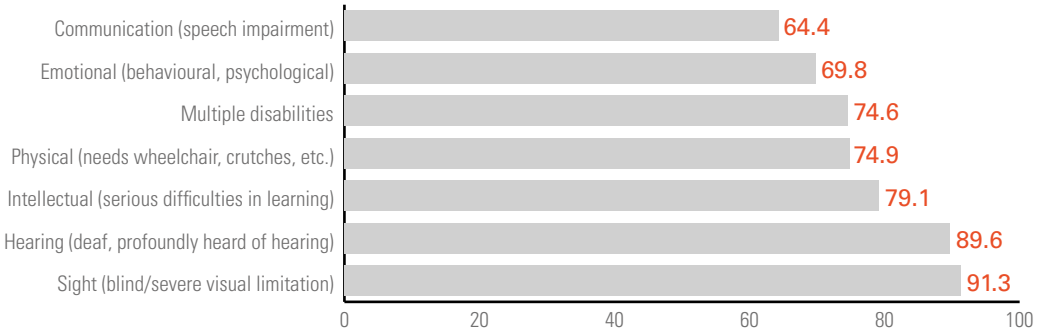
(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

Figure 3.3: Percentage of children with a disability of compulsory school age (7-15 years) attending an educational institution (2002-2008)



(Source: UNICEF South Africa computation based on Stats SA General Household Surveys 2002-2008)

Figure 3.4: Percentage of children with a disability of compulsory school age (7-15 years) attending an education institution by type of disability (2007)



(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

Likewise, a study investigating the link between disability and poverty in the Eastern Cape and Western Cape provinces (2008)[98] found that among those children of school age (5-18 years), a higher proportion of children with disabilities had never attended school (12% in the Eastern Cape and 22% in the Western Cape) compared with children without disabilities (1% in the Eastern Cape and 4% in the Western Cape).

Among those children with disabilities who do get access to schooling, drop-out rates are higher than for those who are not disabled. At the launch of the *Access to Education* report it was reported that 37 percent of disabled youth (between 16-18 years) had dropped out of school, compared to 14 percent of youth (between 16-18 years) without disability.[99]

3.1.3 Health and rehabilitation

The UNCRC requires governments to ensure that children with disabilities enjoy "the highest attainable standard of health and access to facilities for the treatment of illness and rehabilitation of health". There is, unfortunately, a paucity of evidence-based publications on the health conditions of South African children with disabilities and their access to general health care services. National health surveys (such as the Demographic and Health Survey) and administrative data collection systems (such as the District Health Information System) typically do not differentiate between children with and without disabilities. This lack of data on the health status of children with disabilities renders it difficult to identify disparities in common health indicators.

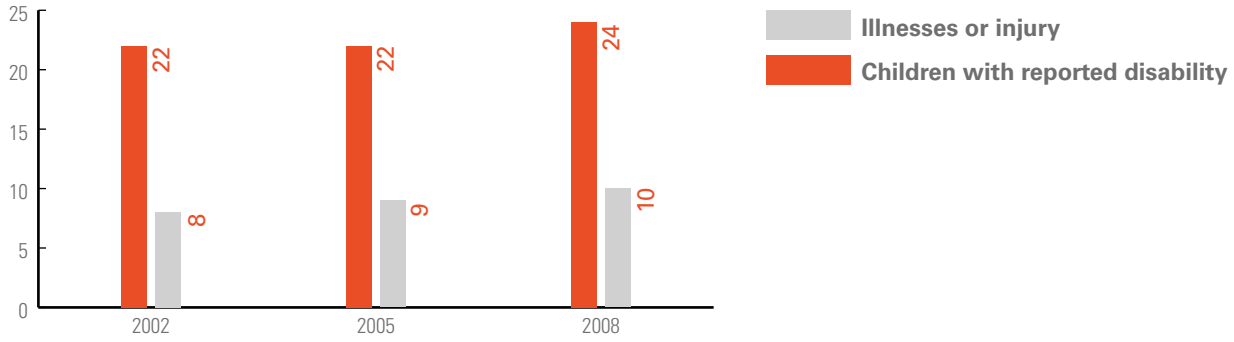
General health status

Parents of children with disabilities are more likely to report that their children suffer from illnesses and poor health than parents of non-disabled children. Findings from the annual GHS between 2002 and 2008 consistently indicate that children with reported disabilities are 2.5 times more likely to be ill or injured than their non-disabled counterparts (see Figure 3.5).

98 Loeb, A., Eide, A.H., Jelsma, J., Toni, M. & Maart, S. (2008) 'Poverty and disability in Eastern and Western Cape Provinces, South Africa' in *Disability & Society,* 23 (4), June: 311–321.

99 Seekoei, K. (2010) 'Disabled at risk of dropping out', *Mail and Guardian* online, November 30. This report, based on data from 4 400 households across the country in 2007, was conducted by Social Surveys and the Centre for Applied Legal Studies: Wits.

Figure 3.5: Percentage of children (under 18 years of age) reported to suffer from any illnesses or injuries during the month prior to the survey by disability status (2002-2008)



Note: Differences between percentages are statistically significant at the one percent level (Pearson's chi-square test, p-values<0.0005)

(Source: UNICEF South Africa computation based on Stats SA [2003, 2006 and 2009] General Household Survey 2002, 2005 and 2008)

Mortality

Little is known about long-term survival and mortality rates of children with disabilities in South Africa and elsewhere. A small body of literature mostly from high-income countries suggests that people with disabilities have a higher risk of premature death, though mortality rates vary depending on the health condition.[100] For example, research conducted in the UK[101] found that mortality rates among people with learning disabilities are three times higher than in the general population. A study in Bangladesh[102] suggests that young rural children with cerebral palsy may have higher rates of premature death.

Immunisation

No data is available on immunisation coverage among children with disabilities in South Africa. Globally, while there is limited evidence regarding the immunisation of children with disabilities, initial data shows that children and adolescents with disabilities are at a significant risk of not being included in immunisation efforts in a timely and effective manner, and are consequently at an increased risk of preventable illness and death.[103]

Disabled peoples' organisations (DPOs) and organisations of parents of children with disabilities (parent organisations) should provide significant collaboration and assistance to public health officials in order to ensure that children with disabilities and their families as well are parents who are themselves disabled are effectively informed and included in all immunisation efforts.[104]

Nutrition

Nutrition and disability are closely linked, although there has been relatively little attention to this issue. Lack of enough food, or a poorly balanced diet lacking certain vitamins and minerals (iodine, Vitamin A and Vitamin D, for example), can leave infants and children open to a host of infections or to specific conditions that can lead to physical, sensory (deafness, blindness) or intellectual disabilities.[105]

Globally, disabled children are also equally at risk for becoming malnourished. Children who are born with a disability (cerebral palsy, for example) or who become disabled may encounter difficulties in chewing and

100 World Health Organisation (2011). *World Report on Disability 2011.*
101 Emerson, E. & Baines, S. (2010) *Health Inequalities & People with Learning Disabilities in the UK: 2010.* Stockton on Tees: Improving Health and Lives: Learning Disabilities Observatory.
102 Khan, N.Z. et al. 'Mortality of urban and rural young children with cerebral palsy in Bangladesh' in *Developmental Medicine and Child Neurology* (1998) 40:749-753.
103 Ibid.
104 UNICEF (2012). *Disability Prevention Efforts and Disability Rights: Finding Common Ground on Immunization Efforts.* UNICEF Working Paper, New York.
105 Gakidou, E, et al. 'Improving child survival through environmental and nutritional interventions: the importance of targeting interventions toward the poor' in *JAMA: Journal of the American Medical Association,* 2007, 298:1876-1887. doi:10.1001/jama.298.16.1876 PMID:17954539.

swallowing that can have significant or severe nutritional implications. Children with some types of physical or intellectual disabilities may have difficulty feeding themselves.[106] Additionally, children with some disabilities will need specific diets or increased caloric intake if they are to maintain a healthy weight. Children who are obese are also at risk of long-term disability.[107]

A review of data collected in 20 countries worldwide by UNICEF[108] suggests that children who are at high risk for disability might also be at risk of malnourishment and micronutrient deficiencies. Research on this issue is required in South Africa.

HIV and AIDS

There are no official statistics of HIV and AIDS prevalence among persons with disabilities in South Africa, and the absence of quantitative data is a serious limitation to understanding the extent of the epidemic in this sector. A study in one district of KZN[109] found that youth with disabilities have generally been exposed to messages about HIV and are aware of basic risk factors. However, they still had many misconceptions surrounding modes of transmission and there is uncertainty about the authenticity of the information received. This study revealed a gap between knowledge of HIV and actual behaviour change, particularly in terms of sexual practices. It concluded that due to negative community beliefs surrounding disability and sexuality, low self-esteem and lack of awareness of sexual and reproductive rights, youth with disabilities are more vulnerable to abusive and unhealthy relationships, and are therefore more at risk of HIV, compared to their non-disabled peers.

In 2009, an informal outreach programme[110] conducted at five schools for the deaf in the Eastern Cape, the Free State and KZN found that deaf children lack knowledge about HIV and AIDS, sex education, rape, abortion, abuse and harassment. In instances where they receive life skills programmes, deaf children are not always able to understand the teachers, as often this information is not given in SASL and/or no deaf people are involved as trainers. The difficulty with access to information on HIV for children with disabilities is compounded by the fact that a high number of youth with disabilities are out of school, and therefore they do not benefit from school-based prevention and information programmes.

Rehabilitation

The few studies on the unmet rehabilitation needs of children with disabilities in South Africa were conducted almost a decade ago. According to a study of 156 disabled children in a peri-urban township in Orange Farm, Gauteng, only a quarter (26%) of children in need of rehabilitation received such services; of the 233 assistive devices required, only 64 (28%) had been issued.[111] Children with motor impairments were found to be significantly more likely to receive rehabilitation than those with intellectual disability. Likewise, a study conducted in Manguzi in KZN found that the rehabilitation staff at the local hospital interacted with just 35 percent of the children requiring rehabilitation services.[112] Research co-ordinated by the Department of Social Development in Mpumalanga, in deep rural areas in Ehlanzeni, Nkangala and Gert Sibande districts,[113] found that only 42 percent of the children with disabilities identified were receiving rehabilitation and only 33 percent had the assistive devices they required. Some 59 percent reported that the caregiver did not know how to apply for an assistive device.

A recent study evaluating the management and implementation of rehabilitation services at a district level, within the context of the National Rehabilitation Policy of the Department of Health, found that despite the

106 World Health Organisation (2011) Developmental Difficulties in Early Childhood: Prevention, early identification, assessment and intervention in low and middle-income countries.
107 Ibid.
108 UNICEF (2010) *Inequities in the Fulfillment of Children's Rights in South Africa: A Statistical Review.* Background Document for UNICEF's Strategic Moment of Reflection. October.
109 Chappell, P. & Radebe, N. (2009) *HIV & AIDS and youth with disabilities: a baseline study of youth with disabilities living in uMgungundlovu District, KZN*. CREATE: Pietermaritzburg and Irish Aid.
110 Submitted by DeafSA, National Director Social Development Francis Prinsloo 23/05/2011 directordevelopment@deafsa.co.za
111 Saloojee, G., Phohole, M., Saloojee, H. & Ijsselmuiden, C. (2007) 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township', in *Child: Care Health and Development,* 33 (3):230-235.
112 Couper, J. (2001) *The prevalence of childhood disabilities in the Manguzi sub-district of KZN, South Africa.* MSc dissertation, Department of Community Health: University of Witwatersrand.
113 Department of Social Services, Population and Development (2002/03) *Report on the Status of Children with Disabilities in the Province of Mpumalanga*. Department of Social Services, Population and Development: Population Unit, Province of Mpumalanga.

call for CBR and the social model of disability to improve access and quality, rehabilitation services are still rooted within the medical model, resulting in poor outcomes for people with disabilities, including children.[114] Policies, norms and standards that aim to guide rehabilitation professionals working in the public health sector where the majority of children with disabilities access services, are not coherent which influences performance negatively and highlights the lack of service integration at an institutional level.

3.1.4 Child protection

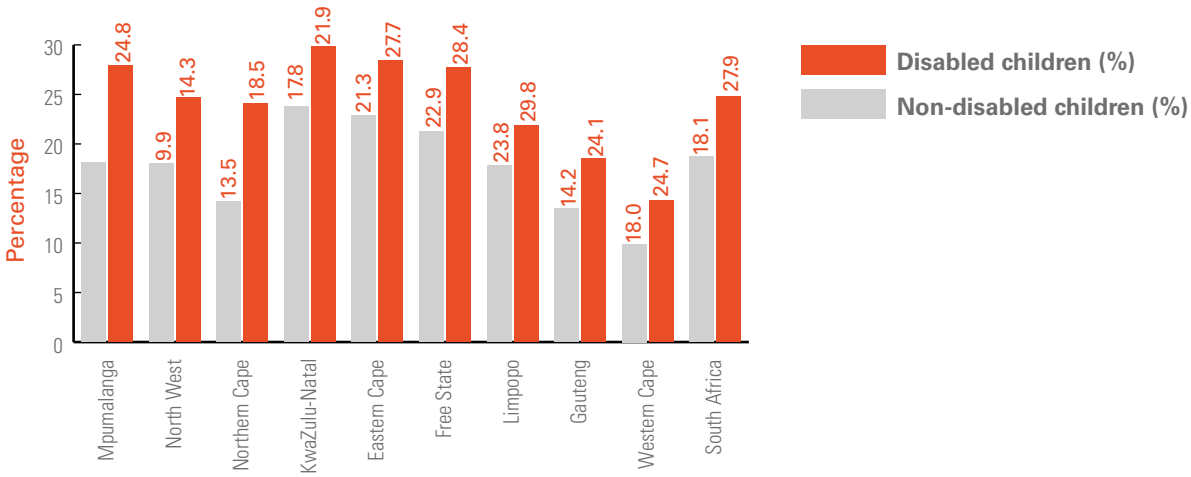
South Africa's Children's Act (2005) as amended is the primary legislation giving effect to the rights of children to protection from abuse and neglect, and to family care or appropriate alternative care when removed from the family environment. The Children's Act obliges the State to provide programmes which focus on "developing appropriate parenting skills and the capacity of parents and caregivers to safeguard the best interests of children with disabilities". The Act also provides for a range of options for alternative care – including foster care, child and youth care centres and temporary safe care.

Research on child protection in the context of disability is limited. The handful of studies that are available highlight the increased vulnerability of children with disabilities.

Children deprived of parental care

According to data from Stats SA's Community Survey 2007, children with disabilities are more likely to be orphaned than their non-disabled peers. One in four children with disabilities nationwide has lost one or both parents, compared to one in five among non-disabled children (Figure 3.6).

Figure 3.6: Percentage of children who have lost one or both parents by province and disability status (2007)



(Source: UNICEF South Africa computation based on Stats SA Community Survey 2007)

Children living in institutions

According to Census 2001, children with reported disabilities were 10 times more likely to be living in an institution than children without disabilities (5% versus 0.5%) (Table 3.5). Moreover, the percentage of disabled children living in an institution increased with age, from 1.2 percent among the 0-4 year-olds up to 9.7 percent among 15-17 year-olds. The breakdown by type of disabilities (Table 3.6) shows that children with multiple disabilities, in particular, were most likely to be living in institutions.

114 Dayal, H. (2009) *Management of rehabilitation personnel within the context of the National Rehabilitation Policy.* Masters dissertation, Department of Public Health: University of Witwatersrand.

A recent survey by the Department of Social Development obtained information on more than 13 000 children staying in registered child and youth care centres across the country, such as children's homes, places of safety and shelter.[115] About 28 per cent of these children were reported to have at least one type of disability. Yet, many centres are not equipped to cater for children with disabilities.

Table 3.5: Type of living quarters of children by age and disability status (2001)

Disability	Type of living quarters[a]	Age group				
		0-4 years	5-9 years	10-14 years	15-17 years	Total
No	Households	99.9%	99.8%	99.4%	98.5%	99.5%
	Institutions	0.1%	0.2%	0.6%	1.5%	0.5%
	Homeless					0.0%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Yes	Households	98.2%	97.5%	94.2%	90.1%	94.9%
	Institutions	1.2%	2.5%	5.7%	9.7%	5.0%
	Homeless	0.6%			0.2%	0.2%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**

a. 'Households' refers to children living in housing units and non-institutional collective living quarters (e.g. hotels or workers' hostels). 'Institutions' comprise hospitals, childcare institutions, boarding school hostels, homes for the disabled, initiation schools, convents, defence force barracks, prisons, community and church halls, and refugee camps. 'Homeless' refers to children with no form of shelter on census night and no known residential address.

(Source: UNICEF South Africa computation based on Stats SA Census 2001)

Pumla Mahlangu, 13 years, learns to read and write Braille.



115 Community Agency for Social Enquiry (CASE) (2010) *Baseline Study on Registered Child and Youth Care Centres.* Study conducted for UNICEF & National Department of Social Development.

Table 3.6: Type of living quarters of children by age and type of disability (2001)

Type of disability	Type of living quarters[a]	Age group				
		0-4 years	5-9 years	10-14 years	15-17 years	Total
Sight (blind, severe visual limitation)	Households	99.7%	99.5%	97.8%	96.0%	98.1%
	Institutions	0.3%	0.4%	2.1%	3.9%	1.8%
	Homeless			0.1%	0.1%	0.1%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Hearing (deaf, profoundly hard of hearing)	Households	99.5%	97.0%	93.3%	87.9%	94.4%
	Institutions	0.5%	3.0%	6.6%	11.8%	5.5%
	Homeless				0.3%	0.1%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Communication (speech impairment)	Households	99.2%	98.2%	95.9%	91.5%	96.3%
	Institutions	0.8%	1.7%	4.1%	8.5%	3.7%
	Homeless		0.1%			
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Physical (e.g. needs wheelchair, crutches or prosthesis; limb or hand-usage limitations)	Households	99.2%	98.1%	93.9%	90.8%	95.3%
	Institutions	0.8%	1.8%	6.1%	9.0%	4.6%
	Homeless		0.1%		0.2%	0.1%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Intellectual (serious difficulties in learning)	Households	99.3%	98.2%	95.6%	91.7%	95.9%
	Institutions	0.5%	1.6%	4.4%	8.1%	4.0%
	Homeless	0.2%	0.1%		0.2%	0.1%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Emotional (behavioural, psychological)	Households	96.8%	96.4%	96.5%	95.8%	96.4%
	Institutions	3.2%	3.6%	3.5%	4.0%	3.6%
	Homeless			0.1%	0.2%	0.1%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Multiple (combination of two or more of the above)	Households	90.1%	92.9%	83.1%	70.5%	84.1%
	Institutions	4.4%	7.1%	16.8%	29.4%	14.9%
	Homeless	5.5%		0.1%	0.1%	1.0%
	Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**

a. 'Households' refers to children living in housing units and non-institutional collective living quarters (e.g. hotels or workers' hostels). 'Institutions' comprise hospitals, childcare institutions, boarding school hostels, homes for the disabled, initiation schools, convents, defence force barracks, prisons, community and church halls, and refugee camps. 'Homeless' refers to children with no form of shelter on census night and no known residential address.

