

**STELLENBOSCH UNIVERSITY**  
**FACULTY OF HEALTH SCIENCES**

**THE FUNCTIONING OF PRIMARY SCHOOL  
LEARNERS WITH PARAPLEGIA/PARAPARESIS IN  
MAINSTREAM SCHOOLS –  
An Exploratory Study**

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MASTER OF PHILOSOPHY  
(MAJORING IN REHABILITATION)

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**DECLARATION**

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Full name \_\_\_\_\_

Date: \_\_\_\_\_

Signed \_\_\_\_\_

## ABSTRACT

South African policy and legislation demands inclusive education for learners with disabilities. According to the Department of Education, learners who can satisfactorily be educated in an ordinary school must be accommodated there. It is however unclear to what extent accommodations are made at the level of schools to ensure inclusion. The purpose of this study is to determine the level of participation of a group of learners with paraplegia/paraparesis in mainstream schools in the Western Cape. Furthermore the contextual factors that hinder or facilitate their participation will be identified. The Craig Handicap Assessment and Reporting Technique and the Craig Hospital Inventory of Environmental Factors were used as measuring instruments. The study population comprised 15 primary school learners with paraplegia/paraparesis, their parents and relevant class teachers. Results were statistically analysed with the ANOVA and Kruskal-Wallis tests. A p value of  $>0.05$  was seen as statistically significant. Results showed that cognitive dependence and decreased mobility restricted the participation of learners most. Insufficient preparation and training of teachers, architectural barriers and poor accommodation into physical activities were the biggest barriers to successful inclusion. Findings from this convenient, small and homogenous sample suggest the existence of major barriers. Therefore a comprehensive research project is advised to ease the process of inclusion and ensure its successfulness. Furthermore the education authorities should develop and implement a uniform selection process and referral system in order to channel learners to the correct facility according to their needs.



## OPSOMMING

Wetgewing en nasionale beleid in Suid-Afrika vereis inklusiewe onderwys vir leerders met gestremdhede. Volgens die Onderwys Departement moet alle leerlinge met gestremdhede wat bevredigende onderrig in hoofstroom skole kan ontvang daar onderrig word. Dit is egter nie duidelik of daar voldoende akkommodasie van hierdie leerders is nie. Die doel van hierdie studie is om vas te stel wat die vlak van deelname van 'n groep leerlinge met paraplegie/paraparese in hoofstroom skole in die Wes Kaap provinsie is. Verder is faktore wat deelname fasiliteer en beperk geïdentifiseer. Die "Craig Handicap Assessment and Reporting Technique" en die "Craig Hospital Inventory of Environmental Factors" is as meetinstrumente gebruik. 15 primêre skool leerlinge met paraplegie/parapareses, hulle ouers en die betrokke personeel van die skole het die studie populasie gevorm. Die ANOVA en Kruskal-Wallis toetse is gebruik om resultate statisties te evalueer en 'n p waarde van  $>0,05$  was geneem as statisties beduidend. Kognitiewe afhanklikheid en mobiliteit was die twee faktore wat deelname die meeste beperk het. Onvoldoende voorbereiding en opleiding van onderwysers, fisiese uitleg van skoolgeboue en onvoldoende akkommodasie binne die skool tydens aktiwiteite wat fisiese deelname vereis was van die belangrikste beperkende faktore. Hierdie beperkinge is gevind met 'n klein en homogene populasie. Dit is essensieel dat die studie opgevolg word met 'n omvattende navorsingsprojek. So 'n projek sal waardevolle inligting verskaf wat die proses van inklusiewe onderrig sal vergemaklik en grootliks kan bydra om die sukses hiervan te verseker. Dit blyk verder dat die onderwys departement 'n uniforme seleksie en verwysing sisteem moet implimenteer om te verseker dat leerders na die mees geskikte skool volgens hul behoeftes verwys word.



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## KEYWORDS

Inclusion, Mainstreaming, Paraplegia/paraparesis, Rehabilitation, Accessibility, Accommodation, Resource availability, Social support, Equality

## DEFENITION OF TERMS

- **Paraplegia/Paraparesis:** The term paraplegia/paraparesis was used to indicate neuro-muscular or bony involvement of the lower limbs that causes locomotor disabilities.
- **School:** The Centre acting on behalf of the Department of Education, offering education to the child within the closest proximity of residence and cost-effective service to the parents. All children are obliged by Law to enter the school setting in the year they turn 7 years of age (Department of Education, 2003).
- **Special Needs School:** Schools including staff and learning materials to specifically assist learners with special needs such as visual impairments, learning disabilities, etc (Department of Education, 2003).
- **Full-service schools:** Mainstream schools that will be equipped and supported to provide for the full range of learning needs among all learners. This is the first station for learners when they are included from Special schools to Mainstream schools (Department of Education, 2003).
- **Child Guidance Unit:** Team of Psychologists and Remedial Educators rendering a support service to the mainstream schools. Referring children to special schools when needed (Department of Education).

- **Mainstreaming:** Placing a child with Special Educational Needs into an ordinary school without making any adjustments or alterations to the environment or class presentation (Educational White Paper 6, 2001).
- **Inclusion:** Including learners with special educational needs into mainstream schools, focusing on overcoming barriers of the system by adaptation of and utilization of support systems available in the classroom (Educational White Paper 6, 2001).
- **Impairments:** Problems in body function or structure such as significant deviation or loss (International Classification of Function and Health, 2001).
- **Activity:** The execution of a task or action by an individual (ICF, 2001).
- **Participation:** Involvement in a life situation (ICF, 2001).
- **Activity limitations:** Difficulties an individual may have in executing activities (ICF, 2001).
- **Participation restrictions:** Problems an individual may experience in involvement in life situations (ICF, 2001).
- **Environmental Factors:** Facilitating or hindering impact of features of the physical, social, and attitudinal world (ICF, 2001).



- **Rehabilitation:** Process that assists people with disabilities to develop and strengthen their physical, mental, and social skills. Rehabilitation has many aspects. At one point in the life of a child with movement-related disability, for example, the most crucial need will be to provide training and equipment for mobility. This child will now be able to join in activities of their families and communities. To achieve such ends, the rehabilitation process requires different types of services, as well as community action (World Health Organisation, 1994).
- **Accessibility:** Evaluates services in the community, policies and rules of the schools, the support given to the learners when making career choices. It also includes the availability and implementation of government policies assessing accessibility (The Craig Hospital Research Department, 1997).
- **Accommodation:** This includes the design of the learner's home, the school and the community as well as the natural environment and surroundings that might cause difficulties (The Craig Hospital Research Department, 1997).
- **Resource availability:** The amount of help needed at school, the attitudes of peers and the teachers. The learners also report on the availability or lack of support at school (The Craig Hospital Research Department, 1997).
- **Social support:** The attitudes of people at home or the community and also the support and encouragement received from this area (The Craig Hospital Research Department, 1997).

- **Equality:** The availability of transport, the information given at school (about medical condition), availability of education programmes, medical care, special adapted devices and personal equipment and level of independency at home and in community (The Craig Hospital Research Department, 1997).

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# **CHAPTER 1**

## **INTRODUCTION**

### **1.1 BACKGROUND**

The schooling system in South Africa is currently facing the biggest challenge of all times. The absence of segregation as well as social acceptance of learners with disabilities must be ensured (Bhagwanjee & Stewart, 1999). Currently learners with disabilities are segregated and educated in special schools. However South African policy demands the inclusion of learners with disabilities into mainstream schools.

Mainstreaming is about “fitting” learners with special needs into a particular kind of system and integrating them into the existing system. Inclusion, on the other hand, is about recognising and respecting differences among learners and building on similarities. It is about supporting all learners and educators in order for the system to meet the full range of learning needs. The focus is on teaching and learning actions, with the emphasis on the development of good teaching strategies that will benefit all learners. This includes overcoming barriers in the system that prevent it from meeting the full range of learning needs, e.g. adaptation of personal equipment, physical accommodations and support systems in the classroom (South Africa, 2001).

For any child to gain normal skills, participation in a balanced, non-segregated environment is of vital importance. The development of any competency, from skills in mathematics to forming friendships, requires students to become engaged with the persons and objects in their environment (Simeonsson, Carlson, Huntington, McMillen, Brent, 2001). However, people with disabilities, including the learner with a disability, are evaluated and managed within a unique and special environment. It is essential that they are removed from this protective, restrictive environment and accommodated in the mainstream environment.

Disability in children is especially devastating. It affects the physical and functional status of the child, and has compelling implications on the social and emotional development of the child and his or her family functioning. The issue of schooling is pivotal in containing the impact of the disability. It is therefore our responsibility to provide every disabled child with the most suitable schooling arrangement possible.

The school and its environment share more or less the same set of morals and belief systems as the community it serves, and this belief system is a binding factor. In that sense, the school plays a vital role as regards the integration of any learner into using community resources and preparation for contributing to the economy by working after graduating from school. The school system has a big impact on the life of any learner (physically, emotionally, socially, intellectually) and should be organised in such a way that it will provide in their needs.

Historically the responsibility for identifying, assessing and enrolling learners with special needs, including those with physical disabilities, was either left to or viewed as the prerogative of psychologists, social workers and other health professionals. Learner support merely took the form of specialised and typically medical interventions on a one to one basis. Rehabilitation services focused mainly on impairments. The medical professions concentrated on diagnosis and treatment and tended to neglect the broader social issues like integration into the community, and the availability of support services. The important role parents had to play in rehabilitation and as part of the health/school team, had been neglected for years.

Previously in South Africa, learners with disabilities were either placed in special schools or classes, or totally excluded from any educational opportunity on the grounds that they are "too severely disabled" (South Africa, 1997). It is estimated



that almost 70% of South African children of school-going age with disabilities are currently not attending school. This results in illiteracy and low skills amongst adults with disabilities, contributing significantly to high levels of unemployment (Anderson & Vogel, 2000).

However, during the last five years policy and legislation have been changed to promulgate inclusion of learners with disabilities into mainstream schools. The Constitution of the Republic of South Africa (South Africa, 1996) is founded on the values of human dignity, the achievement of equality and the advancement of human rights and freedom for all. In accordance with this, the Integrated National Disability Strategy (South Africa, 1997) emphasises the need for including persons with disabilities in the workplace, social environment, political sphere and sports arenas. The Department of Education supports this direction and sees the establishment of an inclusive education and training system as the cornerstone of an integrated and caring society. According to Education White Paper 6 (South Africa, 2001), children, who can satisfactorily be educated in an ordinary school, should be accommodated there. An inclusive education and training system with a wider spread of educational support services will therefore be created in line with what learners with disabilities require (South Africa, 2001).

In the Western Cape Province some progress towards inclusion has been made. The schooling system in the province resorts under the Western Cape Education Department (WCED). The study population comprise learners between 6 and 14 years old with paraplegia/paraparesis who are attending mainstream schools. There are not any formal records of such learners. The study population was found through contacting various hospitals and special schools that might have knowledge of such learners moving to mainstream schools. This would already identify a need for the WCED to do a research study on what disabilities are accommodated where in order to explore the needs of such learners.



The researcher will utilise the Craig Handicap Assessment and Reporting Technique (Whiteneck 1992) to identify activity limitations and participation restrictions. The Craig Hospital Inventory of Environmental Factors (Craig Hospital Research Department, 1997) will be used to determine the contextual factors that facilitate or restrict inclusive education. The questionnaire will be completed with the learners, their parents and relevant class teachers. The views of these three groups will be compared to identify the barriers and facilitators.

## **1.2 RESEARCH PROBLEM AND AIM**

The question that arises is whether this proposed inclusive educational system is feasible only on paper. Society as a whole, including mainstream schools, represents a world full of prejudice, bias, narrow doorways and stairs. Are learners with paraplegia placed in mainstream schools without any adjustments and/or reasonable accommodations? The learner with paraplegia have residual and acquired skills that makes it possible for him/her to function in the mainstream setting. However, (s)he needs changes to the environment as well as in people's attitudes to enable him/her to utilise these skills. (S)he needs equality and social support to improve functioning and potential and (s)he also needs to be accommodated in an accessible environment.

Currently a number of learners with physical disabilities have been placed in mainstream schools. This provides us the opportunity to determine whether they experience any handicap and identify the barriers and facilitators to their inclusion. Findings in this regard will provide valuable information to guide the implementation of inclusive education.

Therefore with abovementioned learners as study population the researcher would like to answer the following questions: Do learners with paraplegia/paraparesis experience any participation restrictions in mainstream schools? How do the parents/caregivers of these learners experience inclusion



into mainstream schools? Does the school environment provide in the needs of these learners? How do the teachers view the functioning of these learners with disabilities in their classes?

From these questions the aim of the study arises. The aim of the study is to describe the functioning of learners with paraplegia/paraparesis to the mainstream school setting in the Western Cape Province. Furthermore the author wants to identify common barriers and facilitators to inclusion.

### **1.3 MOTIVATION**

This study is based on a discussion of disability issues in South Africa. It focuses on policy and legislation that demand the inclusion of learners with disabilities in mainstream schools on the one hand, while questioning the reality and feasibility of implementation of these policies and legislation at the level of the schools on the other. The researcher worked at a special school for 3 years. She experienced the potential and level of achievement of learners with paraplegia/paraparesis in a segregated environment that is geared towards their special needs. While she realises the importance of inclusive education she is concerned that the special needs of learners with disabilities will be overlooked with a resultant decrease in their level of achievement. The study evolved to determine current levels of function of learners with paraplegia/paraparesis in mainstream schools and to identify barriers and facilitators in order to provide guidelines to inclusion. She believes that these guidelines will assist learners with disabilities in mainstream schools to reach their optimal potential not only academically, but also emotionally and socially. The needs of these learners do not seem to be met unless they are kept in the Special School environment.

Since we cannot change any system to suit the needs of the learner with a disability without consulting and engaging in negotiations on their experiences and needs the learners with disabilities, their families and/or caregivers and the relevant class teachers will form the study population.



#### **1.4 SIGNIFICANCE OF STUDY**

Findings will provide the educational authorities with valuable information to assist in the development of an inclusive education programme. It will also act as an advocate to inform the community of the attitudes and norms regarding the learner with a disability and to promote full integration of the learner with a disability (Logan, Diaz, Piperno, Rankin, MacFarland & Bargamian, 1995). Most of all, the study will give learners with disabilities an opportunity to voice their opinion while it will also give practical advice on accommodation of these learners in the mainstream school setting.

#### **1.5. SUMMARY**

It is clear from policy and legislation that inclusive education is a given. In order for it to succeed the learner with a disability need certain accommodations. This study aims to be a pilot for a much bigger project that will provide all the information necessary to ensure successful inclusive education in South Africa.

An elaborate literature review follows in Chapter 2, while Chapter 3 outlines the study aim, objectives and design. It introduces the study population and defines the inclusion and exclusion criteria. In addition, it will discuss the method of data collection by using the chosen measuring instruments, the piloting of the measuring instruments and resultant changes. A report on the preparatory work is included as well as a description of the actual interviews. The method of data analysis is described and the limitations of the study are discussed.

Chapter 4 summarises the results and this highlights the achievement of the set objectives. Demographic information on learners, parents and teachers are presented. This is followed by a discussion on activity and participation levels of learners with regard to personal independence, cognitive independence, mobility, school participation, social integration, and financial resources. Restrictive barriers and inclusive facilitators as elicited through the CHIEF are described in

detail. The chapter concludes by summarising some of the needs of the learner with a disability that became evident during the interviews.

In Chapter 5, the study arrives at an acceptable solution, stipulates recommendations and indicates the academic contribution and possibilities for further research emerging from this study.



## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

The literature review aims to guide the reader through some background information on paraplegia/paraparesis focussing on the specific diagnosis included in this study. The issues around rehabilitation of learners with paraplegia/paraparesis and the possible limitations regarding activity and restrictions to participation that these learners can experience will be discussed. Studies on inclusive education will not only define the term inclusion, but will also indicate the advantages and disadvantages as regards a policy of inclusion of learners with paraplegia/paraparesis in mainstream schooling. Furthermore it is important to discuss the contextual factors that influence inclusion and then to look at the South African situation with regard to schooling for the learner with a disability and policies and legislation promoting inclusion. The literature review is concluded with a discussion on the measuring instruments used in the study.

#### **2.2 BACKGROUND INFORMATION ON PARAPLEGIA/PARAPARESIS**

According to a disability prevalence study funded by the South African Department of Health, 5,9–6,1% of the South African population is disabled (Schneider, Claassens, Kimmie, Morgan, Naicker, Roberts & McLaren, 1999). The exact number of people affected within the total South African population is not contextualised in this study. People with disabilities who do not regard themselves as disabled were also not counted (Schneider *et al.*, 1999).

Schneider *et al.* (1999) found a steady increase in the disability prevalence rate of children from 0 to 10 years old (from 1,6% to 3,3%). Seen as a percentage of the total child population, more white children in the age group 6 to 10 are disabled than children from other racial groups. A possible explanation for this finding might be that white children survive medical conditions or traumas more often than children of other races, but remain disabled. However, the actual



number of disabled African children in this age group is higher than their white counterparts, because the total African population is much bigger than the white population. African respondents between the ages of 16 and 25 are more likely to be disabled than similarly aged respondents from other races. Rural respondents between the ages of 0-10 were more than twice (59%) as likely to have three or more disabilities than their urban counterparts (24%). This suggests that people in rural areas do not have access to services that could prevent a relatively minor disability or impairment from developing into a major one. Unfortunately information on the causes of disabilities was not provided. It is therefore not possible to determine the prevalence of paraplegia in disabled children from this study (Schneider *et al.*, 1999).

The participants of this study suffer from paraplegia/paraparesis that resulted from a spinal cord injury, cerebral palsy or brittle bone disease. The term paraplegia/paraparesis is used communally for the purpose of this study to indicate neuro-muscular or bony involvement of the lower limbs that influence locomotor ability to some extent.

