

**VOICE, DISABILITY AND INCLUSION:  
A CASE STUDY OF BIOLOGY LEARNERS WITH  
CEREBRAL PALSY**



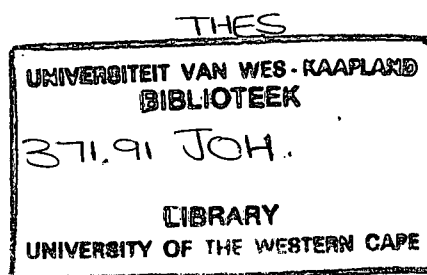
A thesis submitted in fulfilment of the requirements for the degree of  
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May 2006



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*For my father*

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## **ABSTRACT:**

Concern has been raised that South Africa does not have a sufficient supply of scientists and engineers in the 21<sup>st</sup> century. Yet, the potential that resides in learners with cerebral palsy is often not recognised or realised by policy makers. It is argued that society cannot afford to deprive itself of the potential for scientific progress that resides, and all too often remains untapped, in the minds of people with disabilities (Burgstahler, 1994, 1995; Burgstahler and Nourse, 2000).

The study contends that the under-representation of black learners with cerebral palsy (from disadvantaged backgrounds) in career fields and higher education programmes related to biology is not unrelated to: (i) our socio-political history; (ii) the 'outcome' of a particular method and content of teaching; (iii) lack of role models, i.e. successful professionals with physical disabilities; and (iv) the low expectations of learners, teachers, parents and the society as a whole. The purpose of the study was first of all to listen to the voices of learners with cerebral palsy in an attempt to find out if (and why) they have low expectations regarding career prospects in the biology fields. Secondly, it was to uncover the various barriers that might have contributed to such low expectations and under-representation of learners with cerebral palsy in biology related careers.

The central concern of the study was whether or not black learners with cerebral palsy from disadvantaged backgrounds had low expectations of (career) possibilities in biology, and if so, why? A qualitative research design (in terms of five critical stages espoused by Carspecken, 1996) was used as framework for the study. In addition, in-depth interviews were conducted in an attempt to foreground the voices of the learners. An analysis of the results and findings indicated black learners (with cerebral palsy) with above-average performance in biology, mathematics and physical science, expressed an early interest and love for science and



biology and a desire to pursue higher education studies related to those fields. However, the study found that learners with cerebral palsy who entered higher education biology and science related programmes did not complete their studies. Furthermore, that the under-representation of black learners with cerebral palsy, especially from previously disadvantaged backgrounds, could be linked to low expectations from teachers, academics in higher education institutions, parents, medical staff and guidance counsellors.

The study contends further that if transformation is about removing **all** forms of discrimination, then the context where the potential of learners are developed - namely the schools, homes, workplace, and higher education institutions - needs to be re-examined. Moreover, the study attempted to raise awareness of the importance of an inclusive biology curriculum that: (i) includes flexible teaching approaches, accommodation strategies and assistive technologies that adequately accommodate learners with cerebral palsy in the biology classroom; (ii) explores partnerships between various stakeholders to heighten awareness of mentoring, internship programmes and role models in biology and related careers; and (iii) effectively prepares and facilitates transition of black learners with cerebral palsy to biology related career fields in higher education and the workplace.

## KEYWORDS

Voice

Disability

Inclusion

Low expectations

Special Education

Cerebral Palsy

Collective case study

Qualitative research

Education White Paper 6

Barriers to Learning and Development



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## DECLARATION

I declare that *Voice, Disability and Inclusion: A case study of biology learners with cerebral palsy* is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources that I have used or quoted have been indicated and acknowledged as complete references.

Eleanor M. Johannes

May 2006

Signed: .....



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## CHAPTER ONE

### BEYOND ALL EXPECTATIONS

This is what the two young men at Umlazi taught us in the township – this ability to come out and show the world what they could do, to show talent that can only flourish if it is realised and freed from the entrapping walls of attitudes...Through such examples the world will graduate from marvelling at how good people with a disability can be, to accepting them as enriching colours in the majestic social rainbow. This will allow them to be themselves. That is the real freedom of living – to be ourselves.

(Zulu, 2004: 19)

#### 1.1 Introduction

Educators and politicians have voiced concern that South Africa does not have a sufficient supply of scientists and engineers to cope with the demand of the 21<sup>st</sup> century. Yet, the potential that resides in learners with cerebral palsy is often not recognised or realised, and not addressed by policy makers. Lawrence Scadden, Senior Programme Officer for the USA National Science Foundation's Program for Persons with Disabilities (totally blind himself) argues that society cannot afford to deprive itself of the potential for scientific progress that resides, and all too often remains untapped, in the minds of people with disabilities. Burgstahler and Nourse (2000) cite Scadden asserting that:

For too long we've been closing disabled people out of science and math, in the classrooms, the laboratory, and the workplace. There is a vast amount of intelligent people who simply don't know how to accommodate the disabled. They don't have any idea how disabled men and women do science. In some instances, students don't want persons with disabilities in their classrooms or labs. They're afraid they'll be slowed down by them. They don't want competition for their time at the lab bench. These attitudes – the myths and the ignorance – have created a major barrier that must be removed.

(p.10)



Scadden (1998) substantiates his assertion by referring to the following persons with disabilities who have greatly impacted on scientific progress: Galileo, who went blind; Einstein, who was thought to have been dyslexic; as well as the renowned physicist, Stephen Hawking, who has the progressive neurological disease Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease.

Furthermore, research has shown that negative social attitudes may be the greatest barrier to the equality of disabled persons and their participation in community life and development. Burgstahler (1994, 1995) supports Scadden's sentiments and adds that negative attitudes are the most obvious challenge faced by individuals with disabilities in education and in careers in science and engineering. Alston and Hampton (2000) concur and add that people with disabilities have fewer opportunities to pursue careers in science and technological fields, and therefore, are underrepresented as employees in these fields. In addition, the National Science Foundation (NSF, 1996) reported that poor advisement, lack of role models, academic tracking, prejudice and stereotyping, have limited opportunities for ethnic minorities with disabilities.

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A cursory review of the literature has revealed successful American and European educational models that address the under-representation of persons with disabilities in science and engineering professions, such as: Project D0-IT (Disability, Opportunities, Internetworking and Technology), EASI (Equal Access to Software and Information), Sisters-in-Science, Daughters-with-Disabilities, SNOW (Special Needs Opportunity Window), AAAS (American Association for the Advancement of Science)-ENTRY POINT!, etc. Moreover, the extant literature confirms that learners with disabilities have high expectations of possible careers in the field of science, engineering, mathematics and technology, and that low expectations from teachers, career guidance teachers, parents and higher education institutions often prevented learners from pursuing their goals. The goals and dreams of



learners with disabilities have been shaped by the realities of teachers, therapists, parents and the society as a whole. Before 1994 (i.e. the year South Africa conducted the first democratic elections) the medical model shaped teacher's beliefs and practices of possibilities for learners with cerebral palsy, and learners viewed their lives through the teacher's lens. After 1994 learners seemed to be more aware of their rights. But even now many people still believe that high achievements in science, mathematics and technology are for the select few.

In 2004 South Africa celebrated Ten Years of Democracy. People with disabilities celebrated many policy changes e.g. the new Constitution (Republic of South Africa, 1996) protecting the rights of all; the White paper on an Integrated National Disability Strategy (Ministry in the Office of the Deputy President, 1997) and subsequent establishment of OSDP (Office on the Status of Disabled Persons), an umbrella organisation in The Presidency responsible for the coordination, monitoring and implementation of the Integrated National Disability Strategy; the National Skills Development Strategy 2005-2010; the Employment Equity Act (South African Department of Labour Online, 1998) and subsequent Code of Good Practice: Key Aspects on Employment of People with Disabilities (South African Department of Labour Online, 2003) and Technical Assistance Guidelines on Employment of People with Disabilities (South African Department of Labour Online, 2003); the Education White Paper 6: Special Needs Education - Building an inclusive education and training system (Department of Education, 2001) that promotes inclusive educational practices. Despite these significant efforts the status quo of the majority of learners with disabilities has not changed in any significant way. The disadvantaged black learner with cerebral palsy is still under-represented in careers relating to biology. The potential that resides in learners with cerebral palsy is still not recognised by curriculum planners in the Department of Education, in higher education and the business sectors.



## 1.2 Context of Study

In a climate of transformation and redress, and increasing dismay with the poor quality of matriculation results in science and mathematics, it is important to reappraise the curriculum delivery at every level of schooling, especially as it pertains to the disadvantaged and disabled. A cursory review of the literature shows that overall, before 1994, the South African school curriculum was generally silent about learners with disabilities in science, biology and mathematics classrooms. Whereas the debate around the new Outcomes Based (OBE) curriculum known as Curriculum 2005 (to indicate the year of its full implementation) and other policy changes were intensified, the discussion around the inclusion of learners with disabilities in the biology classrooms did not receive the same attention in the school system. The norm has been to approach curriculum development from the point of view of the middle-class, advantaged, able-bodied learners. Therefore, curriculum reform at the time did not afford input from learners with disabilities much attention. Likewise, the availability of adequate and easily accessible resources was not foremost on the agenda. Moreover, even now after two democratic elections, the process of transformation, especially as it relates to learners with cerebral palsy and biology education, does not receive sufficient attention.

