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The impact of inadequate provision of mobility devices on the lives of physically disabled children in Tembalethu Special School in the township of Gugulethu, Cape Town.

> *"He was a lively kid with a sunbeam smile, that suddenly changed. Without his plastic legs he finds it difficult to adapt to being inactive, he swears at other children and when they swear back he hits them."*

A DISSERTATION COMPLETED IN PARTIAL FULFILLMENT OF A MASTERS DEGREE IN OCCUPATIONAL THERAPY

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DECLARATION

I, SIPHOKAZI CELIA GCAZA. hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole nor parts of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the University of Cape Town to produce for the purpose of research, either the whole or any portion of the contents in any manner whatsoever.

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Date

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ABSTRACT

In this qualitative study a case study approach was used out to explore and describe the perceptions of children with mobility impairments in Tembalethu Special School related to the effects of inadequate provision of assistive devices on their lives. Data gathering techniques consisted of a focus group with ten children, six in-depth interviews, participant observations and record reviews. In addition, five in-depth interviews were conducted i.e. with a key informant, two teachers and two care-givers. This added to the data already available and helped to establish the trustworthiness and credibility of the data. Analysis of the data suggested five main themes as follows:

1) **Who am I without my mobility devices?**
2) ***"Mmage ngwana o tswara thipa ka bogaleng."*** (A woman will hold a knife by its sharpest edge)
3) **The burden of care in the absence of mobility devices**
4) ***"Intloko ingena ngeentlontlo"*** (The problem is bigger than it looks)
5) ***"Umdudo wooNonkala"*** (The dance of the Crabs)

The consequences experienced by disabled children in the study revealed that they were deprived of their right to education, play and social interaction as well as adequate health and rehabilitation services. The socio-economic and environmental impact on the needs of disabled children and their caregivers has not been considers by policy makers and service providers. Recommendations were related to the urgent need for transformation in the provision of mobility devices based on the needs of disabled children.

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"In Him all things are Possible"

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LIST OF ABBREVIATIONS

AFO	Orthotic foot appliance
DART	Disability Action Research Team
DICAG	Disabled Children's Action Group
DPI	Disabled People International
DPO	Disabled People Organisation
DPSA	Disabled People South Africa
INDS	Integrated National Disability Strategy
NGO	Non Governmental Organisation
OSDP	Office on the Status of Disabled People
RSA	Republic of South Africa
SAFCD	South African Federal Council on Disability
SAHRC	South African Human Rights Commission
UN	United Nations
WHO	World Health Organisation

DEFINITION OF TERMS

Assistive Devices: Assistive devices are any device and ergonomic solution capable of reducing the handicap experienced by an individual (Integrated National Disability Strategy, 1997).

Assistive Devices: "Equipment for reducing demands of function so that handicap does not arise, or technological tools that restore or extend human functions" (Borg et al, 1995: 23).

Care Dependency Grant: A grant for children between the ages of 1 and 18 years old; the child may qualify if he/she requires and receives permanent home care due to his or severe mental or physical disability.

Disability: A loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Disabled People International, 1982).

H0: Category equating to a social grant i.e. an annual income of up to R6240 (R520 per month).

H1 patient: Category patient with an income of +-R 27000 per year.

Impairment: The functional limitation within the individual caused by physical, mental or sensory impairment (Disabled People International, 1982).

Motor Impairment: Refers to confirmed clinical or radiological evidence of motor impairment, i.e. features elicited objectively or by special investigation.

Mobility device: An aid to assist an individual with mobility from one point to the next.

Primary health care level: It means first contact service delivery at a primary source e.g. a local clinic.

Secondary health care level: Institution-based health care services (not predominantly specialised services).

Sisi: A Xhosa word used to respect an older female.

Skoro-skoro: Township term for a car in a bad condition.

Spaza: Township term for tuck shop.

Tertiary health care level: Specialist institution-based health care services.

Umqombothi: A Xhosa name for brewed beer.

Unopentana: An indigenous skipping game played by young girls.

CHAPTER 1

THE SITUATION WITH REGARDS TO PROVISION OF ASSISTIVE DEVICES TO CHILDREN WITH DISABILITIES IN SOUTH AFRICA

1.1 THE NEED FOR PROVISION OF ASSISTIVE DEVICES

The majority of black disabled children, who are dependent on government for assistive devices, do not have the required provisioning of these devices. Their participation in school and social activities is thus reduced, thereby limiting their potential to develop fully. Department of Education (1997) states that assistive devices, refers to equipment or adaptations, which are required by some learners to access the curriculum and participate in effective process of learning. For some learners with disabilities the provision of assistive devices is central to learning as well as to the maintenance of functional independence. Where learning is forced to take place without necessary devices, learners with disabilities often experience learning breakdown.

Several categories of disabled children require special support from the State. Some of these children are born with disabilities while others are disabled as a result of accidents or illnesses. There is no accurate information on disability prevalence. Crude estimates state a disability prevalence of 6% of the nine million young children. There are approximately 1 183 904 children in South

Africa living with one or more forms of disability. Furthermore, the Census suggests that half a million children in the country are thus in need of disability services (South African Population Census, 1996).

Early provision of assistive devices to disabled children early can prevent secondary disability or complications: the latter might make a child with a chronic illness critically ill. Money, which is currently spent by the government on long hospitalisations could be saved. Furthermore, provision of assistive devices would make the child more functional in activities of daily living and also give him an equal opportunity to participate with peers at school or a day-care centre.

The above is affirmed by the White Paper on an Integrated National Disability Strategy in its policy guidelines for rehabilitation, which states that assistive devices/rehabilitation technology enables individuals with disabilities to participate on equal terms (INDS, 1997). If people with disabilities are to access their rights and responsibilities and participate in society as equal citizens, they must have access to appropriate and affordable assistive devices. The INDS goes on to say that, without access to the provision of assistive devices, disabled people endure firstly, prolonged periods of hospitalisation as independence is not promoted and remain dependent for longer periods; secondly, continue to be accommodated in segregated 'special' institutions where they are 'cared for' and thirdly, continue to experience difficulties in securing rights to education, employment, etcetera.

In order for disabled children to reach and maintain optimal health and function, they need a range of health services. Children also need to be assisted to move through all the developmental phases in their lives. They also need access to basic and advanced curative care, and to rehabilitative care when required.

Robinson (1998) states that Ratification of the Convention on the Rights means that governments commit themselves to the following universal declaration for a "First Call for Children". This simply means that children's rights and needs are prioritised within government's programmes. This is important as government spending on social services affects children and more particularly children with disabilities, directly. The South African government has committed itself to the principle of establishing "first call for children". Despite this, it is my experience (working as a rehabilitation therapist) that there is much to be done for disabled children because health-care services available at local level do not always cater for their needs.

Sait (2000) in her submission to the SA Law Commission pointed out that if current initiatives in government were indicative of the seriousness of the value placed on South Africa's youngest citizens, then they needed to ensure through policy and legislation that children were a priority target area and needed to be budgeted for equally.

1.2 THE RIGHT TO NEEDS BEING MET

1.2.1 The Constitutional Right

The South African government has undergone transformation in education, health, welfare and other sectors so as to meet its vision of achieving better quality of the life of its citizens. The Constitution in Section 9 (2) affirms this in the Bill of Rights, which states that every person has the right to equal opportunities and access to services that are available. This includes persons and children with disabilities.

Direct and indirect discrimination against anyone on the basis of disability by either both the State or individual is prohibited by the Equality Clause contained within the Constitution in Section 9 (3), (4) and (5). If the new Constitution recognizes equal rights and opportunities of all citizens, then it is imperative that disabled people are provided with the necessary support services, including assistive devices so that they have equal access to health and education and other rights. Despite a constitutional right, disabled adults and children do not enjoy the same privileges as other citizens of the country.

1.2.2 The Convention on the Rights of the Child

The United Nation's Convention on the Rights of the Child - Article 24.1 (1990) states that a child has the right to the highest attainable level of health. The disabled child should not be different. Health care should be seen as a pre-condition for disabled children to exercise their other rights. A study by McLaren, P.A, Philpott, S.C. & Hlophe, R. (1997) the DART, suggested that the provision of support services to disabled people is a pre-condition to equalization of opportunities.

1.2.3 The Equalisation of Opportunities

The World Programme of Action Concerning Disabled Persons (1982) sets the equalisation of opportunities, prevention and rehabilitation of disabilities as its primary objective. However, this is impossible without the acknowledgement of certain pre-conditions. These are included in the United Nation's 22 Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1994), chapter on pre-conditions for equal opportunities, containing Rules number one to four concerning awareness-raising, medical care, rehabilitation, and support services.

1.2.4 The Integrated National Disability Strategy: South Africa's Commitment to the Promoting of Rights of Disabled People.

South Africa's commitment to equalisation of opportunities was announced in the White Paper on an Integrated National Disability Strategy (RSA, 1997). The strategy represents a paradigm shift away from perceiving disability as a health and welfare issue that identifies disabled people as ill, different from their non-disabled counterparts, and in need of care. Instead, it takes an integrated approach to addressing their broader social needs by defining disability as a development and human rights issue. The INDS shows that disabled persons have the same rights and obligations as able-bodied people. It is based on a social model of disability where equal opportunities are seen as a constitutional right of disabled people.

Besides disabled women, disabled elderly people and disabled people living in rural areas, the strategy specifies disabled children as a sensitive or vulnerable group whose needs should be prioritized.

1.3 RESPONSE TO MEETING THE NEEDS

1.3.1 District Health Systems

With the establishment of a democratic government and the commitment to basic human rights has come the realization of the need for change on the part of government. Hurst asserted that all societies and communities should have services and that these services should ensure the integration of citizens (Hurst, 1995). Similarly disabled people, as citizens, should have access to health and education services so as to promote their full participation in society.

The government has initiated transformation in the health system to attain equity in health-care for all South Africans by instituting a district-based health system. In this approach, the large national health system is divided into smaller districts, as a means to improve the management and delivery of health services. The Department of Health has tried to provide free health-care at the primary level for all children who use the public sector facilities.

Currently at least 80% percent of children are reliant on the public sector for their health-care (Health Systems Trust, 1999).

1.3.2 Rehabilitation

The Department of Health's District Health policy document states that services based on a wellness approach should be structured such that appropriate emphasis is placed on prevention, health education and promotion of early intervention and rehabilitation (Department of Health, 1995). The primary health-care services are offered at three different levels: primary care level, secondary care level and tertiary care level. It is assumed that health-care services would become more accessible and available to all citizens, once Primary Health- Care Systems are fully in place.

The concern is that, in reality, health-care is not really free for disabled children. Free health-care for children under six years old has not been consistently extended to include rehabilitation. Of special concern is the exclusion of the provision of assistive devices from this programme. This affects the majority of disabled children from disadvantaged backgrounds, especially those with mobility impairments. They cannot access mobility devices within their local health-care facilities. The problem is that rehabilitation is mainly provided at a tertiary level and not at all three levels of health care. This leaves poor disabled children without the critical rehabilitation services, which they need to sustain their lives because they cannot access private health care.

Watson (1997) highlighted the need to break traditions of seeing rehabilitation as only a specialised service and to recognise that rehabilitation is part of all three levels of service provision. She continues to say that, in reality, some disabled people or their families require long-term or lifelong support and assistance. Watson concludes that development occurs within local communities and this is where the greatest needs lie in South Africa. Therefore, rehabilitation extends beyond the boundaries of medicine as it is not only about improved function or loss, but also about how to begin and sustain a different way of life.

The above is clearly stated in the Health Review by McLaren and Philpott (1997). They showed that assistive devices are an essential component of rehabilitation in that they provide a means of compensating for loss or limitation of function. In addition, they are a mechanism for equalisation of opportunities for disabled people by enabling them to participate on equal terms with others in society.

1.3.3 Inclusive Education

Children's abilities should be considered and not merely their disabilities. They should be given appropriate opportunities to play an active role in society. The doors of learning have not been opened to all when a disabled child is without the necessary mobility devices, because he/she will have difficulties in acquiring education. Werner (1998) states that for millions of poor disabled people and children, the lack of low-cost, appropriate mobility aids and assistive equipment is a major barrier to social integration including schooling, jobs, and self-reliance.

The Ministry of Education appreciates that a broad range of learning needs exists among the learner population at any point in time, and that where these are not met, learners may fail to learn effectively or be excluded from the learning. They also acknowledge that the learners who are most vulnerable to barriers to learning and exclusion in South Africa are those who historically have been termed 'learners with special education needs,' i.e. learners with disabilities and impairments. (Education White Paper No. 6, 2001)

The White Paper states that in an inclusive education and training system, a wider range of educational services will be created in line with what learners with disabilities require. This means that inclusion focuses on overcoming barriers in the system that prevent it from meeting the full range of learning needs. The focus is on the adaptation of the environment/teaching materials, and support systems available in the class-room.