According to the website of the Quadriplegia Association of South Africa (QASA, 2004), it is estimated that 400-500 South Africans sustain spinal cord injuries annually. A spinal cord injury could happen to anyone: young children, mothers and fathers, teenagers, and older people, most with active lives still before them. However, the highest incidence of spinal cord injury occurs in the 15- to 29-year old age group. There are no incidence figures available for spinal cord injuries in children of school going age in South Africa or the Western Cape.

Spinal cord injury in children is relatively uncommon in America, approximating 1 500 cases each year (Anderson & Vogel, 2000). However, when it does occur, paraplegia in children is devastating. It not only affects the physical and functional status of the child, but also has compelling implications on the social



and emotional development of the child and the functioning of his or her family (Anderson, Krajci & Vogel, 2003).

According to QASA (2004), statistics from America and elsewhere show that the main traumatic causes of spinal cord injuries are road traffic accidents, whether in a vehicle or as pedestrian, falling from heights, diving and swimming accidents, assault, e.g. gunshot or stab wounds and sport injuries. An approximately equal number of spinal cord lesions in children result from non-traumatic causes such as transverse myelitis and vascular accidents (Bromley, 1991). Reports from hospitals and rehabilitation clinics suggest that the causes of spinal cord injuries in South Africa are similar to those above. However, the level of violent crime adds to the statistics in South Africa. Non-traumatic causes of spinal cord injury are much less common and include viral infections, cysts and tumours (QASA, 2004).

After suffering a spinal cord injury, a child is admitted to either a private or government hospital depending on the income status or health insurance coverage of the parents. In hospital, the child is treated until medically stable and then transferred to a rehabilitation unit, where they receive rehabilitation by a multi-disciplinary team (Horvat, 1990).

In contrast to spinal cord injuries because of damage as a result of injuries to the spinal cord after birth, a child is born with cerebral palsy. Cerebral palsy is classified into three groups, e.g. spastic quadriplegia, spastic hemiplegia or spastic diplegia (St Louis Children's Hospital, 2004). Participants from this study with cerebral palsy all have spastic diplegia (more involvement of lower extremities) with no cognitive involvement. The term spastic is used to describe muscle tone that is too high. When both legs are affected by spasticity, they may turn in and cross at the knees. This abnormal leg posture, called scissoring, can interfere with walking.

If born with spastic diplegia, a multidisciplinary team will treat the child as an outpatient from diagnosis soon after birth on an ongoing basis (St Louis Children's Hospital, 2004).

Brittle bone disease (Osteogenesis imperfecta) is the most common cause of fractures in childhood. It is a genetic disorder usually resulting from abnormalities of the genes that control the production of a protein known as collagen; this is the main protein in bone and essential for its strength. The fragility of bone is due to the collagen problems; it has nothing to do with the calcium part of bone that is what shows on x-rays. Some children are born with fractures that have taken place in the womb. Others have their first fractures soon after birth or several years later. Fractures are difficult to predict, especially in childhood. Some occur with normal handling. Some occur with so little trauma that the usual signs of a fracture may not be seen and the fracture is not identified till some weeks or months later when an x-ray is done for another reason. However the bones do not always behave in a brittle way; fractures may fail to occur when expected from an injury. The reason for these variations is quite unknown. The learners with brittle bone disease in the study population all used a wheelchair to protect them from fractures, but presented normal upper limb and trunk function. Competent occupational therapy help may be invaluable in ensuring that parents are given good advice in handling of a young child, in prescribing the most appropriate seating or wheelchairs, in advising on adaptations to the home and on practical ways of ensuring a good education (University of Dundee, 2004).



### **2.3 REHABILITATION OF LEARNERS WITH PARAPLEGIA/PARAPARESIS**

The goal of rehabilitation and habilitation of learners and adolescents with paraplegia/paraparesis is to help ensure that they are prepared in every way for adult life in order to be able to participate in all social roles. This includes having the same schooling, employment opportunities and employment rate as their peers (Bromley, 1991).

In order for a rehabilitation programme for learners with paraplegia/paraparesis to be effective (i.e. leading to successful transition into a satisfying adulthood), the programme should be dedicated to the ever-changing needs of children as they grow. It has to be sensitive to family goals and dynamics, and abreast of current research. It should participate in clinical trials of new drugs and devices and be comprehensive not only in the provision of medical care but also in the facilitation of rehabilitation and habilitation skills (Anderson *et al.*, 2003). Advances in medicine, surgery and research have led to many options for persons with paraplegia. Coupled with progress in technology, enhancement of public policy, improvement in social acceptance of disability, and broader access to scholastic, vocational and social activities, persons of all ages with spinal chord injury (SCI) have the potential to surpass traditional levels of functional recovery based solely on preservation of motor level (Anderson *et al.*, 2003). Innovative programmes beyond the initial rehabilitation period should therefore be made available to learners with paraplegia.

One of the main problems that learners with paraplegia experience is spasticity. Spasticity can be reduced with exercises, positioning, one of two medications (Baclofen or Botox) or surgery (St Louis Children's Hospital, 2004).

Baclofen could be taken orally or could be administered by means of a subcutaneous pump. The pump permits more effective delivery of the drug directly into the nerve cells in the spinal cord. The pump also yields better and longer-lasting reductions in spasticity with less risk of the lethargy or confusion



associated with the oral drug. However, surgery is required to insert the pump under the skin over the abdomen and the indwelling catheter into the fluid space around the spinal cord (St Louis Children's Hospital, 2004).

Botulinum-A Toxin, also known as Botox, is a toxin that can be purified and used safely and effectively to reduce spasticity in specific muscle groups. Botox is administered by direct injection into the muscle to weaken that muscle temporarily and to allow stretching. The effects of Botox are not permanent. Weakness typically lasts for a few months. In some cases, patients may require repeated injections to treat a shortened muscle (St Louis Children's Hospital, 2004).

In children, there should be constant prevention of spinal deformity, contractures and decreased bone growth (Tingle, 1990). To prevent or minimise these problems, normal growth and development of the skeleton should be promoted. This is currently achieved in South Africa through the use of a body brace. The brace should conform to normal alignment. Special care is taken to support the lordosis in order for the child to be able to remain upright with minimal force applied at the top and bottom of the brace (Tingle, 1990). Callipers are used for weight bearing through the lower extremities to promote normal bone growth. A swivel walker allows the child mobility without using his/her hands for support. A chariot or standing frame may also be used. Elbow crutches offer a faster gait with more independence, for example climbing stairs, but a walking frame may be necessary to provide safety for most small learners, especially at school and in other crowded areas where the risk of being inadvertently knocked down is high (Tingle, 1990). Evaluation for prosthetics, orthotics, wheelchair and other specific equipment is an important ongoing rehabilitation goal to enhance and maintain the mobility level of these learners.

Learners with paraplegia experience specific problems in the school setting, namely problems of access, incontinence, personal hygiene, pain and fatigue,



medical needs, aids to mobility, playtime opportunities, general safety, handwriting, social communication, access to practical subjects, physical education, associated learning difficulties as well as marginalising and discrimination (Tingle, 1990).

For the learner to be able to function successfully in the school setting it is of the utmost importance that strategies be adopted to take care of these special needs as well as to prevent the development of secondary complications. These strategies would include special equipment, trained assistance and environmental adaptations. Special provision for standing might be necessary, such as a standing frame or a high table in the classroom. The learner might need assistance to put an orthoses on or to take it off. Access to the school should be considered and, if necessary, adaptations should be made (Hemmingsson & Borell, 2000; South Africa, 2001).

As a result of the continued physical and intellectual growth of the learner, regular and frequent medical follow-ups every 6 to 9 months are necessary. The most important aspect of the follow-up is to monitor the development of the spine and to check the fit of orthoses and other equipment. Also to ensure that the most ergonomical method is used for activities of daily living.

In addition to abovementioned strategies the learner should have reached a certain level of competence in dealing with his/her disability, special equipment and society before (s)he will be able to function successfully in the competitive world of a mainstream school. According to Landrum, Schmidt and McLean (1995) rehabilitation progresses through five stages that they call *rehabilitation outcome levels*. Only once level 5 has been reached, will the learner be ready to function optimally in a mainstream school. The rehabilitation outcome levels are:

- ***Physiological stability***: The learner is medically stable and can be discharged from an acute setting, usually to a rehabilitation unit.

- **Basic rehabilitation level (Physiological maintenance):** The learner is still in need of the maximum level of assistance and supervision.
- **Intermediate rehabilitation outcome (Home and/or residential re-integration):** The learner requires a moderate level of assistance and supervision in self-care, mobility, safety, communication and basic home management. In the author's experience, South African learners with paraplegia/paraparesis are often re-integrated into school when this level is reached. The more advanced outcomes necessary to function optimally in school have not yet been achieved at this stage. The learner therefore needs medical-related support, e.g. therapy and more than expected assistance in order to make optimal academic progress and to interact with peers.
- **Advanced rehabilitation outcome (Community re-integration):** The learner requires minimum assistance and supervision in self-care, mobility, safety, and communication and home/community re-integration. Although assistance might still be necessary, the learner drives this, e.g. the learner explains to a friend or teacher how to put on his/her braces. The learner therefore takes responsibility for his/her health and well-being. In the school setting, the learner can shift his/her focus from physical needs to social integration and acceptance by peers.
- **Productive activity:** The learner is fully integrated into productive activity that is appropriate to his/her interests and life stage, e.g. school or employment. Assistance may be required, but the learner again drives him/herself (Landrum *et al.*, 1995:46).

Assisting the learner to reach his/her optimum outcome level is the responsibility of the primary rehabilitation team and not that of the teachers at school (Landrum *et al.*, 1995). With holistic rehabilitation every learner with an uncomplicated paraplegia has the inherent potential to reach level 5 and to integrate into a mainstream school without unresolved rehabilitation issues to hamper him/her.



## **2.4 INCLUSIVE EDUCATION**

Inclusive education provides the background for every child with a disability to gain the opportunity for complete school integration. It should be understood that there is a philosophical or conceptual distinction made between mainstreaming and inclusion. Those who support the idea of mainstreaming believe that a child with disabilities first belongs in the special education environment and that the child must earn his/her way into the regular education environment without any special accommodations being made (South Africa 2001).

In contrast, those who support inclusion believe that the learner should always begin in the regular school environment, that accommodations are made as necessary and that the learner is only removed when appropriate services cannot be provided in the regular classroom (South Africa, 2001).

Research on participation by learners with disabilities in mainstream school activities and the role of participation in academic and social outcomes has been an area of growing interest in America and Europe. Both these continents have a longer history of inclusive education legislation than South Africa. In these countries, inclusion has been linked to a number of positive outcomes. Among these are lower rates of school dropout, greater academic achievement, lower delinquency rates, and increased involvement in social activities during early adulthood and increased adult employment levels (Wisconsin Education Association Council, 1996; Daniel & King, 1997; Hewitt, 1999; Kleinert & Kennedy, 1999; O'Shea, 1999; Simeonsson, Carlson, Huntington, McMillen & Brent, 2001; Anderson & Vogel, 2002). Other studies produced less encouraging results. It was found that the disabled learners felt isolated, experienced undue stress and that teachers did not know how to address their needs in the mainstream schools (Daniel & King, 1997; Mills & Cole, 1998; Wood, 1998; Llewellyn, 2000).

Research studies indicate that the academic performance of disabled learners increases when they are included in a regular classroom (Daniel & King, 1997; Mills & Cole, 1998; Hewitt, 1999; Lightfoot, Wright & Sloper, 1999; Hemmingsson & Borell, 2000; Hemmingsson & Borell, 2002). Hewitt (1999) found that, when comparing integrated learners to segregated learners, the mean academic performance of the integrated group was in the 80<sup>th</sup> percentile, while learners in the segregated group scored in the 50<sup>th</sup> percentile. The accepted reasons for this are, that it is expected of these integrated learners to work at higher standards and that the knowledge gained by being in an integrated environment enhanced their academic capability (Daniel & King, 1997).

Higher standards of achievement exist within a classroom that is occupied by non-disabled learners. When disabled learners enter that class, teachers expect them to comply to, adhere to, and meet the same standards as their normal counterparts (Kleinert & Kennedy, 1999). According to Daniel and King (1997), learners will be more likely to graduate from high school, keep their job, and become financially independent as a result these high expectations. In one instance, the employment rate for learners who were integrated was 73%, while only 53% of learners who received special education in the segregated group were employed (Wisconsin Education Association Council, 1996).

Furthermore, disabled learners in a mainstream school are exposed to more subjects than in the segregated group. As a result, they become aware of the subject areas in which they are successful and those in which they are unsuccessful (O'Shea, 1999). Knowing their academic strengths and weakness, disabled learners can therefore strive to improve their abilities, meet academic goals and become aware of their field of interest in order to make sound career choices.



The advantages of inclusion therefore include lower rates of school dropout, greater academic achievement, lower delinquency rates and increased involvement in social activities during early adulthood (Daniel & King, 1997; Mills & Cole, 1998; Hewitt, 1999; Lightfoot *et al.*, 1999; Hemmingsson & Borell, 2000; Simeonsson *et al.*, 2000; Hemmingsson & Borell, 2002). In addition, inclusion also has a motivational effect on able-bodied peers as it teaches them to be considerate and accept that disabled peers do things in different ways (Logan *et al.*, 1995).

However, Daniel and King (1997) found that the needs of low academic abilities and learners with above-average academic abilities tend to be ignored, especially in the case of learners with disabilities, since their abilities vary greatly with regard to social, linguistic, cognitive and motor skills (Mills & Cole, 1998). Teachers find it so difficult to teach each ability level in the class that they usually target their instruction on students in the middle range. The result is that the above-average learners will complete the assignment easily, while the below-average learners or learners with special needs will experience frustration because of the difficulties they experience or because of the nature of the assignment, which is not suited to them (Daniel & King, 1997).

According to Llewellyn (2000), the physical, social and psychological barriers in mainstream schools cause the needs of disabled learners to stay unmet, inclusion being a source of stress for everybody. However, the degenerative nature of the conditions of the six individuals, who formed Llewellyn's study population, as well as the small study sample (6 participants), might have been partially responsible for this negative finding.

From the above it is clear that learners with disabilities can expect to experience a number of limitations as regards activity and participation from childhood throughout their lives.



## **2.5 ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS AS EXPERIENCED BY PERSONS WITH PARAPLEGIA/PARAPARESIS**

The International Classification of Function (ICF) (World Health Organization, 1999) belongs to the family of international classifications developed by the World Health Organization (WHO, 1999) for application regarding various aspects of health. The classification provides a framework to code a wide range of information about health, e.g. diagnosis, functioning and disability, and reasons for contact with health services. The ICF has moved away from being a “consequences of disease” classification (International Classification of Functioning, Disability and Health, WHO 1999) to become a “components of health classification”. This model organises information in two parts: Part 1 deals with functioning and disability of body systems/structures. It is divided into impairments, and activity and participation. Any damage or disease to bones, organs or organ systems is defined as *impairment*. *Activity and participation* as opposed to *activity limitation and participation restriction* (disability) is defined as “... *limitations in the ability to perform activities or participating in social roles that is normal for a specific individual*” (WHO, 1999). Part 2 covers contextual factors including the individual's immediate environment and the general environment. The same impairment can therefore cause different levels of disability in different people, depending on their social roles and environment. The ICF focuses on interaction between the person and the environment (Ogonowski, Kronk, Rice & Feldman 2004). This implies a paradigm shift away from the medical focus towards a broader bio-psychosocial model of disability.

A lack of measuring instruments assessing function at the activity and participation levels of the ICF has been a major problem preventing the objective documentation of meaningful outcomes for learners with disabilities who attend regular schools (Ogonowski *et al.*, 2003). Despite its importance as a rehabilitation goal, participation restriction is the least often measured of all rehabilitation outcomes. Decades of research have already passed and numerous instruments have been developed to assess impairment and disability.



Equal efforts have not been directed towards the comprehensive assessment of handicap or participation restrictions (Craig Handicap Inventory of Environmental Factors, 1997). In addition, most of the outcome measures for participation restriction focus on adult populations (Simeonsson *et al.*, 2003).

In the absence of specific measurements for participation restriction and because participation means different things for different people, the author has decided to use the highest two outcome levels, i.e. community integration and productive activity (Landrum *et al.*, 1995) as indicative of an acceptable level of participation. If an individual reaches these levels, it implies the ability to perform social roles adequately.

Anderson and Vogel (2002) researched the factors that could be associated with integration into the community. They use the Craig Handicap Assessment and Reporting Technique as measuring instrument. Results showed that the five factors most strongly associated with integration into the community were education level, employment, income, functional independence, and health status. This is however only indicative of the adult disabled population.

For learners with disabilities adult employment is one of the most difficult goals to attain (Anderson and Vogel 2002). These authors found that only 39% of adults with paraplegia between the ages of 25 and 34 in the USA were employed full time. Many reasons have been suggested for the low employment rate of individuals with physical disabilities. Anderson and Vogel (2002) emphasise three important barriers:

- low expectations of family, friends and professionals;
- societal expectations that the person with a disability will be dependent;  
and
- lack of knowledge about resources and vocational services on the part of the individual with a disability and his/her family.

According to Statistics South Africa, 19% white disabled people are employed in full-time positions, compared to 6% Africans, 4% Coloureds and 9% Indians (Statistics SA, 2004).

Planning for an adult career is a major developmental task that begins in childhood. For learners and adolescents with paraplegia, preparation for adulthood is equally important, but more complex than for their peers who do not have special needs. Factors found to be associated with higher levels of employment were younger age at injury, less severe neurological impairment, more education, longer duration of living with SCI, and the ability to drive independently (Anderson & Vogel, 2000). Several studies have found whites more likely to be employed than non-whites. Violent origin of paraplegia has been associated with lower employment rates, as have health problems. Other factors associated with employment are internal such as motivation, work values, and self-esteem (Anderson & Vogel, 2000).