In 1994, the first democratically elected government was given the mandate to develop a 'truly national system of education and training' (Bengu, 1994). Sibusiso Bengu, then Minister of Education, challenged South African educators to start the process of transforming and rebuilding the education system and expanding learning opportunities for all (Bengu, 1994). The education system existing at that time was that bequeathed to the new South Africa by the erstwhile apartheid system of government. It was a system rife with all sorts of inequity. While the schools for the minority white children were well resourced, those for the majority black (so-called Coloured, African and Indian) children were poorly resourced. The latter



consisted of a range of schools with sparse resources, with makeshift and bare classrooms, and broken down facilities or none at all. There were 18 different Departments of Education each exercising some autonomy and managing its own human and material resources. In addition, in each of the departments, there existed a dual system of education: a mainstream and special education component. Again, while the departments for the whites had well qualified personnel (including well-trained teachers), the other departments suffered all kinds of abnormalities. Historically, the areas of special needs education have reflected the general inequalities of South African society, with disadvantaged learners (the majority of the learners) receiving inadequate or no provision (Human Sciences Research Council, 1987).

Furthermore, as stated in the Education White Paper 6: Special Needs Education - Building an Inclusive Education and Training System (Department of Education, 2001):

The results of decades of segregation and systematic under-resourcing are apparent in the imbalance between special schools that catered exclusively for white disabled learners and those that catered for black disabled learners. It is therefore, imperative that the continuing inequities in the special school sector are eradicated and that the process through which the learner, educator and professional support services populations become representatives of the South African population, is accelerated. (p. 9)

Given the above constraints, the challenge to build the 'new' within the confines of the 'old' was, and still is, very daunting. Since that historic date in 1994 there has been two elections; two new Ministers of Education; the introduction and subsequent review of the Outcomes Based Curriculum 2005 (C2005); the introduction of the Revised National Curriculum Statement (RNCS); the Report of the National Commission on Special Needs in Education and Training (NCSNET) and National Committee on



Education Support Services (NCESS): Quality Education for all: overcoming barriers to learning and development (Department of Education, 1997); discussions about Inclusive Education, particularly as it relates to special needs teachers and their learners (Engelbrecht, 1999; Naicker, 1999; Engelbrecht, Swart, Eloff & Forlin, 2000) and the subsequent launch of Education White Paper 6: Special Needs Education - Building an Inclusive Education and Training System (Department of Education, 2001).

The dramatic changes in South African society in the past few years have affected both general and special education (Engelbrecht, 1999). The most significant conceptual change from the former to the current policy has been the mainstreaming of schooling based on an inclusive framework. It is expected that as schools become more 'inclusive', the general (mainstream) classrooms will become more diverse. Therefore, mainstream teachers will be given increased responsibility with the inclusion of learners with disabilities in their classrooms. Generally, secondary school teachers in South Africa had very little training and experience with learners with disabilities. In addition, many teachers still battle with the question whether learners with (physical) disabilities should be included in the biology classrooms (Scadden, 1998; Burgstahler, 1994, 1995; Burgstahler & Nourse, 2000).

The Education White Paper 6 (Department of Education, 2001) lists the following requirements for an inclusive education system:

- Acknowledges that all children and youth can learn and that all children and youth need support.
- Creates enabling education structures, systems and learning methodologies to meet the needs of all learners.
- Acknowledges and respects differences in learners, whether due to age, gender, ethnicity, language, class, disability, HIV status, etc.



- Is broader than formal schooling and acknowledges that learning also occurs in the home, community, and within formal and informal manners.
- Is concerned with changing attitudes, behaviours, methodologies, curricula and environments to meet the needs of all learners.
- Aims at maximising the participation of all learners in the culture and the curriculum of educational institutions and uncovering and minimising barriers to learning.

The recommendations above are significant in that they recognise the fact that inclusive education is broader than merely including learners with disabilities in the mainstream classroom. But despite the noble goals above not much has changed. For instance, all provinces still have a dual system of education. Although teachers and managers are more aware of issues relating to disability, the inclusion debate has not shifted significantly. Black learners with cerebral palsy, from disadvantaged communities, face many barriers: political, economic, social, technological, legal and environmental. First of all, politically and legally, blacks and the disabled have always received the least funding. The apartheid laws added to their 'blighted environment' (Yeld, 1993) by the allocation of facilities along racial lines. The laws of the land have marginalised them to the point of invisibility.

Secondly, on the economic front, the world outside is not positively disposed to accommodate the disabled in the various facets of life. Gleeson (1999:132) claims "many employers are unwilling to engage physically impaired people" and that industrial markets (capitalism) exclude 'slow' or 'incapable' workers. The author refers to the "disabling division of labour". The disabled are not offered jobs despite having struggled through many difficulties. Added to that, persons with disabilities cannot get access to buildings, including those where they need to go to obtain government services. Although the Employment Equity Act (South African Department



of Labour Online, 1998) created many jobs in the short term, the perception that learners with disabilities can only get jobs if employers are forced to provide them, and then be given the lowest level of jobs, remains. Morris (2005) reported that people with disabilities represented only 0,25 percent of all people employed in the public service. Furthermore, that the Fourth Annual Report of the Commission for Employment Equity found that only 247 (1,6 percent) of the 15515 people occupying positions at top management level were people with disabilities. Most important, of the 247 reported cases, 20,7 percent were African, 9,3 percent coloured, 7,3 percent Indian and 62,6 percent white.

Further, the transport systems that do exist are inaccessible to learners with disabilities, particularly those who use wheelchairs. So, for example, learners with disabilities who should be attending school are unable to even reach the school or classroom because the public transport system that is available is either physically inaccessible or unwilling to transport them. At the same time they are unable to walk to school or classes and thus totally excluded from the education system (Department of Education, 2001).

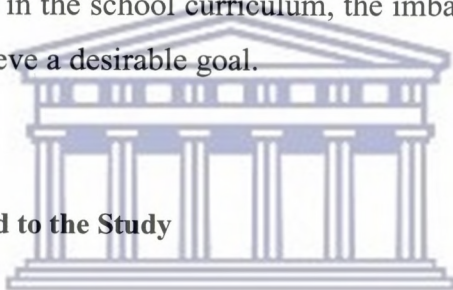
In addition, learners with disabilities are still required to purchase their own appliances to reduce constraints, e.g. learners with cerebral palsy often need wheelchairs, callipers or crutches. Clearly, most learners with disabilities from low socio-economic areas can never afford these costly materials and most often do without them. They are forced to suffer indignities such as being carried in wheelbarrows by relatives. This drastically reduces their independence and ability to support themselves. Besides, technologically, not many learners with disabilities have access to adaptive and assistive technology (Burgstahler, 1994, 1995).

Finally, there are educational and environmental barriers to overcome. Black learners with disabilities are mostly confined to sub-economic homes where there is hardly any green environment. Khan (1990) asserts that the



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apartheid laws successfully excluded blacks from the most beautiful areas and contributed to environmental issues having a very low priority in these communities. Furthermore, learners with physical disabilities from historically disadvantaged backgrounds often had limited exposure to their physical surroundings. Khan (1990) describes them as 'environmentally illiterate' and unable to 'read' their environment and critically appraise the 'quality of life' that different communities have to offer. Moreover, although Ayerst (1989) asserts that biology, in particular, assists learners to make informed decisions about the problems that they will face in their lives, learners with cerebral palsy seem to enter the biology classrooms disadvantaged and dis-empowered, and that is the way they leave the classroom. Hence, while it might be valid to assert that biology has an important place in the school curriculum, the imbalances of the past make it difficult to achieve a desirable goal.



### 1.3 Background to the Study

Learners with physical disabilities are one of the most diverse groups of learners that experience barriers to learning. Some physical disabilities are very obvious; others are subtle. Some learners with physical disabilities will require physical modifications in the classroom environment and a more flexible curriculum to benefit from schooling. But, all learners with physical disabilities need special understanding from their teachers, therapists, parents and peers. This study was an attempt to provide an account of the researcher's journey in the field of disability and biology inclusion, and to highlight how the research questions and assumptions were shaped, formed and changed in the process. The journey began when the researcher started as biology and mathematics teacher at a special school for learners with cerebral palsy. As a newly graduate the researcher was presented with a class with differing disabilities and was often swayed by the opinions and advice of the "experts" and those who had more



experience. These included the social workers, psychologists, therapists, remedial teachers and doctors. Class discussions and case discussions, tools designed to have the whole team give input on a particular case, were often dominated by these experts, all schooled by the medical model of disability. The learner's future career choices were discussed and weighed in terms of the learner's physical ability. Limited hand movement, for example, often meant that a career in science was ruled impossible.

