An analysis of the prevalence of children with disabilities and disabling chronic illnesses in the Western health sub-district of Cape Town, and the services available for them.

by

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DECLARATION

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LIST OF ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
CDG	Care dependency grant
FT	Full time
HIV	Human immunodeficiency virus
ICD 10	International classification of diseases version 10
ICF	International classification of functioning, disability and health
LAMIC	Low and middle-income country
MeSH	Medical Subject heading
NHIS-D	National Health Interview Survey on Disability
NOS	Not otherwise specified
NPO	Non-profit organization
NSH	New Somerset Hospital
OT	Occupational therapist
Physio	Physiotherapist
Child PIP	Child Healthcare Problem Identification Programme
PMTCT	Prevention of mother to child transmission (of HIV)
QUICC	Questionnaire for Identifying Children with Chronic Conditions
RCWMCH	Red Cross War Memorial Children's Hospital
SA	South Africa
SASSA	South African Social Security Agency
SCC	Special care centre
SLT	Speech and language therapist
TQQ	Ten Question Questionnaire
US	United States
WHO	World health organization

GLOSSARY OF TERMS

Care dependency grant: A social grant provided by the South African Social Services Agency to the family member responsible for the care of a disabled child. The child should be severely disabled and require full time and special care in order to qualify. Children between the ages of 0 and 18 years qualify. Households earning above a certain amount per month do not qualify.

Chronic health conditions: "Conditions must have a biological, psychological, or cognitive basis; have lasted or are virtually certain to last for one year; and produce one of the following sequelae: (1) limitations of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development; (2) dependency on one of the following to compensate for or minimize limitations of function, activities or social role: medications, special diet, medical technology, assistive device, or personal assistance; and (3) need for medical care or related services, psychological services, or educational services above the usual for the child's age or for special ongoing treatments, interventions, or accommodations at home or in school."[1]

Children with special health care needs: "Those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[2]

Dependent on technology: The US Office of Technology Assistance in 1987 defined the technology-dependent child as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and on going nursing care to avert death or further disability." The children comprised four main groups, namely: (i) ventilator dependence; (ii) intravenous medication/nutrition; (iii) devices used for other nutritional/respiratory support eg. Gastrostomy, tracheostomy, home oxygen; (iv) other medical devices.

Disability: The following definition is taken from the United Nations Convention on the Rights of Persons with Disabilities 2006: "Persons with disabilities include those

who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[3]

Disabling chronic illness: Disabling chronic illness is a subset of the group of identified as having '*chronic health conditions*' or '*children with special health care needs*,' whose condition results in some degree of functional or activity limitation.

Full service school: The definition of a full service school, as set out by the South African Department of Education in June 2005, is a "mainstream education institution that provides quality education to all learners and students by supplying the full range of learning needs in an equitable manner."[4] The philosophy underpinning a full service school is one of celebrating diversity and inclusive education.

Special care centre: institutions that cater for children with severe intellectual disability, or children with multiple disabilities who cannot be accommodated within special schools. Generally managed privately or by non-profit organisations, as very few government institutions exist. There is no standard educational curriculum or rehabilitation programme followed.

Special school: school catering for learners whose special educational needs cannot be met in a mainstream or full service school. These schools generally cater for a specific special need eg. Cerebral palsy, autism, moderate intellectual disability etc. These schools may follow the national curriculum, or a set alternative curriculum. At high school level, they tend to focus on practical rather than academic subjects.

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ABSTRACT

An analysis of the prevalence of children with disabilities and disabling chronic illnesses in the Western health sub-district of Cape Town, and the services available for them.

INTRODUCTION

Children with disabling chronic illnesses are known to have complex and frequently unmet health care needs. Limited information exists in South Africa regarding the prevalence of children with disability, as well their needs and utilization of services. The purpose of the current study is twofold: (1) identify the number of children known with disability, or disabling chronic illnesses in the western health sub-district of Cape Town; (2) analyse the health services that currently exist for these children.

METHODS

A period prevalence survey was conducted between January 2010 and December 2011. Numerous sources of information were sought to identify as many children with disabling chronic illness as possible. These included the referral hospitals for the Western sub-district, namely Red Cross War Memorial Children's Hospital and New Somerset Hospital, as well as the institutions where children with disability are cared for or educated, and relevant non-profit organisations in the disability sector. Information was gathered between January 2011 and Sept 2012. All results were entered into an electronic database, and duplicates were identified. Non-hospital facilities also provided information on equipment, staff, and amount of ancillary support from medical and allied health professionals. University of Cape Town ethics approval was received prior to commencement (HREC 425/2011).

RESULTS

A total of 1138 children were identified with a disabling condition, giving an estimated prevalence of 1% in the Western sub-district. Eleven out of 18 facilities that were contacted responded. The number of families receiving care dependency grants was 1748. Only 14% of children in facilities attended one of the referral

hospitals during the two year period analysed. The institutions ranged from 62 to 100% of capacity, with an average of 91%. The carer-to-child ratio in the special care centres averaged 1: 4.4, and in the special schools 1:11.8. Medical as well as allied health professional support to special care centres and special schools was very variable and generally quite limited.

CONCLUSION

Significantly fewer children with disabling chronic illnesses were identified than would be expected. The majority of institutions were at or near capacity in spite of this fact. Given the small percentage of children attending hospital, the lack of medical and allied health professional support to children in the community is of concern in terms of their chronic care. The methodology used in this study to calculate the prevalence of children with disability has numerous limitations. The difficulty in identifying these children highlights the lack of adequate information systems. Better information is required for adequate health service planning.

CHAPTER 1 - INTRODUCTION

Children with disabilities and disabling chronic illnesses represent a vulnerable sub-set of the childhood population whose medical, social and educational needs are diverse and complex. It is well known that disabled children, particularly in poorer settings, frequently have unmet needs and do not access the health and educational services essential to their wellbeing.[5] As a result, they are at high risk of not attaining their basic human right as stated in the UN Convention on the Rights of the Child, namely "the right of the child to the enjoyment of the highest attainable standard of health, and to facilities for the treatment of illness and rehabilitation of health."[6]

The Convention puts the obligation on the State to "strive to ensure that no child is deprived of his or her right of access to such health care services". In South Africa (SA), children's rights have been prioritised in government agendas since 1994, and are clearly outlined in the South African constitution (Act no: 108 of 1996). In spite of this, children with disabilities remain largely invisible and neglected members of society. There is a gap between policy and implementation.[7] There is also a paucity of information regarding the prevalence of disabled children, the adequacy of the services that exist for them, and their health and quality of life outcomes.[8–10]

This study was undertaken in the hope that it would shed some light on the extent of the problem in terms of the number of children with disability or disabling chronic illnesses and the services that exist for them. It was also hoped that the methodology would reveal how existing information sources in the health and education systems could be used to provide this information. The intention was that this information could then be used to assist in the planning of health and educational services for disabled children.

This information is timeous in that it comes in the aftermath of the recent High Court ruling of 2010 that found in favour of the plaintiff (Western Cape Forum for Intellectual Disability) against the national government (Case no. 18678/2007). In the ruling it was stated that the state must ensure that "…… every child in the Western Cape who is severely and profoundly intellectually disabled has affordable access to a basic education of an adequate quality…." Historically, children with moderate to severe disability that have not been able to be accommodated in the

educational system, either mainstream or special schools, have been cared for in special care centres. These centres have provided this service without any government funding or subsidy, under the independent management of private or non-profit organisations. As a result of this verdict, multidisciplinary district teams have been set up to look at the transition of the current educational system towards the inclusion of severely disabled children. In this context of change, it is hoped that this study will provide further information not only on the state of services for disabled children, but whether the current information systems in existence are able to accurately represent the scale of the problem to policy makers.

The first aim of this study was therefore to calculate the prevalence of children with disability or disabling illness in the Western sub-district of Cape Town. A review of the literature revealed that no recent prevalence studies on childhood disability had been done in South Africa (SA). In addition to this, previous studies were mostly conducted in rural settings. Given recent trends in urbanization, it was felt that a more recent, urban study would provide valuable information.

Most prevalence studies have used door-to-door or population based surveys. This study used an alternative methodology of attempting to use existing information sources to count the number of disabled children that are 'known' to the health or special needs educational services. By comparing this with the expected number, based on previous prevalence studies, it was possible to estimate the 'gap' between the number of children needing services and the number of children actually receiving them.

The second aim of this study was to provide an overview of the needs of children with disability, and undertake a brief analysis of the services that exist to meet them. The needs of children with disability are diverse and complex, but in fact have been inadequately described, particularly in lower income countries.[11] The World health organization's (WHO) International classification of functioning, disability and health (ICF) framework is a valuable tool that has been used extensively in international literature to describe and assess the needs of disabled people.[12] However, despite its recommended use by the WHO, it has not been widely adopted in SA and other lower and middle-income countries.[12–14]

It was beyond the scope of this study to analyse the needs of children in detail. Instead, through the use of facility-based questionnaires, a cursory overview of the level of dependence of children, as well as the support from medical and allied health professionals was obtained. This provided some insight into the chronic care of children with disability and their access to services.

This thesis begins with a review of the literature regarding the prevalence of disability amongst children, focusing on South African data and research from similar lower and middle-income countries.

There are two main findings in this study. The first is that far fewer children were identified than expected. The significance and validity of this finding are discussed in great detail. The second is that the access of disabled children to medical and allied health professional care seems very limited, and the care of children with chronic disabling conditions occurs largely outside of specialist services.

CHAPTER 2 - LITERATURE REVIEW

2.1 INTRODUCTION

The primary purpose of this study was to calculate the prevalence of children with disabilities and disabling chronic illnesses in the Western sub-district of Cape Town. A secondary objective was to analyse the health services that currently exist for children with disability. This literature review begins by reviewing some of the literature around the definitions of disability and chronic illness, and how the use of different definitions or conceptual frameworks affects the measurement of disability or disabling chronic illnesses. The literature review then focuses on prevalence studies of disability, as well as a description of some of the health service models that exist.

With regards to prevalence, the focus was on literature from low to middle income countries (LAMICs), and particularly to find all the available information on the prevalence of children with disability in South Africa. LAMICs were felt to be the most appropriate for comparison for two reasons. Firstly, it is known that disability disproportionately affects the poor, and therefore the prevalence in likely to be higher in LAMICs. Secondly, challenges in the measurement of disability have some underlying causal similarities in such countries.

2.2 SEARCH STRATEGY

The PubMed database was searched for articles related to children with disability and children with special health care needs. Medical Subject Headings (MeSH) terms included “Children with disability” and “prevalence” or ”epidemiology.” All searches were limited to English articles, involving humans, and dealing with children under the age of 18 years, and restricted to the last 10 years. This yielded 318 citations, of which 23 abstracts were read. Most of the articles were discarded based on the title, which did not seem to indicate that the article would be relevant. Articles that focused on a specific condition (for example, head trauma) or a specific aspect of the care of children with disability (for example, dental caries) were excluded. Only epidemiological studies aimed at the measurement of children with disability were selected. After review of the abstracts, 11 full text articles were selected for further reading.

From these articles several further articles were obtained from the list of references. Emphasis was given to measurements of disability in general, rather than looking at the prevalence of specific conditions.

A separate search for the prevalence of "disabling chronic illness" showed considerable overlap with the aforementioned search strategy. In fact, the term did not really appear at all in the literature. Instead, the terms "chronic childhood conditions" and "children with special care needs" were predominantly used to describe a group of children that would include children with disabling chronic illnesses. Separate PubMed searches with these terms obtained similar articles to those found with the initial search.

To ascertain data regarding the prevalence of childhood disability in South Africa specifically, the same key words of "disabled children" and "prevalence" were used and the term "South Africa" was added. No time period restrictions were applied. This generated 113 articles, of which 12 abstracts and 9 full text articles were reviewed. A number of articles were deemed irrelevant based on their title. Articles that simply were describing a single condition, such as Down's syndrome, were excluded. Only articles that focused on ascertaining the prevalence of disability in general, or the main categories of disability, such as cerebral palsy or intellectual disability, were included. An attempt was also made to find 'grey' literature specific to South Africa. This revealed a limited number of articles, many of which were unable to be accessed.

2.3 DEFINITIONS OF DISABILITY AND DISABLING CHRONIC ILLNESS

Disability presents challenges in terms of definition and measurement. The World health organization defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in life situations."[15] The complexity of the interaction between different factors within an individual, and between that individual and the society in which he or she lives, are some of the factors that make both the measurement and management of children with disabilities challenging. An

alternative definition is that of Newacheck: "disability is defined as a long term reduction in ability to conduct social role activities, such as school or play, because of a chronic physical or mental condition."[16] The lack of a consistent or universal definition applied in the research for measuring disability is one of the likely reasons for wide variations in prevalence.