1.4 SOCIO-ECONOMIC FACTORS AFFECTING DELIVERY OF SERVICES

1.4.1 Financial Resources are Needed

Robinson and Sadan (1999) state that a social security net is crucial for the protection of children with disabilities to alleviate poverty and to facilitate access to social services. There is a need for the voices of disabled children to influence the country's socio-economic policies because their voices are not being heard in the current children's budget.

Masambo (1998) asserts that the question is not whether we can or cannot afford disability-sensitive services and programmes, but rather, what are the implications, consequences and cost to the economy by not including children with disabilities and making planning provisions to meet needs of all?

Robinson and Sadan (1999) suggested that the quality of child health-care services is dependent on the provision of adequate resources, good management of services and the competence of health-care workers to deal with children. Resources from health and welfare sectors are needed desperately. The challenge is for service providers to meet the needs and provide them in a manner that does not create dependency and devalued status.

1.4.2 The Impact of Poverty on Disabled Children and their Families.

Disabled children from disadvantaged backgrounds bear a particular burden as their care-givers have a slim chance of acquiring assistive devices from the private sector. The Centre for African Studies (1999) reported results in the disability survey that, while Africans and Indians with disabilities tended not to have the required medical devices and equipment, Coloureds and Whites generally do have the necessary devices (CASE, 1998).

Young disabled children from birth to ten years are likely to have three or more disability or impairments than their advantaged, urban counterparts. This is according to Philpott and McLaren (1997) who indicated that poverty-related factors lead to many preventable impairments and that social disadvantage feeds into that of impairment.

O'Toole and McConkey (1995) assert that children living in poverty are more vulnerable to disability. Childhood disability affects many children and their families. Chalklen (1998) highlights the close relationship between poverty and disability. He states that poverty is a direct cause of disability due to malnutrition, lack of safe shelter, lack of access to basic health services, crime, amongst others. He also states that disability causes and worsens poverty within families and communities due to high unemployment, lack of appropriate education provisioning, attitudes and additional costs attached to disability. This presents a unique set of challenges to the health and welfare sectors.

Sait (1998) maintains that when children are affected by disability, they, together with their families, become the poorest of the poor. This contributes towards their marginalization. The reported high unemployment and illiteracy of their parents has an affect on the provision of adequate services at household level. Furthermore, Sait suggests that parents are faced with challenging dynamics when trying to meet the needs of their children with disabilities, plus those of their siblings equally and effectively. They experience increasingly high levels of stress, leading to mental and physical ill-health on the part of parents.

1.4.3 The Voice of Parents

Masutha (1998) states that parents are impacted upon daily by the difficulties experienced by their disabled children due to inadequate provision of assistive devices. They have no alternatives for accessing services for their children, as they are poor. When political power does not convert into the necessary services for disabled children, the children, together with their families, ultimately feel completely helpless.

Chalklen (1998) suggests that poverty is closely linked to disempowerment. Furthermore, he sites that the absence of fathers in the upbringing of disabled children is of particular concern, as this worsens the poverty situation in the family and deepens the disempowerment linked to disability.

In the African context the extended family is the basis for the articulation and protection of the rights of families and children. Philpott (1995) indicated in her study that professionals often could not identify with poverty and discrimination. Yet, it is they who are responsible for the assessment of impairment, provision of mobility devices, and care-dependency grants, and the articulation of the problems of disabled people to the public at large. She also cites Nkeli who suggests that it is essential for those affected by the problem to participate in addressing it. This will ensure that services are both appropriate and accountable to the consumer or users.

CHAPTER 2

THE EVOLUTION OF THE STUDY

2.1 PERSONAL JOURNEY

For the first 18 years of my life, I shared the same bed with my disabled father while my mother worked night-duty at a home for the aged in Kalk Bay. It was in this bed that my father shared with me his stories of living with a disability. One thing that amazed me about him was his compassion and generosity towards strangers.

Allowing strangers into our house in the middle of the night became the cause of many arguments, and he would say to me with a big smile: "How would you feel if you were a stranger and you were lost and your life depended on other people opening the door for you?" He would caution me further by saying: "Sipho, never play with people who are in desperate need of your help. If something happens to them, the pain of their suffering would stay with you for the rest of your life." I would be humbled by these words and immediately open the door with a smile and make preparations for these people to sleep in our house.

I was in my third year of Occupational Therapy studies in 1993 when my father was admitted to a secondary hospital here in Cape Town with severe epileptic seizures. Whenever I made a telephone call to him to ask what he wanted me to bring, he always asked for a packet of cigarettes. I brought these packets of cigarettes despite the fact that he did not smoke. He told me that life was not easy in hospital and he bribed the male nurses who looked after him well.

On the Sunday 30th of May 1993 I visited my father with my mother and aunt in hospital. He could not talk. I could see that he was trying to smile for me but that did not work. It was evident that he was in pain. When my aunt and mother started to pray I knew that he was leaving me. There was nothing that I could do to relieve his pain. The next day the hospital telephoned our home to say that my father passed away in the middle of the night.

Three days later, while we were making funeral arrangements, police from Pinelands Police Station came to our house saying that they were investigating the cause of my father's death. The post-mortem showed that he did not die of natural causes but of a head injury caused by a fall. My father was dependent on other people to bathe him and put him on his wheelchair. He could not have jumped out of bed or out of his wheelchair.

2.2 GETTING IN TOUCH WITH MY ROOTS

Driven by the desire of wanting to understand the suffering of people on a personal level, I continued to work in different communities with disabled adults and children, and their care-givers training community rehabilitation workers and working on disability forums and with disabled people organisations (DPO). It was during this time that my understanding of the struggle of disabled people and children started to grow. I also began to understand the impact of the socio-economic barriers that deprive disabled people and children of the opportunity to participate fully in society.

2.3 PROFESSIONAL JOURNEY

While working in the community and at the Tembalethu Special School, I found that most rehabilitation services, to date, are still characterized by the medical model of disability. It focuses on the deficiencies of the individual person removed from their social context.

Most mothers of disabled children are single and the sole breadwinners in their families. For example, care-givers of disabled children spend a lot of money on public and/or privately- hired transport to get to secondary hospitals away from the local day hospitals and clinics to fetch assistive devices. Often these care-givers have to bring the children for fittings and have to pay up front for these assistive devices. If appointments are missed, professionals assume that they do not care. No consideration is given to the fact that the care-giver may be unemployed and unable to afford necessary transport.

Mohale (1995) confirmed the above i.e. that there were many female-headed households and supporting a disabled child made life even harder for such parents who are already struggling to cope. The parents traveled long distances taking their disabled children to hospitals where interventions were expensive and had to be applied over a long period. These interventions often failed. Then the parents would begin the process of trying to get help for their disabled child again.

I felt strongly that professionals should take into consideration societal factors in order not to exclude and marginalize disabled children.

2.4 BREAKING THE SILENCE

When I joined Tembalethu Special School in Gugulethu in 1998 the consequences of inadequate provision of assistive devices for children with mobility impairments became apparent to me. On a daily basis I watched these children struggling to deal with the consequences of not having the mobility devices they needed. The happy faces and the smiles started to fade, and despair set in as inadequate mobility prevented the children from coming to school as well as playing with their peers. Health complications became prevalent e.g. pressure sores, contractures, urinary infections, respiratory infections etc.

In a study by the Disability Action Research Team (DART) the nature and the extent of the problems being experienced by disabled people with regards to the provision of assistive devices was explored. (Philpott, McLaren, and Hlophe,1997) The study highlighted the fact that the current provision of assistive devices was inadequate in meeting the needs of people with disabilities. In my literature search most documents talked of the inadequacies of mobility devices. But few documented the consequences experienced by disabled children due to inadequate provision of mobility devices. The question I asked myself was: Do we know about the consequences that this inadequacy brings to the lives of disabled people, and disabled children in particular?

Seeing the suffering of disabled children and realizing that it is not a privilege, but their inherent right to have their basic needs met, I began to investigate the feasibility of conducting a study which would be on breaking the silence of these children's suffering. I wanted to explore the impact of the barrier brought about by inadequate provision of mobility devices. The focus of the study was aimed at listening to disabled children's stories of the consequences of inadequate provision of mobility devices.

2.5 THE PROBLEM STATEMENT

The majority of physically disabled children from disadvantaged backgrounds in the Western Cape have difficulty getting mobility devices. The problem arose when provincial budget cuts in the Western Cape during 1998 led to delivery and provisioning of assistive devices being stopped. As a result, an orthopaedic workshop based in Conradie hospital was subsequently closed. Backlogs occurred, leaving disabled children without the necessary mobility devices for long periods of time. By the time the children received their mobility devices, the devices were too small or inappropriate. Furthermore, service providers failed to disseminate information about their resource constraints to the people affected and terminated essential services without notice. This left disabled children and their care-givers not only with limited resources, but also disempowered.

Inadequate provision of mobility devices affects the disabled child in many ways. Their schooling is disrupted, they experience restricted mobility in their own environment and their potential to develop becomes compromised.

2.6 RESEARCH QUESTION

What are the consequences of inadequate provision of mobility devices on the lives of disabled children from disadvantaged backgrounds?

2.7 THE AIM OF THE STUDY

The aim of this study is to explore and describe the perceptions of a sample of children from disadvantaged backgrounds with mobility impairments related to the effects of inadequate provision of mobility devices on their lives.

2.8 OBJECTIVES

1. To identify the consequences of inadequate provision of mobility devices as perceived by disabled children.
2. To explore the impact of the inadequate provision of mobility devices has as perceived by care-givers and teachers of disabled children.
3. To obtain a broad perspective of the impact of inadequate provision of mobility devices from the experience of an experienced service-provider.

CHAPTER 3

METHODOLOGY

3.1 MOTIVATION FOR DOING QUALITATIVE RESEARCH

Qualitative research makes an assumption that the whole is greater than the sum of the parts, and the context is essential for understanding the situation. In other words, the researcher takes a holistic view, looking at people in their natural environment, whereby the researcher-informant relationship is based on trust and openness (Holloway & Wheeler, 1996). The qualitative approach aims to gather data on numerous aspects of a situation and to construct a complete picture of the social dynamic of the particular situation or setting.

3.2 CASE STUDY AS A METHOD OF CHOICE

The focus of the study was to explore and describe the perceived consequences experienced by children with mobility impairments as a result of inadequate provision of mobility devices. I hoped to understand the experiences of participants within their natural environments, as a case study is a way of exploring the phenomenon or phenomena in their context. A case study design was therefore adopted as a method of inquiry. Merriam suggests that a case study is an entity which is studied as a single unit and that it has clear boundaries (Holloway and Wheeler, 1996).

Tembalethu Special School is a typical case of what happens in any special school based in a peri-urban or rural area in South Africa. These areas are characterized by poverty, unemployment, and usage of underdeveloped and under-equipped facilities in their local communities. LeCompte and Preissle in Holloway & Wheelers (1996) identified other methods of purpose or criterion-based sampling as the following: extreme-case selection, typical case selection, and unique-case selection. When choosing typical case selection researchers create a profile of characteristics for an average case and find instances of this.

3.3 SAMPLING

3.3.1 Study Population

The study population consisted of physically disabled children between the ages of 8-18 years from historically disadvantaged backgrounds, attending a special school in the Western Cape

3.3.2 Purposive Sampling

The participants were selected to share their experiences related to the consequences of inadequate provision of mobility devices. I identified possible children to be selected for the sample from a list of children with mobility impairments who were applying for mobility devices from the orthopaedic workshop. The list was supplied by the school physiotherapist who was responsible for assessing the children's mobility needs and for ensuring that the children's names went to the orthopaedic workshop for their applications to be considered.

3.3.3 Sampling Criteria

The children selected to participate:

- Were between 8 and 18 years of age;
- Used mobility devices between 1998 and 2000;
- Spoke isiXhosa;

3.3.4 Sample Selection

As the researcher I was familiar with the case of Tembalethu Special School because I had worked at the school for two years prior to the commencement of the study. A group of ten children with mobility impairments was selected as a homogeneous group. They were later interviewed to give relevant information about their personal experiences regarding the provision of inadequate assistive devices. Six of these children from the group were also interviewed individually.

3.3.5 Other Participants

Although the qualitative study started selecting participants after the focus of the study had been identified, further selection of participants continued throughout the study because of emerging ideas. As the children in the group shared their perceptions regarding the consequences experienced certain ideas emerged. These ideas needed to be expanded further, and led to the selection of the physiotherapist as a key informant, and semi-structured interviews with two caregivers and two teachers.

3.4 GAINING ACCESS INTO THE WORLD OF CHILDREN

Permission was first secured from the principal of Tembalethu Special School. A follow-up appointment was made by the researcher to explain the aim of the study to the principal. Subsequent to contacting the principal, contact was made with the physiotherapist and an interview was arranged.

With the permission of the school librarian I used the library to meet with the children concerned. I explained the aim of the study and made an appointment to meet the next Friday for our focus group. Letters of consent were sent to caregivers.

