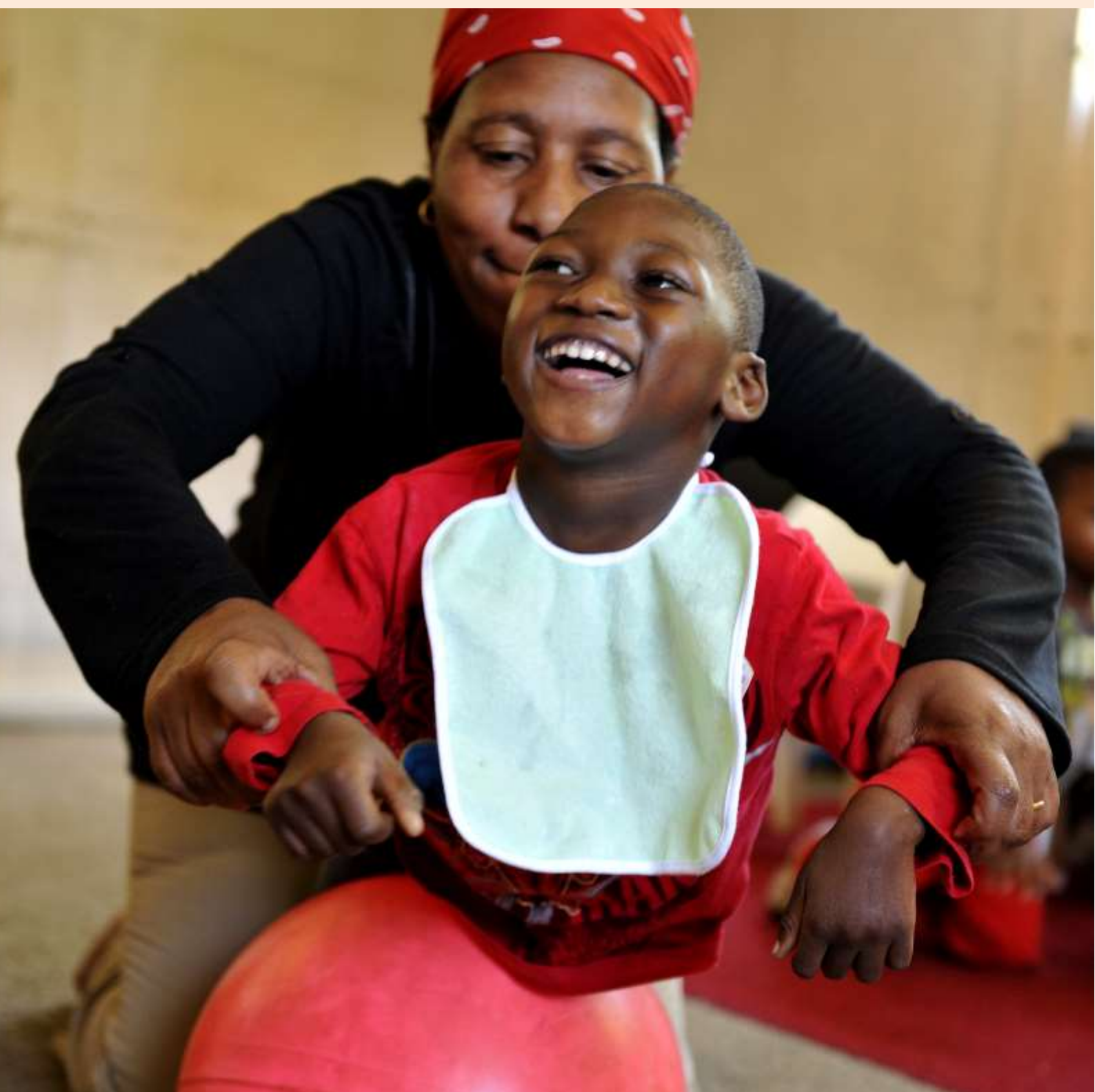


Study on Children with Disabilities From Birth to Four years old



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Study on children with disabilities from birth to four years old 2015

Status: Final. Unedited (this is report still needs to be subjected to a language edit)

This study was commissioned and funded by the Department of Education and the United Nations Children's Fund (UNICEF) South Africa. The research was managed by technical consultant Jean Elphick. This qualitative research project is part of a six month assignment to investigate the barriers that parents, caregivers and ECD practitioners of children with disabilities encounter when navigating ECD services; identify pragmatic resources to promote early identification of disability by parents, caregivers and ECD practitioners; and develop accessible, easy-to-use resources for parents, caregivers and ECD practitioners to utilise in navigating public and private sector services such that CWD will, as they near compulsory school-going age, better access their right to an education.

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The aim of this study was to investigate the barriers that parents, caregivers and Early Childhood Development (ECD) practitioners of children with disabilities (CWD) encounter when navigating ECD services in South Africa. Additional aims were to identify pragmatic resources to promote early identification of disability by parents, caregivers and ECD practitioners and to develop accessible, easy-to-use resources for parents, caregivers and ECD practitioners to utilise in navigating public and private sector services such that children with disabilities will, as they near compulsory school-going age, better access their right to an education.

A literature review informed the methodologies selected for primary data collection and analysis, as well as the choice of screening tools to be field-tested. The study relied on four qualitative data collection methods to increase the validity of findings and aid detailed understanding of what the problems are, and what can be done to bridge policy implementation gaps.

This research report outlines primary research findings pertaining to (i) common disabilities existing among young children in South Africa and the effect of disability on development and family life; (ii) law, policy and guidelines for young children with disabilities in South Africa; (iii) barriers to accessing services for young children with disabilities in South Africa; and (iv) strategies to promote early identification of disability and effective ECD service access for young children with disabilities. The strategies identified to promote early identification, intervention and access to inclusive ECD services are punctuated with short case studies of selected examples of good practice from around the country. The services profiled include services at established ECD programmes, hospitals, clinics, NGOs (non-governmental organisations) and public-private collaborative projects.

Table of Contents

TABLE OF CONTENTS	4
ACRONYMS	7
EXECUTIVE SUMMARY	9
CHAPTER 1: INTRODUCTION	11
CHAPTER 2: RESEARCH METHODOLOGY	13
2.1 INTRODUCTION	13
2.2 RESEARCH SITES	13
2.3 SAMPLING METHODS	14
2.4 DATA COLLECTION METHODS	16
2.5 DATA MANAGEMENT	17
2.6 ETHICAL CONSIDERATIONS	17
2.7 DATA ANALYSIS	18
2.8 LIMITATIONS	19
CHAPTER 3: COMMON DISABILITIES EXISTING AMONG YOUNG SOUTH AFRICAN CHILDREN AND THEIR EFFECT ON CHILDHOOD DEVELOPMENT AND FAMILY LIFE	20
3.1 LITERATURE REVIEW	20
INTELLECTUAL DISABILITIES	20
FOETAL ALCOHOL SYNDROME	21
EPILEPSY	21
PHYSICAL DISABILITIES	21
CONGENITAL DEFORMITIES	22
BURNS OR THERMAL INJURY	23
COMMUNICATION DISABILITIES	23
SENSORY DISABILITIES	24
PSYCHOSOCIAL DISABILITIES	24
NEURODEVELOPMENTAL DISABILITIES	25
SPECIFIC LEARNING DIFFICULTIES	25
MULTIPLE DISABILITIES	26
3.2 FINDINGS	27
WHAT ADVICE DID CAREGIVERS HAVE FOR OTHER CAREGIVERS OF CWD?	30
3.3 CONCLUSION	31
CHAPTER 4: OVERVIEW OF LAW, POLICY AND GUIDELINES FOR YOUNG SOUTH AFRICAN CHILDREN WITH DISABILITIES	33
4.1 INTRODUCTION	33
4.2 EQUALITY	33
4.3 SCREENING AND EARLY IDENTIFICATION OF DISABILITY	35
4.4 EARLY CHILDHOOD DEVELOPMENT	36
HEALTH	37
SOCIAL SERVICES	38
EDUCATION	39
CROSS-SECTORAL INITIATIVES	42
4.5 A RIGHTS-BASED APPROACH TO ECD	42
4.6 CONCLUSION	43
CHAPTER 5: BARRIERS TO ACCESSING SERVICES FOR YOUNG SOUTH AFRICAN CHILDREN WITH DISABILITIES	44
5.1 LITERATURE REVIEW	44
5.2 FINDINGS	45

5.2.1 ATTITUDINAL BARRIERS	45
5.2.2 ENVIRONMENTAL BARRIERS	48
5.2.3 IMPAIRMENT-RELATED BARRIERS	55
5.3 CONCLUSION	55

CHAPTER 6: STRATEGIES TO PROMOTE EARLY IDENTIFICATION OF DISABILITY AND ACCESS TO INCLUSIVE ECD SERVICES	56
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6.1 LITERATURE REVIEW	56
6.2 FINDINGS	60
6.3 SUPPORT FOR CHILDREN WITH DISABILITIES	60
6.4 SUPPORT FOR SERVICE PROVIDERS	73
6.5 SUPPORT FOR CAREGIVERS	76
6.5 SUSTAINABLE LIVELIHOODS	80
6.6 CONCLUSION	80

CHAPTER 7: RESEARCH REPORT SUMMARY	81
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REFERENCES	84
-------------------	-----------



An ECD practitioner listens in on a message for her class from a Persona Doll who uses a wheelchair (Photo credit: Sue Baillie with permission Inclusive Education Western Cape)

Acronyms

AAC	Augmentative and Alternative Communication
ACRWC	Charter on the Rights and Welfare of the Child
ADHD	Attention deficit hyperactivity disorder
ASD	Autism spectrum disorder
CBR	Community-based Rehabilitation
CP	Cerebral Palsy
CRC	United Nations Convention on the Rights of the Child
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CT	Computerised Tomography
CSF	Cerebrospinal fluid
CWD	Children with disabilities
CTEV	Congenital Talipes Equinovarus
DBE	Department of Basic Education
DoH	Department of Health
DSD	Department of Social Development
DWCPD	Department of Women, Children and Persons with Disabilities
EARC	Educational Assessment and Resource Centres
EFA	Education for All
ECD	Early Childhood Development
EEG	Electroencephalograph
FAS	Foetal alcohol syndrome
FASD	Foetal alcohol spectrum disorder
ICF	International Clarification of Functioning, Disability and Health
IEWC	Inclusive Education Western Cape
MDGs	Millennium Development Goals
MICS	UNICEF Multiple Indicator Cluster Survey
MRI	Magnetic resonance imaging
NCSNET	National Commission on Special Needs in Education and Training
NGO	Non-governmental Organisation
RtHB	Road to Health Booklet
SIAS	Screening, Identification, Assessment and Support
TB	Tuberculosis
TQS	Ten Question Disability Screening Tool
UN	United Nations
UNESCO	United Nations Education, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
WHO	World Health Organisation



Learning important lessons for life, like taking turns, the importance of washing hands and patience (Photo credit: Melissa Budge, with permission from Bulungula Incubator)

Executive Summary

This assignment has been undertaken at the request of the South African National Department of Basic Education and United Nations Children's Fund South Africa, with the aim of:

- Investigating the barriers that parents, caregivers and Early Childhood Development (ECD) practitioners of children with disabilities (CWD) encounter when navigating ECD services
- Identifying pragmatic resources to promote early identification of disability by parents, caregivers and ECD practitioners
- Developing accessible, easy-to-use resources for parents, caregivers and ECD practitioners to utilise in navigating public and private sector services such that children with disabilities will, as they near compulsory school-going age, better access their right to an education

A literature review informed the methodologies selected for primary data collection and analysis, as well as the choice of screening tools to be field-tested. The study relied on four qualitative data collection methods to increase the validity of findings and aid detailed understanding of what the problems are, and what can be done to bridge policy implementation gaps. Methods included:

1. Focus group discussions
2. Semi-structured group interviews
3. Observations recorded in field notes
4. Structured telephonic key informant interviews

Data was collected from three groups of people who voluntarily consented to participating, from ECD centres located in Gauteng, Eastern Cape and Free State:

- Parents or caregivers of children with disabilities
- ECD practitioners working with children under the age of four
- Key informants with experience in ECD and disability

Data collected was synthesised and analysed using manual thematic analysis.

This research report outlines primary research findings pertaining to:

1. *Common disabilities existing among young children in South Africa and the effect of disability on development and family life*

The total population of children with disabilities in South Africa remains unclear. The lack of clarity can be attributed to the fact that identification of disabilities is complicated, among others, by the following factors:

- The uniqueness of each child and their impairments
- The underreporting of children's disabilities
- The predominantly adult-centric nature of disability research

- Varying cultural interpretations of childhood and of disability

Despite there being a lack of current research and prevalence data available for some diagnoses the literature review presents the definition, diagnostic criteria and available prevalence data for the most common intellectual, physical, communication, sensory, psychosocial and neurodevelopmental disabilities that present in the South African context. In addition, specific learning difficulties and multiple disabilities are discussed. Foetal Alcohol Syndrome, Epilepsy, Spina Bifida, Spinal Tuberculosis, common congenital deformities, burns, visual and hearing impairment, mental health, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, global developmental delay, Cerebral Palsy, Hydrocephalus and Down Syndrome are presented.

Findings describe the experiences of participants with respect to their reflections on parenthood, how disability affects their daily lives and the effect of having a child with a disability on relationships between parents, with the child's non-disabled siblings, with extended family and friends.

Overwhelmingly the message from participating caregivers was that, although not easy, having a child with a disability is 'not the end of the world' and caregivers advised that others in their position should try to have faith, accept their situation, equip themselves with a support network and as much information as possible, and to remember that their children with disabilities is a child and needs love and parenting just like all children.

2. *Law, policy and guidelines for young children with disabilities in South Africa*

Over the past two decades, South African legal reform has enacted a framework of enabling legislation, policy, guidelines and national instructions affecting State service provision to young children with disabilities. These canvass, notably, the right to equality. This right has a bearing on the realisation of all other rights for children with disabilities; no child can be discriminated against in accessing his or her human rights on the grounds of disability. The legal framework applies also to services related to the early identification of disability and the extension of inclusive ECD services. The rights of the child to health, nutrition, shelter, social services, protection from maltreatment, abuse or degradation, family care or parental care, or to appropriate alternate care and a basic education enjoy an elevated constitutional status in terms of the Constitution. The Children's Act 38 of 2005 has been promulgated with the specific object of, inter alia, giving effect to the Constitution, recognising the special needs that children with disabilities may have and to make provision for

structures, services and means for promoting and monitoring the sound physical, psychological, intellectual, emotional and social development of children. Despite the proliferation of policies, there is still a lack of a focus on dealing with children with disabilities. Further, as with most of the policy documents in South Africa there is a need for an indication of how this will be implemented and where the funds will come from.

3. Barriers to accessing services for young children with disabilities in South Africa

The social model of disability attributes the experience of disablement to the combination of barriers in the environment, barriers presented by the attitudes of society and barriers presented by impairments. The findings of this study included attitudinal barriers, such as stigma, prejudice and stereotyping of disability in the community and disabling attitudes of both ECD practitioners and caregivers hindered full enjoyment of ECD services. Discrimination on the basis of disability remains a leading barrier to inclusion and children with disabilities' enjoyment of ECD services. Environmental barriers were found to include the availability, coordination, accessibility and quality of existing inclusive ECD services, as well as a general lack of information about disability and community resources were identified. In addition, inadequate resource allocation was found to disincentivise inclusive practices. Finally, children with some impairments were found to be more marginalised. These included children with severe and profound disabilities, those with multiple disabilities and those with Autism Spectrum Disorder.

4. Strategies to promote early identification of disability and effective ECD service access for young children with disabilities in South African

Screening for disability and developmental delays is critical as, if properly executed, it should trigger access to vital services, allowing for the appropriate type of assistance to be provided timeously and efficiently. The merits of several screening tools were presented in the literature review including the World Health Organisation Disability Assessment Schedule (WHO-DAS); Denver II; the Ten Question Disability Screen (TQS) and the developmental screening pages of the new Road to Health Booklet (RtHB). In addition the literature review highlighted the ongoing relevance of the NCSNET recommendations on overcoming barriers to education and training for CWD from the Quality Education for All: Overcoming Barriers to Learning and Development (1997) report. Recommendations made by WHO, UNICEF and DSD's recent situational analysis of CWD in South Africa (DSD et al., 2012) were mentioned.

The findings are presented in three sections:

- Supporting children with disabilities
- Supporting ECD service providers
- Supporting caregivers of children with disabilities

To support children with disabilities the following mechanisms were promoted: timeous and fair access to Care Dependency Grants, Early Identification and Intervention; Developmental Screening using the RtHB; extension of inclusive services that address discriminatory attitudes; individualised case management, referral and advice; access to quality therapy, rehabilitation and medical services; and access to assistive devices.

To support ECD service providers findings indicated that sustainable state funding of good practice interventions; ongoing 'hands-on' training, and mentorship; strengthening referral pathways and support for ECD practitioners was promoted. A summary of early signs and risk factors identified by caregivers of children with disabilities is presented.

The indispensable role of the primary caregivers of children with disabilities- be it parents, grandparents, relatives or guardians- was recognised by all stakeholders that participated in the study. The following themes and possible strategies emerged from the data collected to support them: Better coordination of services and trans-disciplinary approaches; empowerment and education programmes; debriefing or counseling; and access to respite and ECD services to allow caregivers to seek employment.

The strategies identified to promote early identification, intervention and access to inclusive ECD services is punctuated with short case studies of selected examples of good practice. The services profiled include services at established ECD programmes, hospitals, clinics, NGOs (non-governmental organisations) and public-private collaborative projects.

Chapter 1: Introduction

All human beings fall on a spectrum of abilities, talents and capabilities. Not everybody is able to climb Kilimanjaro, solve complicated mathematical equations and socialise effortlessly. Everybody is unique. Some have amazing abilities in some areas of life, but are lacking in others, some are good all-rounders, but not exceptional at any one thing. Because everyone is different, we should be dedicated towards giving children the right start in life and the tools to achieve their unique, full potential. Nowhere is this more important than in the first few years of life, especially in a society where children are widely exposed to barriers to development like poverty, poor nutrition and health care, and a lack of stimulation (Grantham-McGregor et al., 2007). In any lifetime, the period of most rapid neurological and biological development occurs between inception and the age of four years old (Britto et al., 2011), and thus the early identification and intervention, and access to integrated services that promote ECD is especially important for CWD.

Traditionally, CWD in South Africa have been ostracised on the basis of their disability. Responses to disability were largely limited to relegating people with disabilities to residential institutions, cut off from mainstream society (UNICEF, 2013). Modern thinking, on other hand, promotes the social or human rights models of disability, which recognises that disability is the combination of the intrinsic impairment that persons with disabilities have as well as the barriers that they may encounter in life, in the real world (Schneider and Hartley, 2006). Barriers are either presented by negative, disabling attitudes, or by the physical, social, cultural, legislative or economic environments in which persons with disabilities in South Africa grow up and live. By extending human rights to all, regardless of their impairments, and addressing attitudes and environmental barriers to accessing human rights, we will go a long way towards building a more equitable society (WHO, 2010).

One mechanism with strong potential to promote the human rights of persons with disabilities is the early identification, intervention and inclusion of CWD. The outcomes of quality, integrated ECD service delivery include the creation of a more equitable and prosperous society (Berry et al., 2013), vital for the achievement of human rights and education for all, and the MDGs (Betts and Lata, 2009).

However, this requires for ECD services to plan for the inclusion of children with a range of developmental delays and disabilities. ECD comprises an essential package of services that include nutritional support and health services for mothers and children, social services, caregiver support and stimulation for early learning (Berry and Biersteker, 2013). These services are directed at promoting the physical, cognitive, language, social and emotional development of the child. The comprehensive delivery of ECD services requires coordinated collaboration between the health, social

and education sectors of government (Berry et al., 2013). ECD interventions may be based at ECD centres or clinics or comprise of community- and home-based programmes.

The South African government's attitude towards CWD has made a clear shift to the social or human rights model of disability, as reflected in its legal and policy changes made over the last 20 years. Since the enactment of the Constitution of the Republic of South Africa (1996), all children in South Africa, including CWD, have the right to equality and a basic education. This right is reiterated in the applicable legislation and policy documents as well as the international conventions which South Africa has since ratified (Department of Education 2001; UN General Assembly, 2006).

The result of these reforms is that ECD programmes are encouraged to include CWD in their programming (DSD and UNICEF, 2007), in preparation for starting Grade 1 in a local school (Department of Education, 2001). Although our laws and policies reflect an inclusive and non-discriminatory approach to education, many CWD grow up behind closed doors and are effectively excluded from the system (Lomofsky and Lazarus, 2001). Both ECD programmes and the South African basic education system remain largely inaccessible to CWD that rely on State services (DSD et al., 2012).

Focusing specifically on the early identification of disability and the coordinated response of ECD interventions for CWD in the birth to four year old cohort, as well as their parents, caregivers and ECD practitioners, this assignment aims to identify what the barriers to State services for CWD in South Africa are, and identify helpful resources and other strategies to address these barriers. The purpose of this study was to utilise qualitative research methodologies to:

1. Investigate the barriers that parents, caregivers and ECD practitioners encounter when navigating services for CWD in their early childhood years. The research was focused on, but not limited to, the departments that play the primary role in providing ECD services for CWD: the Departments of Health, Social Development, and Basic Education. This was achieved by reviewing the relevant literature and conducting qualitative research in three South African provinces.
2. Identify pragmatic methods that parents, caregivers and ECD practitioners can utilise to identify disability in children under the age of four years old. This will include field-testing the Ten Question Disability Screen (TQS) and the new Road to Health Booklet (RtHB) for usability in ECD centres and family homes located in three South African provinces.

3. Develop accessible, easy-to-use resources for parents, caregivers and ECD practitioners to utilise in navigating public and private sector services such that CWD will, as they near compulsory school-going age, better access their right to an education.

Following a description of the methodology employed, this report will set out each research question with its corresponding literature review and findings section in a separate chapter.

Research questions

The South African Department of Basic Education (DBE) and UNICEF (United Nations Children's Fund) South Africa stated objective in mandating this research is to inform the development of resources that will serve to enhance and ensure the early identification of childhood disability, and the early intervention and assimilation of children with disabilities into existing ECD programmes. The ultimate purpose hereof is to better prepare children with disabilities for formal schooling by creating a seamless support system from birth to Grade R.

The research will inform recommendations for disability-screening strategies for children under four years old in alignment with the established principles, values and approach of SIAS. It will also inform the development of guidelines for parents, caregivers and ECD practitioners on how to access services for young children with disabilities.

To this end the following research questions were put forward for investigation by DBE and UNICEF as part of this assignment:

1. What types of disability commonly exist among children under the age of four in South Africa and how does this affect development and family life?
2. What law, policy and guidelines exist that promote access to services for children with disabilities?
3. What barriers do young children with disabilities, their parents, caregivers and ECD practitioners face when accessing services?
4. What tools can assist parents, caregivers and ECD practitioners to assess whether a young child has a disability?
5. How can parents, caregivers and ECD practitioners work to remove barriers and effectively access ECD services for young children with disabilities?

Chapter 2: Research Methodology

2.1 Introduction

The study utilized four qualitative data collection methods to increase the validity of findings and aid detailed understanding of what the problems are, and what can be done to bridge policy implementation gaps. Method included:

- Semi-structured group interviews conducted during educational workshops
- Focus group discussions
- Observations recorded in field notes
- Structured telephonic interviews

The descriptive quantitative data that was collected included:

- Ten Question Disability Screen
- Collection of basic demographic data

Data was collected from three groups of people who voluntarily consented to participating:

- Parents or caregivers of children with disabilities
- ECD practitioners working with children under the age of four
- Key informants with experience in ECD and disability

The following section provides the details of the choice of research sites, the sampling methods, the data collection methods, data management and analysis approaches used, as well as ethical considerations.

2.2 Research sites

Three diverse research sites were purposively selected to represent some of the different environments that children in South Africa may grow up in. Each site will be in a different province. The areas chosen represent the provinces where children are the most deprived (Eastern Cape), the least deprived (Gauteng) and somewhere in between (Free State) (Wright and Noble, 2012). One was in a deep rural setting, one in a town, and finally one in a township.

As 43 per cent of children in South Africa live in rural traditional communities, formerly homelands, a deep rural Eastern Cape site was chosen in the former Transkei. 46 per cent of children in South Africa live in formal urban settings and a further 4 per cent of children grow up on farms. An urban site in the Free State was chosen to represent these demographics. Finally, 7 per cent of South African children live in informal urban settings. A peri-urban township in Gauteng was selected for this demographic (Hall, 2012: 44).

	Percentage of children in the ECD	Total number of CWD in the ECD	Types of impairments present	Diagnoses include
Gauteng	4%	8	Mild intellectual, physical, psychosocial, communication, perceptual, multiple impairments	Cerebral Palsy, Intellectual impairment, Epilepsy, Attention Deficit Hyperactivity Disorder, Muscular dystrophy, Hearing impairment
Eastern Cape	3%	2	Mild intellectual, perceptual impairment	Mild intellectual impairment, visual impairment
Free State 1	100%	20	Mild to profound intellectual, physical, psychosocial, communication, perceptual, multiple impairments	Cerebral Palsy, Intellectual impairment, Autism Spectrum Disorder, Epilepsy
Free State 2	100%	16	Mild to severe intellectual, physical, psychosocial, communication, perceptual, multiple impairments	Cerebral Palsy, Intellectual impairment, Genetic disorders and syndromes, Autism Spectrum Disorder, Epilepsy

Table 1: Summary of CWD attending ECD research sites

Urban informal, Gauteng: Orange Farm

The research was located at the Afrika Tikkun Arekopenang Early Development Centre in Orange Farm, southwest of Johannesburg in Gauteng. Orange Farm is a sprawling township with a combination of semi-formal RDP dwellings and informal shacks. The prevalence of childhood disability in the township is unknown, but there are believed to be about 800 CWD in the area. Arekopenang is a centre-based ECD programme that has been in operation for eight years, and has 230 children enrolled. A third of the children have been identified as orphans or vulnerable children by a social worker. There are currently nine CWD enrolled in the programme.

Rural traditional authority (former homeland), Eastern Cape: Nqileni Village

The research was located at the Jujurha Pre-school and the Bulungula ECD@Home project in Nqileni Village. The village is located on the coast, approximately 90km southeast of Mthatha in the Eastern Cape. The village is home to approximately 1 000 people. Nqileni falls within the fourth most deprived municipality in South Africa- Mbashe (Wright and Noble, 2009). Most live in mud rondavels, with no reliable access to water, sanitation or electricity. The village is extremely remote and accessible via 40km of poorly maintained gravel track. There is extremely limited access to health and education services in the area. The village's local primary school is dysfunctional, and the closest clinic is on the far side of the Xhora river. The Jujurha Pre-school was started in 2009 by the Bulungula Incubator- a rural development NGO (non-governmental organisation). The school has 60 children, in three classes, with two ECD practitioners in each class. They were unsure if they had any CWD in attendance before the research, but two children with mild impairments were identified during data collection.

The hospital used by the Nqileni community is 120-bed Zithulele District Hospital. Zithulele is the site of a rehabilitation department that is staffed by three physiotherapists, four occupational therapists, and one speech therapist. Zithulele is also home to a considerable variety of NGOs including a Community-based Rehabilitation programme, Mentor Mothers, and NGOs that focus on supporting the hospital and education in the surrounding area.

Urban formal, Free State: Bloemfontein

The research was located at The Emilia Active Learning Centre in Bloemfontein, Free State. Bloemfontein is the judicial capital of South Africa and the capital city of the Free State Province, with a population of just more than 250 000. The Centre is managed by the Association for People with Disabilities (APD) Free State and funded by Department of Social Development, Citymed, and the University of the Free State. The Centre caters for 20 CWD, but has a long waiting list.

In addition a focus group was also conducted at a private suburban day care centre for CWD called Illane Learning Centre. Sixteen children attend the centre daily. Most children are of pre-school age, however there are a few children as old as sixteen attending the centre.

2.3 Sampling methods

Five research sites were identified for data collection. This section will detail the sampling methodology that was applied at each site.

A pragmatic approach to sampling was adopted. A contact person at each site was asked to identify and invite parents or caregivers, as well as ECD practitioners to participate.

- At Arekopeneng the contact person was the ECD principal Emily Matamela
- At Jujura the contact person was the health manager Bulelwa Ganca
- At Zithulele Hospital the contact person was Karen Galloway
- At the Emilia Active Learning Centre, the contact person was Free State Association for People with Disabilities Social Auxillary Worker Zandile Nhlapo
- At Illane Early Learning Centre the contact person was Maryna du Plesis

Selection of parents or caregivers of CWD

Purposive sampling will be used to identify between six and nine parents or caregivers of CWD, per site, to participate in the study (Ritchie and Lewis 2003).

Participants were identified at each research site by the contact person listed above. Up to nine participants will take part in each focus group discussion. In one instance less than six participants arrived for a focus group, so a second focus group was conducted at a later date.

As far as is practical, parents or caregivers of CWD under the age of four years old were sought. However, since the many CWD that are accessing ECD services in South Africa are seven years or older (Williams and Samuels, 2001), and the ECD foundation phase extends until children are nine years old (Berry et al., 2012), parents and caregivers of CWD up to the age of nine years old were included. At one focus group two caregivers of children that were ten years old arrived and participated in the focus group.

Not all children of participating caregivers and ECD practitioners had a medical diagnosis at the time of the study, so no exclusion criteria was applied with respect to the type, severity or onset of disability. Participants who self-identified as having CWD, who were recognised by the research site contact person as having a disability were included. The use of the Ten Question Screen was used to determine the nature of the impairment affecting each child.

Description of Focus Group Discussion Participants

A total of eleven caregivers participated in the two FGDs conducted in Gauteng. Because the first FGD was poorly attended a second episode was arranged. Six mothers, three grandmothers and two aunts of CWD participated. Most caregivers (45 per cent) were single, but four (36 per cent) were married, or widowed (18 per cent). The majority of the caregivers were unemployed (91 per cent), however one grandmother received an income from her pension. Four of the caregivers (18 per cent) had completed school and had a Matric certificate. Caregivers had an average of four children in their care at home.

The average age of their CWD was four years old, with a range of ages from three to seven years old. One of the CWD (nine per cent) did not receive a Care Dependency Grant, the others were all successfully accessing the grant.

A total of nine participated in the two FGDs conducted in Eastern Cape. Eight mothers and one grandmother of a CWD participated. Most (46 per cent) were single, but four (44 per cent) were married. The majority of the caregivers were unemployed (89 per cent), however one mother had a job. None of the caregivers had completed school or had a Matric certificate. Caregivers had an average of five children in their care at home.

The average age of their CWD was four years old, with a range of ages from two to ten years old. One of the CWDs (nine per cent) did not receive a Care Dependency Grant, the others were all successfully accessing the grant.

A total of thirteen caregivers participated in two FGDs conducted in Free State. The FGDs were conducted at two different facilities for young CWD. Eleven mothers, one grandmother and one father of a CWD participated. Most (77 per cent) were married, but two (15 per cent) were single, and one was widowed (8 per cent). The majority of the caregivers were unemployed (62 per cent), however some were employed: either full-time (23 per cent), part-time (8 per cent) or self-employed (8 per cent). Eight of the caregivers (62 per cent) had completed school and had a Matric certificate. Caregivers had an average of two children in their care at home.

The average age of their CWD was five years old, with a range of ages from three to ten years old. Five of the CWD (39 per cent) did not receive a Care Dependency Grant, the others were all successfully accessing the grant. Caregivers not accessing the grant did not know about it or didn't know if they qualified for it.

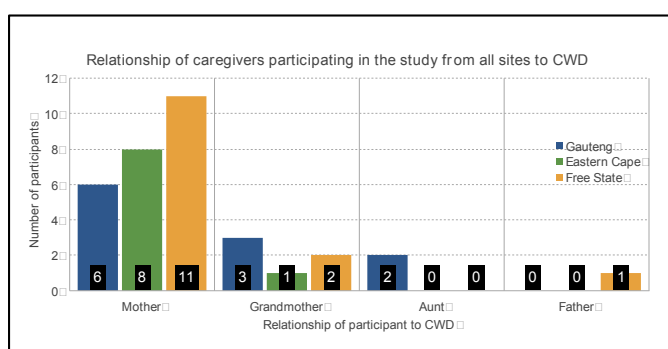


Figure 1: Relationship of caregivers participating in focus group discussions to CWD

In all sites mothers of CWD represented the majority of the sample. Just one male, and one father participated in the study, he was part of the Free State sample. Grandmothers of CWD were also represented at all sites. Two aunts of CWD who are their primary

caregivers participated in Gauteng. In cases where relatives were caring for the child a variety of reasons were given. The CWD had either been orphaned or abandoned by the parents, or the relatives cared for them, in some cases because the parents were at work.

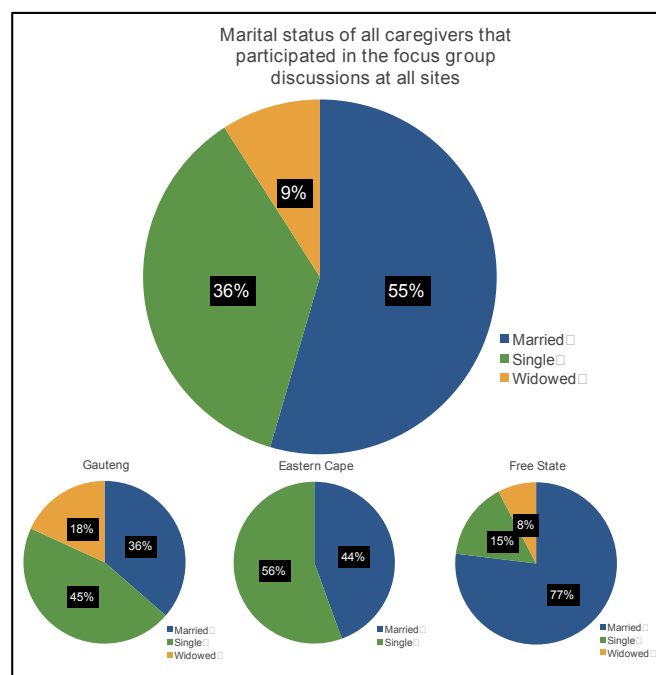


Figure 2: Marital status of all caregivers that participated in the focus group discussions

The biggest sample was drawn from Free State, where the majority of participants were married. However, single mothers were the most common participants in Gauteng and Free State.

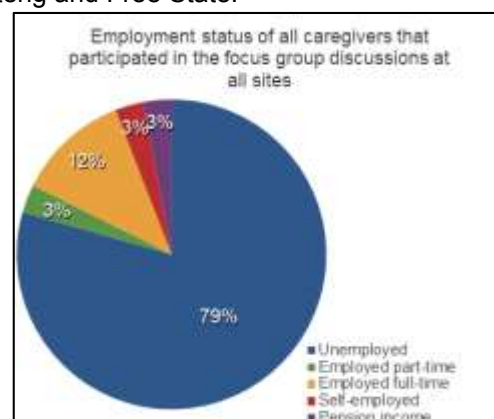


Figure 3: Employment status of all caregivers that participated in the focus group discussions

A clear majority of caregivers were unemployed, at all research sites. In Gauteng and Eastern Cape almost all CWD were in the full-time care of their caregivers. In Free State all participants were caregivers of children that attended centre-based programmes daily. Free State was also the site where the largest proportion of participating caregivers were either employed part- or full-time or self-employed.

Selection of ECD practitioners to test usability of screening tools

At each research site an ECD centre, pre-school or day care centre was identified to participate. Practitioners that work at each facility were identified by the contact person and invited to participate in the study. They were asked to complete the Ten Question Screen and discuss disability and how it impacts them as service providers.

Selection of key informants

Key informants were sought from all provinces, including those where the research sites are located. From an initial list of seven key informants snowball sampling was employed to contact and interview a total of twenty participants.

Key informants included practitioners with experience of disability and ECD. Participants were contacted by email, and willing participants were contacted telephonically at their convenience. ECD practitioners and managers, occupational therapists, physiotherapists, speech therapists, educational psychologists, auxiliary social workers, disability advocates, disability inclusion educators, NGO managers, academics and researchers as well as representatives from the Department of Basic Education; Department of Social Development; Department of Women, Children and People with Disabilities; and Department of Health participated. The key informants that participated lived in Gauteng, Free State, Kwa-Zulu Natal, Eastern Cape and Western Cape.

Data collection continued until data saturation was reached and no new information was emerging from the interviews.

2.4 Data collection methods

A review of literature was combined with several primary data collection methods. These included: focus group discussions; field testing of developmental and disability screening tool; semi-structured group and individual interviews; observation; and structured telephonic interviews. The following section provides an explanation of each of the data collection methods.

Review of literature and legislation

A broad-ranging literature review was conducted in order to gather information in which to situate the primary research of this study.

An online search was conducted using research databases, Google Scholar and an internet search. To gather data relating to the prevalence of disability in South Africa, national non-governmental disability organisations such as Down Syndrome SA, the Cerebral Palsy Association, and AutismSA were contacted directly through their national offices. A hand search was conducted to follow up on papers recommended by the organisations and key informants contacted.

Research into the legal and policy framework applicable incorporated both national and international legal documents. National legislation was sourced through Lexis Nexis. International conventions were sourced through the United Nation's website. Policy documents – white papers and government notices – were sourced through the Department of Social Development's website, the Southern African Legal Information Institute, and internet searches.

Focus Group Discussions

Five focus group discussions were conducted. Participatory methodologies were used to generate discussion. Relevant activities were drawn from the Participatory Rapid Appraisal were drawn upon to encourage lively discussion (Wickenden and Cornielje, 2012). A topic guide, including participatory activities to be facilitated (such as ranking exercises and mapping of outcomes) was used. Contrary to what was expected, even caregivers previously unknown to the researchers were very open about sharing their personal, at times painful, experiences. Gathering data from caregivers was successful, and participants were very forthcoming.

Semi-structured group interviews during educational workshops and individual interviews with ECD practitioners

Three workshops on inclusion were presented for ECD practitioners. The workshops covered an introduction to the social and human rights models of disability; examination of attitudinal barriers and prejudice; typical development and developmental milestones; causes of disability in children; and participatory exercises to identify environmental barriers to inclusion and troubleshoot specific challenges to inclusion raised by the participants. The workshops were presented at research sites where the ECD programmes had both CWD and non-disabled children. Two workshops were presented in Gauteng, and one in the Eastern Cape. Inclusion workshops were not offered at the Free State sites. A total of 36 participants attended the inclusion workshops.



ECD practitioners in small group discussion during an ECD inclusion workshop in Gauteng (Photo credit: Nyaradzo Zembe)

The workshops were designed to document the following:

- Prevailing attitudes regarding inclusion Current knowledge about typical childhood developmental norms
- Knowledge of early signs of delayed development or impairment
- Current understanding of the RtHB and it's possible use in identifying children at risk of impairment
- Current understanding of the causes of disability
- Innovations in inclusive practice

ECD practitioners were asked to describe the children that they had in their groups each day. As each site was different, the number of CWD, their types of impairments and severity of impairment varied:

- For classes that had no previously identified CWD practitioners were asked to complete the Ten Question Screen for children that they felt may have a developmental delay or possible impairment.
- For inclusive classes where CWD were integrated into a class, practitioners were asked about how the children in their classes interacted, what their achievements and challenges were with regard to inclusion, as well as requesting that they complete the Ten Question Screen to identify the types of impairments present.
- For practitioners responsible for classes exclusively for CWD interviews focused on the types of impairments present, as well as the effect of disability on development and family life.

Following the completion of the screening tools practitioners the practical use of the screen was discussed with practitioners in order to better understand the practitioners' experience of using the screening tools.