The attempt to define children with chronic conditions that result in disability has continuously evolved over the last three decades. Stein *et al* were among the first to seek to create a definition that went beyond a mere condition based category, but rather incorporated a non categorical approach to chronic health conditions.[17] The definition they created is as follows: "Conditions must have a biological, psychological, or cognitive basis; have lasted or are virtually certain to last for 1 year; and produce 1 of the following sequelae: (1) limitations of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development; (2) dependency on one of the following to compensate for or minimize limitations of function, activities or social role: medications, special diet, medical technology, assistive device, or personal assistance; and (3) need for medical care or related services, psychological services, or educational services above the usual for the child's age or for special on going treatments, interventions, or accommodations at home or in school."[1,18]

In another one of the early attempts to broadly capture children with chronic conditions that result in some form of disability, the federal Maternal and Child Health Bureau described 'children with special health care needs' as "those who have or at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*"*[2]

Van der Lee *et al* conducted a systematic review of the literature looking at the various definitions that have been used to define the concept of children with chronic health conditions or special health care needs.[19] The most frequently used terms were *chronic health conditions*, *chronic conditions, chronic illness,* and *children with special health care needs*. Most of the frequently cited definitions are based upon definitions suggested either by Newacheck[2] or Stein.[1]

2.4 MEASURING DISABILITY

The measurement of disability is affected by a number of factors. As mentioned above, the first factor is the actual definition of disability or disabling chronic illness that is used. A second factor is the approach or paradigm used to identify or classify children. Examples of different paradigms include using a list of conditions to measure prevalence of disability versus using questionnaires designed to detect functional or activity limitation. Further factors include methodology used and sampling techniques.

2.4.1 FRAMEWORKS FOR DIAGNOSING DISABILITY

Mudrick has discussed how differing definitions and/or paradigms used can have an effect on the estimated prevalence.[20] The literature includes either prevalence of specific conditions, or the assessment of functional[a] or activity[b] limitation through the use of specific questions in population based surveys or specifically designed tools.

A commonly cited study is that of Newacheck *et al* who suggested that 6.5% of non-institutionalized children could be classified as experiencing some form of disability.[16] In this study, disability was defined as any reduction in the ability to perform a normal social activity, occurring as the result of a chronic condition. The basis for this study was the 1994 National Household Interview Survey on Disability (NHIS-D) conducted in the United States. The conditions that were the main cause of disability were impairments of speech, sensory impairments, intellectual disability, respiratory conditions (including asthma), and mental health disorders.

Stein *et al* developed the Questionnaire for Identifying Children with Chronic Conditions (QUICC) to identify children with chronic conditions. The QUICC was based on a specific theoretical framework consisting of three components, rather than by diagnostic label. The three components were: (I) functional limitations, (ii)

[a] A functional limitation is defined as a restriction in activity due to a chronic health condition. Also sometimes referred to as 'participation limitation'.
[b] An activity limitation is defined as a difficulty encountered by an individual in executing a task or action.

dependence on compensatory mechanisms, and (iii) service use or need beyond routine care. Based on this definition, they found the prevalence of chronic childhood conditions to be 14.8%.[18] Within this group, 9.5% of children were found to have functional limitations.

Mudrick noted that increasingly the consensus in measuring disability is to focus on activity or functional/participation limitation, rather than based on specific condition diagnoses.[20] She also noted that the inability to perform certain social or other roles might be the result of societal or environmental influences, rather than individual factors.

2.4.2 METHODOLOGIES FOR MEASURING PREVALENCE

Various methodologies are used to determine prevalence estimates. Population based surveys seem to be one of the commonest methods. In this method, questions designed to identify chronic conditions or functional/activity limitations are included within a population survey. In the case of children, this will generally be by parent report, and the responses will not be verified at all. Thus the recognition of disability or function/activity limitation rests with the parents.

Another method commonly used is a population screening tool. Normally these are two stage studies where an initial screen is then confirmed or refuted by clinical assessment or use of a more sophisticated developmental assessment tool. Various screening tools exist, and they can be administered by trained health care professionals, or rely on parent report. Examples include the Vinelands Adaptive Behaviour Scale or Denver Developmental Screening Test. Through a survey of the literature, it seems that the most commonly used screening tool is the Ten Question Questionnaire (TQQ). This has been validated in several countries.

The advantage of a screening tool is that it tends to be more accurate, with fewer false positives and negatives. This is especially the case where there is a two-stage design. The disadvantage is that the study cohort may be limited in terms of size and feasibility because of the requirement of trained people to administer the tool.

Hutchison *et al* conducted a study in the United Kingdom comparing medical records, population surveys, and parent report, and found a high degree of agreement between the various sources.[21]

2.5 PREVALENCE OF DISABILITY AND CHRONIC CONDITIONS IN CHILDREN

The WHO World Report on Disability 2011 estimated that there were 95 million (5.1%) children under the age 15 years with moderate or severe disability, of which 13 million (0.7%) were severely disabled.[14]

If one broadens the definition to any developmental disability, Boyle *et al* found the prevalence among US children aged 3-17 years increased from 12.8% to 15% in the period 1997-2008.[22] The conditions covered were attention deficit hyperactivity disorder, autism, intellectual disability, cerebral palsy, significant hearing loss, blindness, learning difficulties and other developmental delays, as reported by parents in the NHIS. The increase was seen in all the conditions described above, except hearing loss, although the greatest increase was largely attributable to ADHD (6.7%) and autism (7.7%).

The number of children living with chronic illnesses and/or dependent on technology is recognized to be increasing.[19,22] The reasons for this include improved child survival and long term life support strategies, increasing awareness and recognition of developmental disabilities, and broader definitions.

VD Lee *et al* showed in their review how wide the range of childhood chronic conditions could be based on definition, different operationalization, and population surveyed.[19] Estimated prevalence ranged from 6.5% to 37%.[2,16,23] Prevalence tended to increase in older age groups. Rates varied depending on how restrictive the definition of chronic condition was. The authors also commented on the lack of a standard measure or definition to identify when chronic conditions are classified as disabling.

2.5.1 PREVALENCE IN LOW AND MIDDLE INCOME COUNTRIES

Maulik and Darmstadt conducted a comprehensive review of the literature regarding childhood disability in low and middle-income countries.[11] They found a paucity of

adequate epidemiological studies, which often produced quite disparate results, as will be detailed below. They noted that many studies did not meet accepted scientific standards of research. Lack of standardization in the definition of disability, variations in methodology and diverse population sampling resulted in a wide range of estimated prevalence figures.

The prevalence of overall disability ranged from 0.4% in Bahrain to 12.7% amongst the two lowest socioeconomic groups in India. A door-to-door survey in Nepal yielded an overall prevalence of 1%, with a large predominance of physical disability (89%). In Ethiopia an overall prevalence of 3.1% was found, compared to Ghana that was 1.8%, and China that was 2.7%, of which intellectual disability formed the majority at 1.8%.[11]

The most commonly used screen for studying overall disability was the Ten Question Questionnaire (TQQ). Durkin *et al* presented the findings of an international study validating the Ten Question Questionnaire in three low to middle income countries.[24] The population in all 3 studies was 2 to 9 year old children. It was a two-phase study design. In phase 1, trained community workers used the TQQ. All children that screened positive with the TQQ, as well as a group of children that had screened negative, underwent further clinical evaluation. Physicians or psychologists performed the evaluations, and standard assessment tools such as the Denver Developmental Screening Test were used to confirm developmental delay or disability.

The rates of children who screened positive were 82 per 1000 in Bangladesh, 147 per 1000 in Pakistan, and 152 per 1000 in Jamaica. In Jamaica, Thorburn *et al* found an overall prevalence of childhood disability of 9%, with intellectual disability comprising 8% of this group.[25] Overall the sensitivity of the TQQ was high (80-100) and the specificity good (0.85 to 0.92).[24]

Mung'ala-Odera screened over 10000 children in rural Kenya using the TQQ and found an overall prevalence for neurological impairment of 61 per 1000.[26] Epilepsy was the commonest domain (41 per 1000), followed by cognition (31) and hearing (14), with motor disability only comprising 5 per 1000.

Rates of intellectual disability ranged from 0.2 to 6%.[11] In 2009, reviews on intellectual disability from Asia,[27] Africa[28] and Latin America[29] consistently identified a lack of information to determine accurately the prevalence in these regions. In Asia it was estimated to be between 0.06 & 1.3%, while in China a prevalence of 6.6% was found.

Gladstone reviewed the literature regarding the prevalence of cerebral palsy in low income countries.[30] Prevalence in India and China was 1.5% and 2.5% respectively.

2.5.2 SOUTH AFRICAN DATA

In 2001, Theresa Guthrie, on behalf of the Child Health Policy Institute, published a paper summarizing the literature on disability and chronic illness prevalence in children in South Africa. Her opening statement highlighted the findings of experts at a workshop on research priorities in childhood development, held in 2000, who "stressed that childhood disability was still inadequately described in the region."[9] It is noteworthy that very little has been published since her report. Essentially, robust epidemiological data on children with disability in South Africa is lacking. The information that is available can be divided into two groups: small-scale prevalence studies and national surveys.

South African disability prevalence studies

Some of the earliest studies have been conducted in the 1980's and 1990's. Molteno *et al* followed up a cohort of 1000 children, and screened them for developmental disability. Their study found 4 children with severe disability.[31]

Disler *et al* undertook a door-to-door survey to detect rates of locomotor disability in the Cape peninsula. They surveyed 2072 people (8.5% of households) in a black African residential area, and 9112 people (33% of households) in a mixed ancestry (Coloured) residential area.[32,33] They reported a prevalence of locomotor disability of 18.3 per 1000 in the African population and 11.2 per 1000 amongst the mixed ancestry population in the under 15 year old group. This is one of the few studies to be conducted in an urban setting.

Couper and Christianson each published prevalence studies in rural settings.[34,35] Christianson *et al* screened 6692 children between the ages of two to nine years for

intellectual disability over the period 1993 to 1996. Of these children, 10.8% screened positive using the Ten Question Questionnaire (TQQ). These children then went on to have a further developmental evaluation using the Griffith Mental Development Scale by a paediatrician. The prevalence of severe intellectual disability was found to be 6.4 per 1000, and mild intellectual disability was 29.1 per 1000. Of the children with intellectual disability, 8.4% had cerebral palsy.

The same group published their final results in 2008, looking at overall disability rather than just intellectual disability.[36] They found an intellectual disability rate of 3.6% and motor disability rate of 0.5%. Visual and hearing impairment rates were 0.5% each, to give an overall prevalence of disability of 4.3% in the two to nine year old age group.

Couper used the TQQ in rural Kwazulu Natal to screen 2036 children under the age of 10 years.[35] The TQQ was modified to screen children under the age of two years for disability (although this was unvalidated). Community workers did the first phase of screening using the TQQ, and then a rehabilitation team consisting of two occupational therapists and two other members of the team confirmed the presence of disabilities. They found a confirmed prevalence of 60 per 1000, made up of mild intellectual disability 17 per 1000, motor disability 28 per 1000, hearing loss 20 per 1000, and moderate to severe intellectual disability 6 per 1000. In the age-group under two years, the overall disability rate was 20 per 1000.

Corneljie found a rate of 52 per 1000 in a rural area using unstandardized developmental screening questions.[37]

More recently, Giarelli *et al* studied the prevalence of developmental disabilities and behavioural problems in a cohort of Grade R and 1 pupils.[38] They used the Ten Question Questionnaire and the Developmental-behavioural checklist short form to screen for developmental disabilities and behavioural problems. They found that 42% of children screened positive for possible developmental disability. Although there was no second phase to confirm the diagnosis of a developmental disability, this percentage is still significantly higher than the 18.7% reported by the school as the number of children known with developmental problems. This suggests a marked under-recognition of potential problems and a significant underestimation of

the burden of disease. It is hard to know how generalizable these results are to the rest of the South African population, as this was a rural school population in the Winelands area, which is known to have a very high incidence of fetal alcohol spectrum disorder.

South African national surveys

The last District Health survey was conducted by the Department of Health and the Medical Research Council in 2003.[39] This reported overall disability for the 0-19 year old population as 5.3%. The breakdown of disability in this survey is as follows: Visual 1%, Hearing 0.3%, Speech 0.1%, physical 2.6%, intellectual 1.3%. It was not specified in the report on what basis respondents reported disability.

The General Household Survey is conducted by Statistics SA on a regular basis, and has included screening questions for disability since 2009. The questions are designed to self-report disability, and have been adapted from what is described as "the Washington group." The under five population is excluded, as the questions are not felt to be sensitive enough. The most recent edition is from August 2012, where an overall prevalence of disability in the population was estimated to be 5.1%, with the majority of this being amongst adults.[40] This figure is likely to under-represent childhood disability for a number of possible reasons. Some of these reasons include the fact that the under five age group was excluded, that there is stigma attached to having a disabled child, and due to failure of parents to detect subtler or milder forms of disability.