A difficulty in gaining access to the children arose when one of the school buses and a mini-bus broke down during the week intended by the researcher to conduct focus groups. This meant that most of the children had to leave at lunch time and the teachers had to squeeze the academic programme into the morning. For three consecutive weeks, each Friday for one reason or another, the attempts to meet with the children as a group failed. One of the teachers suggested a change in strategy. The group was moved to the end of term when the children had finished writing their exams and the study would not interrupt the academic programme. This proved to be successful and the focus group with ten participants met.

The interviewing process in the participants' homes was affected by a number of things. In most homes there were young children who sought for the caregiver's attention, thereby interrupting the interview process. Sisi Thandi, the physiotherapy assistant proved to be a resourceful person indeed. She came up with a strategy that, whenever there was a young child or children present, she would ask permission from care-givers or teachers who had children of their own to take the child or children for a ride in her car around the block. She would then go to the furthest ***spaza*** to buy fruit, sweets and chips. She would remain in the car until the children had finished eating. This actually helped conduct the interviews with minimal distractions and interruptions.

3.5 DATA COLLECTION PROCEDURES

According to Holloway and Wheeler (1996), the qualitative approach requires an empathetic understanding. This means that the investigator must try to examine the situations, events and actions from the participant's viewpoint and not impose their own perspective. They also suggest that the participants are part of a group or sub-culture in which they live, and therefore their words, actions and intentions can only be understood in context. This calls for trust between the researcher and participant.

The overall data collection period took six months. The case study draws on ***multiple methods or sources of information*** such as record reviews, participant observations, a focus group interview and in-depth interviews.

3.5.1 Record Reviews

The therapist made documents and records available. These contained demographic information. Files containing the therapist's progress notes on the children's specific impairments and a book containing names of children who had applied for mobility devices from the orthopaedic workshop at the Red Cross Memorial Hospital for Children were made available. These records were reviewed for ideas, insights on mobility devices and information on how the children accessed the service.

3.5.2 Participant Observation

For a week, I ***observed*** the movements, actions and interactions of the children who were to become participants in the focus group. I also ***participated*** in classroom activities like in-door games, storytelling, and sports. I listened to their conversations with their peers and friends. I also observed the children during their visits to the physiotherapist where they reported the state of their mobility devices and where the physiotherapist examined the mobility devices.

I accompanied the children and the physiotherapist on a Wednesday ***trip*** to the orthopaedic workshop in Pinelands. I listened to the conversation between the children and technician made possible by the physiotherapy assistant's ability to speak isiXhosa. The conversations were later recorded in a ***journal*** with the other observations made.

3.5.3 In-depth Interview with the Key Informant

Data collection started with an hour-long ***unstructured interview*** with the ***physiotherapist*** responsible for identifying children's mobility needs. The interview was recorded using a tape recorder. The physiotherapist was used as a ***key informant*** as she was considerd by the researcher to be knowledgeable due to her continuous exposure to the children and the provision of mobility devices. Based on her experience as a service-provider she gave a broad perspective on the situation of inadequate provision of mobility devices and how the children had been affected thus far.

The notes gathered from the interview helped me to develop an interview guide used to structure the later interviews.

3.5.4 Focus Group

I conducted a ***focus group*** with the ten participants in the library. I explained the aim and purpose of the study, the progression of what was going to happen, and also the concept of ***confidentiality.*** Participants expressed their anxiety about being taped. To relieve their anxiety, I explained to the children why I used the tape recorder. The tape recorder was introduced by singing together, and then listening to the song afterwards. The children were amazed to hear their own voices. The younger children in the group initially felt intimidated by the older ones and were shy to sing, but they joined in the singing later.

The focus group was started with a warm-up called "pass the parcel." A parcel was passed around the group with music playing. Once the music stopped, the child that had the parcel did an action chosen by him or her. The emphasis for the warm-up was to encourage expression of each child in the group. The children were encouraged by the researcher to express themselves in their mother-tongue i.e. isiXhosa.

To encourage spontaneous expression and articulation of experiences the children were allowed to decide how they were going to tell the stories. Some of them suggested writing the stories, while others used drawings to tell stories of themselves and mobility devices. Before the individual activity started the following ***group norms*** were developed. Group members should not laugh at each other's stories and drawings; there was no wrong or right; waiting for their turn to speak and not interrupting and asking questions when they did not understand.

The children were then supplied with paper, crayons, and pencils and they were given 30 minutes to individually work on their stories and drawing. At this time I was asked to pass around equipment by participants as some of the children had difficulties in reaching. After 30 minutes the group convened around the table and the tape recorder was switched on. In order to facilitate discussion about the stories, the following ***open-ended*** questions were posed to the children:

- Tell us which mobility device(s) you are using?
- Where do you get your mobility assistive devices?
- What is it like to not have mobility assistive devices?
- How have you managed at school without your mobility assistive devices?
- How have you managed at home without your mobility assistive devices?
- What are the things that have happened to you because you did not have a mobility device?

During the interview I was supportive, showed respect and sensitivity towards the stories that the children were sharing of their experiences. Notes were kept of main ideas or topics that emerged. The children spoke freely about their experiences, to the extent that, instead of the focus group continuing for another 30 minutes, it continued for an hour.

3.5.5 In-depth Interviews with the Children

In the focus group I compiled detailed notes on the overall perceptions of the consequences experienced by the children. Certain ideas or concepts from the stories emerged. ***Confidentiality*** and the right not to disclose information was explained to the children. I explored these further by conducting in-depth interviews with six individual children who participated in the focus group. Three of the children were interviewed at the school and the other three interviewed in their homes. The aim, purpose and confidentiality of information were once again explained to all participants. Three children were away on holiday, and one child chose to withdraw.

I used a list of ideas and concepts to explore with each child to ensure that all the topics were covered in the interview. The list was guided by two main themes:

(1) Tell me about your typical day at home without your mobility devices.

(2) Tell me about your typical day at school without your mobility devices.

Using the topics on the list I framed open-ended questions to facilitate participation in the interview and articulation of issues. The duration of the taped interviews lasted between thirty minutes and an hour.

3.5.6 In-depth Interviews with Caregivers and Teachers

From the stories that were told by the children, it transpired that others were also affected by the problem. Care-givers and teachers were also implicated, revealing the need to gain an understanding about the effect of the problem on them. I interviewed two care-givers, and two teachers individually. ***Confidentiality*** and the right not to disclose information was explained to the participants. The interviews were conducted in isiXhosa and the duration of the interviews ranged between 30 minutes and one hour. These were recorded with a tape recorder.

Throughout the interviews with the care-givers and teachers I sought at eliciting sentiments underlying the participant's accounts of their experiences by posing the following main questions:

1) Tell me, how does the situation of your child not having mobility devices affect you as care-givers?

2) Tell me, how does the situation of your child not having mobility devices affect you as teachers?

I also posed questions to reflect and clarify the meaning of information given by the participants sometimes questioned differently to cover the same topic.

3.6 DATA ANALYSIS

The following steps were taken in the process of data analysis.

1) Data management
2) Content analysis

3.6.1 Data Management

Data from the interviews and focus groups were transcribed and translated into English as the interviews were done in isiXhosa. The transcriber was made aware of confidentiality. The transcriptions were checked by the researcher to ensure that the information on the transcripts was the same as that on the audio-cassettes. The data was then managed using the QSR NUD*ST Vivo software package. The programme was used as a tool with which to manage the coding.

3.6.2 Content Analysis

Content analysis refers to the process of identifying, coding and categorizing the primary patterns within the data (Patton, 1990). Through content analysis, the codes emerged from the data inductively. The researcher went through each of the transcripts and identified those sections that were related to research objectives. Each code was then labelled. The researcher categorized the codes, developed typologies and generated themes.

3.7 ENSURING RIGOUR OF THE STUDY

The researcher has ensured rigour of the study by establishing trustworthiness. Trustworthiness exists as the findings of a study represent a reality. It is central to the whole research process whereby the researcher needs to demonstrate a 'decision trail' that can be followed by other researchers (Sandelowski, 1986).

In this particular study, the techniques of peer briefing, member checking and decision trial were utilized to ensure the accuracy of findings.

3.7.1 Triangulation

Use of several methods or data sources in the study of one phenomenon is referred to as ***triangulation*** (Holloway & Wheeler, 1996). In the study I used a combination of various sources for data collection i.e. focus group, in-depth interviews, participant observations, recorded interviews, and journaling, so that the case could be illuminated from all sides. Three person/participant sources were used to collect the data namely the children, care-givers, and teachers. Denzin (1978) proposed that the greater the triangulation in research, the greater the confidence a researcher will have in his findings. The rationale for this is that no method alone can adequately treat all problems of discovery and testing.

Triangulation was done by presenting the categories and subcategories to the key informant. The key informant clarified points that she felt were poorly represented. She discussed and assisted me in refining and confirming the themes.

3.7.2 Decision Trail

Koch (1994) argues that the reader of a report should be able to audit the trail in terms of decisions taken by the researcher and any influences (biases) that affect the research. The decision trail involves the researcher's presentation, clarification and justification of both the chosen methodology and data analysis. I initially engaged a consultant of the University of Cape Town's writing center in discussions regarding the data. She gave insights on the structure in which to present my data logically. Through ***peer briefing,*** I submitted the draft research report containing the analyses and conclusions to two supervisors for their critical evaluation. They provided new insights into the analyses, findings and confirmed the appropriateness of the conclusions.

3.7.3 Transferability

This concept refers to the way findings may be transferred from a representative sample of the population to the whole group (Lincolin and Guba, 1989). A clear description of the context, together with an explicit audit trail, would assist the reader to judge the transferability of findings in this to other settings. Within the case study method the researcher has studied a typical case, so that ideas from the findings could be explored to other cases or multiple cases. In other words the typical case could be used as a pilot for a larger study to illustrate specific elements of the research.

3.7.4 Dependability

Holloway and Wheeler (1996) suggested that if a study was found to be credible, then it would be dependable as well. The dependability of this study is borne out by the extensive description of the consequences experienced due to inadequate provisioning of assistive devices by the rationale and the methodological and analytical choices explicitly detailed throughout the research report.

3.7.5 Confirmability

The detailed description of the conceptual development contained in the evolution of the study and the method of inquiry of this report allows one to follow the manner in which the study was conducted. This enables one to follow the research process taken from conception to birth of the conclusions.

3.8 ETHICAL CONSIDERATIONS

In order to protect the participants' ***right to withdraw***, an agreement was reached by signing a ***consent form***. Along with the consent forms it was explained to the participants that there ***would not be any financial gains,*** but that refreshments would be offered as interviews could last a long time. I explained that ***confidentiality*** would be guaranteed at all times. The participants were also informed that they were ***allowed not to disclose*** experiences that they considered too personal to share. The participants disclosed their reality and lived experiences, which might have been traumatic. There was a need for ***sensitivity and empathetic understanding*** of the experiences they were sharing. ***(See Appendix (a))***

3.9 LIMITATIONS OF THE STUDY

3.9.1 Sample Selection

I originally intended to take a cross-sectional sample of disabled children from historically disadvantaged backgrounds. In the report of the National Household survey of Health Inequalities in South Africa (1995) it was reported that disabled children from the Coloured communities in the Western Cape had much better access to health-care than African children with disabilities. Therefore, one group of children would have been better off in terms of service-provision. It became obvious that these were two different studies. Similar studies with different groups of children with disabilities might yield interesting results.

3.9.2 Academic Requirements

The sample-size was limited as the research was done in partial fulfillment of a Master of Science degree in Occupational Therapy, which is a combination of course-work and dissertation.

3.9.3 Changing Jobs

The study started in Tembalethu Special School where I was directly involved with the children. However, during the course of 1999 I changed jobs. My new job involved travelling nationally. The momentum of the research slowed down a little. An advantage as a service-provision co-ordinator in the new job was that I was able to engage informally with experts in the disability rights movement and government officials on broader issues concerning the provision of assistive devices. This kept me on track with the latest developments.

3.10 PROFILES

3.10.1 Profile of Participants

The profiles of the six children who participated in the in-depth interviews are briefly described.

Vuyokazi is a 14 year-old girl who was born with Spina Bifida resulting in her being unable to walk or have any feeling in her legs. She makes use of callipers, orthopaedic boots, and crutches to walk. Vuyokazi has just received a wheelchair which she uses for long distances. Previously she used a buggy. She catheterizes herself as she has no bladder control. Vuyokazi loves visiting friends and listening to music. She stays in Delft with her parents and a three year-old sibling in a two-roomed house. Her father is the only one in the family who is working. He works in a dairy.

Mawethu is 14 year-old boy who has a congenital condition called Spina Bifida. As a result, he lacks sensation below his waist, cannot walk and has no bladder control. Mawethu walked independently with the use of callipers once. He now uses a wheelchair because he can no longer walk due to contractures. He also wears orthopaedic boots, which are worn out. He has been in different hospitals several times due to health complications. The boy loves to play soccer but due to long hospitalization he now feels fragile and weak and prefers to stay in-doors. He stays in a migrant labour hostel in Nyanga with his father. He shares a bedroom with his father and three other dwellers. His mother comes to visit him during school holidays. His elder brother supports the family by selling *'umqombothi'* (brew beer). His father is a pensioner.