(Source: UNICEF South Africa computation based on Stats SA Census 2001)

Child abuse and neglect

Abuse of children with disabilities in South Africa is a hidden problem. A study on rights for disabled children in South Africa[116] found that NGOs reported widespread family violence, abuse and rape of children. The study also reported high profile press reports of sexual abuse and rape of disabled children in special schools, which never reached the courts. At times parents were reluctant to take action against the school for fear of the child losing their place at school. Violence has also been found to have a strong link with myths and taboos.[117]

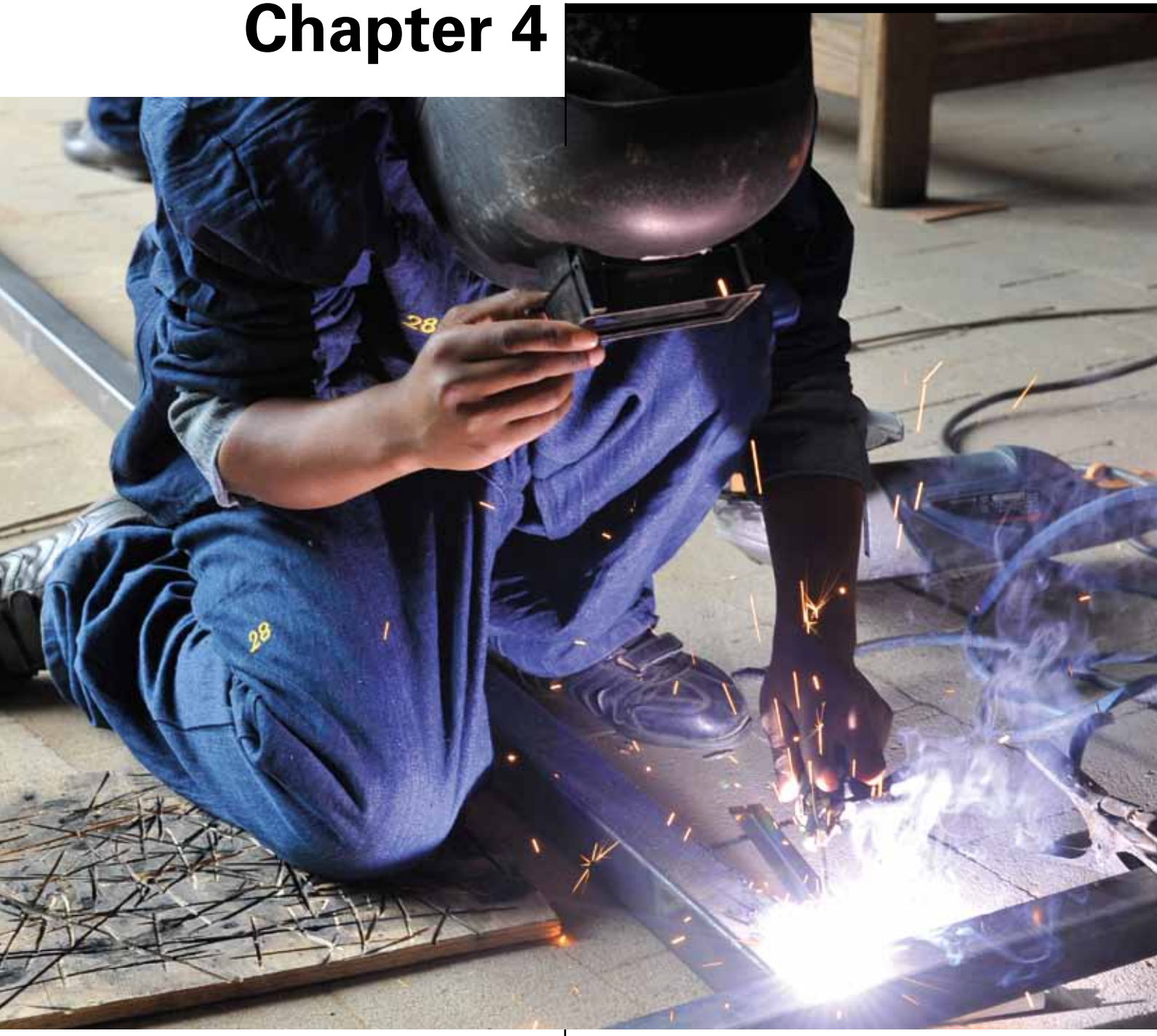
Research suggests that children with disabilities are two to five times more likely to be abused than their non-disabled peers.[118] Children with certain disabilities are prone to particular types of abuse: mentally and physically disabled children are at an increased risk of sexual abuse, whilst those with learning disabilities are especially vulnerable to neglect.[119]

Disabled children's vulnerability to sexual assault also appears high in institutions; studies show that 80-85 percent of criminal abuse of residents in institutions is never reported to authorities.[120] This is compounded by the lack of general information about, and understanding of, sexuality, particularly on the part of young people with intellectual disabilities.[121]

A study by Disabled Children's Action Group (DICAG)[122] found that in a sample of 36 cases of abuse of children with disabilities that came to trial, 14 were withdrawn, and there were eight acquittals and 14 convictions. The prime reason given for this was that "witnesses were seen as being incompetent" when (in many cases) the level of language used in court proceedings was too complex and not understandable to many of the victims.

116 Lansdown, G. (2002) *Disabled children in South Africa. Progress in implementing the Convention on the Rights of the Child*. Rights of Disabled Children. Swedish International Development Agency (SIDA).
117 Commission on Gender Equality (1998) *Report of the National Conference on Witchcraft Violence. Braamfontein*. 6-10 October.
118 Hesselink-Louw, A.E., Booyens, K. & Neethling, A. (2003) 'Disabled children as invisible and forgotten victims of crime' in *Acta Criminologica* 16 (2) 165-180.
119 Deroukakis, M. (2010) *A retrospective analysis of children with and without disabilities attending the Teddy Bear Clinic, Johannesburg*. A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfillment of the requirements for the Degree of Master of Science in Medicine: Paediatric Neurodevelopment. http://wiredspace.wits.ac.za/bitstream/handle/10539/8845/Marilena_Deroukakis_Final%20_Msc%28Med%29%20Child%20Health.pdf?sequence=1
120 Hesselink-Louw A.E., Booyens, K. & Neethling, A. (2003) 'Disabled children as invisible and forgotten victims of crime' in *Acta Criminologica* 16 (2) 165-180.
121 Dhai, A. (2003) Ethical and societal issues in the care and management of the intellectually disabled child as they grow up. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap. Johannesburg General Hospital, Gauteng.
122 Quoted by Hesselink-Louw et al. (2003).

Chapter 4



Pule Moloi in a welding class at Mashediso LSEN.

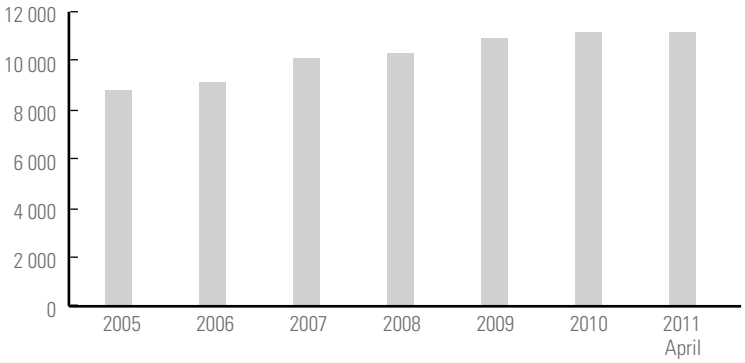
Several policy documents recognise successes with implementation of programmes to support children with disabilities, as well as the many barriers that continue to prevent them from participating fully in society. In the context of limited information, this chapter assesses the provision of key services that aim to enhance social participation of children with disabilities.

4.1 Care Dependency Grant

One of the core functions of the Department of Social Development is the provision of comprehensive social security, with the aim of reducing income poverty among poor and vulnerable South Africans.[123,124] The CDG is awarded in terms of the Social Assistance Act,[125] and is given to poor parents, foster parents or primary caregivers of children with disabilities who require permanent care but are not in state-run institutions.

It is impossible to calculate a take-up rate for the CDG because there is insufficient data on children with disabilities in need of permanent care.[126] Figure 4.1 shows a systematic increase in the number of recipients of the CDG. In April 2011, nearly 111 000 children were receiving the grant.

Figure 4.1: Number of children on the Care Dependency Grant



(Source: SASSA 2011)

The provincial distribution of CDGs is fairly consistent with the distribution of children in the country, with provinces with the largest numbers of children having the most CDG beneficiaries (see Table 4.1).

Khethiwe Stimulation Centre, Daveyton, is a centre for children with autisim, cerebral palsy, and mild and profound mental retardation.



123 Strategic Plan of the Department of Social Development 2010-2015.
124 Other functions are the provision of developmental social welfare and community development services.
125 The Social Assistance Act No. 13 of 2004 (7) states that a person is eligible for a CDG if they are "a parent, primary caregiver or foster parent of a child who requires and receives permanent care or support services due to his or her physical or mental disability".
126 http://www.childrencount.ci.org.za/

Table 4.1: Care Dependency Grant beneficiaries by province

Province	Recipients of CDG
Eastern Cape	18 171
Free State	4 837
Gauteng	13 628
KZN	33 598
Limpopo	12 546
Mpumalanga	6 003
North West	8 552
Northern Cape	4 001
Western Cape	9 257
Total	**110 593**

(Source: SASSA (2011) Beneficiary numbers by grant type)

The Department of Social Development and its grant implementation agency, the South African Social Security Agency (SASSA), are currently reviewing the assessment tool for the CDG, to make it more reliable as a targeting tool (see Box 4.1 for the CDG assessment process).

SASSA has made significant progress in reducing the turnaround time for grant applications and improving the appeals process for those that have been rejected. Currently, the turnaround time for CDG is one month.[127]

On composition of grant recipients, a 2006 national study into the profile of children in receipt of CDGs found that the most frequently mentioned reasons for receiving this grant[128] were intellectual impairments (26%), physical impairments (23%) and speech, intellectual and emotional impairments (10%).

Box 4.1: Application process and screening tool to determine eligibility for CDG

The CDG provides for children with severe disabilities who are in need of full-time and special care. Children who are cared for in state-funded institutions are not eligible. As of April 2011, the CDG is R1 140 per month. If a parent, primary caregiver or foster parent of a disabled child wishes to apply for a CDG, the following steps are taken:

1. They go to the SASSA office which is nearest to their home, with the following documents:
   - proof of South African citizenship or permanent residence;
   - baptismal certificate, Road to Health card and school report (if available);
   - medical assessment/report that confirms the child's disability; and
   - proof of marital status and proof of income (the applicant and spouse must meet the requirements of the means test).
2. The child is referred by SASSA for a state medical officer's assessment.
3. The application is completed with assistance from a SASSA official.

It may take up to three months to process an application. If the grant is approved, payment will be made from the date of application.

(Source: www.services.gov.za)

127 Key informant interviews in KZN.
128 De Koker, C., de Waal, L. & Voster, J. (2006) *A profile of social security beneficiaries in South Africa*. Datadesk. Department of Sociology & Social Anthropology: Stellenbosch University.

Research suggests that the CDG has a significant and positive impact on children and households that are recipients. A study into the profile of social security grant recipients[129] found that 98 percent of households in which a disabled child is a recipient of a CDG indicated that the grant had improved the general well-being of the household. Sixty-five percent indicated that the grant had improved their well-being considerably. Only two percent indicated that the well-being of the household had not been improved by the CDG. Significantly, 78 percent of CDG households also reported that improvement in household well-being was as a result of being able to purchase better quality food. For some (8%) the CDG was used to cover the costs of attending a medical facility, to purchase medicine (7%) or for improved housing (6%).

However, concerns have been raised about the limitations of the CDG in terms of coverage particularly because, to date, assessments to determine eligibility have been based primarily on determination of the severity of the health condition or impairment, without consistent and in-depth assessment of activity limitations and/or participation restrictions or environmental factors that may result in high levels of disability for the child.[130,131]

In addressing the persisting concerns around assessment for eligibility for the CDG, one of the strategic objectives of the Social Assistance Programme in the Department of Social Development's Strategic Plan 2010-2015 is to introduce legislation for the implementation of a common tool to assess disability.

Another concern is the danger that provision of the CDG may be seen as the only intervention required by children with disabilities,[132] thus eclipsing a focus on equalisation of opportunities through education, play and recreation, as well as health and rehabilitation services. Poverty and disability need to be viewed within the context of a multidimensional or livelihoods approach, which acknowledges the poverty-related factors that impact on disability and the disability-related factors that impact on poverty. Access to social security should therefore not be seen in isolation, but as a mechanism for building the capacity of the disabled child to survive and develop, and the ability of their households to extend their livelihood strategies, including increasing access to community activities and social networks.[133]

4.2 Assistive devices

An assistive device is any equipment or product "that is used to increase, maintain or improve the functional capacities of individuals with disabilities".[134] As part of support services for people with disabilities, assistive devices are recognised as being a precondition for the equalisation of opportunities, and a means of promoting independence, facilitating communication and participation, and improving the quality of life of adults and children with disabilities.[135]

In South Africa, assistive devices are provided by the Department of Health and at full-service schools (FSSs) and special schools as resource centres (SSRCs) by the Department of Basic Education.

4.2.1 Assistive devices provided by the Department of Health

It is difficult to report on the coverage of assistive devices as there is no database that systematically tracks the provision of these devices to children with disabilities in the country. The National Indicator Data Set (NIDS) of the Department of Health,[136] provides information on the provision of new wheelchairs, hearing aids and walking aids. Unfortunately, these national indicators do not include data on assistive devices for people with visual impairments. The data is also not disaggregated by age, and therefore does not allow for the monitor-

129 De Koker, C., de Waal, L. & Voster, J. (2006) A profile of social security beneficiaries in South Africa. Datadesk. Department of Sociology and Social Anthropology: Stellenbosch University.
130 Nkeli, J. & Associates (2008) 'Broad overview of the impact and an analysis of the effectiveness and efficiency of disability policy implementation in all spheres of government since 1994'.
131 Many of these are documented in the Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa to the Department of Social Development, March 2002.
132 KZN Stakeholder workshop, 12 May 2011. Redlands Hotel, Pietermaritzburg: Health Group.
133 Graham, L., Selipsky, L., Moodley, J., Mania, J. & Rowland, W. (2006) *Understanding poverty and disability in Johannesburg.* University of Johannesburg & DFID.
134 United States Congress (2004) Assistive Technology Act (Public Law 108-364). Quoted in WHO & World Bank (2010) World report on disability. Geneva: WHO. p.101.
135 Department of Health (2003) *Standardisation of provision of assistive devices in South Africa: a guide for use in the public health sector.* Pretoria: Department of Health.
136 National Indicator Data Set for South Africa 2005. Definitions of data elements and indicators PHC and hospital services.

ing of children with different impairment types who are receiving assistive devices.[137] Provincial level data (obtained through the district health information system [DHIS]) is also not systematically disaggregated by age to allow tracking of provision to children. (See example from the Strategic Plan 2010-2014 of the KZN Department of Health,[138] Box 4.2)

Box 4.2: Data on assistive devices in KZN

Assistive devices issued in 2008/09

- 1 988 wheelchairs
- 1 113 hearing aids

In 2009 there were 49 hospitals and 3 clinics reporting on genetic disorders, as well as 13 Sight Saver hospitals in the province. Through the Child Eye Care project, in partnership with the Department of Education and International Centre for Eye Care Education, a total of 237 556 children were screened, with 6 687 receiving refraction and 1 900 receiving spectacles.

Maintenance of assistive devices

Disabled People South Africa manages the wheelchair repair and maintenance project. There are 23 workshops in which 54 disabled people are employed to repair wheelchairs. There are 24 audio sites in KZN.

(Source: KZN Department of Health Strategic Plan 2010-2014)

One of the concerns noted by rehabilitation personnel during the stakeholder consultations is the failure to refer children for measurement for wheelchairs, and for rehabilitation after a wheelchair has been issued.[139]

4.2.2 Assistive devices provided by the Department of Basic Education

An important element of inclusive education is the equipping of schools that admit learners with disabilities with material resources[140] for teaching and learning, so as to enable educators to include learners with disabilities in classroom activities. It is recognised that this requires not only the supply of the necessary resources, but also training of staff and learners on their use, as well as arrangements for their storage, maintenance and management.[141] The programme of the Department of Basic Education started the provisioning programme in full-service schools and special school resource centres with the intention of establishing loan systems for learners in other schools.

A 2009 assessment by the Department of Education of the Inclusive Education Policy sought to determine what material resources were available to FSSs and SSRCs.[142] However, the information returned from the survey by provincial Departments of Education was incomplete; and there was concern about inaccuracies in completed forms.[143] A system has since been developed to assess, manage and maintain assistive devices within SSRCs.[144]

137 NIDS 27052010. Assistive devices are indicators 118, 119 and 120 on the listing.
138 KZN Department of Health Strategic Plan 2010-2014.
139 KZN Stakeholder workshop, 12 May 2011.
140 In the EDO295 tender this was understood to include learning and teaching support material, assistive devices and auxiliary aids, but not building alterations.
141 Department of Education (2009) *Implementing Education White Paper 6 on Inclusive Education.* Report on the Project Management Tender EDO 295. Pretoria: CSIR.
142 Department of Education (2009) *Implementing Education White Paper 6 on Inclusive Education.* Report on the Project Management Tender EDO 295. Pretoria: CSIR.
143 For example, schools might have under-reported their resources, anticipating that this would put them in a better position to get more equipment, and those items obtained through fundraising may not have been included.
144 Department of Basic Education (2009) *Report on the inclusive education field test: 2004-2009.* Presented to the Heads of Education Committee.

Stakeholder consultations, as part of this study, revealed limited provision of assistive devices in the education sector. In particular, children with mobility impairments are not receiving what they need. In addition, training for educators on the specifications and use of assistive devices is limited.[145]

Factors undermining adequate provision of assistive devices in schools have been noted in several studies and include the dependence on imported products,[146] difficulties in sustaining maintenance services,[147] unclear specification of the material resources that should be available to an SSRC or FSS,[148] and limited collaboration between the Department of Basic Education and the Department of Health.[149]

This situation can be improved if there are clear policies to regulate the budgets, procedures and supply of assistive devices and technology between the relevant departments, namely Health and Education.

4.3 Rehabilitation

Article 26 of the UNCRPD refers to habilitation and rehabilitation as "appropriate measures … to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life". The rehabilitation process includes a range of responses to disability (from interventions to improve functional ability, to those promoting inclusion).

An important means of assessing the adequacy of rehabilitation services is to determine the availability of appropriate human resources for the sector. Effective rehabilitation service delivery depends on the availability of physiotherapy, occupational therapy, speech and hearing therapy, social work, psychology, orthotics and prosthetics. Rehabilitation professionals fall within the 'scarce skills' category in South Africa's public sector. The shortage of rehabilitation personnel impacts most directly on children with disabilities in terms of early identification and intervention. It also significantly affects older children, including adolescents.



Lewis Wynne enjoys an Art lesson.He is in Grade 1 at the Hope School, Johannesburg.

145 KZN Stakeholder workshop, 12 May 2011.
146 Office on the Status of Disabled Persons (OSDP) (2008) *National disability policy framework and guidelines for the implementation of the national disability policy framework*. Pretoria: OSDP.
147 Office on the Status of Disabled Persons (OSDP) (2008) *National disability policy framework and guidelines for the implementation of the national disability policy framework*. Pretoria: OSDP.
148 Department of Education (2009) *Implementing Education White Paper 6 on Inclusive Education*. Report on the Project Management Tender EDO 295. Pretoria: CSIR.
149 Department of Basic Education (2009) Report on the inclusive education field test: 2004-2009. Presented to the Heads of Education Committee.