2.6 HEALTH SYSTEMS AND SERVICES FOR CHILDREN WITH DISABILITIES

Children with disability have increased usage of health care services.[2,19] For a variety of reason, these children commonly have substantially unmet health care needs.[41] One of the problems has been the inadequate description or understanding of the complexity of their needs from health services. There has been a progressive shift in thinking over the last three decades around defining and categorizing the needs of disabled children. Traditional medical models which categorized patients by diagnostic codes have been shown to be inadequate in designing health services that adequately cater for children with disability or chronic illness.[17]

The 'medical home' model

The 'medical home' model is one such model that has been specifically designed to prevent the unmet needs of people with disability. A medical home has the following attributes: "accessible, family-centred, continuous, comprehensive, coordinated, compassionate, and culturally effective." Homer *et al* reviewed all the available literature to show moderate support that the medical home model was effective in improving health provision and outcomes for children with special health care needs.[41] The lack of an adequate primary health care medical home has been shown to be a barrier to accessing needed supportive and therapeutic services for the families of children with special needs.[42] In spite of the purported benefit of this model of community based care, often the difficulties and burdens experienced by families are under-estimated, and the cost and extent of these services means that, even in resource rich settings, the ideal of comprehensive community based care is seldom reached.[5]

The WHO International Classification of Functioning, Disability and Health

In 2001 the World Health Organization released its International Classification of Functioning, Disability and Health (ICF).[43] The ICF attempts to describe populations not just in terms of diagnostic coding but also functional ability. This has resulted in important changes in use of terminology and approaches to thinking about the care of people with disabilities. Cerniauskaite *et al* [12] and Jelsma[44] have independently reviewed the use of ICF in the literature. They both found that the ICF is being used extensively in developed countries to describe disability, but that its use in developing countries is limited. The framework has been used in South Africa to describe the functional limitations of HIV positive adults.[13]

The South African context

Services for children with disability have been studied in South Africa. Cartwright and Grover described services for children with mental handicap in the Witwatersrand and Western Cape province areas respectively.[45,46] They found a significant discrepancy in terms of provision of services between ethnic groups, and a serious under-provision of services, especially for the black African population. More recently, Saloojee *et al* conducted an analysis of the unmet needs of disabled

children in a peri-urban township setting, using 'snowball sampling' to obtain a convenience sample.[8] Of 156 disabled children, only 44% of children of school-going age were in school, and only 26% were receiving rehabilitative therapy. Only 28% of children that were assessed as needing an assistive device actually received it. This study highlights the large gap between need, provision and uptake of services for disabled children. Research done by the Department of Social Services showed that children with disabilities have inadequate access to health services and appropriate schooling, and also that there was insufficient information for programme planning.[10]

2.7 CONCLUSION

It is clear from this review of the limited literature on the subject that there is a large discrepancy between resource rich and resource poor countries in terms of their literature base and consequent understanding of the burden of childhood disability in their respective populations.

In general, there is a paucity of research in childhood disability in low and middle income countries. Much of the research that has been done has limitations in terms of generalizability or validity. In terms of prevalence, commonly used strategies such as the Ten Question questionnaire, with or without a second confirmatory phase, are likely to result in under recognition or under reporting of milder forms of disability. With regards to services for children with disability, Maulik *et al* [11] highlight the lack of research in this area.

In South Africa specifically, there is a lack of research. Regarding prevalence studies, there is no recent research in urban and peri-urban contexts. There is little research characterizing the temporal profile and needs of children with disability, and very little looking at health system models and service utilization. The national surveys in South Africa are likely to be significantly under-representing the burden of childhood disability across the country.

Recent studies, such as that by Giarelli *et al* [38] show that the burden of disability, particularly milder forms of developmental disability, could be significantly under-estimated in South Africa. In terms of health care delivery, Saloojee *et al* have

described a significant under utilization of services in a peri-urban setting, and the situation is likely to be worse in rural settings.[8]

The research focus internationally seems to be shifting towards a more holistic view of children and the consequences of their disability. This includes identifying the functional, social and environmental limitations that children may experience. In fact, in order to allow adequate service planning, children simply 'at potential risk' for increased utilization of health services are counted, in order to estimate the burden of childhood disability. Currently however, the literature has not moved to a standard approach to defining and characterizing the needs of disabled children, such as that provided for by the use of the ICF framework. Research using this tool remains limited, especially in children.

Good and reliable information that enhances our understanding of the burden and needs of children with disability is missing. Information that health care professionals as well as policy makers and health planners require in order to make informed decisions does not exist. This lack of information represents a barrier to the realisation of the rights of disabled children to attaining the highest possible standard of health. This study aims to increase the information available in order to inform health planners and stake holders and ultimately improve health services and care of disabled children.

CHAPTER 3 - AIMS & OBJECTIVES

AIMS

The main aim of this study was to calculate the prevalence of children with disability and disabling chronic illness, under the age of 18 years, in the Western health sub-district of Cape Town. A secondary aim was to obtain a cross-sectional analysis of the facilities and health services that exist for these children.

OBJECTIVES

1. To collect and collate information from as many sources as possible in order to calculate the prevalence of children with disability and disabling chronic illnesses in the Western health sub-district.
2. To obtain information about the services available to children with disability, including documenting the care needs of children in special care facilities, as well as the staffing levels and capacity in these facilities.
3. To quantify the allied health and medical support available to children in special care facilities.
4. Identification of problem areas in the chronic care of children with disability or disabling chronic illnesses.

CHAPTER 4 - METHODS

4.1 STUDY POPULATION

The study population included children with disability, disabling chronic illness and/or dependent on medical technology, between the ages of 0-18 years, living within the Western health sub-district. The Cape Town metropole is divided into Metro West and Metro East, each with four sub-districts. The other sub-districts in the Metro West metropole include Klipfontein, Southern and Mitchells Plain. For a map of the Cape Town metropole delineating the sub-districts as represented in the 2007-8 District Health Plan,[47] see Appendix 1.

Geographical area

The Western health sub-district of Cape Town was chosen because it is the drainage area for the hospitals where the investigators worked, namely New Somerset Hospital (NSH) and Red Cross War Memorial Children's Hospital (RCWMCH). NSH is one of three level two (regional) hospitals in the Metro West metropole, and serves as the referral facility for the Western sub-district. As not all the sub-districts have level two referral hospitals, the presence of such a hospital in the Western sub-district was felt to be advantageous in terms of identifying as many children as possible. It was not feasible to obtain a sample which included the entire Cape Town metropole, given the time and resource constraints.

The following population and health indicator figures are taken from the 2012 Situation Analysis of Metro West.[48] According to the projected 2007 statistics, the Western sub-district is the smallest of the four sub-districts in Metro West. In 2011, the projected under five year old population in Western was 35794, which comprised 19.8% of the under five population in Metro West. The 5-18 year old population was 76455, which comprised 18.7% of this age-group in Metro West.

Age range

The age range of 0-18 years was chosen because it allowed for comparison with the Care Dependency grant (CDG)[c] as a potential reference population, as well as national census data. It should be noted that RCWMCH and New Somerset Hospital paediatric services only see children up to the age of 13 years, although children known with chronic conditions may be kept in the paediatric services longer before being transitioned, due to the lack of adequate adolescent services. There is no strict age limit applied to the special care centres or special schools, where children may be until their early 20's. However, children over the age of 18 were excluded from the analysis.

Time period for data collection

Patients were identified at New Somerset Hospital (NSH) over the 6 month period from January to June 2011. Information was obtained from the electronic patient administration system at RCWMCH for the time period from January 2010 to December 2011. It was felt that children with disabling chronic conditions would visit the hospital at least once within a two-year period. Information from other non-hospital sources was received between December 2011 and December 2012, mainly due to delayed responses. Although the time period reported on by the institutions was not within the same time period as the hospitals, due to the low turnover of children in institutions and the chronicity of their condition, it was not felt that this would significantly affect the results in any way. As the accumulation of information from multiple sources took place over a period of several months, this is a period prevalence estimate.

4.2 INCLUSION AND EXCLUSION CRITERIA

Children with disability/disabling chronic illness

Children were included if they were attending a special school or special care centre[d], or if they were on the database of a non-profit organisation supporting children with disability.

[c] See glossary of terms
[d] See glossary of terms

Children attending NSH were identified based on the opinion of the local paediatrician. Children were identified from the RCWMCH patient administration system through a list of pre-selected International Classification of Diseases version 10 (ICD 10) diagnostic codes. The clinical knowledge and experience of the investigators were used to compile the list of ICD 10 codes (Appendix 2). Predominantly neurological, neurodevelopmental and genetic conditions were considered. Chronic illnesses that were felt likely to have a fairly inevitable progression towards some activity or functional limitation, such as cystic fibrosis, were included. Children with conditions with variable prognoses were excluded. These were conditions that would not necessarily result in disability, such as certain epilepsy syndromes or neuro-metabolic conditions.

Children whose chronic condition would simply result in above average use of medical services (which fulfils the definitions of 'chronic health condition' or 'children with special health care needs' – see Glossary of Terms above) were not included.

Children dependent on technology

In terms of children dependent on technology, two main interventions were measured, namely home oxygen and tracheostomy. These children were identified through databases kept by the relevant organisations that provide the service to them. Home peritoneal dialysis and gastrostomy were excluded, as a large percentage of children with these interventions would have a non-permanent or non-disabling chronic illness, and it was not possible to distinguish these groups in the context of this study.

4.3 METHODS OF DATA COLLECTION

An attempt was made to identify and contact all possible sources of information, in order to identify as many children as possible known with disability or disabling chronic illnesses. The following potential sources were identified:

- RCWMCH Patient administration system (Clinicom). This allows for electronic patient record keeping and patient file management, including a

record of hospital attendances/admissions and diagnostic codes, amongst other things.

- New Somerset Hospital Paediatric Out-patients department and general paediatric ward admissions
- Educational or care institutions where children with disability would attend school or day care. In Cape Town, these are mainly comprised of special care centres and special schools.
- Non-profit organizations involved in the disability sector
- Private organisations that provide a service to the state sector, such as rehabilitation, or technology based services such as home oxygen.
- South African Social Security Agency

Table 1 summarises the information obtained from various data sources. Diagnostic information was only available from RCWMCH Clinicom data and NSH data.

Table 1 Information obtained from each data source

DATA SOURCE	NO. OF CHILDREN	NAME	DEMOGRAPHIC INFO	DIAG-NOSIS	LEVEL OF DEPEND-ENCE	SERVICES INFO	EQPT
RCWMCH Clinicom	■	■	■	■			
NSH	■	■	■	■			
Special care centre	■	■	■		■	■	■
Special school	■	■	■			■	
NPO	■	■	■				
Private org	■	■	■				
SASSA	■						

Red Cross Children's Hospital patient administration (Clinicom) system

Mrs Tessa Strauss, Information manager for the Department of Health, obtained data from the RCWMCH patient administration system on 16 August 2012. The period analysed was 1 January 2010 to 31 December 2011, and included all out-patient attendances and hospital admissions.

In order to identify children with disability/disabling chronic illness from the Clinicom system, children were selected either by ICD 10 diagnostic codes (Appendix 2) or by their attendance in a specialist clinic.

The following specialist clinics were selected:

- Neurodevelopmental
- Cerebral Palsy
- Spinal Defects
- Neuromuscular clinics.

The data from admissions, out-patients attendances and specialist clinics was collated and entered into an electronic database – a more detailed description of the data processing follows in section 4.4.

Personal identifiers (name and date of birth) were collected, as well as age, sex, postcode and ICD 10 diagnostic code. The decision to include personal information was made to allow for the detection of duplicates. This was critically important due to the multiple data sources used. Appendix 3 lists the postcodes used to further identify children only from within the Western sub-district.

New Somerset Hospital Paediatric OPD and ward admission

Patients were identified from the New Somerset Hospital out-patients department over a six month period from January to June 2011. One of the investigators (AW) identified children with disability or disabling chronic illness. Patient details and

diagnoses were manually captured. This information was subsequently entered onto the electronic database.

Special care centres

Institutions were identified through local knowledge or experience of the investigators, and via the Directory of services 2011 for Children with Special Needs produced by the Child Care Information Centre[49] - see Appendix 4 for list of special care centres. A snowball approach was also used, with identification of additional centres as a result of personal communication with people in the field. It was assumed, for the purposes of this study, that children currently placed in special care centres or special schools were appropriately placed, without the need to verify their condition.

The centres were sent two forms to complete, either by email or fax (see Appendix 5 & 6). The forms were accompanied by an introductory letter (Appendix 7), a parental consent letter requesting parents' to consent to sharing their child's personal details (Appendix 8), and an explanatory letter (Appendix 9). The original emails were sent in November 2011. If there was no reply to the original fax or email, then centres were contacted a second or third time, as well as telephonically.

The information requested from the centres was divided into two parts, namely information regarding the children in the centre (see Table 2 and Appendix 5), and information regarding the centre itself (Table 3 and Appendix 6).

Table 2 – Data table for children in special care centres

NAME OF INSTITUTION	NAME	AGE	SEX	FEEDING	MOBILITY	TOILETTING	EQPT

The information on the children included:

- Personal demographical: name, age, sex, race
- Level of dependence with respect to feeding, toileting and mobility
- Any medical equipment/assistive devices the children required, such as Shona buggies, etc

There was no formal assessment tool used to assess the degree of disability or dependence in the children. Instead, all that was requested was an informal assessment, by the relevant manager or principal, of whether they thought the child was independent, partially dependent, or fully dependent, with regards to the three areas mentioned.

The information regarding the institution itself included:

- Number of children at the institution, and the institution's total capacity
- Number of teachers/carers at the institution
- Allied Health professional support - number of days per month
- Medical support (Doctor, psychiatrist, nurse) – number of days per month
- Devices available eg. Buggies, standing frames, side-liers, etc.

Table 3 – Institutional data from special care centres

NAME OF INSTITUTION	NO. OF CHILDREN	TOTAL CAPACITY	NO. OF TEACHERS	PHYSIO	OT	SPEECH	DOCTOR	NURSE	PSYCH	DEVICES

Special schools/education department

The Heads of Special Education for the relevant Western Cape Education Department districts were contacted telephonically, in order to identify special schools in their areas that were likely to have children with disability or disabling chronic illnesses. Furthermore, the Directory of Services 2011 for Children with Special Needs was used to identify and contact schools that were known to serve children from across the metropole, due to their unique service. The list of schools that were contacted can be found in Appendix 4.