Tracy is a 10 year-old girl, who was born with Cerebral Palsy (diplegia). Both her legs are affected, resulting in difficulties with walking. Tracy has had operations on her legs to improve her walking and she requires foot splints (AFO's) to walk independently. If she does not have AFO's she uses crutches. Currently she does not have either to use. I found her at home crawling or leaning on her sisters and against the walls trying to walk. Her mother is single and works as a domestic worker in Mitchell's Plain. Tracy and her three older siblings all stay with their mother in a two-roomed house in Phillipi.

Nandipha is an eight-year old girl who was born with hydrocephallus and Spina Bifida. As a result of these conditions she walks with the use of crutches and callipers and lacks sensation below her waist. She lives with her single mother and a one-year sibling in a two-room RDP house in Delft. Nandipha's mother operates a **'shebeen**' to support her family. The house is always full of people. For this reason Nandipha prefers to play outside with other children. They play **'unopentana'** an indigenous game of skipping and rhymes, and **'upuca'** an indigenous game of counting and throwing small pebbles with eyes closed. Nandipha no longer uses her callipers because they are too small for her. She cannot walk but she hates staying inside the house listening to noisy drunk people.

Mzivukile is a twelve-year old boy who had polio affecting both his legs. He has been without callipers and boots for a long time. As a result he either crawled or used a wheelchair at home and had to be carried on his mother's back to the school bus and for hospital appointments. Mzivukile has a younger sister who is three years old. While waiting for mobility devices he developed contractures in both knees to such an extent that he had to have surgery. All he wanted to do during this time was to play soccer with his peers. He now uses callipers and boots which are worn out.

Nomzamo is a fifteen-year old girl who was born with Athetoid Cerebral Palsy and also has a speech impairment. She has uncontrolled movement of all four limbs, which in turn makes it difficult for her to achieve balance to walk. She has spent almost all her life in a wheelchair and was depressed all along. Nomzamo is a brave young girl who defied everybody when she was eleven years old by refusing to use her wheelchair and refusing to be assisted by others. She started to move around by crawling, and leaning on things. The physiotherapist recognized her potential to walk and started teaching her to walk with her on parallel bars and later on a walking frame. The past is history now: she only uses her wheelchair when she is tired. Her dream is to acquire a walking frame for home, which she will use on weekends on the farm of her parent's employer so that she can pick up apples with the other children.

3.10.2 Attributes of participants

(See Appendix (b): Table 1)

Attributes of the participants are reflected in Table 1 according to the following: age; sex; device used; length waiting for the device; complication as the result of waiting, and hospitalization as the result of complication.

In-depth interviews were conducted with the six children (in gray shade shaded area in Table 1) out of ten children who were involved in the focus group.

3.10.3 Profile of the Key Informant

Ann is physiotherapist who came to work at Tembalethu school from Khayelitsha day hospital in 1996. Her responsibilities at the school include giving therapy to the children with physical disabilities, assessing their mobility needs and ensuring correct seating in classroom. She also takes the children and their care-givers to the orthopaedic workshop and other secondary hospital for collection and fittings of assistive devices. Ann is responsible for ensuring that children are seen by a medical specialist and orthopaedic surgeons at the school. She also established a wheel-chair maintenance group with the children, which ensures that general maintenance of the wheelchairs is done regularly.

CHAPTER 4

RESEARCH FINDINGS

"He was a lively kid with a sunbeam smile, that suddenly changed. Without his plastic legs he finds it difficult to adapt to being inactive; he swears at other children and when they swear back he hits them."

The study was undertaken in isiXhosa. African languages are rich in symbolism that is expressed in proverbs. In the African culture proverbs play an important role in telling the stories of our daily lives. The meaning behind the proverbs explains the true experiences of people in their natural environments i.e. the school in a township, a migrant labour hostel or shacks. Hence some of the findings related to the consequences experienced by disabled children are presented using proverbs to name the themes. Five themes emerged from the analysis and are discussed in this section, namely,

1) **Who am I without my mobility devices?** ;
2) ***"Mmage ngwana o tswara thipa ka bogaleng."*** (A woman will hold a knife by its sharpest edge);
3) **The burden of care in the absence of mobility devices**;
4) ***"Intloko ingena ngeentlontlo"*** (The problem is bigger than it initially looks or the problem is going to get bigger);
5) ***"Umdudo wooNonkala"*** (The dance of the crabs; it looks chaotic).

The findings for each theme are discussed in terms of their categories.

4.1 THEME 1: WHO AM I WITHOUT MY MOBILITY DEVICES?

The findings in this theme represent the disabled children's stories of how the opportunity to "grow" is taken away by not having the required mobility devices. The term grow is used broadly to explain achievement of the developmental tasks of childhood. It also describes how disabled children's lives are affected globally.

It became clear from the findings that a broad range of influences resulting directly from the unavailability of mobility devices, negatively impact on the development of disabled children. Healthy development is the single most important task of childhood and play is an essential component. When play is impaired, the consequences are far-reaching. Children who participated in this study all shared and spoke of how their ability to play had been hampered by inadequate provision of mobility devices.

4.1.1 My development is inhibited.

The findings revealed that disabled children without adequate mobility devices could not realize their potential to develop and grow because their lives were kept in suspense. It became evident that while children waited for their mobility devices they regressed, and this regression affected their holistic development. This suggests that where there is no early intervention and rehabilitation the development of the disabled child is hindered.

This quote by a teacher showed her concern with the child's physical development.

"Their bodies get weak; they are not strong, they do not have balance and they fall all the time. Without these things children are unable to stand and walk."

The teacher commented further that the children's health was at stake.

"The contractures were so bad that he had to be operated."

Many children shared their experiences of how they reverted to earlier mobility strategies, often leading to increased dependence on others.

" I started to learn to walk all over again like a small baby and it takes longer to walk the second time around."

"Pumza and Nwabisa would help me to walk. I would hold Pumza's hand on the other side and Nwabisa's hand on the other. They would help me walk to the dining-hall."

The regression caused by the inadequate provision of mobility devices was made even more cruel when considering the effort that had gone into achieving their independence in the first place.

The teachers identified that the child's self-esteem was damaged in the process:

"The child can see that other children are continuing with their work, and this lowers her self-esteem."

"The child is not free because she knows already she is not on the same level as others."

The teachers also identified that emotions of the children were hampered:

"The child gets frustrated and withdrawn; you have to do your best to help her."

"If the child comes to school depressed there is nothing that she can do in class."

Difficulties in relating to others was noticed by the children and their teachers.

"I scare my friends away from me."

" Without her AFO's she is scared of falling and she hits anything that comes her way. She is not popular with her peers because of that she has become so lonely."

It is clear that disabled children and teachers alike thought that the overall development of the children who did not have the required mobility devices was stunted. Children's development was inhibited in many ways and their health was threatened. Sandoval (1994) stated that all human rights were interdependent, and could not be fragmented. Therefore, recognition of the wholeness of the human being and his or her development at all levels is of importance. He furthermore stated that holistic rehabilitation was closely linked to the right to development. Findings presented here show how adequate provision of mobility devices is essential.

4.1.2 I am stopped from maturing and achieving my goals.

More than one category revealed that when children were sick they were unable to learn and were not making progress at school. They failed their grades as a result of inadequate mobility devices. Most children spoke of the desire to grow and to learn.

"When I am on callipers I am tall; I stand, I walk, chase others. It is exercise and it makes me strong."

"They make me slow and the bus would hoot and leave me. I would not be able to go to school."

Both teachers interviewed voiced their concerns that the children's education was hindered.

"Before he went to hospital his performance was good, but now that he is back things have completely changed. He is now weak and slow in understanding his class-work."

"I guess the stay in hospital is very long; it becomes too much for them to absorb everything when they came back."

It became evident that inadequate provision of mobility devices takes away a disabled child's basic right to mature and their basic right to learn.

4.1.3 I watch the world pass me by.

Persson (1996) asserted that disabled people have the same right as other people to an independent life and participation in society. The findings of this study revealed that children were denied this right as they were confined in-doors as a consequence of inadequate mobility devices. The pain that was caused by this became apparent as the children described how they watched the world pass them by. This reinforced the stigma of disabled children being locked away. Furthermore, these children were not involved in social activities and thus not integrated into their communities.

"I stay in-doors and watch TV; other children come to visit me. They stay for a short time and leave one by one without telling me."

Children spoke about their desire to be a part of the outside world.

"I did not enjoy the rest of the Christmas Holidays because I could not go to church for Christmas day. Also, I could not show anybody besides my family my new Christmas dress that my mother bought for me."

Children indicated that they experienced exclusion from family activities and friendships.

"It was difficult for me when my boots and callipers were small. I just sat by the stairs and watched my friends and their parents go to the beach."

"I love Guy Faulkes Day, but that year I watched other kids dressed funny coming to my house to collect treats and I wished I could join them."

4.1.4 I am excluded from participating in play.

Disabled children in the study regarded playing to be an integral part of their lives. They had an urge to play in order to make sense of their world. It became apparent that inadequate mobility devices isolated disabled children from their peers and excluded them from participating in play. Because they were unable to participate actively, their peers treated them like outsiders. The findings showed that it was important for disabled children to be accepted by their peers.

"I watched my friends playing uNopentana, sitting on the floor rug that my mother put outside for me. They talked and laughed together as if I was not there. I sometimes cried when my mother took me inside."

Persson (1996) confirmed this. A child with a disability was first and foremost a child who had a right to experience stimulation, security and friendship as a basis for his or her development. Findings from this study demonstrated that because of not being able to move around, disabled children's sense of freedom, autonomy, exploration and spontaneity was diminished.

"I would ask my mother to call other children to come and play with me. They would not come because they want to play uAsikhululi (chasing game) outside and without my callipers I could not chase them. My mother would tell me that she could not force them to come."

One child noted that his peers find him a source of ridicule:

"Other children laugh at my old boots because my toes are peeping out; sometimes I go home and cry, but I know eventually I will get my new ones."

4.1.5 I am unable to look after myself.

Coleridge (1993) stated that to be cast in the role of a patient means to be seen only in part. He goes on to say that it is assumed that a disabled person does not have other roles to fulfil. He adds that wholeness is the key for the child to develop to his or her fullest potential. The findings revealed that inadequate provision mobility devices robbed disabled children of their sense of responsibility to themselves. It was clear that when children were unable to perform self-care tasks, they were unable to achieve functional independence.

"Sometimes my mother would leave early for char-work, and I would be left with my sisters who are also going to school, and I have to wait upon them to help me put on my school uniform."

"When I come from school my brother would put me on the bed, and while I take off my school uniform he would make food for me."

This seemed to have a negative impact on the child's self-esteem.

4.1.6 I am unable to make my contributions at home.

When children were unable to make their contributions in their homes because of reduced mobility, they lost their roles as valuable family members.

"My younger sisters did not respect me anymore. For example, when I ask them to make a peanut butter sandwhich after school, they would run and play outside knowing that I can't chase them. I am bound to the floor."

Mbigi and Maree (1995) claim that people gain recognition and status through making a contribution. Children in African families are integrated in family rituals by being given responsibilities to perform. Disabled children have a role to play within their families. Children spoke of their desire to make their individual contributions in the form of errands and house chores within their homes, which was impossible because of their immobility.

"I could not go to the spaza to buy bread."

"I can't make tea for my mother."

4.2 THEME 2: *"MMAGE NGWANA O TSWARA THIPA KA BOGALENG."*

Translation: (*A woman will hold the knife by its sharpest edge)*

Meaning: A mother will put her life on the block to safeguard her child's needs.

The findings in this theme show the socio-economic burden of care-givers, especially women, in accessing services for the provision of mobility devices for their disabled children. It became clear that not only do disabled children suffer, but they suffer together with their families who do not have adequate resources to meet children's mobility needs.

4.2.1 Disability exacerbates poverty.

Coleridge (1993) stated that disability created and exacerbated poverty by the increasing isolation and economic strain, not just for the individual, but for the family as well. Most stories told by care-givers and their children described the socio-economic status of the care-givers and illustrated the struggle of care-givers in making decisions in terms of their limited financial resources. This was a cause of distress for care-givers, as most of them were single parents and unemployed. Care-givers were struggling to make ends meet. Having a disabled child made matters worse, since they had other children, besides the disabled child, who looked upon them to provide food.

"I would leave them hungry and use the last penny to get to hospital. My mind does not rest. I think about the children that I have left behind."

Mzolisi ka Toni (2001) asserted that disabled people were made to compete for resources when they were already faced with bread-and-butter issues. He went on to say that disabled people were rendered powerless by the stress brought on them by their situation. This was the case with the care-givers and disabled children who participated in this study.

4.2.2 Caregivers cannot afford mobility devices and are dependant on the State.

Guthrie (2001) highlighted the need to move away from the medical definition of disability to the one that considered economic and social aspects, as well as the 'cost', or burden to the family. It became apparent that disabled children had additional needs, such as mobility devices, to enable their full development and participation in society. Care-givers indicated in the interviews that they were called upon to pay for services that they could not afford. This posed a challenge for care-givers who were the sole breadwinners and had no extra financial support.