It gradually became clear to the researcher that the classroom practice at the time did not prepare learners with disabilities to maximise their potential. Upon reflection, the researcher recalled her initial response when a learner expressed a desire to pursue a career in biology after grade 12. The learner has cerebral palsy and walks with some difficulty. The researcher's unspoken concerns at the time centred on the learner's unsteadiness when handling lab equipment. There was clearly a tension: as teacher, the researcher tried to instil a love for biology, yet could not visualise the learner pursuing future studies in the field. The response from another learner was more thought provoking. The learner admitted that even though she loved biology, she never really believed that there was a future for her in the field. When asked why not, she said that physical science or biology seemed to be 'more difficult' for someone with cerebral palsy. Also, that she (the learner) considered any accommodations to be made, 'a bother' for teachers. Therefore the learner opted not to explore any future career possibilities in the field of physical science or biology. These accounts were important signposts on the researcher's journey.

An earlier study Johannes (1995) explored the possibility of using journal writing, talking and narratives as a means to assist learners with cerebral palsy to find their voice, identity and place in their surrounding communities. Learners were asked to relate the stories of 'their world' and compare their own stories with the textbook story. Writing and talking were used as tools designed to create an atmosphere where learners could hear

their own voices and stories, and the stories of other learners. The study highlighted the following: (i) the physical world of the disadvantaged, black learner with physical disabilities (e.g. cerebral palsy) is far removed from the textbook world; and (ii) learners are reluctant to become involved in their communities because they feel marginalised and separated from life and living in their immediate and wider community. In addition, the biology curriculum and classroom experience did not prepare learners with cerebral palsy for the 'the real world' and allow learners to maximize their full potential.

Furthermore, the study found that the biology syllabus at that time (1) did not address the needs of the disabled, disadvantaged learner; (2) offered them limited challenges; (3) was not situated in the real life context of the learner; and (4) was divorced from the political, economic and social life of the learners with cerebral palsy. Moreover, the study highlighted that, after successfully completing more than the average twelve years of formal schooling, learners with cerebral palsy discovered that their academic achievements did not offer many opportunities to further their studies in the field of science, especially biology, or afforded limited access to the world of work. Not much has changed since then.

#### **1.4 Rationale**

The study concurs that there is a conceptual connection between the content and method of learning, and the 'outcomes' of learning (what is learnt), and that the under-representation of black, disadvantaged learners with cerebral palsy in careers related to biology is not unrelated to:

- (i) our socio-political history;
- (ii) the 'outcome' of a particular method and content of teaching;
- (iii) lack of role models, i.e. successful professionals with physical disabilities; and



- (iv) the low expectations of learners, their teachers, parents and the society as a whole.

Thus, in order to change the 'outcome', we have to interrogate the history of our classroom practices (Morrow, 1999) and have to examine how we teach, what we teach and why we teach the way we do (Duckworth, 1987).

### **1.5 Statement of the Problem**

The ten years of democracy in South Africa should have been a celebration of possibility for learners with cerebral palsy: a Constitution that protects the rights of all, a National Disability Strategy, the Equity Bill, and the introduction of Education White Paper 6: Special Needs Education - Building an Inclusive Education and Training System, yet persons with disabilities, and in particular black women with disabilities, are still under-represented in careers related to biology. Lack of resources and low expectations remain the major barriers to developing potential. This study assumes therefore, that there is a conceptual connection between the content and method of learning, and the 'outcomes' of learning (what is learnt), and that the origin or root of negative attitudes and low expectations could be traced to this crucial interface.

### **1.6 Purpose of the Study**

The purpose of the study was to (1) listen to the voices of learners with cerebral palsy in an attempt to find out if (and why) they have low expectations of career possibilities in biology and related fields; and (2) uncover the various barriers that contributed to low expectations and under-representation of learners with cerebral palsy in careers related to biology.

## 1.7 Research Questions

In pursuance of the purpose of the study, answers were sought to the following questions:

1. Do biology learners with cerebral palsy have low expectations of (career) possibilities in biology and related fields?
2. Do teachers have low expectations of career possibilities in biology and related fields for biology learners with cerebral palsy?
3. Is there a conceptual connection between curriculum delivery in special education and under-representation of biology learners with cerebral palsy in biology and related career fields?

To answer these questions, a collective case study design of personalised stories adapted from Carspecken five-stage qualitative research design (1996) was used as framework. Details of the five-stage design are provided in chapter 3.



## 1.8 Organisation of the Study

Chapter one poses the under-representation of learners with cerebral palsy in biology and related professions against the background and context of inclusive education in South Africa, followed by the rationale, statement of the problem and aim of the research. This chapter provides a brief account of the view of the world being investigated and an explanation of the main concepts.

The second chapter presents the broad perspectives on the study, assumptions about the worldview and an account of the assumptions that



guide these views. A historical perspective of the journey from special education to inclusion internationally and in South Africa in particular has been presented, ending with the implications of South African legislation and policy documents which attempt to address inclusion and disability for all South African learners.

Chapter three presents the qualitative research design employed to investigate the under-representation of learners with cerebral palsy in biology and related professions. This includes the methods and procedures used to obtain and analyse the data collected. Credibility measures and ethical principles adhered were addressed.

Chapter four presents the profiles and voices of the participants, and an analysis and explanation of the results and findings.

Chapter five offers a summary of the research, the conclusions in respect of theory and practice, the scope and limitations of the study and recommendations for future research.



### **1.9 Scope and Limitations of the Study**

This study attempted to ascertain whether the under-representation of black, disadvantaged learners with cerebral palsy in biology and related careers is linked in any way to the method and content of teaching and learning in special education. In addition, to identify and uncover the barriers that prevent learners with cerebral palsy from pursuing careers in science and technology related professions.

As indicated earlier, a decade of democracy should have been enough reasons for celebration, but for learners with cerebral palsy there is little to celebrate about. The major barriers to learning and development are lack of

resources and low expectations. However, to avoid getting overwhelmed by the challenges facing inclusive education in South Africa in general and learners with cerebral palsy in particular, this study attempted to interrogate the voices of learners with cerebral palsy as a means to create the necessary awareness about the situation.

The study recognises that globalisation and the shifting of borders have impacted on all educational initiatives and innovations. Moreover, that the “real breach of borders is occurring between universities and corporations, between training and education, between universities and vocational colleges, between on-campus and off-campus experiences” (Report no. 38, 2000). The challenge facing inclusion in South Africa is to forge a new identity that preserves the “core business” of inclusive education while exploiting the potential of that blurring of borders. The study contends if transformation is about removing all forms of discrimination, the context where the potential of learners are developed – namely the schools, homes, workplace, and higher education institutions – needs to be re-examined.

It is encouraging to note that newly graduated teachers have been exposed to the policies and practices of inclusion. However, schools and classrooms that these graduates enter have not changed significantly since 1994. In 2005, inclusion of learners with disabilities into the general classroom is still the exception rather than the rule. Furthermore, tenured teachers in the mainstream schools have not received adequate in-service training to prepare them to deal with diversity, disability and possibility. Hence, although the Education White Paper 6 has been ‘rolled-out’ in all the provinces and the second phase is underway, the divide between policy and practice remains a great challenge.



### **1.10 Significance of the Study**

The significance of the study was that the voices of learners with cerebral palsy were heard in an attempt to provide an opportunity to re-examine the links between special education and the under-representation of learners with cerebral palsy in biology and related careers. Furthermore, the study was an attempt to explore the possible ways in which the voices of learners with cerebral palsy can inform discussions towards the development of an inclusive biology curriculum.

### **1.11 Summary**

This chapter posed the problem of the under-representation of black, disadvantaged learners with cerebral palsy in biology and related careers against the historical, political and socio-economic background and context of South Africa before 1994, the year of the first democratic elections. The main purpose of the study was to listen to the voices of learners with cerebral palsy in an attempt to determine their expectations of career possibilities in biology. The rationale for the study was that there is a conceptual connection between the content and method of learning and the under-representation of learners with cerebral palsy in biology and related careers. A collective case study of the personalised stories of learners with cerebral palsy was used as a framework for the research. In addition, the study attempted to provide an account of the researcher's journey as teacher-researcher in the field of disability and biology inclusion.

As stated before, the primary goal of the study was to allow for the voices of learners with cerebral palsy to 'break the silence' and make their stories heard. Moreover, the study was an attempt to raise awareness of the importance of an inclusive biology curriculum that: (i) highlights flexible teaching approaches, accommodation strategies and assistive technologies



that adequately accommodate learners with cerebral palsy in the biology classroom; (ii) explores synergies and partnerships between various stakeholders and role players that value the importance of mentoring, internship programmes and role models in science and mathematics careers; and (iii) effectively prepares and facilitates for the transition of black, disadvantaged learners with cerebral palsy to biology related career fields in higher education and the workplace.