Structured telephonic key informant interviews

The initially researchers made contact with seven key informants. Telephonic interviews were scheduled at their convenience. Researchers conducted a

structured interview designed to probe for ideas on best practice and recommendations for promote early identification and inclusion of CWD in ECD service provision. Their experience of using the TQS and RtHB were interrogated. Participants working in State departments were questioned more specifically about the role of their department in implementing inclusive



Participatory exercises during an ECD inclusion workshop in Eastern Cape (Photo credit: Beryl Bamu)

ECD services.

2.5 Data management

Informed consent forms were completed on-site for focus group discussion participants as well as group and individual interview participants. All completed informed consent forms have been filed.

Key informants were contacted by email with a full description of the study, as well as the inception report attached. Their willingness to participate was confirmed when they scheduled appointments for the telephonic interviews to take place.

Audio recordings of all focus group discussions and interviews were made. Photographs were taken of content generated during ECD practitioner workshops. The recordings have been stored on a password protected external hard drive.

All audio data was transcribed, and translated into English where necessary. Participants were encouraged to share their stories in the language that was most comfortable. In addition to English, participants responded in isiXhosa; isiZulu; seSotho and Afrikaans.

2.6 Ethical considerations

Conducting the proposed research presented the following ethical concerns:

Firstly, for both ethical and practical reasons, CWD did not participate directly in the research. Instead, parents and caregivers of CWD, ECD practitioners and key informants were approached to participate. That being said, by virtue of the discrimination that parents and caregivers of CWD face – by their mothers in particular – the researchers approached participants with

sensitivity and out of an understanding that they themselves are also a vulnerable group.

Secondly, potential harm to participants was considered. Exploring the lived reality of raising a CWD in South Africa, and asking participants to share their experiences was potentially painful and distressing for the participants. This was difficult to prevent, and, in resource-poor settings, referral options were limited. To manage this the following steps were taken:

- Expectations were managed by providing the research site contact person with clear information about the study before the researchers started recruiting their sample group. This information included clear guidelines detailing remuneration (participants were provided with lunch, their expenses on the day of their participation in the study was covered).
- Participants were given very clear information about what was to be discussed.
- Participants received clear information about the study in a language that they could understand that they may withdraw from the study at any time, including during or after data collection.
- During data collection, the researchers used their skill to contain extremely sensitive information that might be disclosed and to manage the situation when participants became emotional.
- Participants were given the contact details of the research site contact person should they require further advice or referral services following the completion of the study. At one site the contact person assisted with arranging counseling for two caregivers identified as needing support.

Participation in all data collection activities was entirely voluntary, and subject to written informed consent. The WHO informed consent form for qualitative studies was used to develop an informed consent form for the study (WHO, 2013). The participants were given a page-long information sheet with the details of the study, which they were encouraged to read and to keep. This information page was however only made available in English. Where English was not the first language of the participants it was explained to them verbally.

Permission from the manager or management team, as appropriate, was sought from each ECD programme before approaching the ECD practitioners of the selected class. Again, the participation of the ECD practitioners is voluntary, and was subject to written informed consent. When conducting the screening tool on each child, the questions are filled out on recall, and the presence of the child will not be required. The ECD practitioners will also be asked to refrain from writing out either the child's name or full date of birth on the screening tool, in order to protect the identity of the child.

Confidentiality was ensured for every participant involved in the study. The only time at which the full names of the participants were recorded was on the

informed consent forms. Beyond this, names were coded and anonymised in all written primary data. In this way, no information were directly attributable any individual participant. In order to protect participants and CWD from indirect identification, identifiable information was removed from examples and direct quotations.



Focus group participants completed informed consent forms (Photo credit: Daniella Chiu)

As in all research the neutrality of the researcher is difficult to guarantee. However, the following steps have been built into the research methodology to increase validity and ensure that a balanced representation of the findings are presented:

- Multiple data collection methods have been used to seek answers to the same research questions from different angles.
- Multiple stakeholders will participate to represent a diversity of perspectives, experience and opinions.
- Multiple diverse research sites have been chosen to represent a diversity of South African contexts.
- Research will take place at both state-funded and private ECD programmes to represent a diversity of service provision models.
- Preliminary findings and recommendations were presented to a DBE-appointed reference group for approval before finalising reports and other deliverables.

The researcher endeavored to uphold the principles of sound and ethical research.

2.7 Data analysis

Data collected was synthesised and analysed using manual thematic analysis. The following data was coded: transcribed audio data collected during focus groups and interviews; photographs of materials created during the focus groups; and field notes made during data collection. Findings of the study have been clearly articulated and recommendations for the early identification, assessment and support of CWD is detailed, as will the possibilities of linking CWD to the support mechanisms detailed in the SIAS. The

research report will inform the recommendation of a pragmatic, user-friendly, and context appropriate screening resources for early identification of disability for use by parents, caregivers and ECD practitioners.

2.8 Limitations

The following limitations were identified with regards to data collection and analysis for this study:

Availability and accuracy of information available describing childhood disability in South Africa

One of the objectives of this study was to investigate the types of disabilities that exist amongst children between birth and the age of four in South Africa. Despite undertaking a comprehensive literature search, there was very limited or outdated information available. It is acknowledged that the various types of disabilities revealed in the study are not an exhaustive list of all the disabilities that exist in children in this age cohort in South Africa. The information presented in the study is that which could be obtained in the desktop review.

Adequacy of the sample

The study undertook, within the available time, to seek the views and opinions from a variety of stakeholders. The sample of the study was drawn from three different districts located in three different provinces in South Africa. Although the recruitment criteria for these districts aimed at representing locations where CWD live, it is acknowledged that the sample is not necessarily representative of the total population (caregivers, ECD practitioners, service providers) under study (Huberman et al., 1994). Further, reflecting on the nature of qualitative research, the selection of the different participants to partake of the study implied delimiting the results to the views of the participants, hence cannot be generalized or presumed as representative (Brantlinger et al., 2005; Pearce et al., 2009). Accordingly, readers are duty-bound to approach and interpret the findings and conclusions of this study with caution.

In addition, more caregivers and service providers participated from Free State, than from the other sites. This is because both focus group discussions arranged were well attended, and all service providers contacted were willing to participate. This may introduce a bias in the findings to those more localized to the Free State. This is not representative of all South African provinces, especially as, for example among the caregiver sample, more caregivers were married and employed than at the other sites. This overrepresentation from one site is acknowledged as a weakness in the study.

Timeframe of the consultancy

The limited timeframe of the study placed constraints on the collection of data. In all sites it was not possible to allow the participants to reflect on our interpretations of their experiences. Participants were not given the opportunity to validate the study findings. Although data saturation was reached among the key informants, some government departments did not respond to our invitations to participate. The researchers did not feel that data saturation was reached among caregivers of CWD, and a more comprehensive study is recommended, to include the views of more caregivers from more provinces.

Bias of the researcher

The role of the researcher as a Community-based Rehabilitation (CBR) practitioner in the strategic and operational management of a CBR programme, implemented by NGO Afrika Tikkun, presented a methodological challenge to the study and introduced a strong risk of bias. This was acknowledged and will require an ongoing commitment to self-reflection to manage. The following measures were worked into the methodology in a concerted effort to counter this risk. In order to avoid influencing programme beneficiary responses, field workers from outside the organisation were employed to conduct the FGDs at the researcher's place of work. Triangulation, using multiple data collection methods, was used to corroborate inferences made and to increase validity. In addition the external assistance of a research assistant and editor were employed to assist with the analysis and drafting of the research report.

Chapter 3: Common disabilities existing among young South African children and their effect on childhood development and family life

3.1 Literature Review

It is difficult to say exactly what the total population of CWD in South Africa under the age of four is (DSD et al., 2012). Due to the complexity of defining, conceptualising and measuring disability, there is a marked lack of disaggregated disability data, as well as conflict between those available prevalence estimates which do exist (Schneider and Saloojee, 2007).

In childhood, identification of disability is complicated by several factors:

1. Every child is unique, and the achievement of developmental milestones varies from child to child. It is possible to mistake normal variations in development with disability. It was for this reason that the 2011 Census excluded children under the age of five in the disability questions- reportedly due to 'misreporting on general health and functioning for children in this age cohort and because children in this age cohort are often mistakenly categorised as being unable to walk, remember, communicate or care for themselves whereas it is due to their level of development rather than any innate disabilities they might have' (Statistics South Africa, 2013: 19)
2. Early childhood is the time for the acquisition of new skills and competencies. For this reason, age-specific measures are needed. For instance, a three-month old baby may not yet be able to walk independently, and may not have a disability, however if a three year old is not able to walk yet it would indicate a physical impairment.
3. Disability does not describe a homogenous group. Great variety exists in the nature, severity, onset and presentation of impairments. For this reason, measures that were sensitive to different types of disability are necessary.
4. Childhood disability remains extremely stigmatised, which can lead to underreporting in household surveys. As the status of CWD is so low, families may not mention CWD when reporting on their children (UNICEF, 2013).
5. Disability programming and research is largely adult-centric, and the study of childhood disability, especially in the global south remains limited (Feldman et al., 2013)
6. The influence of different cultures on the paradigms of childhood, disability and functioning may influence the way people answer census questions measuring disability (Schneider and Couper, 2007).

Despite the lack of information regarding the prevalence of CWD in the early childhood age cohort there is some data available from discreet studies undertaken in different parts of the country. One such study estimated

the prevalence of childhood disability in rural KwaZulu-Natal, revealing a prevalence of 60 CWD per thousand children under ten years old. Most (61 per cent) had mild disabilities, 20 per cent were moderate and 19 per cent were severe. Using the estimated disability prevalence of three per cent for children under five, the study indicated that a possible 155,000 children, between birth and four years of age may have a moderate to severe disability (Couper, 2002). This study is however over 10 years old, and thus it is likely that these estimates are highly unreliable.

The following section of the report brings together the disability prevalence data available, grouping each in terms of the common intellectual, physical, communication, sensory-perceptual, psycho-social, neuro-developmental and multiple disabilities. Under each type of disability the presentation, common causes, diagnoses and impairments were presented. For many of the types of disability and diagnoses listed below the only data available was outdated. For the most part we have only included studies conducted in the past 20 years. All prevalence data quoted however, should be viewed critically in light of the abovementioned reasons for discrepancies in childhood disability research.

Intellectual Disabilities

Intellectual disability indicates a cognitive impairment, present from childhood. Children with intellectual disabilities present with lower than average intelligence, which affects the development of their thinking, language, motor and social skills (Werner, 2009).

Diagnosis

The most common diagnoses for people with intellectual disabilities include: epilepsy; Downs Syndrome; Cerebral Palsy; physical, sensory-perceptual, and communication impairments; behavioural and/or psychiatric disorders (Bray, 2003).

Causes

No reliable data on the cause of intellectual disability exists in South Africa. However, a few studies have examined its causes in small population samples. Congenital causes were reported in 20.6 per cent of children, an acquired cause in 6.3 per cent, and in 73.1 per cent the cause was undetermined (Adnams, 2010: 432). Malnutrition (notably micronutrient deficiencies), head trauma, lead poisoning, low birth weight, malignancies, and infectious diseases (notably mother-to-child transmitted HIV/AIDS and tuberculous (TB) meningitis), and foetal alcohol spectrum disorder (FASD) have been linked to intellectual disability (Guralnick, 2005). Christianson et al. also correlated environmental factors like poverty, child abuse and

neglect with intellectual disability (Christianson et al., 2002; Guralnick, 2005). There is, however, a need for more evidence-based research on the causes of intellectual disability in South Africa (Adnams, 2010).

Prevalence

Three nationwide studies have attempted to describe the prevalence of intellectual disability in the general population. In 1999, the first National Disability Survey reported a 1.1 per cent prevalence, while the National Census Survey in 2001 reported a 0.5 per cent prevalence and a 2007 national survey that examined severe intellectual or learning disability yielded a prevalence of 0.27 per cent (Adnams, 2010: 436- 437). However, the prevalence among children was found to be higher in the Christianson et al study carried out in the Northern Province. This study found a 3.6 per cent prevalence of intellectual disability among children (2002: 179). Of children receiving a Care Dependency Grant, 26 per cent report having an intellectual impairment in the absence of any other impairments (De Kocker et al., 2006).

Foetal Alcohol Syndrome

Foetal alcohol syndrome (FAS) is a set of birth defects-the most severe negative outcome of foetal exposure to alcohol (Urban et al., 2008). FAS is the most severe presentation of FASD (Rendall-Mkosi et al., 2008).

Diagnosis

FAS is characterised by dimorphic facial features, growth stunting, developmental delay, intellectual disability and behavioural problems. Diagnosis is based on clinical observation, and confirmation of maternal alcohol consumption where possible (Rendall-Mkosi et al., 2008).

Causes

FAS is caused by maternal alcohol consumption during pregnancy. Risk factors include binge drinking, maternal social and genetic factors (Urban et al., 2008). The especially high prevalence of FAS in some parts of South Africa has been attributed to the lasting effect of the 'dop system' (McKinstry, 2005). Behavioral change interventions for pregnant women in high prevalence areas have shown some positive results, showing that information about FAS can decrease binge drinking (Marais et al., 2011).

Prevalence

Research describes parts of South Africa as having some of the highest rates of FAS in the world (Rendall-Mkosi et al., 2008). Prevalence among Grade One learners in mainstream Western Cape classes was found to be 6.5 per cent (Viljoen et al., 2005). Studies in other Western Cape towns found that the prevalence of FAS ranged from four per cent to 5.4 per cent (Urban et al., 2008: 877). Studies in the Northern Cape found prevalence rates of more than four per cent, and two per cent in Gauteng (CDC, 2003; Rosenthal et al., 2005).

Epilepsy

Epilepsy is a neurological disorder characterised by recurring epileptic seizures (Chin, 2012). According to the WHO, epilepsy is the most common neurological disorder seen by specialists in Sub-Saharan Africa (Neuroscience et al., 2004). Epilepsy can be effectively and economically treated, however (Christianson et al., 2000), uncontrolled, or prolonged, epileptic seizures cause structural neurological damage, which may lead to Cerebral Palsy, or further loss of function in children under the age of five (Odding et al., 2006).

Causes

Idiopathic Epilepsy of unknown etiology accounts for many cases of Epilepsy. However, brain damage occurring in utero, during or after birth; parasitic, viral and bacterial infections (commonly TB meningitis); fever; dehydration; cerebral malaria; poisoning and hereditary factors are known causes of Epilepsy (Werner, 2009).

Additionally, Neurocysticercosis (cerebral cysts caused by pork tapeworms) is a major cause of Epilepsy in South Africa, especially in the rural Eastern Cape (Krecek et al., 2008; Mafojane et al., 2003). Neurocysticercosis represents a preventable infection, which has escalated into a costly public health issue (Carabin et al., 2006). This serves to highlight the importance of good public health practice: good water and sanitation, and the regular deworming for young children.

Diagnosis

Diagnostic tools for Epilepsy include electroencephalograph (EEG), computerised tomography (CT) or magnetic resonance imaging (MRI) scans, however these tests are not available at clinics or community health centres. A detailed history of the type, frequency and duration of seizures assist with medical diagnosis and management of seizures (Werner, 2009).

Prevalence

Epilepsy is highly prevalent all over Sub-Saharan Africa (Preux and Druet-Cabanac, 2005). It is estimated that one per cent of South Africans will have a seizure at some point in their lifetime (Ackermans, 2012). Several South African studies describe the Epilepsy prevalence among children, ranging from to 0.47 per cent in Eastern Cape (Foyaca-Sibat et al., 2004) to 0.73 per cent in children between the ages of two and nine years old in Northern Province (Christianson et al., 2000). A more recent rural study in the Northern Province demonstrated an active prevalence of Epilepsy in 6.7 per cent of children (Ackermans, 2012).

Physical Disabilities

SPINA BIFIDA

Spina Bifida is a congenital malformation of the neural tube that occurs in utero. This results in a neural tube defect presenting as a full or partial protrusion of the

meninges or spinal cord through the spinal column. Damage to the spinal cord results in loss of motor and sensory function below the lesion. The results may include paraplegia, parasthesia and incontinence. Spina Bifida frequently occurs with hydrocephalus (Mweshi et al., 2011).

Diagnosis

The diagnosis and severity of Spina Bifida depends on the extent of the meningeal or spinal cord protrusion in the lumbar spine region. Surgical intervention is usually initiated soon after birth to protect the nerves and limit further neural injury. Paralysis, weakness and loss of sensation from Spina Bifida may result in secondary complications. These can include hip dislocation, contractures, fixed deformities, muscle spasms, incontinence and pressure sores (Werner, 2009).

Causes

Spina Bifida is caused by a failed neural tube closure or from secondary reopening of a closed neural tube (Kaufman, 2004). The cause of Spina Bifida is genetic, but may be influenced by low socioeconomic status, maternal hyperthermia, and maternal use of some anti-convulsant medications (Ameh and Nwomeh, 2006).

Prevalence

Since 2003 there has been a 30.5 per cent decline in neural tube defects, most notably Spina Bifida, presenting in newborn babies. This has been linked to folic acid fortification of staple foods (Sayed et al., 2008). A higher birth prevalence has been observed in rural areas (Ijumba and Padarath, 2006).

SPINAL TUBERCULOSIS

Spinal TB, TB Spine or Pott's Disease, as the names suggest, describes TB infection of the spine, which destroys intervertebral disc and adjacent vertebra- often in the thoracic spine- resulting in progressive kyphosis (Garg and Somvanshi, 2011). TB can affect most parts of the body. In South Africa, which has areas of very high drug-resistant TB prevalence, spinal TB is not uncommon in children (Seddon et al., 2012).

Causes

The high prevalence of HIV in South Africa, as well as resistant TB strains, attributes for the high levels of TB infection and reinfection, in it's various forms, including spinal TB. TB infection is associated with low socioeconomic status, poverty, crowded living conditions, and poor ventilation (Dunn, 2010).

Diagnosis

Clinical symptoms, over and above the general symptoms of TB, include back, neck and shoulder pain; neurological deficit; localised swelling, kyphosis or gibbus formation. Tuberculin skin tests, blood tests and sputum cultures, radiological investigation by X-Ray or MRI and biopsies assist diagnosis (Dunn, 2010).

Prevalence

Prevalence of spinal TB in South Africa is 0,9 per cent (Dunn, 2010: 37). 16.3 per cent of people who get spinal TB at one level of their spine, will get it at a second level (Polley and Dunn, 2009). Prevalence rates among young children is not disaggregated.

Congenital deformities

There are a number of common congenital deformities recognisable at birth: Cleft lip, cleft palate, finger or toe abnormalities and deformities of the limbs. The causes for these are often unknown or genetic, though poor nutrition during early pregnancy; maternal exposure to some medicines, pesticides and poisons during pregnancy; maternal German Measles infection during pregnancy; falling pregnant once older than 40 years old can cause congenital deformities (Werner, 2009). Although research suggests a general decrease in congenital deformities since the fortification of staple foods with folic acid since 2003 (Sayed et al., 2008), there is evidence an increased incidence of congenital deformities in rural South African communities (Venter et al., 1995).

CLEFT LIP AND PALATE

Orofacial clefts are congenital deformities that disrupt the normal structure of the face. Beyond the cosmetic appearance of the cleft, without surgical intervention the deformity may cause communication disabilities (Nagarajan et al., 2009). The appearance of a cleft can cause considerable concern for parents, and beyond surgical intervention, the role of traditional healers in the South African context has been recognised (Dagher and Ross, 2004).

Causes

The use of some medications; the consumption of alcohol and smoking during pregnancy; maternal dietary and vitamin deficiencies; diabetes; environmental toxins; altitude; low socioeconomic status and maternal age may combine with a genetic predisposition to cause cleft lip and palate (Castilla et al., 1999; Little et al., 2004; Wehby and Murray, 2010).

Presentation and intervention

Cleft lip is either complete or incomplete, and either unilateral or bilateral. Surgery can be performed between three and six months after birth. Cleft palate occurs when the palate cleft affects parts of the soft palate and extends into the hard palate and the gum. The corrective surgical procedure can be performed between four and 12 months after birth and involves repairing the area in layers. First the soft palate muscles are reconstructed to aid better speech and swallowing functions, where after the gap in the gum is closed. If needed, there may be follow up adjustment surgery after this procedure.

Lip cleft *and* palate cleft is a unilateral or bilateral cleft that runs from the base of the nose through the gums and palate. It is possible for this to occur while the nose

and gum remain joined. Surgical procedures for this involve a combination of the above-outlined procedures (The Smile Foundation; 2014). In addition to orofacial and denofacial abnormalities, and early feeding difficulties, clefts may affect communication and psychosocial development (Nagarajan et al., 2009).

Prevalence

Global prevalence of cleft lip and palate is between 0.03 and 0.27 per cent, with higher prevalence rates in developing settings (Prathanee et al., 2006: 500). South African prevalence data is dated, however The Smile Foundation estimates a prevalence of 0.14 per cent (2014).

CLUBFOOT

'Clubfoot', or Congenital Talipes Equinovarus (CTEV), is a common foot deformity. The child is born with unilateral or bilateral fixation of the foot in adduction, in supination and in varus, (turned inwards, rotated outwards and pointing downwards). If left untreated, the child will eventually walk on the top of the foot where the shoelaces usually lie. However, early intervention using the Ponseti Method yields excellent outcomes and can prevent disability altogether (Pavone et al., 2013).

Causes

Clubfoot is not fully understood. Epidemiological studies have identified several factors that are linked the condition including: chromosomal abnormalities, genetic factors, increased uterine pressure, the size and position of the fetus and placental insufficiency (Siapkara and Duncan, 2007).

Prevalence

Approximately 160,000 to 200,000 children are born annually with clubfoot deformities, predominantly in low-income countries (Owen, 2013). Prevalence in South Africa is estimated as 0.12 per cent (Global Clubfoot Initiative, 2014). However, a dated study measured prevalence rates of clubfoot among black South African children as at 0.4 per cent (van Meerdervoort, 1976).

Burns or thermal injury

Burns or thermal injuries result from exposure to hot liquids (scalds), hot solids (contact burns), flames, electricity, chemicals, ultraviolet radiation and radioactivity or lightning. The skin, as well as the respiratory system, may be damaged (Singer and Webb, 2010).

The disability resulting from burn injuries is most often caused by the contractures of healing scars, especially where the injury extends across a joint. Without good scar management, physical disability can result from progressive loss of range of motion and physical impairment (Werner, 2009). In addition, hearing and visual impairments as well as secondary mental health disorders have been observed (Forjuoh, 2006).

Diagnosis

Third degree burns that destroy multiple layers of dermis and nervous tissue are most at risk of leading to impairment.

Causes

The causes of burns in South Africa include hot liquids, fire and exposure to electrical wires. Most cases admitted to hospital with burn injuries are children from informal settlements, where environmental health and safety is low (Parbhoo et al., 2010). Burns sustained during shack fires are frequent (Peck et al., 2008). Multifactorial environmental, domestic and personal circumstances increase the risk of young children, especially those living in informal settlements, to burn injuries (Van Niekerk et al., 2007).

Although it remains very poorly described, the incidence of lightning strike burns is particularly high in some parts of South Africa, resulting in neural and dermal injury (Blumenthal et al., 2012).

Prevalence

Infants and toddlers are especially vulnerable to scald-type burns resulting from upturning pots of boiling liquid (Van Niekerk et al., 2004). Thermal injuries are the most common external or injury-related cause of death of children in South African under the age of four years old (Rode et al., 2011), with as many as 1300 such deaths every year (Bradshaw et al., 2003).

Communication Disabilities

Communication disability is described as '*an impairment in the ability to send, process, and comprehend concepts or verbal, non-verbal and graphic symbol systems*' (Salimbene, 2009: 12). Functional limitations in communication have severe consequences for the development of young children. The role of early intervention and Augmentative and Alternative Communication (AAC) - especially for children with severe disabilities- is therefore vital to enable them to reach their full potential (Alant, 2007; Alant and Bornman, 2012).

Causes

A range of factors may result in a communication disability ranging from intellectual impairments, anatomical abnormalities, impaired or motor function, learning difficulties, hearing or neurological impairments. These impairments may impact on voice articulation and fluency; impairments in the use of the spoken, signed or written language; impaired use or understanding of grammar, phonology, semantic or pragmatics (Prelock et al., 2008).

Diagnosis

Diagnosis of a speech or language impairment can be made by a speech therapist, and would include assessment, not limited to, feeding, speech and receptive language function or comprehension (Prelock et al., 2008).

Prevalence

Children in South Africa are at a high risk of developing communication disorders, with more than ten per cent of children under the age of three likely to have some form of communication disorder (Popich, 2004). In some areas of South Africa, a third of children with disabilities are not able to make themselves understood verbally (Saloojee et al., 2007). These children's diagnoses of Cerebral Palsy, intellectual disability, Global Developmental Delay and Autism Spectrum Disorder are frequently accompanied by an impairment of expressive and receptive language (Harty et al., 2007).

Sensory Disabilities

VISUAL IMPAIRMENT

Visual impairment includes low vision, as well as blindness, with a visual acuity of less than 20/60 in the best eye (Werner, 2009).

Causes

The primary cause of reduced vision among black South African schoolchildren is uncorrected refractive errors. Visual impairments may also be caused by:

- Amblyopia
- Retinal disorders
- Corneal opacity, congenital cataracts and other hereditary conditions
- Corneal scarring caused by Measles
- Vitamin A deficiencies
- Conjunctivitis, especially during infancy
- The use of some traditional medicines
- Albinism
- Glaucoma
- Nystagmus and central visual impairments commonly associated with Cerebral Palsy (Naidoo et al., 2003; Werner, 2009)

Diagnosis

Children visual impairments may show signs of infection, tearing or cataracts. Their eyes may not track moving objects; have involuntary movements (nystagmus); or may not be aligned (strabismus) (Werner, 2009). Screening schoolchildren for visual impairments have in the past included visual acuity tests, and the use of retinoscopy and autorefraction (Naidoo et al., 2003).

Prevalence

A recent review of visual impairment surveys conducted in Sub-Saharan Africa showed that prevalence of blindness ranged from 1.1 to 7.9 per cent in people under the age of 40 (Sherwin et al., 2012). Naidoo *et al.* found that 1.4 per cent of South African schoolchildren have reduced vision (2003: 3764).

HEARING IMPAIRMENT

The WHO defines hearing impairment in children under the age of 15 years as a permanent unaided hearing threshold level of 31 dB or greater in the best ear (WHO, 2013).

Causes

In South Africa, causes of hearing loss in children include:

- Sensorineural defects caused by a toxin exposure or foetal infection
- Middle ear effusion, perforation and infection
- Infectious diseases like respiratory infections, HIV and TB (Copley, 2009)

Diagnosis

Signs of possible hearing impairment include unresponsiveness to loud noises; a delay in expressive language development; communication disabilities and delayed social development (Mayberry, 2003; Werner, 2009). Screening for hearing impairments has been extensively advocated for in newborns.

Prevalence

The prevalence of congenital hearing impairments has been estimated to be between 0.4 and 0.6 per cent in the public sector (Theunissen and Swanepoel, 2008). Daily, approximately 17 babies are born with, or develop, hearing loss in South Africa (Copley, 2009).

Psychosocial Disabilities

Psychosocial disabilities are associated with severe mental health disorders and are thought to be caused by both psychological and social factors. Mental health disorders can influence the way a person thinks; understands reality; makes judgments; the way they feel emotionally; as well as their behaviour (Patel et al., 2008). Common diagnoses in developing settings include depression and anxiety disorders; conduct, disruptive, and reactive behavior disorders; and post-traumatic stress disorder (Cortina MA et al., 2012).

Causes

Although it remains relatively unacknowledged in South Africa, the effect of growing up surrounded by poverty, deprivation and violence on child development and mental health is devastating (Hawkrigde and Kraus, 2012). Violence has been identified as a notable risk factor. A study conducted in the Limpopo province found that 67 per cent of children had directly experienced traumatic events such as watching someone get killed or seriously injured; witnessing the unexpected or violent death of a loved one; and sexual abuse perpetrated against themselves or a friend (Peltzer, 1999). Another study found that the rates of exposure to trauma in South African children and adolescents ranged from 40 to 100 per cent (Suliman et al., 2005). Rates of post-traumatic stress disorder is particularly high in South African adolescents (Seedat et al., 2004).

Further, mental health disorders have been shown to have a strong association with poverty and low levels of education in developing countries. Children in poor rural areas or informal settlements are most at risk (Cortina et al., 2012). Mental health disorders are caused by a combination of genetic, biological, social or

environmental factors (WHO, 2001). In addition, alcohol and substance abuse may also trigger mental health disorders (Baingana et al., 2006; Lachman et al., 2012). As these factors are cumulative, and requires substance abuse we assume that some of these causes are less applicable to the zero to four year old cohort.

Prevalence

The prevalence of post-traumatic stress disorder, anxiety, and depression has been found to be between 20 to 60 per cent in Sub-Saharan African adults (Jamison, 2006; Baingana et al., 2006). A recent systematic review of the prevalence of child mental health disorders in the same region revealed that about 14.3 per cent of children present with psychopathology (Cortina et al., 2012: 276). Although no epidemiological studies exist for children in South Africa specifically, research indicates that about 37 per cent of people requiring psychiatric intervention are 18 years old or younger. Further, the prevalence of psychiatric disorders in children and adolescents is about 17 per cent (Hawkrigde and Kraus, 2012).

Neurodevelopmental Disabilities

Neurodevelopmental disabilities are linked to disorders of the developing nervous system (Barratt and Ogle, 2010). Although Cerebral Palsy (CP), and some other diagnoses discussed in this literature review are neurodevelopmental disabilities, we have chosen to describe them under other sections, like intellectual disabilities or multiple disabilities. For the purposes of this review we have included autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and specific learning difficulties in this neurodevelopmental disabilities section.

AUTISM SPECTRUM DISORDER

ASD is a neurodevelopmental disorder usually presenting in young children under the age of three years old. ASD characteristics may either be present from birth, or emerge suddenly (Troy et al., 2007). Consistent with global figures, ASD has been described as affecting a significantly larger proportion of boys than girls in South Africa (Jacklin, 2006; Springer et al., 2013).

Diagnosis

AutismSA lists the following characteristics for the diagnosis of autism:

- Severe impairment in reciprocal social interaction
- All absorbing narrow interests
- Imposition of routines and interests
- Speech and language problems
- Non-verbal communication problems (2014)

Causes

The etiology of ASD remains largely unknown, though some patterns of genetic susceptibility have been observed (Geschwind, 2009).

Prevalence

Although prevalence data is not well established at a population level, Autism South Africa estimates an annual incidence of over 900 new cases of ASD in South Africa (AutismSA, 2012: 3). The diagnosis of ASD is on the rise in South Africa: incidence at a public Johannesburg neurodevelopmental clinic increased eightfold between the years 1996 and 2005 (Jacklin, 2006). Complex Autism is also described as making up 40 per cent of the caseload at a Cape Town neurodevelopmental clinic (Springer et al., 2013: 97).

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

ADHD is highly prevalent in South Africa (Amod et al., 2013), and is characterised in young children by poor attention, hyperactivity, and hyper-impulsivity. These characteristics negatively affect all spheres of childhood development (Schellack and Meyer, 2012).

Causes

Like ASD, the causes of ADHD are not clearly understood, though some genetic links have been identified (Schellack and Meyer, 2012). Other possible causes include maternal smoking and alcohol ingestion during pregnancy; prematurity; low birth weight; brain injury during infancy or epilepsy; thyroid deficiencies; viral infections; and ingestion of toxins or drug abuse (Millichap, 2008).

Diagnosis

Although controversy about accurate diagnostics persists, the DSM-IV TR¹ is used in diagnosis and classification of ADHD. Symptoms include hyper-impulsivity, poor organisational and planning skills and poor concentration (Schellack and Meyer, 2012).

Prevalence

A systematic review of prevalence studies estimated a global prevalence of 5.3 per cent for ADHD, however prevalence in South Africa is estimated to be between four (Schellack, 2012: 12) and ten per cent in children (Zaytoon, Vorster and Lazarus, 2013).

Specific Learning Difficulties

Learning Difficulties are

'disorder(s) in one or more of the basic processes involved in understanding spoken or written language. This brain variance may influence an individual's ability to speak, listen, read, write, spell, reason, organise information, or do mathematical calculations' (Lerner and Johns, 2008: 2).

Although many of the signs and symptoms may only become apparent in children when they start school, ECD practitioners should be aware of learning difficulties for children having trouble when early literacy and numeracy concepts are introduced.

¹ The DSM IV TR is the most recently revised version of the Diagnostic and Statistical Manual of Mental Disorders, which provides diagnostic criteria for the classification of mental disorders

The different types of learning difficulties include:

- **Dyslexia**
A developmental disorder that affects reading and spelling where the child does not have a cognitive impairment (Snowling and Hulme, 2012).
- **Dyscalculia**
A disorder that affects the learning of mathematics skills (Butterworth et al., 2011).
- **Dyspraxia**
A disorder that affects motor function. Dyspraxia presents as clumsiness, untidy handwriting and/or impaired speech production (Dewey and Kaplan, 1994).
- **Dysgraphia**
A disorder that affects how a child learns to write, which is not attributable to cognitive impairment, psychiatric or neurological disorder, sensory impairment, or the way they have been taught (Thomson and Raskind, 2003).

Causes

A study carried out in Cape Town among pre-school children revealed that, in a quarter of the children with learning difficulties that were identified, the origin of their disability was unknown. However, the etiology of 45 per cent of the cases were of prenatal origin. 17 per cent were perinatal and nine per cent postnatal. Interestingly, the study found that in 40 per cent of cases the learning difficulties could have been prevented (Molteno and Lachman, 1996: 141).

Diagnosis

The diagnosis of specific learning difficulties requires an assessment of a child's reading, phonological processing, use of semantics and syntax (Catts et al., 2005); math and numeracy skills (Butterworth et al., 2011); handwriting skills (Rosenblum et al., 2004); coordination, perceptual skills, speech production, fine and gross motor skills, sensation and proprioception (Addy and Dixon, 2004). Most of these emerge when children are older than four years old, and require assessment by an educational psychologist.

Prevalence

A study conducted among rural children under the age of ten in kwaZulu Natal found learning difficulties in 1,7 per cent of the sample (Couper, 2002).

Multiple Disabilities

Children with multiple disabilities have a combination of impairments. Children in this group make up a large proportion of CWD in South Africa. De Kocker et al reported that of children receiving the Care Dependency Grant:

- 10 per cent had physical, intellectual and emotional impairments (interpreted as neurodevelopmental disabilities associated with ASD)
- 7 per cent had speech (interpreted as communication disabilities), intellectual and emotional impairments

- 7 per cent had speech and physical impairments
- 7 per cent had speech, physical and intellectual impairments
- 5 per cent had intellectual and emotional impairments (2006: 353).

GLOBAL DEVELOPMENTAL DELAY

Global Developmental Delay refers to a generalised developmental delay in young children under the age of five years old. Early intervention and ECD for children with Global Developmental Delay has shown positive results, and most children are able to catch up (Bailieu and Potterton, 2008).

Causes

Global Developmental Delay may be caused by a variety of causes, ranging from genetic syndromes, birth complications, brain malformation, to psychosocial deprivation and exposure to toxins (Srouf et al., 2006). However, in South Africa, the effect of HIV on central nervous system development is recognised as a major cause of developmental delay in children (Bailieu and Potterton, 2008; Ferguson and Jelsma, 2009).

Diagnosis

On assessment, children with Global Developmental Delays display below average performance or a failure to achieve age-related milestones *'in two or more of the following developmental domains: gross or fine motor, speech and language, cognition, social and personal skills, and activities of daily living'* (Srouf et al., 2006: 140).

Prevalence

Because of the high prevalence of HIV in South Africa, Global Developmental Delay is highly prevalent in young children. Significant motor delay was described 66.7 per cent of children with HIV infection in the Western Cape (Ferguson and Jelsma, 2009). It is also commonly associated with comorbid conditions such as ASD, Epilepsy, visual impairments and FAS. A study in a Western Cape developmental clinic found 43.1 per cent of children had a moderate and 31 per cent had a severe Global Developmental Delay (Springer et al., 2013: 97).

CEREBRAL PALSY

CP is a common neurodevelopmental disability which can be understood as a

'group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems' (Rosenbaum et al., 2007: 8).

Causes

CP is caused by damage to a developing brain in children under the age of five years old. There are a vast number of possible mechanisms for brain injury. Typical causes arising in developing countries include:

- Severe perinatal asphyxia, occurring during delayed or complicated labour
 - Intrauterine and perinatal Infection, frequently Tuberculosis Meningitis associated with HIV infection
 - Metabolic hypoglycemia
 - Uncontrolled epilepsy
 - Head trauma
 - Near drowning
- (Cameron et al., 2005).

Diagnosis

Caregivers usually bring children with CP for assessment after encountering severe feeding problems, abnormal postural tone or in more mild cases, or a delay in achieving age-appropriate developmental milestones. Assessment, preferably by a multi-disciplinary team, may include assessments as to the severity and distribution of abnormal postural tone (spasticity, hypotonicity, dystonia, athetosis or ataxia); voluntary movement and postural control; sensation; perception; cognitive function; communication; behavior and motivation; as well presence of a seizure disorder (Brown and Saloojee, 2008).

Prevalence

Global prevalence rates of CP are between 0.2 and 0.3 per cent (Condie and Morris, 2008), however, prevalence is increasing. As global infant mortality rates are reduced- particularly in developing settings - more vulnerable babies survive, many with CP (Maulik and Darmstadt, 2007). It is therefore proposed that prevalence rates are higher in South Africa, especially in rural settings (DG Murray Trust, 2012).

HYDROCEPHALUS

Hydrocephalus occurs when a blockage in cerebrospinal fluid (CSF) circulation causes a build-up of fluid, intracranial pressure and cranial enlargement (Ameh and Nwomeh, 2006).

Diagnosis

Children with hydrocephalus present with an enlarged head circumference; sunken, downward-looking eyes and other signs of central neurological damage (see CP) (Werner, 2009).

Causes

Hydrocephalus is caused by a mechanical blockage to circulating CSF. This may occur at birth, or be acquired later. Possible etiology includes congenital malformation; trauma; neonatal meningitis; fungal, viral or bacterial infection (commonly TB) (Warf, 2010). Children born with Spina Bifida also frequently have accompanying hydrocephalus (Werner, 2009).

Prevalence

Hydrocephalus remains poorly described, however one study described a prevalence of 0.68 per cent measured in 12 public hospitals across four provinces in 2005 (Sayed et al., 2008).

DOWN SYNDROME

Down Syndrome is the most common genetic cause of intellectual disability (Op't Hof et al., 1991), but is also associated with physical - and occasionally sensory - disability, as well as other health conditions.

Causes

Down Syndrome is caused by the chromosomal duplication of Chromosome 21, also called Trisomy 21.

Diagnosis

Genetic screening for Down Syndrome is possible in utero allowing for prenatal diagnosis (Molteno et al., 1997). Babies with Down Syndrome generally appear hypotonic, with decreased reflexes and joint hypermobility. They also have a number of typically syndromic facial features (Werner, 2009).

Prevalence

Most prevalence data on Down Syndrome in South Africa is outdated, however, rural study described prevalence as 0.74:1000 children (Christianson et al., 2002: 179).

3.2 Findings

Caregivers of CWD were asked to share their thoughts, feelings and experiences as they relate to raising their CWD, with a specific focus on the impact that this has had on them personally and on their family unit. Their responses reflect a myriad of insights into the lives of caregivers and CWD, not least because the caregivers that participated in the study had children with a great variety of impairments, and were contending with a range of differing socio-economic situations and support structures. Accordingly, the ways in which their child's impairments impacted on their lives also varied; depending on each individual child's personality, impairments and needs, the challenges facing families differed. For example, some caregivers reported that their families struggled to control Epilepsy, while others described incremental improvements in crawling, sitting, standing and walking with therapy and practice at home.