Although age at injury and cause of injury are not factors that are amenable to change, functional independence is. For example, a continent catheterisable conduit may enable an individual to catheterise independently, and vehicle adaptations may make it possible for an individual to drive. Any intervention leading to more functional independence is likely to improve employment potential.

Anderson and Vogel (2002) compared the work experiences of adolescents, aged 13 to 19 with paraplegia, to those of their peers without disabilities. They found that individuals with paraplegia were significantly less likely to have paid work experience than matched individuals without disabilities. Those with milder injuries and those injured at a young age were more likely to have work experience.



It is clear from the findings in the literature that it is extremely difficult for the disabled child to reach an outcome level 5. This is caused to some extent by the disability, but the environment (contextual factors) significantly influences outcomes at the levels of activity and participation (Mancini & Coster, 2004).

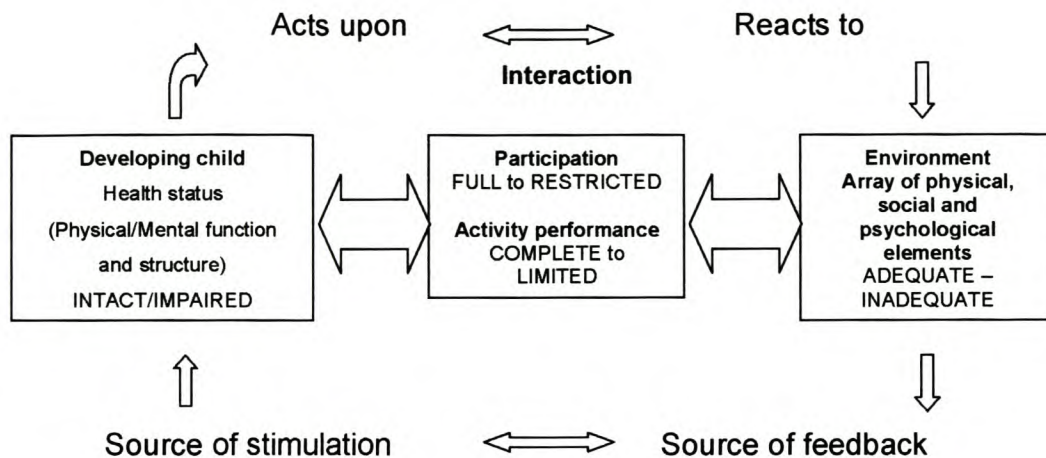
## **2.6 CONTEXTUAL FACTORS INFLUENCING INCLUSIVE EDUCATION**

*Contextual factors* are defined in the ICF as “... those factors both external and personal that facilitate or hinder participation of a person”. These factors range from the person’s own personality to the features of his/her physical, social and attitudinal environment (WHO, 1999).

*Occupational behaviour* may be described as “...an interaction between the person, the task and the environment ...” (Canadian Association of Occupational Therapy (CAOT), 1997; Simeonsson *et al.*, 2001). The person, environment and the occupation are seen as inseparable and interrelated to each other.

- A person-environment fit is achieved when the skills and abilities of the person are balanced with the demands of the environment to promote effective engagement in occupation or schooling (CAOT, 1997).
- Occupational therapy researchers have highlighted the need for environment-centered assessments and intervention strategies in the area of school-based practice (Hemmingsson & Borell, 2000).

A central issue is that children’s environments change dramatically during the stages of infancy, early childhood, middle childhood and adolescence. Each of these changes in the environment influences the child’s interaction through stimulation and feedback. These interactions frame a developmental process of the child’s acquisition of increasingly complex skills involving actions and reactions to the physical and social environment (Simeonsson *et al.*, 2002).



**Figure 2.1 Modelling dimensions of functioning and disability: child-environment interaction (Simeonsson *et al.*, 2001)**

Inclusion therefore has to focus on extending the factors conducive to successful inclusion and overcoming the barriers in the system that prevent disabled learners from meeting their full range of learning needs.

Literature identified the following factors as conducive to successful inclusion –

- support and understanding from parents, teachers and friends (Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000; Llewellyn, 2000; Mukherjee, Lightfoot & Sloper, 2001);
- a flexible working pace (Lightfoot *et al.*, 1999);
- appropriate extra attention (Lightfoot *et al.*, 1999; Hemmingson & Borell, 2002);
- access to facilities (Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000);
- appropriate equipment (Lightfoot *et al.*, 1999; Hemmingson & Borell, 2002);
- good communication (Horvat, 1990; Mukherjee *et al.*, 2001);
- education of parents (Gilbride, 1998; Viljoen, Naudé & Neveling, 2002);
- and
- an assistant (Hemmingson & Borell, 2002).



Inclusive settings offer learners the ability to experience a new environment where the effects of segregation, such as labelling and negative attitudes are limited (Mulvihill, Cotton & Gyaben, 2004). Such an environment is provided with role models to foster the learning of adaptive skills (Mulvihill *et al.*, 2004). The absence of these factors when they are needed will automatically cause barriers to inclusion. Further barriers according to literature are –

- problems related to the teacher (Wood, 1998; Daane, Beirne-Smith & Latham, 2000; Hemmingson & Borell, 2000);
- problems of a physical origin, e.g. pain, tiredness and poor motor co-ordination (Lightfoot *et al.*, 1999);
- prolonged periods of absence from school (Lightfoot *et al.*, 1999); and
- set time limits for activities (Hemmingsson & Borell, 2000).

According to literature, the single most important factor that can make or break inclusive education is the teacher (Wood, 1998; Lightfoot *et al.*, 1999; Daane *et al.*, 2000; Hemmingson & Borell, 2000).

Teachers must have a positive attitude as well as the necessary knowledge and understanding to be able to accommodate learners with physical disabilities in a mainstream class and to assist them to reach their full academic potential (Daane *et al.*, 2000; Hemmingson & Borell, 2000; Hemmingson & Borell, 2002). Teacher attitudes are one of the biggest obstacles confronting successful integration. Daane *et al.* (2000) found that teachers commonly have a low estimation of the abilities of exceptional students with disabilities. Such teachers often misjudge the level of competence of these students and have lower performance expectations for them. The attitude of many teachers is that these students are not capable of learning and that they are a burden to the class. Teachers may react negatively and could display a lack of understanding, preparation, or knowledge concerning some exceptional students (Hemmingson & Borell, 2000).



Some teachers believe that only special education teachers are responsible for the academic growth of learners with disabilities (Wood, 1998). As a result, they only focus on the social behaviours exhibited by these learners. Consequently, although it is the job of the general education teacher to provide academic instruction to all students, it is not done for some students with disabilities (Wood, 1998).

Teachers often do not feel comfortable teaching students with disabilities or they do not have the confidence to do so. They are also at a loss knowing how to teach these students. As was noted by a principal (Daane *et al.*, 2000), "*My teachers have not had enough training on what strategies to use with students with disabilities.*" Students with disabilities therefore do not receive the specialised teaching instructions that are necessary to ensure their cognitive growth (Daane *et al.*, 2000).

In addition, the needs of learners with low academic abilities and above-average academic abilities tend to be ignored by teachers. This is especially true for learners with disabilities since their social, linguistic, cognitive, and motor skills vary greatly (Daniel & King, 1997; Mills & Cole, 1998). Daniel and King (1997) found that teachers find it difficult to teach to each ability level, and therefore focus on the average students. Learners with below and above the norm academic abilities and learners with special needs suffer, because they are not stimulated at the correct level.

According to the Department of Education (South Africa, 2001), classroom teachers will be the primary resource for achieving the goal of an inclusive education and training system in South Africa. It is clear from the above-mentioned literature that teachers will need training and ongoing, structured support for inclusion to be successful.

Apart from the teacher, other people who are closely involved in the process can also influence the outcome. These are the learner with a disability, parents of learners with disabilities, their fellow learners and the educational programming team (Mulderij, 1996; Gilbride, 1998; Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000; Llewellyn, 2000; Simeonsson *et al.*, 2001; Viljoen *et al.*, 2002). The analysis of the opinion of learners with disabilities is crucial if we are to provide them with the appropriate assistance (Mulderij, 1996). The now famous words by David Pheiffer, "*Nothing about us without us*" clearly expresses that the opinion of the child with a disability should be central in any strategy to promote inclusion (Pheiffer, 2002).

In a survey conducted by Lightfoot *et al.* 1999 young people with disabilities valued school and were actively managing the effects of their condition, but needed support from parents, particularly mothers, teachers and close friends. The learners wanted to be involved in decision-making about the kind of help and support they should receive and who should know about their illness or disability (Lightfoot *et al.*, 1999).

On the other hand, Llewellyn (2000) found that the physical, social and psychological barriers in mainstream schools cause the needs of the physically challenged child to stay unmet. This author also found that mainstream education was a source of stress for everybody concerned. This study involved six young disabled people (aged 13 to 18), their parents, and seven teaching staff of one designated school in the United Kingdom. The learners reported that there was no one in school to whom they could talk to about their disability. Three learners suffered from muscular dystrophy, two from spina bifida and hydrocephalus and one from Friedrich's ataxia. The author would like to comment on the progressive nature of these diseases and would like to add that even in a special school these learners and their parents would have experienced a growing need for support.



On the whole, learners with disabilities feel that early stimulation, positive feelings about their bodies, physical competence instead of learned helplessness, the stimulation of social competence and contact with peers are important factors for the facilitation of successful inclusion (Mulderij, 1996).

Peers may have a poor understanding of their friends' disabilities. This might cause students with physical disabilities to have less social contact with peers than is the case with non-disabled students and could negatively influence learning opportunities (Hemmingson & Borell, 2002). Health professionals could play a supporting role in this regard by educating others in the school on the child's condition and the impact it has on school life (Lightfoot *et al.*, 1999).

The author found only one South African study on inclusive education, namely that of Viljoen *et al.*, 2002. The study found that it was difficult to support the child with disabilities in the mainstream educational system (Viljoen *et al.*, 2002). It focused on parenting needs as a precursor to inclusion of the physically handicapped child in a mainstream school. The psychological focus of the study falls on parents' educational needs concerning their physically disabled pre-school child. The researchers promote parent education as key to the success of inclusion and also as an important support service. Parents need feedback from the medical field on new changes and available literature (Viljoen *et al.*, 2002).

It is essential for successful inclusion that all the different professionals as well as child and parent form a team. Team members on the educational programming team can be from a number of different professional fields (Horvat, 1990). These include physical therapists, occupational therapists, school administrators, physicians, nurses, parents, school psychologists and nutritionists. In the ideal setting, cooperation and interaction between all these professional groups would ultimately aid in developing the best educational programme available for exceptional students. However, in many school districts little information is shared amongst professionals for a variety of reasons, including conflicts over



who should assume which role. A qualitative research study carried out during 2001 with young people, parents and teachers, in York, UK, investigated health staff's perspectives on the difficulties of and possibilities for achieving good communication with school staff regarding learners in mainstream schools with physically disabilities. The results showed that good communication was essential and joint meetings, shared documentation and favourable local policy development facilitated it. Sources of difficulty in communication were the parents as source of information, the practical difficulties of arranging meetings and lack of knowledge about other professionals' roles. The ethos of the school with regard to health matters, and the flow of information within health services also have an impact on the communication process (Horvat, 1990; Mukherjee *et al.*, 2001).

Apart from the team factors related to the disease and the child's physical abilities, e.g. pain, tiredness, motor co-ordination, prolonged periods of school absence and slowness in performing activities also influence inclusion (Pollock & Stewart, 1998; Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000). Learners with disabilities reported that it was an advantage to feel secure and positive about their own abilities (Mulderij, 1996). These learners also mentioned the various physical limitations that their bodies could place on them, e.g. the rebellious body that will not do what they want to do; the unreliable body that is less simple to handle; the sensitive body that has its own particular sensitivities and susceptibilities; the body in therapy; the dependent body; the conspicuous body; the vital body and friends accepting a different body (Mulderij, 1996). It is important for pupils that teachers are aware of these difficulties, are flexible about the pace the pupils can work at and that they give these learners the appropriate extra attention (Lightfoot *et al.*, 1999).

The disease and its consequences can cause prolonged periods of school absence, as has already been mentioned. Not only is it difficult to keep up with the academic work, but the child can also start to feel isolated from his/her peers.



This can partly be addressed by sending schoolwork home and assisting the child to stay up to date with academic progress made by the class.(Lightfoot *et al.*, 1999).

Time limits set for examinations and other activities provide one explanation why the average results of learners with disabilities are below that of the entire student body. In addition, the teaching style applied in the classroom determines the working pace in the classroom, which, in turn, influences the opportunities open to students with physical disabilities to participate actively (Hemmingson & Borell, 2000; Hemmingson & Borell, 2002).

An obvious barrier to successful inclusion is an inability to access rooms and other facilities (Pollock & Stewart, 1998; Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000; Hemmingson & Borell, 2002).

Two separate studies (Hemmingson & Borell, 2000; Hemmingson & Borell, 2002) researched environmental barriers in mainstream schools. In the first study (Hemmingson & Borell, 2002), 34 students with physical disabilities underwent a semi-structured interview designed to assess the environmental adjustments needed in the school. Data was collected by 16 experienced occupational therapists, which worked in seven different centres in Sweden. The students attended different schools and were in each case, almost exclusively, the only student with physical disabilities in his/her school. That study was therefore very similar to the current one. According to the authors, the small sample size of 34 was one of the limitations of the study. They found that at age 13, most learners change school, after which the learning environment for older students is akin to that of an upper secondary school. "Younger" students (typically under the age of 13 years) were included in the study if they had spent 1-6 years in academic schools, and older students (13 years and above) if they had spent 7-12 years in academic schools. Results showed that two-thirds of the students experienced barriers to participation in both the physical and the social environment. A



majority of the barriers originated from the way in which school activities were organised and performed. This resulted in restricted participation or exclusion from some of the activities in class. Some classrooms were not accessible because of stairs, lack of door openers or steep ramps. Older students experienced significantly more barriers than younger ones because the school organisation was less favourable. To take part in class, pupils need schools to have the appropriate access facilities and equipment, but these resources are not always available. Examples of accommodation include lower than standard desks, special chairs in the classroom or a computer at the student's desk (Hemmingson & Borell, 2000).

Accommodation can be general for use by anyone in the setting, even if they were of special importance for the students with disabilities e.g. elevators, spacious areas, and automatic door openers. Some accommodations are arranged for and available only to all students with disabilities, e.g. special educational classrooms, sport activities arranged for students with disabilities, or free access to a pool of assistants. Lastly, individual accommodations are those arranged for and used by a specific student: a special chair and desk, assistive devices, or alternative strategies (Hemmingson & Borell, 2000; Hemmingson & Borell, 2002).

In one study by Hemmingson and Borell (2000), 77% of students reported accommodation needs in writing. Although all these students were already using adaptive writing techniques, only ten indicated their devices made them independent in writing tasks. These reported accommodation needs includes the use of more than one strategy to be able to do writing tasks, including self-writing with device, computer, and computer with assistance and without assistance.

Appropriate equipment and a physical assistant where necessary will be valuable in easing inclusive education (Lightfoot *et al.*, 1999; Hemmingson & Borell, 2000; Hemmingson & Borell, 2002). Assistants can either be personal or students can



freely draw from a pool of assistants (Hemmingson & Borell, 2002). Further assistance in the form of support services is also crucial (Viljoen *et al.*, 2002).

The removal of architectural barriers is therefore not enough to fulfil the need for accommodation experienced by students with physical disabilities in the school setting. For inclusion to be successful, students' needs in more academic tasks like reading, writing and remembering things should be addressed and teachers should receive adequate training and support (Sewell, 2004).

In summary, the author wants to share the 10 principles that the Department of Education in the UK adopted to smooth the way for integration:

- Allow few cycles of changing classroom practices (the Action Plan) and have the teaching staff reflect on it.
- The Action Plan needs to be clear and simple and should provide immediate results.
- The members of the senior management team should be able to call on the full range of leadership styles.
- Provide for –
  - an effective discipline system;
  - effective data management;
  - vocational examinations;
  - assertive mentoring; and
  - compulsory after-school master classes.
- Good attendance.
- Failing teachers need to move on, replacements need to be attracted and teams have to be built within the subject staff (Sewell, 2004).

Inclusion is a complex project and needs constant feedback of the needs, the plan of action to address the needs and the feedback on the success of it. It is necessary to describe the situation as it is currently experienced in South Africa to be able to follow the learners experiencing it firsthand.

## 2.7 CURRENT SITUATION IN SOUTH AFRICA

### 2.7.1 Schooling for learners with disabilities

Educationists in South Africa tend to classify people with disabilities according to disability. Learners with disabilities are either placed in special schools or classes, or totally excluded from any educational opportunity on the grounds that they are “*too severely disabled*” (South Africa, 1997).

Historically the responsibility for identifying, assessing and enrolling learners with special needs, including those with paraplegia, was viewed as the prerogative of psychologists, social workers and other health professionals (South Africa, 2001). Learners with disabilities and their parents have had very little or no choice as to which option – mainstream or special school – they wished to access. Learner support took the form of specialised and typically medical interventions on a one to one basis. Rehabilitation services focused mainly on impairments. The medical professions concentrated on diagnosis and treatment, tending to neglect the broader social aspects needed for participation in the community (Landrum *et al.*, 1995). Special schools were built in urban areas with very little if any provision being made for special education in rural areas (South Africa, 1997).

Furthermore, learners with physical disabilities in South Africa are often excluded from the school setting due to societal views, environmental barriers and/or prejudice. This inevitably leads to adult unemployment of these individuals. However legislation is being changed to ensure accommodation of these individuals (South Africa, 1997). The figures on school attendance in South Africa indicate that primary school is the most accessible education level with 79% respondents (including all disabilities) attending mainstream primary school and 12% attending special schools, and only 5% not attending school at this level (Schneider *et al.*, 1999). The earlier the onset of disability, the more likely it is



that the child will attend a special school or be out of school. Of the respondents with onset of disability at birth, 66% attended mainstream primary school compared to 96% of those disabled between the ages of 10 and 18 years (Schneider *et al.*, 1999).