### **1.12 Definition of Terms**

#### *Disabled people/ People with disability*

The study refers to 'people with disabilities' or 'learners with disabilities' or 'learners with cerebral palsy', as the accepted norm in South Africa is to put people first and then the disability (Department of Education, 2001). However, the study also refers to 'disabled people'. Researchers in Disability Studies prefer the term 'disabled people' as it 'refers to people with social disability as a consequence of physical or learning impairment' (Leicester, 1999:9).

#### *Impairment*

'Impairment' is a descriptive term for the loss of a function e.g. sight that may disable the impaired person, i.e. person is unable to read print (Davis, 1997; Johnstone, 1998; Armstrong & Barton, 1999; Corker & French, 1999; Leicester, 1999).

#### *'Handicap'*

A 'handicap' occurs when those who are impaired are discriminated against (e.g. by an environment that fails to provide ramps for learners who use wheelchairs). Therefore, handicap is not an attribute but a condition arising from an interaction with an inadequate social world (Davis, 1997;

Johnstone, 1998; Armstrong & Barton, 1999; Corker & French, 1999; Leicester, 1999).

### *Cerebral palsy*

Cerebral palsy by definition is not progressive, and covers a wide range of physical disabilities caused by injury to the brain at birth or during foetal development before birth. The injury may result from bleeding into the brain, lack of oxygen at or near birth, or an infection that is shared between the mother and the developing foetus. The impairment can range from severe to mild. All children with cerebral palsy have damage to the area of the brain that controls muscle tone. As a result, they may have increased muscle tone, reduced muscle tone, or a combination of the two. The parts of their bodies affected by the abnormal muscle tone, depends upon where the brain damage occurs (Cerebral Palsy, n.d.).

### *Hemiplegic cerebral palsy*

Hemiplegia affects one arm and leg on the same side of the body, and learners have few problems beyond the physical difficulties of the arm and leg that are involved. There are different types of hemiplegia: (i) double hemiplegia that affects all four limbs but affects the right and left sides in different ways; (ii) triplegia affects both legs and the right or left arm; and (iii) diplegia is a form of cerebral palsy primarily affecting the legs. Most children with diplegia have spasticity and have difficulty with balance and coordination (Cerebral Palsy, n.d.).

### *Integration*

‘Integration’ has been used to imply moving learners who are formally segregated in special schools into mainstream schools to learn alongside their non-disabled peers. Integration is not necessarily a once-only event, but more sensibly a staged process from partial to full mainstream inclusion. Integration need not be an ‘all or nothing’ matter either, since some learners may benefit from part of their education taking place in a special school or



unit and part in the mainstream (Leicester, 1999: 9). The Education White Paper 6 (Department of Education, 2001:17) defines mainstreaming and integration as being focused on changes that need to take place in learners so that they can 'fit in'.

### *Inclusion*

The Education White Paper 6 (Department of Education, 2001:17) defines inclusion as “about recognizing and respecting the differences among all learners and building on the similarities” and “about supporting all learners, educators and the system as a whole so that the full range of learning needs can be met”. Leicester (1999:9) asserts that the connotation associated with inclusion is an acceptance of learner diversity, an awareness of a more enlightened perspective on disability. According to Leicester, the aim of inclusion is not to bring a disabled learner into an unchanged mainstream school, but to achieve a mainstream provision that caters for all learners, with their range of abilities, disabilities and needs.

### *Accommodation*

An accommodation is an adjustment to make a program, facility or resource accessible to a person with a disability (Burgstahler and Nourse, 2000).

### *Adaptive Technology*

Hardware or software that provides access to a computer that is otherwise inaccessible to an individual with a disability (Burgstahler and Nourse, 2000).

### *Assistive technology*

Technology used to assist a person with a disability, e.g. wheelchair, handsplints, computer-related equipment (Burgstahler and Nourse, 2000).



## CHAPTER 2

### REVIEW OF RELEVANT LITERATURE

Equality is a more general objective than diversity, difference, and choice. Equality includes the right of everyone to choose to be different and to be educated in their own difference.

(Flecha, p.77 in Castells et al., 1999)

#### 2.1 Introduction: Theoretical and Practical Considerations

This chapter explains the assumptions guiding the study and provide the theoretical context within which the study was conducted. The previous chapter provided a brief outline of the view of the world being investigated. Generally, all learners with disabilities were viewed as a homogenous group in terms of the expected “outcome” of learning. A generation ago learners with disability were not considered as a skills source for careers in science (physical science and biology). Hence, learners with disabilities were not encouraged to pursue careers in biology and related fields. Before 1994 learners with disabilities, who happen to be black and from disadvantaged communities, were at a particular disadvantage. They had to face challenges at all levels: politically, legally, economically, technologically, socially, educationally, and environmentally. Since the first democratic elections in 1994, there has been some shift in the political acceptance of learners with disabilities, though much still need to be done.

Since 1994, learners with disabilities seemingly have more rights. Politically, the constitution of the country protects the rights of all, and provides access to courts if the rights of learners with disabilities are infringed. Socio-economically, the needs and wants of learners with disabilities have moved from the margins to the centre.

The White Paper on Integrated National Disability Strategy (Ministry in the Office of the Deputy President, 1997) states:

- The exclusion experienced by people with disabilities and their families is the result of a range of factors, for example:
  - the political and economic inequalities of the apartheid system;
  - social attitudes which have perpetuated stereotypes of disabled as dependent and in need of care; and
  - a discriminatory and weak legislative framework, which has sanctioned and reinforced exclusionary barriers.
- The key forms of exclusion responsible for the cumulative disadvantage of people with disabilities are poverty, unemployment and social isolation.

The Employment Equity Act (South African Department of Labour Online, 1998) defines disability as follow:

People are considered as people with disabilities (PWD) who satisfy all the criteria in the definition:

- having a physical or mental impairment;
- having an impairment which is long-term or recurring; and
- having an impairment which substantially limits their prospects of entry into, or advancement, in employment.

The same document qualifies physical impairment as:

A partial or total loss of a bodily function or part of the body. It includes sensory impairments such as being deaf, hearing impaired, or visually impaired....

An impairment is substantially limiting if, in its nature, duration or effects, it substantially limit's the person's ability to perform the essential functions of the job for which they are being considered.

(p. 7-8)



Economically, the Employment Equity Act (South African Department of Labour Online, 1998) confirms:

Although many barriers such as widespread ignorance, fear and stereotypes have caused people with disabilities to be unfairly discriminated against in society and employment, South Africa can take pride in its efforts to formulate policies to protect the rights of people with disabilities. (p. 5)

Further, that

[The] Code [of Good Practice] is intended to help create awareness of the contributions people with disabilities can make and to encourage employers to fully use the skills of such persons. (p. 6)

Moreover, educationally, the Education White Paper 6 (Department of Education, 2001) ensures education for **all**. In addition, technologically, there seems a greater awareness of accommodations and accessibility. For example, the Western Cape Education Department embarked on a campaign, namely the Khanya project, aimed to have at least one computer classroom in all schools by 2010. Similar projects were launched in other Provincial Departments of Education.

However, challenges remain. Provincial Departments of Education proceeded to install computers in schools without proper research into assistive devices for learners with disabilities. Furthermore, in 2005 the National Assembly still debated whether, and when, separate schools for learners with disabilities will be available (see South Africa, May 2005). Transport remains a problem. Added to that, living and working conditions of many learners with cerebral palsy have not changed dramatically and the broader societal views of learners with cerebral palsy are still very stereotypical. Moreover, mainstream schools in disadvantaged areas had no significant change in infrastructure, apparently due to financial constraints.

Government policy dictates that schools have to pay for any structural changes like ramps and adjustable tables for learners using wheelchairs. In the poorer areas this will be impossible. This means that if parents want to enrol their child in a school close to where they live (as advised in Education White Paper 6, 2001) the schools will probably not be able to accommodate for the needs of all learners.

Furthermore, the availability of adequate biology and physical science laboratories designed to accommodate all learners remain a huge barrier. Mainstream and special schools still have “one-size-fit-all” laboratory benches and tables. Moreover, biology and science teachers are not sufficiently exposed to tried and tested laboratory accommodations for learners with cerebral palsy and other disabilities. In addition, no training is provided for teachers in specialised and mainstream schools to explore the specialised laboratory settings for learners with cerebral palsy (and other disabilities).

Another challenge is the business sector. The Employment Equity Act (South African Department of Labour Online, 1998) is in place, yet the business sector is still more concerned about profit margins and not enough effort is made to accommodate learners with cerebral palsy in the workplace (Morris, 2005). Although society is presented with examples of successes achieved by learners with cerebral palsy, many institutions are reluctant to accommodate learners. Policies are meaningless without an Act [of law] that enforces implementation on all levels or the willingness of all the stakeholders to play their specific roles to see to the success of such policies.