Although there are close to 6 000 physiotherapists registered with the Health Professionals Council of South Africa (HPCSA), only 1 057 (18%) are currently working in the public sector (see Table 4.2), the sector that caters for the health needs of about 80 percent of the population.[150] This figure is slightly higher for occupational therapists, where 26 percent of those registered with the HPCSA are working in the public sector (see Table 4.3). The tables below illustrate the consistency of this trend over the past five years.[151]

Table 4.2: Number of physiotherapists registered with HPSCA and working in the public sector (2007-2011)

	Registered with HPCSA	Working in the public sector	
Year	**Total**	**Total**	**%**
2007	5 059	850	17
2008	5 314	903	17
2009	5 582	946	17
2010	5 777	1 009	17
2011	5 937	1 057	18

(Source: www.hst.org.za/content/health-indicators)

Table 4.3: Number of occupational therapists registered with HPSCA and working in the public sector (2007-2011)

	Registered with HPCSA	Working in the public sector	
Year	**Total**	**Total**	**%**
2007	3 015	736	24
2008	3 174	785	25
2009	3 325	806	24
2010	3 508	838	24
2011	3 629	940	26

(Source: www.hst.org.za/content/health-indicators)

In comparison, there were 3 657 physiotherapists, 2 139 occupational therapists, and 1 406 speech therapists and audiologists working in the private sector in 2011.[152]

There are also significant disparities between provinces. Based on 2011 data, the ratio of physiotherapists to the population (per 100 000) is 2.55 for the country, and ranges from 1.47 (North West) and 2.05 (Eastern Cape), to 5.9 (Northern Cape) and 3.14 (Western Cape).[153] For occupational therapists, the national ratio is 2.3, and ranges from 1.3 (North West) and 1.3 (KZN) to 3.9 (Northern Cape) and 3.7 (Western Cape).[154]

Aligning the numbers of therapists working in the public sector with child population figures in the different provinces presents a bleak picture. Table 4.4 illustrates that the provinces with the fewest public service therapists are North West province, the Eastern Cape, Mpumalanga, KZN and Limpopo. This is of particular concern because these provinces also have the highest proportions of children. In addition, access to a team of rehabilitation professionals rarely occurs within a health facility or within a district. In order to meet rehabilitation goals for children with disabilities to achieve their maximum potential, referrals are made to the entire team. The reality is that there is often only access to one professional group, thus compromising the achievement of rehabilitation goals and therefore quality of rehabilitation services.

150 www.hst.org.za/content/health-indicators
151 Unfortunately, no figures are available from the South African Health Review (2010), Health Systems Trust for speech and language therapists and audiologists.
152 MEDpages. www.medpages.co.za
153 www.healthlink.org.za/healthstats/96/data
154 www.healthlink.org.za/healthstats/95/data

Table 4.4: Number of therapists in the public sector per province (2010)[155] and number of children

Provinces	EC	FS	GP	KZN	LP	MP	NC	NW	WC	SA
Numbers per province										
Occupational therapists	80	71	171	119	113	55	40	38	151	838
Physiotherapists	110	75	199	231	115	60	56	34	129	1 009
Speech therapists[156]	No data									
Total therapists	**190**	**146**	**370**	**350**	**228**	**115**	**96**	**72**	**280**	**1 847**
Percentages per province										
% therapists[157]	10	8	20	19	12	6	5	4	15	100
% of children (2008)[158]	15	6	18	22	13	8	2	7	10	100

(Source: www.hst.org.za/content/health-indicators; analysis by authors)

The KZN Department of Health's Strategic Plan 2010-2014[159,160] notes the high vacancy rates for occupational therapists (58.8%), physiotherapists (60%), psychologists (63.6%) and social workers (58%) in the province. The high vacancy rate for rehabilitation personnel has significant constraining effects on the provision of services to children with disabilities.

A policy response to address the problem of shortage and maldistribution of rehabilitation professionals is the compulsory one-year community service (CS), which was introduced for rehabilitation graduates in 2003. The policy was also implemented for medical students in 1998, dentists in 2000 and pharmacists in 2001. While this intervention addresses the problem of redistribution to a certain extent and improves access to health care workers especially in rural areas, supervision, continuity of services and support in remote areas remain a challenge. Provinces with majority rural communities are more affected, with KZN in particular providing clear evidence on implementation challenges.

The KZN Department of Health's Strategic Plan[161, 162] notes the high vacancy rates for occupational therapists (58.8%), physiotherapists (60%), psychologists (63.6%) and social workers (58%) in the province. The high vacancy rate for rehabilitation personnel has significant constraining effects on the provision of services to children with disabilities. The CS programme in KZN has had the unintended negative effect of hospitals not creating permanent posts for therapists.[163] Furthermore, CS therapists are inexperienced and not always well supervised,[164]and given that they are only just qualified and often working in isolated conditions, the quality and continuity of their services may not be assured. Their deployment should not be seen as 'replacing' therapists, or reducing the urgency of addressing the high vacancy rates.

Moreover, there are no incentives for CS therapists to stay within rural placements beyond one year.[165] There is also the concern that a new ruling on equal sharing of CS therapists across provinces in 2012, will likely impact negatively on service delivery for children with disabilities in provinces with large child populations.[166]

155 www.hst.org.za/content/health-indicators
156 There is no data for speech language therapists or audiologists in the South African Health Review or in the health indicator data set.
157 www.hst.org.za/content/health-indicators
158 Children's Institute. *South African Child Gauge 2009/2010* edited by Maurice Kibel, Lori Lake, Shirley Pendelbury & Charmaine Smith. University of Cape Town.
159 KZN Department of Health Strategic Plan 2010-2014.
160 This was also raised as an issue of concern at the KZN Stakeholder workshop (12 May 2011).
161 KZN Department of Health Strategic Plan 2010-2014.
162 This was also raised as an issue of concern at the KZN Stakeholder workshop (12 May 2011).
163 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
164 KZN Stakeholder Workshop 12 May 2011. Redlands Hotel, Pietermaritzburg: Health Group.
165 Joyce Gysman, Rehabilitation Co-ordinator, Eastern Cape Department of Health, interview 2 June 2011.
166 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.

Box 4.3: Community-based rehabilitation (CBR)

CBR has been defined as *a strategy within community development paradigm for the rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities.*[167] It is seen as means by which to implement the UNCRPD and to support community-based inclusive development.[168] CBR aims to reduce poverty by ensuring that health, education and livelihood opportunities are available to people with disabilities. It works towards including (mainstreaming) the rights of people with disabilities in development as a way to achieve equality. The CBR guidelines[169] advocate the adoption of a 'twin-track approach', with one track promoting inclusion of disability issues in mainstream development work, and the other track promoting targeted disability-specific activities where necessary.[170]

Research in South Africa has identified the following benefits of CBR for children with disabilities:

- CBR facilitates early intervention for children with disabilities.[171, 172]
- It assists mothers of children with disabilities to set up day care centres and to address their priority needs for finance, education, support groups, assistive devices, skills training and institutions .[173, 174] Empowering mothers with skills to make a difference to their children with disability was found to be a significant factor in preventing maternal depression.[175]
- It supports mothers of disabled children with practical skills and advice to help their child at home, such as with washing and feeding.[176, 177] This is particularly important in light of the finding by O'Brien that many caregivers did not know how to care for a disabled child and found it difficult to cope with challenging behaviour.[178]

In addition to the support provided to mothers in the care of their children, CBR programmes have been found to promote enabling environments and disability awareness at mainstream schools, leading to improved accessibility and support for inclusive education at district level.[179]

In this situational analysis, children with disabilities reported high levels of social inclusion in the rural areas nearby KwaZamokuhle Special School in Estcourt, KZN.[180] This is attributable (at least in part) to the outreach work conducted through the school's CBR programme for the past 20 years, which is likely to have contributed to increased awareness of disability within the community. This is in line with international experience that CBR programmes can challenge negative attitudes in rural communities and lead to greater visibility and participation by adults and children with disabilities.[181]

167 ILO, UNESCO, WHO (2004) CBR: *A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities.* Joint position paper. Geneva: WHO.
168 WHO (2010) *Community-based rehabilitation: CBR guidelines*. Geneva: WHO.
169 WHO (2010) *Community-based rehabilitation: CBR guidelines*. Geneva: WHO.
170 This approach is also advocated by the Office of the High Commissioner: UN (2010). *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for human rights monitors*. Office of the High Commissioner. New York and Geneva: UN.
171 Behr, J. (1997) *The evaluation of impact of interventions by a physiotherapist on intellectually impaired and physically disabled children and their caregivers in two community groups in peri-urban Cape Town*. MSc. Department of Physiotherapy. Cape Town: University of Western Cape.
172 Lloyd, G. (2001) *The role of the community in the rehabilitation of the disabled: a study of medical, psychological and social factors in the effective management of the pre-school English-speaking, hearing-impaired child in Gauteng*. Doctoral thesis. Department of Surgery. Johannesburg: University of the Witwatersrand.
173 Meyer, C. & Moagi, S. (2000) 'Determining priority needs of mothers with disabled children in Wintersveldt' in *South African Journal of Occupational Therapy*. 30(2):7-10.
174 Shipham, E. & Meyer, C. (2002) 'The value of community-based rehabilitation to mothers with children with disability in Wintersveldt' in *South African Journal of Occupational Therapy*. 32(2):6-10.
175 Solarsh, B. (2005) *Report on the evaluation of the Valley Trust Rehabilitation Programme. Community Rehabilitation Workers in rural South Africa – addressing the issue of disability*. The Valley Trust: KZN.
176 Chappell, P. & Johannsmeier, C. (2007) *The impact of CBR as implemented by Community Rehabilitation Facilitators on people with disabilities, their families and communities within South Africa*. CREATE & Irish Aid: Pietermaritzburg.
177 Solarsh, B. (2005) *Report on the evaluation of the Valley Trust Rehabilitation Programme. Community Rehabilitation Workers in rural South Africa – addressing the issue of disability*. The Valley Trust: KZN.
178 O'Brien, F. (1997) *Profile of disabled children in Ingwavuma*. Report commissioned by the PEACE Foundation, Mosvold Hospital and Department of Welfare. Conducted by Department of Social Work: University of Natal, Durban.
179 Disability Action Research Team (2006) *Impact Evaluation of the Mpumalanga CBR Disability Support Project*. Commissioned by Disabled People South Africa (DPSA). November.
180 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
181 WHO & World Bank (2010) *World report on disability*. Geneva: WHO.

4.4 Partnerships to promote community-based rehabilitation

Community-based rehabilitation (CBR) has been advocated as one approach to meet the needs of persons with disabilities including children, that is, in complementarity with accessible and inclusive services at the community level, particularly access to primary health care. However, currently, there is no comprehensive national strategy on community-based rehabilitation in the country. With decentralisation to provinces in the development of strategies and its implementation, certain provincial departments (namely Mpumalanga, Limpopo and KZN) have entered into public-private partnerships with NGOs to plan and implement CBR projects for children with disabilities. However, a cohesive, strategic national position on CBR is still lacking.

In KZN, 22 CBR workers are employed through a service-level agreement between the Department of Health and Disabled People South Africa (DPSA) to work in the province's 11 districts.[182] However, there are challenges around the training and employment status of these mid-level workers within the provincial health system.[183]

In Mpumalanga, 29 unemployed disabled people and parents of disabled children were contracted through DPSA to work as CBR consultants. They render services in all 17 municipalities of the province. Working in partnership with the provincial Department of Health, the Mpumalanga CBR Disability Support Programme has helped children with disabilities to access assistive devices and schooling.[184]

4.5 Access to health facilities

A study on the profile of beneficiaries of social grants[185] found that close to 72 percent of CDG households live within five kilometres of their nearest health facility, while 24 percent live less than one kilometre away; 15 percent live between five and 10 kilometres away; and 13 percent live more than 10 kilometres from their nearest health facility. The study found that, with the exception of the Eastern Cape (where it is 42%), close to two thirds of CDG households live less than half an hour away from their closest health facility. Most (59%) members of CDG household reach the health facility on foot, while the second most common means of travel is by taxi (36%). This implies that for some CDG households, access to health services may be limited by lack of funds for public transport.[186]

Provincial Health Departments report that improved access to health services has been achieved through a number of strategies, including removal of user fees for public PHC facilities and of all fees (including hospital fees) for pregnant women, children under six years of age and people with disabilities. In addition, the introduction of CS, scarce skills allowances, community health workers and mid-level workers has helped to increase access to services.[187, 188] However, research into the impact of the free health care policy found that there are a number of barriers other than tariffs at health facilities which limit access by children.[189] These include a shortage of nursing staff and medicines and a lack of accessible, convenient and affordable transport to and from health care facilities, which is a major challenge for children with disabilities in particular.[190,191] In

182 KZN Department of Health Strategic Plan 2010-2014.
183 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
184 Rule, S., Lorenzo, T. & Wolmarans, M. (2006) 'Community-based rehabilitation: new challenges', in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (eds) *Disability and social change: a South African agenda*. Cape Town: HSRC.
185 De Koker, C., de Waal, L., & Voster, J. (2006) *A profile of social security beneficiaries in South Africa*. Datadesk. Department of Sociology and Social Anthropology: Stellenbosch University.
186 KZN Stakeholder workshop, 12 May 2011.
187 Province of the Eastern Cape Department of Health Strategic Plan 2009/10-2014/15.
188 KZN Department of Health Strategic Plan 2010-2014.
189 Leatt, A., Shung-King, M. & Monson, J. (2006). 'Healing inequalities: the free health care policy' in Monson, J., Hall, K., Smith, C. & Shung-King. M (eds.) *South African Child Gauge*. Children's Institute: University of Cape Town.
190 Leatt, A., Shung-King, M. & Monson, J. (2006). 'Healing inequalities: the free health care policy' in Monson, J., Hall, K., Smith, C. & Shung-King. M (eds.) *South African Child Gauge*. Children's Institute: University of Cape Town. Nkeli, J. & Associates (2008) *Broad overview of the impact and an analysis of the effectiveness and efficiency of disability policy implementation in all spheres of government since 1994*. Commissioned by Office on the Status of Disabled Persons in the Presidency. Pretoria; Department of Social Development (2009) *Strategy for the integration of services to children with disabilities: the right to belong and participate: support services to children with disabilities*. Inter-departmental Task Team (August).
191 National Stakeholder workshop, 24 May 2011.



Granny Seretsane giving her daughter Mpho (six years) physiotherapy. She was taught this skill at the Duduza Clinic, where she meets with a support group of five other women who all have children with disabilities.

addition, while the removal of tariffs is a positive move, it does not provide any benefits if physical, knowledge and attitudinal barriers remain.[192,193]

The National Department of Health Audit of Accessibility of Provincial Health Facilities to Persons with Disabilities undertaken in 2006/07[194] found that district hospitals were less accessible to people with disabilities than tertiary hospitals. Less than 10 percent of the 213 hospitals had a fully accessible toilet for persons with disabilities. The provinces of Gauteng and the Western Cape had the highest accessibility scores, which was attributed to better resources, i.e. a higher number of health professionals, as well as more tertiary and fewer district hospitals. The North West Province, Mpumalanga and Limpopo had the lowest accessibility scores which was seen to result from having the least resources, i.e. the lowest health professional to population ratio and a large number of district hospitals, especially in rural areas.[195]

Focus group discussions conducted as part of this study reported difficulties with physical access to local clinics, including absence of suitable passageways in some clinics and transportation challenges in the wider physical environment.

4.6 Early childhood development

Available data on the number of children in early childhood development (ECD) facilities is not consistently disaggregated by disability status. Analysis of the profile of CDG beneficiaries found that only 24 percent of children aged 0-6 years who were recipients of the CDG attend a crèche or child-minding group.[196]

A local study of disabled children living in Orange Farm, Gauteng[197] found that only 35 percent of disabled children aged three years and over had attended, or were currently attending pre-school.

192 Schneider, M., Couper, J. & Swartz, L. (2010) *Assessment of accessibility of health facilities to persons with disabilities*. Report submitted to Directorate: Chronic Diseases, Disabilities and Geriatrics. National Department of Health. April. Department of Psychology: University of Stellenbosch.

193 KZN Stakeholder workshop, 12 May 2011.

194 Schneider, M., Couper, J., & Swartz, L. (2010) *Assessment of accessibility of health facilities to persons with disabilities*. Report submitted to Directorate: Chronic Diseases, Disabilities and Geriatrics. National Department of Health. April. Department of Psychology: University of Stellenbosch. The response rate was 52 percent as only 213 of the 402 facilities answered the questionnaire, with the Eastern Cape and the Northern Cape not participating in the audit.

195 Less recent data from 2003 give a similar picture. The National Primary Health Care Facilities Survey of 2003 found only 24 percent of facilities to be wheelchair-accessible, while only 28 percent had specific toilet facilities for disabled people.

196 De Koker, C., de Waal, L., & Voster, J. (2006). *A profile of social security beneficiaries in South Africa.* Datadesk. Department of Sociology and Social Anthropology: Stellenbosch University.

197 Saloojee, G. Phohole, M. Saloojee, H. & IJsselmuiden, C. (2007) 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township' in *Child: care, health and development*. 33(3): 230-235.

4.7 Inclusive education

There are difficulties in obtaining accurate and recent data on the number of learners with disabilities at the various stages of education. The *General Household Survey: Focus on Schooling 2010* found that the data on children with disabilities attending school was inconclusive.[198] Data provided by the national Department of Basic Education, Inclusive Education Directorate[199] (see Table 4.5 below) give indications of progress made in expanding inclusive education.

Table 4.5: Indicators on inclusive education for special schools, full-service schools and ordinary public schools

	2008/09	2009/10	2010/11
Special schools			
Number of special schools	413	418	423
Number of learners in special schools	96 535	100 717	104 633
Number of teaching staff	8 057	8 618	8 781
Number of support staff at special schools	5 381	6 108	4 988
Number of special schools with hostel facilities	219	260	261
Number of special schools converted to resource centres	30	60	120
Number of special schools with Grade R	112	121	134
Full-service schools			
Number of full-service schools	30	91	513
Ordinary public schools			
Number of schools	25 875	25 906	25 850
Number of learners with disability in ordinary schools	96 653	82 211	110 273

(Source: Department of Basic Education, EMIS data from annual schools surveys. Supplied by Directorate Inclusive Education. August 2011)

Stakeholder consultations that formed part of this study further indicate that children with disabilities do not have the same access to education in comparison to those without disabilities.[200] A study investigating the link between disability and poverty in the Eastern Cape and Western Cape provinces (2008)[201] found that among those of school-going age (5-18 years), a higher proportion of those with disabilities had never attended school (12% in the Eastern Cape and 22% in the Western Cape) compared with those without disabilities (1% in the Eastern Cape and 4% in the Western Cape). In terms of scholastic achievement (measured as the highest grade or number of years completed), there were also disparities: the average level of education was significantly lower among those with disabilities in both the Eastern Cape and Western Cape (3.5 and 2.9 years, respectively) than that of their non-disabled counterparts (4.5 years in both the Eastern Cape and Western Cape). Similarly, a study in a peri-urban township[202] found that among disabled children of school-going age (7-15 years), only 44 percent were attending a school or specialised institution in Gauteng. Of these children, 55 percent were attending mainstream schools and 45 percent a special school, training centre or daycare training. Of those disabled learners not in school, 42 percent had motor impairments and 44 percent some form of intellectual disability.