Several special schools in the Western Cape provide fairly unique services to a specific sub-group of children with disability. Examples would include Athlone School for the Blind, or the schools for children with autistic spectrum disorder such as Vera and Alpha. As such, they generally have children from throughout the metropole, and not just from their immediate geographical drainage area. Therefore, despite being located outside of the Western sub-district, these schools were also requested to provide the details of any of their learners residing in the Western sub-district. It was assumed that they would be aware of most of these learners because of the school transport system.

Non-profit or private organisations

Non-profit organizations that are involved in the care or education of children with disability were identified using the Directory of services 2011 for children with special needs. Organisations that were contacted are included in Appendix 10. Organisations were contacted either by email or telephonically.

Vitalaire is the company contracted to the Department of Health in the Western Cape to provide home oxygen to patients. The company provided the names and addresses of children residing in the Cape Town area that were contracted to receive home oxygen. From this database, children from the relevant geographical area were identified.

The data of children on the home tracheostomy programme at RCWMCH Children's hospital is kept in a private database. This was obtained with permission from the programme coordinator, and children from the relevant areas were added onto the electronic database.

Key role players/researchers

A number of academic experts in the field were contacted, to seek information from unpublished sources, and particularly to access information from a recent government survey of disabled children. These people were identified through networking, or through scanning the internet for locally published and unpublished literature.

Private Health/Education sector

The 2011 Directory of Services for children with special needs does not include many of the private schools and institutions that provide services to children with disability, especially those in higher socioeconomic groups. Such institutions were identified by an online search or through word of mouth (snowball effect from contacting other institutions). A remedial class in a local private school within the relevant area (Elkhana House), as well as a private crèche (Lilliput Pre-Primary school) were identified but not contacted, as the number of children seemed to be small, and the level of disability mild.

South African Social Security Agency

The South African Social Security Agency (SASSA) administrates the distribution of care dependency grants. In order to qualify for a care dependency grant, a child must be younger than 18 years, not be living in a residential institution, and have a severe disability requiring full time and special care. Information regarding the number of care dependency grants currently utilized in the Western sub-district was sought through contacting the local and national SASSA offices.

Information was requested on two separate occasions, from two different people, regarding the number of care dependency grants claimed by people residing in the

Western sub-district. (For list of postcodes see Appendix 3). As home address is not routinely recorded on the SASSA national database, obtaining this information was difficult.

Interpretation of the initial set of results was unclear (See Results section 5.1.6). Consequently, a second attempt was made to request the same information. However, on this occasion the information was obtained according to the address of the local SASSA pay-point rather than home address. The assumption was that most of the people receiving the CDG from the specific pay-point would reside within the proximate area.

4.4 DATA PROCESSING AND ANALYSIS

The information from all sources was collated into three parts in the first phase of data processing (see Figure 1). The three data sets from the RCWMCH Hospital Clinicom system, namely admissions, out patient attendances and specialist clinics, together with the names of children from New Somerset Hospital, were collated into one data set, and duplicate names were identified and removed. For example, a child may have attended a specialist clinic four times over the two-year period. Therefore three duplicate entries would have been removed from the data set. This information made up the combined hospital data set.

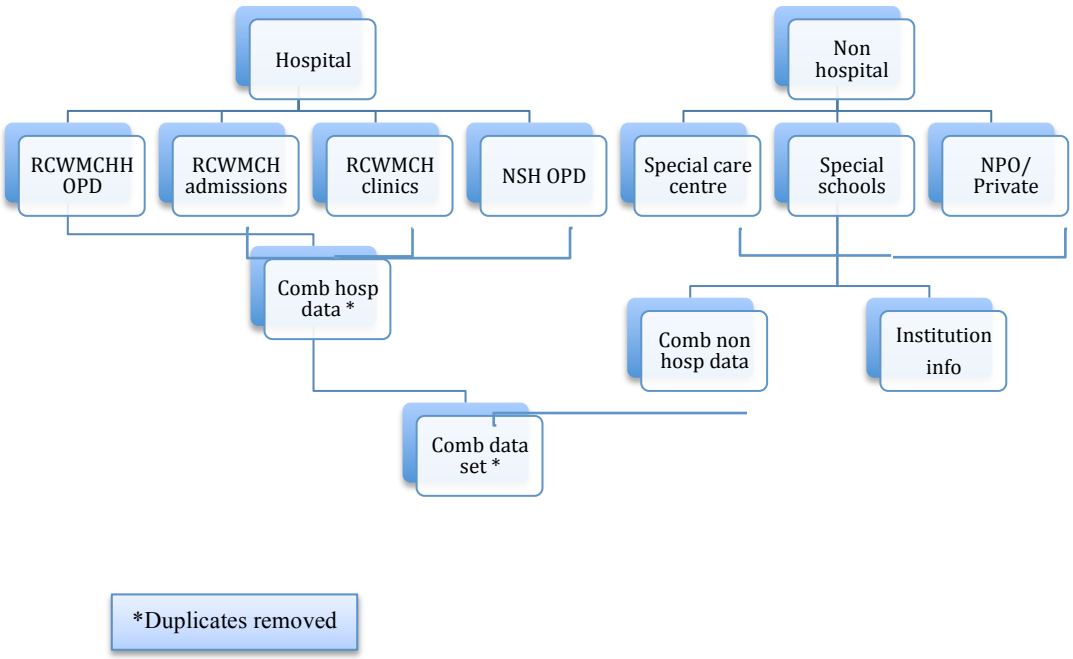
The next part involved collating all the information from the non-hospital sources. This information was divided into two parts, namely information regarding the children in the institutions, and information about the institution itself. Upon receipt of information from the various sources, this data was collated into the non-hospital data set or the institutional information data set.

The final step in data processing involved combining the hospital and non-hospital data sets. It was necessary to re-format the age data, as most of the children from the non-hospital data set did not have a date of birth, but rather age in years. Thus, where date of birth was known, age was calculated as at 16 August 2012, the day

when the hospital information from the RCWMCH Clinicom system was accessed. Statistical analysis was then done on the 'age in years' data.

Once the two data sets had been combined, this allowed the second stage of identification and removal of duplicates, using name and age/date of birth information. The source location of the duplicates enabled the identification of the number of children from special care centres/special schools that had attended either of the hospitals during the study period. Basic statistical analysis of the combined final dataset, including mean and range of age, and sex distribution, was done using Microsoft Excel.

Figure 1 – Data processing of information sources



4.5 ETHICS

Prior to capturing any information, the study received ethics approval from the University of Cape Town's Research Ethics committee (HREC: 425/2011) and the RCWMCH Children's Hospital Research Ethics Committee. The superintendent of RCWMCH Hospital gave permission for accessing the hospital's electronic database.

CHAPTER 5 – RESULTS

5.1 PREVALENCE OF DISABILTY OR DISABLING CHRONIC ILLNESS AMONG CHILDREN

A total of 1138 children 18 years and younger in the Western sub-district were identified as being disabled or having a disabling chronic illness. Table 4 details the sources through which these children were identified.

Table 4: Number of children by source

Source	No. of children
RCWMCH Children's Hospital	545
New Somerset Hospital OPD	14
Special care centres (SCC)	162
Special schools (SS)	395[e]
Non-profit organisations (NPO)	27[f]
Private organisations	1[g]
TOTAL	**1138**

The total number of children for which personal information - name, age and sex – was available was 858. The mean age of this group was 8.1 years, with a range of 3 months to 18.6 years. The median was 7.6 years with a standard deviation of 4.6, suggesting a broadly distributed and positively skewed population, as would be expected. There was a male:female ratio of 1.4:1.

[e] This number excludes Filia school, which has 182 children at the school. Due to its location, it will undoubtedly have a number of children from the relevant area, but this information was not available.
[f] The only NPO which provided information was Autism Western Cape
[g] Vitalaire provided information on children on home oxygen

5.1.1 CHILDREN ATTENDING HOSPITALS

A total of 559 children were identified through their hospital attendance. Of these, 545 children were identified through the RCWMCH Clinicom system, and 14 at New Somerset Hospital.

5.1.2 CHILDREN IN SPECIAL CARE CENTRES

Five special care centres in the Western sub-district were requested for information, and four of the centres provided information regarding the children in their facility, as well as information regarding the facility itself. Jo Slovo was the only special care centre that did not return information (see section 5.3). Table 5 shows the number of children at each facility, as well as the total capacity and current percentage of capacity of the centres. A total of 162 children were identified. Where the total number in an individual facility was higher than the number of children from the Western sub-district, this was most likely due to one of two reasons. Firstly, there were 'children' over the age of 18 years in the centre. Secondly, there were children living outside of the Western sub-district attending the centre. The information was provided by the facility managers.

Table 5 – No. of children in special care centres

Institution	No. from Western sub-district	Total no.	Capacity	% Capacity
Wilge	23	30	30	100,0%
Friends	73	112	120	93,3%
Emmanuel	36	47	75	62,7%
Elundini	30	30	40	75,0%
JoSlovo/Ukwanda	-	-	-	-
TOTAL	**162**	**219**	**265**	**82,6%**

5.1.3 CHILDREN IN SPECIAL SCHOOLS

There were 395 children identified through special schools (Table 6). Most of the schools had learners from outside the Western sub-district, in which case they were

only requested to provide the details of children from the relevant areas. The information was provided by the principals of the schools. Filia School, being located in Goodwood, was likely to have a significant percentage of its learners from the Western sub-district. However, as the school was unable to give an exact number, these children were not included in the total of children with disability.

Table 6 – No. of children in special schools

Institution	No from Western SD	Total	Capacity	% of capacity
Molenbeek	123	164	165	99,4%
Peter Pan	18	60	70	85,7%
Dawn	214	233	233	100,0%
SEAL College	14	14	14	100,0%
Athlone school for the Blind	6	420	450	93,3%
Vista Nova	12	440	480	91,7%
Mountain View	8	-	-	-
Filia	-	182	182	100,0%
TOTAL	**395**	**1513**	**1594**	**95,7%**

5.1.4 CHILDREN IDENTIFIED THROUGH NON-PROFIT ORGANISATIONS

The only non-profit organization that provided any information was Autism Western Cape. The Autism Western Cape database identified 30 children from the Western sub-district area. Of these 30 children, 3 children had attended RCWMCH during the study period.

5.1.5 CHILDREN DEPENDENT ON TECHNOLOGY

Two additional sources of information were used to identify children dependent on technology. Firstly, information on all children with tracheostomies was obtained from a database maintained by Sr Jane Booth, who currently runs the tracheostomy and home ventilation programme at RCWMCH. Ten children from the Western sub-district were identified through analysis of this database, but all of these had already been identified through the RCWMCH Clinicom search.

Secondly, a single company, Vitalaire, has the tender to provide home oxygen to children who need it in the Western Cape. They provided the details of all children currently in the Western Cape on home oxygen. Only 1 child was from the Western sub-district.

5.1.6 CHILDREN RECEIVING CARE DEPENDENCY GRANTS

Two sets of data were received from the South African Social Security Agency (SASSA). The first set of information received from the SASSA national head office is presented in Table 7.[h] This was the information provided when asked to give the number of care dependency grants (CDG's) per residential postcode. In the table, postcode 8000 refers to the regional SASSA office. It was unclear whether all the people that collect their care dependency grant from this office reside in the Western sub-district. However, it seemed more likely that, being a regional office, this represented a greater proportion of the metropole than simply the Western sub-district. The regional office was not contactable in order to clarify this, despite recurrent attempts to get a response.

Table 7 – Number of care dependency grants by postcode

Postcode	**No. of CDG's**
7300	2
7405	6
7441	2
7460	1
8000	3366
8001	8
8051	1
TOTAL	**3386**

[h] Information obtained 30/10/12 from Mr S Malange

Information was then requested a second time from SASSA head office, this time using the address of the local SASSA pay-point, rather than home address. This data is presented in Table 8.[i] This method identified a total of 1748 care dependency grants from pay-points within the Western sub-district.

Table 8 – No. of CDG's by local pay-point

Pay-point	No. of CDG's
ATLANTIS: REG.11 BACKPAY	1
CAPE TOWN	9
CPS POSTBANK PAYMENTS	1438
KATZENBERG	1
KENSINGTON	20
LANGA	35
MAITLAND	7
MAMRE	2
MELKBOSSTRAND	2
MILNERTON	12
PHILADELPHIA	1
REYGERSDAL	52
SEA POINT	2
SEKULULA	125
TABLE VIEW	20
WOODSTOCK	17
YSTERPLAAT	4
TOTAL	**1748**

5.1.7 CHILDREN WITH AUTISTIC SPECTRUM DISORDER

Of the 545 children identified through the RCWMCH patient administration system, 29 patients were diagnosed with autism or pervasive developmental disorder NOS. This comprised 5.3% of the group. The Autism Western Cape database had another 27 children on it. The combined total of 56 children gave an estimated prevalence of 0.5 per 1000 in the under 18 population of the Western sub-district. The mean age in the Autism Western Cape cohort was 7.4 years (range of 2.9 to 16.6 years with a median of 5.6 years). In the RCWMCH cohort, the mean age was 6 years (range 3.1 to 13 years with a median of 5 years). Thus both groups were positively skewed in terms of their distribution. The male to female ratio for the group as a whole was 4.6:1.

[i] Information obtained on 6/9/13 from Mr E Phatlane

5.1.8 ESTIMATED PREVALENCE OF CHILDREN WITH DISABILITY

The estimated under 18 population of the Western sub-district, based on projections from 2007 census data[j], was 112249.[48] As described above, 1138 children were identified through all the various sources, including hospital information from RCWMCH and New Somerset Hospital, special care centres and special schools, and non-profit and private organisations. Using this figure, the estimated prevalence in the Western sub-district of children with disability or a disabling chronic illness was 10 per 1000 or 1.01% (95% CI 0.95 to 1.07).