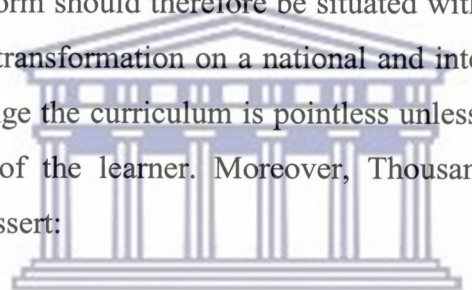
### **2.1.1 *Voice, Perspective and Identity***

As stated in chapter one, the current classroom practice does not seem to prepare learners with cerebral palsy to maximise their potential. The



classroom seems far removed from the real world. Giroux (1981, 1983) asserts that in any society any serious appraisal of the role of education and curriculum, in particular, must situate the three elements - the knowledge, the school and the educator - within the real social conditions that determine these elements. Also, the complexity of the interface between the curriculum, the teacher and the learner is crucial to the process of transformation (Duckworth, 1987; Giroux, 1983; Gudmundsdottir, 1990).

Morrow (1999) contends that meaningful transformation and change requires the examination of the history, and not merely the past of a practice. Morrow refers to the transformation of an education system as a 'project of changing the vast webs of practices, which constitute it'. Curriculum reform should therefore be situated within the historical context of change and transformation on a national and international level, and any attempt to change the curriculum is pointless unless it is underpinned by an understanding of the learner. Moreover, Thousand, Diaz-Greenberg and Nevin (1999) assert:



As we enter the new millennium, we are faced with different challenges in the world of education. The linguistically and ethnically diverse population of schools today demands that we make a change in the way we teach students, new approaches to teaching require that we transform our perspectives and apply innovative pedagogies in the classroom. The Freirean pedagogical approach known as critical pedagogy provides a much-needed paradigmatic change to general and special educators involved in the inclusive education movement. (p. 323)

Brown (1999:366, citing Leonard) asserts critical theory "is a theory having practical intent" and "is understood by its advocates as playing a crucial role in changing society". Furthermore, "critical theory without a practical dimension would be bankrupt on its own terms". Brown further cites Leonard's (1990) three requirements for theory to be considered "critical



theory”, namely it: (i) must locate the sources of domination and oppression in actual social practices, (ii) must project an alternative vision of a life free from oppression, and (iii) must craft these tasks in the idiom, so to speak, of its addressees. This study maintains the under-representation of learners with cerebral palsy in biology and science careers is an example of inequality and domination of the culture of non-disability and attempts to show how the “addressees”, i.e. the participants in this study, confirm this.

Furthermore, the study affirms that the voices of the learners and the stories they tell are central to the process of curriculum development and that by listening to the voices as they tell their stories, educators and researchers might come to appreciate how powerfully educative and truly liberating such an experience can be (Tappan and Brown, 1989). The underlying assumptions of this study is that learners with disabilities have their own special stories to tell about physical suffering and pain, stories about economic and financial struggles, and stories about political struggle. However, the richness of the diversity that learners bring to the classroom is often ignored because the teacher does not have the skills to ‘hear the voices’ of the learners. Moreover, by ignoring their voices and failing to understand their meanings, we are further marginalising and silencing them.

Since the first democratic elections in 1994 there has been some shift in the political acceptance of learners with cerebral palsy, though much still needs to be done. Black learners with cerebral palsy, from disadvantaged communities, still face political, economic, social, technological, legal and environmental barriers. Priestly (1998) asserts:

Much previous research has compounded a view of disabled children as passive, dependent and vulnerable. Moreover, the voices of disabled children themselves have frequently been excluded from the published narratives of this research. As a consequence, such narratives have frequently concealed the way in which disabled



children function as social actors, negotiating complex identities within a disabling environment. (p.93)

Furthermore, Priestley (1999:93) claims disabled children are confronted on a daily basis with ways of speaking about disability that influence their experience and their sense of identity. The author further asserts that within the school environment learners with disabilities are often pressurised to identify with one of two logically opposing categories – disabled or non-disabled – which are hierarchically arranged. According to Davis (1997:1):

We live in a world of norms. Each of us endeavours to be normal or else deliberately tries to avoid that state... To understand the disabled body, one must return to the concept of the norm, the normal body.

Learners with cerebral palsy have been socialised to aspire to the ‘norm’, the non-disabled identity. Although integration and mainstreaming of learners with disability provided many opportunities to blur these socially constructed identities, the language of special needs and special education continues to construct the disabled as the other (Priestley, 1999:102).

### **2.1.2 Disability and Difference**

The study concurs there is an increasing recognition of the importance of personalised experience and life stories in the learning process (Leicester, 1999) and highlights the importance of a flexible, inclusive curriculum that embraces and reflects all voices. It is argued that our perspective on disability and the way we conceive and theorise about disability informs our interactions with learners with disabilities (Weiler, 1991; Meijer, et al., 1994; Gleeson, 1999; Leicester, 1999; Miller and Sammons, 1999; Armstrong and Barton, 1999; Armstrong, et al., 2000; Armstrong, 2004). The following section highlights some of the major differences between the

medical or 'individual' perspective and the social perspectives of disabilities, and how these perspectives have informed our classroom practices.

*Medical model of disability*

The 'medical model' sees disability as an illness, as a condition of the individual. This view of disability locates the problems of disability with the individual (Stalcup, 1997; Leicester, 1999; Armstrong and Barton, 1999; Gleeson, 1999).

*Social model of disability*

The 'social model' views disability as a social construct created by the interactions of the disabled with a physical and social world designed for non-disabled living. It is important to note that social models do not deny impairment, but rather put the emphasis on the social aspects of the world that can be changed (Leicester, 1999; Armstrong and Barton, 1999; Gleeson, 1999). Further, Leicester (1999) makes the following distinction between the 'creationist' social models and the 'constructionist' social models. In 'creationist' models, disability is described as:

the *material* product of societal developments within a particular historical context and the units of analysis are disabling barriers, physical, structural and institutional, and relations of power. (p.18)

Whereas 'constructionist' models describe disability as:

taken to be the product of societal development within a specific *cultural* context where the units of analysis are cultural values and representations, these being relative to a culture and leading to various kinds of social labelling and role expectations. (p. 19)

This study concurs with Leicester (1999) that the individual learner is central to the teaching and learning context, and that cultural values as well



as material barriers may adversely affect the lives of black disadvantaged learners with cerebral palsy. Therefore our understanding of social disability needs to be broadened to reflect the complexity of the experiences of learners with disabilities. According to Leicester (1999):

It seems to me that the experiences of many disabled people encompasses emotional and physical pain, suffering and frustration associated with loss of a function(s) and the experience of socially imposed restrictions such that this impairment is more disabling than it need be. (p. 20)

Learners with cerebral palsy, who happen to be black and from disadvantaged communities were at a particular disadvantage before 1994. Therefore a perspective on disability that integrates the personal and the political would be more appropriate and true to the lived experiences of the learners interviewed in this study. The learners in this study all described experiences of suffering, as well as encounters with prejudice, discrimination and lack of adequate or appropriate resources and accommodations. Leicester (1999) argues:

Without a social perspective on disability, compassion and empathy degenerate into pity and the 'disabled' are marginalised and pathologised; awareness of social discrimination is obscured. But without an understanding of the individual's often physically and emotionally taxing experience of impairment, we may risk failing to empathise with the actual individuals we meet. If we integrate these perspectives we can, perhaps, on the one hand recognise the importance of justice, rights and of ending discrimination, while on the other retaining a compassionate understanding of the suffering of others, and of the diversity and uniqueness of individual experiences, circumstances and need. (p.20)

The successful inclusion of learners with cerebral palsy in the mainstream biology classrooms will depend on teachers and learners developing a broader perspective on disability that “combine considerations of justice and feelings of compassion” (Leicester, 1999). According to Leicester, justice in this context refers to:

... an attempt to see the issue from another’s point of view and not just ‘how I would see it if I were in that position’... enriching [our judgements] through comprehending the perspectives of others. There is an emphasis here on context and human interrelatedness and interdependence, rather than on universability and individual autonomy. (p. 21)

McClaren and Hammer (1989) seem to agree with this approach. The authors assert the aim should be to render problematic the multiplicity of voices students bring with them into the classroom and transform them in the interest of justice; the teacher should take seriously the stories learners tell of their own histories, experiences, and dreams – while at the same time helping them to achieve a critical voice tempered by a politically informed intelligence. Leicester (1999) argues further:

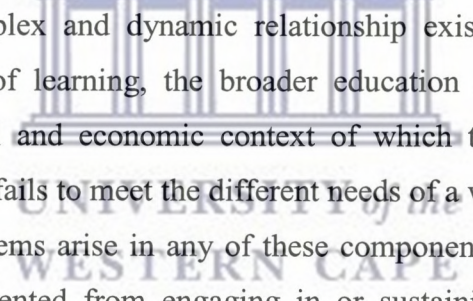
[that] the views of disabled people should be part of determining ‘special’ provision; that we should take specific, individual factors into account in providing for each particular student; and that educational decisions should be characterised by fairness to all pupils, consideration of each pupil’s rights and empathetic understanding of the vulnerabilities of particular pupils. (p.22)

Gleeson (1999) maintains schools are disabling spaces, exclusionary environments where the curriculum promotes the dominant culture. The dual system of specialised and mainstream schooling is evidence of this disabling space. South Africa until 1994 embraced a medical model of disability or a functional limitations model. Learners with cerebral palsy have



often been placed in specialised learning contexts merely because they were labelled as disabled. As stated before, the Education White Paper 6 (2001) claims that negative, harmful and discriminatory attitudes resulting from prejudice against people on the basis of race, class, gender, culture, disability, religion, ability, sexual preference and other characteristics remain a critical barrier to learning and development.