This being said, some patterns were discernable. These were particularly present in the advice that the caregivers were asked to draw out of their experiences, the compendium of which have been used to inform the study's understanding of the information that caregivers of newly diagnosed CWD would value. The following section provides an outline of these findings.

"My name is T. I stay with my three children and two of my sister's children. My disabled child is four years old. I am not married and I am also unemployed" (Caregiver, Eastern Cape)

"She grew up to be a beautiful child that I love so much. Even today, I am married to a man who is a step-father to my child. I used to tell my husband that if you give me problems I will choose my child over our marriage because I have come a far way with this child" (Caregiver, Free State)

Feelings of disappointment at discovering that their child had a disability were shared by many mothers, however most of them had grown to accept their children 'for who they are'. These mothers reflect this sentiment:

Caregiver 1, Eastern Cape: 'At first, I had difficulties in accepting the situation since it was my first baby. The situation was very painful for me.'

Caregiver 2: 'I also had a problem since it was my first child as well.'

Caregiver 3: 'I also had a problem because the child is my only daughter. I have 6 male children and 1 daughter so I was very disappointed.'

For some, the difficulties associated with caring for a disabled child negatively affected their mental health. One Free State mother shared a detailed account of her depression: 'I was crying every night...Until I was starting to forget things- I even forgot to fetch my kids from school...I realised something was really wrong: I would lock myself in the house and watch TV, I didn't want visitors...I went to the hospital and I found a doctor and explained everything to him. He said that I have been through a lot and someone my age shouldn't have had such experiences. So I started medication, which I think that I am doing better.' Negative mental effects was a theme which arose consistently from other caregivers, particularly in relation to worries about the future, which caregivers reported as weighing heavily on them: "It affects me negatively because I always think of what is going to happen to him in the future? Will people understand him?" (Caregiver, Free State).

Some caregivers described constantly 'fighting' for their children as taking its toll. A mother from Gauteng of two children with the same rare chromosomal disorder remarked, 'I am struggling. Obviously it's hard to watch two kids that are abnormal.' Her older son had already undergone four operations and she described losing hope. An occupational therapist from the Western Cape described how many parents feel 'just as segregated and isolated as their children'.

Several instances of the sacrifices made by mothers of CWD were shared. These related mainly to the amount of time that caring for a CWD requires, making the pursuit of personal goals or employment difficult. Despite receiving a 'best performer' certificate in her last year at school, one mother said that 'because of the things I was going through and the lack of support and everything, I dropped out. My marks dropped and I went back to square one' (Free State). Another Free State

mother shared that, even though she was working full-time, she had had to drive in the 'middle of the night' to go and visit her daughter in hospital. Others described how they had to take her child to therapy so it was difficult to keep working hours, or how they would receive panicked phone calls from babysitters while they were at work when their children had seizures or were unwell. Such episodes would mean that they would often have to ask permission to leave work early or take the day off. Several had had to 'stop working', or could not start, because they had to take care of their CWD' which was 'difficult'. For instance one mother recalled how she had been offered a job at a fast food restaurant, but because her child was at home in her full-time care, she had been unable to take up employment.

Despite the difficulties, many caregivers reflected positively on their experience of raising a CWD. A sense of achievement and pride at how they had managed to cope with the challenges of raising their CWD was evidenced by the responses of some. For instance, a mother from the Free State said, 'I accepted her and I was staying with her in big house that I built on my own without anybody's help. I knew what I wanted in life. I was strong.' Another shared, 'I told myself that I must be strong and be there for her. I love her a lot' (Caregiver, Free State). Caregivers also felt rewarded by improvements in their children's function or health: 'I gave my child attention and he got better!' (Caregiver, Free State). Some also described that 'going through so much' with their CWD had drawn them closer. Another mother from the Eastern Cape told of the recognition she had received from her family: 'They always encourage me and praise me for the work that I do in taking care of my child'.

In the Free State, a clearly discernable theme was the relief that finding a day-care centre had provided the caregivers. They reported feeling extremely grateful to have a safe place for their children during the day: 'Then my child got a place here and I was pleased because they are giving them a lot of care'. Many reported that the day-care centres had allowed them to return to work. Nevertheless, even within the Free State, a social auxiliary worker from Free State described how parents 'really struggle' when it comes to finding a centre or school for their children, or navigate the education system when they are old enough.

'She cleans her teeth with toothbrush, eats and goes out to play and wash clothes. She goes to play with her friends all by herself. Her friends call her "the girl who doesn't walk"' (Caregiver, Eastern Cape).

	Diagnoses included
Gauteng	Cerebral Palsy, Intellectual impairment, Epilepsy, Attention Deficit Hyperactivity Disorder, Muscular dystrophy, Hearing impairment, Autism Spectrum Disorder, Down Syndrome, Genetic disorder
Eastern Cape	Cerebral Palsy, Intellectual impairment, Visual impairment, Autism Spectrum Disorder, Down Syndrome, Leg length discrepancy,
Free State	Cerebral Palsy, Intellectual impairment, Autism Spectrum Disorder, Epilepsy, Genetic disorders and syndromes

Table 2: Common diagnoses of CWD of the participants in focus group discussions

Caregivers were asked to share their day-to-day experience of caring for a CWD. Self-evidently, the feedback varied with the types of disabilities that the caregivers contend with. A mother from the Eastern Cape confessed that 'taking care of a child that couldn't walk was a big challenge' for her. Others have 'very hyperactive' children that 'break things in the house' and 'throw things around' or 'can't concentrate'. Some caregivers described their children 'not wanting to touch them'. 'Children with multiple disabilities are extremely marginalised and neglected, so are the deaf and blind...[so] parents suffer the most because these children need 24/7 care and there is no school option for them' (Occupational Therapist, Free State). A Free State mother described how despite needing to wear his hearing aids for up to six hours a day to make his Cochlea implant worthwhile, he found them irritating and pulled them off. Another mother from the same focus group explained how it was difficult 'take her child out with the family'. 'My child is very busy...he will want to go to other people, to grab their food and all...He will disturb them...Other people get irritated and say the child is naughty - they don't understand' (Caregiver, Free State).

'I really appreciate my family and my husband. We have 20 years together' (Caregiver, Free State).

'Most often the husband helps me look after the child. My husband loves children a lot' (Caregiver, Eastern Cape).

While the above quotations reflect that this experience is not shared, it appeared more common that the support of the father of the child was either not guaranteed or completely absent. Many were raising their children as single mothers with unreliable assistance from the father of the child. As one Free State caregiver reported, 'You can imagine: At that time you are not married, you are having a boyfriend who is not serious about you, who doesn't even promise to marry you'. Another mother from Free State remarked, 'His father comes when he feels like coming to give money. If he doesn't, he doesn't. I have to hustle my way the whole month to make sure there is food on the

table.' Still another said that her child's father did give her money to look after the child, however, this alone was not enough support.

Amongst those who were in committed relationships, some described that having a CWD exaggerated existing tensions with their partner, for instance one said, 'My biggest problem was the fact that even before I fell pregnant with the child I had marital problems and I had to work hard to make ends meet' (Caregiver, Eastern Cape).

The gender disparities in caring for CWD was evident from the gender of the participants in the study: Just one father participated in the focus group discussions, in comparison to 32 female caregivers, comprising mothers, grandmothers and aunts. The role of women in caring for and raising CWD was emphasised by an ECD practitioner from the Gauteng site in the following exchange:

ECD practitioner (Gauteng): 'I think more men should be educated about disability'.

Researcher: 'Just in general more people need to be educated?'

ECD practitioner: 'More men.'

Researcher: 'More men?'

ECD Practitioner: 'Men. Because men are mostly traditional. They don't want to deal with that. They will blame the woman about it. They will say, "It's your child, you need to take care of her and all that...Like our children we are having here, now I only see women coming here for their children...I have not seen a guy that is here.'

The role that siblings of CWD play was frequently mentioned. Many caregivers said that they often felt guilty because their CWD demanded a lot 'more time and attention': 'I spend 90 per cent of the time with him because he cannot walk and so the older one gets a little bit of attention from us' (Caregiver, Free State). Another Free State mother said, 'My son doesn't like closed spaces like shopping malls. He freaks out if there is a lot of people and it's sad because I have a [daughter] and she wants to go shopping.' This sentiment was reflected by another mother, who shared the impact of the disability of the family unit as a whole: 'I sometimes feel that we are a dysfunctional family because at this stage it is always me and the older one doing something or my husband and the older one because my disabled child gets agitated. I mean we will take her to Spur and to friends' houses but we can't go to a movie because she will totally <waves her hands>. So it feels to me that we are not doing anything as a family' (Caregiver, Free State).

Several parents reflected positively on the interactions between their CWD and his or her siblings, relating that

they were able to play together and that this had had a positive impact on their disabled child's development. For some, the siblings were the best at including their CWD and a special 'bond' was described between them: 'I realized that my child wasn't able to play with other kids, but now that she has her own [younger] sister, she knows how to play. Her sister is three years old and she knows how to play with her' (Caregiver, Free State). In other families the siblings sometimes bore the brunt, when their brother or sister with a disability 'get irritated with them', 'refuse to speak to them', 'want to play separately' or 'aren't patient with them'. One mother commented: 'The sad part for me is that my older daughter loves her but she doesn't want to play with her. So they can't play together. They have a bond and she understands but I think it is sad that they cannot play together' (Caregiver, Free State)

The reactions of some caregivers revealed that the burden of caring for the CWD fell also to the siblings. As one mother reflected, 'Now I am expecting a second child, it's a girl! I'm so excited. She will grow up and help me with my first born child when time goes on' (Caregiver, Free State). For others, the siblings in fact created a greater burden of care that was somewhat resented: one mother shared that she was used to the quiet companionship her daughter with multiple disabilities and was rattled when she had a second daughter. 'The little one is irritating, I was used to [my firstborn], she doesn't talk...[My younger daughter], she talks. She wakes up talking and goes to sleep talking. And I don't want to talk [I need to study]!' (Caregiver, Free State).

'My mother-in-law is very supportive so she gave me a lot of support. My sister-in-law was the first one to have a child living with a disability so I learnt from her as well. As much as I was hurt when I got this child, I knew I was not alone' (Caregiver, Eastern Cape).

'My aunt's child couldn't walk so my mother would always tell me to be grateful that my child could at least walk. The support I got from her made me strong' (Caregiver, Eastern Cape)

Family members were in many cases extremely helpful and supportive to mothers of CWD, and helped 'encourage' and remind them that their 'situation was not as bad as they thought it was'. For some this had happened after either they themselves or doctors had educated the family about the child's disability: 'My family members understand him- I have explained to them' (Caregiver, Free State). Some families were said to have supported CWD, and 'been there for them' from when they 'were still in hospital'. Mothers explained that their sisters and mothers had accepted their CWD 'as if they were their own'. A grandmother from Gauteng remarked: 'My daughter and I were able to accept the situation and we love our child a lot. So we had no problem.' Relatives helped by learning to feed children, taking care of children when their mothers needed to go

to work, the clinic or back to school, and taking care of siblings to enable the mother to focus on her CWD. Some caregivers explained that their family members helped advocate for their children and were 'very protective' over them: 'My family loves the child to the extent that they do not want other people to refer to my child as a disabled child' (Caregiver, Eastern Cape).

For some caregivers, the loss of a particularly supportive relative had been catastrophic. For instance a mother from Free State described what a blow it was when a grandmother passed away: 'It was hard because she was the only support I had. She loved my child like she was her own. She learnt how to feed my child- which is not easy! My child does not eat hard stuff like Simba [chips], but that granny would crush them with her hands and feed them to her.'

Not all caregivers that participated had good experiences or support. In some cases mothers had been afraid to reveal the CWD to her family. A mother from Free State described the 'drama' caused by her baby, and how her grandmother had thrown her out of the household and told her to 'go away and fend for [her]self'. Another mother from the Free State described being completely abandoned by her family and the father of her disabled baby: 'Nobody came to see me when I was at the hospital. When I got home...they put me in one of the small outside houses and asked me to stay there. I stayed there. I stayed with my baby. I learnt to wash her on my own. And then even her father disappeared on me.' Others, albeit not ostracised by their families, reflected nonetheless that they felt misunderstood: 'I have to fight for him all the time because even some of my family do not understand...they think I am spoiling him' (Caregiver, Free State). Another mother shared that her mother had advised her to pray either for God to take her child 'rather than suffering like this', or for her to be 'healed'. Her mother said that after seeing her child have a seizure her mother had said that 'no one wants to live like that, it's better to die' (Caregiver, Free State).

What advice did caregivers have for other caregivers of CWD?

In the interests of better understanding the type of information that parents of CWD value, which have been used in the guidelines that are to be developed for caregivers and practitioners working with young children, participants were asked what type of advice they would give to parents of young children that have been recently diagnosed with some form of impairment. Caregivers of CWD prioritised having faith, acceptance of the situation, loving the child, seeking medical and rehabilitative services at their clinic or hospital, and treating them like other children.

'Have faith that you will accept your situation'

The strongest theme emerging from the focus groups with caregivers was the role that faith played in finding

peace with having a CWD. The following quotations illustrate how many caregivers felt:

Caregiver 1, Gauteng: 'The first thing is to accept that this is the child and that he has a disability, then I pray and thank the Lord for the child because he is a gift from Him.'

Caregiver 2, Gauteng: 'Accept, because the child is a gift that God gave you.'

Caregiver 3, Gauteng: 'You must pray and trust that God give you strength. You need to prepare yourself to do anything for your child like going to physiotherapy.'

Caregiver 4, Gauteng: 'The first is to accept my child because he or she is also created by God...you know God is doing things his own way. We must gladly accept what he has given us because God knows why he did that.'

'Look for the answers that will help you help your child'

Caregivers conceded that, besides having faith, other factors were also important to help them and their families come to terms with their situations. Some caregivers acknowledged that while praying and having faith had helped them, they also recommended other options like counseling, joining a support group and equipping themselves with information.

'For me, I think that counseling plays the biggest role because I experienced...I would kneel down but I would not know what to say to what. It was a time in my life when I even questioned God. I understand when the ladies say you must pray because sometime it is all you can do. For me to accept I need to have information, I cannot just accept things that I do not know.'

'I went through a stage of denial, for a long time I thought that there must a mistake somewhere, I could not just accept that my child had a disability. Going out there to find information makes things easier, that's when you start to deal with things because you know that when this happens, I must do this' (Caregiver, Gauteng).

Caregivers from Free State said that parents should ask as many questions of health professionals and make sure that they understand before leaving any service provider: 'The mom should keep asking those questions until she gets those answers.' Another participant volunteered that caregivers 'should not leave the room without understanding' (Caregiver, Free State).

'Learn from other parents'

Many caregivers shared that they had had gained a lot from meeting other people in their position. Some said that hearing other people's stories during group sessions had 'taught them a lot' and 'helped put their situation in perspective'. Some felt it gave them strength

to see that 'things could be worse'. One caregiver from Eastern Cape said, "When I saw other mothers being strong enough to accept their situations, I knew that I could do it as well". She and others said that they felt 'comfortable talking about their CWD' with other parents of CWD and that they could often give others advice based on their own experience. The following quote illustrates the benefits that can be gained by participating in a group for caregivers and families of CWD: 'When I first came here, I cried tears and everyone came and hugged me. They started talking to me. It was easy for me now, not angry anymore. I treat my child with more calm and understanding. But when you are at home, thinking it is me against the world – it's sad. There are people like you who face the very same problems, its better now, because we come and talk and laugh' (Caregiver, Gauteng).

'Never forget that your child is a child- love them and treat them as equals'

Several caregivers advised that 'first and foremost children are to be loved' and that having a CWD is 'not the end of the world'. They encouraged other parents to 'love your child regardless of their condition' (Caregiver, Eastern Cape). Although caregivers acknowledged that having a CWD had not been easy, they mostly described their children as a blessing. Many caregivers expressed how much they love their children.

Caregivers also advised that people should treat their CWD as equals or 'normal' children, even if they do not feel like other people in the community are ready to accept children that are different. For instance a caregivers from a Gauteng focus group said:

'My advice would be to get other children to speak normally with the child. The mother should also speak normally with the child, not like the child has a disability.'

'Treat her as a normal child and take her to school. Try to communicate with the child. To play with her.'

'I like to be patient to the child...and to be honest with them. Speak honestly as he is an ordinary person.'

A Free State mother said, 'Treat your child as normal...don't stay at home because you are afraid of what people are going to say.' In accordance with this many caregivers advised that parents not feel ashamed of their children. They advised that parents of CWD are 'not alone'. All caregivers that participated shared that they loved their children and many were proud of their CWD.

3.3 Conclusion

Although for some diagnoses there is a lack of current research and prevalence data available, the literature review presents the definition, diagnostic criteria and available prevalence data for the most common intellectual, physical, communication, sensory, psychosocial and neurodevelopmental disabilities that

present in the South African context. In addition, specific learning difficulties and multiple disabilities are discussed. FAS, Epilepsy, Spina Bifida, Spinal Tuberculosis, common congenital deformities, burns, visual and hearing impairment, mental health, ASD, ADHD, Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, global developmental delay, Cerebral Palsy, Hydrocephalus and Down Syndrome are presented.

The findings describe the experiences of participants with respect to their reflections on parenthood, how disability affects their daily lives and the effect of having

a CWD on relationships between parents, with the child's non-disabled siblings and their extended family.

Overwhelmingly, the message from participating caregivers was that, although not easy, having a CWD is 'not the end of the world' and caregivers advised that others in their position should try to have faith, accept their situation, equip themselves with a support network and as much information as possible, and to remember that their CWD is a child and needs love and parenting just like all children.

Chapter 4: Overview of law, policy and guidelines for young South African children with disabilities

4.1 Introduction

Over the past two decades South African legal reform has enacted a framework of enabling legislation, policy and guidelines. This section provides a targeted desk review of this framework, bringing together the legislation, policy, national instructions and guidelines affecting State service provision to young CWD.

4.2 Equality

An apt starting point for this review is the right to equality. This right has a bearing on the realisation of all other rights; no child can be discriminated against in accessing his or her human rights on the grounds of disability.

The right to equality belongs to an exclusive club of legal norms so intrinsic to our understanding of international law today that they bind all states simply by virtue of their membership of the international community – *jus cogens*, from which no derogation is permitted (Inter-American Court of Human Rights, 2003). South Africa has nevertheless taken several steps to bind itself explicitly under the obligation to treat people equally in terms of a multitude of international human rights conventions: principle amongst these, the International Covenant on Civil and Political Rights (1966: Article 26); the International Covenant on Economic, Social and Cultural Rights (1966: Article 2(2)); the Convention on the Elimination of Discrimination Against Women (1979) and the African Charter on Human and People's Rights (1981: Article 2).

Where these conventions themselves do not explicitly link disability and equality, several of their monitoring bodies have issued general comments on the obligations of states to eradicate discrimination against persons with disabilities in the areas of equal rights for men and women ('double discrimination'), social security, protection of the family, adequate standard of living, the right to physical and mental health, the right to education and the right to take part in cultural life and enjoy the benefits of scientific progress (Committee on Social and Cultural Rights, 1994; Committee on the Elimination of Discrimination against Women, 1993).

With a particular view to protecting the right to equality for CWD, South Africa has signed and ratified the Convention on the Rights of the Child (CRC) (UN General Assembly, 1995), the first human rights treaty explicitly prohibiting discrimination against children on the basis of disability (UN Committee on the Rights of the Child, 2006: para 2), and incidentally also the first human rights treaty signed by the South African government in the post-Apartheid era (Boezaart and Skelton, 2011). The treaty imposes an obligation on

state parties to respect and ensure the rights afforded to children in terms of the CRC without discrimination of any kind, with particular mention of disability as a prohibited ground for discrimination (Article 2).

South Africa again committed to the principle of non-discrimination in terms of the African Charter on the Rights and Welfare of the Child (ACRWC) (Organisation of the African Union, 1999.), which, while not referring directly to disability as a prohibited ground for discrimination (Article 3), provides an open list by prohibiting discrimination on any status other than those directly referred to.

From the perspective of CWD, one of the most significant of all international instruments to which South Africa is signatory is the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations (UN), 2006). In terms of this convention, states parties undertake 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' (section 4(1)). Further, the CRPD endorses measures aimed at positive discrimination which are 'necessary to accelerate or achieve de facto equality of persons with disabilities' (Article 5(4)).

Locally, the principle source of legal rights for CWD is the Bill of Rights, entrenched in the Constitution of South Africa (1996), wherein the right to equality is phrased in the following terms:

- '9. (1) *Everyone is equal before the law and has the right to equal protection and benefit of the law.*
- (2) *Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.*
- (3) *The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.*
- (4) *No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.*
- (5) *Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.'*

Several elements of this provision are notable. Firstly, in so far as equality 'includes the full and equal enjoyment of all rights and freedoms', the Constitution creates an unambiguous link between an interpretation of the content of equality and all other rights and freedoms prescribed in the Bill of Rights. The right to equality defines the relationship that CWD will have to almost every other provision in the Bill of Rights; where CWD face barriers to the full enjoyment of the rights enshrined in the Bill of Rights as a result of their disability, the issue is one of equality. In other words, the right to equality cannot be viewed in a vacuum - its enjoyment has a direct bearing on and is discerned out of the manner in which other human rights are implemented.

This idea has been confirmed by our former Chief Justice himself. Langa recently described the achievement of equality as 'requiring a social and economic revolution in which all enjoy equal access to the resources and amenities of life, and are able to develop to their full human potential' (Langa, 2006: 252-253). This confirms a strong relationship between equality and the achievement of socio-economic rights (Albertyn, 2007).

The interconnectedness and interdependence of rights is an idea further developed by the incorporation of the standard of 'fair' versus 'unfair' discrimination in the equality clause. Throughout Section 9, references are made to discrimination as being either fair or unfair, the latter being the only form that is outlawed. Through use of this terminology, the Bill of Rights provides a framework for substantive equality (Government of South Africa, 1996; Bhabha, 2009). The Constitutional Court has expressly adopted the term 'substantive equality' in *National Coalition for Gay and Lesbian Equality v Minister of Justice* and has given it this meaning in *President of the RSA v Hugo* 1997 (4) SA 1 (CC), at paragraph 41. This is a conception of equality that aims to achieve equality of outcome. Substantive equality thus concerns itself with the 'real world'; it requires an awareness of the context within which the law operates, existing differences between people and an assessment of the impact of legislation and state policies. As per Albertyn, substantive equality requires the law to 'closely attune itself to historical, social, economic and political sources of inequality' within our society (Albertyn, 2003: 257).

The realisation of substantive equality may require the law to address these by 'leveling the playing fields' and the adoption of redistributive measures designed to enable historically disadvantaged groups to achieve equality of outcome (Liebenberg, 2012: 25). Policies of affirmative action are typical examples of efforts designed to achieve substantive equality through discrimination between groups on the basis of historical differences. As much is acknowledged section 9(2), which allows that 'legislative and other measures designed to protect or advance persons, or categories

of persons, disadvantaged by unfair discrimination may be taken' in order to promote equality.

The adoption of this approach is a deliberate rejection of a conception of equality that focuses on treating everyone in exactly the same way regardless of their actual situation or circumstances; formal equality or 'equality of opportunity' (Liebenberg, 2012: 25). Though formal equality certainly has its place in relation to some rights - for example, the right to vote will mean one person, one vote - in most cases equal treatment overlooks the very real differences between groups and socially constructed barriers to equal participation (Liebenberg, 2012). For example, treating a child with intellectual disabilities in the same way as any other learner does not take into account the differences between these children (Liebenberg, 2012). In such circumstances, a formal approach to equality would simply entrench existing inequalities.

On this score, the United Nations Committee on Economic, Social and Cultural Rights has noted that '[e]liminating discrimination in practice requires paying sufficient attention to groups of individuals which suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations. State parties must therefore immediately adopt the necessary measures to prevent, diminish or eliminate the conditions and attitudes which cause or perpetuate substantive or *de facto* discrimination' (UN Committee on Economic, Social and Cultural Rights, 2009: para 8).

Substantive equality is highlighted herein to give background to the finding that equality, as it is understood in the South African context, essentially requires the state to take positive steps to ensure that CWD are able to enjoy their human rights on an equal footing with other children. CWD cannot be treated in exactly the same way as other children. Rather, they must be the subject of positive discriminatory policies aimed at removing the barriers, inherent in their disability, to their equal enjoyment of almost all other human rights. For if we accept the uncontroversial premise that CWD face a combination of social, cultural, attitudinal and physical barriers to the full enjoyment of their rights at present, we are forced to also accept that the strategy for promoting their right to equality must be to *action* to remove those barriers. In the case of CWD, this necessarily entails positive measures. As per Bhabha, 'as one of society's most disadvantaged groups, often living precariously near or in poverty, protection of the interests of [people with disabilities] almost always requires positive measures' (Bhabha, 2009: 219).

As substantive equality applies to children in early childhood, the Committee on the Rights of the Child General Comment No. 7 on *Implementing Child Rights in Early Childhood*:

'Discrimination against children with disabilities

reduces survival prospects and quality of life. These children are entitled to the care, nutrition, nurturance and encouragement offered other children. They may also require *additional, special assistance* in order to ensure their integration and the realization of their rights'. (Emphasis added)(2006: Paragraph 11(b)(ii))

4.3 Screening and Early Identification of Disability

In terms of the CPRD, States Parties are enjoined to recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability (Article 25). In particular, States Parties are required to:

'Provide those health services needed by persons with disabilities specifically because of their disabilities, *including early identification and intervention as appropriate*, and services designed to minimize and prevent further disabilities, including among children'. (Emphasis added)(Article 25(b)).

No other convention makes explicit mention of screening or early identification of disability. They do, however, provide for the right to adequate health care (Article 24 of the CRC; Article 14 of the ACRWC) - with emphasis on the development of primary health care and pre- and post-natal health care for mothers -which should be read to extend the necessary health services for the identification of disability in infancy. Further to this, early intervention services clearly meet the definition of activities that would help CWD achieve their full potential, in line with the best interests standard (Article 3 of the CRC; Article 4 of the ACRWC) and the right to survival and development (Article 6(1) of the CRC; Article 5 of the ACRWC) contained in the ACRWC and the CRC. Specific to CWD is article 23 of the CRC, which determines that CWD have the right to special care (Subsection 2) and, in recognition thereof, State Parties are enjoined to extend assistance to CWD to ensure their 'effective access to and receives' health care and rehabilitation services 'in a manner conducive to the child's achieving the fullest possible . . . individual development' (Subsection 3).

Screening and early intervention is not mentioned directly in any local legislative provision. The right to basic health care, as provided for in the Constitution and the best interests of the child standard may however be interpreted – particularly in their combined force - to extend the right to early screening and identification services for CWD.

The government recognises the importance of early intervention for children in the preventative approach proposed in the *White Paper for the Transformation of the Health System in South Africa* (Department of Health, 1997). The *White Paper* highlights maternal and child health services as being lacking in so far as they

are 'fragmented and poorly coordinated, with inadequate resources being provided' (Paragraph 8(1)). The Department committed to inter-sectoral collaboration for the improvement of services in this area. It also advises that maternal and child health services should be coordinated with disability health services (Paragraph 8(2)(1)(d)). The White Paper places the responsibility for developing national strategies and guidelines for the 'prevention and management of disabilities' with the Chief Directorate of the Department of Health (Paragraph 212(c)(ii)) and calls on the Department to develop clear objectives and targets 'in accordance with the goals of the ... United Nations CRC' (Paragraph 8(3)).

The *White Paper on an Integrated National Disability Strategy (INDS)* (Government of South Africa, 1997) acknowledges that 'there are a number of areas in which policies should exist, but do not' (Government of South Africa, 1997: Chapter 3). Amongst these, policies specifically aimed at the identification of disability are highlighted. Those that have been developed, aimed at prevention of disability, are criticised for being 'not effectively linked to identification and early intervention policies' (Government of South Africa, 1997: Chapter 3). The *INDS* calls for 'early identification of impairments and appropriate interventions' within the primary health care system, while it also announces comprehensive free health care for all CWD under six. The *INDS* highlights that 'improved health services should include 'early identification of impairments and appropriate interventions' as a key strategy. It makes the further bold assertion that:

'All health workers, sports administrators, audiologists, speech therapists, shop stewards, teachers and other local role players should receive orientation courses in *prevention* [which term is explained as including 'early identification of impairments and disabilities followed by prompt treatment' in the context of this White Paper] and intervention.' (Emphasis added)

The *National Strategy on Screening, Identification, Assessment and Support (SIAS)* (Department of Education, 2008), forms part of the implementation of *Education White Paper 6*, aimed at 'special needs' education. It operationalises strategies for screening, identifying and assessing learners who experience barriers to learning, but applies only to children who are already school-going. These strategies do not extend to the screening of children with barriers to learning prior to school-going age.

Similarly, the *Primary Health Care Package for South Africa* (Department of Health, 2008) creates a set of norms and standards applicable to service provision in the Department of Health. These include a 'school health service', which provides that Screening Programmes are to be provided 'to give adequate coverage to identify all children at risk of barriers to learning' and, ostensibly, 'are not limited to certain age groups' (Department of Health, 2000: 88). A

standardised questionnaire for use by teachers to screen for the presence of factors causing barriers to learning in the individual is to be provided (Department of Health, 2000: 88). The service is, however, to be rolled out to schools only, and is not designed to target partial care facilities, day care centres, children's homes, children who attend the hospital or ECD services. In reality, thus, the policy targets only children of school-going age and above.

In the *Strategic Plan for Maternal, Newborn, Child and Women's Health and Nutrition in South Africa 2012-2016* (Department of Health, 2012), the guiding document for the prenatal, post-natal and neonatal healthcare, the only mention which is made of screening for disabilities is as follows:

'Provision of preventive services is key to improving the health of children. These services include: Immunisation, growth monitoring and promotion with early identification and management of growth failure, vitamin A supplementation, regular deworming. Well child visits also provide an opportunity for assessment of the child's development. Children with poor eyesight, hearing loss, and other developmental and behavioural problems can be identified, and referred for the appropriate remedial support.' (Section 2)

Early identification services are, however, offered by the Department of Health as part of the standard rehabilitation services package that is provided at the local clinic level. The purpose of rehabilitation at clinic level is stated as being to 'provide a service to prevent disabling conditions, to *detect disabilities early so to prevent complications and the worsening of the effects of a disability on a person's functional ability*, to treat disabling and potentially disabling conditions and to provide access to rehabilitative services for people with disabilities, making them appropriate and acceptable'. The primary health care doctor that is made available at the clinic must have the capacity to '[d]iagnose disabilities as early as possible, and develop a system of referral' (Paragraph 4.30).

The *Service Delivery Model for Social Services* as developed by the Department of Social Development (2006) advocates approaching provision of services from a social development perspective and recognises the need for prevention of disabilities. However, this document also does not provide a strategy for screening programmes for early identification of disabilities, nor early intervention programmes that could be put in place once a disability is identified in the first four years of life. While there is some reference to 'early identification of and prevention of transmission of genetic disorders', the document does not go further, despite the fact that genetic disorders are only one of many causes of disability.

DSD in its *Guidelines for Early Childhood Development Services* also acknowledges this need for collaboration – more specifically, inter-sectoral collaboration - due to

the lack of facilities for the early detection, management and intervention for CWD (DSD, 2006).

4.4 Early Childhood Development

ECD was first defined by the Department of Education's first effort in its *White Paper on Education and Training* (1995) as 'an umbrella term which applies to the processes by which children from birth to nine years grow and thrive, physically, mentally, emotionally, morally and socially' (Paragraph 73). More recently, under the *Children's Act* 38 of 2005, ECD is recognised and defined as 'the process of emotional, cognitive, sensory, spiritual, moral, physical, social and communication development of children from birth to school-going age' (Section 91(1)).

The CRC defines a child as 'every human being below the age of eighteen years' (Article 1). Consequently, young children below the age of four are holders of all the rights enshrined in the Convention on an equal footing with older children. The same applies for children under the African Convention on the Rights of the Child (Article 2).

The UN's Committee on the Rights of the Child, in its *General Comment No. 7, Implementing Child Rights in Early Childhood* (2006), articulates the idea that the CRC is in itself simply 'a rights-based approach to ECD'. The primary thrust of the Committee's comment is that securing rights articulated in CRC is an effective approach to improving the quality of early experiences. *General Comment 7* provides a 'road map' of how to implement CRC to ECD through the application of the rights contained in the CRC to children in their early years. The rights particularly highlighted in relation to ECD include the rights to: health, adequate nutrition (Articles 12, 24(1)(c), 1(d), 1(e) and 27(3)), social security (Article 24), an adequate standard of living (Article 27), a healthy and safe environment (Article 28), education and play (Articles 29 and 31), as well as through respect for the responsibilities of parents and the provision of assistance and quality services (Articles 5 and 18).

General Comment 7 urges States 'to develop rights-based, coordinated, multi-sectoral strategies in order to ensure that children's best interests are always the starting point for service planning and provision. These should be based around a systematic and integrated approach to law and policy development in relation to all children up to 8 years old. A comprehensive framework for early childhood services, provisions and facilities is required' (Paragraph 22).

These rights exist also in other documents applying to CWD, and the comments of the Committee on the Rights of the Child – although specific to the CRC – apply equally to these documents. The seminal point remains applicable: ECD is achieved through the implementation of the rights of the child as these apply during the child's early years.

Locally, the rights of the child to health, nutrition, shelter, social services, protection from maltreatment, abuse or degradation, family care or parental care, or to appropriate alternate care (Section 28 of the Constitution) and a basic education enjoy an elevated constitutional status (Section 29 of the Constitution). The Constitution provides that the realisation of these rights, as in the case of other socio-economic rights, is not subject to progressive realisation. This is generally understood to mean that they should be immediately available and accessible to all children in South Africa, including CWD. The right to education, an integral element of the ECD package, is dealt with both in this section and the following one.

The *Children's Act* 38 of 2005 has been promulgated with the specific object of, inter alia, giving effect to the Constitution, 'recognising the special needs that CWD may have' (Section 2(h)) and to make provision for structures, services and means for promoting and monitoring the sound physical, psychological, intellectual, emotional and social development of children' (Section 2(d)).

The Act draws a distinction between ECD *services* (Section 91(2)) and an ECD *programme* (Section 91(3)). The former relates to all services intended to promote ECD; and provided by a person, other than a child's parent or caregiver, on a regular basis to children up to school-going age. This would therefore include all health, social and educational services offered by the state to children who are under the age of six years old. An ECD programme, on the other hand, means 'a programme structured within an early childhood development service to provide learning and support appropriate to the child's developmental age and stage'. Its focus is therefore on the content or 'curriculum' of the early stimulation and education the child only.

The *Children's Act* prescribes that the Minister of Social Development must include in the departmental strategy 'a comprehensive national strategy aimed at securing a properly resourced, coordinated and managed early childhood development system, giving due consideration . . . to CWD' (Section 91(1)). The funding for the implementation of this strategy is a matter prescribed for the MECs for social development, who 'may . . . provide and fund ECD programmes for that province' (Section 93(1)).

The three key government departments that play an integral role in ECD are the Departments of Social Development, Health, and Basic Education. Each department acknowledging the ECD sector to various degrees in the law applicable to them, and in a number of their policies and position statements.

Health

Under the *Children's Act*, The Department of Health provides for children in the ECD age cohort through various policies and programmes. None of these are ECD-specific; they address general children's health

needs. The *White Paper for the Transformation of the Health System in South Africa* (1997) includes chapters on nutrition, maternal, child and women's health and environmental health. The priority given to persons with disabilities is reflected in one of the goals contained in the *White Paper*, which is: 'to enable people with disabilities to become less dependent and reach their potential for achieving a socially and economically productive life'.

Further to this goal, various policy initiatives have been undertaken. These demonstrate a commitment to improving access to services for CWD. The *Health Sector Strategic Framework 1999-2004* was implemented to improve access to health care for all, reduce inequities in health care and improve the quality of care at all levels of the health care system. The *Comprehensive Primary Health Care Package*, together with its accompanying Norms and Standards (Department of Health, 2000), indicates the range of services that should be delivered at primary health care level for pregnant women, persons with disabilities and children under age five. The *Free Health Care Policy* was developed to ensure access to public health services for children less than six years of age, all CWD as well as pregnant and lactating mothers (DoH, 1994; DoH, 2003).

Of particular significance is the *Rehabilitation Policy* (DoH, 2000), entitled 'Rehabilitation for All', which adopts CBR

as one of the strategies for improved service delivery to CWD. The policy defines CBR as follows:

'CBR is strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services.' (WHO, 2010)

This definition indicates that CBR is not just about providing community rehabilitation services, it is also about the continual improvement in the quality of life and social integration of all people with disabilities. As a continuation hereof, the *Standardisation of Provision of Assistive Devices in South Africa* was introduced to provide the policy framework for equitable and appropriate provision of assistive devices with a view to opening 'doors to learning . . . and social participation' (DoH, 2003: 3).

Proper nutrition has a major impact on the healthy development of children, including of course CWD, in their early years. Promoting healthy nutrition, and identifying malnutrition, is a major concern of the Department of Health. In August 1994, the new Minister of Health appointed a committee to develop a more comprehensive nutrition strategy for South Africa. The outcome was the production of the *Integrated Nutrition Programme for South Africa*, with implementation

guidelines for the Department of Health (DoH, 1997). The *Integrated Nutrition Programme* aims to, inter alia, reduce the prevalence of malnutrition amongst South Africans; improve inter-sectoral collaboration and community ownership of nutrition programmes; enable all women to breastfeed their children exclusively until six months of age and thereafter to continue breastfeeding in addition to the introduction of appropriate complementary foods, until twenty-four months of age and beyond; and ensure optimal growth of infants and young children.

In its most recent initiative, the *Strategic Plan for Maternal, Newborn, Child and Women's Health and Nutrition in South Africa 2012-2016* (DoH, 2012), the Department has developed a guiding document for the nutritional and health aspects for prenatal, post-natal and neonatal healthcare. While this document makes scant reference to disability, it is notable in its detailed strategising for the identification of and intervention in the malnutrition of children in the early years. It states that 'early identification and appropriate classification of malnutrition is pivotal to appropriate and timely intervention, especially in children below five years of age' (Emphasis added)(Section 2.2.). The Plan aims to address the need for early identification of malnutrition through regular weighing, with correct plotting of the weight and interpretation of the growth curve on the *Road to Health Chart* (Section 2.2.), recently replaced by the RtHB.

However, although these policies guide service planning and implementation, they do not place any budgetary obligations on the State to ensure provision of services to CWD. As a result, 'services are discretionary and subject to competing priorities' (Philpott, 2006: 275)

Social Services

The Department of Social Development prioritises the provision of social development services to children under five years (Department of Education, 2001). The family unit is identified as bearing the primary responsibility towards CWD, with the support of the State. In order to facilitate their role, the *Children's Act* provides for support to the primary caregiver. It ensures that, in any matter concerning a CWD, due consideration must be given to 'providing the child and the child's care-giver with the necessary support services' (section 11(1)(d)).

Further, the Regulations to the *Children's Act* (DSD, 2010) provide for the State's responsibility to inform children and families on how to access the services that they have a right to. The Regulations create *National Norms and Standards for Prevention and Early Intervention Programmes*, which provide for education, information and promotion programmes (Regulation 2). These must 'provide children and families with information and assistance on how to access the full range of government and civil society services available to vulnerable families and children; including health,

social services, education, housing, water, electricity, food parcels, disaster relief and social assistance' (Regulation 2(d)). Similarly, the State is obliged to create information and education programmes to 'provide information and support to families of children with disabilities' (Regulation 2(g)). The Regulations provide further that outreach services must be designed to 'include home-based care, community-based care, home visitation and community outreach support to . . . children with disabilities' (Regulations to the Children's Act, Annexure B, Part IV, Subsection 1(j)).