In 2010, judgment was pronounced by the Western Cape High Court in favour of the Western Cape Forum on Intellectual Disability after finding that there was no provision for children with severe and profound intellec-

198 Department of Basic Education (2010) *Report on the 2009 General Household Survey: Focus on Schooling.* Pretoria.
199 Marie Schoeman, Department Basic Education, Inclusive Education Directorate, interview 13 July 2011.
200 National Stakeholder workshop, 24 May 2011.
201 Loeb, A., Eide, A.H., Jelsma, J., Toni, M. & Maart, S. (2008) 'Poverty and disability in Eastern and Western Cape Provinces' in South Africa *Disability & Society,* 23 (4), June: 311–321
202 Saloojee, G., Phohole, M., Saloojee, H. & IJsselmuiden, C. (2007) 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township' in *Child: care, health and development.* 33(3): 230-235.

tual disabilities in terms of access to special schools. Under the ruling, the government had to take reasonable measures to realise the right to basic education for the affected children.[203]

Drop-out rates are also higher among those disabled children. At the launch of the Access to Education Report,[204] it was reported that 37 percent of disabled youth between 16 and 18 years of age had dropped out of school, compared to 14 percent of youth without disability.[205] Given this trend, further research is required into the causes of higher drop-out rates among disabled children.

Information on the number of learners in special schools who passed the school-leaving examination (Matriculation) was obtained through the Inclusive Education Directorate of the National Department of Basic Education (see Table 4.6). Despite the notable matriculation pass rate of 79 percent in 2009, it should be noted that less than five percent of children with disabilities in the required age cohort took the examination in special schools. The study did not come across data on the participation of children with disabilities in matriculation level examination in public ordinary schools. Nevertheless, interviews with managers of inclusive education indicate that the majority of children with disabilities drop out of school way before the matriculation level due to significant gaps in education support available to them.

Table 4.6: Matriculation pass rate in special schools

	Department of Basic Education data on special schools Matric pass rate		
In special schools	**2007**	**2008**	**2009**
Number of learners who wrote Matric in special schools	727	804	872
Number of learners who passed without Endorsement	430	No data	No data
Learners who received a Conditional Pass	17		
Learners passed with Endorsement	34		
Total pass	**481 (66%)**	**636 (79%)**	**697 (79%)**

(Source: Department of Education: Further Education and Training Assessment Examinations 2007–2009)

One of the key barriers to access by children with (physical) disabilities to education is the lack of an accessible built environment at schools.[206, 207] In the focus group discussions conducted as part of this study,[208] children related how lack of accessible built environment had delayed their schooling. As one child noted:

> *I couldn't find a school for a long time because schools in my community couldn't accommodate me …. I'm happy because no one looks down on me here and no one looks at me differently and that I'm in a school where I can play like other kids….* (17-year-old girl who is a wheelchair user; she started school six years after her peers)

Table 4.7 below, shows findings from the National Assessment Report on Facilities for Disabled Persons,[209] which provides indications of the extent of the (in)accessibility of ordinary public schools in the nine provinces of the country – 98 percent of schools have no paved access from gate to buildings and no appropriate ramps into all the buildings, and 97 percent of schools have no appropriate toilets for disabled learners.[210]

203 Marie Schoeman, Department of Basic Education, Inclusive Education Directorate, interview 13 July 2011.
204 Seekoei, K. (2010) 'Disabled at risk of dropping out', *Mail and Guardian* online. November 30.
205 This report, based on data from 4 400 households across the country in 2007, was conducted by Social Surveys and the Centre for Applied Legal Studies (CALS) at Wits University.
206 KZN Stakeholder workshop, 12 May 2011.
207 Marie Schoeman, Department of Basic Education, Inclusive Education Directorate, interview 13 July 2011.
208 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
209 A person in a wheelchair was assumed to be the norm for 'disabled' facilities. The specifications for access ramps and toilets as published by the CSIR were assumed as the appropriate criteria.
210 Department of Education (2007) *National Assessment Report (Public Ordinary Schools).* National Education Infrastructure Management System. Contract EDO 305. Pretoria: Department of Education.

Table 4.7: Facilities for disabled children at ordinary public schools

Number of ordinary public schools				
Province	**Total number of schools assessed**	**Schools with no paved access from gate to buildings**	**Schools with no appropriate ramps into all their buildings**	**Schools with no appropriate toilets for disabled learners**
Eastern Cape	5 724	5 625 (98%)	5 617 (98%)	5 534 (97%)
Free State	1 717	1 684 (98%)	1 697 (99%)	1 680 (98%)
Gauteng	1 972	1 852 (93%)	1 945 (99%)	1 856 (94%)
KZN	5 822	5 764 (99%)	5 796 (100%)	5 629 (97%)
Limpopo	4 037	3 954 (98%)	3 775 (94.5%)	4 015 (100%)
Mpumalanga	1 981	1 933 (98%)	1 925 (97%)	1 965 (99%)
Northern Cape	620	603 (97%)	610 (98%)	580 (94%)
North West	1 796	1 780 (99%)	1 787 (99%)	1 743 (97%)
Western Cape	1 476	1 424 (96%)	1 449 (98%)	1 440 (98%)
Total	**25 145**	**24 619**	**24 601**	**24 442**
% Total	100%	98%	98%	97%

(Source: Department of Education (2007) National Assessment Report on Facilities for Disabled Persons)

The fact that disabled children are over-represented among out-of-school learners at all levels is a major concern, as this undermines their ability to participate on an equal level with their peers without disabilities. Exclusion from educational opportunities contributes to the number of disabled children who become disempowered adults and dependent on the State.[211]

Moreover, there are concerns about the quality of education being rendered to children with disabilities in special schools. Stakeholder consultations revealed that the standard of curriculum delivery is poor, with a 'one size fits all' approach being used for children with intellectual disabilities. This is of particular concern in relation to children with autism who rely heavily on visual cues for learning. The choice of subjects offered at special schools is also very narrow, limiting options for learners in terms of opportunities after school.[212] The following account was given by a child with a disability in one of the focus group discussions that formed part of this study:

Child: *We used to learn at school. Now we are not learning anymore. I do not know why. It's a special school for children who are using wheelchairs.*

Facilitator: *Are there teachers there?*

Child: *Yes, [but] we just sit … we get bored.*

Facilitator: *Do you have grades?*

Child: *No. [There are] no grades.*

This was substantiated by the Department of Basic Education which stated that "A large percentage of special schools don't even have grades …. And schools for children with severe intellectual disability … don't even teach reading".[213]

211 National Stakeholder workshop, 24 May 2011.
212 National Stakeholder workshop, 24 May 2011.
213 Marie Schoeman, Department of Basic Education. Inclusive Education Directorate, interview 13 July 2011.



Timothy Mahlango (eight years) who is intellectually impaired, learning basic computer skills in the computer laboratory at the Matshediso LSEN Foundation Phase School.

4.8 Provision of institutional care

The evidence suggests that there are access constraints for children with disabilities who due to increased risk of abuse and neglect or the severity of their condition need institutionalised care.[214,215] A shadow report on the UNCRPD gives an example of a 15-year-old girl with cerebral palsy and hearing loss in KZN who gave birth to a baby.[216] She was forced to deliver naturally, which was very traumatic for her as she did not understand what was happening. It was suspected that the girl had been abused by her father who (neighbours reported) locked her in a room during the day. Social workers recommended that the girl and her baby be removed from her home. The report states that:

> *As a province we have failed to protect and care for client N and her baby. It took us four days to secure a safe place for client N, which has left her separated from her baby. Current children's homes offer few placements with many restrictions for children requiring special assistance.*[217]

The Children's Act makes provision for child and youth care centres for children with disabilities. There is however no information on the number of disabled children in these centres (see Box 4.4). Moreover, there is a lack of coherent national statistics on the number of children with disabilities who are in need of care, as well as the resources that are available for them.

214 African Child Policy Forum (2010) *Breaking the silence: Violence against children with disabilities in Africa.* Addis Ababa. African Child Policy Forum. www.africanchildforum.org

215 Report of the independent expert for the United Nations study on violence against children, United Nations, General Assembly, sixty-first session, August 2006, A/61/299.

216 KZN Stakeholders workshop (12 May 2011) and Umgungundlovu Disability Forum (2010) *Shadow Report to the Committee on the Rights of Persons with Disabilities*. CREATE: KZN, South Africa. p.11.

217 Umgungundlovu Disability Forum (2010) *Shadow Report to the Committee on the Rights of Persons with Disabilities*. CREATE: KZN, South Africa. p.11.

Box 4.4: Children with disabilities living in institutions

Both the Department of Health and the Department of Social Development provide some institutional care services for children with disabilities. The Audit on Services for People with Disabilities in South Africa[218] and a Resource Directory on Disability[219,220] in the nine provinces lists day care centres, disabled persons organisations, homes for disabled persons, protective workshops, schools for the disabled, self-help groups, social work services and contact details of disability co-ordinators. However, there is no detailed information on disabled children in institutions.

Given the absence of a comprehensive data collection system, it is impossible to determine:

- the number and profile[221] of residential care facilities providing for children with disabilities (which are registered and funded by the Department of Health or the Department of Social Development);
- the number of children with disabilities currently in residential care facilities; and
- the current expenditure per facility or per child.

It is also impossible to monitor whether the numbers of children in institutional or residential care are increasing or decreasing, nor to track expenditure trends.

4.9 Summary findings on adequacy of services

This chapter has reviewed the adequacy of measures to reduce the impact of disability and enhance social participation. Emphasis was placed on assessing the adequacy of essential services for children with disabilities.

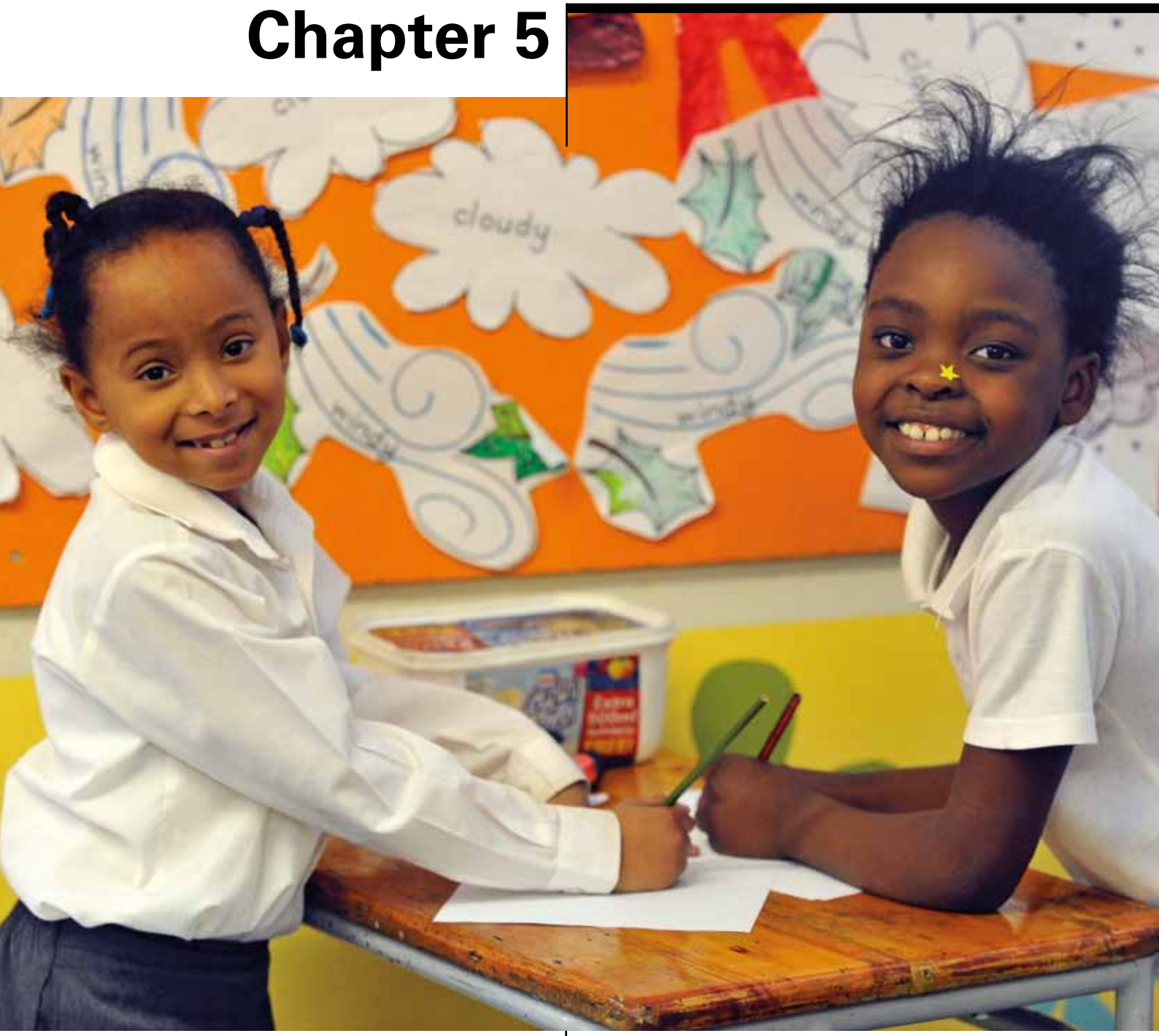
Overall, the CDG's reach has been on the increase, with probable positive effects on improving income security among children with disabilities and their families. Access to the grant continues to grow, with a 30 percent increase from 2005 to 2011.

However, significant gaps remain in access to other essential services. In particular, access to assistive devices remains constrained among children with disabilities. The shortage of rehabilitation personnel in the public health sector persists and the built environment poses severe risks for children with disabilities. Several policy documents have been prepared to guide the expansion of inclusive education. Efforts have been made to implement various aspects (of inclusive education). Yet, huge access-related challenges remain, denying significant numbers of children with disabilities from participating in inclusive education.

The next chapter will assess the factors that underlie the observed challenges in the delivery of essential services for children with disabilities.

218 Department of Social Development (2007) Audit of Services Available to Children with Disabilities.
219 Department of Social Development (undated) *Resource Directory on Disability. Building a caring society. Together.* Department of Social Development: Pretoria.
220 For example, "Disability All Sorts" is a directory of organisations and resources for persons with disabilities compiled by staff at UNISA. It contains a basic description and contact details of many kinds of services, including residential care facilities in each of the provinces. It can be accessed on www.unisa.ac.za/contents/management/arcswid/docs/Disability_directory_allsorts09.pdf. The Sponge Project provides information on disability services in South Africa through SMS. It can be accessed on thespongeproject.yolasite.com
221 For example, residential care could comprise the hostel facilities of a special school.

Chapter 5



Hope Williams (left) and Nomakhosi Aphiri (right) in an Art lesson at the Hope School, Johannesburg.

In understanding the reasons for inadequate progress in providing for children with disabilities, it is important to acknowledge how the history of apartheid shaped services in the sector. Provision of services in the apartheid era was biased not only in terms of race (favouring whites) and geographical spread (favouring urban areas), but was based on the principle of segregation of adults and children with disabilities, coupled with the unequal distribution of resources among various groups. Post-apartheid South Africa has had to grapple with deep-seated inequities in the provision of inclusive services that fulfil the rights of all children with disabilities in the country.

There are other factors besides the historical legacy of apartheid that constrain the provision of services for children with disabilities in South Africa. These include attitudes of society and service providers, gaps in legislation, policies and budgets, skill shortage, and co-ordination and data challenges.

5.1 Attitudes

Although a shift has been made at policy level from an approach based on the medical/welfare model of disability to one based on the social model (which sees disability as a human rights issue),[222] this is often not reflected in the attitudes and approaches of service providers and society at large.

Stakeholders report that many in the education sector, for example, have found it difficult to embrace the attitude and behaviour changes that are inherent in the paradigm shift underlying Education White Paper 6[223] on inclusive education. They further report that teachers at special schools often equip children with disabilities to function and communicate in a very narrow environment, without consideration for the need to integrate them with the wider community. As a result, these children do not learn the skills necessary for mainstreaming and they are isolated from their families and communities. Teachers also tend to be over-protective, with low expectations when it comes to what children with disabilities can achieve.[224] Furthermore, stakeholders report that

> *the biggest weakness of the special schools is the attitude of the teachers in terms of curriculum … there is a lowering of expectations and an overemphasis on skills development. Even before trying to make the curriculum accessible, teachers regularly go on to skills programmes.*[225]

Personnel from the health sector identified one of the greatest challenges as the negative attitudes of service providers, which are seen to be based on ignorance, lack of understanding and stereotyping of disability. There is frequently a primary focus on the disability, rather than on the child.[226]

Constraints regarding the understanding of disability on the part of government officials arise when untrained people are moved across from redundant posts to be employed as Disability Focal Persons.[227] Staff therefore lack understanding of disability, resulting in overall negativity and a focus only on the health condition and impairment of the child.[228] At the institutional level, there may be reluctance by units/directorates focusing on children to embrace issues relating to children with disabilities:

> *Officials from departmental structures on Services to People with Disabilities find themselves directly addressing issues of children with disabilities, due to resistance from the Children's Units as well as other structures [to do so].*[229]

This 'separatist' approach is compounded by the lack of clear role clarification between the Children's and the Disability Units within the Department of Social Development, and the lack of resources required for mainstreaming.[230]

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222 This is reflected in policy documents such as the Office of the Deputy President (1997) *Integrated National Disability Strategy* and OSDP (2008) *National disability policy framework and guidelines for the implementation of the national disability policy framework.*
223 KZN Stakeholder workshop, 12 May 2011.
224 KZN Stakeholder workshop, 12 May 2011.
225 Key informant interviews, Department Basic Education, Inclusive Education Directorate, interview 13 July 2011.
226 KZN Stakeholder workshop, 12 May 2011.
227 KZN Stakeholder workshop, 12 May 2011. These are staff employed within each municipality to raise disability awareness at the local level.
228 National Stakeholder workshop (2011) p.19.
229 Manthipi Molamu, Department of Social Development, interview 31 May 2011.
230 Manthipi Molamu, Department of Social Development, interview 31 May 2011.



In the stimulation room at the Lebohang Centre.

In addition, caregivers who participated in focus group discussions that formed part of this situation analysis[231] related experiencing negative attitudes on the part of service providers in the health sector.

Adults and children with disabilities are frequently viewed by society as objects of pity and deserving (only) of charity.[232] Negative perceptions of children with disabilities may be rooted in religious beliefs that disability is an embodiment of evil or the result of bewitchment. Disability is also seen by some as punishment for the sins of parents.[233]

Children who participated in the focus group discussions[234] reported that people's negative attitude towards them was one of the most difficult things for them to deal with. Their greatest dislikes were being laughed at, being called derogatory names and being teased about their disabilities.[235] Several cited instances of people making judgements about their abilities:

> *I don't like people when they think that I can't do certain things, 'cause I'm disabled.* [urban group]
>
> *I don't like people to look at me and feel pity because I was created like this.* [urban group]
>
> *It would upset me when [this] granny would call me "stshikwane" [someone whose body is crooked].* [rural group]

Other people's prejudicial attitudes mean that children with disabilities may face many difficult experiences in their lives. They are in danger of becoming isolated because of the tendency to want to avoid social situations. In a research exercise in which they could choose a stone or a sweet to represent what was hard (difficult) or sweet (good) in their lives, most of the children from the urban-based focus group discussions (that were carried out as part of this situation analysis) chose stones and explained as follows:

> *I take a stone, because disability is hard; people laugh at me. It is hard to be a disabled person. People talk badly about me.*

231 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
232 Nkeli, J. & Associates (2008) *Broad overview of the impact and an analysis of the effectiveness and efficiency of disability policy implementation in all spheres of government since 1994*.
233 Ford-Shubrook, A. (2008) *Disability inequality within Orange Farm: barriers to education for children with disabilities with a township community in Johannesburg, South Africa*. BA Dissertation, Department of Geography, Royal Holloway: University of London.
234 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
235 Similar themes emerged from the study by Clacherty, G., Matshai, K. & Sait, W. (2004) *How do children with disabilities experience poverty, disability and service delivery?* A report on participatory workshops. Cape Town: Idasa.