Based on the number of care dependency grants (n = 1748), the estimated prevalence of children with disability in the Western sub-district was 16 per 1000. The number of children in the 'dependent on technology' group was 11, giving an estimated prevalence of 0.1 per 1000.

5.2 SERVICES FOR CHILDREN WITH DISABILITY

5.2.1 CARE NEEDS OF CHILDREN IN FACILITIES

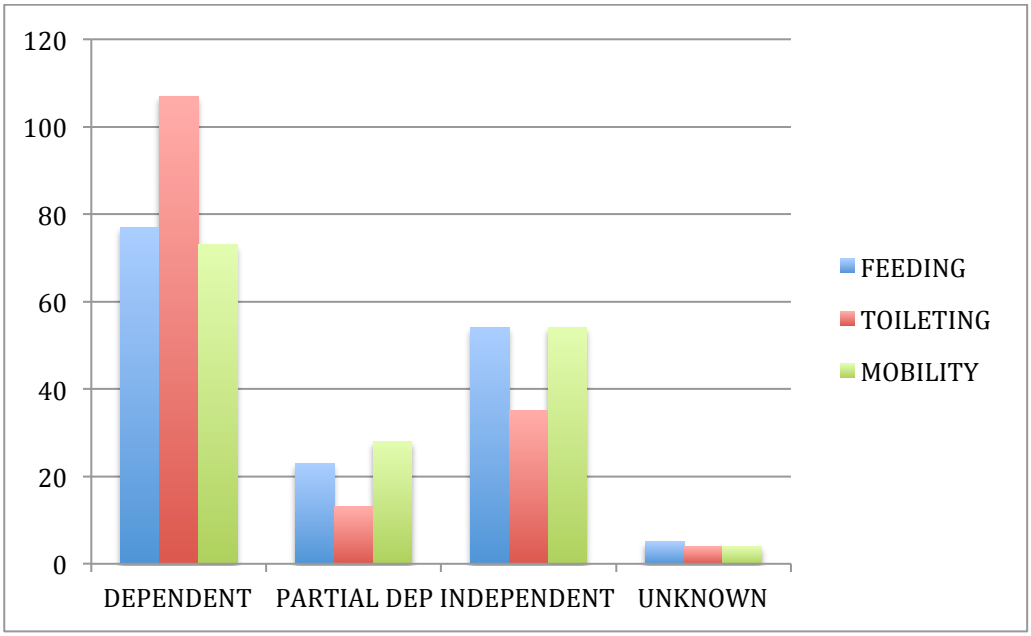
The facilities (special care centres and special schools) were requested to give a subjective assessment of whether each child in their facility was independent, partially dependent, or completely dependent, with respect to feeding, toileting and mobility. In the case of mobility, the options were 'walks independently', 'walks with assistance', or 'can't walk'. The purpose was to gain some insight into the care needs of the children in the facilities, in order to better interpret the appropriateness of the staffing ratios and training levels. Three special care centres and one special school responded, which provided information on 159 children.

As expected, children in the special care centres were less independent compared to children in special schools, who generally had a less severe degree of disability (Graphs 1 and 2). The majority of children in special care centres were either partially or fully dependent for feeding and mobility. In the special schools, only 22% and 11% respectively were dependent for feeding or mobility. 75% of children

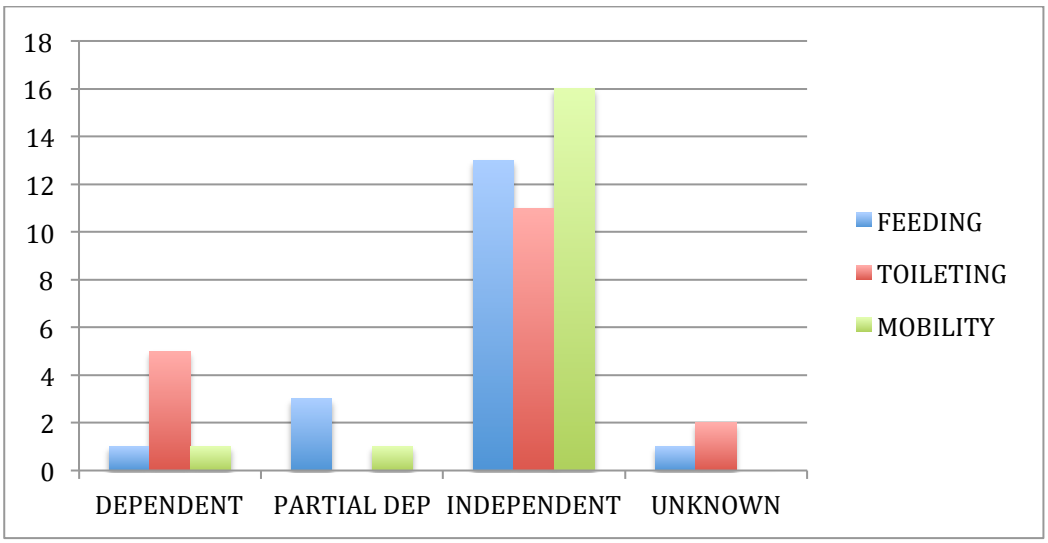
[j] The 2011 Census data was not available yet when these calculations were done. The actual population in Western sub-district, according to 2011 Census data, was 9% higher compared to the projected figures.

in the special care centres were either partially or fully dependent for toileting, compared to 28% of children in the special school.

Graph 1 – Care needs of children in special care centres



Graph 2 – Care needs of children in special school



5.2.2 CAPACITY IN FACILITIES

The special care centres were on average at 82% of capacity (Table 5). There were significant differences between centres, with two of the centres over 90%, while another two were relatively low (63% and 75% of capacity). In contrast, many of the special schools were at or close to 100% capacity, with the overall percentage being 95,7% (Table 6) and the range being much smaller, with the lowest being 85% of capacity.

5.2.3 HOSPITAL ATTENDANCE OF CHILDREN IN FACILITIES

The number of children currently in a facility (special care centre or special school) that simultaneously were attending one of the two hospitals is detailed in table 9. This information was acquired through the analysis of the hospital and non-hospital data sets for duplicates, or by asking the facility managers/principals. Overall, 14% of children in facilities attended hospital. In the three special care centres for which this information was available, the percentage of children who attended hospital ranged from 5 to 30%.

Table 9 – Hospital attendance of children in facilities

Facility	**No children attending hospital (RCWMCH/NSH)**	**Total no children at facility**	**%**
Peter Pan	3	15	20
Athlone School for Blind	1	6	17
Molenbeek	4	123	3
Dawn	2	214	1
Vista Nova	3	12	25
Wilge	7	23	30
Friends	4	73	5
Emmanuel	4	36	11

Special schools for children with intellectual disability (Dawn and Molenbeek) had very few of the children attending hospital (1 and 3% respectively). On the other hand, special schools that catered for children with other or multiple disabilities (such as Vista Nova and Peter Pan) had a much higher percentage (17-25%) of children attending hospital.

5.2.4 STAFF IN FACILITIES

The staff composition in the special care centres and special schools is outlined in tables 10 and 11 respectively. Information was available for four special care centres and six special schools. The number of carers/teachers required in a facility varied according to the level of care needed for the children and the educational/therapeutic programme offered.

Table 10 – Staffing in special care centres

Institution	**No. children**	**Staff details**						
		Paid staff	**Volunteer staff**	**Total staff**	**Manager**	**Carer**	**Teaching assistant**	**Other**
Wilge	30	7	1	8	1	5	1	1
Friends	112	48	5	53	2	13	13	6
Emmanuel	47	14	0	14	2	2	8	-
Elundini	30	8	3	11	-	-	-	-

Special care centres tended to have predominantly ‘edu-carers,’ who generally had no formal qualification and often had not completed their matric. These edu-carers had varying amounts of training in caring for disabled children, ranging from basic first aid to mental health courses. Several centres had in-house training programmes. Special schools had qualified teachers predominantly, rather than edu-carers. In the one centre, many had done first aid and early childhood development training.

The ratio of carers/teachers to children in the special care centres was 1 to 4.4, which was much higher than that in the special schools, at 1 to 11.8 (see Table 12). This was expected, given that the children in special care centres were more severely disabled and had greater levels of care required, as described in section 5.4.1.

Table 11 – Staffing in special schools

Institution	No. children	Staff details					
		Paid staff	Volunteer staff	Total staff	Manager	Teaching assistant	Helper
Molenbeek	164	13		13	1	9	1
Peter Pan	60	11	2	13	4	6	-
Dawn	233	-	-	-	-	-	-
SEAL College	14	4	2	6		1	3
Athlone school for the Blind	420	54	-	54	-	-	-
Vista Nova	440	42	-	42	-	-	-
Mountain View	-	-	-	0	-	-	-
Filia	182	22	-	22	-	22	-

Table 12 – Ratio of teachers/carers to children

	No children	Teacher/carer	Ratio
Special schools			
Molenbeek	164	9	18,2
Peter Pan	60	6	10,0
Dawn	233		
SEAL College	14	1	14,0
Athlone school for the Blind	420	42	10,0
Vista Nova	440	42	10,5
Filia	182	22	8,3
Special care Centres			
Wilge	30	5	6,0
Friends	112	26	4,3
Emmanuel	47	10	4,7
Elundini	30	11	2,7

5.2.5 ALLIED HEALTH PROFESSIONAL SUPPORT IN FACILITIES

The availability of allied health professional services to children in facilities is detailed in Table 13. With regards to the special care centres, they generally had very limited support from allied health professionals. With one exception (Wilge), not a single centre had a therapist as often as weekly. Although none of the allied health professions were represented well, it was noteworthy that speech therapists were particularly scarce.

Table 13 – Allied health professionals in facilities

INSTITUTION	**Health professional support (Full time or No. days per month)**		
SCC's	**Physio**	**OT**	**SLT**
Wilge	2 days per year	1	4
Friends	3	0	0
Emmanuel	2	2	0
Elundini	0	0	0
Special schools			
Molenbeek	0	1	0
Peter Pan	FT (1)[k]	FT (1)	FT (1)
Dawn	0	FT (1)	0
SEAL College	4	0	4
Athlone school for the Blind	FT (1)	FT (5)	0
Vista Nova	FT (4)	FT (4)	FT (3)
Filia	FT (1)	FT (2)	0

The special schools showed a wide variation in terms of the amount of allied health professional support, but were generally much better supported compared to the special care centres. Dawn and Molenbeek stood out as schools with very little allied health professional input. Five of the seven special schools had at least one full time therapist. The allied health professional sub-group most poorly represented was speech and language therapy.

5.2.6 MEDICAL/NURSING SUPPORT IN FACILITIES

Table 14 outlines the support by medical personnel to the special care centres and special schools. Only one special care centre received any direct medical support. Wilge had a full time nursing sister, and a paediatrician who visited quarterly.

[k] FT = full time. Number in brackets is the number of people who are full time.

The medical support to special schools was quite variable. The schools for children with intellectual disability had no medical support, while the schools that catered for children with other or multiple disabilities had nursing and psychological support, and varying degrees of support from a doctor.

Table 14 – Medical/nursing support in facilities

INSTITUTION	Health professional support (Full time or No. days per month)		
SCC's	**Doctor**	**Psychologist**	**Nurse/Sister**
Wilge	4 days per year	0	FT (1)
Friends	0	0	0
Emmanuel	0	0	0
Elundini	0	0	0
Special Schools			
Molenbeek	0	0	0
Peter Pan	Yes	0	Yes
Dawn	0	0	0
SEAL College	0	0	0
Athlone school for the Blind	0	FT (3)	FT (1)
Vista Nova	Yes	Yes	Yes
Filia	2 days per term	4	FT (1)

5.3 MISSING INFORMATION

Children without personal information

Personal information was not available for 280 of the 1138 children. The reason for this was that five institutions did not provide personal information on the children in the institution. This consequently precluded the identification of duplicates between the hospital data set and these non-hospital institutions. Where this was the case, the institutions were asked to estimate how many of their children, from the Western sub-district, were attending one of the relevant hospitals. As children with chronic conditions are likely to attend hospital fairly frequently, this seemed to be a reasonably reliable strategy.

Out of 280 children from 5 different institutions, only 7 children were identified as attending hospital (Table 15). Two institutions did not provide information, but the numbers in these institutions are relatively small.