Special schools absorb a large proportion of the budget to serve a few learners with disabilities. These schools furthermore do not facilitate the integration of learners with disabilities into society. Special schools would not be the route of choice within a human rights framework that aims to facilitate the integration of people with disabilities (Schneider *et al.*, 1999). In South Africa there are policies and legislation to guide the process of inclusion.

### **2.7.2 Policies and legislation on inclusion**

The Integrated National Disability Strategy (South Africa, 1997) condemns the segregation of persons with disabilities from the mainstream of society. It emphasises the need to include persons with disabilities in the workplace, social environment, political sphere and sports arenas. The Department of Education supports this direction and sees the establishment of an inclusive education and training system as the cornerstone of an integrated and caring society. It is important to provide an effective response to the unsatisfactory educational experiences of learners with special educational needs, including those within the mainstream whose educational needs were inadequately met (South Africa, 1995).

The Department of Education sees it as a priority to implement a national advocacy and information programme in support of the inclusion model. This programme will focus on the roles, responsibilities and rights of all learning institutions, educators, parents and local communities (South Africa, 2001).

In an inclusive education and training system educational support services will be created and spread according to the needs of learners with disabilities (South



Africa, 1997). This means that learners who require little support will be receiving education in ordinary schools and those requiring moderate support will attend full-service schools. Full-service schools will have access to coordinated professional support services and can draw on expertise in assisting education programmes, addressing barriers to learning and increasing participation by learners and educators. The focus will be on altering the environment such as teaching strategies and learning resources with the emphasis on the development of good teaching strategies and resources that will be of benefit to all learners (Hemmingsson & Borell 2000; South Africa, 2001).

The Department of Education (South Africa, 2001) has set the goal of integrating the approximately 280 000 learners with disabilities outside the school system (South Africa, 1997:30). To achieve this, approximately 500 out of 20 000 primary schools (mainstream) will be converted into full-service schools. The process will start with the national District Development Programme, which identified three schools in the Western Cape as pilot projects. These schools are situated in Beaufort-Wes, Khayelitsha and Mitchell's Plain. They will be equipped and supported to provide for a range of learning needs. This will include physical and material resources and professional development of staff. These pilot projects will be carefully monitored and evaluated.

Furthermore, special schools will be transformed into resource centres (South Africa, 2001:47). These resource centres will render a service to the mainstream schools. The health care workers from these centres will be deployed as resources to mainstream and full-service schools. In the author's opinion there will be too few of the health care workers in the system to address the needs of the mainstream school as well as fulfilling the normal duty at the special schools comprehensively. This means that the learners with special educational needs will be accommodated in various mainstream and special schools. It would be difficult for the health care workers to cut themselves in so many portions to still provide a one to one service. It would however be manageable if the roles and



work programmes of these health care workers change according to the new plan of service delivery.

In the meantime, many parents of children with disabilities have however enrolled their children in mainstream schools, and disabled learners are being transferred from special schools to mainstream schools. These schools have to manage with all these different exceptional people with disabilities, without structured support by the Education Department who are awaiting the results of the pilot projects. Learners with disabilities are currently accommodated in mainstream schools without any support services (Viljoen *et al.*, 2002).

South Africa has very formal and definite legislation in place. It is necessary to comply with this in order to ensure that segregation is replaced with inclusion and social acceptance of the disabled. Admission criteria has to change, special schools have to be re-aligned as resource centres to assist mainstream schools and the Child Guidance Unit should become a part of the Department of Education's team (South Africa, 2001:55). In addition, referral systems for special education, empowering of mainstream schools and creating opportunities for the child with a disability should be put in place (South Africa, 2001:7).

## **2.8 MEASURING INSTRUMENTS**

The researcher wants to assess participation as well as the contextual factors that might influence participation of disabled learners in mainstream schools. The Craig Handicap Assessment and Reporting Technique (CHART) and Craig Hospital Inventory of Environmental Factors (CHIEF) were chosen as measuring instruments to assess participation and contextual factors respectively.

The Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, 1992) was designed to provide a simple, objective way of measuring the degree to which impairments and disabilities (activity limitations) result in participation restrictions in the years after initial rehabilitation. The original

CHART, developed in 1992, included domains to assess five of the WHO dimensions of handicap, namely

- *physical independence*: the ability to sustain a customarily effective independent existence;
- *mobility*: the ability to move about effectively in his/her surroundings;
- *occupation*: the ability to occupy time in the manner customary to that person's sex, age, and culture;
- *social integration*: the ability to participate in and maintain customary social relationships; and
- *economic self-sufficiency*: the ability to sustain customary socio-economic activity and independence.

The WHO (1999) model includes a sixth dimension of handicap called *orientation* (the ability to orient oneself to your surroundings). Subsequently the CHART was revised and a sixth domain designed to assess orientation, entitled *cognitive independence* was included (Craig Hospital Research Department, 1999). Items assessing cognitive independence focus on observable criteria and have been worded to minimise ambiguity and to promote consistent interpretation.

Each of the domains or subscales of the CHART has a maximum score of 100 points. This is considered the level of performance typical of the average non-disabled person. Achieving the maximum score indicates that roles within the domain are fulfilled at a level equivalent to that of the norm: an able-bodied person. High subscale scores indicate less handicap, or higher social and community participation (Whiteneck, 1992).

The instrument was designed for administration by interview, either in person or telephonically. It takes approximately 15 minutes to complete. Participant-proxy agreement across disability groups on the CHART has provided evidence in support of the use of proxy data for persons with various types of disabilities. It is possible to use the instrument as a mailed or self-administered questionnaire,



although some valuable data might be lost in the absence of interaction with an interviewer who provides consistent prompts (Whiteneck, 1992).

The reliability of the CHART has been established by examining the test-retest reliability for the total CHART score and for each of the five dimensions. The test-retest reliability coefficient for the overall CHART score was 0.93. Each dimension was almost equally reliable: the coefficients were 0.92 for physical independence, 0.95 for mobility, 0.89 for occupation, 0.80 for economic self-sufficiency, and 0.81 for social integration. By dividing the test subjects into two distinct groups, low and high level of handicap, the instrument was tested for validity. The mean total CHART scores revealed significant differences and four of the subscales also showed significant differences. The fifth subscale, measuring economic self-sufficiency, revealed no significant differences. Despite that, the statistical differences across the board support the validity of the instrument (Whiteneck, Charlifue, Gerhart, Overholser & Richardson, 1992).

Segal and Schall (1995) compared the CHART to the FIM (Functional Independence Measure) in a sample of stroke survivors. The FIM measures activity limitations and the CHART focuses on community integration. Proxy agreement for the CHART total score was good with an intraclass correlation of 0,77. Low intercorrelations were found in social integration and economic self-sufficiency. High intercorrelation was found in physical independence, mobility, and occupation. A correlation of 0,50 was found between the CHART and FIM disability scores, but increased to 0,70 when the economic self-sufficiency area was removed. The FIM does not measure handicap at all and only focuses on activity limitations due to a physical pathology. The CHART has added sections integrating participation of the individual in the community, i.e. social integration, economic self-sufficiency and occupation.

The CHART will be used on learners, and no previous studies done with such a population was found. The questions were revised and then tested during the



pilot study to ensure that learners aged 6-14 would understand it. The most important factor is that the answers will be coming from the learners with disabilities themselves. Answers to specific questions, i.e. the amount of hours per day that assistance is needed, might not be factual, but according to the child's perspective. After all, it is the learners who have to cope in the mainstream school setting either independently, with assistance or by asking for assistance.

Two other assessment tools were identified as potential measuring instruments for this study, namely the School Function Assessment (SFA) (Mancini & Coster, 2004) and The Canadian Occupational Performance Measure (COPM)© by the Canadian Occupational Therapy Association (1997). The School Function Assessment (Mancini & Coster, 2004) facilitates the description of multiple levels of function among learners with impairments who attend elementary schools. It was conceptually based on the international model proposed by the WHO. One or more school professionals who know the learner well filled out the questionnaire, which does not require any active participation of learners. The instrument was designed to provide a measure of elementary school participation by learners with disabilities as well as to describe their profile of functional performance. Seven different school settings are evaluated in the first of two parts: Transportation, Transitions, Regular classrooms, Specialised Classroom, Mealtime/snack time, Bathroom/toileting and Playground/recess. Part 2 deals with activity performance in eleven physical tasks and nine cognitive/behavioural tasks. The SFA is cost-free. This instrument was not used in this study, because it does not allow the learners with disabilities to express their opinions.

The Canadian Occupational Performance Measure (COPM)© is an individualised outcome measure designed for use by occupational therapists. The measure is designed to detect change in a client's self-perception of occupational performance over time. It allows the client to identify the areas of occupational performance that present them with problems and to prioritise those concerns.



The COPM is not diagnosis-specific, can be used across all developmental ages, and can be used with caregivers as well as clients. The outcome measure is copyrighted and can be ordered from Canada. Due to the financial implications and time restraints, it was not considered for this study.

To assess the influence of contextual factors, the researcher will use the CHIEF. The Craig Hospital Inventory of Environmental Factors (Craig Hospital Research Department, 1997) was developed to provide a new type of instrument that will allow the quantification of environmental barriers. This leads to a better understanding of the degree to which environmental elements impede or facilitate the lives of people with disabilities (The Craig Hospital Research Department, 1997).

Development of the CHIEF began at Craig Hospital in 1997, with funding from The Centres for Disease Control, Disability and Health Branch. The CHIEF is designed to assess the frequency and magnitude of perceived physical, attitudinal, and policy barriers that keep people with disabilities from doing what they want or need to do. It is designed to be a short inventory of environmental barriers that can be utilised in large-scale surveys and surveillance systems, and are valid for both individuals with and those without disabilities. The CHIEF has demonstrated that compared to non-disabled people, people with disabilities encounter more frequent and more problematic environmental barriers. Moreover, the CHIEF has demonstrated that the impact of barriers is associated with the type and severity of the disability (Craig Hospital Research Department, 1997).

There is no set time period for administering the CHIEF. It is however recommended that multiple measurements be taken over the course of a person's lifetime to assess changes with adaptation to the disability, and to gain insight into changes in environmental barriers that may occur over time (Craig

Hospital Research Department, 1997). Questions from the CHIEF will be used to compile a set of questions for this study.

Test-retest reliability of individual items and the total scale were calculated for the CHIEF using both the intra-class correlation coefficient (ICC) and the percentage of cases with exact agreement between both tests. Mean difference scores between the test and retest was also calculated and significance assessed. This process was repeated for frequency scores, magnitude scores, and frequency-magnitude product scores. In general, the product scores showed a slightly higher reliability co-efficient and they became the focus of additional psychometric analysis. These data indicated a total scale score ICC reliability of 0.926, indicating acceptable reliability for the instrument.

Across all disability sub-groups subject proxy interclass correlations ranged from 0,494 to 0,618 with a total scale ICC of 0,618. These data indicate that subject proxy agreement is marginal and results in the recommendation that proxies not be asked to complete CHIEF when subjects are unavailable to do so. No proxies will be used during the study and therefore no problems are expected.

Another measuring instrument that would have been suitable for measuring the influence of contextual factors is the School-Setting Interview. The School-Setting Interview (SSI) is designed to assess the accommodation needs of students with physically disabilities in the school setting. The SSI is based upon concepts from the model of human occupation (Hemmingsson & Borell, 2000), specifically the model's conceptualisation of the environment (i.e. objects, spaces, forms and groups) and Canadian concepts of client-centered practice (Hemmingsson & Borell, 2000). The SSI uses a collaborative approach to assessment, which enables small teams of people with diverse expertise (e.g. the student and the occupational therapist, teacher) to define problems mutually and to generate creative solutions (Hemmingsson & Borell, 2000).



Students with physical disabilities who are able to communicate adequately enough to discuss their experiences in school can be interviewed with the School-Setting Interview (SSI). The SSI is a semi-structured interview that is designed to assess the way in which the student fits the given environment and to identify the need for accommodations in the school setting. The SSI includes 14 content areas that explore the student's functioning in this setting: Write, Read, Say Something, Remember Things, Do Homework, Maths/Physics/Chemistry, Examinations, Sport/Art/Music, The Classrooms, Field Trips, Assistance.

The SSI guides clinical practice by providing suggested interview questions, which facilitate the investigation of the impact of the physical and social environment on the student's occupational performance, habits, meaning, and values. This will provide an in-depth evaluation of the school setting. Most learners in South Africa are included in the mainstream setting because parents feel they can cope there. Few physical adjustments have been made from the Department of Education's side to accommodate these learners at mainstream schools. The SSI would be appropriate for a formal research study in a school that has been enrolling learners with physical disabilities on a regular basis. The SSI can be obtained from the USA, but is very expensive and was not considered for this study due to financial implications and time restraints.

## **2.9 SUMMARY**

The literature shows that inclusion can be highly successful and can improve results for all. However, it is also clear from the literature that the process of inclusion has to be managed carefully, or it will fail. Attitudes, physical barriers, accommodations and teacher training should be dealt with for the process to be successful. Furthermore, the learner should have completed rehabilitation and should be able to function in the community and direct his/her own medical management.

In South Africa, policies and legislation demand inclusion. However it is unsure whether the support to ensure success is available at the level of the schools.



## **CHAPTER 3**

# **RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

The following aspects will be discussed in this section:

- Study aim
- Study objectives
- Study design
- Study population
- Inclusion and exclusion criteria
- Data collection
- Measuring instruments
- Pilot study
- Preparatory work
- Interviews
- Data analysis
- Limitations of the study

### **3.2 STUDY AIM**

The aim of the study is to determine the functioning of 6-14-year old primary school learners, with paraplegia/paraparesis, in mainstream schools of the Western Cape Province.

### **3.3 STUDY OBJECTIVES**

The objectives of the study are to:

- describe the demographic details of the study population
- determine the activity and participation levels of 6-14-year old learners, with paraplegia/paraparesis, in mainstream schools;
- determine restrictive barriers and inclusive facilitators in the mainstream school environment, including physical, social, cultural and academic barriers/facilitators; and

- make recommendations on inclusion to the stakeholders, i.e. the Department of Education, parents, school personnel and learners.

### **3.4 STUDY DESIGN**

This is a descriptive study. Qualitative data was collected and questions were asked during the interviews to determine the needs of the learners. The functioning of learners with paraplegia in the mainstream setting was measured with the CHART (Craig Handicap Assessment and Reporting Technique). The CHIEF was used to determine contextual factors that influence inclusion. Learners, their parents and the relevant staff members of the mainstream schools that these learners are attending, completed the CHIEF.

### **3.5 STUDY POPULATION AND STUDY SAMPLE**

The study population consisted of all primary school learners (age 6-14 years) with paraplegia or paraparesis, within the mainstream school setting of the Western Cape Province. The learners use a wheelchair for mobility, walk with assistive devices or walk with an abnormal gait. There is no formal list of these learners and the Education Department did not have any formal knowledge of suitable candidates. The following special schools and rehabilitation units in the Western Cape were therefore contacted to compile a list of candidates:

- \* Astra School (Durheim)
- \* Eros School (Athlone)
- \* Grootte Schuur Hospital School (Observatory)
- \* Jan Kriel School (Kuilsriver)
- \* Maitland Cottage Home (Newlands)
- \* Paarl School (Brackenfell)
- \* Princess Alice Hospital School (Observatory)
- \* Red Cross Children's Hospital School (Rondebosch)
- \* Sonstraal Hospital School (Mitchell's Plain)
- \* St. Joseph's School (Howard Place)
- \* Thembaletu School (Clareinch)



- \* Tygerberg Hospital School (Parow)
- \* Vista Nova School (Rondebosch)
- \* Agapé School (Mitchell's Plain)
- \* Carpe Diem Skool (George)

Astra School noted that no child was mainstreamed within the last two years. The four hospital schools were contacted but they could not supply suitable candidates. The Conradie Hospital was not able to provide any assistance as the hospital was relocating. Other hospitals had ethical issues around permission to access medical records in order to reach parents of suitable candidates. Mainstream schools provided names of families and learners with disabilities.

Seventeen suitable candidates were identified. They formed the study population. No further sampling was done. The parents of two candidates declined the invitation to participate in the study. The study population therefore consisted of the 15 learners, their parents and the teaching staff at the mainstream schools that accommodate them. No additional candidates could be contracted due to time and resource constraints.

### **3.6 INCLUSION AND EXCLUSION CRITERIA**

#### **3.6.1 Inclusion criteria**

- All participants had to be paraplegic or paraparetic and between 6 and 14 years old. As previously stated, this means lower limb involvement to the extent of using a wheelchair, walking device or walking with an abnormal gait.
- Participants had to have intact upper limb function. This applies to all the diagnosis i.e. paraplegia, spastic diplegia and brittle bone disease.
- All learners should have reached at least a rehabilitation outcome level 3 where they require a moderate level of assistance and supervision in self-care, mobility, safety, communication and basic home management.

- All learners had to attend a mainstream school in the Western Cape Province.

### **3.6.2 Exclusion criteria**

- Learners below level 3 of the Rehabilitation Outcomes.
- Learners with upper limb involvement (quadriplegia). The reason being that technology to substitute upper limb function is not generally available in South Africa (QASA, 2004).
- Progressive diagnosis, i.e. muscular dystrophy, Friedrich's ataxia.
- Learners with cognitive impairment.