I have a stone because when I go outside to other people who do not know me, you find that they look at you, pointing at you, talking about you. This hurts me.

I have chosen a stone because I struggle in my daily life; people tease me and call me names just because I can't hear. They laugh at me and it hurts a lot.

The history of segregated education and the current status of educational provision for ordinary schools in the country have shaped the attitudes of parents and communities towards special schools. During the data collection phase of the situation analysis, key informants noted that:

In many ways special schools in terms of facilities are better than the surrounding ordinary schools. In terms of staff, the national ratio is 1:11 which is a very small class size. [This] … creates an incentive for parents to continue to send their children to the special schools … because they are getting individual attention.[236]

5.2 Laws and policies

Although South Africa's achievements in terms of law reform around disability have been widely acknowledged, stakeholders have expressed frustration about the disconnect between policies and practice in the country.[237]

5.2.1 Lack of alignment of policies to specific plans

There are numerous policies in place that are intended to fulfil government's constitutional and legal obligations towards children with disabilities. However, these have not been consistently linked to national and provincial planning processes. The following examples illustrate this pattern:

- One of the priorities contained in White Paper 6[238] is the need to support children with disabilities who are not in school. However, a review of strategic plans at the national and provincial levels reveals the absence of a clear strategy to identify and support these children.[239]
- Although the National Rehabilitation Policy is in place, none of the Department of Health strategic plans reviewed (at the national and provincial levels) make reference to this policy or the Policy on Standardisation of Assistive Devices.[240]
- The Strategy for the Integration of Services for Children with Disabilities cites the Department of Social Development as one of the lead departments in the provision of habilitation and rehabilitation services for children with disabilities,[241] but neither national nor provincial strategic plans reviewed indicate strategies for this.[242]
- The Directorate for People with Disabilities participated in the development of the Policy on Social Rehabilitation, which identifies CBR as an important community-based service for people with disabilities. Although there has been some success in integrating disability into some programmes (such as the Sustainable Livelihoods Programme) to ensure that the projects of people with disabilities are funded at the provincial and local levels, the Directorate for People with Disabilities in the Department of Social Development has not made much progress in terms of integrating habilitation or rehabilitation into the Community Development programme.[243]

236 Key informants interviews, Department Basic Education, Inclusive Education Directorate, interview 13 July 2011.
237 KZN Stakeholder workshop, 12 May 2011.
238 Department of Education (2001) *Education White Paper 6: Towards an inclusive education and training system.*
239 See: KZN Department of Education (2010) Annual Performance Plan 2011/12; Strategic Plan of the Provincial Government of the Western Cape Education Department 2010-2014.
240 Provinces were the Eastern Cape, KZN and the Western Cape. Indeed, the Strategic Plan of the Eastern Cape Department of Health 2009/10-2014/15 does not make any reference to rehabilitation (or provision of assistive devices) as part of the core functions of the department.
241 Department of Social Development (2009) *Strategy for the Integration of Services for Children with Disabilities*. Interdepartmental Task Team.
242 Strategic Plan of the Department of Social Development 2010-2015.
243 Manthipi Molamu, Department of Social Development, interview, 31 May 2011.

A particular challenge is to ensure that implementation plans reflect the intention of policy and lead to the expected outcomes. Evidence shows that the specific needs of many children with disabilities are not met,[244,245,246] leading stakeholders in the disability sector to ask whether the child with disability has "gotten lost in the state's mainstreaming efforts".[247]

5.2.2 Not all sectors align plans with the UNCRPD and with legislation

Although the South African government has ratified the UNCRPD and the Office on the Status of Disabled Persons (OSDP) has developed implementation guidelines, these are not clearly reflected in the strategic plans of the Departments of Basic Education and Health in particular.[248] Only the Department of Social Development makes reference to the UNCRPD in its national strategic plan.[249,250] The discrepancies between different departments in terms of the implementation of the UNCRPD have been attributed to a "lack of strategic direction from the OSDP".[251] The danger of the current situation is that it reinforces the perception that disability is the responsibility of the Welfare Branch of the Department of Social Development. This situation undermines the potential to build synergies towards protecting the rights of children with disabilities across different sectors.

Although legislation provides for prioritising children with disabilities in the provision of social services, this is not consistently reflected in national or provincial plans.[252]

5.2.3 Biases that marginalise children with disabilities

Reference to "persons with disabilities" in policy-related documents[253] and national and provincial strategic plans frequently implies a bias towards adults. Review of the Social Development Department's strategic plans at the national level and for three provinces revealed a trend of focusing on adults when referring to developmental social services for persons with disabilities (e.g. protective workshops, economic empowerment opportunities, employment equity).[254]

These biases are also evident through data collection:[255,256]

- *Information on children does not include children with disabilities*. For example, the number of children attending ECD centres is given in some provincial plans, but not the number of children with disabilities who are at registered centres. The number of children living in relative or absolute poverty may be given, but there is no breakdown to show how children with disabilities are affected. As a result, the presentation of data masks increased vulnerability of disabled children to poverty, sexual and other abuse and to exclusion from services such as ECD.
- *Information on people with disabilities does not include children*. In the situation analysis of the Western Cape Department of Social Development, which precedes its strategic plan, none of the disability prevalence figures quoted is age-specific, with the only reference made to age being "a higher

244 National Stakeholder workshop, 24 May 2011, p.18.
245 Saloojee, G., Phohole, M., Saloojee, H. & IJsselmuiden, C. (2007) 'Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township', *Child: care, health and development.* 33(3): 230-235.
246 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF. Caregivers from a rural area in KZN related unsuccessful attempts to get their children into day care centres and special schools.
247 National Stakeholder workshop, 24 May 2011, p.14.
248 See for example: Department of Basic Education (2011) Strategic Plan 2011-2014. Pretoria.
249 The Strategic Plan of the Department of Social Development 2010-2015 states that policy initiatives that are planned include the aligning of social service policies with the CRPD.
250 Manthipi Molamu, Department of Social Development, interview 31 May 2011.
251 Manthipi Molamu, Department of Social Development, interview 31 May 2011. It must be noted that the OSDP has been restructured within the Ministry of Women, Children and People with Disabilities.
252 ECD is provided for in Chapter 7 of the Children's Act (2007).
253 For example, the review of the role and effectiveness of disability legislation in South Africa conducted by Dube (2005) has a major focus on economic issues; disability statistics are not disaggregated for children and the only focus groups run were with employed and out-of-work disabled adults.
254 In the Eastern Cape, the strategic goal of services for people with disabilities is to promote integrated social and economic developmental programmes for people with disabilities. The focus areas are development and implementation of minimum norms and standards for residential care for people with disabilities, facilitation of linkages to labour markets and finalisation of a policy on transformation of protective workshops. In KZN the indicators used for disability services all refer to 'persons with disabilities' but mostly refer to those impacting on adults.
255 See for example, the Western Cape Department of Social Development Strategic Plan 2010/11-2014/15. The programmatic bias towards adults with disabilities was also acknowledged by Bukiwe Sapepa, Disability Co-ordinator, KZN Department of Social Development, interview 7 July 2011.
256 Within the health sector, non-communicable diseases are considered to be 'diseases of lifestyle' and therefore exclude a number of causes of childhood disability such as accidents, cerebral palsy and foetal alcohol syndrome.

proportion of males between the ages of 10-59 are disabled. Most of them have a physical disability which they acquire mainly in their late teens or early twenties".[257] This is of particular concern in relation to strategic plans for the sub-programme for services for persons with disabilities, as there is no indication as to whether the services are targeting adults or children with disabilities. Lack of acknowledgement of the specific situation of children with disabilities increases the likelihood of marginalisation in terms of service provision, as compared to adults.[258]

5.2.4 Lack of consistency in use of terminology

Another factor that undermines coherent policy implementation is the inconsistent use of terminology. For example:

- The national Department of Basic Education's Strategic Plan[259] refers to "special needs learners", whereas White Paper 6 uses the term "learners experiencing barriers to learning and development".
- Current plans of the Eastern Cape Department of Health refer to the implementation of a "home community-based rehabilitation programme".[260] The term "CBR" is internationally and nationally recognised and defined; it is the term used in the National Rehabilitation Policy and in other documents of the Department of Health. Therefore, prefixing it with "home" is likely to create confusion regarding what is being referred to.
- Within the social development sector, it has been recognised that the different terms used to refer to facilities catering for children with disabilities (e.g. day care centres, stimulation centres, special care centres) have contributed to the exclusion of children with disabilities from mainstream ECD provision.[261]

One of the children who live at the Lebohang Centre.



257 Western Cape Department of Social Development Strategic Plan 2010/11-2014/15, p.15.
258 Patiswa Momoza, Kholeka Koko-Mhlahlo, Disability Unit, Western Cape Department of Social Development interview 13 June 2011.
259 Department of Basic Education (2011) Strategic Plan 2011-2014. Pretoria.
260 Eastern Cape Department of Health Strategic Plan 2009/10-2014/15.
261 Manthipi Molamu, Department of Social Development, interview 31 May 2011.

5.2.5 'Policy change fatigue'

The Department of Basic Education has noted that constraints with regard to communicating new polices in a co-ordinated manner have created 'policy change fatigue' in the schooling system.[262] This is a particular challenge for the introduction of new tools and strategies to support inclusive education, such as the SIAS assessment tool.

5.2.6 Lack of appropriate policy

Despite the numerous policies in place within the disability sector, there are still some gaps that have been identified, including the lack of a national policy on disability prevention.[263] The reason for the absence of this policy is stated by officials as "avoiding vertical programming in favour of integration."[264] It appears that in the process of "integration", a comprehensive policy (and strategy) has not been prioritised.

5.3 Plans and budgets

There are also difficulties related to monitoring of budgets for children with disabilities. The lack of specific information on service provision and related budget allocations appears to be a major barrier to the monitoring and protection of the rights of children with disabilities.[265]

5.3.1 Reduction in resource allocations at provincial level

Review of the strategic plans of the lead departments at national level and for three provinces indicates that services for children with disabilities are facing resource constraints. For example:

- For all of the programmes directly affecting children with disabilities, the budget allocations of the Eastern Cape Department of Social Development decrease significantly over the Medium Term Expenditure Framework:[266]
- In KZN, the training of community health workers has stopped due to financial constraints.[267]
- The Western Cape Department of Education's strategic plan notes the following for public special school education (Programme 4): "Currently the increase of funds allocated is 4.5 percent per annum; this is lower than the inflation rate and not in line with the growing demand for specialized services that need to be provided. This has an adverse effect on service delivery."[268]

A review of the progress in implementation of inclusive education also found that funding difficulties have contributed to the delay in the full implementation of White Paper 6.[269]

5.3.2 Difficulties around funding of non-government organisations

Under the Children's Act (2007), government is responsible for ensuring that comprehensive social services are provided for children, with priority being given to funding of services in poor communities, and to ensure that these services are accessible to children with disabilities.[270] However, although NGOs are rendering services which are mandated by the Act,[271,272] funds paid to them do not cover the full cost of providing these services.[273]

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262 Department of Basic Education (2011) Strategic Plan 2011-2014. p.14.
263 National Stakeholder workshop, 24 May 2011.
264 Maluta Tshivhase, National Department of Health: Rehabilitation Programme, interview 2 June 2011.
265 Philpott, S. (2004) Budgeting for children with disabilities in South Africa. Cape Town: IDASA. p.115.
266 Strategic Plan and Annual Performance Plan 2008-2011 of the Province of the Eastern Cape Department of Social Development, p.145. The majority of disabled children are unlikely to benefit from reforms being planned for residential centres for people with disabilities.
267 KZN Department of Health Strategic Plan 2010-2014.
268 Strategic Plan of the Provincial Government of the Western Cape Education Department 2010-2014. p.44.
269 Wildeman, R.A. & Nomdo, C. (2007) *Implementation of inclusive education: how far are we?* Occasional paper: IDASA Budget Information Service. www.idasa.org.za
270 For example, for ECD Children's Act (2007) 93(4)
271 Participants of the KZN Stakeholder workshop (12 May 2011) reported that despite policies and structures being in place, mainstream schools still refer children with disabilities to NGOs and not to government structures.
272 Patiswa Momoza & Kholeka Koko-Mhlahlo, Disability Unit, Western Cape Department of Social Development, interview 13 June 2011.
273 Budlender, D., Proudlock, P. & Giese, S. (2011) *Funding of services required by the Children's Act.* Summary of publication commissioned by USAID, UNICEF, SA National Treasury, CASE & Children's Institute.

At national level, the Department of Social Development has acknowledged difficulties with the funding of services provided by partner organisations, stating that "[the] underfunding of service delivery partners remains a challenge, and the economic recession has worsened the situation. This area will receive attention in the medium term."[274]

That the Department intends to address this in the "medium term" suggests that the issue is not seen as urgent, despite the fact that the well-being of many children with disabilities is in jeopardy because of the lack of funding of NGOs.

NGOs working in the disability sector have expressed grave concerns regarding accessing government funding.[275] Some organisations have reported that even where a service level agreement is in place, funding does not always come through as agreed.[276] Furthermore, difficulties extend beyond the extent of funding and funding procedures, to a lack of understanding regarding the nature of services required for children with disabilities:[277]

> *"We only get subsidies for social workers – but we have trainers, mobility instructors, etc. There needs to be recognition that programmes should be the basis for funding, not just social work posts."*[278]

On the other hand, the Department of Social Development at national and provincial levels,[279,280,281] is concerned about NGOs' lack of administrative capacity, skills for financial management and writing of business plans, stating that "Many non-profit organisations (NPOs) do not comply with the NPO Act due to lack of capacity, and are bound to be struck from the register. During the next few years the unit will focus on simplifying registration and strengthening the capacity of NPOs."[282]

5.4 Human resources

Another problem that has been identified as a barrier to the provision of adequate and appropriate services for children with disabilities in the health, education and social development sectors is the shortage of human resources in these sectors[283] – a shortage that is further compounded by the unequal distribution of available resources.[284]

5.4.1 Health

Lack of priority given to habilitation and rehabilitation

The national Department of Health's Strategic Plan contains no reference to habilitation or rehabilitation, nor does it comment on levels of provision of rehabilitation personnel or assistive devices. This is a concern with regard to children with disabilities because rehabilitation and habilitation services are a key element of their well-being, as well as a means for the equalisation of opportunities and access to many other services.

Expertise for assessment, early identification and intervention

Stakeholders in the health sector[285,286] reported a critical shortage of specialists for assessment of children (e.g. neuro-developmental paediatricians[287]).

274 Strategic Plan of the Department of Social Development 2010-2015. p.42.
275 National Stakeholder workshop, 24 May 2011; KZN Stakeholder workshop, 12 May 2011.
276 For example, the Pietermaritzburg Cerebral Palsy Association reported that funding from DSD had come several months after it had been promised, and did not match the amount that the organisation had requested. KZN Stakeholder workshop, 12 May 2011.
277 Bukiwe Sapepa, Disability Co-ordinator, KZN Department of Social Development, interview 7 July 2011.
278 KZN Stakeholder workshop, 12 May 2011.
279 Department Social Development (2010) p.54.
280 KZN Department of Social Development Strategic Framework 2010/11-2014/15 including the Annual Performance Plan 2011/2012.
281 Nosipho Sishuba, Disability Co-ordinator (services to persons and children with disabilities), Eastern Cape Department of Social Development, interview 8 July 2011.
282 Department Social Development (2010) p.54.
283 National Stakeholder workshop, 24 May 2011.
284 Vuyi Zondi, Special Schools, Chief Education Specialist KZN Department of Education, interview 30 May 2011.
285 National Stakeholder workshop, 24 May 2011. p.12.
286 Joyce Gysman, Rehabilitation Co-ordinator, Eastern Cape Department of Health, interview 2 June 2011.
287 For example, in Gauteng there is only one neurodevelopmental paediatric service that assesses school-going children.

For identification and early intervention, both mid-level workers and rehabilitation therapists are required. However, the availability of the necessary human resources is undermined by:

- a high vacancy rate for rehabilitation therapists[288,289] (see detailed discussion in Chapter 4);
- abolishment of vacant (therapy) posts, such that it is no longer possible to measure the gap between what is in place and what is required: "In the past posts were created based on need – now they have to be motivated for in relation to the load of work (measurement of the number of clients seen per day). The challenge is that therapists do not know how to do the motivation";[290]
- therapists at the PHC level having a very high curative load with very little time for rehabilitation[291]; and
- therapists from urban areas not being equipped to cope with the challenges and realities of children with disabilities living in rural areas.[292]

CBR personnel

In the past, mid-level community rehabilitation workers called community rehabilitation facilitators (CRFs) received training at the Institute of Urban Primary Health Care, Tintswalo Hospital and CREATE. However, this was stopped by the HPCSA in favour of training (hospital-based) rehabilitation assistants[293] and no training of CRFs is currently taking place.[294]

In KZN, the contracts of 22 CBR workers (two in each of the 11 health districts) have recently been renewed for another year. These workers are linked with the district rehabilitation co-ordinator, and are responsible for the identification and referral of adults and children with disabilities. However, a number of key challenges persist for this category of personnel:

- the level of training and skills is inadequate;
- stipends are low;
- distances are great and funds for travel are insufficient; and
- CBR is still a contested concept.[295,296]

Nursing and medical staff

Lack of expertise among health sector personnel may result in false reassurances and inaccurate information being given to caregivers, as illustrated by the following account given by a caregiver in one of the focus group discussions that formed part of this study:[297]

> *I fell pregnant with Z and when I gave birth they said my baby girl didn't have much strength. For years she couldn't sit…. She would just fall over when I tried to support her with a blanket. I took her to the hospital and they said she will walk. I took her to doctors and they said she will walk. When she tried walking, she had already developed contractures…. She tried walking with her toes…. She has a wheelchair but can't use it….*

Also of concern are allegations of malpractice and incompetence on the part of medical professionals, resulting in primary or secondary disabilities.[298] One caregiver tells her story:[299]

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288 KZN Department of Health Strategic Plan 2010-2014.
289 KZN Stakeholder workshop, 12 May 2011. Refer also to section 3.3.2 of this report.
290 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
291 Richard du Plessis, Assistant Director: Rehabilitation and Prevention of Blindness, District Health Services and Programmes, Western Cape Department of Health, interview 1 June 2011.
292 Joyce Gysman, Rehabilitation Co-ordinator, Eastern Cape Department of Health, interview, 2 June 2011.
293 This is documented more fully in Rule, S., Lorenzo, T. & Wolmarans, M. (2006) 'Community-based rehabilitation: new challenges', in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (eds) *Disability and social change: a South Africa agenda*. Cape Town: HSRC.
294 Joyce Gysman, Rehabilitation Co-ordinator, Eastern Cape Department of Health, interview, 2 June 2011.
295 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
296 Nosipho Sishuba, Disability Co-ordinator, Eastern Cape Department of Social Development, interview 8 July 2011.
297 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
298 Stakeholders at the National workshop (24 May 2011) noted the high expenditure being paid out by the Department of Health as a result of litigation for ante- and post-natal neglect, e.g. for retinopathy of prematurity resulting in blindness of premature babies.
299 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.