"I'm a single mother with no man to support me, and the money from char work is so little you can absolutely do nothing with it."

It was also evident that care-givers had difficulties in accessing care-dependency grants (CDG) for their disabled children's needs. The care-givers were told that their disabled children did not qualify for grants because the government was already subsidizing the school. One of the eligibility criteria for a care-dependency grant states that the child must be under permanent home-care for 24 hours. This posed a problem for these children, as they were cared for at their school for almost two thirds of the day. The disability needs of the individual child were not considered.

The problem seemed to be that the current disability assessment has been mostly based on a medical diagnosis. This is shown by the following quotes from caregivers.

"When I go and I ask for the grant they tell that my child is not disabled enough as she is at the school"

Pension officers processing care-dependency grant applications were found to be insensitive towards the needs of care-givers and their disabled children.

"When I go to the pension office they ask me if Mandela made me pregnant?"

4.2.3 Money up front is not reasonable.

Tiroler (1995) stated that poverty meant lack of income. Poor people lack access to influence, power, information and resources, meaning that they have very little control over basic decisions about their lives. This is especially true for poor disabled people. The findings of this study showed that most care-givers of disabled children had to travel distances and pay for transport to access assistive devices at secondary and tertiary institutions, only to discover at arrival that money had to be paid for mobility devices. Care-givers were also discouraged by the attitude of health professionals. They become unmotivated to go back to the institution

"We take a bus or a taxi to hospital but they charge an extra fare for the wheelchair of the child. It becomes a third head."

"I was called to come and fetch Vuyokazi's wheelchair in hospital, I could not come back with it because I did not have the R100 deposit. I was told that the chair would have to wait until I bring the money. Her excitement was replaced by sadness. She came back crying."

The study also reflected the lack of understanding and insensitivity of health services towards the socio-economic circumstances of care-givers. The hospitals expected care-givers to pay deposits for their children's mobility devices, regardless of their circumstances.

"Even though care-givers declare their unemployment status, an H1 patient is still required to pay a minimum of R60 towards the mobility device of child. Most care-givers owe the hospital a lot of money."

4.2.4 Care-givers are willing to pay.

Through doing this study I came to the realisation that although caregivers did not have much to offer, they were willing to pay with money from an old age pension, char-job, selling brew (beer) umqombothi, sheep trotters (amanqina), sheep's head ("Smiley"), intestines (amathumbu), reject potatoes crisps (amashwam-shwam) and fruit. Care-givers spent their last cent on their children and this put a strain on family maintenance. Having discussed the financial difficulties experienced with them, it became clear that care-givers were willing to pay what they were able to afford.

"With the R80 that I made from selling brewed beer this week we had to pay the workshop for wheelchair repairs and we were left with nothing to eat. I am so stressed."

This was confirmed by the key informant.

"Care-givers show their willingness to pay by fetching their accounts from the workshop and pay them off bit by bit no matter how long it takes."

Coleridge (1993) stated that it was very rare to find a parent who did not want to do the best in the interests of a disabled child. Neglect is usually not their intention, but only an option when no services are available. As soon as some kind of service is available at community level there is a flood of applicants to use it.

4.2.5 "Wathinta abafazi wathinta imbokotho.

Translation: *(Strike the women and you strike a rock)*

(A slogan reflecting the solidarity of women in the pass law campaign of 1951)

Meaning: To most African women in South Africa the slogan is the basis for collective solidarity. It symbolizes the resilience of women as a collective, especially when challenged on survival issues. Togetherness (**umanyano**) is the foundation of everything in the African society.

In this category the children's interviews showed that care-givers did not sit back without attempting to change their children suffering:

"Together with the care-givers we organized an Awareness Campaign about the problem through Cape Times."

Mbigi and Maree (1995) he speaks of **Ubuntu** (humanity) as a concept. It is marked by collective solidarity of the poor on survival issues. The study showed that mothers felt the pain of their children's suffering. The social action by care-givers was used as a means of breaking their silence about the suffering of their children. Together they initiated public awareness campaigns about the problem of inadequate assistive devices. However, the campaign did not make a wide local impact. It seemed that the few isolated voices of care-givers of children in Tembalethu Special School were not loud enough. The campaign resulted in measures or interventions that were temporary and unsustainable.

One child reflected the poignancy of the situation faced by their caregivers:

"Our parents went to plead with the technicians at the workshop not to put tools down and they informed them that they were told to close the workshop because they are few to work on the backlogs."

Philpott and Sait (2001: page 158) said: "The voices of disabled children largely remain unheard. Their cries are submerged in a quagmire of ignorance, fear and extreme negative attitudes where politicians and policy-makers hide behind

Article 23 of the Convention on the Rights of the Child (UN 1980:6), which refers to addressing their rights 'subject to available resources'

4.3 THEME 3: THE BURDEN OF CARE IN THE ABSENCE OF MOBILITY DEVICES.

The findings in this theme indicated that without adequate mobility devices children were helpless. They became a double burden, or an overload to those who directly cared and work with them. Not only were caregivers of children with disabilities subjected to stressful conditions, so were the professionals who worked with these children. It was noted that these professionals often had to grapple at a personal level with the consequences of children's suffering. They could not turn a blind eye to the crisis. They were forced to reach out to the children beyond their call of duty to make sure that the lives of these children were as productive as possible.

4.3.1 Health of caregivers and professionals is at stake.

Tiroler (1995) suggested that caring for disabled people or children may sap the time and energy of relatives and neighbours, particularly of women who play the main caring role. The health of those who help suffered, resulting in the reduced well-being of the other non-disabled children that they were responsible,

One child spoke about her mother:

"When she complains of a backache; she says I am heavy for her. I put rubbing salf (muscle relaxant cream) on her back and rub her."

The teachers stated that their health suffered:

"You end up having waist and back pains and when you come home you feel so tired that you do not want to do anything."

The teacher's poor health impacts on the well-being of other children.

"At one time the doctor booked me off for a backache for almost two weeks and I did not come to school, I stayed at home. My pupils were not happy."

Sibling rivalry was also indicated by the comment of a care-giver.

"...and my three year old boy would be upset, maybe he was jealous but at the end of the day I would be too tired to look after my baby."

The study also found that children became a burden to people outside their immediate families. For example, the neighbours stepped in to look after these children when their care-givers were sick.

" My neighbour fetches me and prepares food for me when my mother goes to the clinic for her back."

When people were reluctant to help, children found it to be more difficult.

"They are tired; they want to know when my callipers are coming back."

"My friends would run away because I am slow and the teacher would help bring the wheelchair from outside."

4.3.2 The double load of the physiotherapist.

Reaching beyond the call of duty came at a price. This was reflected in the strenuous schedule of the physiotherapist in an attempt to make sure that children had some form of mobility at school. It was described by the children and teachers interviewed. It was found that the time spent by the physiotherapist organizing temporary measures of mobility devices was done at the expense of individual therapy to other children.

The teachers commented that:

"She spends the whole day repairing mobility devices for the children."

"She would come to the bus in the morning to take a roll-call of children who were without mobility devices and who is sick and swop mobility devices."

The children also highlighted the hectic schedule of the physiotherapist:

"Ann borrowed me Nandipha's calipers while she was sick at home and took mine to the workshop for repairs."

"She would look at how bad are our sores were, and she would either send us to the sister (the school nurse) or send us with a letter home for our mother to take to the clinic."

4.3.3 The double load of teachers.

Extra time was spent by teachers on children who were behind in their work because of long hospitalization. This was done at the expense of individual attention for other children and impacted on the academic progress of the rest of the pupils in the classroom.

The teachers said this about their experiences:

"You need extra time helping this child. We have catching up to do because his schoolwork is behind. This then causes other children to suffer because this child needs to catch up."

"The work they do at the hospital is not the same as ours here in Tembalethu so we have to prepare work and send it to them in hospital."

""They do not do Xhosa at all in Maitland Cottage; things become difficult especially for those in their early grades who are beginning to write and spell in their mother tongue."

Another aspect that became apparent from the children's stories about the long stay in hospital was that they repeated grades.

"I do not want to go to hospital because when you come back the other children are far and the work is too much for the teacher."

"I have been away from school for three months and I did not do well in my exams so I failed grade four."

Sait (2000) in her submission on early childhood development to the SA Law Commission (2000) stated that children whose earliest years are blighted by disease are far more likely than their more fortunate peers to do poorly in school, to drop out early, to be functionally illiterate, and not to be employable in market related jobs. They high-lighted that if children have been deprived of the basic rights in early life, labour productivity and national economic prosperity are affected.

4.3.4 People are not sensitive to my needs.

The findings revealed that life for disabled children in institutions of care has not been easy. The findings illustrated the insensitivity shown by nurses towards children's needs when they are hospitalized. Children reported that they were subjected to verbal abuse when they asked for help. It should be noted that they would have been independent, had they been given the mobility devices needed.

"They shout at us and threaten to give us a hiding, but they never hit us. You become so frightened that you do not want to ever ask for anything, even if it means to pee on the bed. Then you are more frightened."

"When we request for something the nurses tell us they are watching TV; they don't want to be disturbed especially when it's Bold and Beautiful time."

"I do not like the hospital, it is not like home. At Sarah Fox the older children hit the younger ones and no elderly person comes around at night. But I can fight for myself."

When triangulation was done with the key informant, she explained that the insensitivity might not have been intentional as the nurses were short-staffed and were working under stressful conditions. While the shortage of staff could explain the situation, it does not make it acceptable. The children's stories portray their experiences. It is saddening to know that children would probably not have had these experiences had it not been for the inadequate provision of mobility devices.

4.4 THEME 4: *"INTLOKO INGENA NGENTLONTLO."*

Translation: (*You go in head first, and then the whole body follows*)

Meaning: The problem is bigger than it initially looks or the problem is going to get bigger.

The findings in this theme revealed the numerous difficulties care-givers and their disabled children have going from one service provider to the next in an attempt to access services that offer assistive devices. It was also high-lighted that the help that is available cannot meet the needs of disabled children. The demand for assistive devices is big, leaving the disabled children and their care-givers desperate, and with unfulfilled needs.

4.4.1 Help within my community not appropriately placed.

The South African Law Commission (2000) claims that health services are meant to impact maximally on prevention and early intervention. However, such services for children with disabilities and families are inadequate, because of the factors explained, which leads to a range of other barriers that excludes them from participation.

The study highlighted that the help available within the communities or primary health care services do not meet the needs of disabled children. This often left their care-givers desperate. It also became evident from the responses of care-givers and the key informants that the provision of assistive devices was not regarded as a primary health care issue. Assistive devices were regarded as expensive luxury items. The needs of disabled children were not catered for. Facilities seemed to be adult disability centered.

"We never get any mobility devices from the local day hospital for our children; they have wheelchairs and walking sticks for adults."

The physiotherapist said this about the service:

"I guess they can not do otherwise. Day hospitals or clinics do not have budgets dedicated for assistive devices; they are seen as luxuries."

The care-givers stated that:

"Even when children have pressure sores, they do not have dressings for us at day hospital."

Robinson & Sadan (1999) stated that total health budget allocations between national and provincial are decided at the national level, without provincial input. However, the provinces have greater autonomy to decide how resources are allocated between and within those functions for which they are responsible.

The South African Human Rights Commission's (SAHRC) (2000) report affirmed the rationale for budget cuts. District Health services accounted for one of the largest programme allocation increases in spending. However, a disproportionately high amount has been spent on personnel to the detriment of non-personnel expenditure.

4.4.2 Help outside my community is not easy.

The previous category showed that improvements in primary health care facilities were slow. Caregivers of disabled children were forced to use specialist institutions outside their communities. The care-givers highlighted that the assistive devices were available in specialist or secondary health care level institutions but that accessing the service in these institutions was not easy.

"I don't bother nowadays. I just go to Red Cross; the nurses shout at us to go to our day hospital; they treat us like children."

The Conradie orthopaedic workshop does not serve only disabled children in special schools, but the rest of the disability sector in the Western Cape as well. Although some of the children had written motivations from medical doctors and orthopaedic surgeons as to why their mobility needs should be prioritised, they had to wait their turn.

Children had this to say of the service in secondary institutions:

"The budget is cut all the time, and so is the piling up of orders."

"They told our parents that they are short-staffed and the orders are too much for them."

"I was given mobility devices that were not mine, and I had to do the fittings all over again which meant going back to the end of the list."

From the physiotherapist's point of view there was a suggestion that inappropriate assessments in these institutions made matters worse.

"It is sad, Sikelela has got a potential to be independent at school. He pushes a paediatric wheelchair and gets down to play with others all by himself. At home he uses a buggie, which his mother pushes for him. I don't think he was properly assessed when they issued it to him in the first place."