## **3.7 DATA COLLECTION**

### **3.7.1 Measuring instruments**

The Craig Handicap Assessment and Reporting Technique (CHART) and The Craig Hospital Inventory of Environmental Factors (CHIEF) were used as measuring instruments in this study. Learners had to complete both the CHART and the CHIEF, whereas parents and teachers completed the CHIEF only. These two instruments were chosen, because it was easily obtainable, user-friendly and free of charge. The author contacted the Craig Hospital asking for copyright for only the CHART. They gave permission for the use of the CHART for research purposes and also informed the author about the CHIEF. They felt it could be beneficial to use the CHIEF for the purposes of this study. The CHIEF was used in the same format as the original, but some changes were made to the CHART. This was done because the author felt the study population would have difficulty in understanding some of the questions. Most questions referred to number of hours or reflecting days in a month. It became evident during the pilot study that the questions had to be more concrete to suit the developmental level of the study population (See Appendix A). The questionnaires are only available in English, and the use of Afrikaans/Xhosa interpreters were suggested by <sup>1</sup>Committee C after approval of the proposal. It was also decided that the

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<sup>1</sup> Committee C of the Stellenbosch University approving the research proposal



author would do every interview personally to keep the line of prompting consequent, thereby also keeping costs to a minimum since it was a small population. The option of having an interpreter for the interview was given to every candidate. The researcher conducted the questionnaires in English or Afrikaans as requested.

The names of the learners and contact details of their parents were gathered from the special school they had previously attended or the mainstream school, which they attended at that stage. Demographic information was gathered from the parents using a data capture sheet (Appendix D). The information included date of birth, chronological age, gender and grade completing at that stage. Information about the schools that they previously attended as well as the area (urban or rural) where the school was situated was included.

### **3.7.2 Pilot study**

Since there were a limited number of learners who complied with the inclusion criteria, the pilot study was done with five learners from a special school (ELSEN School). These five learners were physically challenged with intact cognitive functioning. The learners were asked by the multi-disciplinary team of the school to participate. Their parents were informed by letter and asked for permission before the interviews were conducted.

The learners completed the Revised-CHART and the CHIEF and the parents and teachers completed the CHIEF, in order to test the study design and data collection method (CHART and CHIEF). The five learners boarded in the hostel during the week and went home for weekends. This had to be kept in mind, as the study population would attend school from the home environment. The learners who participated in the pilot study had trouble distinguishing between the home and the hostel environment in answering the questions. Provision of attendants/caregivers was different and some had less cognitive independence at the hostel, than at home.

The school provided transport in the form of accommodated vehicles. There was usually no transport available at home. The questions determining social integration were difficult to answer, considering the hostel arrangement.

Of the five learners, three spoke Afrikaans at home and two were Xhosa-speaking. The interviews were conducted with a Xhosa interpreter present to clear misconceptions. The interpreter was one of the class assistants who regularly work with the learners. The questions seemed confusing to the learners. The researcher had to use more concrete terms to describe questions. This confirmed the original idea that the researcher needs to conduct all the interviews personally in order to keep the line of questioning and prompting consistent.

It was evident that the learners responses to the CHART questions would differ from those of their parents'/caregivers', but for the purpose of the study the learners own responses would be recorded. The learners would rather report that they helped themselves, than disclose the assisted care they were getting from parents or caregivers. When prompted about the different activities of daily living where they needed help, it became evident that they do receive assistance after initially saying that they do not need assistance. It is also difficult for a child to assess assistance in terms of hours per day. Their perception of nights away from home may also not be consistent with that of their parent's/caregivers.

The CHIEF was verbally interpreted into Afrikaans and Xhosa by the researcher and interpreter and answered by relevant learners, their parents and class teachers.

The parents seemed more concerned with the physical well being of the learners and seemed grateful for what the school managed to provide for their learners. They felt their learners were better off attending a special school. The teachers were also asked what they thought the needs of the disabled child would be:



would the child manage a balance between self-care, play and rest; what changes would be necessary and how could the therapists assist in this?

The learners found it difficult to understand and therefore answer certain questions from the CHART. These questions were revised and are included as Appendix A. The questions determining personal independence had complex terms like "*how many hours in a typical day/month*", which the learners found hard to conceptualise. The questions around cognitive independence had to start clearly by stating "*at home*" or "*away from home*" and then the amount of supervision needed. Questions for mobility were changed from "*how many hours per day*" to rather asking at what time they woke up and went to bed. The researcher then calculated the number of hours per day the child spent out and about. The same procedure was followed regarding questions assessing school participation. Instead of asking for the number of hours, starting and finishing times of school were used to calculate the number of hours spent at school. The question focused on periods attended every day rather than on prompting for the number of hours spent in class studying. Social integration was determined by asking whether the child stayed with family and friends instead of identifying with whom they spent time. Questions in the CHIEF caused no difficulties and the instrument was left unchanged.

### **3.7.3 Ethical issues**

- A protocol was adjusted and summarised in formal letter format and submitted to the Western Cape Education Department for approval.
- A formal proposal was submitted to the Committee C of the Stellenbosch University for permission to execute the project within the Faculty of Health Sciences. The proposal was accepted and registered as project: N04/01/015.
- The researcher undertook to ensure confidentiality and anonymity. No schools, headmasters, teachers, learners or parents who participated in the study would be named.

- <sup>2</sup>Dr R. Cornelissen granted permission on behalf of the Western Cape Education Department (WCED). He allocated time from March to October 2004 during which the study could be executed. The WCED also provided a letter with criteria for cooperation and proof of permission granted to be addressed to relevant headmasters.
- The researcher contacted the headmasters of the relevant schools and explained the basic concepts of the study to them and asked permission to conduct the interviews, with the cooperation of the staff, at the school. They all received a copy of the letter of permission from the WCED.
- The parents of the relevant learners were contacted telephonically to inform them about the intended research study and they were invited to participate. They had the freedom of choice whether to consent or reject the offer. The parents signed consent as legal guardians/parents for their children to participate and also signed another consent form to complete the second instrument (CHIEF) themselves. Two families declined and chose not to take part in the study due to personal reasons. This was respected.
- The researcher visited the schools to meet the headmasters and to arrange for private facilities in which to conduct the interviews. She also met with the parents and the relevant members of staff. Some interviews were conducted via the telephone, because the teachers requested this. This was out of class time. All interviews took place at a time, place and in the language that were convenient to the person being interviewed.
- Participants who agreed to partake in the study had to sign a consent form prior to any interviews or completing of the inventory. The outcome of the study will be disseminated to all the stakeholders and the stakeholders' permission will be asked to publish any of the findings.

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<sup>2</sup> Head of research: Department of Education



### 3.7.4 Interviews

- The researcher conducted all interviews. This was done to ensure that consistent prompts were provided and to prevent interrator bias. All participants was given the choice of language for the interviews and all interviews were done in English and Afrikaans, by the researcher.
- The venues were prepared in consultation with the participants. Some did not feel comfortable being called from the education program and venues had to be down stairs in a room where privacy could be ensured.
- A Data Capture Sheet was developed where demographic information of each learner was summarised, and space was created for the results of the CHART and the CHIEF 1 (Learners), 2 (Parents), 3 (Staff).
- The researcher used the CHART scoring form to fill in the answers. Any contributing comments were added onto the questionnaires for use during qualitative analysis.

### 3.8 DATA ANALYSIS

- Data from the interviews of the CHART was collated on the scoring form for interpretation. The CHART and the CHIEF were scored using the given formulas.
- Each aspect of the CHART would receive a count out of 100. A score of 100 was perceived as “normal” (Craig Hospital, 1997). A score close to 100 indicated a high level of participation.
- Data from the CHIEF would be plotted according to the analysis of variance between the students, parents and teachers. Environmental characteristics range from restrictive barriers (-) to inclusive facilitators (+). When problems with *accessibility (question 22-25)* and *accommodation (question 2-6, 11)* occur, it would be classified as “restrictive barriers” and when *resource availability (question 13,16,19)*, *social support (question 15,17-18,20-21)* and *equality (question 1,7-10,12,14)* are experienced, it would be noted as “inclusive facilitators”. The questions concerning

subheadings were shuffled as not to give the respondents any hints on what barriers or facilitators seemed problematic.

- Correlation would be drawn between the severity of the impairment and level of participation, activity level and environmental barriers.
- Results will be presented using histogram analysis and frequency distribution tables. The results were broken down in analysis of variance comparing the demographic information with the components of the CHART. Where the asymmetries of the box and whisker plots were evident and insignificant, the results from the non-parametric Kruskal-Wallis test were used. The CHIEF was interpreted using the repeated measure analysis of variance (ANOVA).
- No qualitative data were formally collected; only a list of needs was transcribed from the interviews as seen by the study population.

### **3.9 LIMITATIONS OF THE STUDY**

- The study was limited to learners with paraplegia or paraparesis. Learners with other impairments might provide different views.
- Only primary school aged learners were interviewed. Secondary school learners might have different experiences.
- The caregivers or parents might reply differently to some questions in the CHART, because their perceptions might differ.
- The study sample was one of convenience. This could have an impact on the results.
- The CHART is a reliable instrument to measure handicap after rehabilitation and would provide a good framework or foundation to sum up learners' abilities. However, reliability with a population of children had not been investigated.
- No developmental guidelines for adapting tools to the level of primary school-aged learners were available. Adjustments made were the result of feedback from the pilot study.



## **CHAPTER 4**

### **INTERPRETATION OF RESULTS**

#### **4.1 INTRODUCTION**

Results will be discussed under the following headings:

- Demographic information of learners, parents and teachers
- Activity and participation levels of learners –
  - Personal independence
  - Cognitive independence
  - Mobility
  - School participation
  - Social Integration
  - Financial resources
- Restrictive barriers and inclusive facilitators –
- Restrictive barriers –
  - Accessibility
  - Accommodation
- Inclusive facilitators –
  - Resource availability
  - Social support
  - Equality
- Summary

#### **4.2 DEMOGRAPHIC INFORMATION**

The study sample consists of 15 learners with paraplegia/paraparesis who access a mainstream school in the Western Cape Province, their parents and class teachers. Demographic information will be discussed separately for these three groups (Appendix D).

#### 4.2.1 Learners

##### → Ages and grades

The ages of the learners varied from 9 to 14 years old. Eight of the learners were in grade 7, while the rest of the population was evenly distributed from grade 3 to grade 6. The age distribution and different grades can be seen in Figures 4.1 and 4.2.

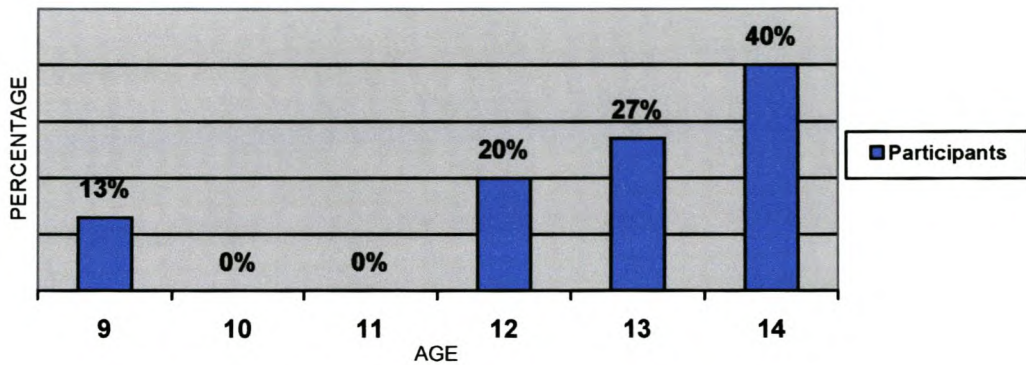


Figure 4.1: Age distribution of participants

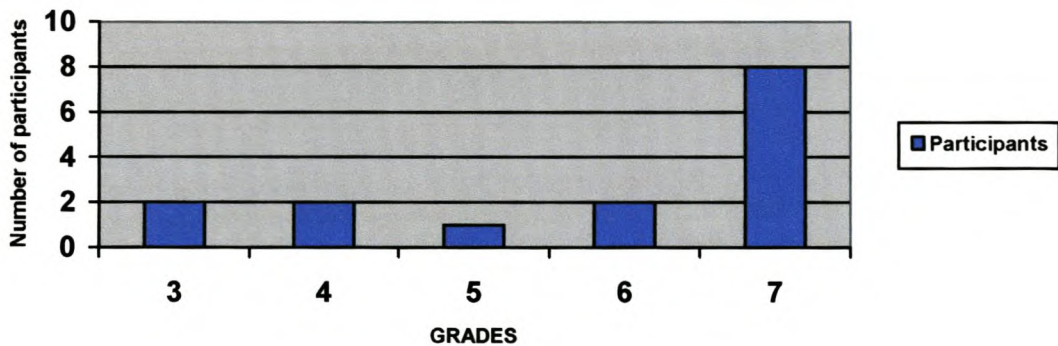


Figure 4.2: School grade distribution of participants

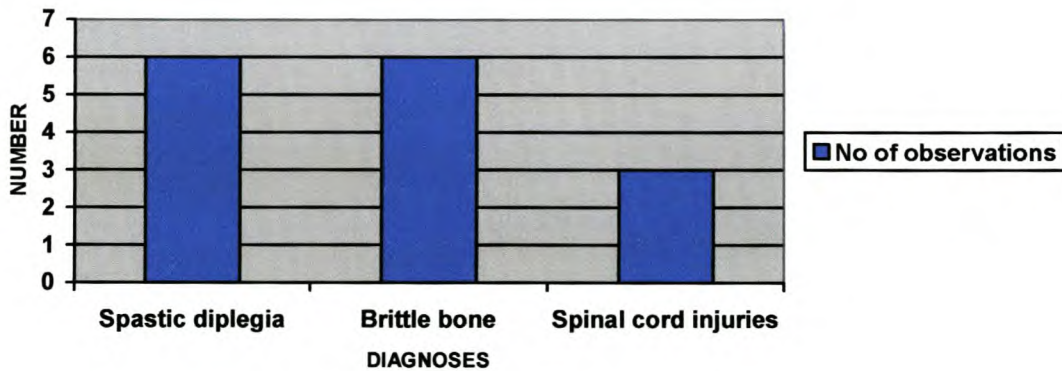
It is clear from the information in Figure 4.1 that the ages of the sample population was concentrated in the upper half of the planned age group for the



study which could be between 6 and 14. Being older and in higher grades indicated that these learners were further along the development process. They should therefore have had less difficulty in understanding the questions of the CHART. <sup>3</sup>Academically they fell within the norm of their peer group. More than 50% of the participants were attending grade 7, according to Figure 4.2. Only 40% of the participants were 14 years old and therefore expected to be in grade 7. 47% of the participants were 12-13 years old, representing the grade 5 and 6 peer group (20% of participants attending these grades). Only 13% attended grade 3, and 4 (27% of participants were 12-13 years old).

→ **Diagnoses**

The diagnoses included in the study were learners with spinal cord injuries, brittle bone disease and spastic diplegia. The total number of observations for each diagnosis is summarised in Figure 4.3.



**Figure 4.3: Different diagnoses**

According to Figure 4.3, 40% of the participants had a diagnosis of spastic diplegia, and 40% that of brittle bone disease. Only 20% of the total study

<sup>3</sup> As a group they were therefore attending a grade above the norm for their ages. When starting school at age 6, turning 7 in that year, a child should be turning 9 in grade 3, 10 in grade 4, 11 in grade 5, 12 in grade 6 and turning 13 in grade 7.

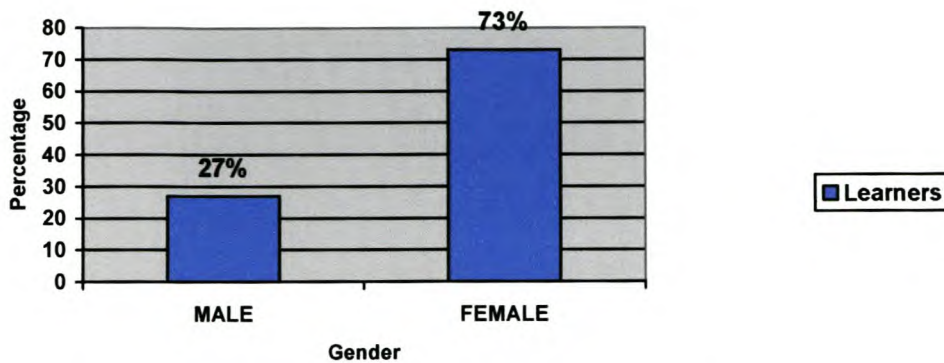
population had a spinal cord injury. The six learners with brittle bone disease all used a wheelchair and presented functionally like learners with lower extremity weakness/paralysis. Three of the learners with spastic diplegia walked without assistive devices, but had involvement of balance, coordination and postural alignment, and three used elbow crutches. They were all born with the disability. All three learners with SCI were wheelchair-bound and acquired the injury traumatically due to either motor vehicle accident (2), or gunshot wound (1). Two of the SCI used gait orthoses during therapy sessions to enhance bone growth and to train strength and endurance. This was done outside of school and was privately funded. The third child with SCI used a standing table during therapy sessions.

The three learners with SCI attended a special school for an interim period before being mainstreamed. They had been mainstreamed for less than six months. Four of the six learners with brittle bone disease also attended special schools and were mainstreamed because the multi-disciplinary team at the special school felt they could benefit more from mainstream schooling. They had attended mainstream for 1-3 years. Two learners with brittle bone disease entered the mainstream at school entry. All the learners with spastic diplegia were mainstreamed within the last 3-4 years. It is obvious that mainstreaming is still very new and has only been done for an average of two years, according to the study population.

→ **Gender**

The study population included male and female participants. The percentages are summarised in Figure 4.4.





**Figure 4.4: Gender distribution of learners**

According to literature, there are more males living with SCI than females (South African Spinal Cord Association, 2004). There is no difference in gender distribution for spastic diplegia and brittle bone disease. The author is therefore unsure as to why the study population consists of twice as many females as males. It might just be because of the small study population or a coincidence that females with disabilities had more opportunities to be mainstreamed than their male counterparts.