I was very ill when I was pregnant… I had terrible headaches. On the ninth month, I went into labour for about three days. When I got to the hospital, they didn't pay much attention to me; it took a while for them to deliver the baby. I went to the hospital when my water had broken… the day before at about 5 p.m. I went to the hospital… and sat there. When I got there, they took me to the labour ward and laid me down and I stayed there a while. It was a weekend and there weren't that many doctors. I sat there till evening. Doctors would come in to check on me, saying the baby is still too far. I fell asleep and woke up when the doctor came in. He said they were going to perform a caesarian section, only to find that the baby was already showing, all I had to do was push…. I could feel it but they had injected me twice. They took the baby out with forceps. When they did that, they must have mishandled the baby's head, because the baby was hurt. They washed him, but he didn't even cry or move. He was in hospital for three months, didn't cry, or move, he just lay there. They asked me if I wanted to keep him on life support. They said the machine is doing the breathing, there's no life. They took him off life support. He got better, [but] he was still in a coma but kept having seizures. He came out of the coma, but wore an oxygen mask. On Sunday they discharged me. They knew it was their fault, so they didn't tell me what was wrong with my baby. After being home, I went back and forth to clinics. The baby was so sick….

5.4.2 Early childhood development

Most early childhood development (ECD) practitioners are trained in standard child development and lack experience working with children with disabilities. As a result, they are reluctant to accommodate children with disabilities in mainstream services.[300]

5.4.3 Education

Within the education sector, several human resource management challenges have been identified, the most pressing of which are discussed below.

Assessment

Stakeholders in KZN noted that children with disabilities are often referred from special schools to NGOs and the Department of Health for assessment. However, the lines of communication and role definitions between service providers are not always clear which can create difficulties for the children who require assessments. Such a lack of co-ordination and collaboration results in late identification of children with barriers to learning and delay in appropriate placement.

The lack of adequate skills and facilities for assessment contributes to:

- Long delays in placement while the child is waiting for an assessment;[301]
- Children not being assessed and therefore unable to access the required service;
- Educators not knowing the extent of a child's impairment (e.g. hearing loss)[302] and therefore not assisting the child appropriately;
- Children developing secondary disabilities (e.g. a child may develop a 'learning disability' because they cannot see the blackboard[303]); and
- Many disabled children only starting school long after the age of seven years which, in turn, raises challenges for educators: "How does an educator cope with a child of 12 who has never been to school?"[304]

In addition, late or inappropriate placement of disabled children may result in stigmatisation, frustration and anger and/or dropping out from school.[305]

300 National Stakeholder workshop, 24 May 2011.
301 Participants at the KZN Stakeholder workshop (12 May 2011) reported that for deaf children, it is compulsory to have a psychological assessment, but it may take two years to get it.
302 National workshop. p.6.
303 National Stakeholder workshop, 24 May 2011. p.7.
304 National Stakeholder workshop, 24 May 2011.
305 National Stakeholder workshop, 24 May 2011.

Curriculum differentiation

One of the major barriers to the effective implementation of inclusive education is the lack of appropriate training for teachers. To date (2011), 28 000 teachers have been trained, but there is still a lack of skills in the area of curriculum differentiation.[306] In 2011, the Department of Basic Education (DBE) completed the Guidelines for Responding to Learner Diversity in the Classroom which was introduced during the national orientation programme on the National Curriculum Statement, Grades R to 12 of 2011. The DBE has emphasised in the Integrated Strategic Planning Framework for Teacher Education and Development in South Africa (2011–2015) that skills and knowledge on curriculum differentiation should become a key feature of all teacher development programmes.

Furthermore, the Department of Basic Education appointed a ministerial task team to oversee the development of a curriculum for South African Sign Language, Grades R to 12. Once this curriculum has been completed and introduced into the system, it will remove a substantial barrier to learning for learners who are deaf and who have been unable, to date, to optimally develop their literacy skills in their mother tongue, namely sign language.

Specialised intervention

Most teachers at ordinary public schools (i.e. mainstream public schools) are not trained to deal with the diverse needs of children with different health conditions and impairments (e.g. Down syndrome, autism, chronic illness). Stakeholders reported that schools approach NGOs to assist them with training, but it is unclear whose responsibility it is to provide this training.[307]

The DBE has introduced several training programmes for the period 2011–2014 to equip key district and school staff in a range of specialised skills such as how to implement the national strategy on SIAS, how to ensure the delivery of quality education and support in full-service schools and special school resource centres, and specialist knowledge required to teach in schools for visual impairment, deaf and hard of hearing.

Accessible learning and teaching materials

There are inadequacies in the supply of textbooks and other teaching and learning materials in Braille and large print for learners with visual impairment. Since 2009, the DBE has introduced a programme of ordering Braille textbooks and workbooks for all schools for visual impairment and also for learners in the mainstream who require accessible materials.

Due to the general lack of capacity in the country to produce Braille, the process has been very slow and complex.

5.4.4 Social development

Challenges around human resource capacity in the social development sector impact negatively on service delivery for children with disabilities at two levels. First, at both the national and provincial levels services from the Disability and Children Directorates are not integrated.[308] There is a lack of capacity for guiding and sensitising the various units of the Department on the subject of disability.[309]

The issue of mainstreaming services to disabled children has not been resolved, e.g. when the Department of Social Development's Programme on Child Care and Protection receives a call about a disabled child they refer to the Disability Unit. This confusion needs to be resolved. Childhood disability is a complex and specialised area. This causes a problem when a disabled child is abused and has to be placed in alternative care and there are no accessible places for placement.[310]

Second, at the local and NGO levels, working with children with disabilities usually requires some specialised skills. For example, a social worker dealing with deaf children needs to be fluent in sign language, so that they can counsel without a sign language interpreter. However, such skilled staff are difficult to retain in the NGO sector.[311]

306 Marie Schoeman, Department of Basic Education, Inclusive Education, interview 13 July 2011.
307 National Stakeholder workshop, 24 May 2011.
308 Bukiwe Sapepa, Disability Co-ordinator, KZN Department of Social Development, interview 7 July 2011.
309 Manthipi Molamu, Department of Social Development, Directorate Disability, interview 31 May 2011.
310 Patiswa Momoza, Kholeka Koko-Mhlahlo, Disability Unit, Western Cape Department of Social Development, interview 13 June 2011.
311 KZN Stakeholder workshop, 12 May 2011.

Meal time at MC Kharbai School for the Deaf. The school has a daily feeding scheme.



5.5 Planning standards/access to a disability-friendly built environment

> *Inaccessible environments deny people with disabilities their rights to equality, dignity and freedom …. Lack of physical access both to and within built environments, is a major factor contributing to the exclusion of people with disabilities from mainstream society.*[312]

Despite increasing awareness of the need for environmental accessibility for adults and children with disabilities, many government services are not disability-friendly, and severe challenges with the built environment exist.[313] Some of the factors contributing to this are deficiencies in the regulatory framework and constraints faced by less-resourced hospitals.

A review of the legislation related to environmental accessibility identified a number of deficiencies in the current regulatory framework, including a lack of consideration of the requirements of adults and children with different impairments.[314] In addition, the non-statutory guidelines of the South African Bureau of Standards code of practice are not legally enforceable, and this results in non-compliance by property developers. This is compounded by the lack of enforcement of Part S of the National Building Regulations by building control officers, resulting in the majority of public buildings being inaccessible to adults and children with disabilities.

Inaccessible district hospitals are often located in poorer rural areas with limited resources and fewer professionals.[315]

5.6 Difficulties with implementing the social model of disability in assessment

Currently, the assessment process for determining eligibility for the CDG is based on the medical model of disability. Other than the means test, the medical officer's assessment of the child's health condition is the primary indication of the need for social security. This does not take into account other elements of disability as reflected in the International Classification of Functioning, Disability and Health (ICF) for Children and

312 South African Human Rights Commission (SAHRC) (2002) *Towards a barrier-free society*. SAHRC.
313 National Stakeholder workshop, 24 May 2011, refer 3.3.2 (c).
314 For example, provision of tactile surfaces and cane detection areas may help persons with visual impairments, but building regulations primarily focus on the needs of wheelchair users.
315 Schneider, M., Couper, J. & Swartz, L. (2010) *Assessment of accessibility of health facilities to persons with disabilities*. Report submitted to Directorate: Chronic Diseases, Disabilities and Geriatrics. National Department of Health. April. Department of Psychology: University of Stellenbosch.

Youth – such as the extent of activity limitations or participation restrictions, nor does it consider environmental or contextual factors.[316, 317]

A 10-year review of the impact of government policies towards persons with disabilities[318] reported that the Department of Social Development identified a number of key concerns regarding assessments for social security for adults and children with disabilities. These included:

- Lack of uniformity of assessment tools across provinces;
- Lack of clarity regarding eligibility criteria for children;
- The subjective nature of assessment in determining eligibility;
- The need for training of assessors;
- Lack of awareness regarding availability of grants, particularly in rural areas; and
- Corruption around grant administration and payment processes.

As a result of these concerns, the Department of Social Development undertook to formulate and pilot new tools for the assessment of social security for adults and children with disabilities. It is anticipated that this would help to shift the focus from a purely medical approach to assessments (focusing on the health condition), to one which took into account both activity limitations and participation restrictions. Staff of the Department of Social Development indicated that the assessment tool is yet to be approved.[319]

5.7 Lack of co-ordination and fragmentation of services

A number of factors have contributed to the lack of co-ordination and fragmentation of services to children with disabilities.

5.7.1 Lack of synergies between policies

There are various government departments, all with different policies and approaches to children with disabilities. In instances where these policies and approaches are not synchronised, they undermine the potential for departments to work collaboratively. For example, the classification system used by the Inclusive Education Directorate for the provision of material resources (assistive devices) is incompatible with the system used by the Department of Health. The former distinguishes between "assistive devices" and "auxiliary aids",[320] a distinction which is not used by the Department of Health. The Department of Basic Education has expressed the urgent need to align the policies and practices of the Departments of Health and Education regarding the supply of assistive devices,[321] with a clear indication of which department is responsible for the supply of which category of devices.[322]

5.7.2 Lack of consultation between government and non-government organisations

The lack of co-ordination between government departments and NGOs is a feature of limited communication.[323] NGO service providers expressed high levels of frustration about this during the stakeholder consultations:

> *Departments come up with different policies and strategies, but they don't consult with NGOs until these have been finalised, and then the NGOs are not informed about implementation. For example, the last feedback to NGOs about White Paper 6 was about six years ago! There is no communication on what is happening, and so NGOs cannot respond effectively.*[324]

316 Andrews, J., Fourie, M. & Watson, R. (2006) 'Issues in Disability Assessment' in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (eds) *Disability and social change: a South African agenda*. Cape Town: HSRC.
317 This was confirmed by stakeholders at the KZN Stakeholder workshop (12 May 2011).
318 OSDP (Office on the Status of Disabled Persons) (2003) Impact of government policies towards persons with disabilities. Pretoria: Office of the Deputy President.
319 Manthipi Molamu, Department of Social Development, Directorate Disability, interview 31 May 2011.
320 Department of Education (2009) *Implementing Education White Paper 6 on Inclusive Education*. Report on the Project Management Tender EDO 295. Pretoria: CSIR.
321 Department of Basic Education (2009) *Report on the inclusive education field test: 2004-2009*. Presented to the Heads of Education Committee.
322 Department of Basic Education (2009) *Report on the inclusive education field test: 2004-2009*. Presented to the Heads of Education Committee.
323 National Stakeholder workshop, 24 May 2011.
324 KZN Stakeholder workshop, 12 May 2011.

Stakeholders acknowledged that fragmentation also results in inappropriate allocation of funding, because departments or NGOs are not recognising and complementing each other's roles.

5.7.3 Lack of intradepartmental collaboration and tendency to work in silos

Stakeholders in the health sector reported a challenge with the lack of integration of services within the sector. Currently the Department of Health has many directorates and sub-directorates that impact on the health of children, such as maternal and child health, health promotion, school health, and chronic diseases, disabilities and geriatrics.[325,326] However, there is no co-ordinated and coherent response to the requirements of children with disabilities.[327] For example, the Department of Health recently developed the RtH booklet, containing a table of developmental milestones which are to be tracked on a regular basis when children under five years visit a clinic. If there are developmental delays, the child is to be referred to an occupational therapist, speech and language therapist, audiologist or physiotherapist. Despite the human resource requirements (in terms of therapists) that this new tool assumes, at national level the Directorate of Chronic Diseases, Disabilities and Geriatrics was not integrally involved in its development.

5.7.4 Lack of effective mechanisms for co-ordination

While stakeholders recognise that the Department of Women, Children and People with Disabilities has a role to play in co-ordination of the sector, they do not see clear evidence that this is being done, and the absence of a national forum to address disability issues has meant that service providers continue to work in silos.[328]

In some provinces, the Department of Social Development has taken responsibility for co-ordinating and monitoring services for children with disabilities with the aim of addressing the challenges of 'silo planning' and ensuring the inclusion of children with disabilities in service delivery streams. The difficulty, however, has been the lack of a formalised system for these co-ordination forums – they do not have a budget and so are unable to work effectively.[329]

A bakery class at Mashediso LSEN School.



325 Maluta Tshivhase, National Department of Health: Rehabilitation Programme, interview 2 June 2011.
326 Genetics falls under Maternal and Child Health, while eye conditions fall under Geriatrics.
327 National Stakeholder workshop, 24 May 2011. p.12.
328 National Stakeholder workshop, 24 May 2011.
329 Nosipho Sishuba, Disability Co-ordinator, Eastern Cape Department of Social Development, interview 8 July 2011.



Nkhuseli Mabuza, aged six, plays with Dikeledi Kgopo, the toy library operator at Khethiwe Stimulation Centre. Nkhuseli has delayed development.

5.7.5 Disconnect between national and provincial levels

Although at the national level the Department of Health has prioritised the need to improve access to health facilities for disabled adults and children,[330] this priority is not reflected at the provincial level. For example, the strategic plan of the Eastern Cape[331] states that access to health services has been improved through the waiving of fees for children and adults with disabilities, but no reference is made to the urgency of improving physical access in health facilities.[332]

5.7.6 Lack of norms and standards for services

Health personnel report that there are limited norms and standards in place for programmes and services for children with disabilities.[333,334] This is associated with a lack of clarity regarding what a particular service entails and the funding that would be required for it.[335] Within the ECD sector, there is also a lack of clarity regarding who is providing early intervention services and the respective roles of government and NGOs.[336]

Within the education sector, stakeholders reported that there are no guidelines to indicate what is required from NGOs to deliver high quality services (e.g. staffing, skills, learning materials guidelines) or to guide NGO collaboration with the Department of Basic Education.[337]

330 As indicated by the commissioning of the study: Schneider, M., Couper, J. & Swartz, L. (2010) *Assessment of accessibility of health facilities to persons with disabilities*. Report submitted to Directorate: Chronic Diseases, Disabilities and Geriatrics. National Department of Health. April. Department of Psychology, University of Stellenbosch.
331 Western Cape Department of Health Strategic Plan 2009/10-2014/15.
332 Leatt, A., Shung-King, M. & Monson, J. (2006). Healing inequalities: the free health care policy. In Monson, J., Hall, K., Smith, C. & Shung-King. M (eds) *South African Child Gauge*. Children's Institute: University of Cape Town.
333 KZN Stakeholder workshop, 12 May 2011.
334 Nosipho Sishuba, Disability Co-ordinator, Eastern Cape Department of Social Development, interview, referring to the lack of clear guidelines for the implementation of home community-based rehabilitation programmes.
335 For example, rehabilitation is often assumed to be a short-term process but for children with disabilities it may require a long-term process of support.
336 National Stakeholder workshop, 24 May 2011.
337 National Stakeholder workshop, 24 May 2011. p.7.

As a result of the lack of co-ordination, there is no coherent response to children with disabilities. In addition, fragmentation of services undermines potential benefits for children with disabilities:[338]

> *The impact of this is that it minimises the number of services that the child will be able to access and it compromises the quality of services …. This leaves the disabled child more vulnerable to abuse and neglect. It could also lead to the disability becoming more severe.*[339] *Children and parents become apathetic when they get shunted from pillar to post.*[340]

5.8 Information systems

There are a several factors with regard to information systems that have contributed to limited action being taken by the State and society:

5.8.1 Challenges with service delivery data of accurate and disaggregated data

One of the biggest challenges is the lack of accurate and disaggregated data on children with disabilities and the extent to which they are able/unable to access services.[341] Information systems on social services for children consistently do not disaggregate data on the basis of disability and this undermines the potential to plan, monitor and evaluate services.

There is also no system or register in place to track the progress of children with disabilities from birth, into ECD and education.[342] As a result, many children do not have access to state subsidies through ECD or education because from the beginning, they have not been part of the systems of provision.[343]

Education

Stakeholders in the disability sector in KZN reported that there is limited information available at the local level for teachers and caregivers or parents. One of the reasons for this is seen to be the limited capacity for gathering data on learners with barriers to learning.[344]

Health

Data on users of key services provided by the Eastern Cape Department of Health (as reflected in the province's strategic plan) does not disaggregate users by age or disability status. This is a trend across much of the information presented in the plan, and as a result the inequities in service provision and access are masked.[345] Similarly, in the national Department of Health's Strategic Plan there is no disaggregated data on coverage or access to services for children with disabilities. Data is provided on financial resources that have been made available to national disability-related organisations by the national Department of Health, but there is no breakdown of the number of children receiving such services.

In addition, there are no specific targets for children within rehabilitation services.[346] At the national level, there are no indicators for children with disabilities in the NIDS – it only focuses on assistive devices as an indicator for rehabilitation, and statistics are not disaggregated for children.[347]

Collection of data through the DHIS has also been weak.[348]

338 See also National Stakeholder workshop, 24 May 2011. Social Development Group p.18.
339 KZN Stakeholder workshop, 12 May 2011.
340 National Stakeholder workshop, 24 May 2011.
341 National Stakeholder workshop, 24 May 2011.
342 National Stakeholder workshop, 24 May 2011.
343 National Stakeholder workshop, 24 May 2011.
344 KZN Stakeholder workshop, 12 May 2011.
345 Eastern Cape Department of Health Strategic Plan 2009/10-2014/15.
346 Joyce Gysman, Rehabilitation Co-ordinator, Eastern Cape Department of Health, interview 2 June 2011.
347 National Stakeholder workshop, 24 May 2011.
348 Maluta Tshivhase, National Department of Health: Rehabilitation Programme, interview 2 June 2011.

Social development

The national Department of Social Development's Strategic Plan 2010-2015[349] acknowledges the limitations of current information collection systems, specifically with regard to NGOs and NPOs. However, it does not identify the need for disaggregation of data, particularly of users of social welfare services, which is essential for the targeting of services.

5.9 Rigid prioritisation processes and marginalisation of children with disabilities

The national Department of Health's Strategic Plan 2010/11-2012/13[350] places great emphasis on maternal and child well-being, particularly on the reduction of mortality. The focus is on child survival and decreasing mortality in light of the Millenium Development Goals.[351] Indeed, this is a critical issue and a necessary goal. However, what of those children who survive but have cognitive stunting? What of those instances where peri-natal care is inadequate and children have cerebral palsy? Or the underweight babies of teenage mothers who survive, but have cognitive impairments?

Stakeholder consultations that formed part of this study indicated that the limitations of the health care system in not preventing impairments are often unacknowledged. There is therefore a lack of planning for programmes of early identification and intervention, as well as the provision of rehabilitation services. Furthermore, within the health sector, the District Health System has not been adequately strengthened for the provision of services to deal with children who are at high risk for impairment and disability.[352]

5.10 Awareness

Stakeholders in the disability sector noted the general lack of information and awareness about children with disabilities. This manifests at different levels.

At the individual and family level, many caregivers need to be provided with adequate information about their children's disability, including how to reduce activity limitations.[353]

The stakeholder consultations revealed that generally the ability of caregivers to advocate for services for their children is often undermined by their lack of knowledge on what services "which are controlled by government departments" are available.[354]

At a societal level, there is a lack of information dissemination on the rights of children with disabilities, and on the UNCRPD.[355] As a result, discriminatory attitudes and practices towards disabled children are not challenged.