The "help outside my community is not easy" category, in particular, high-lighted that the hierarchy of decision-making impacted on the provision of assisitive devices. The technical personnel did not seem to be in control of the situation. Care-givers and children came under the impression that personnel took orders from their superiors to stop the service. The study highlighted that technicians in these institutions could not meet the existing demands of disabled children who required mobility devices. It became evident that the backlogs were piling up and the needs of disabled children were at the bottom of this pile.

4.4.3 Goodwill not good enough.

The study highlighted that, besides government, there were other sources from which children received mobility devices. Most of the mobility devices that were donated were inappropriate in the sense that they were for adults, not age-specific, in poor condition and did not come with their accessories. This resulted in health complications and secondary disabilities for the children.

The statement from the physiotherapist reflected the sources:
"The children also get mobility devices from Game, Rachel Swart Foundation, individual donations and other schools that are well off."

Werner (1998) stated that a common shortcoming of large rehabilitation centres was that aids and equipment tended to be standardised and generic. Also, when standard commercial aids were prescribed, too often an attempt was made to adapt the person to the equipment, rather than equipment to a person. This was the case with this particular group of children, as indicated by the physiotherapist added that most of these devices were inappropriate.
"Most of the wheelchairs that children get from these sources are adult wheelchairs. The last time that children got age appropriate wheelchairs was when they went to Madiba's Birthday in 1996."
"These children get 'vrot' wheelchairs from other schools, which are useless. We sometimes take parts from them."

Accessories were in the form of donations from individuals, other special schools, NGO's, private companies and through fund-raising. The school saw accessories as a priority for the prevention of health complications and secondary disabilities. This resulted in extra costs for both the school and care-givers who had to pay for repairs and purchasing of accessories. These costs added to the burden of care-givers and schools, which would be avoided by giving appropriate mobility devices in the first place.

"The mobility devices that you get from both the state and these sources do not come with accessories. I mean basic accessories like pressure care cushions, chair inserts, straps - you name it. She has just repaired this one from Game for R80. She is complaining that the wheelchair is working on her nerves because she does not have money to buy a cushion and I have a sore already."

"Look at how Sesethu is struggling to breathe sitting in a chair without inserts."

While donations by NGOs were considered to be valuable, they do not offer reliable and sustained provision of mobility devices as deserved by the children.

"The school pays a fortune to repair these 'vrot wheelchairs, so do caregivers."

"The funds that were raised through the awareness campaign only paid for mobility devices of seven children out of twenty two children. The need is big"

4.4.4 Back to square one.

This study highlighted the losing battle of care-givers. It became apparent that care-givers were disillusioned with the inadequate provision of mobility devices from the state. They were dependant on the goodwill of others.

"When school is closed everything stands still."

"I will go when the school re-opens end of July. It is easier when I go with Ann."

It was found that this goodwill was short-lived and unsustainable. Hence, the care-givers were dependent on the schools dwindling resources, thus "over-burdening" the school.

"I go to the school and the school bus takes me to [Conradie] workshop."

"The school buys pressure cushions for all the wheelchairs in the school."

4.4.5 Charity creates dependency.

"Really now Sipho! Have you seen on TV a few days ago how the disabled children hung helplessly on those big wheelchairs donations. I don't think there has been an effort to assess the needs of those specific children. I do not think we are doing children justice at all." (Thompson, 2001)

Milton (1992) stated that the charities invoke levels of pity in the way they use images of disabled people, particularly disabled children in advertisements. The charitable organizations often decide what they think the disabled person needs He goes on to say that the charity model portrayed the tragic disabled person who passively and gratefully receives help. A similar attitude was reflected in the interviews with care-givers and teachers.

"What can we do? Little is better than nothing."

"It does not help to complain my child, there is nothing that you can do without money. We sort of got used to this."

"The children and their care-givers accept the status quo and they adopt a better than nothing attitude."

4.5 THEME 5: *"UMDUDO WOONONKALA"*

Translation: (The dance of the Crabs)

Meaning: This theme symbolizes the chaos and confusion created by not knowing where you are going to. The symbolism is based on a visualization of what it would be like if crabs attempted to dance.

The findings reflected the contradictory messages sent to disabled children. For example, it was revealed that disabled children had the use of mobility devices at school, but not at home. Also, when children expected to receive their devices, they did not get them. The waiting was prolonged again and again, confusing them about what they were entitled to. It became apparent that, as a result of inadequate mobility devices, disabled children "lived in waiting". The children in this study did not have a sense of stability, and this created chaos in their everyday lives. They accepted whatever came their way, regardless of the condition or the sustainability of the mobility device with the hope of getting something better one day.

4.5.1 "You give it to me and you take it away."

The children were confused about what they were entitled to. The interviews with them revealed that the children's lives were put on hold indefinitely because mobility devices belonged to the school and they got their devices in bits and pieces.

"At school we have the mobility devices, we do all the things we want to do. After school we can't take them with us because they belong to the school. At home we have nothing, we must wait until the next day."

"Just when I think at last I will get my calipers to do all the things I miss to do. On the day of fetching at the workshop the man will tell Ann that the measurements are missing."

This was conferred by the key informant.

"Sitsaba waited for almost a year for his callipers, only to find out his measurements were lost at the workshop, he had to do fittings all over again. I can say he almost stayed for two year without his callipers."

4.5.2 Children are dying.

"Extinguishing the life of any infant we are denying the world the contribution that infant can make by simply being alive" (Coleridge, 1993, p71).

The consequences in the lives of disabled children brought about by inadequate provision of mobility devices were many-fold and detrimental to their lives. It became apparent that most respondents were vulnerable and susceptible to health complications, and developed secondary disabilities. It came as a shocking realization that children were dying because of inadequate mobility devices. Interviews with the teachers and the key informant showed that death at a young age was a reality. This was reflected by the recent deaths of two children, aged six and nine years, due to respiratory and pressure-sore complications.

"Do you remember Fezeka, she died of these complications and her parents are poor and struggling."

"Aphiwe passed away last month. He was not able to sit properly in the buggie. Therefore he struggled to breathe and he passed away because of that. The school was forced to bury him because the mother who is a bread-winner does not work."

Robinson and Sadan (1999) claimed that poor children in our country suffered and died from diseases that could easily have been prevented by improving basic health conditions. This experience was supported by one of the teachers.

"Siyanda has been in hospital for pressure sores since last year. We are worried of what is going to happen to him; he is not getting discharged."

4.5.3 " *Akulahlwa mbeleko ngakufelwa.*"

Translation: (*You do not lose hope of giving birth again, when you have had a miscarriage)*

Meaning: This is symbolic of perseverance and hope that things will improve

The findings showed that children with disabilities were battling to live without their devices. Care-givers and disabled children were not asking for much, only for the necessary mobility devices to continue functional daily living. Children continued to believe that provision of assistive devices would improve, and that their mobility needs would be met adequately.

"The old ones are on top of the wardrobe. Maybe when Ann comes back she will take me to the workshop for new fittings. Maybe this time they will be quick."

"I am still hoping that when school re-opens they will find money to buy the cushions for our chairs"

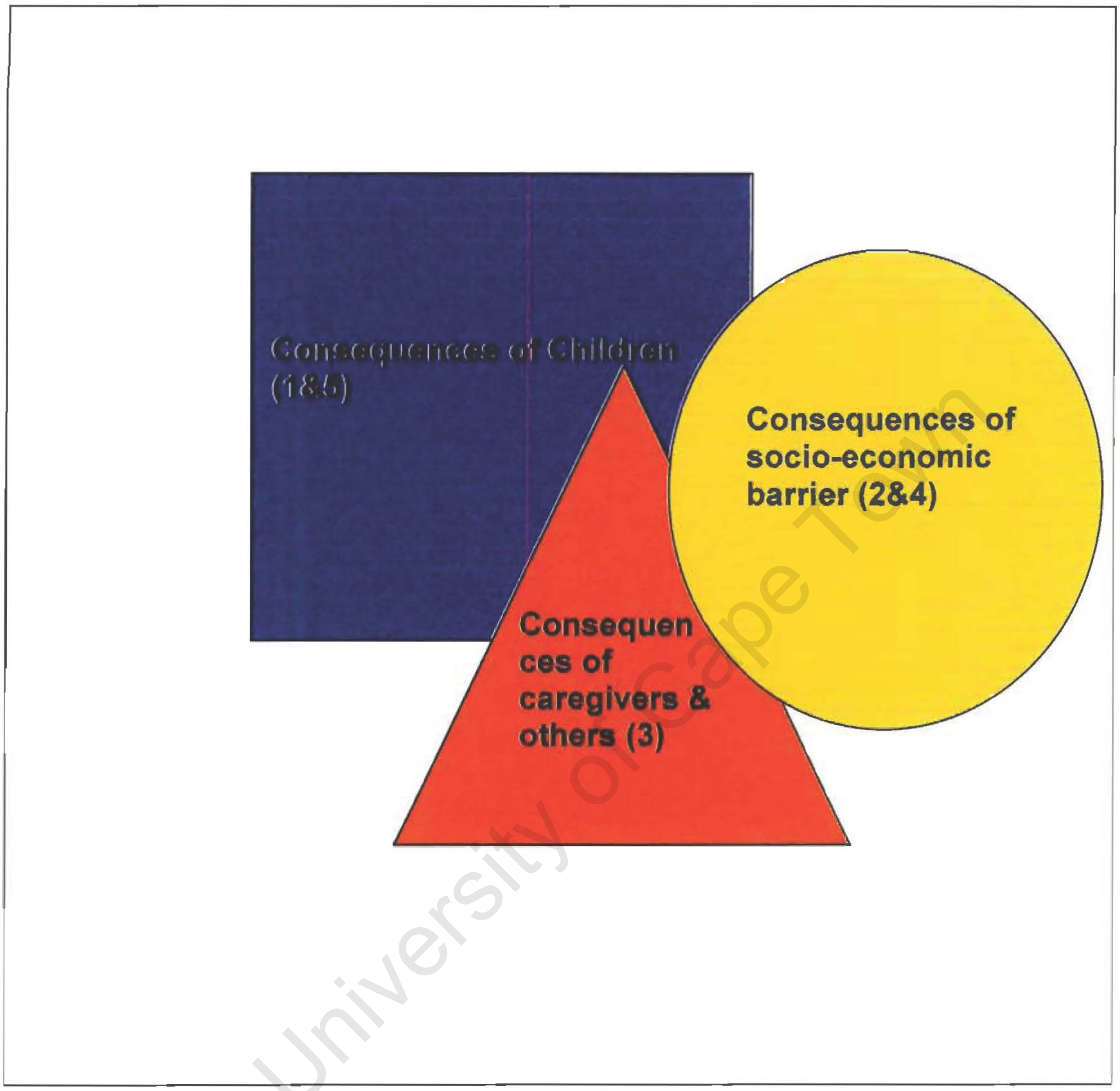
Philpott & Sait (2001) concurred with the findings of this study, in that they explained how the government of South Africa had made a number of specific attempts to address the many difficulties facing children in the country. Children were promised a "better life", and children's needs had been prioritized in an effort to address poverty. They went on to say that whilst these initiatives were commendable, and a great deal had been achieved to date, the challenge remained to bridge the gap between the rhetoric of progressive policies and the reality faced by disabled children on a day-to-day basis.

4.6 SUMMARY OF FINDINGS

Figure 1 reflects the relationship of the consequences for disabled children, together with their care-givers and others, and the socio-economic barriers related to the provision of mobility devices for disabled children at Tembalethu Special School. The consequences arose as a result of an absence of awareness of the needs of disabled children and the socio-economic constraints of their families, poorly resourced rehabilitation services, and inaccessible health care, (especially at the primary level of care), negative attitudes of service providers and the inadequate provision of support services related to mobility devices for disabled children. The model talks to the preconditions, outlined in the UN Standard Rules for the Equalization of Opportunities of Disabled Persons (1994), and more specifically the Preconditions model developed by Barnes (2001).

The model attempts to show how the results obtained in this study could shed some light on the possible consequences that would result if the Standard Rules are not met, specifically support services e.g. mobility devices. It depicts the consequences of one aspect, specifically rule number four, and a lesser extent rules number one to three, and could as such only be understood when read together with the original document. See Appendix (c) for further details on the model developed by Barnes (2001).

Figure 1: Relationship of the consequences of inadequate provision of mobility devices for disabled children.



The relationship of the themes to the objectives of the study as reflected in Figure 1, is:

a) The **consequences experienced by disabled children** as a result of inadequate mobility devices are reflected in themes 1 & 5 in the blue square.

b) The **consequences experienced by care-givers together with teachers, and therapist** as a result of inadequate mobility devices are reflected in theme 3 in the orange triangle.

c) The **consequences of the socio-economic barrier experienced by care-givers, and the gap in the provision of mobility devices as described by the key informant (physiotherapist), caregivers and their children** are reflected in themes 2 & 4 in the yellow circle.

CHAPTER 5

CONCLUSION

5.1 CONCLUDING STATEMENT

The government does not truly, fully and adequately provide for the mobility needs of children with disabilities. The findings reflected that if the policies related to provision of services related to mobility devices are not adequately implemented the services are bound to be insufficient. Poor conceptualisation and implementation related to the provision of mobility devices results in inadequate services. The consequences experienced by the children in the study reflected that there was a large gap between the initiatives of new policies and their successful implementation. This continues to further marginalize and deny the majority of disabled children their right to adequate services.