→ **Cultural groups**

The cultural groups represented were African (33%), Coloured (20%) and White (47%). This is not a representation of the general population distribution in the Western Cape. There are, however, no disability statistics available for school-age learners. This could also be indicative of the fact that learners with disabilities from African groups have more problems accessing mainstream schools (South Africa, 1997).

→ **Urban versus rural**

The study population included learners from rural (47%: 8 participants from Southern Cape-Karoo Region) and urban (53%: 7 participants from Cape Metropole Region) schools. There was a strong link between the geographical area of residence and the school attended. This eased school access in terms of

transport, because the school is geographically closer. Parents however had to provide their own transport in contrast with special schools where the schools provide transport. This meant that some learners had to walk or propel their wheelchairs to and from school. The effects of this are discussed fully in paragraph 4.4.1, *Restrictive barriers: Accommodation*. Time of departure to and from school was also shortened and more convenient for the learners. Some families made use of after-care facilities because they worked office hours.

→ **Medical care**

40% of the families involved belong to a medical aid, 47% make use of government services and the Road Accident Fund supports the medical expenses of 13%.

Two of the participants in this study experienced long periods of school absence due to corrective surgery as a result of postural misalignment because of spasticity. The literature mentions periods of school absence as a barrier to successful integration (Lightfoot *et al.*, 1999). The parents of these two participants motivated for schoolwork to be sent home, to ensure that their children do not fall behind. During the interview with the teachers involved, they mentioned that sending work home was a solution, making it possible to monitor that the learners stayed on the same level as the rest of the class, although studying at home. Aftercare and rehabilitation take place after school hours and at parents' own expense. This and own transport are normal for mainstream schools and express the very equality that the disabled crave (South Africa, 1997).

→ **Rehabilitation outcome levels**

Although not specifically assessed, the author could determine the outcome levels of participants through the interviews. Three participants were on a level 3 (Landrum *et al.*, 1995). They are still mastering the skills of self-care, mobility, safety and the home environment. They are in need of developing control within



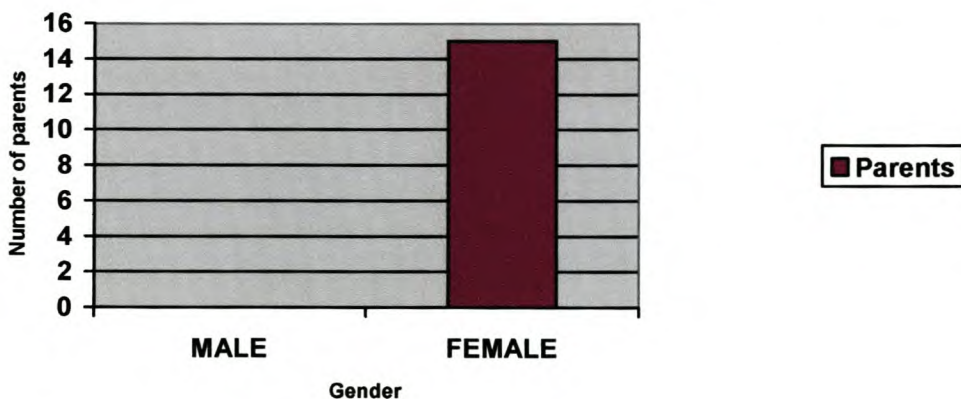
their personal space and then only will they start to develop community integration skills. These learners would find the inclusive education environment very demanding. All three learners had brittle bone disease and had difficulty bridging the gap between home and school integration.

The majority of learners (8) had reached level 4, an advanced rehabilitation outcome (Landrum *et al.*, 1995). They displayed skills like assertive behaviour, social skills, and mobility in the community, monitoring their own health and some recreational preferences. These learners should master being included in mainstream education, as it would be the next goal for them. They would however need support and assistance during the process.

Only four learners reached level 5 of the productive activity (Landrum *et al.*, 1995). These learners could move around freely in the community, did volunteer work and managed to take responsibility, for example to look after their younger brothers/sisters or involvement in church activities. These learners should have the ability to integrate well in the mainstream schools.

#### 4.2.2 Parents

The gender distribution of the parent population is presented in Figure 4.5.

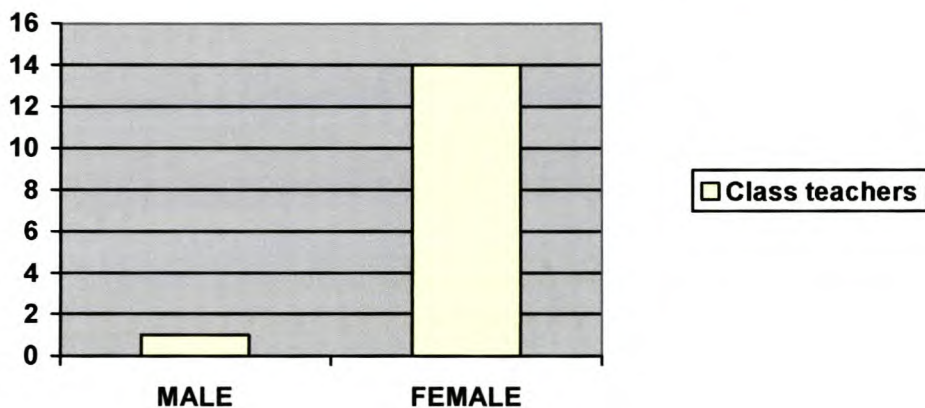


**Figure 4.5: Gender distribution of parents**

It is clear that only mothers participated in this study. Consequently, the results of this study cannot be readily generalised to fathers. Although mothers are often the primary caretakers of children, the significant lack of participation by fathers raises many important questions concerning the attitudes and adjustment of fathers toward a child with a disability. These questions are however beyond the scope of this study.

#### 4.2.3 Teachers

Figure 4.6 reflects the gender distribution of the participating teachers.



**Figure 4.6: Gender distribution of class teachers**

From Figure 4.6 it is evident that only one of the teachers was male. According to the Western Cape Education Department, primary schools have a bigger ratio of female teachers to male teachers. This finding might therefore be in keeping with those statistics. The results of this study can however not be readily generalised to male class teachers. Three of the teachers mentioned that they had remedial training. According to them, this equipped them to manage learners with special educational needs.

#### 4.3 ACTIVITY AND PARTICIPATION LEVELS OF LEARNERS

The CHART (Whiteneck *et al.*, 1992) was chosen as measuring instrument, to provide a simple, objective measure of the degree to which impairments and



disabilities result in participation restriction. It must be kept in mind that the CHART was not developed originally for use with children as such and that it was adapted by the researcher. The researcher felt that it was a priority to take the opinion of the learners with disabilities into account, and this instrument was therefore used because it is effective in assessing the extent of the handicap or social disadvantage.

Each of the domains or subscales of the CHART has a maximum score of 100 points, which is considered the level of performance typical of the average non-disabled person. Achieving the maximum score indicates that roles within the domain are fulfilled at a level equivalent to that of the norm: an able-bodied person. High subscale scores indicate less handicap, or higher social and community participation.

The CHART consists of the following sections:

*Physical independence (PI):*

The type and amount of assistance that the learner needs as well as the person taking responsibility for instructing and directing attendants, are measured.

*Cognitive independence (CI):*

Cognitive independence measures the amount of supervision that a child receives. This includes assistance needed with decision-making, judgement and remembering as well as the independence around controlling spending money and difficulty in communicating with other people.

*Mobility (M):*

Mobility is calculated by taking into account the number of hours out of bed and the ability to move between different activities, the assistance

needed to enter and exit the home, access to all areas of the home and the independent use of transport.

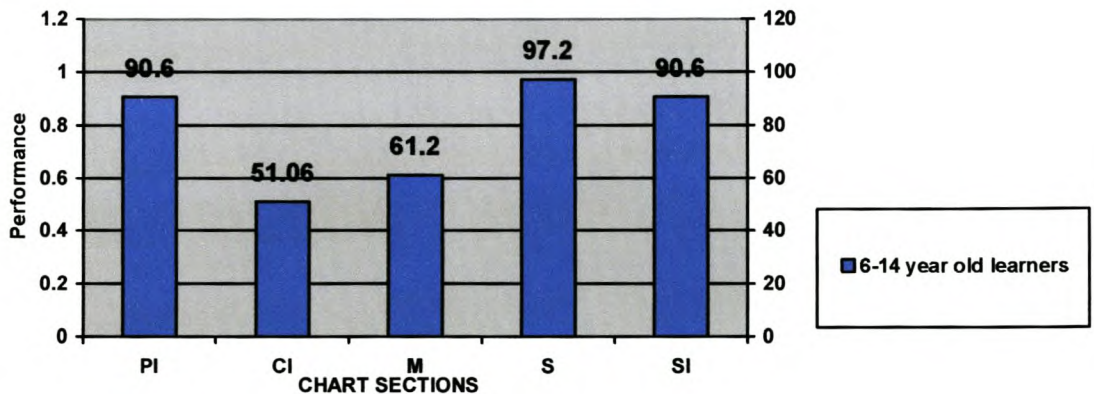
*School (S):*

This area assesses productive activity (Landrum *et al.*, 1995). The amount of time spent at school, doing voluntary work, chores and hobbies are assessed.

*Social integration (SI):*

This section measures the time the learner spends with family, friends and people they do not know.

The scores of the subsections of the CHART are presented in Figure 4.7.



**Figure 4.7: Mean CHART scores**

Scores will be analysed and discussed in the order in which they are recorded in Figure 4.7.

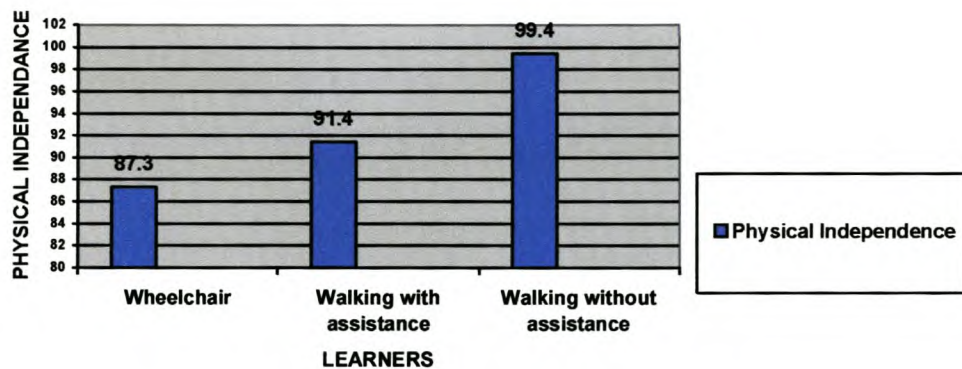
The results were analysed using the analysis of variance (ANOVA) test as well as the non-parametric methods (Kruskal-Wallis) where the distribution of the



results was <sup>4</sup>skew. A p-value of 0,05 or smaller was seen as an indication of statistical significance.

#### 4.3.1 Physical independence

According to Figure 4.7, PI tested at 90,6%. This is a high score indicating a high standard of personal independence. There was a significant difference in physical independence between learners from rural and urban areas ( $p = 0,0228$ ). The urban learners were more independent. However all seven rural participants were using a wheelchair, while only two of the eight urban participants used a wheelchair. Physical obstacles, like stairs, will decrease the physical independence of a wheelchair user more than that of someone walking even with assistive devices. In Figure 4.8, the average scores for physical independence were compared between the three different means of mobility for learners participating in the study, i.e. wheelchair-bound, walking with assistive devices (elbow crutches) and walking without assistive devices, but with postural involvement affecting balance and coordination.



**Figure 4.8: Comparison between physical independence scores and means of mobility**

<sup>4</sup> The results did not group together in order to indicate a significant difference.

It is clear from the graph that personal independence scores increase as the means to mobility change from wheelchair to walking with assistance and then to walking without assistance.

The differences in personal independence due to attending a different grade had a p-value of 0,043 on the analysis of variance test. This indicates a significant difference in the level of performing personal independence by learners attending different grades. The scatter plot shows a positive connection, indicating that personal independence increases as the grade increases. It could not be proven scientifically, since the p-value of the scatter plot was only 0,87.

#### **4.3.2 Cognitive independence**

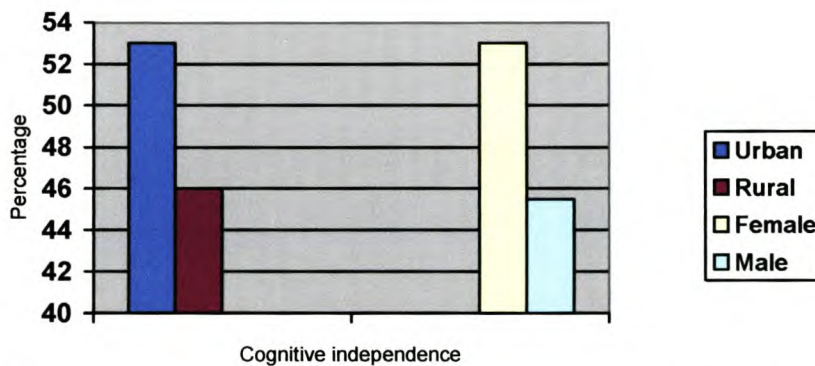
Learners in the study sample scored relatively low in this area (51,06%), as are shown in Figure 4.7. The influence of the environment and developmental stage on the performance and functioning of the learner is particularly important when interpreting the cognitive independence scale (Simeonsson *et al.*, 2001). The author contemplated the question as to what the norm for able-bodied learners of this age group would be when completing the CHART. Without further research, this question remains unanswerable. What should be noted is that the learners who were tested were constantly in the company of someone assisting him or her with judgement, decision-making and care. There is a possibility that these learners could be over-protected, which may create cognitive dependency. However, one boy from the study sample actually looked after his sister in the afternoons while his parents were at work. This proves just the opposite. One expects learners of this age to have some autonomy, but a score of 100 or close to 100 would have been surprising as learners of this age would not be completely independent cognitively as assessed by the CHART.

According to the analysis of variance and scatter plot cognitive, independence seems to be positively linked to age, but not statistically significant (p-value =



0,36). One might be able to prove this with a bigger study sample or a wider spread of ages.

Figure 4.9 reflects the cognitive independence scores for the urban and rural participants parallel to the same scores between the male and female participants.



**Figure 4.9: Comparisons between urban/rural and male/female cognitive independence scores**

Figure 4.9 indicates a higher mean score for cognitive independence amongst females (53) than males (45,5). This might be related to the fact that 73% of the participants were female. The mean score for cognitive independence in the rural areas is lower (46%) than in the urban areas (53%). The trend of cognitive independence increasing with age needs to be kept in mind. The average age for the rural participants was 12 years and that of the urban counterparts, 13 years. All the rural participants were wheelchair-users, which could have been interpreted as though they needed more supervision and assistance to prevent incidents (Figure 4.8).

### 4.3.3 Mobility

Figure 4.7 reflects a mean mobility score of 61,2%. This low mobility score is to be expected as paraplegia mainly affects the person's mobility. The mobility mean amongst grade 3 learners was 75%, decreasing to 60% for grade 7

learners. The trend in this study was that mobility decreases as age increases. This is supported by the literature. Older students experienced significantly more barriers than younger ones because the school organisation is less favourable (Hemmingsson & Borell, 2002). The study sample consisted of primary school learners, but with the increase in age a decrease in mobility was already noted in this population. As grades get higher, students have to move more between classes and according to qualitative feedback; little adaptation is made to accommodate physical challenges in the school organisation.

#### **4.3.4 School participation**

In Figure 4.7, the study sample shows high scores of 97,2% for time spent in productive activity. However, the attendance of a formal mainstream school provided structure to the day and might have inflated the score (This structure is normal for all learners). Some students had to do extra classes after school, limiting their recreational activities and not allowing time to do volunteer work. Only two participants actually did volunteer work at their local church. Sport and recreational activities were limited. During physical exercise periods, these learners would go to an alternative class or use the time to finish academic work. Although the score for productive activity therefore seems pleasing, it could be better managed to suit the needs of the learner with disabilities in allowing special programmes motivating participation in physical exercises and recreational activities.

The Kruskal-Wallis non-parametrical test had a p-value of 0,38, indicating no significant difference between learners attending school in urban and rural areas.

#### **4.3.5 Social integration**

The mean score for SI according to Figure 4.7 was 90,6%. Most learners had a good balance between time spent with family and time spent with friends.



### 4.3.6 Financial resources

The section on financial resources was not included, because the learners do not earn an income and do not pay their own expenses.

## 4.4 RESTRICTIVE BARRIERS AND INCLUSIVE FACILITATORS

The CHIEF aims to quantify environmental factors and to provide a better understanding of the degree to which elements of the environment impede or facilitate the lives of people with disabilities. It contains 25 questions measuring accessibility, accommodation, resource availability, social support and equality in no specific order. These headings are never revealed to the respondents. Each question is graded according to the frequency of the problem (FS= 0-4), the magnitude of the problem (MS=0-2) and then added to measure the overall impact (OI=0-8) of the barrier/facilitator. Two extra options, *never* and *not applicable*, is added under overall impact. Tables 4.1 and 4.2 give the mean percentage score of each component indicating the extent of the problem as perceived by the learners, their parents and the relevant class teacher:

**Table 4.1: Mean percentage scores of restrictive barriers**

	CHILD	PARENT	TEACHER
Accessibility (FS)	15%	20%	19%
Accessibility (MS)	17%	24%	28%
<b>Accessibility (OI)</b>	<b>12%</b>	<b>16%</b>	<b>17%</b>
Accommodation (FS)	21%	27%	23%
Accommodation (MS)	25%	32%	31%
<b>Accommodation (OI)</b>	<b>17%</b>	<b>21%</b>	<b>20%</b>

The repeated analysis of variance test (ANOVA) is the most effective statistical measure to compare the opinions of the learners, parents and teachers with each other. The three measurements of opinion correlate throughout. There was no

significant difference found between the opinions of the learners, parents or teachers.