Table 15 – Children without personal information by source

INSTITUTION	NO. OF CHILDREN FROM WESTERN SUB-DISTRICT	NO. ATTENDING HOSPITAL
Vista Nova	12	3
Elundini	30	-
Dawn School	214	2
SEAL College	14	2
Mountain View Academy	8	-
TOTAL	**278**	**7**

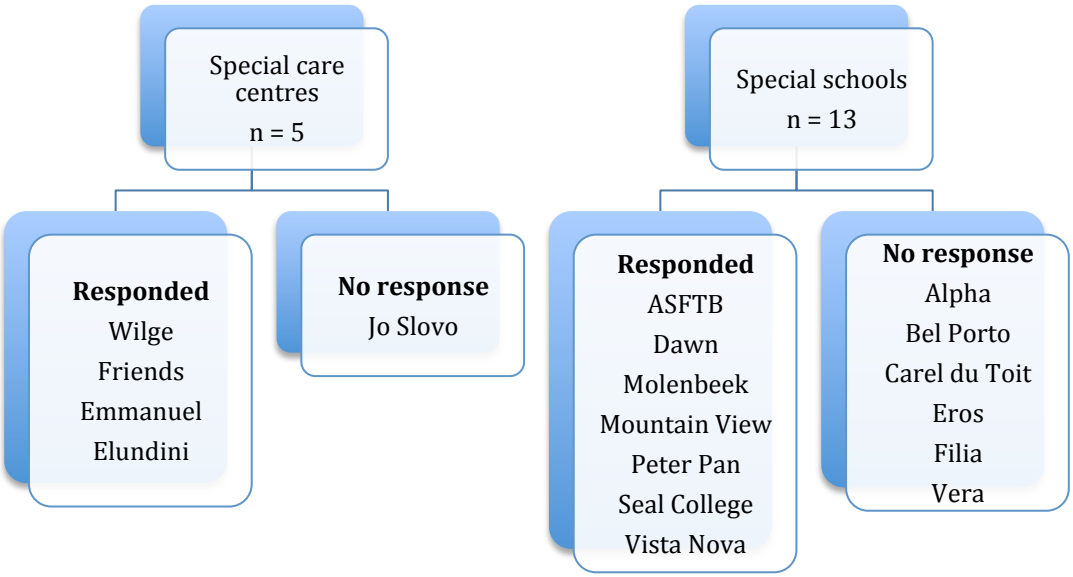
Non-responders

A number of schools or special care centres did not respond to the request for information (Figure 2). Apart from Filia School, these non-responders are unlikely to represent a significant number of children, due to their geographical location or the profile of children attending their institution.

Private sector

Mountain View Academy was the only private institution that provided information on the number of disabled learners and services available at the school. Other private educational institutions, as well as patients attending private health care practitioners or hospitals, were not identified.

Figure 2 – Institutions not responding to request for information



CHAPTER 6 - DISCUSSION

6.1 PREVALENCE OF DISABILITY OR DISABLING CHRONIC ILLNESS AMONG CHILDREN

The main aim of this study was to determine the prevalence of children with disability or disabling chronic illness through the use of a methodology that sought to identify children through existing health and educational services. In this study, 1138 children were identified as being disabled or having a disabling chronic illness, which gives an estimated prevalence of 10 per 1000 in the under 18 population.[1] This figure is significantly lower than expected when compared to other prevalence studies in the literature. The WHO suggests a global figure of 51 per 1000 for moderate to severe disability.[14] This is probably a realistic figure to compare with, as this study was biased towards identifying children with moderate to severe disability. Other estimates range from 82 to 152 per 1000 in LAMICs.[11,24,25] In South Africa itself, previous prevalence estimates ranged from 43 to 60 per 1000 for overall disability.[35,36] In the Couper study, the severity and/or type of disability was classified. If one removed the mild ID group from this study, one is still left with a prevalence of 43 per 1000 for moderate to severe disability. Based on these estimates, one would have expected to identify about 5000 children in this study. Possible explanations to explain this finding need to be considered in detail.

Western sub-district not representative

There are a number of reasons why the Western sub-district may have a significantly lower childhood disability when compared with the rest of South Africa or other low and middle-income countries.

The first reason is that the Western sub-district has relatively good socio-economic indices compared to the rest of SA, and most LAMICs. According to the latest 2011 Census data, 82% of the labour force in the Western sub-district is employed, and more than two thirds of the population live above the poverty line.[50] More than 60% of adults above the age of 20 years have completed high school. This suggests that

[1] Based on 2007 Census estimates, which proved to be 9% lower than the actual figures – see footnote *j* page 44.

causative factors of disability that are associated with poverty may be less in the Western sub-district, consequently resulting in lower disability rates.

The second reason is that the Western sub-district has relatively good health system indicators, especially in areas relevant to childhood disability. The major causes of disability in LAMICs include prematurity/low birthweight, hypoxic ischaemic encephalopathy, trauma and neonatal jaundice.[30] The majority of these are preventable in a well functioning health system. The mortality indicators for Western sub-district are considerably lower compared to the rest of SA, suggesting that it has a health system that is functioning better than average. For example, the under-five mortality rate in 2010 was 15.5 per 1000[48] compared to the SA average of 42.[51] The infant mortality rate was 12.9 per 1000 compared to the national average of 30. The Western sub-district also had significantly lower early neonatal mortality rates in the weight categories between 1000 and 2500g. The high immunisation rate of 116% obviously needs to be examined further, but suggests that high levels of immunisation coverage are likely to be protective against intracerebral infections.

HIV infection is another significant cause of disability in SA and other countries. HIV may cause neuro-disability through opportunistic central nervous system infections or through HIV associated encephalopathy or neurocognitive defects, or may result in activity limitation as the result of other mechanisms such as chronic lung disease or malnutrition. The Western sub-district has a low antenatal HIV prevalence of 21% compared to the national average of 29.5%, and a successful Prevention of Mother to Child Transmission (PMTCT) programme, resulting in a very low HIV transmission rate of 1.24%.[48] Both of these factors will reduce the burden of HIV in this population.

Finally, socio-cultural factors may also play a role. Due to its relatively sound socio-economic position and the effects of urbanisation, the Western sub-district is likely to have a significant number of rural immigrants. It is fairly commonplace in African culture for children to be raised by extended family members, especially if both parents are working. Urban immigrants who are working will frequently send children to stay with relatives in rural settings. This mobility of family members is

even more apparent in the case of illness or adversity, as has been described with the HIV epidemic for instance.[52] Therefore, it is highly likely that a number of disabled children may be similarly re-located to other family members, often in other provinces, so that the parents could continue to work. The extent to which this may occur in Cape Town or the Western sub-district is not known.

Therefore, it can be concluded that favourable socio-economic conditions and a well functioning health system, as well as possible socio-cultural factors, may in part explain why the prevalence of children with disability may in fact be lower than expected in the Western sub-district as compared to the rest of South Africa. However, given that the prevalence found in this study is even lower than most high income countries, it is likely that there are other factors to consider as well.

Limitations of the study design

There are a number of factors related to the design of this study that may have influenced the number of children found.

Firstly, the study design relied to a large extent on children accessing the health or educational system. It is likely that a significant number of children with disability do not access the health or education system in the South African context. One such reason is that there is frequently a perception that it is useless to offer care or education to a disabled child, or a desire to avoid the stigma of taking a disabled child out of the house into public areas such as a school or hospital. This is well described in the African context.[53,54] Other practical reasons such as lack of transport or finances to get to hospital may prevent disabled children from accessing care. Many children are cared for in their homes, and utilise community-based services. This study may well have missed many of these children.

Similarly, it is known that a significant number of children who require special schooling are not in these schools due to lack of capacity.[55] There are also likely to be many children that have developmental disabilities but are still within the mainstream educational system for a variety of reasons: either they have not been

identified as having a developmental disability, or because it is sufficiently mild enough to not warrant special schooling, or because there is no viable alternative for them.[54] Given that this study was biased towards children with more moderate to severe disability, and relied on children having accessed special educational institutions, this is likely to have resulted in a number of children being missed.

Secondly, this study focused on specialist (level two and three) health services. Often, children with disability or disabling chronic conditions are not considered for referral from primary health care services, because it is perceived that 'not much can be done for them,' or that their condition is permanent and therefore beyond the need for remediation. The lack of information therefore from primary health care sources may have resulted in a number of children being missed.

Thirdly, the methodology used to identify children through the RCWMCH patient information system was not exhaustive. Only a selected short list of ICD 10 codes was provided as diagnostic search criteria. This was intended to cover the majority of common conditions associated with disability, rather than being exhaustive. Many conditions associated with disability, such as the epilepsies, were not included, as ICD 10 coding is not specific enough to determine disability. In addition to this, only patients from a few specific clinics were captured. Other clinics could have been selected, but then potentially inappropriate patients would have been included.

New Somerset Hospital

New Somerset Hospital, despite being the level two (regional) referral hospital for the Western sub-district, identified very few children. A possible reason for this could be that a large percentage of the children were referred to RCWMCH as the tertiary referral facility, due to various factors such as specialist expertise or the presence of multi-disciplinary clinics that were felt to offer better long-term care. Another potential factor is related to the methodology employed in terms of identifying children with disability at New Somerset Hospital. Due to the limited time period over which data was captured (six months), and the fact that only one paediatrician at the facility was identifying children, it is likely that a number of children were missed. Extending the data capture period, and training both junior

doctors and paediatricians at the facility to capture cases could have significantly increased the identification of children.

Children dependent on technology

There is not a lot of information in the literature regarding the prevalence of children dependent on technology. Prevalence studies in the United States range from 1 to 2.2 per 1000.[56–58] The prevalence of 0.1 per 1000 found in this study is significantly less than that. However, the sub-group of children dependent on technology in this study was restricted to children either on home oxygen or having a tracheostomy. This was firstly because information sources to identify these children were known to exist. Secondly, due to time and resource constraints, other forms of technology that were not specific to children with disability, such as gastrostomy or need for renal dialysis, were excluded. This undoubtedly resulted in a number of children that are dependent on some technology as a result of their disabling chronic condition being missed. However, it should also be noted that no data on the prevalence of children dependent on technology could be found in a resource poor setting. This is important in terms of comparison, as technology is highly resource intensive and therefore much more likely to occur in well-resourced settings.

Children with autistic spectrum disorder

The prevalence of children with autistic spectrum disorder has been felt to be increasing over recent decades, with estimates as high as 10 per 1000.[59–63]

The prevalence of 0.5 per 1000 identified in this study is therefore significantly less than expected. However this figure is probably very inaccurate as many important sources of information were missing.

Care dependency grants

In January 2012, SASSA was providing 9803 care dependency grants (CDG's) in the Western Cape. Based on 2007 Census data, the Western sub-district comprises approximately 11% of the population in the Western Cape. If one assumes that the number of people receiving CDG's is distributed evenly across the province between

the various sub-districts, then one would expect there to be 1078 care dependency grants paid out in the Western sub-district.

The comparison of the number of children identified through this study with the number of children receiving CDG's was considered an important potential indicator of the accuracy of the results. However, the interpretation of the information received from SASSA is extremely difficult. Two sets of data were received, and despite being asked to provide the same information, they produced vastly disparate results. The first set seemed to be implausible. The second set, which revealed 1748 families in receipt of CDG's from pay-points within the Western sub-district, seemed to be more accurate.

However, this figure also needs to be interpreted with some caution. Firstly, it may be that people living outside the area received their CDG's from pay-points within the Western sub-district. As described in the results section, due to the fact that the national database does not record the home address of the recipient, the accuracy of this method is difficult to ascertain. Secondly, the majority of these CDG's were Cash Payment Service (CPS) Postbank payments. It is not clear whether there payments were from SASSA pay-points, or from other merchants. Therefore the accuracy of this figure in terms of geographical location seems uncertain.

Based on the eligibility criteria for CDG's, only children with severe disability qualify. However, it should be noted that the eligibility criteria for the CDG's are not clearly specified, and are open to the healthcare professional's discretion. The WHO estimates the prevalence of severe disability to be 7 per 1000.[14] It is difficult to compare this with local prevalence studies, as the studies conducted in SA did not specify severe disability as a separate category.

Therefore, if one uses the WHO's estimate, the number of children expected to be on CDG's in the Western sub-district is 785. However, it is likely that a proportion of children that are categorised as moderate using the tools upon which many of the prevalence studies are based, would in fact be deemed eligible for a CDG. It is consequently difficult to interpret whether the number of children receiving CDG's

is in fact higher or lower than expected, as the eligibility criteria for CDG's are not completely clear, and the prevalence of moderate versus severe disability is not known.

6.2 SERVICES FOR CHILDREN WITH DISABILITY

The second part of this study had to do with an analysis of the services available to children with disability. The focus was primarily on the day care and educational facilities (special care centres and special schools) that accommodate these children. Aspects that were looked at included the level of dependence of the severely disabled children, staff capacity and training in the facilities, and the amount of support from allied health and other medical professionals.

Needs of the children and staffing in special care centres

The information obtained regarding the children and the staff in the special care centres was not intended to be a detailed analysis, but rather a superficial overview of the situation within the special care centres in general.

As expected, the level of dependence of the children was high for basic needs such as eating, toileting and mobility. This is not surprising given that these centres only accept children who have severe disability. The ratio of staff to children, which ranged from 2.7 to 6, is within international recommendations.

Although not presented in detail here, the level of training of staff was quite low when one considers the level of dependence of the children and the likely complexity of their medical, psychological and social needs. The fact that most 'carers' had not finished school, and had little or no formal training in early childhood development or the care of children with special needs, is of concern. In the Department of Basic Education's White Paper on Inclusive Education,[55] although improved training for educators is proposed, no specific details or norms and standards are given.

Capacity in special schools and special care facilities

In this study it was found that the special schools in general were full or very nearly full. Among the special care centres the results were quite disparate.

It is consistent with the experience of the investigators and research done by the Department of Education previously that there is inadequate capacity within the educational system and the special care centres for children with disability.[10] The Department of Education's White Paper of 2001 indicated that there were 64200 children in special schools, and an estimated 280000 children who were not appropriately placed in such schools.[55] Saloojee *et al* found that only 44% of disabled children of school going age were in school.[8] Potential reasons for this are that disabled children are not being accepted in schools, parents may not be applying for special schools, or that there is lack of capacity in special schools. It is therefore not surprising that the special schools in this study were on average 95% full.