For parents who have the capacity and are willing to care for their CWD, the *Social Assistance Act* 13 of 2004 provides for a Care Dependency Grant; a monetary amount that is to be paid monthly up until the CWD turns 18. Persons eligible for the grant are a 'parent, foster parent or caregiver of a child who requires and receives permanent care or support services due to his or her physical or mental disability' (Section 7). The grant is payable to both South African citizens or permanent residents, as established in the case of *Khosa v Minister of Social Development; Mahale v Minister of Social Development* 2004 6 SA 505 (CC). Children of non-citizens who may be based within the territory for a considerable period of time (such as the children of stateless persons or asylum-seekers) are ominously ineligible, as are undocumented foreign children. The grant is means-tested, and a state medical officer must assess the child before the grant have been approved.

The Department of Social Development has also been extremely active in developing policies aimed at CWD and ECD. Their initiatives began with the then Department of Welfare's *White Paper on Social Welfare* (1997). This document was developed to guide the Ministry's strategy in service provision. It highlights that:

'Disadvantaged children under five years of age will be the primary target for early childhood development services as they are the least serviced at present and the most vulnerable group. The needs of children in the age group birth to three years old and of disabled children will also be addressed urgently.' (Paragraph 46(d))

Key points of the paper include: It promises that a range of ECD programmes will be made available: such as home and centre-based services; stimulation programmes including part-day programmes; and family, education, health and nutrition programmes; it calls for an inter-sectoral national ECD Strategy bringing together other government departments, civil society and the private sector; it emphasises service delivery in ECD targeting all care givers, parents and social service professionals; it promises training for all those engaged in ECD service delivery and all care-givers, parents and social service professionals; it provides for the registration of ECD programmes and promises that appropriate national standards for these centres will be developed (Paragraph 46). Further, the

White Paper on Social Welfare recognises the importance of the family as “the basic unit of society” and indicates the importance of family-oriented policies and programmes to strengthen family life. The main focus of intervention is placed on the household and community, with minimal emphasis on formal service provision. Specific to CWD, the *Social Welfare Paper* suggests that children with ‘special needs’ should be included in the mainstream.

Subsequently, the Department of Social Development has developed a document called *Guidelines for Early Childhood Development Services* (National Department of Social Development, 2006). This document sets out the importance of ECD services, the roles and responsibilities of provincial departments of social development as well as minimum standards for the provision of ECD services in South Africa.

In its most recent initiative, the Department of Social Development launched its Policy on Disability, with the stated aim of guiding the department in the ‘mainstreaming and integration of disability within social development practices’ and facilitating the ‘transformation shifts in line with the current policy framework to promote inclusion for People with Disabilities’ (2009). Amongst the services aimed at CWD, the Department of Social Development lists: support for the provision of ECD programmes; the provision of parenting skills for parents of CWD; the development and strengthening of support groups for caregivers and parents of CWD; and facilitating alternative care placements for CWD in need of care and protection such as places of safety, foster care, children’s homes (DSD, 2009: 34 – 35).

Education

At the international level, the right to education is most clearly enunciated for CWD in Article 24 of the CRPD (2008). This provision enjoins States Parties to recognise, without discrimination, the rights of disabled people to education; to ensure the provision of an ‘inclusive education system at all levels’ (emphasis added).

The importance of this provision is twofold. To begin with, inclusive education is explicitly endorsed as a fundamental right. Inclusive education is aimed at ‘all levels’ would indicate that, although not themselves explicitly mentioned in the provision, pre-school and ECD programmes be read into the right to education. Such a reading is supported by the provision itself, which continues to say that the education system must be directed to ‘[t]he development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential’.

Importantly, the CPRD focuses on ‘full inclusion’ as a goal in the education of disabled children; children with disabilities are not to be excluded from the general education system on the basis of disability. In addition,

the CRC recognises the right to education ‘on the basis of equal opportunity’ (Article 28(1)). The ACRWC provides that ‘[e]very child shall have the right to an education’ and ‘[t]he education of the child shall be directed to... the promotion and development of the child’s personality, talents and mental and physical abilities to their fullest potential...’ (Article 11(1) and (2)(a)). Linking education to development is elaborated in article 29(1): ‘States parties agree that the education of the child shall be directed to . . . the development of the child’s personality, talents and mental and physical abilities to their fullest potential’.

Although Article 28 of CRC (right of the child to education), does not list pre-school education or ECD programmes explicitly as the obligation of the State, *General Comment No. 7* clarifies as follows:

‘The Committee interprets the right to education during early childhood as beginning at birth and closely linked to young children’s right to maximum development (art. 6.2). Linking education to development is elaborated in article 29.1: “States parties agree that the education of the child shall be directed to: (a) the development of the child’s personality, talents and mental and physical abilities to their fullest potential”’.

General comment No. 1 on the aims of education explains that the goal is to ‘empower the child by developing his or her skills, learning and other capacities, human dignity, self-esteem and self-confidence’ and that this must be achieved in ways that are ‘child-centred, child-friendly and reflect the rights and inherent dignity of the child’ (para. 2). States Parties are reminded that children’s right to education include ‘all children . . . without discrimination of any kind’ (art. 2).

At the local level, the right to education is enshrined in the Constitution of the Republic of South Africa (1996). The right to a ‘basic’ education was specifically extended to ‘everyone’ (Section 29(1)), and the State is specifically tasked with the duty to take ‘equity’ into consideration in ensuring ‘effective access to, and implementation of, this right’ (Section 29(2)(a)). Unlike several other socioeconomic rights, such as the right of access to housing, the right to a basic education is not made contingent upon the resources of the state. In *Governing Body of the Juma Masjid Primary School v Essay NO (Centre for Child Law as amici curiae)* 2011 (8) BCLR 761 (CC), the Court categorically stated that ‘[u]nlike some of the other socio-economic rights, this right is immediately realisable. There is no internal limitation requiring that the right be “progressively realised” within “available resources” subject to “reasonable legislative measures” (Paragraph 37).

The right to a basic education has both a positive and negative dimension, as was recognised by the Constitutional Court in *Gauteng Provincial Legislature In re: Gauteng School Education Bill of 1995* 1996 (3)

SA 165 (CC), in which case the court stated that the provision on education ‘...creates a positive right that basic education be provided for every person and not merely a negative right that such a person should not be obstructed in pursuing his or her basic education’. A recent High Court case again presented the judiciary to interpret the right to a basic education, this time in direct reference to CWD, in the case of *Western Cape Forum for Intellectual Disabilities v The Government of the Western Cape and the government of South Africa* 2011 (5) SA 87 (WCC). The Court found it unconstitutional to exclude children with severe and profound intellectual disabilities from education, ordering the government to take reasonable measures to ensure right of access to basic education for *all*.

The *Children’s Act* 38 of 2005 provides for basic education as it relates to CWD. It ensures that, in any matter concerning a CWD, due consideration must be given to making it possible for the child to participate in educational activities, recognising the special needs that the child may have; and providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community (Sections 11(1)(b)-(c)). The *Children’s Act*, as amended in 2007, now also addresses the issue of ECD programmes in partial care centres. The implementation plan on this section must also address how the Departments of Basic Education, Health and Social Development will collaborate to ensure that children with severe and profound disability will have access to education programmes in partial care centres funded by Health or Social Development (Section 76).

The provisions of the *Children’s Act* as they relate to ECD programmes acknowledge the right to education as it is understood under international law to apply also to children in their early years. The *Children’s Act* provides for the early stimulation of the child through its recognition of the need for ‘the child to participate in social, cultural, religious and educational activities, recognizing the special needs that the child may have’ (Section 11(1)(b)). ECD programmes form a major component of the State’s commitment to the child’s stimulation for early learning. The *Children’s Act* prescribes that any partial care facility or child and youth care centre that services children below school-going age, such as day-care services, must provide an ECD programme (Section 93(5)).

The *Children’s Act* outlines that a set of national norms and standards for early childhood development programmes must be developed by the Minister for Social Development, the terms of which must be appropriate to the needs of CWD (Section 94(3)). These have subsequently been so developed - after consultation with the Ministers for Justice and Constitutional Development, Safety and Security Health, Education, Finance, Transport - under the Regulations to the *Children’s Act* (DSD, 2010). These do not provide directly for CWD, though they do determine that ECD programmes must be ‘be appropriate to the

developmental stages of children’ (Part II of Annexure B). Further, programmes must be aimed at helping children to realise their full potential by, inter alia, promoting and supporting the ‘development of motor, communication and sensory abilities in children’.

The *Children’s Act* sets out the procedures for the registration of ECD centres (Sections 95-96) and lays out the process for the Department of Social Development’s response to applications for ECD centres (Sections 97), which allows the state to monitor the standard these centres and to ensure that they comply with national norms and standards. If the centre is not managed in accordance with national norms and standards, the DSD is also empowered to deregister the centre (Sections 99 and 84).

The Regulations to the *Children’s Act* also creates requirements for the staff working in ECD programmes. Specific to CWD, Regulation 27(g) provides that an applicant for registration of an early childhood development programme must possess the ability to provide ECD programmes that are appropriate to the needs of the children to whom the services are provided, including CWD. This requirement is reiterated by Annexure B (part II), which requires that require that the person who is making application for registration of an ECD program must have the skills to provide ECD programmes appropriate to CWD.

However, the *Children’s Act* places no obligation on the government to fund ECD programmes that meet the prescribed requirements of the norms and standards. Section 4(2) provides that government must, in the implementation of the *Children’s Act*, take reasonable measures to the maximum extent of their available resources to achieve the realisation of the Act. Furthermore, provincial MECs for Social Development are not obliged, but ‘may’ provide and fund ECD programmes (Section 93(1)).

The National Department of Basic Education is seen as the ‘key role-player in driving ECD policy’, though ECD services are acknowledged as a provincial responsibility shared between Education, Health and Social Development (HSRC, 2004: 4).

As its first initiative in the area of ECD, the Department of Education developed the *White Paper on Education and Training* (1995), which focused on the birth to nine years cohort (Paragraph 73). It highlighted the crucial role that ECD can plays in community development and education in South Africa (Paragraph 74). The policy determined that ECD programmes should help to empower parents with the knowledge and skills of effective parenting. Need to establish inter-departmental ECD committees to develop and promote a comprehensive and multi-disciplinary approach to the welfare and development of young children from birth to nine years of age, and effective integration and promotion of ECD services for young children and their families (Paragraph 75). Crucially, the document

acknowledges that the scope of ECD policy, and appropriate educational guidance and support for families and communities in need, should in principle cover the full early childhood phase from birth onwards, in collaboration with the other state departments with direct responsibility in this area (Paragraph 80).

The document established the 'Directorate of Early Childhood Development and Lower Primary Education', which was given the responsibility of coordinating the reshaping of curriculum frameworks and related advice on teaching methodology for early childhood for the purpose of setting national norms and standards. Relating specifically to CWD, recognising that the rights of access and protection from unfair discrimination have profound implications for the education system, and these merit urgent investigation, the Ministry of Education established a 'National Commission on Special Needs in Education and Training' (NESNET) to address these and other important issues of policy in this field (Paragraph 22).

Thereafter, the Department of Education adopted the *Interim Policy on Early Childhood Development* (1996). This document focuses on the provision of services for children from birth to nine years, with an acknowledgment of the importance of the collaboration of different government departments as well as the importance of linking with community based ECD programmes and non-governmental organisations. Significantly, however, the policy makes no reference to CWD.

The *White Paper on an Integrated National Disability Strategy* (Office of the Deputy President, 1997), which highlights 'very young CWD (pre-school)' as in need of 'urgent attention' in order to increase their access to education. The paper specifically acknowledges the role that ECD programmes can play: stating that these should be 'integrated to enable all young children to benefit'. Curriculum development and teacher training are highlighted, inter alia, as key areas for action.

Building hereupon, the *White Paper 5 on Early Childhood Development* was introduced (Department of Education, 2001). It identifies a number of critical areas to be addressed in an integrated ECD strategy. The *White paper 5* called for: an inter - sectoral strategic plan that would target appropriate and integrated ECD programmes for children younger than five years; an improvement in the quality of pre - Grade R programmes, inclusion of health and nutrition, appropriate curricula and practitioner development and career-pathing. It identifies a need to develop services and programs for children under the age of four with special education needs, among other 'special populations' in need of more focused attention and service provision.

In 2001, the Department of Education adopted *White Paper 6: Special needs education, building and inclusive education and training system*. The *White*

Paper 6 outlines the Department's commitment to promoting 'inclusive education and training', defined as '[e]nabling education structures, systems and learning methodologies to meet the needs of all learners'; '[b]roader than formal schooling and acknowledging that learning also occurs in the home and community, and within formal and informal settings and structures; and '[c]hanging attitudes, behaviour, teaching methods, curricula and environment to meet the needs of all learners' (Section 1.4.1.)

The *White Paper 6* provides a blue-print for the Department's transformation of its education and training institutions. Amongst other things, it outlines strategies for the human resources development for classroom educators (Section 1.5.2.), the creation full-service schools with a bias towards particular disabilities (Section 1.5.6.3.), the removal of curriculum and institutional barriers to learning (Section 1.5.3.), the qualitative improvement of 'special schools' (Section 1.5.6.1.), the mobilisation of CWD outside of the education system, (Section 1.5.6.2.) and budgeting for additional resources for the education-system overhaul (Chapter 3). It is also clear, however, that the transformation envisioned will not be achieved overnight and that an incremental approach will be followed (Section 1.5.4). The *White Paper 6* also indicates how learners with disabilities will be identified, assessed and incorporated into training centres, full-service and ordinary schools in an incremental manner, and introduces strategies and interventions that will assist educators to cope with a diversity of learning and teaching needs to ensure transitory learning difficulties are ameliorated.

Very little of *White Paper 6* is directed toward children in their early (pre-school) years. As above, the Ministry of Education does indicate its intention to design and implement 'early identification, assessment and education programmes for learners with disabilities in the age group 0-9 years' (Section 2.2.1.2.). The *White Paper 6* also draws the important link between access to the right to education for CWD and early identification. In this, the *White Paper 6* envisages the establishing of mechanisms at the community level for the early identification of severe learning difficulties, in collaboration with the provincial departments of education and the Ministries of Health and the Department of Social Development. The Department of Education committed to investigating 'how learners that experience severe barriers to learning during the pre-school years can be identified and supported' (Section 4.3.7.1.).

In implementation of the *White Paper 6*, the *Guidelines to Ensure Quality Education and Support in Special Schools and Special School Resource Centres* (Department of Education, 2007) were adopted to provide guidelines for 'special schools', which will ensure that they function well and offer appropriate, quality education to learners and to provide guidelines on the requirements for 'special school' resource

training centres. The Department also adopted SIAS (Department of Education, 2007), which strategy outlines a process of identifying individual learner needs in relation to the home and school context, to establish the level and extent of additional support that is needed. Further, it outlines a process for enabling the accessing and provisioning of such support at different levels. Supporting this strategy is the *Operational Manual to the National SIAS* (Department of Education, 2008). These policy changes highlight the model of full inclusion that has been adopted in the State education sector. They do not, however, focus on the birth to four years cohort.

In order to ensure barriers to learning are identified with the necessary action plans in place with the move toward inclusion, the Department of Education developed the *National Strategy on Screening, Identification, Assessment and Support* (Department of Education, 2008). The key focus on early identification of barriers to learning is to ensure typical early childhood development and effective inclusion into society, and the document therefore recognises the importance of public centre, community centre and home-based ECD service providers in the provision of information and recording of factors that may impact on a child's education (Department of Education, 2008: 21). There is an awareness of the importance of training parents and caregivers to be more knowledgeable in the early identification of problems that may lead to barriers to learning and an acknowledgment of the role of ECD service providers in informing and equipping schools with the information and necessary strategies on how to deal with these learners with special educational needs (Department of Education, 2008: 22).

The *National Early Learning and Development Standards* have been developed by the DBE (2009). They set out the kinds of stimulation that infants and young children should receive, and what ECD programmes are expected to offer to children in the birth to four years age group. The *National Early Learning and Development Standards* also provides early learning standards expressed as desired results, indicators and competencies of expected learning achievements for young children in a designated age range. The document makes no specific mention of CWD, however.

Cross-sectoral Initiatives

Aside from these fairly specific developments in the area of health, social services and education, there have also been a number of crucial inter-sectoral initiatives. These began with the Cabinet-appointed Inter-Ministerial Steering Committee's *National Programme of Action for Children in South Africa* (1996). This document highlighted seven policy areas for special attention, amongst which ECD features. The document outlines strategies and targets for each 'priority area'. Under ECD, the document commits to developing minimum standards for services to pre-school children; to expand subsidies to ECD

programmes especially in disadvantaged communities; to provide training to care-givers and other professionals involved with pre-school children; and to provide access to ECD programmes for all, including CWD in particular. The other priority areas include water sanitation, child and maternal health, nutrition and child protection measures – all of which have a bearing on ECD.

The realisation of the need for an integrated plan for ECD and the importance of the inter-sectoral collaboration led to the National Interdepartmental Committee for ECD's development of the *National Integrated Plan for Early Childhood Development in South Africa South Africa 2005 – 2010* (Government of South Africa, 2005). This plan places specific emphasis on the birth to four years cohort (UNICEF, 2005: 6). The main aims of the *National Integrated Plan for Early Childhood Development* are to provide access for all young children to a range of services and programmes to support their development; and to provide extra support to especially vulnerable children such as CWD and children from poor households and communities. The *National Integrated Plan for Early Childhood Development* recognises a variety of sites of care - at the home level, at community level and in formal settings.

The document aims to provide access for all young children to a range of services and programmes to support their development; and to provide extra support to especially vulnerable children such as orphans, CWD, children in child-headed households, children affected by HIV and AIDS, and children from poor households and communities. The national plan recognises the importance of collaboration between different departments, the necessity of partnerships between government, NGOs and private enterprises, and the importance of the involvement of families and communities.

4.5 A Rights-Based Approach to ECD

Despite the proliferation of policies, there is still a lack of a focus on dealing with CWD. Further, as with most of the policy documents in South Africa there is a need for an indication of how this will be implemented and where the funds will come from.

As the above-outlined provisions demonstrate, the current approach to the provision of ECD is premised on the philosophy of progressive realisation. However, ECD services should be constitutionally compliant and not subject to progressive realisation. Even if they are made subject to progressive realisation, there are clear obligations on the state to take legislative and other supporting steps to ultimately ensure realisation of the right. Such steps must be reasonable. This means it is not enough to enact a law recognising the right(s) in question. The state must have a plan that is capable of realising the rights, and it must implement that plan.

Most critically, the right to equality ensures, as we have seen above, ensures that special and additional measures by the state are necessary to secure the rights of CWD to ECD.

4.6 Conclusion

Over the past two decades, South African legal reform has enacted a framework of enabling legislation, policy, guidelines and national instructions affecting State service provision to young CWD. These canvass, notably, the right to equality. This right has a bearing on the realisation of all other rights for CWD; no child can be discriminated against in accessing his or her human rights on the grounds of disability. The legal framework applies also to services related to the early identification of disability and the extension of inclusive ECD services.

The rights of the child to health, nutrition, shelter, social services, protection from maltreatment, abuse or degradation, family care or parental care, or to appropriate alternate care and a basic education enjoy an elevated constitutional status in terms of the Constitution. The Children's Act 38 of 2005 has been promulgated with the specific object of, inter alia, giving effect to the Constitution, recognising the special needs that CWD may have and to make provision for structures, services and means for promoting and monitoring the sound physical, psychological, intellectual, emotional and social development of children. Despite the proliferation of policies, there is still a lack of a focus on dealing with CWD. Further, as with most of the policy documents in South Africa there is a need for an indication of how this will be implemented and where the funds will come from.

Chapter 5: Barriers to accessing services for young South African Children with Disabilities

5.1 Literature review

'When pupils with disabilities receive education, it is often in segregated classes or schools where valuable physical, medical, behavioural and pedagogical support can be provided. However, underlying notions of 'individual deficit' and persistent discriminatory attitudes often limit their curricular options and perpetuate large-scale institutionalisation, failing to offer equal and meaningful education to CWD and exacerbating their isolation in society' (Betta and Lata, 2009: 2).

Although it is now 20 years since the end of Apartheid, CWD in South Africa still face structural and attitudinal discrimination in the access of basic services (DWCPD, 2013). Unfortunately human rights violations perpetrated against CWD persist. Research indicates that CWD struggle to reliably access the chronic medications, therapy and assistive devices they require. It has also been shown that public health programmes and interventions, such as the national response to the HIV epidemic, have failed to plan for the inclusion of people with disabilities (Hanass-Hancock, 2012). The Care Dependency Grant for CWD is not reaching targeted children effectively despite the fact that they desperately need it to cope with the expensive extra costs of having a child with special needs (Barberton, 2000; Barbosa et al., 2009; Lansdown, 2002; Saloojee et al., 2007). Just a small fraction of CWD ever go to school (Department of Education, 2001; Ford-Shubrook, 2007), and just a handful matriculate and are able to access basic livelihood assets on an equal basis with others their age (Lorenzo, 2012). Finally, CWD have been shown to be at extremely high risk to abuse and sexual harassment (Ellery et al., 2011), yet the justice system remains largely inaccessible to people with disabilities and justice is rarely served (Combrinck, 2012).

In this context, equitable ECD service access has the potential to drastically alter the social landscape for people with disabilities in South Africa. However, while International frameworks are specific about CWD and how they should access equitable, inclusive primary and secondary education, they are less specific about access and rights to ECD (Thornton and Underwood, 2013). Some organisations have identified this disparity and have begun to stress the importance of providing ECD services for CWD. The Department of Social Development and UNICEF South Africa indicated how important the early years are to a child's development and how critical it is for children who are at risk to be identified (2007) so that they have a chance of gaining access to treatment and rehabilitation (DSD et al., 2012).

Children with disabilities should have access to and be included in ECD services and programmes. The Children's Act also recognises the needs of children with disabilities and chronic illnesses. Section 11 says that consideration must be given to:

- providing the child with parental, family or special care (as and when appropriate)
- creating conditions that ensure dignity, promote self-reliance and facilitate the
- child's active participation in the community;
- providing support services to the child and his or her caregiver; and
- creating opportunities for the child to participate in social, cultural, religious and educational activities" (DSD and UNICEF, 2007: 15)

Inclusion of CWD goes beyond the tokenistic acceptance of CWD in a regular classroom. It requires flexible curricula that can accommodate various impairments, suitable teaching methods and learning strategies that are not hindered by disability (Thornton and Underwood 2013: 60). Achievement of inclusion, especially at the early childhood stage, requires a paradigm shift in attitudes about disability (DSD et al., 2012). CWD are particularly prone to discrimination from those who do not understand the nature of disabilities. This is phenomenon is not unique in the South African setting. For example, a survey of Canadian pre-schools in Toronto found that 35 per cent would not accept a child with a disability, and 40 per cent of those who did had practitioners who were unwilling to provide care for children with certain types of disabilities (Thornton and Underwood 2013: 62).

In South Africa, challenges to implementing ECD- like infrastructure, nutrition, ECD practitioners training, institutional capacity and funding- exist even in the absence of efforts to promote inclusive ECD provision. Although progress has been made in the ECD sector, making early childhood education more accessible and more equitable (Atmore, 2013), many of the barriers to access for CWD identified by NCSNET in 1997 persist. In summary they identified the following barriers to learning and development:

- Socioeconomic Barriers
- Lack of access to basic services
- Poverty and underdevelopment
- Factors which place children at risk including physical, emotional and sexual abuse; alcohol abuse; crime and political violence; migration; the HIV/AIDS epidemic; and discrimination on the basis of disabilities
- Attitudinal barriers
- Inflexible curricula
- Language and communication barriers
- Inaccessible and unsafe built environments
- Inappropriate and inadequate provision of support services
- Lack of parental recognition and involvement
- Some types of disability (including severe ASD, intellectual disabilities and multiple disabilities)
- Lack of human resource development strategies

- Lack of capacity and commitment toward breaking down exclusionary barriers (1997: 11-17).

More recently a situational analysis of CWD in South Africa identified the following additional barriers to early identification of disability, and access to the essential package of ECD services:

- Lack of developmental screening and follow-up of at risk babies despite the fact that many health conditions, impairments and secondary complications can be cost-effectively dealt with if caught early
- Persisting ignorance, lack of understanding, stereotyping and prejudicial attitudes of stakeholders and State personnel in all sectors
- Gaps in law and policy
- Poor resource and funding allocation to programmes prioritising CWD
- Shortage of human resources from the health, social development and education sectors with disability-related skills
- Relative absence of disability training for ECD practitioners
- Poor built-environment regulatory framework
- Discrepancies in the way children are assessed and granted the Care Dependency Grant
- Poor synergy, communication and coordination between departments working on issues affecting CWD
- Dearth of reliable, current, and disaggregated descriptive data about CWD in South Africa
- Lack of prioritisation of prevention of impairments
- Poor awareness of disability issues affecting CWD (DSD et al., 2012: 71-86)

In 1997 there was just one study that described less than one per cent of children admitted to the ECD programmes in their sample were CWD. The few CWD that were accessing ECD were predominantly accessing 'pre-school' programmes at schools for CWD (NCSNET, 1997: 20). In 2010, it was calculated by DBE that approximately 32 per cent CWD between birth and the age of four were attending ECD facilities (DBE, 2012: 40). This statistic is questionable since the same report stated that 32 per cent of all children between the ages of zero and four were attending an ECD facility (DBE, 2012: 8). These calculations were quoted by the South African Baseline Country Report on progress towards implementing the UN Convention on the Rights of Persons with Disabilities. The estimated figures indicated that 665 247 CWD out of a total of 1.39 million, between the ages of zero and four years old in South Africa, have access to and attend ECD facilities (DWCPD, 2013: 75).

Empirical evidence and existing research on CWD in South Africa indicate not only that the true incidence of disability in young children is unknown, but also that access to services- not least ECD facilities- is extremely limited. Just 24 per cent of Care Dependency Grant beneficiaries under the age of six years old reported attending any form of crèche or day-care (De Kocker et al., 2006: 561), and although data on the proportion of

CWD receiving the grant is not available (Hall, 2013) research available indicates that uptake is low (Barberton, 2000; Saloojee et al., 2007). Atmore reported that just 1,14 per cent of children attending centre-based ECD programmes had disabilities (2013: 154).

The field of ECD for CWD has been neglected-unjustifiably so. Chataika et al argue that some of the reasons for this neglect could be because:

- The ECD access agenda may be led by interests in disabled adults' issues and not those of early childhood
- ECD services are offered predominantly by private institutions in many African countries and therefore are beyond the public concern
- Late diagnosis of disabilities in children may result in CWD being overlooked (2013: 390)

Whatever the reasons, it is clear that there is much room for improvement, and many barriers to accessing ECD to be tackled for CWD.

5.2 Findings

The social model of disability acknowledges that the barriers facing CWD and their caregivers are not all inherent to the disability itself. These emanate also from disabling environmental and attitudinal barriers. This is reflected clearly in the following section, which aims to highlight the study's findings as to the obstacles that caregivers reported have experienced in seeking appropriate service provision for their CWD.

As such, and in accordance with the social model of disability's analysis of the barriers facing CWD, the data collected for this section of the study has been structured into three areas: (1) Attitudinal barriers such as stigma, prejudice and stereotyping of disability in the community, by ECD service providers and caregivers of CWD; (2) environmental barriers, such as the poor availability, accessibility, quality and coordination of inclusive ECD services, a lack of knowledge and awareness about inclusion and ECD and a lack of funding for inclusive services; and (3) impairment-related barriers which create a hierarchy of exclusion.

5.2.1 Attitudinal Barriers

Stigma, prejudice and stereotyping of disability in the community

Discrimination on the basis of disability remains a leading barrier to inclusion and CWD's enjoyment of ECD services. Children and their caregivers reported facing discrimination at every level of society. Examples of explicit discrimination were made, for instance: 'Strangers - especially in taxis - always treat my child differently from other children' (Caregiver, Eastern Cape). Discrimination was not just fielded from strangers and members of the broader community; examples of discrimination within the family were also detailed. One mother reported that, 'Staying with my in-laws was not nice at all...there was no acceptance from

my in-laws. They were very cruel and made it difficult for me' (Caregiver, Eastern Cape). ECD practitioners shared derogatory names that they had heard used for CWD: 'We call them different names. Like we say "*jump amanzi*" or "*seqhwala*" for those ones that is walking funny. And like "*nozindende*" for those ones that is always drooling' (ECD practitioner, Gauteng). Other examples of derogatory language used included remarks such as 'half normal, half disabled' and 'they are very silly'.

Caregivers described how they feel when their children are called names: 'I don't like the name *disability* at all because in my language they say "*segole*". I cry when they call my son that' (Caregiver, Gauteng). Some caregivers expressed that they wished their children would be referred to by their names, not their disabilities, as the following conversation illustrates:

Researcher: 'She mentioned that she doesn't like the use of the word 'disability'. Do you dislike with the use of that term?'

<General agreement>

Researcher: 'What would you prefer?'

Caregiver 1, Gauteng: 'To treat them like they are normal. They should not be given a name!'

Caregiver 2: 'If his name is S, they must be called S!'

Caregiver 3: 'Even when he came here I told the other parents his name is T, meaning "I must have strength". I would like everyone to call him T. He has a name, like other children.'

It was felt by many that the community's generally poor understanding of disability and its causes perpetuates harmful beliefs. Some of the mothers' responses revealed an interesting theme: the belief that a traumatic experienced during their pregnancy, be it physical or emotional, had precipitated the disability that their child was subsequently born with. For example, caregivers from rural Eastern Cape remarked:

'I worked under extremely dangerous conditions for the child I was carrying. My husband would abuse me physically and ended up leaving me for three months.'

'I received very poor treatment from my in-laws. I was expected to go to the river to fetch water at night although I was heavily pregnant'

'When I was pregnant with the child things were not easy. I lost my father and my siblings and I had to stay with my mother. All of us at home (siblings) could not study beyond Grade Nine. My mother passed away...that made things worse at home since she was the one looking

after us. She was poisoned by someone. That affected my aunt's health negatively and as a result she passed away soon after my mother's death.'

Many other instances of misguided views of disability were shared. Some caregivers reported that the community has scorned their family, saying, for instance, that a CWD is a 'disgrace to the family' and that 'something was done wrong for [the child] to be like that'. This sentiment was reflected also by a Gauteng inclusion educator in the following terms: 'In too many provinces in South Africa it is firmly believed that the mother has done something evil to deserve the birth of a CWD- she is being punished and the child is the victim of her evil act'. Interestingly, participants in the study who had not been exposed to disability-specific training demonstrated a poor understanding of the causes of disability, and themselves perpetuated negative stereotypes about CWD. In the table below the lack of information with regard to the causes of disability, as listed by participants from the Eastern Cape, is linked to the misconception that the mother of a CWD is responsible for the disability in some way. Almost all the causes listed implicate the mother in the cause of disability.

The outcomes of these beliefs and misconceptions were reported to be devastating exclusion. Caregivers from the Eastern Cape described neighbours and people in their village 'having a problem' with their children's drooling, or smelling bad when wearing nappies. They said that people and other children 'teased', 'starred' or 'chased their children away' as described in the following examples:

'The neighbours have a problem with the child, especially when he drinks something. They hate the fact that the child drools a lot and the saliva gets inside the glass.'

'My problem is that other children tease him about his disability and he gets hurt. That hurts me a lot as a mother.'

'I have a four year old boy and he is still using nappies. In the community...some people chase him away from their homes when he smells.'

In some reports, the negative attitudes reported presented a danger to the safety of the CWD, further exacerbating their exclusion from the community. As one ECD practitioner reflected the sentiment: 'The community will feel bad. Why does God not take the child away?' (ECD practitioner, Eastern Cape). These attitudes were said to lead to 'parents [being] afraid of bringing their children out of the house' (Occupational therapist, Western Cape), leaving them 'locked in back rooms' and 'hidden from the public'. On this score, one participant shared a story from the Northern Province, where the mother was tied up and the CWD was buried (Inclusion educator, Gauteng).

However, community members also were said to look on the situation with pity, and to sympathise with the burden of care of a CWD. '[She] can't attend the village meeting because she is always home looking after that child, so the community feels sorry for her' (Home-based carer, Eastern Cape).

Attitudes of ECD service providers

Discrimination against CWD continues to be perpetrated by those delivering services to young children. Deep-rooted prejudice was described as a 'cultural imperative', 'caused by fear'. 'In some cases teachers are repulsed by deformities' (Inclusion educator, Gauteng). Many of the ECD practitioners that participated in the study felt 'pity' or 'pain' when confronted by CWD. 'I feel sorry for the child because she can't walk and is still wearing [nappies] at the age of four' (ECD practitioner, Eastern Cape). One participant alluded to the difficulty in bringing about a shift in the mindsets of ECD service providers, 'I can go

practitioners in Gauteng had the following questions about inclusion:

'How do we engage the CWD with the other children in our classroom?'

'How can we include them in sports and cultural programmes?'

'How do we cope with aggressive children?'

'Will we get more practical skills training?'

'How will we cope with these children when there is a shortage of staff?'

'Is there a budget for special resources?'

'Will we have a nurse to care for them?'

'I'm not sure how we will communicate with them?'

Lists compiled by ECD Practitioners and Nomakhayas, Eastern Cape:

Causes of disability

Epilepsy of the mother (caused by traumatic event i.e. loss of her husband).

Accident during pregnancy.

When you pregnant you hurt yourself.

You drink alcohol during pregnancy.

Medications that are not to be taken by pregnant women.

Attempted abortion.

Contraceptive injections.

Poor diet.

Unknown cause: Sometimes everything is right but you still have a disabled child.

Preventing disability

Avoid stress [during pregnancy].

Go to clinic for check-up.

for 18 months of training people...and they will show good understanding [of inclusion] but their attitudes will reveal that the shift has not been made' (Inclusion educator, Western Cape).

In contrast, some expressed that they felt CWD were treated as equals. However, in qualifying these opinions, it was evident that they did not have enough information about the situation facing CWD. Some expressed that CWD are treated well because 'they go to special schools' and their 'grant is more than a normal child' (Home-based carer, Eastern Cape). Some participants felt that it was the parent's fault if their CWD did not access ECD or education services, saying the parents 'don't take care' of CWD, and that CWD want to go to school but their parents don't take them. It was however acknowledged that poverty might contribute to lack of proactivity on the part of parents of CWD.

Beyond this, some ECD practitioners related their fears associated with including CWD in their classes. ECD

Some ECD practitioners were very adamant in their views, showing an unwillingness to be open to inclusive ECD service provision.

'On a personal level, I would never like to work with people with disabilities...I do not have the tolerance.'

'Ha-ha, there is nothing you can do about the teasing, it is going to be there whether you like it or not.'

'How can I teach someone who is disabled and not able to speak properly presenting skills amongst people who can speak properly?' (ECD practitioners, Gauteng).

Some practitioners were weary that the parents of non-disabled children would not approve of the inclusion of CWD in their ECD. 'Are the other parents aware of the mixing of the children?' (ECD practitioner, Gauteng). This sentiment was echoed by a DBE official: 'I think that centres are scared that if they open up [to including CWD] that other children wouldn't want to go there' (Gauteng).

All this being said, some practitioners did reflect that inclusion inspired them to provide better services. As one ECD practitioner revealed, 'I feel pity, but also a personal challenge to work hard as a practitioner to help the child' (Eastern Cape). The issue of sensitising non-disabled children to the needs of their peers who have impairments was also raised as a means of improving access to ECD services for CWD; it was felt that 'disability sensitisation' was required among young children to 'celebrate diversity' and non-discrimination. Issues of tolerance, and education about diversity were discussed at the Eastern Cape research site. ECD practitioners there had experienced success in engaging children in their classes in conversations about equality, dignity and acceptance. They felt that

raising children for a more tolerant and inclusive society was possible with early intervention.

The attitudes of State personnel with regard to CWD was identified as a problem. An official from the DWCPD described the challenge of working through other departments where people did not 'internalise' inclusion or 'engage' with disability-related issues. It was felt that duty bearers in many government departments fail to plan services that reasonably accommodate people with a wide spectrum of needs, because they have 'no interest' in promoting equality or inclusion.

Attitudes of parents or caregivers of CWD

Some barriers to accessing inclusive services were attributed to the attitudes, perceptions and fears of the caregivers of CWD. As one occupational therapist described, 'Parents are afraid to bring their children out of the house...If there is an ECD facility for CWD, [taking their children there] is a way of admitting they have a problem...and that they have done something wrong to have a CWD' (Western Cape). Indeed, some caregivers did describe that they were weary of enrolling their CWD in a mainstream programme. They explained that their hesitation was rooted in the discrimination and exclusion that they anticipated:

'Mainstream schools.... are not willing to accommodate [CWD], or maybe they do not know how to accommodate them' (Occupational therapist, Western Cape).

'My child wants to go to school but the problem is that the child still uses nappies at six years and there is no school that can accommodate my child' (Caregiver, Eastern Cape).

'I am reluctant to take her to school because I am not sure if the child will be accepted at school because the child still uses nappies' (Caregiver, Gauteng).

Some caregivers indicated that the attitudes of other parents is also a problem. They perceived that the parents of non-disabled children opposed inclusion because they felt their children would not receive enough attention because teachers would focus more on CWD.

Although the presence of stigma and exclusion was widely acknowledged as a problem, some participants felt it was possible to change attitudes. One Gauteng ECD practitioner said, 'I can talk to the parents first and work hand in glove to develop or help the child or to meet the child's needs.'

5.2.2 Environmental Barriers

Availability of inclusive ECD services

Participants in the study were unanimous in agreeing that there are simply not enough services available to

nurture the early development of CWD. The problem was described as being worse in rural areas, although not significantly better in urban areas. 'There was just no option for CWD to obtain any kind of ECD, or Grade R. There are just no facilities...This is a common problem in the rural areas. In more urban areas [in Cape Town] there is still limited access' (Occupational therapist, Western Cape). This was strongly emphasised by a physiotherapist who works in all provinces: 'There are many barriers, but probably the first thing I will say is the lack of service. There are simply *no* such services available, especially in more rural and remote areas...I come across children in areas where there is no such thing as an ECD service' (Physiotherapist, KwaZulu Natal). In areas where ECD services are available, as outlined above, participants reported that they are not always open to including CWD and in many instances 'point blankly refuse to take them' (Occupational therapist, Free State).

Waiting lists emerged as a prominent barrier. All of the inclusive ECD programmes visited during the study had waiting lists of CWD, the majority of whom were staying at home with no other inclusive options in their areas. Many caregivers described that although they had been able to find a centre or school that is suitable for the needs of their children, they had been unable to enroll the child due to high demand and a lack of capacity. This was described as resulting in long, 'never-ending' waiting lists. Where ECD programmes seemed to be making an effort to maintain high standards, this reportedly resulted in long waiting lists that frustrated parents. In the result, it was reported as difficult even for District-based Support Teams to find options for children: 'All our schools have waiting lists, so the children that we see so far this year, none of them have been placed, they are all on waiting lists' (Occupational therapist, Free State). An ECD practitioner from the Free State explained how their waiting list can have up to twenty students, most of whom are never enrolled due the fact that they are funded for a limited number of children. An occupational therapist expanded that even expensive, private centres - costing between R1000-R3000 per month - have waiting lists.

Long distance travel, necessitated by the shortage of specialist services in their area, also emerged as a strong theme in the experiences of caregivers. Caregivers seeking services for their CWD described taking their children from rural Eastern Cape to Umtata; East London to Durban; and Bloemfontein to Cape Town and Johannesburg. A speech therapist from the Free State pointed out that they did not have an occupational therapist in their district team, despite the importance of having one, especially for CWD (Speech therapist, Free State). Another therapist described the strain on her services as she was expected to service all the children with 'educational support needs' in 150 schools in her district. This constraint on resources has a reported effect on the regularity with which CWD are able to access services. The intervals between therapy sessions for CWD were described by some as monthly,

though others reported being able to see a therapist only 'once a term', if ever.

