Children with Disabilities in South Africa

A Situation Analysis 2001-2011

Executive Summary
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Design and typesetting: Handmade Communications
Acronyms

ACRWC  African Charter on the Rights and Welfare of the Child
CBR  Community Based Rehabilitation
CDG  Care Dependency Grant
DICAG  Disabled Children's Action Group
DSD  Department of Social Development
ECD  Early Childhood Development
FSS  Full Service School
GHS  General Household Survey
ICF  International Classification of Functioning, Disability and Health
KZN  KwaZulu-Natal
NGO  Non Governmental Organisation
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
UNCRCD  UN Convention on the Rights of the Child
UNCRPD  UN Convention on the Rights of Persons with Disabilities
WHO  World Health Organisation
Acknowledgements

The Department of Social Development, Department of Women, Children and People with Disabilities and UNICEF would like to acknowledge with immense appreciation the contribution of the principal authors: Sue Philpott, Pam McLaren, George Laryea-Adjei and Bjorn Gelders.

Many thanks also go to the members of the Study Steering Committee: Ms Manthipi Molamu (Chair), Matu Jafta from Department of Social Development, Harsha Dayal from the Human Sciences Research Council and DPME, Marie Schoeman from Department of Basic Education, Ria Mathivha from Department of Women, Children and People with Disabilities, Barbara Monyemore and Nomvula Sibanyoni from Department of Health, George Laryea-Adjei, Bjorn Gelders and André Viviers from UNICEF.

Thank you to Sophie Mkhasibe, Maureen Motepe, Tshidi Maaga, Lorraine Bam and Krish Shunmugam from Department of Social Development, Benny Palime and Sinah Moruane from Department of Women, Children and People with Disabilities, and Mekonnen Ashenafi and Rosangela Berman Bieler from UNICEF, for their valued contribution.

Finally, we would like to thank Robyn Grimsley and Liz Haines of Handmade Communications for the final editorial work.
Learners at the Hope School, Johannesburg. The school follows the same curriculum as mainstream schools.
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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
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
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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. 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.

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, 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. 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.

A study by the Disabled Children’s Action Group (DICAG) 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
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

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6 National Stakeholder workshop, 24 May 2011.
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), 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.

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. 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, but neither national nor provincial strategic plans reviewed make clear provisions for implementation.

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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.
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.
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, 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. Some organisations have reported that even where a service level agreement is in place, funding does not always come through as agreed, 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, 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.

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.

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 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. 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, 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.

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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”. 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. 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. Information must be disseminated in different formats and in ways that take cognisance of parents’ and children’s level of education. 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 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.
23 National Stakeholder workshop, 24 May 2011.