That some of the special care centres were at 75% or less capacity was unexpected. If one estimates the number of severely disabled children in a population to be about 0.5%, then one would have expected to find about 561 severely disabled children in the Western sub-district. It is of concern that only 162 children were found to be in special care centres, and that there was only capacity for about 265 children across all the centres. One can only speculate about the reasons for the special care centres not being fuller, but it is unlikely that it is due to a lack of demand for places. It is more likely that lack of uptake of places is due to social or financial factors such as lack of transport or inability to afford even minimal school fees, or due to reluctance of parents to enrol children for fear of the stigma attached. There is also the possibility some of the centres were being inefficiently managed.

Allied healthcare professionals

The amount of support from allied healthcare professionals to children in the special care centres or special schools was quite different, and consequently they deserve separate discussions.

Five of the seven special schools analysed had at least one full time therapist. Occupational therapists were the most prevalent, and speech and language therapists the least. As expected, the schools for children with multiple disabilities were more likely to have all the allied health professionals, whereas schools for children with intellectual disability generally only had occupational therapists. The special schools were, on the whole, much better supported in terms of allied healthcare professionals compared to the special care centres. However, there was significant inequality between the schools. For example, Vista Nova had 11 full time therapists for 480 children, whereas Dawn and Molenbeek each had one therapist for 233 and 165 children respectively. These discrepancies may be the result of historical inequalities left over from the apartheid era.

The situation is very different in the special care centres. All the special care centres have virtually no or very limited support from allied health professionals. Speech therapists are especially scarce. Given the multiple and complex needs of the majority of children in these centres, there is no doubt that these children require, and would benefit from therapy provided by a diverse range of allied health professionals. This is even more essential when one considers the level of training of the staff at these facilities as described above.

One could argue that the children receive therapy outside of the centres. For instance, could the children within these facilities be receiving therapy at the local or regional hospitals? It is the policy of most government health facilities that children discontinue receiving therapy from hospital based services once placed in an appropriate community based facility. In the case of a child with autism for example, they would no longer receive speech therapy from the hospital based speech therapy services, but rather from the school where they were placed. This is definitely the policy of RCWMCH and NSH, and therefore it is highly unlikely that the children in these facilities were receiving therapy from either of these institutions.

There is a possibility that some children receive therapy at primary healthcare or district hospital facilities. Although this question was not formally asked of the

facility managers, it is the experience of the principal investigator that this was not the case. Reasons for this include the lack of capacity of the facilities in terms of staff and transport to take these children to outside facilities, and due to the perception that this therapeutic intervention is in fact taking place in the facilities.

The lack of allied health support to special care centres in general, as well as the lack of formal training and capacity building for carers in these facilities, suggests that a number of children are in fact receiving hardly any therapy at all. The results of this study would support the findings of Saloojee et al that only 26% of disabled children were receiving therapy.[8]

Medical support to children in facilities

The medical support to children in special schools and special care centres was highly variable. The majority of facilities received no support at all from a doctor, psychologist or nursing professional. Only one facility had regular contact with a paediatrician. It should be remembered that a number of these children will have complex medical needs, require medication or assistance with mobility or feeding, etc. It should also be noted that only 14% of children in these facilities had attended specialist services at RCWMCH or NSH during the period studied. The coordination of the chronic care of these children is therefore brought into question.

Evaluation of the current services and service model

It is known that disabled children and children with special health care needs have an increased utilization of health services.[2,19] It is also known that these children frequently have unmet needs.[5,8,42] Internationally, one of the models that has been shown to be moderately effective in meeting some of these challenges is the medical home model.[5,41,42] Essentially the medical home model aims to provide coordination of care that is "family-centred, community-based, accessible and continuous" through a trained primary health care practitioner.[41]

Although the analysis of the services for children with disability conducted in this study was superficial, it does raise questions about the current service model that

exists for the chronic care of children with disability or disabling chronic illness. This study seems to suggest that the majority of children with disability and disabling chronic conditions receive little in the way of on-going care or support from hospital or community based services.

This study suggests that there is a need for children with chronic conditions to have something similar to a medical home or primary healthcare provider. The functions of such an entity would include the coordination of care for the patient between community based and specialist services, support to the families, and on-going assessment of educational, developmental and therapeutic needs. For children with disabling chronic illnesses in the Western sub-district of Cape Town, it would appear that there is currently a significant gap between specialist and community based or chronic care services.

6.3 LIMITATIONS

The intention of this study was to identify children with disability or disabling chronic illnesses through existing sources of information, rather than a population based or cohort study. There are a number of limitations to this study design.

Missing or incomplete information

A major source of information used in this study was the RCWMCH patient information system (Clinicom). In terms of study design, the utilization of this information has several limitations. Firstly, it has been acknowledged above that a list of selected ICD 10 codes could never identify all children with disability. In fact, this reversion to the use of diagnostic labels is in direct contrast to the growing trend of describing functional limitation through the use of a tool such as the ICF framework for example.

Apart from this limitation, it is also commonly acknowledged that the Clinicom system does not capture 100% of clinic visits, and that diagnostic information is often inaccurate and incomplete. This may be due to lack of proper coding from clinical personnel, or due to errors in data capturing from admin personnel.

There are a number of potential gaps in this data as a result of either lack of response from potential information sources, or from failure to identify potential information sources. The need to obtain information from third parties resulted in incomplete information. Several special care centres and special schools did not reply to numerous emails or telephonic requests for information. Several institutions expressed concerns about divulging personal information, and were thus only prepared to provide details on the number of children in their facility, without including personally identifiable information. Attempts were made to overcome some of the difficulties that this caused in terms of duplication of children, but these were not without potential fallibility.

It is possible that facilities for children with disability exist that were not contacted. Although the Directory of Services for children with special needs was updated in 2011, it is possible that there were some facilities not included in the Directory.

Potential sources of information that were not sought after were community based services and the district health system. This was mainly due to the lack of a central database or adequate patient information system.

Accuracy of data

It was not possible to verify the diagnostic accuracy of the ICD 10 coding system used in the Clinicom patient information system. Therefore the identification of children with disability or disabling chronic illness through the use of ICD 10 diagnostic coding is potentially inaccurate.

The accuracy of information received from external or third parties was not verified in this study. Human error may have resulted in incorrect information. The information requested from the special care centres, detailing the level of dependency of the children with regards to feeding, toileting and mobility, was completely subjective and therefore potentially inaccurate.

Some institutions were unwilling to divulge personal information but were happy to estimate the number of children in their institution that were disabled, or attending hospital for a disability/disabling chronic illness. It was decided to include this telephonic information despite the risk of counting children twice.

It is acknowledged that the inclusion of children without personal information may have resulted in duplication and consequent over estimation of the number of children with disability. However, due to the relatively small number of children reported to be attending hospital from these institutions, it was felt that the inclusion of the children without personal information into the total number of children was warranted.

Sample bias

The sample in this study is likely to be biased towards children with moderate to severe disability. One of the reasons for this is that children with more severe forms of disability are more likely to access hospital care, and are also more likely to require special day care facilities or special schooling. In this study design, children with milder forms of disability were therefore less likely to be identified. Significant under-recognition of children with milder forms of disability, and especially developmental disabilities, is likely to be widespread in the South African context, as shown by Giarelli *et al.*[38]

Another source of bias is the fact that RCWMCH and NSH paediatric services only see children up to the age of 13 years. Therefore, although this study aimed to determine the prevalence of children under the age of 18 years, the lack of information from adult hospital services biases the sample towards a younger age group 13 years and under.

The validity of this methodology is therefore questionable. The prevalence of children with disability as found in this study should be interpreted with caution, given the limitations of the study design and incomplete information. In addition to this, the Western sub-district may not be representative of other parts of Cape Town

or South Africa. Therefore the generalizability of these results is also brought into question.

In comparison with alternative methodologies such as population screening, population surveys or cohort studies, this methodology appears inferior, in spite of the deficiencies identified in the former.[11,30] However, one can infer from this study that a number of children with disabling chronic illnesses are not accessing health care, social grants and educational support services.

CHAPTER 7 - CONCLUSIONS AND RECOMMENDATIONS

It is clear from this study that a number of children with disability or disabling chronic illnesses are 'missing.' In other words, the number of children identified in this study is significantly less than expected. This is most likely due to a combination of limitations in the study design and the fact that many disabled children are not accessing specialist health care or schooling.

The issue of definition is also important. It is clear from the literature and this study that how one defines disability or disabling chronic illness has a significant impact on the identification of children. It should be noted that the methodology used in this study never anticipated identifying 100% of children with disability or disabling chronic illness. Instead, the intention was to identify as many children as possible using existing information within the health and education systems, in the hope that this methodology might in fact be reliable and reproducible in other sample populations.

The brief analysis of the needs of children in special care centres, and the services that exist for them, raises concerns regarding the chronic care of children with disability. There appears to be insufficient capacity in special schools for the number of children with intellectual or other forms of disability. Centres where children with severe forms of disability are cared for do not have adequate staffing levels, and the staff in the facilities are frequently poorly trained with little formal qualification.

With regards to therapy, there is great variation between different institutions regarding the availability of allied health professionals. Most notable is the paucity of speech therapists. The special care centres have very little input from allied health professionals in general. Similarly, both the children in special schools and the children in special care centres received very little in the way of medical input. A small minority of children receive specialist paediatric care. It is unclear how many children are accessing allied health and medical staff in primary health care or district level facilities.

The methodology used in this study is different from most of the methodologies in the literature that have been used to estimate prevalence. Several limitations are apparent with this methodology, and it is unclear to what extent these results are valid and generalizable. Perhaps more important however is the knowledge gaps that this study highlights. This study demonstrates firstly that existing information systems are unable to quantify the number of children with disability or disabling chronic illness. Secondly, the ability to monitor and evaluate the health system in terms of its chronic care of children is virtually non-existent. As such, the ability to plan health services effectively and ensure the rights of children with disability is severely constrained.

Recommendations

- Adequate epidemiological studies need to be conducted in order to establish the size of the problem, both in terms of the number of children with disability, and a detailed analysis of the chronic care that they receive. To this end, the formation of a register or equivalent central database would be a necessary and vital first step in ascertaining the size of the problem, and facilitating the planning, provision, coordination and evaluation of the chronic care of such children.

- In order to adequately describe the health and social needs of children with disability in South Africa, and allow for comparison internationally, the ICF framework needs to be adapted and applied to our context. Research that describes the service needs of children with disability, and randomized control trials that evaluate interventions in a resource poor context, is necessary.

- In terms of policy-making, a determination of the norms and standards for the care of severely disabled children in the special care centres would be beneficial. This would include recommended staffing levels and competencies, training requirements, equipment, etc.

- A more detailed analysis of the facilities and therapeutic support available to children in special care centres would be beneficial in terms of understanding the chronic care context of these children. Further investigation of the links between children in the centres and the health care system, especially the primary and district health care systems, would be interesting.

- Specialist centres need to consider training or outreach programmes to build capacity at primary health care level, so that adequate chronic care can take place within the community based services without over-burdening specialist services.

In summary, the number of disabled children identified in this study through the health and educational services is unexpectedly small. This may be the result of limitations in the study design and methodology, but may also reflect a lack of access to health and educational services for disabled children. These health and educational services are also inadequately equipped to provide coordinated and comprehensive chronic care to disabled children. This study highlights the lack of information available regarding disabled children, and consequently the failure of the health and educational systems to provide for their needs.