Some respondents described how parents had responded to the lack of services for their children- by coming together and founding inclusive services. 'In those years there were no NGOs...it was not as structured as it is now' (Inclusive ECD manager, Western Cape). Many felt these responses had not been recognised sufficiently, especially in light of the important role NGOs were seen to play in bridging implementation gaps. Some respondents criticised the ECD model as being unviable in the South African context as it relies on 'highly skilled professionals', effectively subjugating the role of parents in the early development of children. They felt that, in order to make basic services available to all children in South Africa, 'more grassroots-type', 'community-based', 'bottom up' approaches would be better suited. Alternative approaches are discussed more fully under the section on strategies to address barriers to services.

Partial explanation for the poor provision of services was attributed the dearth of information regarding the prevalence, distribution and nature of disabilities facing children in South Africa. Without accurate mechanisms to record and report instances of impairment and support needs, it remains unknown where the CWD are situated and what their specific needs are. This has both the effect of creating a marked lack of advocacy for improved services and recognition of CWD in the planning and implementing of the State's strategies to address the ECD needs of children.

Coordination of ECD services

Poor coordination of service delivery was cited as a major cause of persisting barriers to the effective inclusion of CWD in mainstream education and the improvement of the availability of ECD services to CWD. The nature of ECD requires a multi-sectorial approach to the development of young children. However it appeared from the experience of the study's participants that the communication, collaboration and coordination that ECD requires is not taking place between the various role-players. Several respondents - caregivers, ECD practitioners, disability advocates, and State personnel - commented on the poor connection between the DoH, DSD and DBE with respect to ECD. However some participants felt that improving access to ECD extended beyond these three key departments, to include other government departments such the DHA, and the Departments of Labour, Infrastructure Development and Transport. The role of and achievements of the DWCPD was also questioned.

Service providers were described as polarised by their professions and unwilling to provide holistic services or stray too far from their mandated responsibilities: 'community developers or community practitioners, even social workers, go into communities where these children can be identified. But it goes again to the issue

of understanding disability and also relegating responsibilities to some officials, not yourself. You see this child with a disability and you just say, "my job is to do this and not to identify children with disabilities"' (DSD official, Gauteng).

Caregivers voiced their dissatisfaction with being 'sent from pillar to post' and with service providers continuously 'passing the buck' and 'refusing to take responsibility' for including CWD in their services. In places where the appropriate professionals or practitioners are available, caregivers often have to endure endless referrals from one person to the other, without accomplishing anything. One caregiver commented that 'when you want to take your child to another school, you must go for evaluation to this person and when you make the appointment with the person, the person will say no it's not me, you must go there. So you go from pillar to post' (Caregiver, Eastern Cape). An occupational therapist working in the Western Cape described her observations: 'What I have noticed is that these departments don't talk to each other, there is no or very little inter-sectorial collaboration between these departments. This has become a problem, for example, if you have a child with a learning disability and you want to take them to a health-care facility to be assessed, the people at the health-care facility will say this is not the responsibility of health, it is the responsibility of education. In this case, the CWD will often fall through the cracks between departments because they do not communicate with each other'. Transferring from services traditionally within the jurisdiction of DSD and DoH, to those primarily of DBE when children need to enter school, was described as 'impossible' and 'very tricky'.

Although children usually start school at age six or seven, some schools for children that need to learn Braille or sign language for example, begin their intake as young as three or four. Beyond ECD, not only is the process of applying to schools unclear to caregivers, but they felt that their children had limited to no options for starting school. A Free State occupational therapist who's job includes coordinating referrals to schools said: 'every special school has each got their own admission criteria and we have got no control over [that].' The following interviews reveal the frustrations with the application process and the transition from ECD to education:

Auxiliary Social Worker, Free State: 'The challenge is that when the kids reach six, the system they are using now is Department of Education...You want to take the child to school but you must go for an evaluation...and when you make an appointment with that person they say "No, it's not me. You must go there". And so you go from pillar to post.'

Researcher: 'So for getting a child into school, the process is not clear?'

Auxiliary Social Worker: 'Yes, the process is not clear and you are unable to find out. It is challenging.'

As an inclusive ECD manager from the Western Cape described, 'We have a battle when the children have to go to school...because they want to go to school. It's a battle when they have to move to primary school, it's a battle when they move to high school. When parents have to find a place for their children when they are rejected from a mainstream school, it's a battle.'

Correspondingly, study participants currently working within government expressed their challenges in making inclusive ECD services available and frustration was expressed by those wishing to provide child-centered services. For instance, a therapist working at a hospital described that she found it extremely difficult to get the necessary clearance to provide sessions at a school for CWD. Similar feelings were shared by an occupational therapist from the Free State, who spoke of how learners are diagnosed late and do not have access to early intervention because schools and health care services do not have a good 'partnership'. It was felt that nobody from the DoH, DBE or DSD had shown leadership in developing inclusive ECD services. 'I started working here in 2007 and they told me that these three departments are taking the lead in the disability centres, and nothing has happened' (Occupational therapist, Free State). A DSD official summed it up by concluding that 'we do not support each other's initiatives. Our referral systems are not appropriate and have not been appropriately developed. So we do not actually have a way of referring any other child that we actually come across that might not fall under our responsibility' (Gauteng).

Within State departments, it emerged that disability issues were not promoted internally because of a lack of skills and capacity. Within DSD, it was explained, across five children's units there is just one person charged with disability issues. The integration of disability issues in discussions across the other units and consideration of inclusion was described as limited to situations in which these issues were raised by the 'focal disability person'. In addition, segregated service planning and delivery by separate units 'working in silos' for children in different categories - for instance, children with HIV or CWD- was found to hamper inclusive service delivery.

Further, the frustration of staff turnover was raised. The process of training people from local and provincial levels, such that these would be properly trained to spearhead inclusion, was found to be futile when that person gets reallocated or moves and is replaced by somebody new with no disability experience. Although it was described that the only 'direct service' provided by the DWCPD is to 'capacitate' other departments and organisations to provide better services for children and people with disabilities, no mention was made by State

personnel of having access to such training or capacity-building activities offered by the DWCPD.

Bureaucratic processes were also found to be responsible for delays in implementation. The following explanation by an official from DSD sheds light on some reasons for slow changes on the ground in line with policy: 'We've got guidelines in terms of how identification can be done, who should do it and where would it lead to. The challenge that we are having is that the document hasn't been finalized. The second thing is that the document is just a strategy, it doesn't have that oomph to be enforceable. The third issue is that it doesn't even have monitoring systems that we can actually enforce to make sure that issues in the strategy do happen. And the main one is that it hasn't been [budgeted for] as yet' (Gauteng).

Where legislation had been 'costed', such costing did not always include consideration of CWD: it was reported for instance that the Children's Act 'costing' did not make provision for CWD.

The long process required before strategies can be implemented was said to include a review of legislation; a situational analysis; a review of strategies and their alignment with the findings the situational analysis; the creation of implementation guidelines and budgets; the garnering of support from the Director Generals of key government departments and their agreement with the protocol of commitment for implementation; and finally referral to the Cabinet committee was described.

Despite these drawbacks, some understanding of the issues and attempts to address issues with coordination of service delivery were described. Some evidence of interdepartmental cooperation, public-private collaboration and service coordination was also found. One example was shared describing collaborative efforts to improve early identification of CWD: 'Currently we are working with the Department of Basic Education to look at their assessment tool and our assessment tool and try to integrate [them]. So that when we assess the child once, we know that we have assessed the child for a number of issues: education, health and social issues- so that we don't send parents to three different offices for the assessment of one child' (DSD official, Gauteng).

Accessibility of services

Where services were available, significant socio-economic barriers hindered accessibility. Poverty was identified as a prominent barrier. Mothers from the Eastern Cape focus group relayed that during their pregnancy, and before they had even received the diagnosis of their child's disability, they felt very worried about how they would provide for their children:

'The main challenge I faced during pregnancy was figuring out how I would support my child because my husband and I were both unemployed and my parents are not working.'

'I delivered the baby on the same year that the child's father lost his job and that really put me under pressure. I was stressed and worried about how I would raise the child.'

Most of the parents that participated in this research related that the CDG made a remarkable difference in their lives, allowing them to cover some of the extra expenses that their CWD incurred. Expenses that caregivers incurred over and above the costs incurred by their non-disabled children included nappies, high school fees, transport, accommodation, and 'special foods'. Some CWD also require assistive devices and frequent medical attention that adds financial pressure on caregivers.

However, this grant money was said to be misused in some instances where, due to poverty, the money is used to support the whole family. Some participants felt this could lead to neglect of the special needs of the CWD:

'Some of the parents are depending on the grants...they do not want to take the kids to the centres because they are living with the disability grants' (Inclusive ECD manager, Western Cape).

'Many families live off that grant, so they can't usually afford to send the child to school because they use the grant for hospital fees and then the parents don't want to send them to school because they are living from it' (Occupational therapist, Free State).

These assertions, although invariably true in some families, may not show sensitivity towards the secondary costs of children accessing regular ECD services. Access to ECD services and education invariably involves travelling long distances, especially in rural areas. It was felt that, even if services are offered completely free of charge, the cost of getting children to the point of service is prohibitive. 'I think the big problem is actually getting to schools, like the distance a child has to cover. They have to walk or use a wheelchair or if there is no bus service for them- which of course there isn't- taxis are too expensive' (Occupational therapist, Eastern Cape).



A 'bakkie': public transport on bad roads in rural Eastern Cape (Photo credit: Jean Elphick)

Transport money refunded to caregivers attending the focus group discussions

Gauteng	Caregivers walked, or spent an average of R12 on taxis
Eastern Cape	One caregiver walked, the rest spent an average of R 60 on taxis
Free State 1	Caregivers spent an average of R16 on taxis
Free State 2	Most caregivers had their own cars

Table 3: Illustration of the return fare to get to the focus group discussion venue, in most cases ECD centres

The table above illustrates how much more expensive it is for rural caregivers and children to get to points of service. Instead of having services within walking distance or a local taxi distance away, these caregivers must travel up to 70 kilometers to attend. This is both prohibitively expensive and time consuming, even if the service is available. 'Where local transport is available it is exorbitantly expensive, and in some areas there isn't even public transport' (Physiotherapist, KwaZulu Natal). Caregivers in the Eastern Cape described how they had delivered their children at home because the transport they had arranged had not come to fetch them in time. One mother described carrying her child on her back because the rural terrain was impassable by a wheelchair. This prevented her from attending regular follow-ups with a physiotherapist. She described slipping and falling whilst carrying her daughter through the rain to an appointment at the closest clinic, which she described as being on the far side of a river. Another mother in Gauteng described how her daughter was offered a space at a pre-school that had therapists, but that she was unable to afford the cost of getting her there: 'Now I found a school for [my daughter] and it's almost a thousand rand [per month] with transport, but now I am not working. Am I going to sit with her at home? No! I want my daughter to be in a school!'

In addition, accessing public transport with CWD who use assistive devices such as wheelchairs adds additional complexity and cost to travel arrangements: 'The children are facing a lot of barriers especially transport-wise. As you know, the taxis are not very keen to take children with disabilities...not that they wouldn't take them but it is a challenge for mums as they will have to pay extra fees and carry them on their backs' (Occupational therapist, Eastern Cape).

The result of these difficulties is that, when services are not community-based, close to where children live, caregivers of CWD are often forced to forego that service altogether. CWD miss appointments because 'getting the children there and getting them home can be pretty difficult particularly if the services are not available within walking distance of the child's home' (Disability researcher, KwaZulu Natal).

The inaccessibility of ECD classroom curriculums was also highlighted. Participants involved in promoting inclusion described how ECD practitioners lack the skill

to 'differentiate' the curriculum, so as to 'adapt the programme that you are offering to meet the needs of children' in the class (DBE official, Gauteng). More specialised knowledge and skills were highlighted as necessary for the inclusion of children on the Autism Spectrum, those with multiple disabilities, and visual or hearing impairments.

Finally, although assistive devices can make tangible differences to functional childhood development for children with impairments, access to these was widely described as lacking. Applying for devices was described as taking a long time to be processed, and even longer for the devices to be delivered. This problem was not limited to access through public health services: 'I have been applying for more than three years with my medical aid to get the wheelchair, I only found it now, the wheelchairs are so late to be delivered' (Caregiver, Free State). However, the inaccessibility of State-sponsored assistive devices was ubiquitous. The following story was not unique: 'My child is ten and she doesn't have a wheelchair. I am still using the baby stroller, she sits there and I push it' (Caregiver, Free State).

The impact of this lack of access to assistive devices is devastating to CWD. It was described that many children who could be participating in ECD activities 'don't get that opportunity to get the devices they need so they are stuck at home or lying in a corner...They can't get out, they can't play with their friends, they can't go to school' (Occupational therapist, Western Cape). As a disability researcher summarised, 'CWD could be included in a much more meaningful way if they have the [devices] they need. I think our children struggle because they don't have access' (KwaZulu Natal). One caregiver described how something as simple as playing with the children next door was made difficult without a way to get there: 'I need a wheelchair because she wants to go to the neighbours to play and it's difficult. If she had a wheelchair the other kids could take her there' (Caregiver, Eastern Cape).

Quality of available services

Mothers of CWD that participated in the study were asked to reflect on their experience of pregnancy and giving birth. Just one participant on the study related that she was told before her child was born that the child would have a disability, for the rest they either found shortly after birth, or in the years that followed.

Some mothers shared detailed descriptions of their experiences at birth. In the Eastern Cape a number of the mothers reported having delivered at home. Although the correlation between home births without access to health professionals cannot be made by this study, complications during labour and lack of access to emergency medical care can have devastating consequences for the mother and baby.

For those who were able to access health services for the birth, some related having received shockingly poor

treatment, the result of which was the disability of their child in extreme cases. A particularly harrowing story was shared by a mother from Free State. She described being 'shocked and traumatised' after the experience of giving birth to her child at age 16. Being an orphan herself she had no support from the extended family she was living with when she fell pregnant. Disgraced, she was made to walk to the clinic alone when she went into labour prematurely. She described how she had to sit down each time she had a contraction, and it took her a long time to get there. Despite being told during ante-natal check-ups that she would 'definitely need a Caesarean Section because her baby would not fit through her pelvis', she was made to walk up and down at the clinic for hours in extreme pain. After watching another woman giving birth on the floor 'with blood everywhere' while the 'nurses played cards' she was taken to theatre without explanation about what was about to happen to her. She described hearing the sound of her abdomen being 'torn open' during the operation. Her child is now four years old and has severe spastic quadriplegia resulting from birth asphyxia.

Participants described dissatisfaction with the quality of ECD services, describing many as 'overcrowded', 'under-resourced' and 'poorly staffed'. 'We simply don't have enough ECD services of good quality to service all the children who need them' (Disability researcher, KwaZulu Natal). It was felt that centres in these situations were unable to offer meaningful inclusion of CWD. 'A CWD gets lost because there are too many children and there are not enough resources to meet the needs of all the children let alone the CWD' (Physiotherapist, KwaZulu Natal).

With specific reference to health care, in extreme cases of poor service quality, claims were made that the negligence of practitioners had resulted in disability or secondary complications. A caregiver from the Free State shared her feelings: 'If somebody had just seen my child's high blood pressure he would not have had the stroke that caused his hearing loss' (Caregiver, Free State). An occupational therapist echoed this, 'If we can have a system in place to really support these mothers, we can prevent a lot of disability' (Western Cape). In some cases, health practitioners were described as undermining of the agency of the caregiver, which led to poor service provision and health complications. Examples of this included performing medical procedures without consent and being dismissive of symptoms reported by caregivers. Caregivers described being told that they had 'nothing to worry about', only to later be told that their children's problems could have been avoided or better managed, 'had they been caught earlier'. Several caregivers described seeing their babies having seizures only for them to look 'perfectly relaxed' when they had managed to call a nurse. The observations by key informants included the following:

'I then learnt in my research in South Africa, you have a hell of a lot problems with ignorance in the health sector. Lack of compassion, and lack of caring in the health sector' (Inclusion educator, Gauteng).

'Every time the mother went to the hospital they would say "Oh, today is not the day for the bone doctor", until the child was two and a half years old and they had gone to the hospital once every month for two years and nobody had assessed that child' (Academic, Gauteng).

In all the research sites, a common narrative from caregivers of CWD was that they had not had adequate explanations of their children's diagnoses, as the following exchange illustrates:

Researcher: 'Did anyone explain to her what was happening?'

Caregiver, Eastern Cape: 'No one really explained to me. The head was soft but nobody told me what the cause was.'

Researcher: 'And to date has anybody explained?'

Caregiver: 'No.'

In a further example:

Caregiver of CWD, Gauteng: 'You know your child talks, and then the next moment he doesn't talk. It's very difficult. But going to speech therapy has helped my child a lot.'

Researcher: 'Did they explain why he stopped talking?'

Caregiver: 'No. Nothing!'

There were also several examples of clear misunderstandings or miscommunications between service providers and caregivers. For instance, a Gauteng mother explained that doctors at Chis Hani Baragwanath Hospital had given her child some drops when she noticed he was not talking. She said the drops 'had helped and now he sometimes tries to pronounce some words'.

However, not all parents had had negative experiences with the quality of service provision in health facilities. Some reported being well equipped for their child's disability by their doctors. There was also some acknowledgement with regards to the efforts that the DoH is making to reduce child mortality. These were however tempered by suggestions that, although more children survive, efforts to ensure 'not only ensure survival but quality of life as well' were called for (Academic, Gauteng).

With reference to inclusion at ECD centres, various concerns about quality were raised. Some caregivers were fearful of inclusive schools, pointing to how it is difficult for their children to be integrated into mainstream classes. Caregivers were in agreement that most ECD practitioners 'failed to understand' their children and were not well equipped in order to properly take care of their children. A Cape Town academic elaborated: 'Another barrier is the level of ECD provision generally, you know some of the centres are not well equipped and there are concerns about safety, accessibility and some parents especially of children with more severe disabilities they are concerned about the fact that their children will not be looked after properly. Children with [Cerebral Palsy] their feeding...and another thing that happens is, if children are not toilet trained, that's a big problem for caregivers. They don't want to deal with that.'

The following are a sample of issues raised by caregivers in Gauteng:

'She came home hungry, they did not feed her enough.'

'He doesn't eat very well at school because the teachers do not feed him properly.'

Many caregivers were particularly protective of their children, and approached the care they received at centres with mistrust. For instance this Gauteng caregiver: 'You will have to wait for 30 minutes at the gate [of the centre] before you can get in and now I am wondering if my son goes there, what is it that I am not supposed to see? It doesn't sit well with me.'

The quality of care and safety were seen to be of particular importance given the increased vulnerability of CWD to abuse. In some areas infringements of human rights- like sexual abuse, degradation and neglect- were blamed on 'parents who do not really pay attention to the fact that their children have disabilities and do not take special care of their children' (Caregiver, Eastern Cape). However, the complex reasons for their vulnerability was also acknowledged and it was felt that close supervision was needed to make inclusion safe for CWD:

Caregiver 1, Gauteng: 'The name of the centre means "God is great" but when you get to that place, there is no God there. And they mix the children there: big children with small ones, and they even mix children who can walk with children who cannot walk.'

Researcher: 'So what I am getting is that you do not want your children to be mixed with other children?'

Caregiver 2: 'Yes, you cannot mix a child with [Cerebral Palsy] with a child with Down Syndrome, because most of the children with Down Syndrome they move, they jump and they are hyper: what if he jumps on my child?'

The threat of sexual abuse was a concern to many caregivers. Sexual abuse was said to often go unreported and the perpetrator 'hardly ever convicted'. 'It once happened in my village where certain man abused a child with a disability but the police were not involved in the matter' (Caregiver, Eastern Cape). 'It also happened in my village, a certain child- female child- was abused sexually and the boy was also not arrested' (Caregiver, Eastern Cape). In these cases the community were said to 'handle the issue'.

Caregivers expressed their agency in selecting the institution that they felt they could in good conscience allow their CWD to attend. They reported being aware of the negative reputation that some ECD facilities in their areas had and were careful not to enroll their children in facilities that other parents were weary of. They also did not hesitate to withdraw their children from centres that they were not satisfied with, search of other ones, or in some cases, opt to look after them at home.

Lack of knowledge and awareness

Persisting ignorance, lack of skills, knowledge and understanding was identified among both service providers and caregivers of CWD. It was highlighted that access to information about disability, ECD services and community-based resources was poor.

The problem of a lack of training in dealing with CWD was highlighted most particularly in relation to the services offered by DoH. Teachers were reported as being ill-equipped to deal with CWD. 'ECD practitioners do not actually know how to include these children in an ECD facility, so there is a lot of what I would say "practice barriers" in terms of just knowledge about how to teach CWD and how to adapt teaching situation for them' (Academic, Gauteng).

A lack of training was believed by caregivers and practitioners alike to be at the root of most of the challenges that CWD face in schools. A lack of training fosters negative attitudes and maltreatment of CWD, leading to very low attendance rates. On this topic, comments such as the ones below were prominent from caregivers:

'The teachers are not trained to deal with our children, they do not understand our children' (Occupational therapist, Free State).

'The people who were taking care of the child could not understand the child so I decided to take care of the child myself' (Occupational therapist, Free State).

An official from DWCPD in Gauteng explained that improving knowledge and capacity of people working with children forms part of their mandate: 'We promote the right of children but where there is a need for capacity development- like where the teachers in the school will say "we've got four children with disabilities

here. We don't know how to deal with them. They are all on wheelchairs, how do we deal with that?" Then we can organize to capacitate those people, so that they can know how to relate with a child that is on a wheelchair. So we are also doing capacity development and intuitional support but around areas of children, women, and people with disabilities.' Despite this statement, many key informants indicated that the Department did not have 'teeth' and was not fulfilling its mandate.

It was alleged that caregivers, service providers and community members do not have access to information about disability, inclusion or the resources that are available to assist CWD. Some caregivers indicated that the only information that they were able to access was generic information available online. Parents also had to find out facts about their children's disabilities for themselves after their children showed signs of disability. They did not feel fully equipped to properly deal with the disability and had found it an extended process to realise the extent of their children's impairments. A caregiver from Gauteng explained that, 'It was difficult...and I am still trying to find information. At the same time I am still trying to understand the child. So for me, it was a very hard and long journey because I had no source of information at all. I had to find things on my own.'

There is a gap in terms in terms of how much information government departments disseminate to individuals. Even State personnel identified that government departments are failing to 'reach out' with explanations of what services are available and what 'steps they can take' to access services for their CWD. In addition, education about disability being limited, some parents are unaware of the value of ECD facilities altogether, even where they are available. 'Parents sometimes do not see the importance of an ECD intervention and to put the child to an ECD service, so a lot of children stay at home' (Occupational therapist, Western Cape).

Inadequate resource allocation to inclusive ECD services

'Even when the minister is doing her budget, the budget should actually include CWD' (DSD official, Gauteng).

'The Children's Act was costed but when we were tasked to develop the strategy to back the Department on how to integrate CWD we found that the costing...didn't include issues on CWD' (DSD official, Gauteng).

All of the participating service providers - both State and private - were unanimous in asserting that a 'lack of specific funding provided to make provision for the extra needs of a child with a disability' was a leading constraint on their services (Inclusion educator, Western Cape). It was explained that the funding model used by DSD for ECD interventions allocated funding

for each child irrespective of the expenses specific to providing adequately for CWD.

Within government departments, the failure of budgeting for inclusion in interventions was raised. It was explained that even where government departments have developed strategies to integrate CWD, and their implementation plans and guidelines have been approved, funding has not been allocated. Private organisations described the ongoing battle to provide affordable services, whilst 'struggling' to raise funds to provide services. Indeed, two of the key informants interviewed had over the past few years lost funding for the work that they were doing on promoting inclusion of CWD, forcing them to shift their focus to other work.

5.2.3 Impairment-related Barriers

A hierarchy of exclusion was detected in all the research sites. The difference in 'burden of care' between different impairments and diagnoses was evident. For instance, it was mentioned several times that some types of impairments and disabilities were more difficult to find inclusive services for.

Children with Cerebral Palsy often presented with multiple impairments and complex needs. The most severe impairments were described as leading to 'profound disability'. These children were described as 'often being more neglected'. A key informant explained: 'We do not have any services provided by government, by education, by social development, or by health that provide educational support system, especially for multiple disabilities or severe physical or mental disabilities' (Occupational therapist, Free State).

Children on the Autism Spectrum, and those who's behavior was unmanageable' are particularly marginalised. The following conversations illustrates the challenges faced:

Auxiliary Social Worker, Free State: 'We don't normally work with Autism but we take only the ones that are not severe...we had some of them but we had to let them go because most of our kids you will see them lying down so if they are hyper they are a danger.'

Researcher: 'So for those children, where would they go?'

Auxiliary Social Worker: 'They would just go home, there is no other place [for them to go].'

In other examples:

'One of our special schools says we don't admit children with Autism and so you can't refer a child with Autism to that school' (Occupational therapist, Free State).

'Because sometimes a child comes to us let's say an autistic child at the age of seven but then he's still on nappies, he cannot sit still for one second, he never learned you know just the basics...no school wants to take him because he is too wild and he is not appropriately trained for any formal education' (Occupational therapist, Free State).

Finally, several participants made a link between delayed toilet training and effective denial of access to ECD services: 'If a special school says children must be potty trained, then they would not admit a child who is on nappies' (Occupational therapist, Free State). It was described as being very difficult to find placements where practitioners accepted continence and bowel management as part of their jobs.

5.3 Conclusion

The social model of disability attributes the experience of disablement to the combination of barriers in the environment, barriers presented by the attitudes of society and barriers presented by impairments. The findings of this study included attitudinal barriers, such as stigma, prejudice and stereotyping of disability in the community and disabling attitudes of both ECD practitioners and caregivers hindered full enjoyment of ECD services. Environmental barriers were found to include the availability, coordination, accessibility and quality of existing inclusive ECD services, as well as a general lack of information about disability and community resources were identified. In addition, inadequate resource allocation was found to disincentivise inclusive practices. Finally, children with some impairments were found to be more marginalised. These included children with severe and profound disabilities, those with multiple disabilities and those with Autism Spectrum Disorder.

Chapter 6: Strategies to promote early identification of disability and access to inclusive ECD services

6.1 Literature Review

REVIEW OF POSSIBLE TOOLS TO ASSIST IN EARLY IDENTIFICATION

Screening for disability and developmental delays is critical as, if properly executed; it should trigger access to vital services, allowing for the appropriate type of assistance to be provided timeously and efficiently. It is also important, because early intervention, with any impairment, gives the child the best chance of developing their *'personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential'* (UN General Assembly, 2006: Article 24(b)); the earlier a disability is identified, for example, the sooner it can be treated (and sometimes removed or prevented). Finally, early identification leads to the most efficient use of State resources, as it may help offset the development of secondary complications and impairments, as the child grows older.

The purpose of this assignment is to identify strategies to assist people who may not have special training in disability - like parents, other caregivers and ECD practitioners - to identify developmental delays and disabilities in children below the age of four. One strategy is to promote developmental screening for all young children accessing ECD services. Early screening for developmental delays can be done at home, at a primary health care institution (most likely a local clinic) and at institutions offering ECD programmes. However screening will always need to be followed up with clinical examination and observation.

The home-based examination of the child is usually focus on what the child can and cannot do, and what they may have the potential to be able to do. Further assessment, usually undertaken by a health or rehabilitation worker, are related to the child's environment and the way in which they have adjusted to the disability, as well as prescribing medical and assistive interventions. A professional assessment includes the recording of a family history, as well as observation and examination of the child to establish how well they are able to function physically, intellectually, and socially. This may also be supplemented by referral for diagnostic tests; for example to an audiologist who will submit the child a hearing test (Werner, 2009).

There are a number of disability screening tests that can be used to identify disabilities:

The **World Health Organisation Disability Assessment Schedule (WHO-DAS)** is designed for adults and is based on the International Classification of

Functioning, Disability and Health² (ICF). It is a set of 12 questions, the content of which focuses on gross and fine motor skills, vision, hearing, communication, social behaviour and cognition (Baxter, 2011).

The disadvantage of this screen is that not all questions are internationally applicable and the screen is too long for census use (which most countries rely on for data collection). In addition the questions are not designed for children making this an ineffective measure of childhood disability.

The questions that make up the WHO-DAS are as follows:

In the last 30 days, how much difficulty (none, mild, moderate, severe, extreme, or cannot do) did you have in:

1. Standing for long periods such as 30 minutes?
2. Taking care of your household responsibilities?
3. Learning a new task, for example, learning how to get to a new place?
4. How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
5. How much have you been emotionally affected by your health problems?
6. Concentrating on doing something for ten minutes?
7. Walking a long distance such as a kilometer?
8. Washing your whole body?
9. Getting dressed?
10. Dealing with people you do not know?
11. Maintaining a friendship?
12. Your day-to-day work? (Luciano et al., 2010, 45)

The **Denver II** is a popular Western developmental screening tool (Sand, Silverstein, Glascoe, Gupta, Tonniges and O'Connor, 2005). However, it has been found to require extensive revision and adaptation for use in the African context because there are many aspects of the tool that have been found to be culturally and socio-economically inappropriate (Gladstone et al., 2008).

Educational Assessment and Resource Centres (EARC) are used extensively in Kenya. There are 52 district-based EARCs. Their purpose is to equalise opportunities for CWD and aid their inclusion into schools, as well as provide counseling and training for CWD, their parents and their teachers. The facilities are established within existing schools and cater to children up to the age of 16 years old. EARCs provide psychological and educational assessment. In 2003, 80 000 CWD in Kenya were identified and assisted through this initiative. EARCs assess children individually to establish the degree and type of disability.

² The ICF is a framework developed by WHO to understand health relative to their functioning and participation in daily life

However, their disadvantage is that they depend on the ability of teachers to identify difficulties that a child may be experiencing that may indicate the presence of impairment. They are also fairly resource-intensive and centralised, which may decrease access to children living in rural areas (Muga, 2003).

The **Ten Question Disability Screen (TQS)** is the most appropriate disability screening tool for use in the ECD setting because it was designed for children; it is easily adaptable for low-cost use across a variety of settings; it can be administered by people without disability-specific training; and it is effective at identifying children that should be referred for further assessment. It consists of ten questions that are administered as a personal interview. Children that screen positive on the questions need to be referred for assessment by a health or rehabilitation practitioner (often an Occupational Therapist or doctor) (Loaiza and Cappa, 2005).

The questions that make up the TQS are as follows:

1. Compared with other children, did the child have any serious delay in sitting, standing or walking?
2. Compared with other children does the child have difficulty seeing, either in the daytime or at night?
3. Does the child appear to have difficulty hearing?
4. When you tell the child to do something, does he/she seem to understand what you are saying?
5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?
6. Does the child sometimes have fits, become rigid, or lose consciousness?
7. Does the child learn to do things like other children his/her age?
8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?
9. For three to nine year olds ask: Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?
OR
For two year olds ask: Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?
10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow? (Loaiza and Cappa, 2005)

The TQS is used to identify children with disabilities. The questions are used to detect intellectual disabilities (questions one, four, seven, eight, nine and ten), physical disabilities (questions one and five), sensory disabilities (questions two and three) and seizures (question six) (Durkin, 1994).

The TQS has been extensively tested in developing contexts, and has been adapted and tested in a variety of settings. The TQS has been applied intensively in

Jamaica, Bangladesh and Pakistan, revealing disability prevalence rates of 82:1000, 142:1000 and 147:1000 respectively (Eide and Loeb, 2005: 11). The collective prevalence rate in Kenya, South Africa and Ethiopia was found to be 60:1000 (Eide and Loeb, 2005, 12). More recently, the TQS has been used for the disability module in the UNICEF Multiple Indicator Cluster Survey (MICS) (Robertsons et al, 2009).

The TQS is a low-cost method that can be adapted for use in a range of cultures. It can also be administered in a range of different settings, including in the child's home and by the child's parent or caregiver, such that even children who are not attending centre-based ECD programmes or health care centres can be screened. It has been found to be quick and easy to administer, which makes it an ideal screening tool in low- and middle-income countries (Robertsons et al, 2009: 15), and for use in epidemiological studies (Robertsons *et al*, 2009: 14). The adaptability of the screen was demonstrated in a study of children in India, Rwanda and Mongolia. To target a specific age cohort a subset of the questions were used to detect disabilities in children between the ages of five and 17 years old (Loaiza and Cappa, 2005).

The TQS has been used extensively and validated in a variety of developing countries. In a study conducted across 16 countries - ranging across the spectrum of cultural and socioeconomic settings - the TQS was used to determine the influence of context on the development of children. The disabilities determined by the TQS varied according to type, child age and by country (Bornstein and Hendricks, 2013). Language disabilities were found to be more prevalent than sensory disabilities. Younger children were in turn reported to have more of the reported language disabilities than older children. The prevalence of disabilities also varied between countries: three per cent screened positive on the TQS in some countries, while in other countries the percentage was as high as 45 per cent. Generally, more children screened positive in countries with low Human Development Index scores. Countries with lower educational levels had more children screen positive on the communication and physical disability questions (Bornstein and Hendricks, 2013). Consequently, children enrolled in school were less likely to screen positive on the TQS in many countries (Gottlieb et al., 2009). These comparisons of the TQS outcomes across different cultures and socioeconomic settings have proved the screen to be reliable despite the evident tendency to 'over-identify' in some settings (Robertsons et al 2009: 15).

Zaman et al. found that the TQS provides no evidence of age or gender bias, and that it is sensitive to both moderate and severe disabilities. It is however, less sensitive in detecting mild impairments (1990: 616). This has been further tested in several studies. Using the TQS, Loaiza and Cappa (2005) identified the variables that influence disability in developing settings to be age, gender, place of residence, household wealth

and the mother's level of education. Bornstein and Hendricks (2012) found disability to be more prevalent in younger children whose parents believed the child to have a limitation. Across all countries included in their study (Lesotho, Madagascar, Cameroon, Iraq and Jamaica), disabilities were found to be more prevalent in boys than in girls. The differences by gender were, however, very small. In addition, there were more positive TQs in rural areas of Lesotho and Madagascar than in urban areas (Loaiza and Cappa, 2005). No systematic differences emerged according to gender in the cross-cultural study conducted by Bornstein and Hendricks (2013).

The TQS has been shown to be effective at assisting people without disability-specific training to identify children with disabilities. Durkin (1995) conducted a study in Pakistan to assess the accuracy of the TQS in identifying disability amongst children aged between two and nine years old and found some limitation in sensitivity to visual and hearing impairments. TQS has been shown to have an 80 to 100 per cent sensitivity for identifying serious developmental disabilities; 75 per cent of those who screened positive were clinically diagnosed with some form of impairment on follow-up assessment (Gottlieb 2009: 1837). However, in contradiction, the screening tool has been found to underestimate some developmental disabilities and should therefore not be viewed as a diagnostic tool (Bornstein and Hendricks 2013).

The TQS has been used in studies in various South African settings, including rural settings. Irjam (1996 unpublished report quoted in Couper 2002) used the TQS for children aged between two and nine years in rural KwaZulu Natal and found the disability prevalence to be 33:1000, whilst it was found to be higher in Mpumalanga (64:1000) and the North West Province (52:1000) (Couper, 2002: 550). However, another study conducted in KwaZulu Natal revealed a prevalence of 83:1000 in children under ten years old and an overall confirmed prevalence of 60:1000 (Couper 2002: 550). Of these, 53 per cent of the children identified with disabilities were boys, which is consistent with the cross-country findings reported by Loaiza and Cappa (2005, 13). The South African findings are also consistent with research elsewhere that indicates that the prevalence of disability increases with age (Loaiza and Cappa 2005; Couper 2002). A more recent study conducted by Giarelli et al (2009) in the Western Cape used the TQS to identify developmental disabilities in among 42 per cent of their sample of Grade R children between the ages of five and eight years old in a area known for high prevalence of FAS.

Although the TQS can be effectively used by people with no disability-specific training, those administering the TQS by interview do need to be able to read and understand the questions. Thorburn et al reported that an attempt to use key informants in Jamaica was not effective in identifying children with disabilities. In their study many children screened positive, but on follow-up

assessment were not found to have any disability (1992). In Kenya, the need for training of people administering the TQS was identified because they found that it mainly picked up problems that were of concern to families. They also concluded that parents answering the questions needed to be sensitised to the symptoms of various impairments (Muga, 2003).

As with any tool, the TQS has some limitations. It has been shown to have limited positive predictive values as many children screen positive when they do not have a disability. However we argue that there is no loss in false positive screens if they facilitate access to services that may be required by the child even if they are not found to have a disability on follow-up assessment. Further, it has been shown to be an ineffective tool for detecting mild impairments, or disabilities that caregivers may not notice. This is especially true for vision and hearing, as the screening tool was found to have poor sensitivity for sensory disabilities that had not been previously identified (Durkin, 1994). For these reasons, the TQS cannot operate in isolation and must be supplemented by clinical testing.

In conclusion, screening methods that are sensitive, specific, inexpensive, simple and accurate - as is the TQS - are the most effective, particularly in developing countries with a large child population. In the result, such a test is well suited to South Africa. Though the TQS tool is not diagnostic, it has the potential to successfully identify disabilities among children in South Africa. It has excellent sensitivity for detecting serious disabilities in children between the ages of two and nine years old; it is valid among children of different genders, socioeconomic backgrounds and cultures (Durkin 1994); it can be adapted slightly; it has already been used in several local studies; and it has been found to reliably screen children who require further assessment and follow-up.

In addition to the screening tools detailed above, we also recognise the utility of the following other resources that might inform a strategy that promotes early identification of disability:

The new parent-held **Road to Health Booklet (RtHB)**, launched in early 2011, is based on updated WHO growth monitoring standards (Cloete et al. 2013). In addition to addressing many of the weaknesses of the *Road to Health Card*, which has been used in various forms in South Africa since 1995, the RtHB includes a number of revisions that have the potential to promote early identification of disability. A section for 'any disability present' has been added to the general details of the child and family section to be filled by a health practitioner (DSD et al., 2012: 41). A new section on 'Developmental Screening' has also been added. This includes information about the ages at which childhood development should be assessed by a primary health practitioner, as well as when and where to refer children for further assessment (Mulaudzi, 2012). Developmental milestones are detailed for six age-

group categories ranging from 14 weeks to 6 years old. In addition, the following three screening questions have been included:

1. Can your child see?
2. Can your child hear and communicate as other children?
3. Does your child do the same things as other children do? (Mulaudzi, 2012)

The RtHB has the potential to be a vital tool for early identification of impairments in children. However, there is a need for improved nurse knowledge and skills in using the RtHB (Cloete et al. 2013).

For the purposes of this assignment we recommend building on the TQS and the RtHB to develop resources to facilitate early identification of disabilities among children between the ages of zero and four years old.

REVIEW OF RECOMMENDED STRATEGIES TO PROMOTE ECD ACCESS

There are a number of documents and reports that provide ideas and frameworks for the promotion of effective service delivery and access for CWD.

The NCSNET made extensive recommendations on overcoming barriers to education and training for CWD in the 'Quality Education for All: Overcoming Barriers to Learning and Development (1997). The report lays out a detailed implementation plan outlining the multi-sectorial approach required by duty-bearing governmental Departments as well as other stakeholders. Some of these recommendations were carried forward to White Paper Six, but much of the ECD orientated content was omitted.

WHO's review entitled 'Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries' (2012) includes extensive sections on early intervention and provides examples of best practice and well-considered recommendations for promoting effective responses to childhood disability like training local personnel, empowering caregivers and improving disability-related data.

WHO and UNICEF, in their discussion paper entitled 'Early childhood development and disability' recommend the following steps be taken in six key areas to promote ECD access for CWD:

"1. Inclusion of CWD in mainstream policies, systems and services that support and maximise their development potential.