The learners with cerebral palsy interviewed in the study were all born before the “dawn of the democratic South Africa in 1994”, before the Employment Equity Act, the National Disability Strategy and Education White Paper 6 brought disability and employment into the public discourse. As stated before, barriers are found in all aspects of the system: within the school, within the community, within local and national policies. Education White Paper 6 (Department of Education, 2001:13) asserts:



A complex and dynamic relationship exists between the learner, centre of learning, the broader education system, and the social, political and economic context of which they are all part. If the system fails to meet the different needs of a wide range of learners or if problems arise in any of these components, then the learner may be prevented from engaging in or sustaining an ideal process of learning. Those factors which lead to the inability of the system to accommodate diversity, which lead to learning breakdown or which prevent learners from accessing educational provision, have been conceptualised as barriers to learning and participation.

The next section will highlight some international experiences of inclusion and present a brief overview of the South African journey from special education to inclusive education.

## 2.2 From Special Education to Inclusion

### 2.2.1 *Reflections on the International Journey*

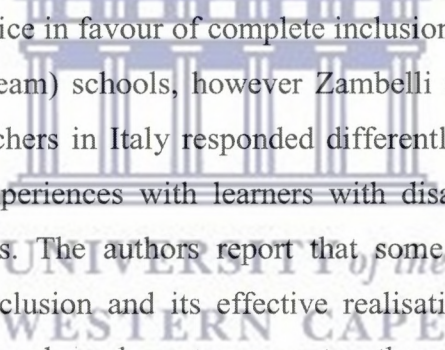
The debate as to whether the general classroom can provide optimal quality education for learners with cerebral palsy has been on-going ever since people began to question the dual system of special schools and ordinary schools. Inclusive Education was proposed as an alternative and claims to provide the best solution for a schools' system that can meet the needs of all learners. The principle of inclusive education was adopted at the World Conference on Special Needs Education: Access and Quality (UNESCO, 1994a) and was restated at the World Education Forum in Dakar, Senegal in 2000. The United Nations Standard Rules on the Equalization of Opportunities (UNESCO, 1994b) further supported the idea of inclusion for Persons with Disabilities proclaiming participation and equality for all. UNESCO (2000) asserted that the universal goal is to achieve Education for All children (EFA) by the year 2015.

UNESCO (2004) defines inclusive education as 'a developmental approach seeking to address the learning needs of all children, youth and adults with a specific focus on those who are vulnerable to marginalisation and exclusion.' Also, that inclusive education means that the school can provide a good education to all learners irrespective of their varying abilities and that all learners will be treated with respect and ensured equal opportunities to learn together. Moreover, that inclusive education is an on-going process, and that it is important to showcase examples of positive experiences, which demonstrate that inclusive education can most certainly address quality issues in education. In addition, UNESCO (2004) emphasises that inclusive education cannot be developed in isolation from overall school development.

Many countries embraced the Salamanca Statement. However, a cursory review of the literature reveals varied responses and highlights that



implementation is indeed an 'on-going process'. Spalding (2000) states that in the City of Liverpool, with a history of special education and relying heavily on special schools, the City Council determined in 1997 that Inclusive Education would be the policy imperative for the following decade and that the development of mainstream schools additionally resourced for children with additional/special educational needs should form the core of the move away from segregated provision. However, Benjamin (2000) recounts a drive in recent years to 'improve standards' in British schools that included an increased emphasis on quantifiable test and examination results in determining what counts as 'success' for students, teachers and schools. This drive resulted in learners who struggle and often fail to reach benchmark standards, being positioned as 'needy' and often 'labelled' as 'academically excluded'.



Italy made a choice in favour of complete inclusion of disabled children into normal (mainstream) schools, however Zambelli and Bonni (2004: 363/4) showed that teachers in Italy responded differently to inclusion depending on their past experiences with learners with disabilities and their beliefs about disabilities. The authors report that some teachers still doubt the usefulness of inclusion and its effective realisation, and that not enough attention is focused on how to guarantee the successful inclusion of a disabled learner into a mainstream school.

In the United States of America (USA) there is a continuum of alternative placements: general education with full inclusion, part-time inclusion with resource rooms and special classes, and special schools for learners who are severely disabled. The USA has a long history of integration, mainstreaming and inclusion. In 1975 the P.L. (Public Law) 94-142 was adopted and mandated a free public school education for every student regardless of the severity of the learner's disability. The law legislated that learners in need of help were to receive the assistance required and that public schools provide this assistance. Subsequently, the REI (Regular Education



Initiative) and IDEA (Individuals with Disabilities in Education Act) were adopted and mandated all learners identified as special needs should have an individual education programme (IEP). In the late 1990s the Rights Movement questioned the 'scientific basis' of the established system, and claimed that the established system is "an instrument of social division, maintaining the privileges of the more advantaged members of society at the expense of the life-opportunities of those who were already disadvantaged" (Clark, et al. 1997:5). The debate surrounding partial/full inclusion and successful implementation of policy is ongoing.

According to Eleweke and Rodda (2000) approximately 80% of the world's population of people with disabilities live in the developing countries of Asia, Africa, the Caribbean, Latin America and the Middle East, yet only 2% are receiving any form of special needs services. Research shows that inclusive education is not being satisfactorily implemented in these countries, citing factors such as the absence of support services, relevant materials, inadequate personnel training programmes, lack of funding structure and the absence of enabling legislation as the major problems of effective implementation. The authors suggest community based inclusive education programmes be considered as the major initiative to utilise in-service delivery for people with disabilities in the developing countries.

Khan (1998) presents an overview of the educational system and structures in Pakistan during the late 1990s. Historical developments in special education were reviewed, including legislation, policy, administration and organization at the national, regional and local levels. The author asserts Pakistan is moving away from the dual system of education, in which children with special educational needs receive educational services in special schools, towards an inclusive school system. Khan (1998) claims the first step in promoting inclusion should be to consolidate the dual administrative structure into a single system, with a clearly defined policy and plan for accommodating children with special needs within ordinary



schools and reports initiatives to mainstream learners are being launched in pilot projects, and efforts are being made to build linkages between special and regular schools.

African countries have their own challenges to face with regards to inclusive education. Agegnehu (2000) asserts that in Ethiopia negative attitudes of the causes of child disability impacts negatively on: (1) the potential of children with disabilities; (2) the benefit of inclusive education; and (3) the rehabilitation of children with disabilities. The author further maintains in the developing world disabled persons often live without dignity, victimized by beliefs that they are possessed by evil spirits or proof of divine retribution. Furthermore, even though education for all is the motto, opportunities to exercise this right are limited, with only 7% of the 5.3 million persons with disability in Ethiopia having access to educational services.

Grol (2000) relates the status of educational projects for pupils with Special Educational Needs in Botswana, Kenya, Nigeria, and Zimbabwe. However, the author claims the projects have not been evaluated and have poor or non-existent records. This lack of written and scientific processing appears to be a specific African characteristic of projects catering for children with special education needs in Africa, and therefore African projects hardly play a role in the debate on the education of pupils with special education needs in Africa. Furthermore, Grol maintains the African context is barely taken into consideration when discussing this type of education in Africa. According to Grol any debate on the education of pupils with special education needs in Africa should keep in mind the following African characteristics:

- The African education system, namely:
  - The African curriculum.
  - Teachers in Africa.
  - The medium of instruction in Africa.

- Traditional and cultural African attitudes, namely:
  - The position of the child in traditional African society.
  - Traditional African attitudes towards children with a disability.
  - Socio-economic views.

The author rightly cautions that Inclusive Education in Africa should reflect the African context, culture and traditions. Inclusion in Africa (including South Africa) should draw on the experiences of European and American journeys, but develop policies and practices that reflect the uniqueness of the African context and history.

### ***2.2.2 Reflections on the South African Journey***

In 1994, the first democratically elected government was given the mandate to develop a ‘truly national system of education and training... for **all**’ (Government Gazette, 1994). According to Section 29 of the Constitution of the Republic of South Africa, “Everyone has the right to a basic education, including adult basic education; and to further education, which the state, through reasonable measures, must make progressively available and accessible”. This commits the state to the achievement of equality and non-discrimination, and above all protects **all** learners, including learners with disabilities. In response to the above, the Education White Paper 6 (Department of Education, 2001) outlines a 20 year plan for an Inclusive Education and Training System in South Africa across all bands of education which includes: Early Childhood Education (i.e. from age 0 – 5), General Education and Training (i.e. compulsory schooling from grade R to grade 9), Adult Basic Education and Training, Further Education and Training (i.e. schooling from grades 10 to 12) and Higher Education.