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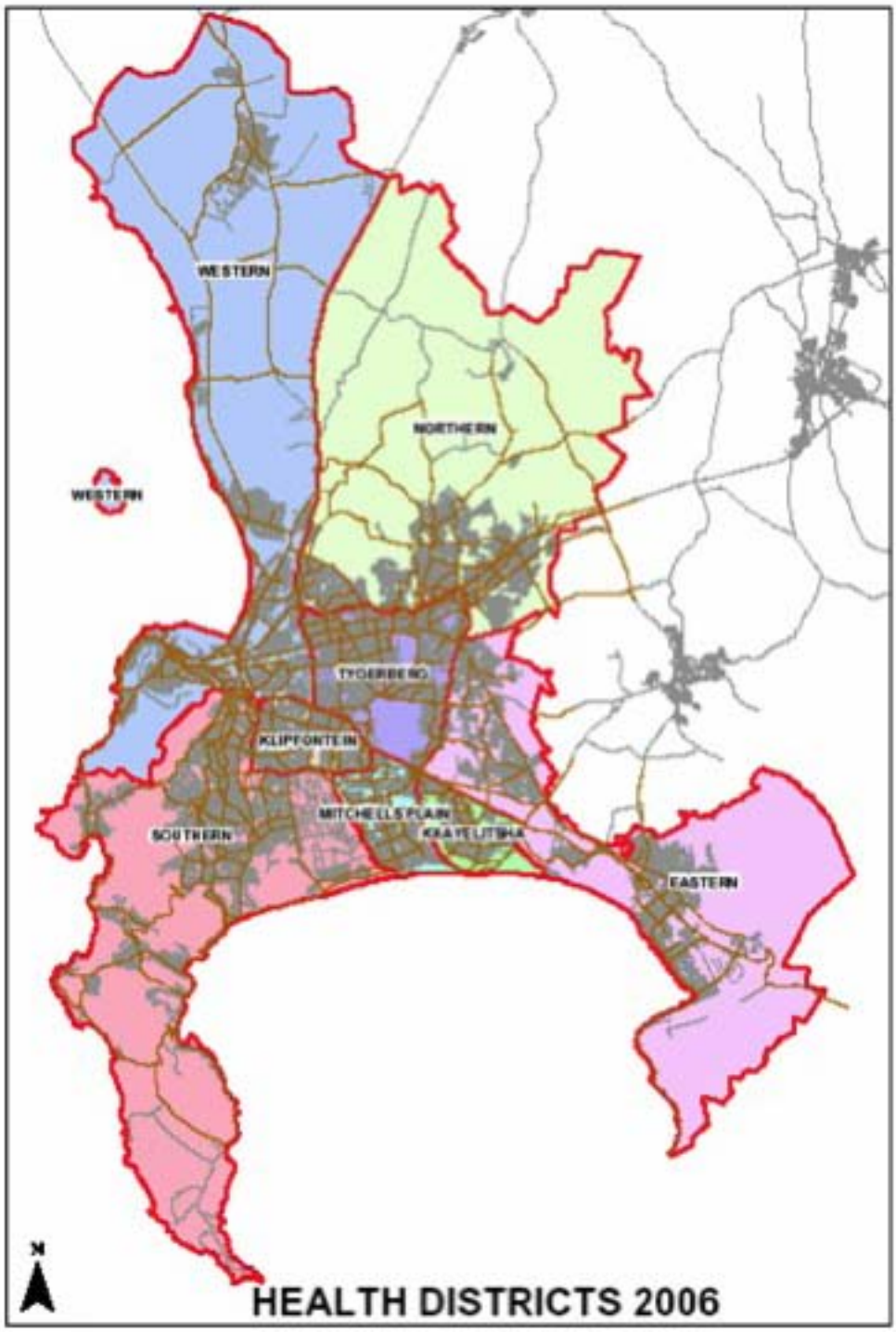
APPENDIX 1

MAP OF HEALTH SUB-DISTRICTS



APPENDIX 2

LIST OF ICD 10 CODES USED TO IDENTIFY CHILDREN WITH DISABLING CONDITIONS

CONDITION	ICD-10		
Cerebral palsy - ataxic	G80.4	Neuronal migration disorder	Q04.3
Cerebral palsy - athetoid	G80.3	Schizencephaly	Q04.6
Cerebral palsy - choreoathetoid	G80.3	Cervical spina bifida with hydrocephalus	Q05.1
Cerebral palsy - diplegic	G80.1	Thoracic spina bifida with hydrocephalus	Q05.2
Cerebral palsy - dystonic	G80.3	Lumbar spina bifida with hydrocephalus	Q05.3
Cerebral palsy - hemiplegic	G80.2	Spina bifida with hydrocephalus	Q05.4
Cerebral palsy - hypotonic	G80.8	Cervical spina bifida without hydrocephalus	Q05.5
Cerebral palsy - quadriplegic	G80.0	Thoracic spina bifida without hydrocephalus	Q05.6
Cerebral palsy - triplegic	G80.8	Lumbar spina bifida without hydrocephalus	Q05.7
Cerebral palsy - unspecified	G80.9	Sacral spina bifida without hydrocephalus	Q05.8
Deafness	H91.9	Hypoplasia and dysplasia of spinal cord	Q06.1
Blindness	H54.7	Diastematomyelia	Q06.2
Mental retardation, moderate (IQ 35-49)	F71.9	Anophthalmos	Q11.1
Mental retardation, severe (IQ 20-34)	F72.9	Tracheostomy care	Z43.0
Mental retardation, profound (IQ under 20)	F73.9	Tracheostomy malfunction	J95.0
Autism	F84.0	Tracheostomy present	Z93.0
Development, pervasive developmental disorder	F84.9	Myasthenia,congenital	G70.2
PDD	F84.9	Duchenne muscular dystrophy	G71.0
Huntington's disease	G10.X	Dystrophia myotonica	G71.1
Friedreich's ataxia	G11.1	Congenital muscular dystrophy	G71.2
Ataxia telangiectasia	G11.3	Mitochondrial myopathy	G71.3
Spinal muscular atrophy, Type 1	G12.0	Myopathy, congenital	G71.9
Spinal muscular atrophy, Type 2 or 3	G12.1	Myopathy, other, specified	G72.8
Mitochondrial disorder	G31.8	Myelomeningocoele	Q05.9
Brain, degenerative disease	G31.9	Holoprosencephaly	Q04.2
Epilepsy, Lennox Gastaut	G40.4	Brain damage, post meningitis	G09.X
Spinocerebellar degeneration	G11.8	Huntington's disease	G10.X

CONDITION	ICD-10		
Basal ganglia, degenerative disease	G23.8	Hereditary spastic paraplegia	G11.4
Multiple sclerosis	G35.X	Opsoclonus myoclonus	G24.8
Acute transverse myelitis	G37.3	Dystonia	G24.9
Hereditary motor and sensory neuropathy	G60.0	HIV infection, encephalopathy	B22.0
Intellectual disability	F79.9	Friedreich's ataxia	G11.1
Ataxia, hereditary	G11.9	Trisomy 21	Q90.9
Hereditary spastic paraplegia	G11.4		

APPENDIX 3

LIST OF POSTCODES

AREA	POSTCODE	AREA	POSTCODE
Albow Gardens		Melkbosstrand	7441, 7437
Atlantis	7349	Pinelands	7405
Central Cape Town	8000, 8001	Protea Park	7349
Chapel Street		Saxon Sea	
Du Noon	7441	Sea Point	8005, 8060
Facreton	7405	Schotschekloof	
Green Point	8005, 8051	Spencer Rd	
Kensington	7405	Table View	
Langa	7455	Woodstock	7925, 7915
Maitland	7405	Vanguard	
Mamre	7349		

APPENDIX 4

LIST OF INSTITUTIONS CONTACTED

SPECIAL CARE CENTRES

Elundini Centre, Milnerton

Emmanuel Day Care Centre, Atlantis

Friends Day Care Centre, Maitland

Jo-Dolphin Swartland, Malmesbury

Orion Special Day Care Centre (Wilge), Atlantis

Ukwanda/Joe Slovo Special Care, Joe Slovo

Mountain View Academy,

SPECIAL SCHOOLS

Dawn School, Atlantis

Karitas School, Vredenburg

Molenbeek School, Maitland

Peter Pan Centre, Maitland

SEAL College, Milnerton

Filia

Carel du Toit

Alpha

Bel Porto

LSEN (SCHOOLS FOR LEARNERS WITH SPECIAL EDUCATIONAL NEEDS AND SCHOOL OF SKILLS

Atlantis School of skills

De Grendel Special Needs School, Milnerton

St Joseph's

Athlone School for the Blind

Vista Nova

APPENDIX 5

LEARNER DETAIL CAPTURE FORM FOR SPECIAL CARE CENTRES OR SPECIAL SCHOOLS

FORM 2 - DETAILS OF LEARNERS IN THE INSTITUTION

	HOSP NO (if known)	FIRST NAME	SURNAME	DOB	SEX	RACE (W/C/ B/I)*	POST CODE	Feeding (I /P/ D)#	Toile ting (I/P/ D)	Mobil ity (1,2,3)	Medical eqpt child needs (please specify)

*W = White, B = Black, C = Coloured, I = Indian, # *I = independent, P = partially dependent, D = dependent, 1= walks independently, 2 = walks with assistance, 3 = can't walk*

APPENDIX 6

INSTITUTIONAL INFORMATION CAPTURE FORM FOR SPECIAL CARE CENTRES & SPECIAL SCHOOLS

FORM 1 - FACILITY SURVEY

NAME OF INSTITUTION _____DATE_____

TYPE OF INSTITUTION (eg. Special Care Centre, School for children with Special Educational Needs, etc.)

_____

Number of children currently at institution _____ Capacity _____

No. Of permanent staff _____ Volunteers _____ Paid _____

No. Of temporary staff _____ Volunteers _____ Paid _____

Staff details **Please list the number, position, and qualifications/training received of permanent staff.** ***Example:***

1	*Manager*	*BA*	*Management course*
3	*Teachers assistant*	*Dip Ed*	
5	*Carers*	*None*	*Hambisela training*

No.	Position	Qualifications	Additional training

Services provided by health professionals:

Please specify either F/T (full time) or no. of days per month

Physio _____ Occupational therapist _____ Speech therapist_____ Doctor_____ Sister/Nurse_____ Psychologist_____

Other (specify) _____

DEVICES AVAIL (*please tick*): Standing frame _____ Side-lyer _____ Physio mats _____ Supported seating _____

Shona buggies_____ Wheelchair friendly Y/N Other _____

Further comments_____

_____

_____

_____

Perceived needs _____

_____

_____

NAME OF PERSON FILLING IN FORM: _____ CONTACT DETAILS: _____

APPENDIX 7

INTRODUCTORY LETTER

UNIVERSITY OF CAPE TOWN
SCHOOL OF CHILD & ADOLESCENT HEALTH
DIVISION: PAEDIATRIC MEDICINE
RED CROSS WAR MEMORIAL CHILDREN'S HOSPITAL
KLIPPONTEIN ROAD
RONDEBOSCH
7700

TEL: +27 21 658 5535
FAX: +27 21 6585530

Dr Andrew Redfern
Senior Registrar Developmental Paediatrics
Red Cross Children's Hospital
Andrew.Redfern@uct.ac.za

9 September 2011

To whom it may concern

RE: PARTICIPATION IN STUDY OF SERVICES FOR CHILDREN WITH DISABILITY OR DISABLING CHRONIC ILLNESSES IN THE WESTERN SUB-DISTRICT OF CAPE TOWN

I am conducting research into the number of children with disability or disabling chronic illnesses in the Western sub-district of Cape Town, and analysing the adequacy of the health and educational services that exist for them. This research is being conducted under the auspices of the University of Cape Town, and has been approved by the UCT Human Research Ethics Committee (HREC No. 425/2011).

Your cooperation and participation is requested in providing the information as set out in the attached questionnaire. All information will be treated with strict confidentiality, and no personally identifiable information of any individual or institution will be contained within the published research.

You will receive a R50 Pick&Pay voucher to say 'Thank You' for your time and effort in completing the questionnaire. Your assistance is greatly appreciated.

Yours sincerely

Dr Andrew Redfern FCPAED, MRCPCH
Developmental Paediatrics
Red Cross Hospital

Prof Anthony Westwood FCP, MD, MMed
Clinical Coordinator, Child Health Services
Metro West

APPENDIX 8

PARENT CONSENT FORM

Departement van Gesondheid
Department of Health
iSebe lezeMpilo

16 February 2011

REQUEST FOR INFORMATION

A STUDY OF THE PREVALENCE OF DISABLED CHILDREN & THE SERVICES THAT EXIST FOR THEM IN THE WESTERN SUB-DISTRICT OF CAPE TOWN (HREC: 425/2011)
UNIVERSITY OF CAPE TOWN
DEPT OF HEALTH, WESTERN CAPE

Dear parent/caregiver

You are kindly requested to give consent to the acquisition of your child's personal details, including name and date of birth, as part of the above research study. Your child's details will be entered onto a secure database, and then anonymised. No personal details will be published in any manuscript or publication.

Yours sincerely

Dr Andrew Redfern
Senior Registrar Developmental Paediatrics
Red Cross Children's Hospital
School of Child & Adolescent Health
University of Cape Town

I hereby give consent for my child's personal details to be given to Dr Andrew Redfern for the purposes of the abovementioned research (HREC 425/2011).

_____
Parent/caregiver signature

APPENDIX 9

EXPLANATORY GUIDE TO FILLING IN QUESTIONNAIRES (FORMS 1 & 2)

Reference:
Enquiries: A Redfern
Tel: 021 6585030
Fax: 0866599881

Departement van Gesondheid
Department of Health
iSebe lezeMpilo

A situation analysis of the needs and services available for children with disabilities, and disabling chronic illnesses in the western health subdistrict of Cape Town

GUIDE TO FILLING IN QUESTIONNAIRE FORMS

1. Please complete Form 1, the Facility Survey, either electronically or by hand. The completed form should be emailed to andrew.redfern@uct.ac.za or faxed to 0866599881 (Att: Dr A Redfern). This form provides a brief description of your institution, the services provided, number of staff and level of training of staff. Please feel free to add further comments or write down problem areas/needs.
2. Please complete Form 2, providing the details of every child in your institution. The key at the bottom of the page should be used to answer questions regarding race, feeding, toiletting, and mobility. Make as many copies as necessary to include all the children in your institution.
3. If a child requires any special equipment, such as oxygen, gastrostomy, wheelchair, please fill these in under medical equipment.
4. The forms can be completed by hand, or electronically. The completed form(s) should be emailed to andrew.redfern@uct.ac.za or faxed to 0866599881.

Please do not hesitate to contact me via email or phone (0837099831) should you require further assistance with completing any of the forms.

Your assistance is greatly appreciated.

Warm regards

Dr Andrew Redfern MBChB (UCT) FC PAED (SA)

APPENDIX 10

NON-PROFIT ORGANISATIONS INVOLVED IN DISABILITY SECTOR

Autism Western Cape
Cape Mental Health Society
Cape Town Society for the Blind
Child Care Information Centre
Deaf Cape Town and District Association for the Hearing Impaired
DEAFSA
Down syndrome support Cape
Hi Hopes
League of Friends for the Blind
Orion Organisation
Western Cape Council for the Blind
Western Cape Forum for Intellectual Disability