- Review national policies in relevant sectors—health, education and social—to ensure they are aligned with international conventions and commitments and inclusive of young CWD.
- Analyse sector-wide strategies, programmes and budgets to determine whether they include concrete actions to support young CWD and their families.
- Develop, implement and monitor a comprehensive multi-sectorial national strategy and plan of action

for young CWD that addresses family support, community awareness and mobilisation, capacity of human resources, coordination and service provision.

- Advocate for and seek sustainable financial and technical support to address the service delivery gaps that have been identified.

2. Programmes and services which specifically target young CWD and their families.

- Assess the capacity of current programmes and services to accommodate the needs of CWD and their families. Where gaps exist facilitate the integration of specialised services, such as early childhood intervention.
- Strengthen the capacity of parents' associations and disabled people's organisations to provide care and support; undertake advocacy and public awareness initiatives; and participate in policy development, service design and programme monitoring.

3. Involvement of CWD and their families in all early childhood development activities including policy development, service design and programme monitoring.

- Encourage the building of strong partnerships between parents and professionals to ensure ECD services relevant to CWD are child/family focused.
- Provide assistance to strengthen the capacity of CWD to participate in ways that they themselves find rewarding and meaningful while also promoting inclusive attitudes and behaviours of their peers.

4. Capacity development of human resources across relevant sectors to address disability.

- Provide education and training on disability for relevant stakeholders. Training may cover the rights of children with disabilities, the need for both mainstream and targeted services, and strategies for the inclusion of children with disabilities and their families.

5. Public awareness and understanding about CWD.

- Undertake advocacy at all levels to highlight the urgent need to include CWD in ECD initiatives and provide targeted services.
- Utilise diverse communication channels, including mass and community media, traditional media, such as puppetry, poetry, song and storytelling, and interpersonal communication to eliminate stigma and prejudice and to promote positive attitudes towards CWD and their families.

6. Data collection and research.

- Identify existing data collection systems for children and ensure they include provisions for the collection of information on CWD, ensuring sex and age disaggregation.
- Monitor and evaluate ECD efforts for CWD.
- Collect evidence on what works—including examples of good practices—in promoting and

supporting ECD for CWD. Attention should be paid to times of transition such as from preschool to primary education” (2012: 32-33).”

Finally, the recent situational analysis of CWD in South Africa points to scalable projects that are achieving early identification, intervention and ECD service access for CWD. It also makes extensive reference to opportunities for extending the rights of CWD, and makes recommendations on how the opportunities might be utilised (DSD et al., 2012). These should be viewed, in addition to the other available references, and in alignment with the international and national legal frameworks to which South Africa is bound, as recommendations for prioritising CWD in ECD service planning and provision.

6.2 Findings

This section details the findings of the study with regard to possible strategies to promote both early identification of disability and improved access to inclusive ECD services. This section is presented in three sections, namely: Support for CWD, service providers and caregivers of CWD. Each section includes fictional case study examples of South African service providers who currently provide examples of good practice. A list of contact details for the departments and organisations included is available in the appendices.

6.3 Support for children with disabilities

CARE DEPENDENCY GRANTS

Poverty was identified as a major barrier to the access of CWD to ECD services. It is intuitive, therefore, that financial support afforded caregivers in the form of the CDG was highlighted by many as extremely helpful. The Grant was described as being used to pay for transport to day care centres, the costs associated with attending hospital follow-ups, emergencies, disposable nappies, 'special food', and the fees at day care centres. Access to a CDG was described as being 'life-changing' - with many parents describing them as the single most helpful support mechanism at their disposal - but also as 'not nearly enough'.

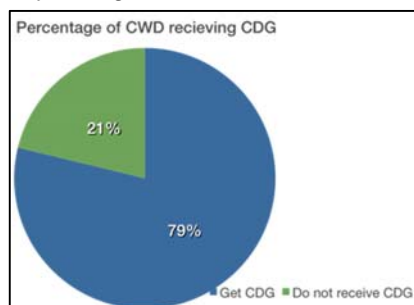


Figure 4: Percentage of CWD of caregivers participating in focus group discussions that receive Care Dependency Grants

Some caregivers were able to provide for their CWD through the financial support they receive from private sources such as medical aid and/or their personal incomes, while others reported relying solely on the CDG. Amongst those who do not access the Grant, prominent reasons for their lack of access emerged. Several caregivers reported having experienced difficulty in accessing the Grant, to the extent that some had been 'turned down by SASSA', despite their legal right to the CDG. Some reasons given for CWD failing to qualify for a CDG included lacking requisite documentation or the child having one or both parents who were not South African citizen. However, for some CWD it was unclear why the child had not qualified, and some felt that it was because their child 'didn't look disabled'.

Caregivers that participated in Gauteng were concerned about undocumented CWD particularly, as they do not qualify for social grants. They explained that not having a birth certificate made it very difficult to access services. One story was shared of a child who's mother had no documentation but was from Swaziland. The father of the child was South African. Even though the child was born in Gauteng and had always lived here she did not have a birth certificate and could not apply for a grant. Finally, some caregivers were unaware that the CDG existed at all, the information of its availability having been at no stage of their interactions with service providers communicated to them.

Reliable statistics describing both the uptake of, and access of those who qualify to the CDG are not available. In addition to promoting further research in these areas, interventions that assist in streamlining the application process were suggested.

EARLY IDENTIFICATION AND INTERVENTION

'If inclusion is ever going to work then we need to identify the children early and include them in services and pre-schools and daycare facilities from a very early age' (Inclusion educator, Gauteng).

'Also the early identification and placing them in the most appropriate facility is very important. It is only when so many of our disabled children reach school-going age that so many people start asking the questions: "Now what? Where is this child going to go? How are they going to go to school?" 'I think often if they had been included with other children from an earlier age, it would be much easier to get them into the system' (Academic, Gauteng).

The experienced practitioners who participated in the study expressed that early intervention and the mainstreaming of CWD in ECD services from an early age are both integral to the development of CWD- better equipping them with the ability to integrate into the education system when older. It was also felt that early inclusion helped children function better in society more

broadly, as well as improving their ability to 'bond' and 'mix' with other children. Beyond the benefits to the CWD themselves, it was described that inclusion from the beginning of life has a positive effect on community acceptance and tolerance of diversity. 'Identifying children early and including them really early is the first thing. The families and community accepts them as part of the community from a very early age' (Academic, Gauteng).

Insofar as early identification is concerned, the practitioners were asked to highlight the sites that they would describe as were said to be good places for screening children. They responded that these would be in the home, within health care facilities and ECD services. ECD services mentioned included pre-schools, community crèches, day care centres and toy libraries. Examples were shared of hospitals that have implemented follow-up protocols for babies identified at birth as being at risk. Caregivers were also able to share the signs they noticed that their children may have an impairment.

Good practice: Following up on high risk babies

The St Apollinaris Hospital is a district hospital with 155 beds located in rural kwaZulu Natal. Their rehabilitation department established a High Risk Baby Policy (HRBP) to promote early intervention for high risk babies. Thokozani is a baby who was born at 33 weeks, and weighed just 1,5 kg. He was delivered prematurely because he was a twin, and sadly his twin sister passed away in utero. At first he wasn't breathing, and his APGAR scores were low. He was resuscitated immediately and had low oxygen saturation levels, so he was placed on oxygen via nasal cannula.

Because of his birth history, Thokozani was referred to an occupational therapist, who assessed Thokozani using their standardised HRBP evaluation form and kept in touch with his mother while they remained in the ward. When they were discharged to go home, they were provided with dates to attend Kilmun clinic, their closet health facility. They were also placed on the HRBP register. His achievement of developmental milestones were continuously monitored at monthly follow-up sessions with the occupational therapists. The therapists were also able to help with problems that his mother experienced with breastfeeding, provide a home exercise and stimulation programme, and show Thokozani's mother how to make and use homemade toys made with recycled items.

What risk factors and first signs of disability did parents of CWD identify?

One participant described how she found out while pregnant that her child would have a disability: 'They took some water and did some tests and they found out that there is going to be something wrong with the child' (Caregiver, Gauteng). Another Eastern Cape mother

recalled how she knew that the 'nurses were suspecting complications' when they referred her from her local clinic to a tertiary hospital in Umtata to give birth. However, for most participants, the disabilities of their children were apparent only at birth or slowly became apparent during early childhood.

For those who became aware of their child's disability during their pregnancy, several common early signs or symptoms emerged from the caregivers' descriptions. These included:

1. **Teenage pregnancy:** 'I was very young when I fell pregnant' (Caregiver, Free State).
2. **Premature birth:** 'I had a pain at six months...I went to the hospital and they told me: "You are giving birth". I was shocked' (Caregiver, Free State).
3. **Difficult, delayed labour:** 'I experienced labour pains for five days and the nurses kept telling me that it wasn't time yet' (Caregiver, Eastern Cape).
4. **Fetal distress and emergency Cesarean Section:** 'They checked and told me that the heart was beating too fast and they had to operate' (Caregiver, Free State).
5. **Baby 'not breathing' and 'not crying' after birth:** 'I found out right at birth, because when he was born he didn't cry' (Caregiver, Eastern Cape).
6. **Low birth weight, under 2kg:** 'My son was born at 37 weeks but he was only 930 grams' (Caregiver, Free State).
7. **Early referral to intensive care:** 'They couldn't get him off the ventilator' (Caregiver, Free State).
8. **Early surgery:** 'She had three operations on her head' (Caregiver, Free State).
9. **Jaundice:** 'At that time the skin was very light looking- like plastic- and the child's eyes were also very light looking. So the doctors thought it was jaundice and started treating him for it' (Caregiver, Eastern Cape).
10. **Physical deformity of part of the body:** 'My son was born with his brain out of the skull...yeah...at the back of the head' (Caregiver, Free State).
11. **Seizures:** Researcher: 'I just want to ask in general, how many of your CWD have had fits before?' <Six out of seven caregivers raise their hands> (Eastern Cape).
12. **Abnormal muscle tone:** 'When I gave birth to [my daughter] I see something is wrong...she came out weak' (Caregiver, Gauteng).

For some caregivers, their children's disabilities only became apparent some time after birth. Below is a compilation of common observations shared by caregivers:

1. **Delayed milestones:** 'He is three and he cannot speak and cannot sit on his own or walk' (Caregiver, Gauteng).
2. **Delayed processing:** '[My son] has Down Syndrome and he is slow in everything he does' (Caregiver, Gauteng).
3. **Difficulty with feeding:**
 Researcher: 'How many of your CWD had trouble right from the beginning with feeding?'
 <Two mothers raised their hands>
 Researcher: 'And how many of your children had problems with chewing?'
 <Two mothers raised their hands>
 Researcher: 'Whose children had problems with swallowing their food, like choking when they swallow?'
 <Two mothers raised their hands>
 Researcher: 'So feeding has been a major challenge for you?'
 Participants (all): 'Yes!'
4. **Delayed speech or communication disability:** 'But he hears, he doesn't speak. Sometimes he speaks but he doesn't pronounce [words clearly]' (Caregiver, Free State).
5. **Difficulty in social situations:** 'He didn't want to mix with other kids. He will be crying all the time...he would just sit alone. He didn't even want to take instructions. As he was going to the clinic some sisters advised us that we should take him to some specialists because it could be that he couldn't hear what we were saying or that he wasn't happy somehow' (Caregiver, Free State).
6. **Development of physical deformity:** 'When she was four months her head was growing big and the body became thin and weak' (Caregiver, Eastern Cape).
7. **Hyperactivity:** 'He was playing around, destroying everything...until he was taken to [hospital] where they diagnosed him Autistic' (Caregiver, Gauteng).
8. **Not responding to noise:** 'I had him with me in the kitchen and there was so much noise with the pots and pans. He was right next to me and I could see that he couldn't hear a thing' (Caregiver, Free State).
9. **Repeated hospital admissions:** 'The doctors suspected jaundice and started treating for it. As time passed the doctors noticed the child was underweight and we were hospitalized again' (Caregiver, Eastern Cape).

10. **Delayed potty training:** 'He is seven [and] he is still in nappies' (Caregiver, Gauteng).

DEVELOPMENTAL SCREENING

Strategies for screening children to identify developmental delays and impairments for follow-up assessment and early intervention were discussed. The disability question, and developmental screening section of the new Road to Health Booklet (RtHB) was promoted by several key informants on the study as having the potential to assist in the early identification of disability, particularly in children with moderate to severe disabilities. It was demonstrated that in the 'details of child and family section' practitioners completing the section are required to indicate if there is 'any disability present' (see photo). There is also a developmental screening chart included in the booklet (see photo), which indicates age-appropriate visual and adaptive behavioural responses to stimuli; hearing and communication; and motor function milestones at 14 weeks old; six, nine and 18 months; three and five to six years old.

'Any disability present?' question in the RtHB (Photo credit: Beryl Bamu)

Although it was advised that the RtHB be promoted for use by health practitioners every time a child comes into contact with a health professional, and certainly, when they come in for immunisations, the screen was considered to be of undetermined benefit. Some participants did caution that the RtHB developmental screening section had not been rigorously tested, casting doubt on its effectiveness in the identification of disability. The particular concern was raised that it might not identify children with mild disabilities. However the consensus was that it had potential to promote the screening of development at primary healthcare level. It was also viewed as a good resource for caregivers to check for themselves their child's achievement of milestones. Additionally it is something that almost all South African-born children since 2011 should have been issued, making it a resource which all caregivers should have at their disposal. Indeed, every caregiver that participated on the study indicated that their CWD had a Road to Health Card or Booklet. As one participant summarised: 'There are issues with the [RtHB developmental screening] tool...but as far as what we have available, that is the tool we should be using' (Academic, Gauteng).

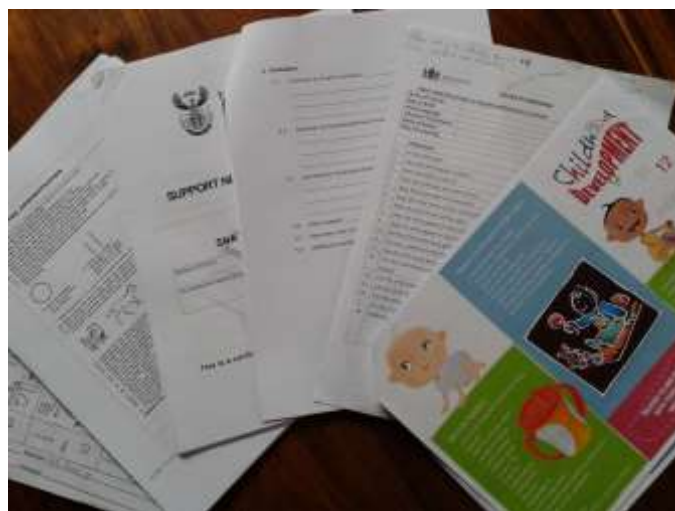
DEVELOPMENTAL SCREENING			
	VISION AND ADAPTIVE	HEARING AND COMMUNICATION	MOTOR DEVELOPMENT
ALWAYS ASK	Can your child see?	Can your child hear and communicate as other children?	Does your child do the five same things as other children of the same age?
14 weeks	Baby follows close objects with eyes	Baby responds to sound by stopping sucking, looking or turning	Child lifts head when held against shoulder
3 months	Baby recognises familiar faces	Child turns head to look for sound	Child holds a toy in each hand
6 months	Child's eyes focus on far objects Eyes move well together (No squint)	Child turns when called	Child sits and plays without support
18 months	Child looks at small things and pictures	Child points to 3 simple objects Child uses at least 3 words other than names Child understands simple commands	Child walks well Child uses fingers to feed
3 years	Draws small shapes clearly at 5 metres	Child speaks in simple 3 word sentences	Child runs well and climbs on things
5-6 years, School readiness	No problem with vision, use a Snellen E chart to check	Speaks in full sentences and interact with children and adults	Hops on one foot Able to draw a stick person
REFER	Refer the child to the next level of care if child has not achieved the developmental milestones. Refer motor problem to Occupational Therapist/Physiotherapist and hearing and speech problem to Speech therapist/Audiologist if you have the services at your facilities.		

Developmental Screening page in the RtHB (Photo credit: Beryl Bamu)

Key informants were concerned that nurses had not been trained to complete the information meaningfully. They also felt that busy nurses often skipped over the screening pages. Indeed, of the few RtHBs seen during the study, not one had had the milestones page filled out. During educational workshops ECD practitioners and home-based carers (nomakhayas), in Gauteng and Eastern Cape, expressed that they did not before understand that they could use the birth history, APGAR scores or developmental screening pages in the RtHB to determine young children at risk of disability. This finding was also described by a key informant that provides training for ECD practitioners on the use of the RtHB: 'We find that the RtHB or clinic card is not really understood and not well used, so in our training we include sections on that and it is a huge eye-opener to practitioners...Usually they go through the motions of asking for copies of clinic cards and they go straight in the filing cabinet. They are not looked at. So we look at what the possible risk areas might be' (Inclusion educator, Western Cape).

The RtHB was seen to have the potential to allow community-level primary health care workers and ECD practitioners to identify children that could benefit from further assessment and support. It was, however, acknowledged that further research was required if the tool is to be standardised, and to determine the specificity and reliability of the screen. In addition, research was said to be required to understand how the new RtHB is currently utilised; whether, for instance, the developmental screening section should be completed

when children receive their immunisations. Finally, it was said that much awareness-raising was required to alert people working with young children, as well as parents and caregivers, about the developmental screening section.



Screening tools and assessments are prolific, however, not all are appropriate for use by caregivers and ECD practitioners (Photo credit: Jean Elphick)

SUGGESTED SCREENING TOOLS

The following table provides an overview of screening tools and developmental assessments mentioned by key informants on the study. Whilst many of them are validated, standardised assessments, they do not meet the criteria for a screening tool to assist caregivers of CWD and ECD practitioners in the early identification of disability.

Screening or assessment tools suggested by key informants	Description	Utility as a screening tool for caregivers and ECD practitioners
Developmental milestone charts	<p>Indicate a typical developmental sequence that each child should go through at specific ages. Milestones provide an indication of areas that may require intervention and can be useful to detect developmental delay.</p> <p>However, the exclusive use of milestones has been criticised as promoting 'wait and see'</p>	Milestones signal to parents what to expect at a certain age, for example a baby should be able to kick with both legs and sit up straight between the ages of 6 – 9 months. If not, parents are advised to seek the help of a health professional.

	recommendations from health practitioners that in turn, limits early identification.	
Road to Health Booklet (RtHB)	The RtHB is an example of a milestone chart that shows the medical record summary of children under the age of five years old. It is simple to understand and easy to use. In addition to keeping a track of then child's physical development, it also records the vaccination status.	Although the developmental screening in the RtHB has identified flaws, and may be currently underutilised, it is widely accessible. Every CWD that participated on the study had a birth certificate and a RtHC or RtHB. The RtHB is also a document that can carry information between practitioners in different sectors giving this client-held record an advantage.
Screening or assessment tools suggested by key informants	Description	Utility as a screening tool for caregivers and ECD practitioners
Department of Basic Education (Draft) Support Needs Assessment (SNA)	SNA assists teachers in identifying the strengths and needs of learners with regards to communication, learning, behaviour, health, wellness and personal care. The tool is diverse but can only be used once the child is enrolled in school, which may result in late identification. High numbers of children per classroom may	This is an assessment and not a screening tool and is time-consuming to complete. It is designed to be completed by teachers and District-based Support Teams. It is not for completion by ECD practitioners or caregivers. It is also designed for school-going children.

	also limit the teacher's ability to pay close attention to each child's needs. The tool asks the teacher of the child's successes and challenges in different areas of the learning environment and for the teacher to express their areas of concern. For example 'Which factors within the school's environment are impacting on the learner's participation in the programmes offered at the school?'	
START Home Intervention Programme	Sunshine Association has developed a detailed developmental checklist that can be used by mothers and health professionals to identify disabilities in young children.	START requires users to complete a course. This training as well as on-going access to the tool is not free. Although highly esteemed, the tool is inaccessible to most caregivers of CWD and ECD practitioners
Picture-based screening tools	Picture-based screening tools are very simplistic in that identification is based on a comparison of what the child looks like and what the picture screen demonstrates. Picture screens leave room for parents to miss some signs that are difficult to represent pictorially such as hearing loss or	Though these tools can be helpful and educational they cannot be relied upon in isolation, and require some extrapolation. They can however be useful for experienced ECD practitioners.

	behavioural problems. Examples of these type of screens include the Ten Picture and Word Picture tools.	
Screening or assessment tools suggested by key informants	Description	Utility as a screening tool for caregivers and ECD practitioners
Developmental checklists	A checklist provides a list of questions that require a 'yes or no' response. These questions are usually simple enough for parents to answer without any assistance. However, this simplicity could also mean that there are some signs that go unnoticed. Checklists also have the disadvantage that they do not allow for the different environments that children grow up in to be factored into the responses.	Questions are usually simple and straightforward such as 'does the child play well with others?' This is a 'yes or no' question that may have different explanations to the answers provided.
Ten Question Screen (TQS)	This short ten question screen is straightforward and quick to administer. It has been tested extensively in developing contexts.	Although the TQS was completed successfully by both caregivers and ECD practitioners that participated on the study, it has a limitation with regard to ages of children. The screen is designed for children

		between two and nine years old. For this reason it is not appropriate for children under two.
Denver II Developmental Screening Test	Used to screen intellectual impairment and developmental delays in children under the age of six. It is very precise and determines a diagnosis from 125 performance-based parent report items. The test monitors very specific aspects of the child's physical development such as ability of the child to brush their own teeth, feed themselves, imitate speech or sit with no support.	Despite its advantages, the test is not a screen, and can only be administered by a paediatrician or health professional.
Screening or assessment tools suggested by key informants	Description	Utility as a screening tool for caregivers and ECD practitioners
Ages and Stages Questionnaire (ASQ)	The ASQ is a test that comprises drawings and simple directions for parents to indicate their child's skills in language, personal-social, gross and motor, and problem solving skills. Consultation with a professional is only required should there be a concern. This tool is also adaptable to the needs of different families. The questionnaire asks questions such as 'does your child jump with both feet leaving the floor	Although used successfully in inclusive ECD programmes the ASQ is detailed and inaccessible. Although it claims to take less than 20 minutes to complete at home the test requires a high level of English proficiency and literacy. It was however highly recommended and could be considered.

	at the same time?' and also provides an illustration to aid parent's understanding of the question.	
Malawi Developmental Assessment Tool (MDAT)	The tool was designed to identify children with disabilities and delayed development.	The MDAT was designed specifically for use in rural Malawi. It may not be applicable to other settings and has mostly been used for research studies rather than as a screening tool.
Screening Posters	<p>Disability screening posters are often the simplest ways in which to raise awareness. When they are put up in public places such as the waiting rooms of hospitals, clinics and schools, parents can be made aware of the signs that signal that they need to seek professional help for their children.</p> <p>Posters are usually made of simple annotated diagrams that are easy to understand but informative, however they cannot be relied upon as a screening tool.</p>	Posters are usually not detailed enough to serve as either a screening tool but they are an effective way of raising disability awareness and promoting early identification.

Gauteng Department of Health Childhood Development pamphlets (0 to 3 Months; 3 to 6 Months; 6 to 9 Months; 9 to 12 months; 12 to 18 Months; 18 to 24 Months)	A series of colourful A4-sized pamphlets that include sections on 'What to expect'; 'Warning signs'; 'Things to do with your baby'; and 'Tips for parents' in simple language with some pictures.	Although not designed to be a screening tool, these pamphlets offer clear advice and could be very useful to raise awareness about developmental milestones and early warning signs of possible impairment.
Screening or assessment tools suggested by key informants	Description	Utility as a screening tool for caregivers and ECD practitioners
Activity-Focused Classification Tools	These tests are used to determine the level at which a child can be classified in terms of mobility, handling objects and communication.	These tests are extremely detailed and specific and can only be administered by a trained health professional. They are also designed specifically for Cerebral Palsy.
Gross Motor Function Classification System (GMFCS)	<p>The GMFCS is a testing tool for Cerebral Palsy that is based on self-initiated movement. It determines which level, out of five distinct ones, represents the child's abilities and limitations in gross motor function.</p> <p>General headings per each level:</p> <ul style="list-style-type: none"> • Level I - Walks without Limitations • Level II - Walks with Limitations • Level III - Walks Using a Hand-Held Mobility Device • Level IV - Self-Mobility with Limitations; May Use Powered Mobility • Level V - Transported in a 	

Unedited

EXTENDING INCLUSIVE SERVICES THAT ADDRESS DISCRIMINATORY ATTITUDES

'When people experience [inclusion] they say: "I don't see any children with special needs", because they are so well integrated and we don't see that' (Inclusive ECd manager, Western Cape).

'CWD...should be a part and parcel of our planning; part and parcel of our intervention; part and parcel of our programme; part and parcel of our processes. In everything that we do, we should promote the rights of CWD' (DSD official, Gauteng).

Some caregivers reported having managed to find a local crèche that was willing to include their CWD in their mainstream programme. For instance a Gauteng mother described how her son with a chromosome disorder had seen other children going to crèche and he wanted to go too. She managed to find a crèche that was willing to accommodate her son, and had included CWD in the past. Her experience was, however, the exception. Most caregivers described having either nowhere to send their children or having access only to centres that cater exclusively for CWD.

Both caregivers and key informants advocated strongly for inclusive services. Caregivers shared sentiments about how they felt inclusive ECD services would benefit their children in the following terms:

Caregiver, Free State: '[Inclusion] would be good for my son because he needs stimulation, especially from other children. For instance here [at this centre for CWD] many of the children are not speaking so he deals with the silent atmosphere. [At this centre] they say the other CWD are encouraging him to walk, so can you just imagine if he was surrounded by 'normal' kids?'

Caregiver, Gauteng: 'At crèche the first time I did not want to put him in a crèche with only CWD. I wanted to put him together with the 'normal' children because he likes running around.'

Many key informants felt that new 'separate, special or specialised' services for CWD are not what is needed to improve the situation for CWD. They advocated rather for increasingly inclusive, egalitarian interventions that 'accept a child for who they are' and 'change things...to accommodate that child' (Occupational therapist, Western Cape). As a researcher from kwaZulu Natal explained, 'In fact we've been excluding those who need [services] the most up 'til now.' In order to change the situation 'positive planning for inclusion' was suggested: 'Even for things like health immunization programmes, how can we make sure we are planning for everybody? It's a challenge to Government and NGOs...to ensure that services get to everyone that needs them.'

A key informant from the Western Cape highlighted that inclusion works both ways. It was described how a

centre that started for a group of CWD was opened up to 'all children': instead of 'taking a child with 'special needs' and placing them a class with non-disabled children' (Inclusive ECD manager, Western Cape), the process of inclusion at that school happened the other way around. It was described as an effective and 'natural' way of creating an inclusive environment. The same programme also takes on volunteers with disabilities, some of whom graduate to permanent employment. All of their staff members started as volunteers. This was offered as an example of offering a truly inclusive environment, 'because our doors are open to everybody' (Inclusive ECD manager, Western Cape).

Another approach was employed by an inclusive ECD centre in Gauteng. The ECD started off with a separate class for CWD, which class was dissolved in favour of including all children separated only in accordance with their age-groups. The process was supported by parents of CWD, as well as a CBR empowerment programme. This process reportedly has had some challenges. For instance, children with high support needs were excluded from the centre because specialised continence and feeding assistance was no longer catered for. ECD practitioners also raised concerns that they felt ill-equipped to cope with their new inclusive classes, especially when they were short-staffed and some practitioners were away for training.

The skills of 'curriculum differentiation' were seen to be important to help ECD practitioners adapt to the children that are present in the class. The ability to 'adapt' programmes to make learning outcomes accessible to children with various impairments is required. An DBE official drew attention that the fact that all ECD practitioners should be equipped with the basic tools to identify children with impairments and other barriers to learning during their basic training. They should then have access to guidance from an 'outreach team' of 'multi-skilled specialists' with skills on 'how to deal with visual impairments, CP or autism or all those specific things where those specialist knowledge is needed' (DBE official, Gauteng).



Grade R learners have a disability experience guided by people with disabilities to Celebrate Casual Day. The children experienced sensory, physical and communication disabilities by doing activities at five activity stations, followed by a motivational speech from a local disability activist (Photo credit: Jean Elphick, with permission Afrika Tikken)

A Free State occupational therapist did caution that even if a child does have access to early intervention and inclusion through ECD programmes in the foundation phase, this does not guarantee success in mainstream schools. She explained that CWD may get 'lost' in big classes where the quality of instruction is low and even the 'brightest' children are at a disadvantage. She shared this story to illustrate this: 'If our "ordinary" children are not taught to read and write, what will happen to our children with challenges or barriers?...We have had experiences where these children do so well in ordinary preschool and foundation phase then in ordinary school nobody learns to read and write so the child with Down Syndrome is more marginalized that he would have been in a "special" school.'



Making an ECD classroom inclusive means adapting the programme to accommodate a spectrum of learning styles and needs (Photo credit: Jacqui Dudley, with permission IEWC)

In spite of the participants perception of discriminatory attitudes being unbending, it was evident that change was possible. 'One of the first steps towards inclusion is to raise awareness about disability because the idea of stigma and segregation comes from lack of understanding' (Occupational therapist, Western Cape). Indeed, after participating in a workshop on inclusion, ECD practitioners in Gauteng remarked that they would try to make their children 'understand the new children', 'include them with others', 'make them feel at home', 'develop them holistically even if they have a disability', 'give moral support and never discriminate against the



Gauteng ECD practitioners use a participatory community mapping exercise to identify issues with physical accessibility of their ECD centre (Photo credit: Jean Elphick)

child', and 'love them like any other children'. They were also able to come up with practical ideas for how to make the ECD Centre more physically accessible to CWD. At a rural Eastern Cape ECD centre, Nomakhayas and ECD practitioners collaborated on finding solutions for a child with physical disabilities to access their centre. On a community level, the empowerment of parents to act as disability advocates and raise awareness was endorsed.



Workshop participants in Eastern Cape work on finding ways to include fictional character Thandi- who cannot walk- at their ECD (Photo credit: Jean Elphick)

Good practice: Teaching children about inclusion

Prudence received training on how to use Persona Dolls in her ECD class. The Persona Doll Approach is a non-threatening, active learning approach for adults and children about identity and diversity through story and dialogue. Prudence used her life-like Persona Doll named Alana to help young Melusi to fit in.

Melusi is three years old and lives in a rondavel in the Eastern Cape. He only started going to the new ECD centre at the beginning of the year. Although he can see well, he has a squint. When he first started at the ECD, his classmates were very curious about his eyes. Some of the older children started teasing him, and he was given a nickname that meant 'cross eyes'. When Prudence realised that Melusi was being teased she knew she needed to do something. She had used Persona Dolls before to address the attitudes of her class towards human rights issues such as racism, gender, HIV/AIDS stigma before, and she knew they could also be used to talk about disability.

And so she introduced Alana during morning ring. Alana is a girl, and she wears glasses just like Melusi does. Prudence was able to explain all about Alana's visit to the doctor and the clinic to get help with her eyes, and the children could ask questions. This is what Prudence said:



'This is our friend Alana who has come to visit us today. Alana wants to know if you notice anything different about her today. That's right she's wearing glasses. Why do you think Alana is wearing glasses? Alana says that her eyes had been hurting a lot and she sometimes got headaches. When she looked at books she had to hold them very close to her eyes. So her mother took her to

an eye doctor. Has anybody been to an eye doctor? What did you do there? The doctor asked her to look at a chart and afterwards said, "You need glasses." She tried on lots of different kinds of glasses until she found these ones. Alana wants to know if you like her glasses. Alana loved her glasses. She thought they looked great and she could see more clearly.

Now Alana has a problem that she would like to talk to you about. She thought it would be fun to go to school wearing her new glasses, but it's not. She doesn't like it one little bit. Some of the children laugh at her and tease her because she wears glasses. And it's even worse that that. They stand in a circle around her and call her "four eyes, four eyes!" She doesn't know what to do except cry. She wants to stop wearing them. How do you think Alana is feeling? Is it fair that the children are teasing her? How can we help Alana?

What should she do? Alana says she is going to try out some of your ideas. Thanks for talking to her.'

The children were encouraged to discuss what it might be like to see in a different way or to walk and talk in a different way.

Good practice: Celebrating the lives of children with Cerebral Palsy

Helen the CP Bear is a travelling teddy bear that visits children with Cerebral Palsy all over the country. Helen's originator is Lesley Potgeiter, is a mother of two from the Western Cape who has Cerebral Palsy herself. Helen is posted to families along with her travel diaries for two week-long home stays. Over the past year Helen has visited 17 families. She spends time with the children she is visiting, and goes everywhere they go. Each child Helen visits adds a diary entry and photographs to give insight into their lives. This gives each family Helen visits a sense that they are not alone and that Cerebral Palsy affects families regardless of where they live, or how much money they have.

In addition Helen is an important conversation starter, and has been used to introduce children at countless schools to what Cerebral Palsy is. Everywhere she travels, Helen the CP Bear spreads goodwill and a message of inclusion and tolerance. When Helen visited Thando, a four year old in Gauteng, Helen went with Thando to Occupational Therapy at her local Clinic and to her ECD. At the ECD's assembly Thando's mother Phindile was able to introduce Helen to children from all the classes. She explained that, just like Thando, Helen has Cerebral Palsy. She was able to show the children the splint on Helen's paw and explain the cause of her hemiparesis. The children were fascinated by Helen's travel tales and very excited to meet her.

Good practice: Regular staff meetings to facilitate successful inclusion of CWD

Lebo is four years old and has been diagnosed with a degenerative neurological condition that makes her legs very weak. She cannot walk on her own, and is very shy. As her mother explained, 'She is now in a class with 'normal' children'. Although her ECD practitioners at Afrika Tikkun's Arekopeneng ECD Centre have had some training on disability and inclusion, their primary concern is Lebo's safety because her classmates can be quite rough and inconsiderate. The practitioners were able to bring this up at a monthly 'inclusion meeting'. It was agreed that a guest lecturer on inclusive classroom management would be invited to the next meeting to give the practitioners some practical 'troubleshooting' ideas.

INDIVIDUALISED CASE MANAGEMENT, REFERRAL AND ADVICE

'The role of a case manager is really important for coordinating services. Often the school doesn't know what the therapists are doing at the clinic. And the clinic doesn't know what is happening at the school. And nobody knows what is happening at home. I think that coordination of services as a working team between the parents of the child, and the healthcare professionals, and the educators is really important' (Researcher, KwaZulu Natal).

Two programmes observed by this study offered individualised support for children. Children benefitted from having their 'whole story' heard, and they were given advice on where to go and what services might help them. They also received referral letters to assist them in accessing relevant services. 'If a parent or teacher or a principal has a child that they are concerned about they can approach us and get support around what the best programme might be for that child. We can put them in touch with other support possibilities' (Inclusion educator, Western Cape). The referrals may assist with a wide spectrum of needs- from accessing the correct grant; finding the closest appropriate ECD or day care centre; connecting with local occupational-, speech- or physiotherapists; to following up on epilepsy medication or finding a support group for parents.

Good practice: Providing parents with advice and support for their child

Megan is a bright three year old who has Cerebral Palsy. Her main problem with getting around is that her legs are very stiff, but with a rollator and her ankle splints she can get where she needs to go most of the time. Her mother has taken her to physiotherapy since she was a baby, and her therapist is adamant that Megan should be in a play-school. Megan's mother agrees and worries that Megan is missing out by spending all day every day home alone with her. However, when Megan's mother approached the closest play-schools to where they live in Wynberg, they all refused Megan because of her rollator. They said they didn't have the 'expertise' to handle her.

Megan's mother then approached Inclusive Education Western Cape, where she was able to meet with an Inclusive Education advisor. Together they approached one of the play schools and negotiated to have Megan admitted for a trial. They were also able to discuss some ideas on how to help Megan get around, and fit in with the other children. With ongoing support the play-school has been able to successfully include Megan and learn from her. They also now understand a bit more about Megan's condition so that they can explain to the other children that although she struggles with some things, she is really just like them! Megan is doing really well, and will hopefully be ready for Grade R at the local primary school in a few years' time.

THERAPY, REHABILITATION AND MEDICAL SERVICES

'I got medical support for my child and psychological support for myself from the hospital'
(Caregiver, Eastern Cape).

'I could say the speech therapy- that helped'
(Caregiver, Eastern Cape).

'And physio and the OT and also the [Cerebral Palsy] group. It's nice to have them, I don't wana lie!'
(Caregiver, Free State).

'The first time I was bringing my child [to the daycare centre] I was told that there is occupational therapists that are coming every week. I was- you know- relieved' (Caregiver, Free State).

Medical intervention, explanation and education about a child's diagnosis and improvements in a child's medical condition was highly valued by caregivers. Many participants described that understanding their children's disabilities and seeing their children 'get a bit better' with good medical management made them feel 'stronger', 'encouraged' and 'supported' as caregivers.

However, situations in which medical staff did not take them seriously were related. For instance, when some caregivers saw their children having seizures for the first time, they retold of their frustration at being treated like 'they were seeing things'. One caregiver described

running for a nurse with painful Cesarean stitches when she saw her newborn babies eyes roll back. When the nurse came, the baby was no longer having a seizure. By the third time this happened the nurse shouted at the young 16 year old mother. A week later, she was told that it was seizures that had caused irreversible neurological damage. Another mother felt that if the doctor had listened to her, the catastrophic loss of her son's hearing could have been prevented. Caregivers appreciated it when medical personnel listened to them and trusted the information that they could provide about their children.

Caregivers also appreciated honest communication from doctors, even where the prognosis was not good. They expressed preferring frank communication to vague information in 'big words we don't understand' about the progression of their children's impairments. It was also felt that honesty from service providers would help avoid disappointment after being 'given false hope', as the following statements illustrate:

'Caregivers were getting completely wrong information from doctors who were saying the child would get better. Meanwhile the child had a severe disability. That really creates a lot of mistrust...When you have wrong information or no information it is really a problem' (Researcher, KwaZulu Natal).

'Up to now I still do not know what happened to my child. There is no doctor that has ever done a test or gave me a paper that said your child has Cerebral Palsy and this is what happened to her'
(Caregiver, Free State).

Caregivers of CWD in all the research sites expressed that stimulation and therapy had been helpful for their children. Many related improvements in function. One caregiver from deep rural Eastern Cape explained that the improvement in her child's function as a result of attending therapy had helped challenge the perceptions of the people around her: 'I got help from a physiotherapist. Because there was no other child living with a disability in my village the improvement of my child changed the ideas of the community members about disabilities. They got to understand that living with a disability doesn't mean that it's the end of the world.'

Good Practice: Rehabilitation services at a deep rural hospital

Zithulele Hospital's rehabilitation department is a good example of a rural rehabilitation service that benefits young CWD. Buhle is now three years old and has Cerebral Palsy as a result of having contracted TB Meningitis when he was young. When Buhle was first referred from the HIV clinic to the therapists, his hemiplegia meant that his motor development had regressed and he was no longer able to walk independently. The therapists assessed him and invited

Buhle and his grandmother to join their monthly therapeutic groups. Unfortunately, Buhle's home was so far from the hospital that coming regularly for therapy put his grandparents under financial strain. To get around this, the therapists booked Buhle and two other children with similar impairments, into the paediatric ward for a weeklong 'block' of therapy. This meant that for just one return fare, Buhle got ten sessions of therapy. He and his grandmother received daily Occupational Therapy and Physiotherapy throughout the week. His grandmother learnt how to hold Buhle's hips to help him practice walking, and how to use their rondavel wall at home to practice standing and strengthen Buhle's legs. Buhle was not quite able to stand by the end of the week, and the therapists did not see him for a few months. However, at their 'CP Group' last month, Buhle and his proud grandmother returned to show his remarkable improvement. Buhle can walk now, and even though he gets tired, he is able to get to the neighbouring homestead to play with his friends.