Box 5.1 provides a summary of existing research on the effectiveness of disability policy implementation in South Africa.

349 Strategic Plan of the Department of Social Development 2010-2015.
350 National Department of Health Strategic Plan 2010/11-2012/13. Pretoria.
351 National Stakeholder workshop, 24 May 2011. p.11.
352 National Stakeholder workshop, 24 May 2011. p.11.
353 National Stakeholder workshop, 24 May 2011. p.19.
354 National Stakeholder workshop, 24 May 2011. p.19.
355 National Stakeholder workshop, 24 May 2011. p.19.

Box 5.1: Summary of key factors that influence the effectiveness of disability policy implementation in South Africa

Research on the effectiveness of disability policy implementation in South Africa found that:

- Policies are not aligned to programmes of action for implementation.
- There is a lack of monitoring tools.
- There is a lack of personnel in departments with expertise and knowledge on disability issues.
- There is a lack of internal policies on disability.[356]
- The definition of disability and nature of disabled people's participation have been inadequately articulated.
- Policy requirements for disability mainstreaming are not linked to performance management.
- There is a lack of budgetary allocations.
- There is ignorance on the part of civil servants who have responsibility for implementing disability policies.
- Procedural bottlenecks.[357]

Within the social cluster, some significant progress has been made:

- Education – There is increased awareness of White Paper 6, but progress on implementation remains slow and the problem of out-of-school learners remains an immense challenge.
- Welfare – There has been a steady increase in the number of adults and children with disabilities who have access to social security; there has been a focus on research to inform policy and programme development.
- Health – Programmes on prevention of disability have been effective in reducing the incidence of new polio infections and achieving high rates of immunisation coverage; there is also improved proximity to health facilities.[358]

Some provinces have developed integrated provincial disability strategies, but no budgetary allocations were made and therefore there has been no significant implementation of these strategies in any of the provinces.[359]

Recommendations:[360]

- Departments develop plans of action around disability with associated budgets.
- There are incentives and/or punitive measures in place to encourage compliance.
- The disability sector must be supported in order to play a more active role in monitoring and evaluation of services.

356 Nkeli, J. & Associates (2008) Broad overview of the impact and an analysis of the effectiveness and efficiency of disability policy implementation in all spheres of government since 1994.
357 Dube, A.K. (2005) *The role and effectiveness of disability legislation in South Africa*. Disability Knowledge and Research.
358 Nkeli, J. & Associates (2008)
359 Dube, A.K. (2005)
360 Nkeli, J. & Associates (2008)

Chapter 6



Students enjoy a story-telling session at the Kharbai School for the Deaf.

South Africa is recognised for its progressive policies on disability. As this study has noted, there are many success stories in addressing the challenges that confront children with disabilities and their families to date. Yet, there remains a myriad of obstacles to fulfilling the rights of these children. This chapter reviews some of the important opportunities that exist in the country for accelerating the fulfilment of the rights of all children with disabilities.

6.1 Ongoing health sector reforms

Recent policies on the National Health Insurance (NHI) and the re-engineering of Primary Health Care (PHC) present huge opportunities to address several of the health-related challenges faced by children with disabilities in South Africa.[361]

The NHI is a financing system that is intended to ensure that all citizens of South Africa (and legal long-term residents) are provided with essential health care, regardless of their employment status and ability to make a direct monetary contribution to the NHI Fund. The NHI is being implemented gradually in three phases over a 14-year period. The first phase will take five years to complete starting in April 2012, and includes strengthening of the health care system, improving the service delivery platform, and policy and legislative reform.[362]

Re-engineering PHC will include, among other actions, state-led provision using health agents at the ward level (lowest level of municipal administration) and in schools, and a revitalisation of health care infrastructure and equipment. The emphasis is on a continuum of services – from promotive and preventive, to curative, rehabilitative and palliative care, with a shift away from the clinic- or hospital-based model to a community-based model. It is anticipated that the renewed emphasis on PHC will improve the prevention aspect which has often been neglected in favour of curative care.[363]

Furthermore, the national Department of Health's strategic plan[364] makes provision for the training of health professionals in new categories (mid-level workers) to support clinical service delivery,[365] including deployment of rehabilitation therapists at district level. A link with PHC teams will potentially give early identification and intervention a boost.

In these reforms, the disability sector should actively engage with the Department of Health to ensure the mainstreaming of solutions to health-related challenges encountered by children (and indeed adults) with disabilities. For example, the recent audit of the accessibility of health facilities[366] provides both the rationale and the tool to ensure that planned improvements include increased physical accessibility of the built environment using universal design principles.[367, 368, 369]

The revitalisation of the PHC also provides an opportunity to re-emphasise primary prevention through:[370]

- Identification and prioritising of children at high risk. The progress of these children needs to be tracked, including their entry to school;
- Improvement of screening programmes at MCWH services, especially at antenatal clinics, to identify high-risk pregnant mothers;
- Development of PHC guidelines which reflect the importance of disability prevention, early identification and early intervention for children at risk for impairment and disability, with protocols to include minimum standards for screening, assessment and appropriate referral for different impairment types, as well as the definition of specialised services for children with different impairments;

361 Department of Health Strategic Plan 2010/11-2012/13. Pretoria.
362 http://www.doh.gov.za/list.php?type=National Health Insurance
363 http://www.doh.gov.za/list.php?type=Primary Health Care
364 Department of Health Strategic Plan 2010/11-2012/13. Pretoria.
365 This is also reflected in the Strategic Plan 2010-2014 of the KZN Department of Health, and the Strategic Plan 2009/20-2014/15 of the Eastern Cape Department of Health.
366 Schneider, M., Couper, J. & Swartz, L. (2010) *Assessment of accessibility of health facilities to persons with disabilities.* Report submitted to: Directorate: Chronic Diseases, Disabilities and Geriatrics. University of Stellenbosch.
367 KZN Stakeholder workshop, 12 May 2011.
368 Department of Health (2011) Accessibility of health facilities to persons with disabilities. Assessment form (22 pages). Guidelines to the accessibility assessment of hospitals (8 pages).
369 Christian Blind Mission, *Promoting universal access to the built environment: Guidelines.*
370 National Stakeholder workshop, 24 May 2011.

- Continuation of initiatives to place paediatricians in all 52 health districts of the country;
- Provision of support and information to caregivers and parents of children with disabilities to assist them to care for their children;
- Improved networking and collaboration with NGOs and key stakeholders; and
- Strengthening of school health services.[371]

The new (extended) RtHB contains a table on developmental milestones which should be used by PHC nurses for early identification and referral for children with developmental delays.[372,373] This provides a unique opportunity to strengthen early identification and intervention services.[374] However, effective use of this important tool requires a clear roll-out process, with all stakeholders being informed of plans and programmes, and appropriate training being done timeously.[375,376] It also requires sufficient rehabilitation therapist capacity at the clinic level, as well as an effective referral chain.[377]

6.2 Rehabilitation

The revitalisation of the PHC and the proposed Strategy for Integration of Services for Children with Disabilities provide opportunities to revisit the implementation of rehabilitation and CBR and to assess the effectiveness of approaches currently being used in the country. Rule et al.[378] call for a broad understanding of rehabilitation that is not limited to individual therapy, but is seen as an enabling process that promotes poverty eradication, survival and the development of people with disabilities, as well as community participation.[379] Indeed, the proposed Strategy for Integration of Services for Children with Disabilities envisages habilitation and rehabilitation programmes as a means of promoting the well-being of children with disabilities.[380]

In developing appropriate and accessible rehabilitation services for children with disabilities, the following issues need to be considered:

- The concept of social inclusion needs to be integrated with CBR.[381]
- Implementation mechanisms for CBR need to be developed, based on a common understanding of CBR as a strategy within community development to address poverty.
- There needs to be an interdepartmental policy framework for CBR, with clear mandates and role differentiation between different stakeholders. Greater collaboration is required between rehabilitation professionals, mid-level CBR workers and other stakeholders within the sector.[382]
- The recruitment, training and deployment of mid-level CBR workers should be done concurrently with developments around community health workers and community development practitioners so that CBR workers have comparable training and remuneration opportunities.[383]
- There is need for systems to constantly monitor and evaluate CBR and the training of practitioners in order to ensure continuity along the continuum of service delivery.[384]

371 Marie Schoeman, Department of Basic Education, Inclusive Education, interview 13 July 2011. The Health Promotion Unit of the Department of Health has a programme for screening of children in Grade 1 in quintile 1. In 2010, 160 000 learners were screened on vision, hearing, height for weight, worms and communication difficulties.
372 McKerrow, N. (2011) Implementing the new Road to Health Booklet. Pietermaritzburg Metropolitan Hospital Complex. Presented at KZN Stakeholder workshop, 12 May 2011.
373 National Stakeholder workshop, 24 May 2011.
374 KZN Stakeholder workshop, 12 May 2011.
375 KZN Stakeholder workshop, 12 May 2011.
376 Maluta Tshivhase, National Department of Health: Rehabilitation Programme, interview 2 June 2011.
377 KZN Stakeholder workshop, 12 May 2011.
378 Rule, S., Lorenzo, T. & Wolmarans, M. (2006) 'Community-based rehabilitation: new challenges' in Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestly, M. (eds) *Disability and social change: a South African agenda.* Cape Town: HSRC.
379 The focus group with children from rural areas found that the CBR programme in a special school contributed significantly to increased awareness of disability within the community.
380 DSD (2009) Strategy for the integration of services to children with disabilities. Inter-departmental Technical Task Team. Pretoria.
381 Manthipi Molamu, Department of Social Development, interview 31 May 2011.
382 Rule, S., Lorenzo, T. & Wolmarans, M. (2006) Community-based rehabilitation: new challenges.
383 Rule, S., Lorenzo, T. & Wolmarans, M. (2006) Community-based rehabilitation: new challenges.
384 Rule, S., Lorenzo, T. & Wolmarans, M. (2006) Community-based rehabilitation: new challenges.

6.3 Inclusive education

International experience has shown that inclusive education provides a means of improving access to education, as well as appropriate support for learners experiencing barriers to learning.[385]

White Paper 6 on Special Needs Education[386] continues to provide an important framework to fulfil the right to quality education for children with disabilities. The following issues need to be addressed in accelerating the implementation of the White Paper:

6.3.1 Environmental accessibility of schools

There is considerable room for new ordinary public schools to be built in compliance with the principles of universal design and environmental access specifications, thus avoiding the costly process of upgrading them at a later stage.[387]

6.3.2 Assessment and provision of support

The progress made in implementing inclusive education has contributed significantly to the development of SIAS – a tool for the screening and assessment of learners experiencing barriers to learning, as well as the provision of appropriate support.[388,389] (See Box 6.1 for details on SIAS.) There is urgent need for an action plan on the implementation of SIAS.[390] This must be accompanied by norms and standards for inclusive education, and the required funding must be secured.[391]

Emphasis should also be placed on further training of (ordinary school) teachers in curriculum differentiation, and how to adjust their classroom activities when teaching learners with a range of disabilities or learning difficulties. The first such programme intends to improve knowledge on how to differentiate the curriculum and plan support for learners with visual impairment, deaf and hard of hearing. This programme will be followed by others which focus on specific disabilities such as autism. The needs of all learners who experience



Story telling time at MC Kharbai school for the deaf. The children are taught how to sign and on saturdays parents can come to the school to learn sign language for free.

385 Peters, S. (2004) *Inclusive education: an Education for All strategy for all children*. Geneva: World Bank.
386 Department of Education (2001) *Education White Paper 6, Special Needs Education: Building an Inclusive Education and Training System*. Pretoria.
387 Department of Basic Education (2009) *Report on the inclusive education field test 2004-2009.* Presented to the Heads of Education Committee.
388 Department of Education (2009) *Implementing Education White Paper 6 on Inclusive Education.*
389 Department of Basic Education (2011) Strategic Plan 2011-2014. Pretoria.
390 KZN Stakeholder workshop, 12 May 2011.
391 Nosimo Yabo, Acting Director & Billie Mnikina, Inclusive Education, Eastern Cape Department of Basic Education, interview 2 June 2011.

learning difficulties will be addressed through improving the capacity of teachers to plan their day-to-day teaching and learning activities in a differentiated way.[392,393] The strengthening of district-based support teams and school-based support teams[394] provides an opportunity to improve referral and monitoring mechanisms between different levels of support (namely, ordinary schools, FSSs and special schools).

Box 6.1: Screening, Identification, Assessment and Support (SIAS)

As part of promoting the implementation of inclusive education, the Department of Basic Education has developed a tool to assist educators in schools with identifying and removing barriers to learning. In contrast to previous approaches to assessment which focus on health conditions and impairments (e.g. autism), SIAS focuses on barriers to learning and development, towards provision of appropriate support. The aim is to bring support to the learner, rather than taking the learner to support. Indicators for the design and monitoring of support programmes are provided as part of action planning.

The SIAS process follows four stages:[395]

Stage 1: SCREENING Learner profile

The teacher and school obtain background information about the learner in order to understand their needs as well as their strengths and aspirations.

Stage 2: IDENTIFICATION Identify barriers to learning and development

An in-depth profile of the learner is compiled in consultation with parents and there is identification of contextual factors that may impact positively or negatively on learning and development.

Stage 3: ASSESSMENT Assess support requirements

There is a review of the impact of the school and analysis of its capacity to improve. There is also identification of community resources and assessment of learner support needs. Application may be made for additional resources and eligibility for access to alternative specialised programmes determined. Inputs are made to the action plan.

Stage 4: SUPPORT Action planning, provisioning and monitoring of additional support

Assessments are reviewed and a decision is made about the provision of additional support to the school and to the learner. This may entail additional resource allocation. There is also training, counselling and mentoring of the school, teachers and parents, and there is monitoring of the support provided.

(Source: www.education.gov.za)

392 Marie Schoeman, National Department of Basic Education, Inclusive Education, interview 13 July 2011; Strategic Plan of the Provincial Government of the Western Cape Education Department 2010-2014.
393 Nosimo Yabo, Acting Director & Billie Mnikina, Inclusive Education, Eastern Cape Department of Basic Education, interview 2 June 2011.
394 Department of Basic Education (2009) *Reports on the inclusive education field test: 2004-2009*. Presented to the Heads of Education Committee.
395 Department of Education (2008) *National Strategy on Screening, Identification, Assessment and Support: School Pack*. pp.10-11. www.education.gov.za

6.3.3 Inclusive education part of care and support in schools

The whole school development approach within inclusive education has been affirmed, with full-service schools being recognised as Care and Support for Teaching and Learning (CSTL) schools.[396] This programme provides the opportunity for the Department of Basic Education to address the vulnerability of learners in a broad sense, not focusing on disability as a separate issue.[397] (It is currently being implemented in KZN[398] where there is synergy between inclusive education and other initiatives of the KZN Department of Education, namely, schools as nodes of learning, care and support.[399]) There is an important opportunity for the Department of Basic Education to scale up this initiative in all nine provinces.

6.3.4 Enhanced collaboration

There are many different sectors and stakeholders that can contribute to effective quality education for children with disabilities. For example, the Departments of Health and Basic Education both have roles in the provision of assistive devices, screening of learners at school, and assessment of learners with barriers to learning and development.[400] Disability-specific NGOs provide specialist skills and expertise within the education sector,[401] and parents have a unique role to play in support of their children:

Thulani Nkabinde, of Mashediso LSEN School, in woodwork class.



396 The CSTL programme was adopted by Education Ministers of SADC in 2008. Its goal is to realise the education rights of vulnerable children in the region through schools becoming inclusive centres of learning, care and support. Objectives include harmonising care and support policies towards improved education outcomes and improving enrolment, retention and achievement of vulnerable learners. http://www.miet.co.za/?miet_content&global%5BcategoryISbb_content_categoriesID%5D=45

397 Marie Schoeman, National Department of Basic Education, Inclusive Education, interview 13 July 2011.

398 KZN Stakeholder workshop, 12 May 2011.

399 KZN Department of Education Annual Performance Plan 2011/12. In contrast, in the Eastern Cape, certain schools have been designated 'schools for treatment, care and support' and focus primarily on HIV issues. (See Eastern Cape Department of Education 5 Year Strategic Plan 2010/11-2014/15.)

400 National Stakeholder workshop, 24 May 2011. p.6.

401 National Stakeholder workshop, 24 May 2011; Marie Schoeman, National Department of Basic Education, Inclusive Education, interview 13 July 2011.



Assembly at the Matshediso LSEN School.

> *Schools where there are children requiring a high level of support are developing home preparation programmes for the parents – often children who have only been at home and are not well-socialised require behaviour modification and preparation for entering a school situation.*[402]

This is an opportunity to ensure that there are mechanisms in place to promote collaboration and joint strategies which take cognisance of the contributions of all stakeholders.

6.4 Early childhood development

The government of South Africa is implementing a plan to universalise access to Grade R by 2014. The rationale behind this is that:

> *Grade R is an important equaliser, in that, the programmes offered … can address poor development of cognitive, social and motor skills that occurred during the early childhood years brought about by poor socioeconomic conditions and low family literacy levels. Grade R can ensure that learners are correctly assessed and placed in appropriate programmes that will remedy any barriers to a successful formal schooling career.*[403]

The Department of Social Development has also prioritised the scaling up of ECD services for younger children (0-4 years).[404]

The prioritisation of ECD, as well as the recognition of its potential for early identification and intervention for children with developmental delays, provides a unique opportunity for early intervention and social integration for children with disabilities:

> *Promotion of access to mainstream ECD programmes with the necessary support will assist with integration and acceptance of diversity and building up of self-esteem of disabled children. If children grow up together they do not notice differences.* [405]

Furthermore, all ECD programmes should be inclusive for every child.

402 Vuyi Zondi, Special Schools, CES KZN Department of Education, interview 30 May 2011.
403 Department of Basic Education (2011) Strategic Plan 2011-2014. Pretoria.
404 Department of Social Development Strategic Plan 2010-2015.
405 Patiswa Momoza & Kholeka Koko-Mhlahlo, Disability Unit, Western Cape Department of Social Development, interview 13 June 2011.

In line with the Children's Act (2007), expansion of ECD must target those children most in need of early childhood stimulation and development – including children with disabilities and those from poor communities. This means that not only do facilities need to be accessible, but programmes need to be appropriate and inclusive of children with disabilities. ECD practitioners need to be equipped to provide the necessary support for these children. The expansion of ECD services therefore creates the opportunity to mainstream measures to improve access for children with disabilities, including adequate training of ECD practitioners.

6.5 Care Dependency Grant

A strategic objective of the Department of Social Development is to introduce legislation for the implementation of a common tool to assess disability in the administration of the CDG.[406] This provides an opportunity to move away from a purely medical model of disability, and to use the International Classification of Functioning, Disability and Health (ICF) for Children and Youth to reflect the complex and dynamic nature of disability, as well as the contextual factors that shape it.

6.6 Maximising human resources

The Department of Health has recognised that current community health care workers do not provide the extent of community-based services required for comprehensive PHC, and for this reason community care givers (CCGs) are to be trained and deployed.[407]

Given the shortage of skills within the children's disability sector, strategies are necessary to ensure that available human resources serve the areas of greatest need. Such strategies include building on the CCG concept to (among others) prioritise services to children with disabilities, and providing scarce skills incentives and rural allowances for therapists.[408] In addition, there needs to be a staff retention strategy within both government and NGOs.

Those responsible for human resource development in the Department of Health need to consult with both the Chronic Diseases, Disabilities and Geriatrics Directorate as well as disability service organisations in order to determine the role of the CCG in provision of disability and CBR services.