Various reasons are offered to explain why South Africa, as a developing country, embraced inclusive education in its policy development since the 1994 democratic elections. Hay and Beyers (2000) argue that the inclusive education movement has become internalised in the sense that developed



and developing countries have adopted the rhetoric. Another view is that the legacy of apartheid, and colonialism, has been a very strong force influencing South Africans to embrace the anti-exclusionary ideology of inclusion (Artiles, 1998; Artiles & Larsen, 1998; Daniels, 1999; Daniels & Garner, 1999; Van Der Merwe, 2000). Leach (1989) claims the return of a large number of African National Congress exiles appointed in key educational positions, brought with them the most recent educational ideas. Du Toit (1996) asserts that the concept of inclusive education fitted neatly with the new policy of a unitary education system where racial classification, as well as disability, was no longer used to differentiate between departments.

The inclusive education thrust in South Africa has been part of the democratisation of the country after 1994. After 1994 inclusive education was seen as a perfect way of including all marginalised learners into education for all - that included disabled learners, learners of colour and those neglected during the apartheid era. The 18 different Departments of Education have been reduced to nine Provincial Education Departments, all of which resorted under the National Department of Education. The governance of special schools was relocated to the provincial departments, and there seemed no longer a need for administration of special schools through a separate, centralised department.

The history of exclusion and marginalisation plays an important part in forging future policy in South African special education. The Report of the National Commission on Special Needs in Education and Training (NCSNET) and National Committee on Education Support Services (NCESS): Quality Education for all: Overcoming Barriers to Learning and Development (Department of Education, 1997) states that:

The history of education for learners with special needs and education support services in South Africa, like much of the history of our country, reflects massive deprivation and lack of provision for

the majority of people. The inequities evident in the areas of concern addressed by the NCSNET/NCESS can be directly attributed to those social, economic and political factors which characterised the history of South African society during the years of apartheid.  
(p. 21)

The same document adds:

The divisions in the education system were reinforced under the apartheid system by separate education departments being governed by different legislation. The area of special needs was doubly fragmented - on the one hand by legislation which enforced separation among racial lines and on the other by a separation between "ordinary" learners in the mainstream and learners with "special needs" in a secondary system. (p 22)

The above report highlights the history of a fragmented, divided education system. Furthermore, the subsequent Consultative Paper 1 on Special Education: Building an Inclusive Education and Training System, First Steps (1999) states:

Recognizing that until now the education and training system has failed to accommodate fully a diverse range of learning needs and that as a result, high levels of learning difficulties and exclusion continue to be experienced, the Ministry is deeply committed to establishing an inclusive education and training system as part of our Constitutional responsibility to building an inclusive society. (p. 8)

Moreover, the Draft Education White Paper: Special Needs Education - Building an Inclusive Education and Training system (2000) situates race, disability and special education in the historical context as follows:



Special Needs Education is a sector where the ravages of apartheid were most evident. The segregation of learners on the basis of race was extended to incorporate segregation on the basis of disability ... (p. 4)

And further states that:

This policy framework outlines the Ministry's commitment to the provision of educational opportunities in particular for those learners who experience or have experienced learning difficulties or dropped out of learning arising from the inability of the education and training system to accommodate the diversity of learning needs and those learners who continue to be excluded from it. (p 6)

The draft paper was the first step away from a perspective of disability that is shaped by the medical model to a perspective underpinned by a social-rights model. Advocates for inclusive education in South Africa argue that special education theories were located predominantly within the medical paradigm and that supporters of special education theory believed any breakdown in the system of teaching and learning was caused by deficiencies in the individual learner. Moreover, the advocates for inclusive education assert the manner in which learners are socialised and taught in schools have not been taken seriously in understanding why there is a breakdown in learning.

Furthermore, the White Paper on an Integrated National Disability Strategy (Ministry in the Office of the Deputy President, 1997) acknowledges "in the past, disability issues were viewed chiefly within a health and welfare framework... [and] this led naturally to a failure to integrate disability into mainstream government statistical processes" (p.1). The same document adds:

'the majority of people with disabilities in South Africa have been excluded from the mainstream of society and have thus been prevented from accessing fundamental social, political and economic rights...[and that] the key forms of exclusion responsible for the cumulative disadvantage of people with disabilities are poverty, unemployment and social isolation. (pp 2-4)

The new understandings relate to barriers to learning and development, and attempt to explain how in many cases the system is responsible for difficulties experienced with learning. Education White Paper 6 (Department of Education, 2001) identifies 'barriers to learning' as located within the site of learning, within the education system and within the broader social, economic and political context and defines barriers to learning as "those factors which lead to the inability of the system to accommodate diversity, which lead to learning breakdown or which prevent learners from accessing educational provision" (p.13). Moreover, these barriers manifest themselves in different ways and only become obvious when learning breakdown occurs, when learners 'drop out' of the system. In addition, barriers may also arise during the learning process and are seen as transitory in nature, requiring different interventions or strategies to prevent them from causing learning breakdown or excluding learners from the system.

Furthermore, it is believed that the key to preventing barriers from occurring is the effective monitoring and meeting of the different needs among the learner population and within the system as a whole. Systemic barriers include a lack of access to basic services, poor teaching, lack of basic and appropriate learning and teaching support materials and assistive devices, inadequate facilities at schools, and overcrowded classrooms. In recognising the impact of a variety of barriers on learners and the system, it follows that overcoming and preventing these barriers must involve a range of mechanisms that recognise the needs of the learner and the needs in the society that must be met.



The Education White Paper 6 views the move to Inclusive Education as “a cornerstone of an integrated and caring society and an education and training system for the 21<sup>st</sup> century” (p.10) that acknowledges that “learners who are most vulnerable to barriers to learning and exclusion in South Africa are those who have historically been termed ‘learners with special education needs’, i.e. learners with disabilities and impairments” (p.18), and that the ‘vulnerability’ may arise due to the following factors:

- Negative attitudes to and stereotyping differences
- An inflexible curriculum
- Inappropriate communication
- Inaccessible and unsafe built environments
- Inappropriate and inadequate support services
- Inadequate policies and legislation
- The non-recognition and non-involvements of parents
- Inadequate and inappropriately trained education managers and educators (p.18)

Furthermore, Education White Paper 6 claims that Inclusive Education means a shift from the medical, pathological model to a more social model where barriers to learning are defined as systemic and not as deficiencies located within the individual learner. The policy document further states that learners will be admitted to a centre of learning based on learners’ support needs rather on the basis of disability. Moreover, Inclusive Education as envisaged in Education White Paper 6 signals an end to segregation of learners into special facilities and limited possibilities. The following table summarises the shift.

Table 2.1: Shifting from Special Education to Inclusive Education

<b>Theory</b>	<b>Special Education Theory</b>	<b>Inclusive Education Theory</b>
Assumptions	<ul style="list-style-type: none"> <li>- Pathological</li> <li>- Deficits within the child</li> <li>- Categories</li> </ul>	<ul style="list-style-type: none"> <li>- Barriers to learning</li> <li>- Barriers in the system and environment</li> <li>- Levels of support needed, e.g. high, moderate and low levels of support</li> </ul>
Practices	Segregation of learners into special facilities	Includes all learners and reorganises support
Tools	Standardised tests	Criterion referenced tests Teacher produced tests Assessing the potential to learn
Model	Special Education Act	South African Schools Act
Pedagogy	Limited pedagogical possibilities	<ul style="list-style-type: none"> <li>- Pedagogy of possibility taking into consideration barriers to learning, multiple styles of intelligences and learning.</li> <li>- High expectations, expanded learning opportunities</li> </ul>

Source: DOE (2005); Guidelines for Inclusive Learning Programmes, p.10.

The table highlights the shift from the medical model of disability that views the problem or “deficit” in the learner to a social model that views the system of teaching and learning as the barrier preventing full participation. Furthermore, that inclusive education in South African schools will mean, “high expectation [and] expanded learning opportunities”. The following section will examine this statement.



## 2.3 Inclusion, Curriculum and Learners with Cerebral Palsy

### 2.3.1 Introduction

Education White Paper 6 (Department of Education, 2001), regarded as an important guideline for school re-organisation and curriculum development in 21<sup>st</sup> century South Africa, maintains one of the most serious barriers to learning and development can be found within the curriculum itself, relating primarily to the inflexible nature of the curriculum that prevents it from meeting diverse needs among learners. The white paper highlights that a “flexible curriculum and assessment policy” (p.31) is central to the accommodation of learners with disability. Furthermore, the policy document states “curricula create the most significant barrier to learning and exclusion of learners” (p.31). The Department of Education seems committed to the “provision of educational opportunities in particular for those learners who experience or have experienced barriers to learning and development” (p.6) and recognises learners with disabilities and impairments as the most vulnerable to barriers to learning and exclusion.