Unathi's turn for therapy has come! (Photo credit: Deb Rowes, with permission S'khumbuzo Zulu Memorial Disability Outreach Program)

Good practice: Public-private partnerships

The S'khumbuzo Zulu Memorial Disability Outreach Program and Clinic is a rural kwaZulu Natal empowerment initiative of Creighton Sunflower HELP (Health, Education and Life Projects) in association with the Pietermaritzburg and District Cerebral Palsy Association (CPA), the local DoH, DSD, other organisations.

Unathi has Cerebral Palsy and is able to attend the clinic they have established twice a month. A team of physiotherapists, occupational therapists, a dietician, dentist and a speech therapist from the local hospital visits the clinic, which is run out of a pre-school. Sometimes the team is supported also by a paediatrician and a multi-skilled Neuro-developmental Therapist, who comes all the way from Pietermaritzburg to mentor them.

Through the clinic, Unathi's caregivers received Hambisela training and a home therapy programme. Unathi himself gets much-needed therapy. In the past, around the time that Unathi's mother passed away and his grandparents started looking after him, the clinic assisted the family with clothing, food parcels, nappies, and a chair for Unathi to sit in. Unathi's grandmother has made close friends with some of the other regular attendees and they have an 'unofficial support group'. They have even begun a craft workshop and make beautiful greeting cards.

Good Practice: Toys and play

Uhambo is the Shonaquip foundation founded to promote and support the rights and equal participation of people with disabilities in their communities, create opportunities and assist in the development of people with disabilities, and provide appropriate holistic, needs driven support services, in order to positively impact the quality of life of people with disabilities.

Sivuyile is a young boy with Cerebral Palsy. Before his mother Ntokozo came to Uhambo, he was unable to communicate and could not interact with other non-disabled children or his siblings. Ntokozo was not sure of how to play with or interact with her son so Sivuyile would spend most of his time lying down or watching television at home with very little interaction with anyone. Ntokozo was introduced to the Ndinogona 'I can' stimulation kit which is designed to assist caregivers to interact with and stimulate CWD. The kit allows CWD to play and participate more in daily activities. It is colour coded, fun and easy to use. The four colour-coded themes focus on the CWD and his body, the food he eats, his family and community and the last one is centred on learning. Uhambo offered training to Ntokozo on how to effectively make use of the kit. She is most grateful that she and her family are able to engage more meaningfully with Sivuyile, and that he has toys to play with rather than passively watching TV.

ASSISTIVE DEVICES

'In terms of wheelchairs and ECD, the wheelchairs should be taken to the children and adapted as they grow so they can function in the environment optimally' (Occupational therapist, Western Cape).

As above, it was widely felt that improved access to assistive devices, such as wheelchairs and communication aids, is needed. Two key issues were identified that need to be addressed: the supply of assistive devices to local clinics, and long waiting lists. An organisation in the Eastern Cape that builds and donates assistive devices like standing frames and postural management chairs also highlighted the fact that, when assistive devices are issued, caregivers benefit greatly from fitting and demonstration of the device in the home setting. They found that this ensures that the device is appropriate for the home environment

and greatly assists caregivers, who in many cases would otherwise have to pay for private transportation to get the bulky equipment home.



Good postural management is essential for the prevention of secondary impairments and to promote function (Photo credit: Melissa Budge)

Good Practice: Facilitating access to postural management

Somila is a four-year old little girl living with her mother, granny and aunt in an under-served area near Cape Town. She is a relatively 'healthy' child but Somila has Cerebral Palsy and a severe intellectual impairment. She is dependent on 24-hour care at home. When therapists from Uhambo Foundation first met Somila and her family, it was observed that she spent most of the day on slumped on the couch at home or in a folding pram. The donated wheelchair she had been given two years ago was stacked, unused, behind their shack because she had outgrown it. Her family was unaware of how to assist her with correct positioning so as to prevent secondary problems like contractures and pressure sores. Somila's spine and legs were already developing deformities. Access to an occupational therapist specially trained in seating to assess Somila was arranged and she was referred to Red Cross Children's Hospital to be waitlisted for a new wheelchair.

She now has a wheelchair that helps her sit upright so that she can look around. Her caregivers have been taught how to look after the wheelchair and put Somila in it correctly so that her spinal curvature is corrected. They also know how to check her skin for signs of pressure sores, and understand that it is really important for Somila to change position throughout the day to avoid skin breakdown.

Good Practice: Overcoming communication disabilities

Sipho is a three year old child with Cerebral Palsy. He communicated using just a few sounds and by looking at objects he wanted. Because of the involuntary movements of his hands and head, it was difficult for him to demonstrate his intelligence. His parents were unable to communicate effectively with him and had not sent him to pre-school.

Sipho went to the Centre for Augmentative and Alternative Communication (CAAC), at the University of Pretoria, for a multi-professional consultation. The CAAC provides consultations to children and adults with severe disabilities who are unable to communicate using speech. The aim of these consultations is to support families of CWD, as well as the therapists working with them, to facilitate communication and participation.

Sipho's consultations involved an occupational therapist, physiotherapist and speech therapist. During the consultations they saw Sipho playing with toys, making choices and smiling. Using toys, cutlery, crayons and books the therapists were able to allow Sipho to communicate in a way that his parents could never have imagined. He learnt to move toys with switches even though his hands could not move them before. Sipho demonstrated the ability to use pictures to communicate his messages. He also learnt to control a communication device and select messages that are spoken for him.

Sipho's family and his team discovered strategies to support him at home and even with people that didn't know him. They realized that there were many ways of communicating that did not require speech.

Sipho's family started applying to their medical aid for funds for a communication device for him. They enrolled him at a pre-school where he is progressing well. His teachers had other CWD in the classroom, so they asked for training from the CAAC to help train the all the teachers, assistants and parents about AAC. Everyone has realized that even though Sipho could not speak, it did not mean he did not have anything to say.

6.4 Support for service providers

RELIABLE DATA ON EARLY CHILDHOOD DISABILITY

'We have CWD but we cannot categorically say that from this year to this year, we have X number of

CWD and with this nature of disability. To me it simply say we need to embark on some kind of research, you know to be able to tighten our information and to ensure that we actually base our policy making, our planning for services on data that has been collected. So we still need research, really in this area' (DSD official, Gauteng).

The dearth of accurate, disaggregated data on disability in South Africa hampers both advocacy and strategic planning for CWD. Several key informants strongly promoted the need for better data describing disability in general, and CWD under the age of five specifically. Furthermore the role of evidence-based interventions, and measuring and disseminating the outcomes of inclusive ECD services was indicated. Some research was mentioned, specifically the situational analysis of CWD in South Africa undertaken by the DSD, DWCPD and UNICEF South Africa. Work on 'profiling' of the situation facing CWD was also said to be underway in an attempt to 'map out services' and identify 'gaps', although it was confessed that six provinces are yet to start the 'profiling'.

STATE FUNDING OF GOOD PRACTICE INTERVENTIONS AND INCLUSIVE ECD SERVICES

Participants felt that it is important for good practice models to be encouraged and supported by adequate State funding. For ECD services not currently offering inclusion, one of the leading reasons was that they were unsure that their services would be able to cope with the additional cost incurred. 'If the state would provide a subsidy [for inclusion] people would not be anxious about taking [CWD] on' (Inclusive ECD manager, Western Cape). In addition, it was felt that ECD services that currently provide inclusion should benefit from State funding and support if they are to act as resource centres for other ECD services in their area.

ONGOING 'HANDS-ON' TRAINING, AND MENTORSHIP

Although there are few truly inclusive ECD services in operation, these institutions and their staff house a wealth of institutional knowledge and experience about the practical implementation of inclusion. An inclusive ECD manager said: 'We have been doing [inclusion] for 28 years. Come and see our children, come and see our classes' (Western Cape). Some inclusive ECD centres are able to provide training and mentorship on developing inclusive services, as well as modeling good practice to other service providers. Some do so already: they run courses or workshops, provide support to developing services or offer 'ECD practitioner exchange' programmes.

Many participants felt that training was an important mechanism for promoting inclusion. Most felt that training for anyone working with children in any field should have 'some understanding of childhood disability and the principles of inclusion' included in their basic training (Academic, Gauteng). It was mentioned that all ECD staff, teachers and health personnel should have a basic working knowledge of commonly found

disabilities. Further, it was suggested that those providing training should have practical experience of implementing inclusion. As one participant put it, 'There needs to be far more training input from education colleges, and serious training of trainers. In a lot of colleges we have many people who teach inclusion but who have never really lived or experienced inclusion' (Inclusion educator, Western Cape). Some such programmes are in place: a key informant from DSD in Gauteng described a 'rigorous drive' to train 'key officials' at the province and local levels on the Children's Act and ECD policy.

Some participants felt that the extension of services to young children should ideally be extended beyond the 'highly-specialised', 'professionalised' conception of ECD. It was felt that providing equitable services to all children requires broad-based improvement in the skills and competence of all people working with children. It was felt that training for people working with young children in the community was necessary for them to better understand disability: 'It would be helpful if community crèches - not ECD centres but just crèches for toddlers - [were] trained and empowered to screen, refer and access ECD services' (Physiotherapist, kwaZulu Natal).

Good Practice: Sharing experience in including CWD

Peter Pan is a pre-school in Cape Town whose classes are open to all children. Manny is almost five years old and attends one of the Grade R classes. Although Manny is on the Autism Spectrum and sometimes finds it difficult to concentrate, or needs to be reminded to be polite, the routine and skill of the practitioners at the school have done wonders. He has become a bit more flexible and his family is now able to take him with them when they go grocery shopping or on an outing to the Waterfront.

His ECD practitioner, Ruth, sometimes hosts practitioners from other centres at Peter Pan for a week at a time in Manny's class. This is so that they can come and learn how to manage a class full of children with a spectrum of impairments and differing support needs. It provides them with the opportunity to experience inclusion in practice and get hands-on training. This way Ruth is able to share her approach and experience with practitioners from all over, to help them learn how to approach true inclusion.



People with disabilities, caregivers, community health and child and youth care workers listen attend training offered by Uhambo Foundation, Afrika Tikkun and Peter Pan on disability (Photo credit: Jean Elphick)

STRENGTHENING REFERRAL PATHWAYS

'If I was a parent of a CWD and I went to hospital it would be excellent if they could know which local services and schools are able to include that child. It would be excellent if they could provide me with pamphlets about how to support my child' (Inclusion educator, Western Cape).

Strengthening the links between local crèches for young children in the community, ECD services, local clinics, therapists and social workers was emphasised as a priority. It was felt that better knowledge of available resources and services at a local level was needed. Building up networks of support is vital for assisting children to efficiently enter the public health, social development and education systems. One participant suggested that an 'ECD-trained practitioner' be situated at each clinic to assist in connecting families with local ECD services. Other participants felt that social workers were better positioned to play this role. Participatory methods such as community-mapping exercises were suggested as a good place to start identifying local resources.

SUPPORT FOR ECD STAFF

'I wish there was someone who could teach us about different disabilities- even the [ECD] teachers' (Caregiver, Gauteng).

Beyond learning about developmental milestones in their ECD training, it was felt that practitioners were not equipped with the practical skills to adapt to including children with a wide spectrum of different impairments and support needs into their classrooms. Both training on inclusion as well as ongoing support to ECD practitioners were identified as needs. 'ECD teachers are given developmental milestones when they do level four or level five³ but again there is the issue of practical application. This is where a lot of support is needed' (Inclusion educator, Western Cape).

The ECD practitioners that participated in the study demonstrated a very limited understanding of disability. One participant related that she often gets called to crèches for help in understanding 'what is going on with a child' (Physiotherapist, KwaZulu Natal). In some cases where they might have identified a child with support needs, many of them expressed that they were unsure of how to approach the situation with the child's parents. They were also mostly unclear on what other services were available to assist children with different support needs.

Providing support for children in their classes who may have a spectrum of support needs; adapting teaching styles to accommodate different ways of learning; and coping with different impairments and behavioural problems were key areas identified in which ECD practitioners require training and hands-on support. ECD practitioners who reported having recently begun including CWD in their classes expressed practical concerns about the safety of children with physical disabilities, communication and the time required for changing nappies and assisting with feeding, especially when short-staffed.

It was strongly felt that once-off training was inadequate and that an ongoing support mechanism was necessary to evolve inclusive services. 'ECD practitioners will never be therapists and for every situation where they don't know what to do they need ongoing support. This is a relief, because if something starts they will have help' (Academic, Gauteng). This support mechanism was observed in a Gauteng ECD centre. The practitioners received a two-day training workshop on inclusion to start with, followed by monthly attendance by CBR practitioners at their staff meetings. Guest speakers are invited to provide more information on disability-related topics that the practitioners identify as a need, and teachers are invited to talk about the children in their classes. Referral options for specific children are also discussed.

Good Practice: Supporting ECD programmes to include all children

Pat is a Principal from one of the ECD centres that IEWC supports. IEWC identifies community ECD centres that have shown a willingness to include young CWD and provides them with the necessary support to enable them to identify the real barriers to learning a child may be experiencing and to support each child to learn at their own level. IEWC provides ECD practitioners with training on planning for Intervention, multi-level teaching and differentiation within the classroom, utilisation of community resources, effective referrals, and positive behavior management.

Pat noticed foster mother Faiza and her child Tomi at church. She suggested Faiza bring Tomi for an interview at her ECD Centre. Apart from Pat's innate

³ This refers to ECD qualifications on NQF Level IV and V

interest in supporting all children in their learning and participation in society, IEWC offered her the tools she and her ECD practitioners required to include Tomi. Tomi has various developmental challenges and has been a happy and integrated member of the ECD centre since. Pat has supported him through her partnership with Faiza, and other support members, including professionals at Red Cross Children's Hospital. She has used the tools she was introduced to through IEWC, such as The Word Picture, which assists in identifying specific barriers; an Individual Support Plan; and various classroom strategies such as laddering activities based on developmental stages. She and Faiza are currently in conversation with IEWC's Client Support staff to figure out what options are available for Tomi's future schooling.

6.5 Support for caregivers

The indispensable role of the primary caregivers of CWD - be it parents, grandparents, relatives or guardians - was recognised by all stakeholders that participated in the study. The following themes and possible strategies emerged from the data collected.

BETTER COORDINATION OF SERVICES

'There needs to be far more collaboration in big capital letters between health, social development and education and that's not happening' (Inclusive educator, Gauteng).

The active and coordinated support of the three departments for existing ECD programmes was advocated for across the board. It was also expressed that a lack of communication as between public- and private-sector service providers has led to the duplication of efforts, with government officials 'reinventing the wheel' where NGOs have spent years developing good practice models. Several participants mentioned that better networks of support for and between service providers for young children would assist in providing more coordinated services. 'It would be useful to have a multi-disciplinary initiative because everybody works in a very isolated way. In some ways we are really reinventing the wheel...which is not a skillful way of using energy or human resources' (Researcher, KwaZulu Natal).

Multiple service providers were described as a confusing 'headache' for caregivers. A trans-disciplinary approach was advocated for where people working with young children - be they ECD practitioners or therapists, for example - develop skills beyond their professional 'pigeonholing'. Coping with the complexity of the South African context requires an 'army' that is willing and capable of stretching boundaries and addressing the 'bigger picture' of the children's lives with whom they work. 'This requires appropriate training of staff that can provide the services. It is not sufficient to teach people in a particular profession only to refer to someone else' (Academic, Gauteng).

Where inclusive programmes span multiple sectors, study participants highlighted the practical and administrative problems with different departments funding and registering different parts of their services. For instance, an inclusive ECD manager commented: 'We didn't get funding at all from DoH [and] our school is somewhat split up: two to four year olds fall in the DSD sector and our four to seven year olds fall in the DBE. It becomes difficult because everybody is not working on the same page' (Western Cape). Issues of jurisdiction also arose surrounding the individual child. For instance participants shared instances where a child placed in Grade R needed a wheelchair and both the health and education departments thought that the funding should come from the other.

To combat these issues various suggestions were made:

1 Positive planning and 'affirmative action' for inclusion of CWD as a general approach was advocated for. Interventions- from immunisation drives to nutrition programmes- should plan ahead to make sure they are accessible and available to CWD. This requires mindfulness of the needs of CWD during strategic development.

2 Formal communication channels about individual children. Better collaboration between state officials working at a local level was called for to coordinate and manage individual 'cases'. A British approach called 'Every Child Matters' was suggested where different departments meet to discuss if a child has an issue. A similar 'conference' was described by a Free State occupational therapist. Although a multidisciplinary meeting between District-based Support Team members was described, inter-Departmental 'case conferences' were not mentioned.

3 Use of a 'transition form'. Widespread use of a parent-help record of the child's development was suggested. 'We have a transition form that talks about, "Who is this child? How does this child best learn? What support has been offered? What is their particular need? What are the challenges?"' (Inclusive educator, Western Cape). It was described that children and their caregivers use the transition form at clinics, ECD programmes, and schools. A similar concept for older children, the Department of Basic Education's Grade R to Grade 10 'Learner Profile' was promoted to facilitate the 'hand-over' of children from early intervention and ECD services to the education system (the first page of the Learner Profile is detailed in the appendices). The 'Learner Profile that they fill in for every child when they go in to school and it picks up proven vulnerability: something like "does the child have a disability? Is the child getting a grant? What is the nature of the disability?"' (DBE official, Gauteng). The Learner Profile includes sections on areas in which the learner requires on-going support (in the areas of academic, emotional, behaviour, social and learning development, vision, mobility, communication). It also includes a section for ECD practitioners and educators on services related to

barriers to learning including poverty, health, disability, and social assistance.

Better use of the RtHC or RtHB could possibly assist in providing a bridge between multiple service providers. The Learner Profile should be accompanied by the RtHB, and 'the section on disability within the RtHB must be filled in' (DBE official, Gauteng).

Good Practice: Exposing therapists in training to trans-disciplinary approaches

The Adopt the Child project in Grahamstown, Eastern Cape is an example of collaboration between DoH district hospital therapists, psychology students from Rhodes University and the Association for Persons with Disabilities' (APD) physiotherapists and social worker. They joined forces with caregivers of CWDs and a local crèche coordinator, resulting in a number of successful projects have flourished. The multi-stakeholder collaboration has led to the implementation of a developmental clinic run by a multi-disciplinary team, a play-group with a toy library and, more recently, a day care centre for CWD. Caregivers of CWD are able to access therapy, Hambisela training, education and other forms of support. In addition, a good model of integrated, multidisciplinary service delivery is modeled to young therapists who are still in training.

Shannon is a third-year psychology student. For a term of her academic year, she was placed within the developmental clinic team. Initially she was nervous and felt out of her depth assessing children, conducting home visits and working with CWD. However with the support of the team and the experience of the other members, she managed to settle in and started forming close working relationships with her clients -CWD and their caregivers. After spending time in the township where her clients lived, providing activities and home programmes for CWD, their siblings and friends, she gained an invaluable understanding of family issues like single parenthood, poverty, domestic violence and stigma. This exposure, coupled with her experience of working in a team, are what Shannon will carry with her as she embarks on her career after graduating.

Good Practice: Utilisation of community resources to overcome barriers to access

Mihla was found by the community workers from the Hlanganani Ngothando Organisation- who run a day care centre in rural kwaZulu Natal- during a community visit. Milani and her two and a half year old twin sister were abandoned by their parents in the care of their grandmother. Although Mihla's twin was running around and very curious about their visit, Mihla was half her size and apathetically drinking out of a bottle. She was carried everywhere by her grandmother who was struggling to care for the sisters. Her severe physical and intellectual impairments were clearly observed. In addition she appeared to have trouble breathing.

Hlanganani Ngothando offered to admit Mihla to the day care centre but their homestead was at the bottom of a hill- totally inaccessible by car. Mihla's grandmother was also not able to bring her to carry Mihla up to the road each day. In order to get Mihla to the centre a woman who lives in the next valley was employed to carry Mihla. It is quite a walk for her but she was willing as she was in need of employment.

Mihla has been attending the centre for about a year. At the centre the children receive two meals, and physical followed-up in daily sessions- not by therapists, but by local community members who have been trained to work with the children. Mihla's chest has improved greatly as a result of her daily session on a nebulizer daily followed by chest physiotherapy. The person that treats her is supervised by a therapy manager, and gets advice from community-service therapists and a retired physiotherapist who visit monthly. She has also been seen several times by the doctors at the closest district hospital. Mihla has learnt to eat mashed food. When she first attended her distress was evident in her expression but now she smiles when someone touches her face or talks to her.

EMPOWERING CAREGIVERS WITH KNOWLEDGE AND SKILLS

'They should make information available to us about disability, at the hospital, in the maternity ward. They should give you information when you have a baby, just like they give you information when you have an HIV test' (Caregiver, Gauteng).

Many participants felt that information about development, disability and available ECD services should be made available 'wholesale', making sure that they 'reach everybody'. Information on preventing disability was called for as being necessary from when a woman falls pregnant. 'A huge amount of information coming into research... about the effect on the brain of alcohol, drugs and smoking. People are totally unaware' (Inclusion educator, Gauteng). Particularly in the Western Cape, the prevalence of Tik usage and FAS was described as problematic. A Gauteng academic promoted home visits from community-based 'health visitors', 'trained in what to look for [and] how to support [mothers]' to visit every new child born at home. This concept echoed what the role that 'nomakhayas' were said to play in the Eastern Cape.

Community-based care workers, or 'nomakhayas' were promoted by ECD practitioners in the Eastern Cape as 'helping the most'. They were said to provide practical assistance by advising caregivers to go to the clinic or a social worker; providing family support and advice; explaining to community members about the impairment of their neighbour's child and enlisting community assistance with 'babysitting'. With respect to caregivers of children identified as having developmental delays or impairments, it was felt that caregivers needed access to information about the diagnosis or disability and its management and

progression; their rights as parents and children; and the services available in their areas.

CBR was also promoted as a strategy to empower caregivers to seek the relevant services for their children and advocate on behalf of their children where services exclude them. Some evidence of empowered caregivers advocating for their children was captured. For instance a mother from Gauteng described how, at her local clinic, she challenged the practice of leaving CWD in the outpatients department 'until last':

Caregiver, Gauteng: 'When it happened to me I can't just shut up. When things happen I speak up.'

Researcher: 'Ok so how exactly did you deal with it?'

Caregiver: 'We laid a complaint and we made sure they followed that complaint until they saw it through. There is no way I am going to wait for a child that came [to the clinic] after me [to be seen before my CWD].'

Caregivers from the same focus group also expressed that they refused to accept a centre for CWD where parents were not allowed inside.

Researcher: 'So if I understand you correctly, you want a place where the parents are not separated from what's going on at the school?'

Caregiver, Gauteng: 'Yes, where I am free to come in.'

Caregiver 2: 'I agree that the parents must be involved.'

Researcher: 'Why do you think they keep you out though?'

Caregiver 3: 'They are trying to hide something. There is no supervision, so when the parent is at the gate, they want to make sure that everything is in order.'

Caregiver 1: 'When I got there, I was not happy with the place. The environment is not good for our children, the place is not even clean.'

In addition, caregivers expressed concern about centres where their children were not carefully supervised. As one Gauteng caregiver exclaimed, describing how something must have been thrown at her son but 'no one could explain because nobody was watching the children': 'What type of parent would I be if I just accept this situation?'

These strong sentiments expressed by caregivers in some cases translated into actions that promoted the improvement of service provision. Empowering caregivers with knowledge about their rights, 'boosting their confidence' and encouraging them to utilise their agency when negotiating services for their children was

advocated for as a mechanism for improving services more broadly. Many of the key informants expressed that caregivers should be seen as 'essential resources' who are able to make the biggest impact on the 'quality of life and development of their children' (Occupational therapist, Western Cape). It was felt that they 'need to be part of [any programme that promotes inclusive practice]' (Inclusion educator, Western Cape).

Some advised against increasing awareness in areas where services are not available in order not to raise 'false hopes'. It was also emphasised that caregiver 'cooperation' is needed to improve State services, and empowerment-based approaches should encourage substantive justice.

Good Practice: Community-based interventions

Two years ago Zinzi was assessed by a community child and youth care worker from the Isibindi Project in Mbotyi, Eastern Cape, as a four year old. The project was developed by the National Association of Child Care Workers using a community-based model to care for the needs of vulnerable children, those at risk and CWD. Integral to the initial assessment was Zinzi's socio-medical and therapeutic needs. Zinzi lived with her mother and grandmother in a very remote rural Eastern Cape village, far away from any hospitals or towns. Her parents are separated and her father lived in Johannesburg. Zinzi refused to be separated from her mother- she was born with bilateral club-feet and could not walk. She was also on ARV's. Although she received a CDG, her mother's two biggest concerns were her daughter's feet and her education.

Zinzi's community child and youth care worker drew up an 'independent development plan' to support her and her family, using a developmental approach. After the first home visit, Zinzi was referred to an orthopaedic clinic to see if there was any hope of having her feet operated on so that she could learn to walk. Her care worker explained to Zinzi's family the importance of attending the many appointments it took to get her feet operated on and supported Zinzi during the rehabilitation following her surgery. Zinzi is now walking on flat feet in her beautiful bright red shoes.

Good Practice: Guiding parents through the system

When Zinzi and her mother moved to Johannesburg to join Zinzi's father, Isibindi helped the family towards finding a school for Zinzi. An appropriate school was identified near her father's home by an Isibindi disability facilitator, assisted by Zinzi's child and youth care worker. They supported the family through the application process, and helped them to complete the requisite forms. They also had to accompany Zinzi to her local clinic, to get an assessment to accompany the application and liaise with Zinzi's former school to get a report. Although it is usually very difficult to secure an

assessment at a 'training centre' the Isibindi project leader was informed by the school in Johannesburg that Zinzi has been booked for an appointment in a few weeks time. As a collective, the team are preparing the family for Zinzi's upcoming assessment. Without their coordination and guidance Zinzi's family may have spent years trying to navigate the education system and find an appropriate placement.

Good practice: Comprehensive practical education for caregivers of CWD

Thabo was just a few months old, but he was very floppy, and he couldn't lift his head. A neighbour of Thabo's family have a daughter with Cerebral Palsy, so the mother recognised some signs that Thabo might need some help. Over the years Thabo's neighbours had developed a close relationship with the therapists and therapy assistants at the Parents Guidance Centre Reakgona, situated at their closest hospital, Gelukspan District Hospital, in the Northern West Province. The neighbour took Thabo and his mother to the Centre to meet the therapists and have an assessment. After meeting him, the therapists recognised that he had Cerebral Palsy too, so they enrolled Thabo and his mother on their upcoming CP course. The two of them attended their first full-time four-week course a few weeks later. Each day they would start off with a prayer, followed by interactive lessons on child development, childhood disability and understanding learning of children; practical group stimulation sessions; individual counseling and more hands-on sessions. Thabo's mother learnt how to handle and play with Thabo, how to position him and how to build on his strengths. She made friends with other parents who had also just discovered that their children may grow up with a disability. To date she has attended several courses and feels competent, not only to help Thabo reach his potential, but she can now spot other children with disabilities and refer them to the Centre.

Good Practice: Peer-led training on therapeutic management

When Precious gave birth to Thando, no one at the hospital told her that her child had Cerebral Palsy and that she would require special care. She struggled with feeding, playing and engaging her child. Although Thando started attending regular therapy sessions at their local clinic, these sessions lasted just 20 minutes once a month and this was not nearly enough. The occupational therapist at the clinic invited Precious to attend a Hambisela course, which would be taught in her home language of Xhosa by another mother of a child with Cerebral Palsy. In the early stages, she learnt how to assess Thando. Once Precious was aware of what her child's limitations were, she learnt how to engage with the Thando and what to expect. She also learnt about correct positioning of the child, feeding, playing as well as how to communicate with the child amongst other everyday activities.

PAYING ATTENTION TO CAREGIVER MENTAL HEALTH

Caregiver, Gauteng: 'I am struggling, it is hard, obviously it is hard to have two kids that are 'abnormal'. Especially now having to...have operations of eyes all the time. So now I am about to lose hope. I really need the support because now it is about four operations that I am going to do for this child.'

Researcher: 'So what kind of support do you think you would need?'

Caregiver, Gauteng: 'Like maybe people who will encourage me <starts crying>. I must not lose hope...' Many caregivers described their experiences of pregnancy, birth and raising a young CWD as 'traumatic' and 'painful', and many felt at times that they were unable to 'cope'. It was heavily emphasised, especially by caregivers in the Free State that it was really important to have someone to talk to for emotional support. For some, 'supportive family' and 'spiritual life and faith' helped immensely, however for many of the single mothers, family members and friends did not provide adequate psychological support during their children's infancy, and around the time that their children's impairments were recognised. Caregivers in all sites indicated that they felt that doctors and therapists often focused so closely on the CWD that they did not cater for the needs of the rest of the family.

A number of strategies were suggested for making better provision for the mental health care of caregivers and family members. Mother-to-mother peer-support strategies, such as Mentor Mothers, were mentioned as ways of improving support and knowledge from pre-natal stages of child development. Community-based family support service models that have been implemented in Brazil and other parts of South America were mentioned by several participants as an egalitarian approach to ECD service delivery. The self-help group element of the empowerment component of CBR was described as being helpful for enabling peer-led support of caregivers in need by providing a space to 'share stories and stress' (Caregiver, Gauteng). Participants in the Eastern Cape promoted the role of Community-based Care Workers or 'nomakhayas', although concerns about HIV-related stigma, lack of confidentiality and fairness of selection of community members to be employed as 'nomakhayas' were raised. Caregivers that participated in one of the Free State focus groups felt that counseling was the role of social workers.

Good Practice: Self-help groups for caregivers of CWD

The Sidinga Uthando Self-help Group meets weekly in a township near Johannesburg. This group is the outcome of a CBR empowerment programme. Elsbeth is a young mother of Mpho who has Down Syndrome. She is a regular member of Sidinga Uthando and explained:

'During our first meetings as a group, we focused more on learning about children's rights, particularly those of CWD. Not only did we focus on the rights of children, but we also learnt about our rights as parents of CWD. We try to meet weekly as parents facing similar challenges to come up with ways of educating our local community about different kinds of disabilities. As caregivers of CWD we felt that the community was not giving our children the respect and support that they need. We were tired of the fact that the community regarded disability as a death sentence. Most importantly, we want to support each other as caregivers.' She is now the coordinator of education and training for the group so it is her responsibility to invite and host a guest speaker at the group meeting each week. She has lined up speakers from several NGOs and local therapists to come and address the group. This has helped members to understand their children's disabilities better, make contacts with people that might be able to answer questions about individual children, and has empowered them to achieve their self-stated mission of 'being leaders in understanding our children and teaching our community to accept and love our children too'.



Dr Paul Chappell teaches Sidinga Uthando members about how to engage CWD in sexuality education using the Western Cape Forum For Intellectual Disabilities 'All About Me' manual (Photo credit: Jean Elphick)

6.5 Sustainable livelihoods

In all the sites, caregivers that had managed to find a place for their young CWD during the day, and had subsequently been able to look for a job, expressed that having the time to earn an income was extremely helpful. However, very few participants on the study were employed. Participating caregivers in Gauteng expressed how important making some sort of income was for non-South African parents because their children do not qualify for social grants. One Free State mother described her employers and colleagues as

being supportive and understanding of her situation. Their compassion allowed her some flexibility in her job. In contrast, another described how she had had to change her job to a part-time position because her son had so many appointments to attend even though he was placed in a pre-school.

6.6 Conclusion

Screening for disability and developmental delays is critical as, if properly executed, it should trigger access to vital services, allowing for the appropriate type of assistance to be provided timeously and efficiently. The merits of several screening tools were presented in the literature review including the World Health Organisation Disability Assessment Schedule (WHO-DAS); Denver II; the Ten Question Disability Screen (TQS) and the developmental screening pages of the new Road to Health Booklet (RtHB). In addition the literature review highlighted the ongoing relevance of the NCSNET recommendations on overcoming barriers to education and training for CWD from the Quality Education for All: Overcoming Barriers to Learning and Development (1997) report. Recommendations made by WHO, UNICEF and DSD's recent situational analysis of CWD in South Africa (DSD et al., 2012) were mentioned.

To support CWD the following mechanisms were promoted: timeous and fair access to Care Dependency Grants, Early Identification and Intervention; Developmental Screening using the RtHB; extension of inclusive services that address discriminatory attitudes; individualised case management, referral and advice; access to quality therapy, rehabilitation and medical services; and access to assistive devices.

To support ECD service providers findings indicated that sustainable state funding of good practice interventions; ongoing 'hands-on' training, and mentorship; strengthening referral pathways and support for ECD practitioners was promoted. A summary of early signs and risk factors identified by caregivers of CWD is presented.

The indispensable role of the primary caregivers of CWD- be it parents, grandparents, relatives or guardians- was recognised by all stakeholders that participated in the study. The following themes and possible strategies emerged from the data collected to support them: Better coordination of services and trans-disciplinary approaches; empowerment and education programmes; debriefing or counseling; and access to respite and ECD services to allow caregivers to seek employment.

The strategies identified to promote early identification, intervention and access to inclusive ECD services is punctuated with short case studies of selected examples of good practice. The services profiled include services at established ECD programmes, hospitals, clinics, NGOs and public-private collaborative projects.

Chapter 7: Research report summary

This assignment has been undertaken at the request of the South African National Department of Basic Education and United Nations Children's Fund South Africa, with the aim of:

1. Investigating the barriers that parents, caregivers and Early Childhood Development (ECD) practitioners of children with disabilities (CWD) encounter when navigating ECD services
2. Identifying pragmatic resources to promote early identification of disability by parents, caregivers and ECD practitioners
3. Developing accessible, easy-to-use resources for parents, caregivers and ECD practitioners to utilise in navigating public and private sector services such that CWD will, as they near compulsory school-going age, better access their right to an education

A literature review informed the methodologies selected for primary data collection and analysis, as well as the choice of screening tools to be field-tested. The study relied on four qualitative data collection methods to increase the validity of findings and aid detailed understanding of what the problems are, and what can be done to bridge policy implementation gaps. Methods included:

1. Focus group discussions
2. Semi-structured group interviews
3. Observations recorded in field notes
4. Structured telephonic key informant interviews

Data was collected from three groups of people who voluntarily consented to participating, from ECD centres located in Gauteng, Eastern Cape and Free State:

1. Parents or caregivers of CWD
2. ECD practitioners working with children under the age of four
3. Key informants with experience in ECD and disability

Data collected was synthesised and analysed using manual thematic analysis.

This research report outlines primary research findings pertaining to:

1. Common disabilities existing among young children in South Africa and the effect of disability on development and family life:

The children in the sample had a range of impairments including intellectual, perceptual, physical impairments. Many children had multiple impairments, communication or neurodevelopmental disabilities. Common diagnoses included Cerebral Palsy; intellectual impairment or mental disability; Epilepsy, Autism Spectrum Disorder and genetic syndromes. Although for some diagnoses there is a lack of current research and prevalence data available, the literature review presented the definition, diagnostic criteria and available prevalence data for the most common

intellectual, physical, communication, sensory, psychosocial and neurodevelopmental disabilities that present in the South African context. In addition, specific learning difficulties and multiple disabilities are discussed. Fetal Alcohol Syndrome, Epilepsy, Spina Bifida, Spinal Tuberculosis, common congenital deformities, burns, visual and hearing impairment, mental health, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, global developmental delay, Cerebral Palsy, Hydrocephalus and Down Syndrome were presented.

2. Law, policy and guidelines for young CWD in South Africa

South African legal reform has enacted a framework of enabling legislation, policy, guidelines and national instructions affecting State service provision to young CWD. These canvass, notably, the right to equality. This right has a bearing on the realisation of all other rights for CWD; no child can be discriminated against in accessing his or her human rights on the grounds of disability. The legal framework applies also to services related to the early identification of disability and the extension of inclusive ECD services. The rights of the child to health, nutrition, shelter, social services, protection from maltreatment, abuse or degradation, family care or parental care, or to appropriate alternate care and a basic education enjoy an elevated constitutional status in terms of the Constitution. The Children's Act 38 of 2005 has been promulgated with the specific object of, inter alia, giving effect to the Constitution, recognising the special needs that CWD may have and to make provision for structures, services and means for promoting and monitoring the sound physical, psychological, intellectual, emotional and social development of children. Despite the proliferation of policies, there is still a lack of a focus on dealing with CWD. Further, as with most of the policy documents in South Africa there is a need for an indication of how this will be implemented and where the funds will come from.

3. Barriers to accessing services for young CWD in South Africa

Screening for disability and developmental delays is critical as, if properly executed, it should trigger access to vital services, allowing for the appropriate type of assistance to be provided timeously and efficiently. The merits of several screening tools were presented in the literature review including the World Health Organisation Disability Assessment Schedule (WHO-DAS); Denver II; the Ten Question Disability Screen (TQS) and the developmental screening pages of the new Road to Health Booklet (RtHB). In addition the literature review highlighted the ongoing relevance of the National Commission on Special Needs in Education and Training (NCSNET) recommendations on overcoming barriers to education and training for

CWD from the Quality Education for All: Overcoming Barriers to Learning and Development (1997) report. Recommendations made by WHO, UNICEF and Department of Social Development's recent situational analysis of CWD in South Africa (DSD et al., 2012) were mentioned.

To support CWD the following mechanisms were promoted: timeous and fair access to Care Dependency Grants, Early Identification and Intervention; Developmental Screening using the RthB; extension of inclusive services that address discriminatory attitudes; individualised case management, referral and advice; access to quality therapy, rehabilitation and medical services; and access to assistive devices.

To support ECD service providers findings indicated that sustainable state funding of good practice interventions; ongoing 'hands-on' training, and mentorship; strengthening referral pathways and support for ECD practitioners was promoted. A summary of early signs and risk factors identified by caregivers of CWD is presented.

The indispensable role of the primary caregivers of CWD- be it parents, grandparents, relatives or guardians- was recognised by all stakeholders that participated in the study. The following themes and possible strategies emerged from the data collected to support them: Better coordination of services and trans-disciplinary approaches; empowerment and education programmes; debriefing or counseling; and access to respite and ECD services to allow caregivers to seek employment.

The strategies identified to promote early identification, intervention and access to inclusive ECD services is punctuated with short case studies of selected examples of good practice. The services profiled include services at established ECD programmes, hospitals, clinics, NGOs and public-private collaborative projects.

4. Strategies to promote early identification of disability and effective ECD service access for young CWD in South African

The social model of disability attributes the experience of disablement to the combination of barriers in the environment, barriers presented by the attitudes of society and barriers presented by impairments. The findings of this study included attitudinal barriers, such as stigma, prejudice and stereotyping of disability in the community and disabling attitudes of both ECD practitioners and caregivers hindered full enjoyment of ECD services. Environmental barriers were found to include the availability, coordination, accessibility and quality of existing inclusive ECD services, as well as a general lack of information about disability and community resources were identified. In addition, inadequate resource allocation was found to disincentivise inclusive practices. Finally, children with

some impairments were found to be more marginalised. These included children with severe and profound disabilities, those with multiple disabilities and those with Autism Spectrum Disorder.

The findings described the experiences of participants with respect to their reflections on parenthood, how disability affects their daily lives and the effect of having a CWD on relationships between parents, with the child's non-disabled siblings and their extended family. Overwhelmingly, the message from participating caregivers was that, although not easy, having a CWD is 'not the end of the world' and caregivers advised that others in their position should try to have faith, accept their situation, equip themselves with a support network and as much information as possible, and to remember that their CWD is a child and needs love and parenting just like all children.