Inadequate provision of mobility devices interferes with the development of disabled children. This has led to severe health complications, even death. Disabled children in the study were deprived of their basic right to education, to play and to social interaction. Providers of mobility devices are ignoring the socio-economic and environmental impact on the needs of disabled children. In addition, cognisance of the rights of the disabled child, contained in the Convention on the Right of the Child, as discussed in the literature review, is not taken.

Care-givers experience problems in their daily lives. They cannot afford the services of private agencies, which sell mobility devices for disabled children. They are dependent on the goodwill of the government to resolve the situation. The policy of the categorization of disabled children is a barrier preventing care-givers from accessing care-dependency grants thus causing a lot of distress. The philosophy that defines the provision of assistive devices as a privilege or a luxury needs to change to one that sees it as a right.

Disabled children and their care-givers are not merely complaining or saying that the existing services should be stopped or taken away. They are demanding their right to the transformed provision of mobility devices through systems that address the needs of disabled children. There is an urgent need for the government to change the status quo.

5.2 RECOMMENDATIONS

This section will make recommendations directed at policy makers, disabled people's organizations (DPOs) and service providers in health, social development and education sectors.

5.2.1 Personalised experiences and needs of disabled children should be understood.

The experience of disability is personal and unique for each child. The findings reflected that ignoring individual needs resulted in inappropriate mobility devices being issued to disabled children. The concept of cost-effectiveness of providing mobility devices for a large number of disabled children through buying in bulk needs to be rethought. In addition, accepting donations of consignments of mobility devices should not be done at the expense of the development of a disabled child, who is dependent on the appropriate mobility devices to grow. Therefore, the system of determining the needs for mobility devices should change from broad categorization to the capturing of the individual needs of disabled children. This recommendation is closely linked to 5.2.2.

5.2.2 Develop a needs measurement tool.

Support services are needed to enable care-givers to provide mobility devices for their disabled children. Categorization of disability based on medical diagnosis alone is a barrier to accessing social assistance. The findings of this study reflect that the system of categorizing is not working. Categorization is too generalised and that does not reflect the actual needs. Eligibility criteria need to be reviewed so as to consider criteria related to needs and thereby develop a needs measurement tool.

Consideration should be given to creating a mobility devices grant as an alternative source of funding for the provision of mobility devices. It is essential for participation, especially for disabled children.

5.2.3 The needs of disabled children should be prioritized.

The findings have shown that mobility devices were provided on an *ad hoc* basis to disabled children. This caused huge backlogs. The consequences for children were health complications and death. It is therefore imperative that the needs of disabled children be prioritized. The budget should be dedicated towards the relevant provision of mobility devices in order to avoid child mortality or regression in the development of disabled children.

5.2.4 An implementation strategy for provision of assistive devices is needed.

The study illustrated that disabled children were already at risk for the inadequate provision of mobility devices. Creative implementation strategies for addressing the backlogs need to be created in consultation with DPOs. Disabled children and their caregivers are in the best position to articulate their needs. Therefore, consultation with the users is essential if solutions are to be found.

The current Department of Health's strategic report (2001) on Standardisation of Provision of Assistive Devices in South Africa is limited. It is based on what is envisaged. It does not have a clear plan of how the existing backlogs and infra-strutural inadequacies in the current provision of assistive devices are going to be addressed. Guidelines without support- mechanisms are not ready to be used by Provincial Health departments. Therefore, Department of Health must use existing ties, or contact with the South African Federal Council on Disability (SAFCD) as the platform for the development of the implementation strategy for provision of assistive devices.

5.2.5 Awareness of service providers related to socio-economic and environmental context needs to be raised.

Service-providers should be aware of the socio-economic and environmental constraints on the care-givers and/or the disabled child and change their attitudes. In order to relate to the socio-economic barriers that disabled children and their care-givers face on a daily basis, service providers involved in rehabilitation should strive to work with disabled children and their caregivers in their communities. Service-providers need to recognize the value of the role played by disabled people and care-givers of disabled children in articulating their needs. They should be called upon to build partnerships with DPOs like DPSA and DiCAG and other service-providers.

5.2.6 Social action by Disabled People's Organisations (DPOs) needs to be more focussed.

The findings showed that care-givers were disempowered and they did not benefit maximally from addressing the needs of their disabled children through self-reliance and independence. DICAG needs to take the lead in strengthening and supporting care-givers to advocate and lobby as a collective for the adequate provision of mobility devices. Care-givers need to be informed of their children's rights so that they can join hands in mass-action with the broader disability movements in campaigns for mobility devices and services for disabled children. Better health will open up other opportunities for disabled children.

5.2.7 Key existing stakeholders should lend support to ensure adequate provision of mobility devices.

- The South African Human Right's Commission (SAHRC): To monitor all National and International policies impacting on the lives of disabled children in South Africa.
- The Office on the Status of Children: To make a concerted effort to recognize and integrate meeting the mobility needs of disabled children in their programme planning and policy-making initiatives.

5.2.8 Hospital-based teaching to disabled children needs to be improved.

The study showed that due to inadequate provision of mobility devices disabled children often spent a large part of their lives in hospitals, recuperating from health complications. This often resulted in their scholastic progress being jeopardised and the repeating of grades. The curriculum for the training of teachers needs to have a childhood disability module included. The teacher's intern practicals should be done in the hospitals in which the majority of children are hospitalised. More posts should be created for hospital-based teachers, as a short-term strategy.

5.3 SUGGESTIONS FOR FUTURE RESEARCH

It is suggested that future investigations should:

1. Explore the consequences experienced by disabled children due to inadequate provision of mobility devices in a rural area. This could be done in partnership with a parent body, like DICAG, so as to impart research skills to care-givers of disabled children. This would build their capacity to explore other areas of service provision for disabled children.
2. Explore the socio-economic barriers that inhibit care-givers from accessing the service of mobility devices for their children in more depth.
3. Extend the research to other cases or multiple cases of special schools in townships around South Africa so as to make comparisons. This could be used to apply and adapt the preconditions model for equal participation developed by Barnes (2001).

"Yet after climbing one hill, there are many more hills to climb."

(Mandela, 1996)

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APPENDICES

Appendix (a): Consent Form

Mna ……………………………… mzali womntwana……………………

ndiyamkhulula ukuba athathe inxaxheba kwingxelo ntetho emalunga nophando olujolise ekuphandeni kabanzi ukuba abantwana abakhubazekileyo bachaphazeleka njani ebomini babo yinkonzo esilelayo yezixhobo zokuhamba. Kwaye umntwna wam uvumelikeliyo ukuba akroxe nanina xa ethandile.

Ndiyayiqonda into yokuba igama lomntwana wam nomxholo wentetho yakhe iyakuphathwa ngokusekhusini nobunono. Kwaye nolwazi olufumanekileyo luyakusetyenziswa kuphando kuphela. Kwakho ulwazi ulufunyenweyo lusakusetyenziselwa ukuphucula inkonzo yezixhobo zokuhamba zabantwana.

Umhla: ……………………….

Umtyikityo:…………………….

Umphandi: Siphokazi Gcaza

……………………………………………………………………………………

I …………………………………the caregiver of …………………………. give permission for him/her to participate in an interview regarding the consequences experienced resulting from inadequate provision of mobility devices. The child may decide to withdraw from the study if he/she chooses to.

I am aware that the confidentiality and privacy of my child's name, and the content of the interview would be kept at all times. The information would be used for research purposes. The findings from the research would be used to influence policy-makers to give a better service of assistive devices to disabled children.

Date:

Signature:

Researcher: Siphokazi Gcaza

……………………………………………………………………………………

Appendix (b): Table 1 : Attributes of Participants

Participant	Age	Sex	Device used	Length waiting for device	Complication	Hospitalization
Vuyokazi	14	F	Calipers, crutches, orthopaedic boots, wheelchair	8 months	• pressure sores	Yes
Mawethu	14	M	orthopaedic boots, wheelchair	1 year	• pressures sores • contractures	Yes
Tracy	11	F	AFO's, crutches	8 months	• contractures	Yes
Nandipha	9	F	Calipers, crutches, orthopaedic boots,	1 year	• pressure sores	Yes
Nomzamo	14	F	AFO's, walking frame, wheelchair	Used inappropriate device for 2 years		No
Mzivukile	13	M	Calipers, crutches, orthopaedic boots,	18 months	• contractures	Yes
Sitsaba	13	M	Calipers, crutches,	2 years	• pressure sores	Yes

			orthopaedic boots, wheelchair			
Simphiwe	14	M	Calipers, crutches, orthopaedic boots,	10 months	• contractures	No
Thuleka	16	F	Calipers, crutches, orthopaedic boots,	1 year	• pressure sores	Yes
Nokhanyo	9	F	AFO's	4 months	• contractures	No

Grey shade comprises the six children that were interviewed individually.

Appendix C:

RETHINKING CARE

From the perspective of disabled people

Background Document

Rethinking Care

by Colin Barnes

SOSIAL- OG HELSEDEPARTEMENTET
Ministry of Health and Social Affairs

Rethinking Care

Background Document

Colin Barnes

Introduction:

> 'Everything is structured in such a way that people with disability are entirely left out' ***(A disabled student from Ghana, Central Africa).***
>
> 'Over the fifteen years of my disability, I have learned what it is like to be isolated, segregated, and discriminated against. I know this not only because of my own experience, but because I have joined an organization of others who have the same condition, and who have the same experiences' ***(A psychiatric system survivor from the United States of America).***
>
> 'Disabled people have been the most destitute of Africans. Government planners have tended to emphasize the majority and thus they have ignored the needs of disabled people and their families. African society already accorded women a lower status than men..... disabled women face discrimination because they are women and because they are disabled' ***(Disabled woman from Zambia, Central Africa).***
>
> 'We, (disabled people) have to gain control of our own lives, our own physical rehabilitation, our own personal assistance' ***(A disabled activist from Belgium - the heart of the European Union***).
>
> 'Today's challenge is the participation of disabled people as members of civil society; as leading characters in the diagnosis, elaboration and evaluation of public policies.... so as to reach a better approach' ***(A disabled lawyer from Chile)***.
>
> 'Society has to acknowledge that, until there is a coordination of effort between a range of medical, allied health, and developmental services, families (with disabled children) will go on facing stress and pain' ***(A professional working with families with disabled children in India)***.
>
> 'All treatment should have the objective to improve human life. not just the body'. ***(A representative of an International non-government organization for disabled people)***.

These statements represent the wide range of views submitted to the World Health Organization's (WHO) Disability and Rehabilitation (DAR) Team during 2000. They were received in response to an informal request for testimonials on the experience of disability and rehabilitation from disabled people, parents and 'carers' of disabled individuals from across the world. Over 3000 responses were received, almost 80 per cent of these were from disabled individuals themselves, and many by email.

This is a remarkable response given that the overwhelming majority of the world's disabled population are unlikely to communicate in English nor are they likely to have access to a computer. In global terms, less than one in ten people are linked to the internet. It is widely recognised that in most countries educational provision for disabled children and young people is, at best, inadequate and, at worst, non-existent. Also computers are both expensive to buy and to use and, in rich and poor nations alike, disabled people are amongst the poorest of the poor.

What is also striking about these testimonials is the alarming degree of multiple deprivation: economic, political and social, experienced by disabled people and their families. Also, that this situation is widely attributed to the inadequacy and/or ineffectiveness of current 'care' services, both medical and rehabilitational, for this increasingly large section of the world's population. Further, whilst this is the case in all countries, whether rich or poor, it is particularly so in the poorer 'developing' nations of the majority world where medical and rehabilitation resources are disturbingly scarce, and where abject poverty is an all too common experience. Undoubtedly, there is a growing disenchantment with current provision amongst both users and providers which can be traced back at least to the 1960s if not before and especially in developing coutries.

There is, therefore, an urgent need for a substantial reformulation of current thinking on services for disabled people and their families at the international level. The WHO ***Rethinking Care*** Initiative and Conference marks a significant stage in this process.

This unique event will bring together various stakeholders from across the world to reflect on and discuss current policies within the context of the first four United Nations' (UN) ***'Standard Rules on the Equalization of Opportunities for Persons with Disabilities'***. These concern the provision of awareness raising, medical care, rehabilitation and support services. Participants will include disabled people, parents and carers of disabled individuals, rehabilitation professionals and practitioners, and politicians and policy makers.

Organized by the World Health Organization (WHO) and hosted by the Norwegian Ministry of Health and Social Affairs the ***Rethinking Care*** Conference will be held at the SAS Radisson Hotel, Oslo, from the 22nd to the 25th of April, 2001.