#### **4.4.1 Restrictive barriers**

##### **4.4.1.1 Accessibility**

This evaluated services in the community, policies and rules of the schools, the support in career choices and the availability and implementation of government policies assessing accessibility.

In Table 4.1, the parents and teachers have marked higher frequency scores than the learners, indicating that they experience this as a bigger problem. The magnitude of the problem was 11% smaller for the learners than for the teachers. The overall impact of accessibility as a restrictive barrier was 5% lower according to the learners than to the teachers.

Teachers felt that policies on inclusion in the educational sector are a challenge for staff members, as they do not know much about different disabilities. Teachers saw these policies and rules as the biggest problem. They seemed to be familiar with learning problems, but not with physically challenged learners. Some schools experienced problems with policies and being forced to manage learners with physical disabilities by means of rules, regulations and protocols. Not all teachers felt adequately trained to handle these learners. This confirmed the literature findings on teacher's attitude towards learners with special needs (Daniel & King, 1997). Teaching staff is only the receivers of new policies like inclusive education, since all these decisions are taken at departmental level. Teachers will only be trained once the new inclusive education policy has been implemented. At a meeting held by the Western Cape Education Department in August 2002 to determine the attitude of teachers toward inclusive education, the majority of teachers complained about problems and reflected an overall negative attitude.



Parents also experience inclusion policies as a problem. One parent noted that her child was sent to mainstream school without them being ready to handle the full consequences. Another noted that the policies actually confused the learners. She felt that her child was better off attending a special school, but was asked to leave in order to be mainstreamed. The parents are experiencing a need for structures and policies that suit their children with disabilities.

There are few sports programmes in the schools/communities that cater for the physically challenged. Most of the learners taking part in the study did not take part in any physical periods or sporting activities. They preferred cultural activities like singing in a choir and playing chess. Some learners also had difficulties in partaking in life orientation, as no adaptation for their physical limitations were made.

One teacher noted that her remedial teaching training prepared her thoroughly for the challenge of inclusive education. The ideal would be for mainstream schools that include learners with disabilities, to present a staff development programme in order to enhance the teachers' knowledge, provide opportunity to ventilate feelings and build skills to manage these learners better (Mulvihill *et al.* 2004).

#### **4.4.1.2 Accommodation**

The questions formulating physical and structural accommodation include the design of home, school and community, the natural environment and the surroundings that might cause difficulties for the learner. The weight of problems with accommodation at mainstream is evident from Table 4.1.

The parents felt according to the CHIEF scoring that the frequency of accommodation as a barrier was 27%, 6% higher than the learners. Being accommodated on a daily basis seems to be a higher priority to the parents than

the learners, who experience these restrictions first hand. The learners considered the magnitude of the problem to be 25% and the parents 32%. Teachers also scored the magnitude quite high at 31%. Stairs and upper level classrooms seemed to be a general barrier as well as schools not being user-friendly to the disabled, including narrow passages and inaccessible toilets. This is similar to findings from the literature (Pollock & Stewart, 1998; Lightfoot *et al.*, 1999; Hemmingsson & Borell, 2000; Hemmingsson & Borell, 2002). Some learners had to be carried to the first floor for classes. Others battled to carry heavy bookcases and preferred using cases on wheels.

The parents indicated accommodation to be a relatively big problem for them (21%). The problem includes both frequency (regularity) and magnitude of not being accommodated. In one school parents offered to fund a ramp and in another school offered to fund toilet rails. The parents felt perplexed and gave in to all the pre-requisites from the school. Some parents provided the chosen alternative for seating their learners in the classroom setting. One school expected parents to provide a facilitator who could shadow their child at school. This causes a learner to become dependent on someone and creates a learnt dependency. In other cases, the learners with disabilities were hardly ever left to their own devices. This type of situation could have contributed to the low scores on cognitive independence.

In the community findings vary. On the one hand, the community judged by parent, teachers and learners during this study provided escalators and lifts in some instances for easy access to different levels in shopping centres, while on the other hand, one supermarket asked a girl with a disability to stay outside the shop while her mother did her shopping.

During winter, some learners battled with their health and needed to wear extra protective headgear. It is also more difficult to walk at the same pace consistently in colder months. The level of spasticity increases with cold



temperatures, making mobility and physical activity more difficult. Furthermore, rough roads; a lack of curbs or inaccessible curbs might hamper wheelchair mobility. According to table 4.1 the learners rated the overall impact of being accommodated at mainstream schools only 17%, showing a higher level of contentedness. The staff indicated their awareness of the problems concerning accommodation by scoring its overall impact at 20%.

Throughout restrictive barriers the learners scored the impact the lowest of the three groups. This could be due to their voice of opinion that needs to be developed or that they found being in a normal environment a positive experience and will therefore make do.

When prompted as to what the learners felt their needs were, different priorities came up. There was a need for more programmes in the communities (outside the school system), providing opportunities for sport, recreational and volunteer work, even if the programme was only of a supportive nature. A mother made the author aware of a successful Ubuntu-project running in their community. This is a project initiated by the local community, which consists of community members voluntarily developing programmes to see to the welfare of learners or the aged or to empower the members of the community concerning certain issues. These initiatives could be directed from and supported by Community Health or Welfare Government Departments.

There seemed to be a need for a caregiver-system in the mainstream school, providing a pool of caregivers trained and knowledgeable to help learners with disabilities in the toilet, on the playground, between classes, etc. This is confirmed by literature (Hemmingsson & Borell, 2000; Hemmingsson & Borell 2002).

Correct placement and positioning in classes was also noted as a need. Some teachers already changed the environment by allowing seating measures in class

such as special chair inserts provided at the parents' cost or exchanging the desk for a table to allow the wheelchair to fit in underneath it. It is important for the child to be able to rise safely and walk with devices where necessary. One child battled with attention problems and was very distracted when seated more towards the back of the class.

#### 4.4.2 Inclusive facilitators

##### 4.4.2.1 Resource availability

Resource availability indicates the amount of help needed at school, the attitudes of peers and teachers as well as the availability or lack of support at school. The overall impact of the resource availability amongst the three groups is given in percentages on Table 4.2.

**Table 4.2 Mean Percentage Scores of Inclusive Facilitators**

Resource avail. (FS)	16%	24%	15%
Resource avail. (MS)	21%	32%	22%
<b>Resource avail. (OI)</b>	<b>13%</b>	<b>20%</b>	<b>13%</b>
Social Support (FS)	15%	15%	12%
Social Support (MS)	20%	21%	14%
<b>Social Support (OI)</b>	<b>12%</b>	<b>13%</b>	<b>9%</b>
Equality (FS)	21%	21%	16%
Equality (MS)	28%	26%	20%
<b>Equality (OI)</b>	<b>18%</b>	<b>17%</b>	<b>13%</b>

The parents felt that the schools provided 24% in the need for resources. The parents saw the magnitude of the availability of resources as 32%. They considered having resources available the most important amongst the three groups. The learners and the teachers scored the magnitude of resources availability at 21% and 22% respectively.



Learners and teachers scored the overall impact at a low 13%. Qualitatively it seemed like the unavailability of resources causes discomfort to the learners. Some learners needed help with bladder management and experienced the humiliation of wetting their pants on the playground. One mother noted that the lack of support varied from teacher to teacher. Each learner is only a number in mainstream schools. Some schools do not have access to computers and one parent supplied their child with a personal laptop in order to keep up with the pace of work. A mother paid for extra classes after school and felt her child needed extra time to complete a paper in mathematics and languages. This is in keeping with findings in literature (Lightfoot *et al.*, 1999).

One teacher noted that having a learner with a physical disability at school was a “new” thing and everybody helped. It was a case of offering help or assisting when it was necessary. In one instance, the attitudes of others worried the class teacher, but the child adapted well.

It seems worrying that there is no formal structure in place to ensure the availability of resources, especially when needed by the learners. Currently any form of structure depends on the attitudes of the various people.

#### **4.4.2.2 Social support**

Social support measures the attitudes and support and encouragement at home and in the community. The standard deviations scored by the learners were  $<1$ , which, according to the normal distribution, indicates that although these learners have a physical challenge, they are supported well socially. The families included in the study came from average to above average socio-economic environments with close family ties. It is suspected that findings might be different in poverty-stricken areas.

According to Table 4.2, the teachers scored the frequency of social support given to these learners at 12%. This resulted in teachers seeing the overall impact of social support as only 9% facilitating inclusion. One mother believed in positive child rearing and that discrimination should not affect anyone. No discrimination was noted as such at schools involved with this study. One boy however felt that learners of other languages tended to torment him more than they did the other learners.

In most cases when learners with disabilities access the communities, someone else accompanies them. Some parents indicated that more support from the community was needed. One boy reported experiencing negative attitudes from his own sister. The questions cover the balance between friends and family outside the school setting. Teachers are not always aware of who is living in the house, and how many friends a child have inside and outside the specific school and at recreation and free-time activities.

#### **4.4.2.3 Equality**

Equality indicates the availability of transport, information given at school, availability of education programmes, medical care, special adapted devices/personal equipment and help needed at home and in the community. Table 4.2 shows equality as the biggest inclusive facilitator. As the different scores of 18% and 17% by learners and parents respectively are very low, this indicates a need for improvement of inclusive facilitators.

In a mainstream school transport is the parents' responsibility. Some of the participants walk or come to school by wheelchair. This is a problem in rainy weather, for wheelchair-bound learners more than for able-bodied learners who walk, because of the condition of the gravel/tar roads, accessibility of curbs, etc.

In many cases, the medical information given to the school personnel is not sufficient to protect the child from potentially hazardous situations. Learners with



brittle bone disease, for instance, have the tendency to acquire fractures of the big bones of the body when exposed to force. Even grabbing them by the hand could cause a fracture with long-term implications. School personnel need adequate medical information to understand procedures and the management of each individual learner in so far as it impacts on his/her time at school, e.g. managing spasticity. Teachers should understand the basic guidelines for positioning and stretch exercises throughout the day and medication. They should realise that, if spasticity is not constantly managed throughout the day it will increase with a resultant decrease in productivity, e.g. writing speed and quality of writing. These are only two examples where school personnel need specific medical knowledge to prevent complications and to ensure an optimal outcome for the learner.

Both parents and learners experienced that the mainstream school functions at a faster rate. This is in accordance with literature findings (Sewell, 2004). One parent felt the academic pressures in grade 7 were already too much for her child. In another case, the learner was referred from a special school setting to that of a mainstream school, where the mother was informed that the child would perform better in a practical school as opposed to the academic set-up in the current mainstream school she attended. One parent felt learners with special educational needs had more needs than what mainstream could provide. One child took longer to learn, and operated better in a smaller group. It was evident from these problems that the learners might not have been selected correctly for mainstreaming and that they are the ones who will need full-service schools. The Department of Education therefore needs to adopt a multi-disciplinary approach to channel these learners correctly to the optimal school according to their needs.

It furthermore became known to the researcher that when a child with a physical disability could not take part in any activity, he/she was rather left out instead of making adjustments or alterations to include him/her in the activity. This

confirmed that little adaptation is made to accommodate physical challenges in the school organisation (see 4.3.3 Mobility). One mother had an intense need for guidance on the decision as to which secondary school she should send her child to. This could also be linked to future support necessary for making the ideal career choice.

Some parents felt they needed support in their children's pathologies and that they also needed growing medical and social support to ensure successful adjustment of their children as adolescents, functioning in secondary schools, and going on to early adulthood and career choices.

One child mentioned that, although she has a physical disability, walks slower, needs a bookcase on wheels and cannot sit on the floor during hall-periods like all the others, she would like to be treated like everybody else. Like one athlete arriving back from Athens in 2004 after winning gold for the 200m in 22 seconds, said, he could not wait for the day to compete against normal athletes, but on the basis of his time and not on the basis of his disability.

#### **4.5 SUMMARY**

It is important to note that the study sample was one of convenience and that it was relatively small and homogenous as regards age and type of disability. One therefore has to be careful in extrapolating results. It is however evident that cognitive independence and mobility are the two areas that most restricted participation of the individual in the community.

Resource availability, social support and equality are the cornerstones of facilitating inclusion at mainstream schools. Every school and district accommodating a learner with a physical disability should set a reachable aim for each of these inclusive facilitators to facilitate positive transformation.



## **CHAPTER 5**

### **RECOMMENDATIONS**

This study is significant against the background of disability as a human rights issue and especially within the changing world whereby finding a workable solution to grant the people with disabilities access to a “normal life” is regarded as a challenge to the community. The shift in focus from the medical to the social model has been initiated by the INDS (South Africa, 1997). South Africa has very formal and structured legislation on inclusive education. However legislation should be implemented at school level in order to ensure that segregation of learners with disabilities is replaced with inclusion and social acceptance.

The Western Cape Education Department has taken on the challenge to provide mainstream education to those who can successfully be accommodated in mainstream schools (South Africa, 2001). The Department sees it as a priority to implement a national advocacy and information programme in support of the inclusion model. This programme will focus on different aspects like the roles, responsibilities and rights of all learning institutions, educators, parents and local communities (South Africa, 2001).

However there are numerous challenges. Special schools need to be re-aligned as resource centres to assist mainstream schools, and the Child Guidance Unit should become part of the Department of Education team (South Africa, 2001:55). Referral systems for special education, mainstream and full-service schools should be highlighted. Mainstream schools need to be empowered to handle challenged learners at the schools’ level and still produce academic results. Opportunities should be created for the learners with disabilities to develop to their maximum potential (South Africa, 2001:7). Classroom teachers will be the primary resource for achieving the goal of an inclusive education and training system in South Africa. At the moment, these teachers feel

overwhelmed and negative. They will need training and ongoing, structured support for inclusion to be successful.

The author believes no system can be changed to suit the needs of learners with disabilities without consulting them and engaging in negotiations on their experiences and needs. This study therefore evolved to summarise the perspectives of the learners with a disabilities, their families and/or caregivers and teachers and enlist a basic list of needs.

Based on these opinions, the following recommendations can be made towards successful inclusion:

➤ *A comprehensive research project*

The priority recommendation is for the Education Department to repeat a similar research project over a larger base with a more representative study population. The results will provide them with significant information (disability prevalence in mainstream schools, in-depth needs analysis of learners with disabilities) that will ensure effective and efficient transformation from segregation to inclusion.

➤ *Teacher support and training*

Teachers need the opportunity and assistance to develop a positive attitude towards the changing education system. Currently teaching staff is passive receivers of new policies, like inclusive education, since all these decisions are taken at departmental level. This has led to an overall negative attitude towards inclusive education. Teachers have to adapt to changing circumstances and have to provide the education without proper support or training. Those teachers in the study population who had remedial training felt it helped them in teaching the learners with a disabilities, but they all felt that they needed formal training and assistance.



The author suggests that mainstream schools, which have learners with disabilities within their organisation, present a staff development programme with the assistance of the Department of Education. This will enhance the teachers' knowledge and provide an opportunity for teachers to ventilate their feelings and to build skills to manage these learners better (Mulvihill *et al.*, 2004).

➤ *Physical assistance*

Personal independence increases as the grade increases, and therefore more physical assistance would be needed for learners of a younger age concerning the use of bathrooms, mobility between classes, provision of space during assembly periods, etc.

Furthermore, literature indicates that older learners experience significantly more barriers than younger ones because the school organisation is less favourable (Hemmingsson & Borell, 2002). It seems that while the learners' level of personal independence increases, the barriers also increase. This phenomenon was noticed in the current study that consisted of a population of primary school learners. According to literature, the problem escalates in secondary schools (Hemmingsson & Borell, 2002). It is suggested that the Department of Education conduct a study on the physical barriers of secondary schools and learning institutions.

➤ *Physical activities*

The score for productive activity at school seems pleasing, but activities were mainly of an academic nature. The study population expressed a need for an adapted physical exercise programme. This will lead to a healthier lifestyle for the learners with physical disabilities and will improve their overall health status. The provision of specific recreational and

cultural activities according to particular physical needs will improve the balance in activities of daily living.

➤ *Physical accessibility*

It would be appropriate for the schooling system to develop a master plan on how physical barriers will be overcome. In the study population, schools expect parents to finance these changes. Luckily most of the parents had the financial means to provide resources where the schools experienced a need. However not all parents will be able to finance these changes and their children still have a right to education (South Africa, 1997). The provision of resources according to the need of the disabled population is very controversial and real in the changing South Africa. It is also necessary to provide resources in a structured way in order to be effective and to ensure that the correct person receives the appropriate resource.

➤ *Transport*

The unavailability and inaccessibility of public transport to the disabled is one of the barriers limiting inclusion. It is the parent's responsibility to get the learner to school. However, it is the responsibility of the Department of Transport to ensure safe, accessible public transport.

➤ *Medical information*

Personnel of mainstream and full-service schools will need basic medical information in order to develop effective management strategies for disabled learners. A system whereby these schools receive medical information from a multi-disciplinary team consisting of health professionals, parents and educational specialists should be established. The team should meet with mainstream educators to provide the medical information necessary for the development of a structured educational plan for each learner with a physical disability. It is essential for



successful inclusion that all the different professionals as well as child and parent form a team.

➤ *Selection process*

According to some parents, their children might not have been selected correctly for mainstream schools. Their child, for instance, still needs assistance and would benefit more from attending a full-service school, than from a mainstream school. This way the child could still benefit from therapeutic and extra attention in class and it would save the parents the costs and sacrifice of extra classes after school. The Department of Education needs to look at a multi-disciplinary approach to ensure that each learner is channelled towards the school where he/she can reach his/her optimal potential.