Importantly the findings indicate the need for advocacy, and inform the following recommendations:

1. There is an urgent need for better prevalence data for this age cohort, as 'unaccounted' children are do not enjoy national-level planning to support their needs. As the Washington Group on Disability Statistics disability-related questions utilised by both the General Household Survey and the national Census are not appropriate for children under the age of five, adequate sets of big data indicating the prevalence of childhood disability do not exist for children from birth to the age of four years old. Research into the use of both the TQS and the RthB for these purposes is indicated.
2. In order for inclusive ECD programmes to be equally enjoyed by disabled children in the birth to four year old cohort, coordination of plans of action, budget allocation and inter-departmental communication is required, primarily between the directorates of the Department of Health, Department of Social Development and Department of Basic Education responsible for the health and development of young children.
3. Training for ECD practitioners should cover inclusive strategies throughout, as well as providing practical skills to enable practitioners to extend truly inclusive services. This importantly includes the examination of personal prejudices and attitudes about disability, as well as comprehensive knowledge with regard to typical childhood development.
4. Recognition of the value of the information captured in a child's RthB is required by parents, caregivers and ECD practitioners. ECD programmes are encouraged to make better use of the RthB. Intake and follow-up data on health, nutritional status, grant access, disability and development can be obtained from a completed RthB. Incomplete Booklets or Booklets that are not up-to-date should be referred by ECD services to a health practitioner.
5. Parents, caregivers and ECD practitioners are the most important partners in providing for CWD's early development needs. They require

unambiguous information and resources to aid timeous recognition of developmental delay and provide clear guidelines on how to follow up and access further assessment, diagnosis, management and support. Though comprehensive,

SIAS- in its current format- does not provide an accessible platform to trigger appropriate support mechanisms for the birth to four year old cohort of CWD as they approach school-going age.

References

- Ackermans, S., 2012. Managing first time seizure and Epilepsy in children. Continuing Medical Education 30.
- Addy, L., Dixon, G., 2004. Making Inclusion Work for Children with Dyspraxia: Practical Strategies for Teachers. Routledge, London.
- Adnams, C.M., 2010. Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. *Curr Opin Psychiatry* 23, 436–440.
- Alant, E., 2007. Training and Intervention in South Africa [WWW Document]. URL <http://www.asha.org/Publications/leader/2007/070814/f070814a1.htm> (accessed 1.19.14).
- Alant, P.E., Bornman, M.J., 2012. Augmentative and Alternative Communication. *South African Family Practice* 15.
- Albertyn, C., 2003. Substantive equality and transformation in South Africa. *South African Journal on Human Rights* 2, 23, 253.
- Ameh, E.A., Nwomeh, B.C., 2006. Paediatric Trauma Care in Africa: A Practical Guide. Spectrum Books Limited.
- Amod, Z., Vorster, A., Lazarus, K., 2013. Attention-Deficit/Hyperactivity Disorder (ADHD) as a Barrier to Learning and Development within the South African Context: The Perspective of Teachers, in: Banerjee, S. (Ed.), *Attention Deficit Hyperactivity Disorder in Children and Adolescents*. InTech.
- Atmore, E., 2013. Early childhood development in South Africa – progress since the end of apartheid. *Int. J. Early Years Educ.* 21, 152–162.
- Autism South Africa, 2012. Annual Report (Period April 1st 2011 – March 31st 2012). Autism South Africa, Johannesburg.
- Autism South Africa, 2014. Autism South Africa: Understand Autism [WWW Document]. Autism South Africa. URL <http://www.aut2know.co.za/understand-autism.php> (accessed 1.20.14).
- Bailieu, N., Potterton, J., 2008. The Extent of Delay of Language, Motor, and Cognitive Development in HIV-Positive Infants. *Journal of Neurologic Physical Therapy* 32, 118–121.
- Baingana, F., Alem, A., Jenkins, R., 2006. Mental Health and the Abuse of Alcohol and Controlled Substances, in: Jamison, D.T., Feachem, R.G., Makgoba, M.W., Bos, E.R., Baingana, F.K., Hofman, K.J. and Rogo, K.O. (Eds.), *Disease and Mortality in Sub-Saharan Africa*. World Bank Publications, Washington DC.
- Barberton, N. 2000. Budgeting Concerns around the Care Dependency Grant and Rough Estimates of the Cost of Extending the Grant to Children Affected by HIV/AIDS. Revised input paper to workshop on Social Assistance Policy for Children with Disabilities and Chronic Illnesses. University of Cape Town: Child Health Policy Institute.
- Barbosa, M.A.M., Pettengill, M.A.M., Farias, T.L., Lemes, L.C., 2009. Care of disabled children: social support accessed by mothers. *Rev Gaucha Enferm* 30, 406–412.
- Barratt, J., Ogle, V., 2010. Recorded incidence and management of dysphagia in an outpatient paediatric neurodevelopmental clinic. *South African Journal of Child Health* 4, 38–41.
- Baxter, P., 2011. Clinic based screening for disability – a structured approach. *Dev. Med. Child Neurol.* 53, 291–291.
- Berry, L., Biersteker, L., Dawes, A., Lake, L., Smith, C. (Eds.), 2013. *South African Child Gauge 2013*. University of Cape Town Children's Institute: Cape Town.
- Betts, J., Lata, D., 2009. Inclusion of Children with Disabilities: The Early Childhood Imperative (UNESCO Policy Brief on Early Childhood No. 46). UNESCO, Paris
- Bhabha, F., 2009. Disability Equality Rights in South Africa: Concepts, Interpretation and the Transformation Imperative. *South African Journal of Human Rights* 25, 2, 217–220.
- Biersteker, L., Streak, J., 2008. Scaling up early childhood development (ECD) (0-4 Years) in South Africa. Human Sciences Research Council: Pretoria.
- Blumenthal, R., Trengrove, E., Jandrell, I.R., Saayman, G., 2012. Lightning medicine in South Africa. *South African Medical Journal* 102, 625–626.
- Bornstein, M.H., Hendricks, C., 2013. Screening for developmental disabilities in developing countries. *Soc. Sci. Med.* 97, 307–315.
- Boezaart, T. and Skelton, A., 2011. From pillar to post: legal solutions for children with debilitating conduct disorder, in: Grobbelaar-du Plessis, I. and T van Reenen, T. (Eds.) *Aspects of Disability Law in Africa*. Pretoria University Law Press, Pretoria.
- Bradshaw, D., Bourne, D., Nannan, N., 2003. What are the leading causes of death among South African children? (Policy Brief No. 3). Medical Research Council & UNICEF, Tygerberg.
- Bratlinger, E., Jimenez, R., Klinger, J. K., Pugach, M., Richardson, V., 2005. Qualitative studies in special education. *Exceptional Children*, 71(2), 195–207.
- Bray, A., 2003. Demographics and characteristics of people with an intellectual disability. National Advisory Committee on Health and Disability, Washington DC.
- Britto, P.R., Yoshikawa, H., Boller, K., 2011. Quality of Early Childhood Development Programs in Global Contexts: Rationale for Investment, Conceptual Framework and Implications for Equity (Mathematica Policy Research Reports No. 6967). Mathematica Policy Research.
- Brown, E., Saloojee, G., 2008. Course Notes: Basic 8 week Paediatric Course in Neurodevelopmental Therapy. South African Neurodevelopmental Therapy Association, Port Elizabeth.
- Butterworth, B., Varma, S., Laurillard, D., 2011. Dyscalculia: From Brain to Education. *Science* 332, 1049–1053.
- Cameron, D.L., Nixon, S., Parnes, P., Pidsadny, M., 2005. Children with disabilities in low-income countries. *Paediatr Child Health* 10, 269–272.
- Carabin, H., Krecek, R.C., Cowan, L.D., Michael, L., Foyaca-Sibat, H., Nash, T., Willingham, A.L., 2006. Estimación del coste de la cisticercosis por *Taenia solium* en la Provincia Oriental del Cabo, Sudáfrica. *Tropical Medicine & International Health* 11, 906–916.
- Castilla, E.E., Lopez-Camelo, J.S., Campaña, H., 1999. Altitude as a risk factor for congenital anomalies. *American Journal of Medical Genetics* 86, 9–14.

- Catts, H.W., Adlof, S.M., Hogan, T., Weismer, S.E., 2005. Are Specific Language Impairment and Dyslexia Distinct Disorders? *J Speech Lang Hear Res* 48, 1378–1396.
- Centres for Disease Control and Prevention (CDC), 2003. Fetal alcohol syndrome--South Africa, 2001. *Morbidity and Mortality Weekly Report*. 52, 660–662.
- Chataika, T., McKenzie, J.A., Swart, E., Lyner-Cleophas, M., 2012. Access to education in Africa: responding to the United Nations Convention on the Rights of Persons with Disabilities. *Disabil. Soc.* 27, 385–398.
- Chin, J., 2012. Epilepsy treatment in sub-Saharan Africa: closing the gap. *Afr Health Sci* 12, 186–192.
- Christianson, A.L., Manga, P., Rosen, E., Venter, A., Kromberg, J.G.R., 2000. Epilepsy in rural South African children - prevalence, associated disability and management. *South African Medical Journal* 90, 262–266.
- Christianson, A.L., Zwane, M.E., Manga, P., Rosen, E., Venter, A., Downs, D., Kromberg, J.G.R., 2002. Children with intellectual disability in rural South Africa: prevalence and associated disability. *Journal of Intellectual Disability Research* 46, 179–186.
- Combrinck, D.H., 2012. Violence against woman with intellectual disabilities and woman with psychosocial disabilities: Promoting access to justice. Centre for Disability Law and Policy.
- Condie, D., and Morris, C., 2008. Recent Developments in Healthcare for Cerebral Palsy: Implications and Opportunities for Orthotics: Report of a meeting held at Wolfson College, Oxford, 8-11 September 2008. Oxford.
- Cloete, I., Daniels, L., Jordaan, J., Derbyshire, C., Volmink, L., Schubl, C., 2013. Knowledge and perceptions of nursing staff on the new Road to Health Booklet growth charts in primary healthcare clinics in the Tygerberg subdistrict of the Cape Town metropole district. *South Afr. J. Clin. Nutr.* 26, 141–146.
- Copley, G., 2009. An approach to hearing loss in children. *South African Family Practice* 52, 34.
- Cortina MA, Sodha A, Fazel M, Ramchandani PG, 2012. Prevalence of Child Mental Health Problems in sub-Saharan Africa: A systematic review. *Arch Pediatr Adolesc Med* 166, 276–281.
- Couper, J., 2002. Prevalence of childhood disability in rural KwaZulu-Natal. *South African Medical Journal* 92, 549–552.
- Dagher, D., Ross, E., 2004. Approaches of South African Traditional Healers Regarding the Treatment of Cleft Lip and Palate. *The Cleft Palate-Craniofacial Journal* 41, 461–469.
- De Kocker, C., De Waal, L., Vorster, J., 2006. A profile of social security beneficiaries in South Africa. Datadesk, Stellenbosch.
- Department of Education, 1995. White Paper on Education and Training, Notice 196 of 1995. Parliament of the Republic of South Africa: Cape Town.
- Department of Education, 1996. Interim Policy for Early Childhood Development. Government Printer: Pretoria.
- Department of Education, 1997. Report of National Commission on Special Needs in Education and Training and National Committee on Education Support. Government Printer: Pretoria.
- Department of Education, 1999. Consultative Paper (Department of Education. Consultative Paper No. 1 on Special Education: Building an Inclusive Education and Training System. Government Printer: Pretoria.
- Department of Education, 2001. White Paper 5 on Early Childhood Development. Government of South Africa: Pretoria.
- Department of Education, 2001. Education White Paper 6: Special Needs Education: Building an Inclusive Education and Training System. Government Printer: Pretoria.
- Department of Education, 2007. Operational Manual to the National Strategy on Screening, Identification, Assessment and Support. Government Printer: Pretoria.
- Department of Education, 2008. National Strategy on Screening, Identification, Assessment and Support. Government Printer: Pretoria.
- Department of Education, 2012. General Household Survey (GHS) 2010: Focus on Schooling. Department of Basic Education, Pretoria.
- Department of Health, 1994. Free Health Services for Pregnant Women and Children under the age of 6 years. Government Notice 657, Government Gazette 15817.
- Republic of South Africa, 1997. White Paper for the Transformation of the Health System in South Africa. 1997 Vol. 382 No. 17910.
- Department of Health, 2000. The Primary Health Care package for South Africa – a set of norms and standards. Government Printer: Pretoria.
- Department of Health, 2000. Rehabilitation for all: National Rehabilitation Policy. Government Printer: Pretoria.
- Department of Health, 2003. Free Health Care for Disabled People at Hospital level. Government Printer: Pretoria.
- Department of Health, 2003. Standardisation of provision of assistive devices in South Africa: A guide for use in the public health sector. Government Printer: Pretoria.
- Department of Social Development, 2006. Service Delivery Model For Developmental Social Services. Government Printer: Pretoria.
- Department of Social Development, 2006. Guidelines for Early Childhood Development Services. Government Printer: Pretoria.
- Department of Social Development, 2009. Policy on Disability. Government Printer: Pretoria.
- Department of Social Development, 2010. Regulations to the Children's Act. Government Printer: Pretoria.
- Department of Social Development, UNICEF, 2007. Guidelines for Early Childhood Development Services. Department of Social Development/UNICEF, Pretoria.
- Department of Social Development, Department of Women, Children and Persons with Disabilities, UNICEF, 2012. Children with Disabilities in South Africa: A Situational Analysis 2001-2011.
- Department of Social Development/ Department of Women, Children and People with Disabilities/ UNICEF, Pretoria.
- Department of Social Development and UNICEF, 2007. UNICEF South Africa - Resources - Guidelines for Early Childhood Development Services. Department of Social Development and UNICEF South Africa, Pretoria.
- Department of Welfare, 1997. White Paper for Social Welfare. Government Printer: Pretoria.

Department of Women, Children and Persons with Disabilities, 2012. Draft First Country Report to the United Nations on the Implementation of the Convention on the Rights of Persons with Disabilities. Government Printer: Pretoria.

De Kocker, C., De Waal, L., Vorster, J., 2006. De Koker, Christell, Liezel De Waal, and Jan Vorster. "A profile of social security beneficiaries in South Africa." Datadesk: Stellenbosch (2006).

Dewey, D., Kaplan, B.J., 1994. Subtyping of developmental motor deficits. *Developmental Neuropsychology* 10, 265–284.

DG Murray Trust, 2012. The DG Murray Trust Learning Brief: Providing access to intervention support for rural children with cerebral palsy [WWW Document]. URL <http://www.dgmt.co.za/2012/10/providing-access-to-intervention-support-for-rural-children-with-cerebral-palsy/#.Utz5gWT8lxc> (accessed 1.20.14).

Dunn, R., 2010. The medical management of spinal tuberculosis. *SA Orthopaedic Journal* 9, 37–41.

Durkin, M.S., 1994. Validity of the ten questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica, and Pakistan. *Epidemiology* 5, 283.

Ellery, F. Lansdown, G. and Csáky, C., 2011. Out from the Shadows: Sexual violence against children with disabilities. Save the Children.

Eide, A.H., Loeb, M.E., 2005. Data and Statistics on Disability in Developing Countries. *Disability Knowledge and Research*.

Engelbrecht, P., 2006. The implementation of inclusive education in South Africa after ten years of democracy. *European Journal of Psychology of Education* 21, 3, 253–264.

Feldman, M.A., Battin, S.M., Shaw, O.A., Luckasson, R., 2013. Inclusion of children with disabilities in mainstream child development research. *Disabil. Soc.* 28, 997–1011.

Ferguson, G., Jelsma, J., 2009. The prevalence of motor delay among HIV infected children living in Cape Town, South Africa. *Int J Rehabil Res* 32, 108–114.

Ford-Shubbrook, A., 2007. Disability inequality within Orange Farm: barriers to education for children with disabilities within a township community in Johannesburg, South Africa. University of London, London.

Forjuoh, S.N., 2006. Burns in low- and middle-income countries: A review of available literature on descriptive epidemiology, risk factors, treatment, and prevention. *Burns* 32, 529–537.

Foyaca-Sibat, H., Del Rio, A., Ibanez-Valdes, V., Vega-Novoa, E., 2004. Neuroepidemiological survey for epilepsy and knowledge about neurocysticercosis at Sidwadweni location, South Africa. *Electronic Journal of Biomedicine* 2, 40–48.

Garg, R.K., Somvanshi, D.S., 2011. Spinal tuberculosis: a review. *J Spinal Cord Med* 34, 440–454.

Geschwind, D.H., 2009. Advances in Autism. *Annu Rev Med* 60, 367–380.

Gladstone, M.J., Lancaster, G.A., Jones, A.P., Maleta, K., Mtitimila, E., Ashorn, P., Smyth, R.L., 2008. Can Western developmental screening tools be modified for use in a rural Malawian setting? *Arch. Dis. Child.* 93, 23–29.

Global Clubfoot Initiative, 2014. South Africa [WWW Document]. Global Clubfoot Initiative. URL <http://globalclubfoot.org/countries/south-africa/> (accessed 1.18.14).

Gottlieb, C.A., Maenner, M.J., Cappa, C., Durkin, M.S., 2009. Child disability screening, nutrition, and early learning in 18 countries with low and middle incomes: data from the third round of UNICEF's Multiple Indicator Cluster Survey (2005–06). *The Lancet* 374, 1831–1839.

Government of South Africa, 2005. National Integrated Plan for Early Childhood Development Early Childhood Development in South Africa South Africa 2005 – 2010. Government Printer: Pretoria.

Grantham-McGregor, S., Cheung, Y.B., Cueto, S., Glewwe, P., Richter, L., Strupp, B., 2007. Developmental potential in the first 5 years for children in developing countries. *The Lancet* 369, 60–70.

Guralnick, M., 2005. Early Intervention for Children with Intellectual Disabilities: Current Knowledge and Future Prospects. *Journal of Applied Research in Intellectual Disabilities* 18, 313–324.

Hall, K., 2013. Income poverty, unemployment and social grants, in: Berry, L., Biersteker, L., Dawes, A., Lake, L., Smith, C. (Eds.), *South African Child Gauge 2013*. University of Cape Town Children's Institute, Cape Town, pp. 90–94.

Hanass-Hancock, J., 2012. The intersection of disability and HIV in eastern and southern Africa. Praeger.

Harty, M., Alant, E., Uys, C.J.E., 2007. Maternal self-efficacy and maternal perception of child language competence in pre-school children with a communication disability. *Child: Care, Health and Development* 33, 144–154.

Hawkrige, S., Kraus, R., 2012. Child and adolescent mental health: Key challenges in the South African health system. URL: <http://www.doh.gov.za/docs/misc/2012/mental7.pdf>, (Accessed 19.12.201)

Huberman, A.M., Miles, M.B., 1994. Data Management and Analysis Methods. In *Handbook of Qualitative Research*. Denzin, N.K., Lincoln, Y.S. eds. 428–444. Thousand Oaks, Sage.

Human Sciences Research Council: Child Youth and Health Development, 2004. Going global with indicators of child wellbeing: Phase 1 & 2 Report for UNICEF South Africa. Human Sciences Research Council, Cape Town.

Ijumba, P., Padarath, A. (Eds.), 2006. South African health review 2006. Health Systems Trust, Durban.

Jacklin, L., 2006. The changing profile of autism in a clinic for children with developmental delay: A ten-year survey. Presented at the Autism Safari 2006: 2nd World Autism Congress & Exhibition, Cape Town.

Jamison, D.T., 2006. Disease and Mortality in Sub-Saharan Africa. World Bank Publications.

Judicial Condition and Rights of the Undocumented Migrants, 2003. Advisory Opinion, Inter-American Court of Human Rights (ser. A) No. 18 (2003)

Khosa v Minister of Social Development; Mahaule v Minister of Social Development 2004 6 SA 505 (CC).

Kaufman, B.A., 2004. Neural tube defects. *Pediatr. Clin. North Am.* 51, 389–419.

Krecek, R.C., Michael, L.M., Schantz, P.M., Ntanjana, L., Smith, M.F., Dorny, P., Harrison, L.J.S., Grimm, F., Praet, N., Willingham III, A.L., 2008. Prevalence of *Taenia solium* cysticercosis in swine from a community-based study in 21 villages of the Eastern Cape Province, South Africa. *Veterinary Parasitology* 154, 38–47.

- Lachman, A., Nassen, R., Hawkrigde, S., Emsley, R.A., 2012. A retrospective chart review of the clinical and psychosocial profile of psychotic adolescents with co-morbid substance use disorders presenting to acute adolescent psychiatric services at Tygerberg Hospital. *South African Journal of Psychiatry* 18, 53–60.
- Langa, P., 2006. Transformative Constitutionalism. *Stellenbosch Law Review* 3, 351.
- Lansdown, G., 2002. Disabled Children in South Africa: Progress in implementing the Convention on the Rights of the Child. Committee on the Rights of Disabled Children, Cape Town.
- Lerner, J.W., Johns, B., 2008. Learning Disabilities and Related Mild Disabilities: Characteristics, Teaching Strategies, and New Directions. Cengage Learning.
- Little, J., Cardy, A., Munger, R., 2004. Tobacco smoking and oral clefts: a meta-analysis. *Bull World Health Organ* 82, 213–218.
- Liebenberg S., 2012. Equality rights and children: Moving beyond a one-size-fits-all approach, in: Hall, K., Woolard, I., Lake, L., and Smith, C. (eds) *South African Child Gauge*. Children's Institute, Cape Town.
- Loaiza, E., Cappa, C., 2005. Measuring Children's Disability via Household Surveys: The MICS Experience. Presented at 2005 Population Association of America (PAA): Philadelphia
- Lomofsky, L. and Lazarus, S., 2001. South Africa: First steps in the development of an inclusive education system. *Cambridge Journal of Education* 31, 303.
- Lorenzo, T., 2012. Advocating for Equality in Accessing Livelihood Assets for Disabled Youth, in: *South African Human Rights Commission Equality Report- Commentaries on Equality: Race, Gender, Disability and LGBTI Issues*. South African Human Rights Commission, Johannesburg.
- Luciano, J.V., Ayuso-Mateos, J.L., Aguado, J., Fernandez, A., Serrano-Blanco, A., Roca, M., Haro, J.M., 2010. The 12-item World Health Organization Disability Assessment Schedule II (WHO-DAS II): a nonparametric item response analysis. *BMC Med. Res. Methodol.* 10, 45.
- Mafojane, N.A., Appleton, C.C., Krecek, R.C., Michael, L.M., Willingham III, A.L., 2003. The current status of neurocysticercosis in Eastern and Southern Africa. *Acta Tropica* 87, 25–33.
- Marais, S., Jordaan, E., Viljoen, D., Olivier, L., de Waal, J., Poole, C., 2011. The effect of brief interventions on the drinking behaviour of pregnant women in a high-risk rural South African community: a cluster randomised trial. *Early Child Development and Care* 181, 463–474.
- Maulik, P.K., Darmstadt, G.L., 2007. Childhood Disability in Low- and Middle-Income Countries: Overview of Screening, Prevention, Services, Legislation, and Epidemiology. *Pediatrics* 120, S1–S55.
- Mayberry, R., 2003. Cognitive development in deaf children: the interface of language and perception in neuropsychology, in: Segalowitz, S.J., Rapin, I., Boller, F., Grafman, J. (Eds.), *Handbook of Neuropsychology*. Elsevier, pp. 71–107.
- McKinstry, J., 2005. Using the Past to Step Forward: Fetal Alcohol Syndrome in the Western Cape Province of South Africa. *Am J Public Health* 95, 1097–1099.
- Meyersfeld, B., Elphick, J., and Bick, L., 2012. Written Submissions on the UN Convention on the Rights of People with Disabilities & Optional Protocol, 2012. Centre for Applied Legal Studies, Afrika Tikkun Empowerment Programme: Children with Disabilities and thier Families, Werksmans Attorneys: Johannesburg
- Millichap, J.G., 2008. Etiologic Classification of Attention-Deficit/Hyperactivity Disorder. *Pediatrics* 121, e358–e365.
- Molteno, C., Lachman, P., 1996. The etiology of learning disability in preschool children with special reference to preventability. *Ann Trop Paediatr* 16, 141–148.
- Molteno, C., Smart, R., Viljoen, D., Sayed, R., Roux, A., 1997. Twenty-year birth prevalence of Down syndrome in Cape Town, South Africa. *Paediatric and Perinatal Epidemiology* 11, 428–435.
- Muga, E., 2003. Screening for disability in a community: the “ten questions” screen for children in Bondo, Kenya. *Afr. Health Sci.* 3, 33–39.
- Mulaudzi, M., 2012. Road to health chart/ booklet. Presentation at Kalafong Hospital, University of Pretoria, URL: https://web.up.ac.za/sitefiles/file/45/1335/877/UPdate%202012_Road%20to%20Health.pdf (Accessed 19.01.2014)
- Muthukrishna, N. and Schoeman, M., 2000. From “Special Needs” to “Quality Education for All”: a participatory, problem-cantered approach to policy development in South Africa. *International Journal of Inclusive Education* 4, 317.
- Mweshi, M.M., Amosun, S.L., Ngoma, M.S., Nkandu, E.M., 2011. Managing Children with Spina Bifida in sub-Saharan Africa: The Zambian experience? *Med. J. Zambia* 38, 13–23.
- Nagarajan, R., Savitha, V.H., Subramaniyan, B., 2009. Communication disorders in individuals with cleft lip and palate: An overview. *Indian J Plast Surg* 42, S137–S143.
- Naidoo, K.S., Raghunandan, A., Mashige, K.P., Govender, P., Holden, B.A., Pokharel, G.P., Ellwein, L.B., 2003. Refractive Error and Visual Impairment in African Children in South Africa. *Investigative Ophthalmology & Visual Science*. 44, 3764–3770.
- Odding, E., Roebroek, M.E., Stam, H.J., 2006. The epidemiology of cerebral palsy: Incidence, impairments and risk factors. *Disability & Rehabilitation* 28, 183–191.
- Office of the Deputy President, 1997. Integrated National Disability Strategy White Paper. Government Printer: Pretoria.
- Op't Hof, J., Venter, P.A., Louw, M., 1991. Down's syndrome in South Africa—incidence, maternal age and utilisation of prenatal diagnosis. *South African Medical Journal* 79, 213–216.
- Organisation of African Unity, 1990. African Charter on the Rights and Welfare of the Child CAB/LEG/24.9/49. Adis Ababa: Organisation of African Unity.
- Owen, R., 2013. Clubfoot in low and middle income countries: Snapshot 2011. Global Clubfoot Initiative.
- Parbhoo, A., Louw, Q.A., Grimmer-Somers, K., 2010. A profile of hospital-admitted paediatric burns patients in South Africa. *BioMedical Central Research Notes* 3, 165.
- Patel, V., Flisher, A.J., Nikapota, A., Malhotra, S., 2008. Promoting child and adolescent mental health in low and middle income countries. *Journal of Child Psychology and Psychiatry* 49, 313–334.
- Pavone, V., Testa, G., Costarella, L., Pavone, P., Sessa, G., 2013. Congenital idiopathic talipes equinovarus: an evaluation in infants treated by the Ponseti method. *Eur Rev Med Pharmacol Sci* 17, 2675–2679.
- Pearce, M., Grey, J., Campbell-Evans, G., 2009. The inclusive secondary teacher: the leaders' perspective. *Australian Journal of Teacher Education*, 34. 6.
- Peck, M.D., Kruger, G.E., van der Merwe, A.E., Godakumbura, W., Oen, I.M.M., Swart, D., Ahuja, R.B., 2008. Burns and injuries from

- non-electric-appliance fires in low- and middle-income countries: Part II. A strategy for intervention using the Haddon Matrix. *Burns* 34, 312–319.
- Peltzer, K., 1999. Post-traumatic Stress Symptoms in a Population of Rural Children in South Africa. *Psychological Reports* 85, 646–650.
- Philpott, S., 2006. Vulnerability of Children with disability: The impact of Current Policy and Legislation, in: Ijumba P, Padarath A (Eds.) *South African Health Review*. Health Systems Trust, Durban.
- Polley, P., Dunn, R., 2009. Noncontiguous spinal tuberculosis: incidence and management. *Eur Spine J* 18, 1096–1101.
- Pompe van Meerdervoort, H.F., 1976. Congenital musculoskeletal malformation in South African Blacks: a study of incidence. *S. Afr. Med. J.* 50, 1853–1855.
- Popich, E., 2004. The development of a tool for parents for the stimulation of communication skills in infants (0-12 months) [WWW Document]. URL <http://upetd.up.ac.za/thesis/available/etd-06042004-110117/> (accessed 1.19.14).
- Prathanee, B., Dechongkit, S., Manochipinig, S., 2006. Development of community-based speech therapy model: for children with cleft lip/palate in northeast Thailand. *J Med Assoc Thai* 89, 500–508.
- Prelock, P.A., Hutchins, T., Glascoe, F.P., 2008. Speech-Language Impairment: How to Identify the Most Common and Least Diagnosed Disability of Childhood. *Medscape J Med* 10, 136.
- Preux, P.M., Druet-Cabanac, M., 2005. Epidemiology and aetiology of epilepsy in sub-Saharan Africa. *The Lancet Neurology* 4, 21–31.
- Rendall-Mkosi, K., London, L., Adnams, C.M., Morojele, N., McLaughlin, J., Goldstone, C., 2008. Fetal Alcohol Spectrum Disorder in South Africa: Situational and Gap Analysis. UNICEF, Pretoria.
- Republic of South Africa, 1996. The South African Constitution, Number 108, Government Gazette 17678.
- Republic of South Africa, 1996. The South African Schools Act number 84. Government Gazette 17579. Government Printer: Pretoria.
- Republic of South Africa, 1996. The National Education Policy Act number 108. Government Gazette 17118. Government Printer: Pretoria.
- Republic of South Africa, 2000. The Promotion of Equality and Prevention of Discrimination Act number 4. Government Gazette 20876. Government Printer: Pretoria.
- Republic of South Africa, 2005. The Children's Act number 38 Government Gazette 28944. Government Printer: Pretoria.
- Rode, H., Berg, A.M., Rogers, A., 2011. Burn Care in South Africa. *Ann Burns Fire Disasters* 24, 7–8.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B., Jacobsson, B., 2007. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl* 109, 8–14.
- Rosenblum, S., Weiss, P.L., Parush, S., 2004. Handwriting evaluation for developmental dysgraphia: Process versus product. *Reading and Writing* 17, 433–458.
- Rosenthal, J., Christianson, A., Cordero, J., 2005. Fetal Alcohol Syndrome Prevention in South Africa and Other Low-Resource Countries. *Am J Public Health* 95, 1099–1101.
- Salimbene, J.B., 2009. Biopsychosocial Risk Factors and Language Delays in a Sample of Preschool Children. ProQuest.
- 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, 230–235.
- Sayed, A.-R., Bourne, D., Pattinson, R., Nixon, J., Henderson, B., 2008. Decline in the prevalence of neural tube defects following folic acid fortification and its cost-benefit in South Africa. *Birth Defects Research Part A: Clinical and Molecular Teratology* 82, 211–216.
- Schellack, N., Meyer, H., 2012. The management of attention deficit-hyperactivity disorder in children: evidence-based pharmacy practice. *South African Pharmaceutical Journal* 79, 12–20.
- Schneider, M., Couper, J., 2007. Testing a disability schedule for Census 2011: Summary report on 26 focus groups presented to Statistics South Africa. Human Sciences Research Council, Pretoria.
- Schneider, M., Hartley, S., 2006. International Classification of Functioning, Disability and Health (ICF), and Health, in: CBR as Part of Community Development. University College London, Centre for International Child Health, London.
- Seddon, J.A., Donald, P.R., Vlok, G.J., Schaaf, H.S., 2012. Multidrug-resistant tuberculosis of the spine in children—characteristics from a high burden setting. *J. Trop. Pediatr.* 58, 341–347.
- Seedat, S., Nyamai, C., Njenga, F., Vythilingum, B., Stein, D.J., 2004. Trauma exposure and post-traumatic stress symptoms in urban African schools Survey in CapeTown and Nairobi. *The British Journal of Psychiatry*, 184, 169–175.
- Sherwin, J.C., Lewallen, S., Courtright, P., 2012. Blindness and visual impairment due to uncorrected refractive error in sub-Saharan Africa: review of recent population-based studies. *Br J Ophthalmol* 96, 927–930.
- Siapkara, A., Duncan, R., 2007. Congenital talipes equinovarus: a review of current management. *J Bone Joint Surg Br* 89, 995–1000.
- Singer, M., Webb, A.R., 2010. Trauma and burns, in: Oxford Handbook of Critical Care. Oxford University Press.
- Snowling, M.J., Hulme, C., 2012. Annual Research Review: The nature and classification of reading disorders – a commentary on proposals for DSM-5. *Journal of Child Psychology and Psychiatry* 53, 593–607.
- South Africa National Commission on Special Needs in Education and Training, South Africa National Committee on Education Support Services, 1997. Quality education for all: overcoming barriers to learning and development: report of the National Commission on Special Needs in Education and Training (NCSNET), National Committee on Education Support Services (NCESS). Department of Education, Pretoria.
- Springer, P.E., van Toorn, R., Laughton, B., Kidd, M., 2013a. Characteristics of children with pervasive developmental disorders attending a developmental clinic in the Western Cape Province, South Africa. *South African Journal of Child Health* 7, 95–99.

- Srour, M., Mazer, B., Shevell, M.I., 2006. Analysis of Clinical Features Predicting Etiologic Yield in the Assessment of Global Developmental Delay. *Pediatrics* 118, 139–145.
- Statistics South Africa, 2013. General Household Survey (GSH) 2012. Pretoria.
- Suliman, S., Kaminer, D., Seedat, S., 2005. Assessment techniques and South African community studies of trauma and posttraumatic stress disorder in children and adolescents. *Journal of Child & Adolescent Mental Health* 17, 55–62.
- The Smile Foundation (2014) Cleft Lip and Palate, URL: <http://www.smilefoundationsa.org/medical/cleft-lip-palate/> (Accessed 20.01.2014)
- Theunissen, M., Swanepoel, D., 2008. Early hearing detection and intervention services in the public health sector in South Africa. *International Journal of Audiology* 47, S23–S29.
- Thomson, J., Raskind, W., 2003. Genetic influences on reading and writing disabilities, in: Swanson, H.L., Harris, K.R., Graham, S. (Eds.), *Handbook of Learning Disabilities*, Second Edition. Guilford Press, New York.
- Thorburn, M., Desai, P., Paul, T.J., Malcolm, L., Durkin, M., Davidson, L., 1992. Identification of childhood disability in Jamaica: the ten question screen. *Int. J. Rehabil. Res.* 15, 115–127.
- Thornton, C., Underwood, K., 2013. Conceptualisations of disability and inclusion: perspectives of educators of young children. *Early Years* 33, 59–73.
- Twoy, R., Connolly, P.M., Novak, J.M., 2007. Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners* 19, 251–260.
- UN Committee on the Rights of the Child, 2005. General Comment No. 7, Implementing child rights in early childhood CRC/C/GC/7/Rev.1. Geneva: United Nations.
- UN Committee on the Rights of the Child, 2006. General Comment No. 9, The Rights of Children with Disabilities CRC/C/GC/9/Corr.1. Geneva: United Nations.
- UN Committee on the Elimination of Discrimination against Women, 1993. General Recommendation 18, Disabled women A/46/38, reprinted in *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6. Geneva: United Nations.
- UN Committee on Economic, Social and Cultural Rights, 2009. General Comment No. 20. Non-discrimination in Economic, Social and Cultural Rights, E/C 12/GC/20. Geneva: United Nations.
- UN General Assembly, 1989. Convention on the Rights of the Child, Treaty Series, vol. 1577. Geneva: United Nations.
- UN General Assembly, 2006. Convention on the Rights of Persons with Disabilities A/RES/61/106. Geneva: United Nations.
- UN General Assembly, 2006. Convention on the Rights of Persons with Disabilities.
- UNICEF, 2013. State of the World's Children 2013- Children with Disabilities, 2013. UNICEF: New York.
- Werner, D., 2009. Disabled village children: a guide for community health workers, rehabilitation workers, and families. Hesperian Foundation.
- Urban, M.F., Chersich, M.F., Fourie, L.-A., Chetty, C., Olivier, L., Viljoen, D., 2008b. Fetal alcohol syndrome among grade-one children in the Northern Cape Province: prevalence and risk factors. *South African Medical Journal* 98, 877–882.
- Urban, M.F., Stewart, C., Ruppelt, T., Geerts, L., 2011. Effectiveness of prenatal screening for Down syndrome on the basis of maternal age in Cape Town. *South African Medical Journal* 101, 45–48.
- Van Niekerk, A., Rode, H., Laflamme, L., 2004. Incidence and patterns of childhood burn injuries in the Western Cape, South Africa. *Burns* 30, 341–347.
- Van Niekerk, A., Seedat, M., Menckel, E., Laflamme, L., 2007. Caregiver experiences, contextualizations and understandings of the burn injury to their child. Accounts from low-income settings in South Africa. *Child: Care, Health and Development* 33, 236–245.
- Venter, P.A., Christianson, A.L., Hutamo, C.M., Makhura, M.P., Gericke, G.S., 1995. Congenital anomalies in rural black South African neonates—a silent epidemic? *South African Medical Journal* 85, 15–20.
- Viljoen, D.L., Gossage, P.J., Brooke, L., Adams, C.M., Jones, K.L., Robinson, L.K., Hoyme, E.H., Snell, C., Khaole, N.C.O., Kodituwakky, P., Asante, K.O., Findlay, R., Quinton, B., Marais, A.S., Kalberg, W.O., May, P.A., 2005. Fetal Alcohol Syndrome Epidemiology in a South African Community: A Second Study of a Very High Prevalence Area. *J Stud Alcohol* 66, 593–604.
- Warf, B.C., 2010. Pediatric Hydrocephalus in East Africa: Prevalence, Causes, Treatments, and Strategies for the Future. *World Neurosurgery* 73, 296–300.
- Wehby, G., Murray, J., 2010. Folic acid and orofacial clefts: a review of the evidence. *Oral Diseases* 16, 11–19.
- Werner, D., 2009. Disabled village children: a guide for community health workers, rehabilitation workers, and families. Hesperian Foundation.
- Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Another 2011 (5) SA 87 (WCC).
- WHO, 2001. Mental Health: New Understanding, New Hope, 2001. World Health Organization: Geneva
- WHO, 2004. Atlas: country resources for neurological disorders 2004 : results of a collaborative study of the World Health Organization and the World Federation of Neurology, [WWW Document]. URL http://apps.who.int/iris/handle/10665/43075?mode=simple&submit_simple>Show+simple+item+record (accessed 1.15.14).
- WHO, 2010. WHO Community-Based Rehabilitation Guidelines [WWW Document]. WHO. URL <http://www.who.int/disabilities/cbr/guidelines/en/> (accessed 21.01.2014).
- WHO, 2012. Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries: a review [WWW Document]. WHO. URL http://www.who.int/maternal_child_adolescent/documents/development_difficulties_early_childhood/en/index.html (accessed 1.8.14).
- WHO, 2013. Deafness and hearing loss [WWW Document]. WHO. URL <http://www.who.int/mediacentre/factsheets/fs300/en/> (accessed 1.19.14).
- Wickenden, M., Cornielje, H., 2012. How can we crack the CBR Evaluation nut? Exploration of possible innovative approaches to impact evaluation of CBR.

Williams, T., Samuels, M., 2001. The Nationwide Audit of ECD Provisioning in South Africa.

Wright, G., and Noble, M. (2009) The South African Index of Multiple Deprivation 2007 at Municipality Level, Pretoria: Department of Social Development

Wright, G., and Noble, M. (2012) Spatial inequality: Persistent patterns of child deprivation in South African Child Gauge 2012. University of Cape Town Children's Institute: Cape Town.

Zaman, S.S., Khan, N.Z., Islam, S., Banu, S., Dixit, S., Shrout, P., Durkin, M., 1990. Validity of the "Ten Questions" for Screening Serious Childhood Disability: Results from Urban Bangladesh. Int. J. Epidemiol. 19, 613–620