Background: the growing demand for change

The general disenchantment with disability and rehabilitation services began in the late 1960s with the politicization of disability by disabled activists and disability oganizations in different parts of the world. Notable early examples include the American Independent Living Movement (ILM), the Swedish Self Advocacy Movement and a host of self help groups across Europe. As a consequence, orthodox wisdom on the causes of disability were increasingly questioned and so too was the organization and structure of the services upon which the overwhelming majority of disabled people have to depend.

It was evident that individualistic medical explanations, emanating mainly from the west, could not explain the systematic exclusion of disabled people from the mainstream of economic and cultural life. It was also apparent that conventional rehabilitation services often exacerbated the problem by focusing almost exclusively on the functional limitations of disabled individuals rather than on the disabling environments: economic, political and social, in which they lived. As a consequence, disabled activists across the world began to demand a greater say in the organization and running of disability services and/or to develop their own.

The movement grew in both stature and confidence during the 1970s and culminated with the formation of Disabled People's International (DPI) in Singapore in 1981. The DPI is an international umbrella organization controlled and run exclusively by disabled people.

These initiatives generated a flurry of activity at the national and international level. Many national governments now have some form of anti-discrimination law to secure the equal rights of disabled persons. USA was one of the first nations to recognise the need for a reappraisal of disability policy with the introduction of the 1973 Rehabilitation Act. This legislation enhanced environmental access, recognised the need for more comprehensive services, including user led initiatives referred to as Centres for Independent Living, and prohibited discrimination against disabled people in federally funded programmes. The initiative was subsequently strengthened considerably with the historic 1990 Americans with Disabilities Act. Today, countries as diverse as Britain, India and China have anti discrimination laws.

Government responsibility for securing equal rights for disabled people was formally recognised at the international level by the UN in 1981: the UN's International Year of Disabled People. The following year the UN General Assembly adopted by consensus a World Programme of Action Concerning Disabled Persons which outlined a global strategy on the prevention of disability and the realization of the full potential of disabled persons. The programme was to be implemented over the subsequent decade: the UN Decade of Disabled Persons. Furthermore, between 1990 and 1993 the UN developed the Standard Rules on the Equalization of Opportunities for Persons with Disabilities referred to above. The Standard Rules include a preamble, 22 Rules covering all aspects of social life and a monitoring system.

Perhaps unsurprisingly, these developments generated a gradual realization amongst traditional professionally led organizations, including those for specific chronic diseases and impairments, that disabled people must have a greater say in the development and delivery of disability and rehabilitation services. Equally important is the growing recognition that in all countries residential facilities are appropriate for acute conditions and particular medical treatments only, and that disability services and support should be situated within rather than without the community. It is also the case that the more accessible and supportive the material and social environment becomes for disabled people, the demand for disability and rehabilitation services decreases.

The WHO's Disability and Rehabilitation (DAR) Team has actively supported these developments. Located in the WHO's Department for the Management of Non-communicable Diseases in Geneva, Switzerland, the Disability and Rehabilitation Team aims to enhance the quality of life and equality of opportunity for disabled people by supporting member states in framing policy, developing appropriate services, and strengthening community participation. WHO/DAR has promoted and supported several Community Based Rehabilitation (CBR) projects in developing countries.

All of which has led to a growing recognition that health and disability can no longer be understood in purely medical terms. Consequently, several points must be considered, only some of which are listed below:

- The principal causes of ill health and impairments in both the wealthiest and poorest nations of the world are poverty, inadequate sanitation, poor diet, bad housing, environmental pollution, violence and war.

- The rapid rise of noncommunicable diseases, mainly cardiovascular diseases, cancer, diabetes and chronic respiratory diseases represents one of the major health challenges leading to impairments. Adding to these are challenges posed by increasing number of traffic and industrial accidents.

- People with all chronic conditions and impairments suffer the physiological and psychological consequences of living in societies geared for the non-disabled irrespective of any diagnosis and subsequent labelling.

- Rehabilitation and related interventions are extrememly limited in what they can achieve in terms of enabling disabled individuals to live in a society organized almost exclusively for non-disabled lifestyles.

- Worldwide, people with accredited chronic diseases and impairments encounter various economic, political, cultural and social barriers which cannot be resolved only by traditional individualistic, medical solutions.

- Whilst there is a growing need for the most basic of medical treatments across the globe, and particularly so in poor countries, a disproportionate amount of resources, both financial and human, are increasingly being poured into the development of costly medical treatments which will benefit only a relatively small percentage of the world's population.

*****

CONFERENCE AIMS AND OBJECTIVES

The **primary aim** of the *Rethinking Care Conference* is to:

> give disabled people requiring health and social support an opportunity to contribute to the process of **Rethinking Care** with respect to policy regarding the development of health and social services, and, in so doing, provide new insights and knowledge for the formulation of appropriate recommendations for WHO member states.

In terms of **specific objectives** the Conference will:

- *bring together disabled people, parents and carers of disabled individuals, service-providers and policy makers from all over the world to reflect on and discuss relevant issues and concerns:*
- *identify the strengths and weaknesses in current provision within the context of the first four Standard Rules on the Equalization of Opportunities for Disabled Persons:*
- *formulate appropriate policy recommendations for WHO member states with respect to awareness raising, medical care, rehabilitation and support services:*
- *produce a report outlining conference proceedings and recommendations for distribution to WHO member states.*

A word on language and its imitations

The main language of the conference will be English. However, although this language is used widely throughout the world, words and phrases often have different meanings in different cultural contexts and geographic locations. To complicate things even further, words which may have a specific meaning in one language may appear to mean something quite different once translated into another.

Consequently, although debates about the significance of language and its use are profoundly important there is, as yet, no international agreement on terminology and its usage with respect to this subject. This may help to explain why the WHO is currently attempting to revise the terminology used in discussions of disability and related areas.

It is hoped, therefore, that participants will respect cultural differences and avoid protracted debates about linguistic differences. Within the context of this Conference such discussions are unlikley to produce any satisfactory outcomes and will only detract from the task at hand; namely, to contribute to the re-formulation of meaningful policies for the empowerment of the world's disabled population, a task which can no longer be ignored.

Rethinking Care

GROUP DISCUSSIONS DURING THE CONFERENCE

To fulfil the aim of the conference, participants will be divided into workgroups for discussions. These groups will meet twice during the course of the conference: Monday 23rd April and Tuesday 24th April.

The discussions will focus on Care services and activities in four areas, within the context of the first four '**Standard Rules on the Equalization of Opportunities for Persons with Disabilities**'. These are: awareness raising, medical care, rehabilitation, and support services. Copies of relevant sections of the Standard Rules are provided in the **Annex** of this document, for consultation.

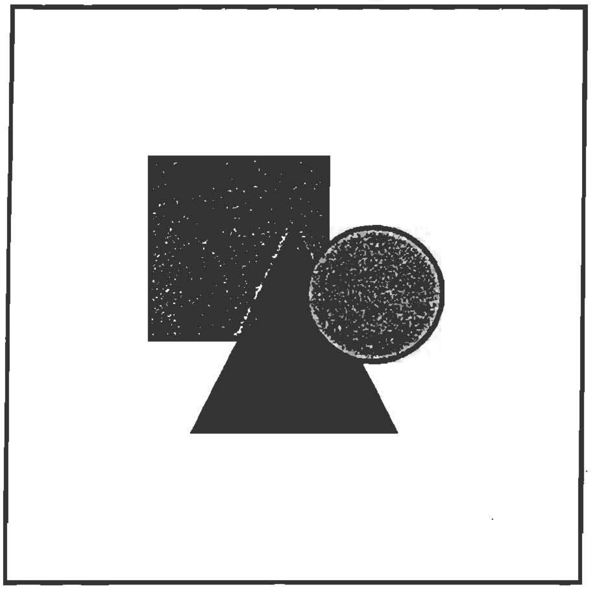
On the first day, *23rd April*, the group discussions would be asked to focus on strengths and weaknesses of the existing situation of care services and activities. This means looking at the constraints, gaps and strong points of *existing* services and activities.

On the second day, *24th April*, the group discussions would focus on future opportunities and challenges for the future strategies of Care services and activities. This means looking at the way care services and activities can be shaped and developed in the *future*, including the possible future risks.

Each workgroup will be composed of about 10 persons. For each workgrup a facilitator will be nominated with the following tasks: ensure that discussions continue to focus on themes of the conference; ensure possibility for expression of opinion by all members of the group; ensure that report and recommendations of the workgroup are prepared for presentation in the plenary session. **Lists of members** of the different workgroups as well as, the facilitators for each worksgroup will be provided during the conference.

Extracts from Standard Rules for Equalization of Opportunities for Persons with Disabilities

PRECONDITIONS FOR EQUAL PARTICIPATION



Rule 1. Awareness-raising

States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

1. States should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.

2. States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.

3. States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.

4. States should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.

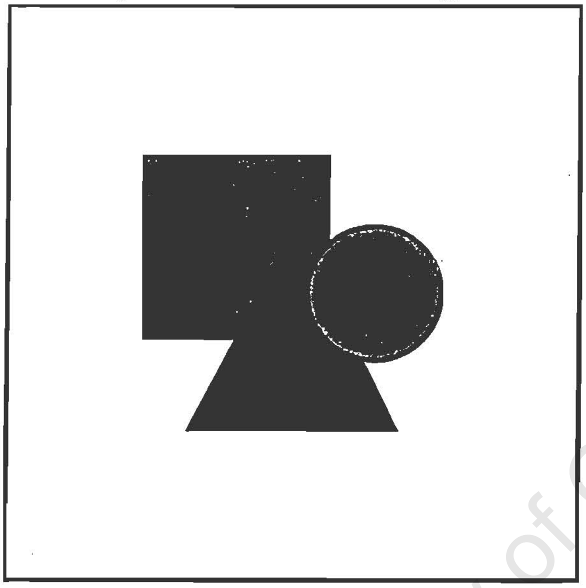
5. States should invite persons with disabilities and their families and organizations to participate in public education programmes concerning disability matters.

6. States should encourage enterprises in the private sector to include disability issues in all aspects of their activity.

7. States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them.

8. Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities of their own organizations.

9. Awareness-raising should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.



Rule 2. Medical care

States should ensure the provision of effective medical care to persons with disabilities.

1. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.

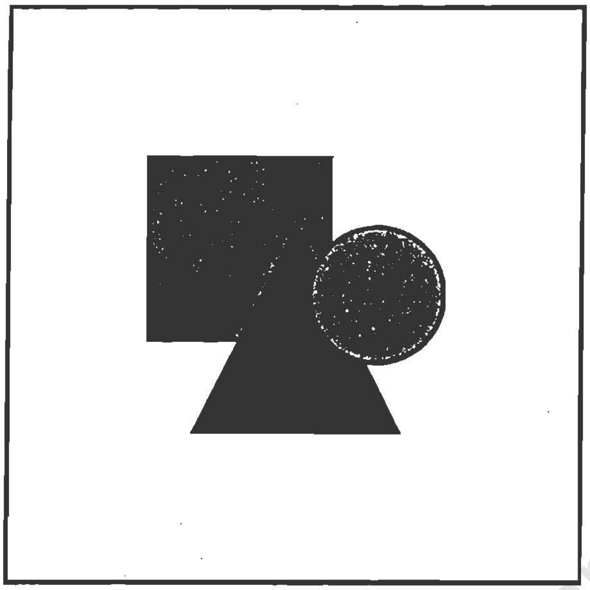
2. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.

3. States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

4. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.

5. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.

6. States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.



Rule 3. Rehabilitation

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

1. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.

2. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.

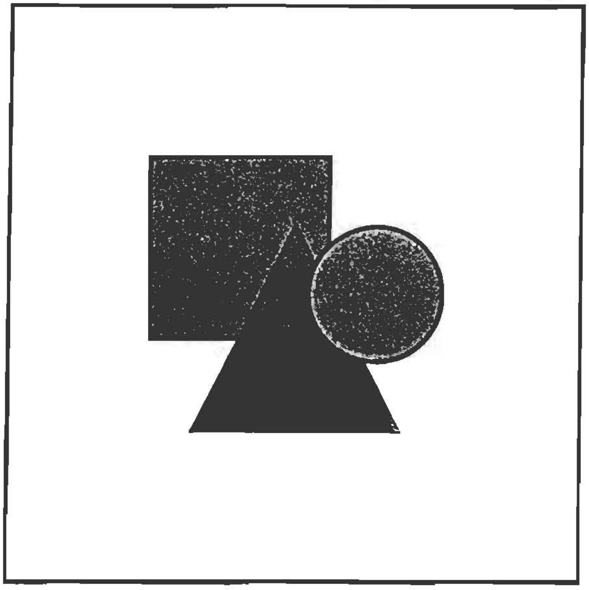
3. All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.

4. Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.

5. All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.

6. Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.

7. States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.



Rule 4. Support services

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

1. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.

2. States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.

3. To achieve this, generally available technical know-how should be utilized. In States where high-technology industry is available, it should be fully utilized to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible. Persons with disabilities themselves could be involved in the production of those devices.

4. States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.

5. In rehabilitation programmes for the provision of assistive devices and equipment, States should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness of assistive devices and equipment.

6. States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.

7. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.