➤ *Rehabilitation*

The team of health professionals has the responsibility to provide rehabilitation up to level 3 in any hospital or care centre. The number of problems persisting at this stage will cause barriers moving further along the suggested rehabilitation outcomes (Landrum *et al.*, 1995). The team of professionals needs to stay involved or should refer the client to community-based specialists in order to ensure that the measures for level 4 and 5 will be achieved. At these levels, integration will occur most successful.

In summary, this study establishes the need for a comprehensive research project by the Department of Education to gather significant statistics on the prevalence of disability and the needs of the disabled learner in terms of activity limitations and participation restrictions to ensure successful integration. Teacher support and training would assist in keeping the workforce motivated and informed. Physical assistance needs to be provided in a structured,

appropriate way. Physical activities are seen as an integral part of the individual educational plan for the learner with a disability and the opportunity for this should be provided. Physical accessibility, transport and medical information need to be addressed at school level. The education authorities should develop and implement a selection process and referral system to channel every learner according to his/her needs, to the correct type of school.

Inclusive education, not mainstreaming, should be implemented if we want to ensure education for every learner with a disability. The Department of Education has taken some steps towards the transformation of its service delivery. A master plan should however be developed to achieve a successful end-result, within budget and a set time frame. The education authorities in South Africa need all the support they can get to ensure successful transformation. When considering a move from traditional/regular special educational programming to a more inclusive approach, it is important that the entire school community be involved in a thoughtful, carefully researched transition. Dramatic top-down directives will polarize parents and teachers and will create environments that are hostile to any change.

As is true in other areas of school restructuring, change must be based on research and broadly shared beliefs and philosophies.

*Education, then, beyond all other devices of human origin, is the great equalizer of the conditions of men - the balance-wheel of the social machinery." – Horace Mann.*



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## APPENDIX A

TABLE 1: REVISED CHART QUESTIONS

<b>CHART (Revised)</b>	
<p><b>PERSONAL INDEPENDENCE:</b> What physical assistance do you need?</p> <p><b>Question 1:</b> How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?</p>	Who assists you with personal care activities such as bathing, dressing, toileting and mobility? How many hours per day do you spend on this?
<p><b>Question 2:</b> Not including any regular care as reported above, how many hours in a <u>typical month</u> do you occasionally have assistance with such things as shopping, laundry, room-keeping and medical needs because of the disability?</p>	Who assists you with other activities like shopping, laundry, room-keeping and medical needs? How many hours in a month do you have assistance?
<p><b>Question 3:</b> Who takes responsibility for instructing and directing your attendants and/or caregivers?</p>	Do you direct your family member/attendant?
<p><b>COGNITIVE INDEPENDENCE:</b> How much supervision do you need?</p> <p><b>Question 4:</b> How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgement?</p>	AT HOME: How much time do you spent totally on your own? Option 1-6 kept as it is
<p><b>Question 5:</b> How much of the time are parents/assistants with you to help you with remembering, decision-making, or judgement when you go away from home?</p>	WHEN YOU GO AWAY FROM HOME: Do you have a parent/assistant with you to help with supervising? Option 1-4 kept as it is
<p><b>Question 6:</b> How often do you have difficulty communicating with other people?</p>	Kept as it is
<p><b>Question 7:</b> How often do you have difficulty remembering important things that you</p>	For example: Doing homework, taking requested items to school, to do chores



must do?	at home.
<b>Question 8:</b> How much of your spending money do you control?	Do you receive spending money? How much of this spending money do you control? Option 1-4 kept as it is
<b>MOBILITY:</b> Are you up and about regularly? <b>Question 9:</b> On a <u>typical day</u> , how many hours are you out of bed?	On a <u>typical day</u> , what time do you wake up and go to bed again? Do you take an afternoon nap every day?
<b>Question 10:</b> In a <u>typical week</u> , how many days do you get out of your house and go somewhere?	Kept as it is
<b>Question 11:</b> In the <u>last year</u> , how many nights have you spent away from your home (excluding hospitalisations?)	<u>In the last month</u> , how many nights have you spent away from home (excluding hospitalisations?)
<b>Question 12:</b> Can you enter and exit your home without any assistance from someone?	Kept as it is
<b>Question 13:</b> In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone and TV (or radio)?	Kept as it is
<b>Question 14:</b> Can you use your transport independently?	What means of transport do you use to get around? Can you use the transport independently?
<b>Question 15:</b> Does your transport allow you to get to all the places you would like to go?	Kept as it is
<b>Question 16:</b> Does your transportation let you get out whenever you want?	Kept as it is
<b>Question 17:</b> Can you use your transportation with little or no advance notice?	Kept as it is
<b>SCHOOL:</b> How do you spend your time? <b>Question 18:</b> How many <u>hours per week</u> do you spend at school?	What time does your school start and finish 5 days a week?
<b>Question 19:</b> How many <u>hours per week</u> do you spend in school working in class and	How many periods do you attend <u>per day</u> and how long are they each? How



studying?	many of them are academic periods per day?
<b>Question 20:</b> How many <u>hours per week</u> do you spend in home doing chores, feeding the dog, gardening, washing dishes, doing laundry?	How many <u>hours per day</u> do you spend in home chores like feeding the dog, washing dishes, etc?
<b>Question 21:</b> How many hours per week do you spend in ongoing volunteer work for an organisation?	Kept as it is
<b>Question 22:</b> How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? DO NOT include time spent watching TV or listening to the radio.	Kept as it is
<b>Question 23:</b> How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? DO NOT include time spent watching TV or listening to the radio.	Kept as it is
<b>SOCIAL INTEGRATION:</b> With whom do you spend time? <b>Question 24:</b> Do you live alone? 24a (If you don't live alone) do you live with a spouse or significant other? 24b How many children do you live with? 24c How many other relatives do you live with? 24d How many roommates do you live with? 24e How many attendants do you live with?	Do you live with family/alone?  24a With whom do you live? 24b How many brothers/sisters live in your house? 24c How many other relatives do you live with? 24d How many attendants do you live with?
<b>Question 25:</b> Do you have a boy- or girlfriend?	Do you have a boy-/girlfriend?
<b>Question 26:</b> How many relatives (NOT in your household) do you visit, phone, or write to at least once a month?	Kept as it is
<b>Question 27:</b> How many school friends do you visit,	Kept as it is

phone, or write to at least once a month?	
<b>Question 28:</b> How many friends (non-relatives) contacted OUTSIDE school do you visit, phone, or write to at least once a month?	Kept as it is
<b>Question 29:</b> With how many strangers have you initiated a conversation in the last month (to ask for information or place an order?)	Kept as it is



## APPENDIX B

### CHART



**CHART (Revised)**  
**Revised Craig Handicap Assessment and Reporting Technique Scoring Form**

**PHYSICAL INDEPENDANCE**

1. Who assists you with personal care activities such as bathing, dressing, toileting and mobility? How many hours per day do you spend on this?

\_\_\_\_\_ hours paid assistance    \_\_\_\_\_ hours unpaid (family, others)

2. Who assists you with other activities like shopping, laundry, room-keeping and medical needs because of the disability? How many hours in a month do you have assistance?

\_\_\_\_\_ hours per month

3. Do you instruct and direct your attendants and/or caregivers?

- \_\_\_\_\_ Self
- \_\_\_\_\_ Someone else
- \_\_\_\_\_ Not applicable, does not use attendant care

A. Total hours of paid and unpaid care	
B. Divide the hours of occasional care by 30	
C. Add the sums of "A" and "B"	
D. If the respondent instructs and directs his own, multiply by 3. If someone other than respondents instructs, X 4	
E. Subtract the total "D" from 100.	
<b>TOTAL</b>	



**COGNITIVE INDEPENDENCE**

4. AT HOME: How much time do you spend totally on your own:

- 1\_\_\_ Someone else is always with me to observe or supervise
- 2\_\_\_ Someone else is always around, but they only check on me now and then.
- 3\_\_\_ Sometimes I am left alone for an hour or two
- 4\_\_\_ Sometimes I am left alone for most of the day
- 5\_\_\_ I have been left alone all day and all night, but someone checks in on me
- 6\_\_\_ I am left alone without anyone checking on me

5. WHEN YOU GO AWAY FROM HOME: Do you have a parent/assistant with you to help you with supervising?

- 1\_\_\_ I am restricted from leaving, even with someone else.
- 2\_\_\_ Someone is always with me to help with remembering, decision making or judgement when I go anywhere
- 3\_\_\_ I go to places on my own as long as they are familiar
- 4\_\_\_ I do not need help to go anywhere

6. How often do you have difficulty communicating with other people?

- 1\_\_\_ I almost always have difficulty
- 2\_\_\_ I sometimes have difficulty
- 3\_\_\_ I almost never have difficulty

7. How often do you have difficulty remembering important things that you must do for example doing homework, taking requested items to school, to do chores at home:

- 1\_\_\_ I almost always have difficulty
- 2\_\_\_ I sometimes have difficulty
- 3\_\_\_ I almost never have difficulty

A Assign points: #2=1 points; #3=2; #4=3; #5=4; #6=5	
B Multiply points in "A" by 8	
C Assign points #1=0; #2=1; #3=2; #4=3.	
D Multiply points in "C" by 8	
E Assign points: #1=0; #2=1; #3=2; #4=3.	
F Multiply points in "E" by 6	
G Assign points: #1=0; #2=1; #3=2.	
H Multiply points in "G" by 6.	

8. Do you receive spending money? How much of this spending money do you control?

- 1\_\_\_ None, someone makes all money decisions for me
- 2\_\_\_ Small amount of spending money is given to me periodically
- 3\_\_\_ Most of my money, but someone does help me make major decisions
- 4\_\_\_ I make all my own money decisions

I Assign points: #2=1; #3=2; #4=3.	
J Multiply points in "I" by 4	
K Add the sums of "B", "D", "F", "H", and "J".	
<b>TOTAL</b>	



**MOBILITY**

9. On a typical day, what time do you wake up and go to bed again? Do you take an afternoon nap every day?

\_\_\_\_\_ hours per day spent in bed

10. In a typical week, how many hours do you get out of your house and go somewhere? \_\_\_\_\_ days

11. In the last month, how many nights have you spent away from your home (excluding hospitalizations?)

\_\_\_\_\_ none \_\_\_\_\_ 1-2 \_\_\_\_\_ 3-4 \_\_\_\_\_ 5 or more

12. Can you enter and exit your home without any assistance from someone?

Yes \_\_\_\_\_ No \_\_\_\_\_

13. In your home, do you have independent access to your sleeping area, kitchen, Bathroom, telephone, and TV (or radio)? Yes \_\_\_\_\_ No \_\_\_\_\_

14. What means of transport do you use to get around? Can you use your transport independently? Yes \_\_\_\_\_ No \_\_\_\_\_

15. Does your transport allow you to get to all the places you would like to go?

Yes \_\_\_\_\_ No \_\_\_\_\_

16. Does your transport let you get out whenever you want?

Yes \_\_\_\_\_ No \_\_\_\_\_

A Multiply no of hours in bed by 2	
B Multiply no of days per week out of house by 5	
C No nights out=0; 1-2 n/o=10; 3-4 n/o=15; 5 or more=20	
D Questions 12-17: assign 5 points 'yes' 0 points for 'no'	
#13	
#14	
#15	
#16	
#17	
<b>TOTAL</b>	

17. Can you use your transportation with little or no advance notice?  
 Yes\_\_\_\_\_ No\_\_\_\_\_

**SCHOOL**

18.. What time does your school start and finish every day of the week?\_\_\_\_\_ hours at school.

19. How many periods do you attend per day and how long are they each? How many of them are academic periods per day?\_\_\_\_\_ hours studying

20 How many hours per day do you spend doing home chores: feeding the dog, gardening, washing dishes, doing laundry? \_\_\_\_\_ hours

21. How many hours per week do you spend in ongoing volunteer work for an organization?\_\_\_\_\_ hours

22. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio. \_\_\_\_\_ hours

23. How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? Please do not include time spent watching TV or listening to the radio. \_\_\_\_\_ hours

A Multiply the no of hours at school by 2	
B Multiply no of hours in school by 2	
C Multiply no of hours in active homemaking by 2	
D Multiply no of hours in home maintenance by 2	
E Add no of hours in volunteer work to the no of hours in recreational activities and no of hours in other self-improvement activities	
F Add the sums of A, B, C, D and E. If total sum is greater than 100, enter 100.	
<b>TOTAL</b>	



**SOCIAL INTEGRATION**

24. Do you live with family/alone? \_\_\_\_\_ Yes \_\_\_\_\_ No  
 24.a With whom do you live? \_\_\_\_\_  
 24.b How many brothers/sisters live in your house? \_\_\_\_\_  
 24.c How many other relatives do you live with? \_\_\_\_\_  
 24.d How many attendants do you live with? \_\_\_\_\_
26. Do you have a boy-/girlfriend? \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_N/A
27. How many relatives (not in your household) do you visit, phone, or write to at last once a month? \_\_\_\_\_ Relatives
28. How many school friends do you visit, phone, or write to at least once a month? \_\_\_\_\_ Friends
29. How many friends (non-relatives) contacted out of school do you visit, phone or write to at least once a month? \_\_\_\_\_ Friends
30. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order?)  
 \_\_\_\_\_ none \_\_\_\_\_ 1-2 \_\_\_\_\_ 3-6 \_\_\_\_\_ 6 or more

A Assign 30 points if living with family or assign 20 points if living with unrelated roommate and/or attendant	
B If points allocated in A, then B equals 30 - A	
C Add no of children in household and no of other relatives in household to no of relatives contacted monthly: multiply by 5. Max score of 25	
D No of school friends contacted: multiply by 2. Max score of 20	
E Add extra roommate to no of friends contacted monthly. Multiply by 10. Max score is 50.	
F Assign points as follows: none=0; 1-2=10; 3-5=15; 6>=20	
G Add sums of A,B, C, D, E, F. If greater than 100, enter 100.	
<b>TOTAL</b>	

**APPENDIX C**

**CHIEF**



# Craig Hospital Inventory of Environmental Factors

© (for information contact [charrison-felix@craighospital.org](mailto:charrison-felix@craighospital.org) or [dmellick@craighospital.org](mailto:dmellick@craighospital.org))

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors help or improve a person's participation in these activities while other factors can act as barriers and limit participation. First of all, do you think **you** have had the same opportunities as other people to participate in and take advantage of:

education	_____yes	_____no
employment	_____yes	_____no
recreation/leisure	_____yes	_____no

Next, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never**. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

Note: if a question asks specifically about **school or work** and you neither work nor attend school, check not applicable)

	Daily	Weekly	Monthly	Less than monthly	Never	Not applicable	Big problem	Little problem
1. In the past 12 months, how often has the availability of transportation been a problem for you? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
2. In the past 12 months, how often has the design and layout of your home made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
3. In the past 12 months, how often has the design and layout of buildings and places you use at school or work made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. In the past 12 months, how often has the design and layout of buildings and places you use in your community made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
5. In the past 12 months, how often has the natural environment - temperature, terrain, climate - made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
6. In the past 12 months, how often have other aspects of your surroundings - lighting, noise, crowds, etc - made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>



7. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
8. In the past 12 months, how often has the availability of the education and training you needed been a problem for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
9. In the past 12 months, how often has the availability of health care services and medical care been a problem for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
10. In the past 12 months, how often has the lack of personal equipment or special adapted devices been a problem for you. Examples might include hearing aids, eyeglasses or wheelchairs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
11. In the past 12 months, how often has the lack of computer technology been a problem for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
12. In the past 12 months, how often did you need someone else's help in your home and could not get it easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
13. In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
14. In the past 12 months, how often did you need someone else's help in your community and could not get it easily?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
15. In the past 12 months, how often have other people's attitudes toward you been a problem at home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
16. In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
17. In the past 12 months, how often have other people's attitudes toward you been a problem in the community?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>



18. In the past 12 months, how often has a lack of support and encouragement from others in your home been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
19. In the past 12 months, how often has a lack of support and encouragement from others at school or work been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
20. In the past 12 months, how often has a lack of support and encouragement from others in your community been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
21. In the past 12 months, how often did you experience prejudice or discrimination?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
22. In the past 12 months, how often has the lack of programs and services in the community been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
23. In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
24. In the past 12 months, how often did education and employment programs and policies make it difficult to do what you want or need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>
25. In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
When this problem occurs has it been a big problem or a little problem?						<input type="radio"/>	<input type="radio"/>

**APPENDIX D**

**Data Capture Sheet**

<b>NAME:</b>	<b>DOB:</b>	<b>SCHOOL:</b>	<b>GRADE:</b>
<b>DIAGNOSIS:</b>	<b>ASSISTIVE DEVICE:</b>	<b>REHAB UNIT:</b>	<b>REHAB OUTCOME LEVEL:</b>
<b>CHART:</b>			
<b>Physical Independence</b>	<b>/100</b>		
<b>Cognitive Independence</b>	<b>/100</b>		
<b>Mobility</b>	<b>/100</b>		
<b>School</b>	<b>/100</b>		
<b>Social Integration</b>	<b>/100</b>		
<b>Economic Self Sufficiency</b>	<b>/100</b>		
<b>CHIEF: CHILD</b>	<b>Frequency Score (0-4)</b>	<b>Magnitude Score (0-2)</b>	<b>Overall Impact (0-8)</b>
<b>A Accessibility</b>			
<b>B Accommodation</b>			
<b>C Resource Availability</b>			
<b>D Social Support</b>			
<b>E Equality</b>			
<b>CHIEF: PARENTS</b>	<b>Frequency Score (0-4)</b>	<b>Magnitude Score (0-2)</b>	<b>Overall Impact (0-8)</b>
<b>A</b>			
<b>B</b>			
<b>C</b>			
<b>D</b>			
<b>E</b>			
<b>CHIEF: STAFF</b>	<b>Frequency Score (0-4)</b>	<b>Magnitude Score (0-2)</b>	<b>Overall Impact (0-8)</b>
<b>A</b>			
<b>B</b>			
<b>C</b>			
<b>D</b>			
<b>E</b>			