Furthermore, given that service delivery depends largely on the availability of skilled community development workers, there needs to be collaboration between social services professional bodies and tertiary institutions to ensure adequate supply of human resources.[409] Attention needs to be given not only to mid-level workers, but also to improving human resource capacity and developing specialist skills for staff working with children with disabilities. The Department of Higher Education should train more therapists, and health professional bodies (occupational therapists, physiotherapists, speech therapists and audiologists) must advocate for more therapist posts in education.

There needs to be more explicit recruitment of young people with disabilities to be trained as ECD practitioners, teachers, therapists and child and youth care workers. Those who become disabled when they are already in the system must be retained.[410] Subsidies or bursaries should be offered to disabled students who undertake training as therapists, social workers or teachers.

6.7 Scalable projects

The table below identifies examples of projects that could be up-scaled or replicated in order to improve early intervention and support services for children with disabilities, as well as to improve networking and information dissemination.

406 Strategic Plan of the Department of Social Development 2010-2015.
407 Department of Health Strategic Plan 2010/11-2012/13. Pretoria.
408 KZN Stakeholder workshop, 12 May 2011.
409 KZN Department of Social Development Strategic Framework 2010/11-2014/15 including the Annual Performance Plan 2011/2012.
410 National Stakeholder workshop, 24 May 2011.

Table 6.1: Examples of projects that could be up-scaled or replicated[411]

Early intervention	Health condition or impairment	Early intervention programme
	Hearing	HI HOPES Tiny Handz
	Cerebral palsy	Pietermaritzburg Cerebral Palsy Association Malalumelele Onward
	Visual and autism	Children's Disability Centre
	Little or no functional speech	Centre for Augmentative and Alternative Communication[39] Interface KZN
Information on childhood disability	The.Sponge.Project Directory of Services 2010 for the Lavender Hill/Capricorn Area, Inclusive Education Western Cape	
Networks for child disability	Western Cape Forum for Intellectual Disability Inclusive Education Western Cape	
Identification and support of disabled children within programmes to support orphans and other vulnerable children	Isibindi Disability Project	

(Source: Authors' compilation based on stakeholder consultations)

6.8 Enhancing data collection

It is encouraging to see strategic plans that reflect available research, particularly when it comes to children. For example, the situation analysis of the Western Cape Department of Social Development's Strategic Plan 2010/11–2014/15 is well-informed by research conducted within the Department of Social Development (e.g. the audit of ECD facilities), research conducted by other departments (e.g. the Departments of Education and Health) and research conducted by academic institutions. However, this and other provincial Departments of Social Development need to go further in requesting information that unmasks the inequities in provision. In order to do this, it will be necessary to disaggregate data in terms of age, socioeconomic and disability status of children, otherwise it will be impossible to effectively target services towards those whose well-being and safety are most at risk.

There is a strong need for more robust, comparable and complete data on children with disabilities in the country. Definitions of child disability should be standardised based on the ICF. Stats SA is encouraged to develop, test and include child disability questions – or a child disability module – in existing national surveys such as the General Household Survey. Data needs to be systematically disaggregated by socioeconomic characteristics such as sex, age and location to uncover patterns and trends, and to monitor inequalities in access to services and child well-being. Additionally, dedicated disability surveys (possibly with clinical confirmation of results) could be carried out to gain more in-depth information on child disability and specific at-risk groups, such as children living in institutions.

There is also need for issue-specific research, including epidemiology of childhood disability, the burden of childhood disability and the cost of care if there is no early identification and early intervention, children's experiences of services, etc.

411 Maluta Tshivhase, National Department of Health: Rehabilitation Programme, interview 2 June 2011.

Furthermore, there is need for a common platform with information on available resources for children with disabilities,[412] as well as a centralised database on children with disabilities, to enable transparent monitoring of the situation of children with disabilities.[413,414] DBE's Learner Unit Record Information and Tracking System (LURITS) is a good starting point for children with disabilities in the school system.

6.9 Mainstreaming

The Integrated National Disability Strategy, the Strategy for Integration of Services for Children with Disabilities and the Children's Act all provide opportunities for policy makers and managers to discourage the silo approach to planning for services for children with disabilities.

Mainstreaming should be pursued,[415] including in the provision of alternative care, addressing topics such as HIV and AIDS, and violence and abuse, as well as the provision of education and health services, etc.

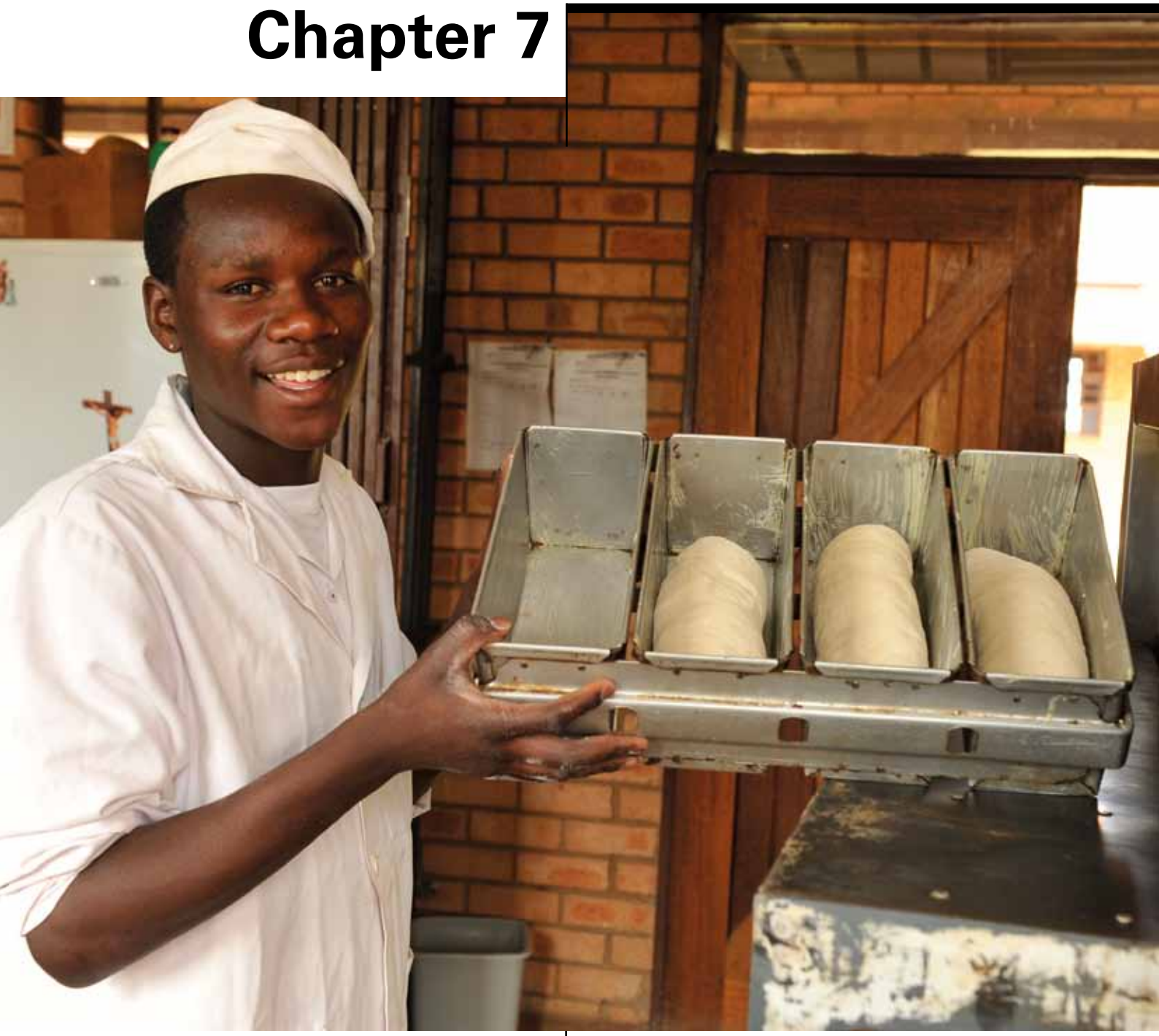
Although catering for diversity needs to be a value that underlies all services, there is the danger that children with disabilities may be 'lost' in the effort to mainstream. International experience shows that even with mainstreaming, disability-specific programmes are still required. This has been termed the 'twin-track approach'. The Office of the High Commissioner on Human Rights[416] recommends this approach to monitoring the UNCRPD. It includes both a specific focus on the rights of people with disabilities, as well as monitoring of the rights of people with disabilities, which is integrated into general human rights monitoring work.



Teacher Agnes Matloga, who has been teaching at the Sibonile School for the visually impaired for six years, washes Kgotso Khalo's hands. Kgotso is six years old and is deaf and blind.

412 National Stakeholder workshop, 24 May 2011. p.15.
413 Berenice Daniels, Western Cape Department of Basic Education, interview 16 July 2011, reported that discussions are underway between the Directorate Specialised Education Support and the Directorate Information Management to develop a system for tracking support and progress using the unique learner number/WCED CEMIS number and the District Information System.
414 Stakeholders at the national workshop (24 May 2011) noted that currently there is a database on children receiving CDGs. This could be a starting point. Information on the RtH booklet is captured by the Department of Health, and most children do have these charts, as they are required when a child starts school. The school system will help to pick up disability, and schools then provide the necessary support.
415 African Child Policy Forum (2010) *Breaking the silence: violence against children with disabilities in Africa*. ACPF: Addis Ababa.
416 Office of the High Commissioner for Human Rights (2007) *From exclusion to equality: realizing the rights of persons with disabilities*. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

Chapter 7



At Mashediso LSEN School, learners are taught many different skills such as sewing, woodwork, metal work, brickmaking and baking. For the intellectually impaired, these skills allow the learners to obtain work on leaving school. The local Spar has already employed five learners in their bakery.

7

This concluding chapter discusses potential channels for utilising opportunities that exist in South Africa towards fulfilling the rights of all children.

7.1 Disability Act and strengthening of existing legislation

The debate as to whether the interests of children with disabilities would be better served by disability-specific legislation or within mainstream (i.e. children's) legislation is important. Some argue that disability-specific legislation undermines the goal of inclusion, while others feel that disability rights will not be realised within mainstream systems of provision alone. Whatever the final position, consideration needs to be given not only to the outcome, but to what it represents as a means of promoting the goal of inclusion and equal rights for children with disabilities.

There is currently no disability-specific legislation in South Africa. The country's first democratic government developed the Integrated National Disability Strategy[417] with the aim of ensuring that disability would be incorporated into all relevant legal and other provisions in the country. Within the children's sector, the Children's Act has extensive provisions for children with disabilities.[418]

However, the strategic plan of the Department of Social Development[419] includes a long-term goal to develop legislation on the provision of social services to people with disabilities that is aligned to the UNCRPD. This will begin with a review of the policy on the provision of social services to people with disabilities, followed by draft legislation on the same. A Bill is planned to be tabled in 2013/14 and the Act promulgated the following year.

Australia's Disability Discrimination Act of 1992 and Disability Discrimination Act Standards for Education of 2005[420] present useful lessons, particularly in terms of the introduction of equity standards for elimination of discrimination against people with disabilities in their access to services.

In addition to considerations for a Disability Act, existing legislation and policy frameworks need to be strengthened to ensure compliance with the UNCRPD. The Education White Paper 6 of 2001, for example, needs to be translated into tighter legal provisions to make Article 24 of the UNCRPD legally binding in South Africa.

7.2 Conditional grants

The allocation of conditional grants from national to provincial departments has provided a means for national government to ensure that its priorities are reflected at the provincial level. It therefore provides the opportunity to prioritise programmes that fulfil the rights of children with disabilities. For example, the Department of Basic Education[421] records the allocation of a number of conditional grants for the National school nutrition programme,[422,423] HIV and AIDS (life skills) education,[424] education infrastructure,[425] transportation,[426] etc.

Opportunities exist around amending the regulations on these grants to prioritise children with disabilities. In addition, opportunities to design conditional grants for the specific needs of children with disabilities, such as for rehabilitation and the provision of assistive devices, should be explored.

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417 Office of the Deputy President (1997) *White Paper on an Integrated National Disability Strategy.*
418 Jamieson, L. & Proudlock, P. (2009) *From sidelines to centre stage: the inclusion of children with disabilities in the Children's Act.* Children's Institute Case Study No. 4. UCT: Children's Institute.
419 Strategic Plan of the Department of Social Development 2010-2015.
420 http://www.deewr.gov.au/Schooling/Programs/Pages/disabilitystandardsforeducation.aspx
421 Department of Basic Education Strategic Plan 2011-2014. Pretoria.
422 Department of Basic Education Strategic Plan 2011-2014. p.49. Pretoria.
423 It is envisaged that the programme will continue in all quintile 1 to 3 primary schools and quintile 1 secondary schools and then expanded into quintile 2 and 3 secondary schools.
424 See for example: Johns, R. (2007) *All about me: a life skills, sexuality and HIV & AIDS programme.* Western Cape Forum for Intellectual Disability.
425 See also inclusive education 5.1.2 (a).
426 KZN Department of Education Annual Performance Plan 2011/12.

7.3 UN Convention on the Rights of Persons with Disabilities

The Department of Social Development[427] has begun the process of aligning policies to the UNCRPD, as well as developing a department-specific disability mainstreaming strategy, training manual and implementation plan. This is recognised as essential to ensuring that people with disabilities enjoy full and equal human rights and freedoms, and that there is respect for their inherent dignity.

The UNCRPD provides an important basis of commonality for different stakeholders in addressing issues around disability. For example, it contains definitions of habilitation and rehabilitation, which can serve as guides for the Health and Social Development sectors specifically.

While there has been increasing recognition of disability as a human rights issue,[428] stakeholders in the disability sector emphasise that the link between disability and rights needs to be supported by personnel and services, so that rights can become realities for adults and children with disabilities.

7.4 Service delivery environment

There is a need to create a sustainable environment for service delivery partners (NPOs) through "capacity-building, collaboration and agency".[429] This requires the development of an effective service delivery model that ensures good planning, adequate funding, improved co-ordination and appropriate monitoring of implementation. Appropriate norms and standards should accompany this delivery model.

7.5 Partnerships and co-ordination

Strategic partnerships can ensure that available resources are used optimally and that legislation is localised.[430] However, those in partnerships need to have clear mandates and lines of accountability, as well as guidelines based on the principles of good governance.[431] Partnerships between government and NGOs, different spheres of government and NGOs in the disability sector (DPOs) need to be strengthened in order to provide more effective and efficient services for children with disabilities.

Inter-sectoral collaboration is critical, especially at the planning and implementation, levels (including the provincial sphere of governance)[432] and requires networking between various departments (Health, Basic Education and Social Development), as well as NGOs who are providing services to children with disabilities.[433] This is important both to ensure early identification and appropriate referrals, and to promote the sharing of resources. A Directory of Services and/or a website, and joint planning and monitoring could be important starting points for co-ordination.[434]

The importance of a central co-ordinating structure for children with disabilities was stressed at stakeholder consultations. Formal mechanisms for co-ordination are essential, and should be set out in provincial strategic plans.[435] There should also be a memorandum of understanding between the respective departments and NGOs, outlining their roles and responsibilities with regard to children with disabilities. The following are possible mechanisms to facilitate co-ordination:

- A disability forum or task team could promote co-ordination and the sharing of information at national, provincial and local levels. Where forums are already in place, they need to be strengthened, particularly in terms of government presence and involvement.[436]

427 Strategic Plan of the Department of Social Development 2010-2015.
428 KZN Stakeholder workshop, 12 May 2011.
429 Department of Social Development Strategic Plan 2010-2015.
430 National Stakeholder workshop, 24 May 2011. It was noted that there are a large number of excellent programmes that have been developed to assist disabled children.
431 National Stakeholder workshop, 24 May 2011.
432 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
433 National Stakeholder workshop, 24 May 2011.
434 See for example Cape Gateway, a website which provides a single point of access to government information and services for residents of the Western Cape.
435 Mncedisi Mdunyelwa, Acting Provincial Rehabilitation Co-ordinator, KZN Department of Health, interview 31 May 2011.
436 KZN Stakeholder workshop, 12 May 2011.

- An advisory council with different subgroups for different impairment types could provide the necessary professional support in the field of childhood disability to parents and caregivers.[437]
- An inter-departmental working group could assist with identifying who provides particular services, how they are monitored and how children with disabilities and their families access them.[438]

Strategic leadership is needed at the national level to plan and implement appropriate services for children with disabilities. This requires joint planning for the development of services with clear objectives and guidelines for implementation so as to achieve a common goal, with specific timeframes, and focused on particular types of disabilities. Priority must be given to creating a strategy for early identification and intervention for children aged three years and younger.

7.6 Changing attitudes and providing community-based support

Changing attitudes towards children with disabilities is an ongoing challenge. An important part of this challenge is to provide the necessary support to parents, caregivers and community members who play a critical role in the lives of their children with disabilities. Such support should include tracking developmental milestones, teaching independence and caring for children.[439]

However, in order for them to care for and support their children, parents need to know their rights and responsibilities, and what resources are available to them. Parents need to be given information if they are to make informed decisions about the development and education of their children, and where possible, children need to be empowered for informed decisions as well. Information must be disseminated in different formats and in ways that take cognisance of parents' and children's level of education.[440]

Furthermore, disability and diversity awareness programmes need to be recognised as a critical component of social cohesion, and as a means of reducing the vulnerability of children with disabilities to abuse and neglect.

Gugu Shibalanto, 11, and Luleka Gayi, 14, in a junior art class at Matshediso LSEN School. Both children are intellectually impaired.



437 National Stakeholder workshop, 24 May 2011.
438 National Stakeholder workshop, 24 May 2011.
439 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.
440 National Stakeholder workshop, 24 May 2011.

The children who participated in the focus group discussions that formed part of this study[441] acknowledged the support they receive from different sources. For some, it was their mothers, whose love and practical support is evident through positive messages of acceptance as well as provision of practical help such as signing at church for deaf congregants.

> *Whenever I ask my mom for anything, she just gives it to me.*
>
> *My mother [helps me] – whenever I feel down and sad, she says sharp! It's alright! Mother comes back [from work] and I am happy… she brings me sweets.* (Urban focus group discussion)

Others articulated a deep sense of spirituality which gives meaning to their lives. This helped to build a sense of self-acceptance, as expressed by one of the children:

> *I am satisfied with the way I am, whatever the next person thinks of me. It's ok. God created me like this. So whatever they say, it does not concern me much.* (Urban focus group discussion)

And while religious buildings and events are not always easy to access, a number of the children indicated that they draw strength and encouragement from their participation as part of these communities. It is thus important to accelerate the pace of expanding the home/community-based focus of programmes for children with disabilities.

7.7 Adopting a twin-track approach

Although catering for diversity needs to be a value that underlies all services, there is the danger that children with disabilities may be 'lost' in the effort to mainstream. International experience shows that even with mainstreaming, disability-specific programmes are still required. This has been termed the "twin-track approach". The Office of the High Commissioner on Human Rights[442] recommends this approach to monitoring the UNCRPD. It includes both a specific focus on the rights of people with disabilities and monitoring of the rights of people with disabilities which is integrated into general human rights monitoring work.

441 Philpott, S. & McLaren, P. (2011) *Hearing the Voices of Children and Caregivers: Situation Analysis of Children with Disabilities in South Africa*. Pretoria: Department of Social Development/UNICEF.

442 Office of the High Commissioner for Human Rights (2007) *From exclusion to equality: realising the rights of persons with disabilities.* Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

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