The African National Congress (ANC) Policy Framework for Education and Training (ANC, 1994) describes the term "curriculum" as referring to all of the teaching and learning opportunities that take place in learning institutions - including the aims and objectives of the education system, the content taught, the skills imparted, strategies of teaching and learning, forms of assessment and evaluation, how the curriculum is serviced and resourced, and how it reflects the needs and interests of those it serves. In other words, curriculum is concerned with what institutions teach, and with what, how and under what conditions learners learn. This definition resonates with what Duckworth (1987) described as curriculum:

Curriculum becomes a set of accounts by teachers of how they went about engaging their students in the subject matter, what the students did, said, and thought, why the teachers did what they did, what they thought about what they did, what they would do another time.

(p. xv)

In 1999, Kader Asmal, then newly elected Minister of education, commissioned a specially appointed committee to review the Outcomes-Based Curriculum-2005 (indicating the year of full implementation). The following recommendations relates to the present study:

- Human Rights Education and education for civic responsibility should be infused throughout the curriculum. Issues of anti-discrimination, anti-racism, anti-sexism and *special needs* require particular attention throughout the curriculum. The implication of this for all learning areas should be clearly spelt out.
- All learning should go beyond the limited and narrow pre-C2005 curriculum. Learners should be afforded opportunities to apply what is learnt to '*authentic*' problem situations and so make learning relevant and applicable to their lives. (Researcher's emphasis)

It is encouraging to note the acknowledgement that 'special needs' as a human rights issue should receive attention "throughout the curriculum". Moreover, there seem to be an implied inference that the curriculum should be more flexible, relevant and authentic to the lives of all students. This resonates with the broader aims of this study, namely to raise awareness of a more inclusive (biology) curriculum that reflects the lives of **all** learners.



### 2.3.2 *Education White Paper 6 and the Biology Curriculum*

The National Curriculum Statement Grades 10-12 (Department of Education, 2003) states that for the curriculum to become truly inclusive, it is important for all teachers and educators to understand how to review their own understanding of teaching and learning in order to accommodate inclusive education. In addition, the statement asserts that officials involved in the management, development and monitoring of the curriculum need to understand that inclusion is a central curriculum issue and that curriculum delivery can constitute a significant barrier to learning, leading to the exclusion of many learners in 'special' and 'ordinary settings'. Moreover, the statement highlights the importance of the notion of inclusivity becoming a central part of the organization, planning and teaching at each school and claims that this can only happen if all teachers have a sound understanding of how to recognize and address barriers to learning, and how to plan for diversity.

The Education White Paper 6 (Department of Education, 2001) maintains within Inclusive Education the new pedagogy is described as an Inclusive Outcomes Based Education that provides a theoretical framework that can allow teachers to think about learning in a new holistic and systemic way, and provide concepts of teaching that will assist the transformation of classroom practices. The central strands of the new curricular approach that has been adopted in South Africa are the 12 Critical Outcomes:

- Identify and solve problems in which responses display that responsible decisions using critical and creative thinking have been made.
- Work effectively with others as members of a team, group, organisation, and community.
- Organise and manage oneself and one's activities responsibly and effectively.

- Collect, analyse, organise and critically evaluate information.
- Communicate effectively using visual, mathematical and/or language skills in the modes of oral and/or written presentation.
- Use science and technology effectively and critically, showing responsibility towards the environment and health of others.
- Demonstrate an understanding of the world as a set of related systems by recognising that problem-solving contexts do not exist in isolation.
- Reflecting on and exploring a variety of strategies to learn more effectively.
- Participating as a responsible citizen in the life of local, national and global communities.
- Being culturally and aesthetically sensitive across a range of social contexts.
- Exploring education and career opportunities.
- Developing entrepreneurial opportunities.

Furthermore, the Guidelines for Inclusive Learning programmes (Department of Education, 2005) suggest that in the learning programme Natural Sciences (biology and physical sciences for grades 7–9) all three learning outcomes - Learning Outcome1: Scientific Investigations; Learning Outcome2: Constructing Science Knowledge, and Learning Outcome3: Science, Society and the Environment - need adaptation to accommodate **all** learners and offer the following recommendations:

- Learning and teaching support material should accommodate different communication needs.
- The use of real objects or representations of such objects would facilitate learning example e.g. having real flowers instead of pictures or using a globe instead of just explaining certain aspects of earth and beyond. Should the learners be unable to have access to real objects or natural phenomena it should be made available to them. (p.71)



In the inclusive classroom the teacher will have to identify the different types of support required by all the learners. If a learner with cerebral palsy is included, the teacher will have to design her assessment tasks to ensure that the learner is assessed on performance and ability. However, as the following table illustrates, the guidelines are very general. For example, general strategies are offered for safety measures in the inclusive natural sciences classroom but the teacher is not provided with examples of specific strategies to consult when doing experiments.



Table 2.2: Barriers, Implications and Strategies for Learning area: Natural Science

BARRIERS EXPERIENCED BY LEARNERS	IMPLICATIONS:	STRATEGIES:
<p>Scientific investigations</p>	<ul style="list-style-type: none"> <li>• <b>Safety: Due to limited motor control / lack of understanding / lack of memory for the correct procedure the student may be at risk of injury.</b></li> <li>• The learner may have difficulty understanding some terminology that is specific to the Learning Area. E.g. Habitat, Botanist, radical root etc.</li> <li>• The learner may experience difficulty in reading the typical texts used in this Learning area.</li> <li>• Slower readers will experience barriers to read the required volume.</li> <li>• The learner may struggle to find relevant information in the library or in a book or page.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Use peer/adult support.</b></li> <li>• <b>Use pictures to enhance safety procedures.</b></li> <li>• <b>Allow the student more time to complete experiments.</b></li> <li>• Relevant key information could be photocopied and the volume could be handled by the learner through highlighting and/or underlining key words.</li> <li>• A reader could read the texts to the learner or texts could be listened to on an audiotape.</li> <li>• Provide texts on a lower reading level.</li> <li>• Visual aids: Videos, films, role-plays, models, real life examples and excursions could assist the learner to understand text more.</li> <li>• Step by step strategies for research need to be taught. Allow the learner to repeat in his own words what he is to do. A sequence map can be used to map the sequence of which the learner needs to follow. This map may be cued with pictures. E.g. scan the</li> </ul>



	<ul style="list-style-type: none"> <li>• They will experience problems with extracting specific information out of a text.</li> </ul>	<p>text. Read headings and subheadings and look at pictures, graphs etc. Read text. Highlight keywords. Answer questions. Write conclusion.</p> <ul style="list-style-type: none"> <li>• Encourage group work with peers to complete an assignment. The participation of the learner in the group could be adapted to address his needs.</li> <li>• Reduce the amount of work on the worksheet or/and divide the worksheet in segments. Learner may complete part one, part two is group work and part three is homework.</li> </ul>
<p>Constructing science knowledge</p>	<ul style="list-style-type: none"> <li>• Abstract concepts may not be relevant to their life experiences that will also be problematic with comprehension skills.</li> <li>• Lack in exposure to, understanding and experience of the topic discussed.</li> <li>• The learner may experience barriers with types of question because they may struggle to interpret what information is required. Learners may have problems with the 'how, why and when type of questions.</li> </ul>	<ul style="list-style-type: none"> <li>• Teach the specific meaning of all terminology and talk through the concepts and ideas with them. Be aware of specific words with different meanings in different contexts, e.g. the word 'base' can be used as: a platform, or the bottom of an object etc.</li> <li>• Parents could help to revise concepts and information at home.</li> <li>• The presentation of a assignment could be adapted in a variety of ways, e.g. cut and paste, pictorial representation, a display, a tape recorded report, a model etc.</li> <li>• Complicated drawings and sketches could be done by the</li> </ul>

	<ul style="list-style-type: none"> <li>• The learner may experience problems with the planning of a task</li> </ul>	<p>learner tracing the drawing or photocopying a drawing.</p> <ul style="list-style-type: none"> <li>• Use simpler language and shorter questions. Ask fewer questions. Ask multiple-choice questions.</li> <li>• Reduce page turning. Try to put answers and questions on same page. Give good guidelines in order to sequence the task in a structured way. Talk the assignment through and make use of visual cues. Make sure the learner understand the steps of conducting and experiment. E.g. Aim, Method, Observation and Conclusion. A sequence map with picture cues can be used to map the sequence of which the learner needs to follow.</li> </ul>
<p>Science, society and the environment</p>	<ul style="list-style-type: none"> <li>• Due to the lack of life experience, the learner may experience difficulties interpreting the integration between science, society and environment.</li> <li>• The learner may not automatically transfer knowledge and skills learnt from one setting to another.</li> </ul>	<ul style="list-style-type: none"> <li>• It will be necessary to talk through concepts/ideas with them. Ask relevant questions to guide them to interpret this information. Use visual organizers such as timelines and flowcharts to help the learner it interpret the texts.</li> <li>• Be prepared to teach the skill in all new settings.</li> </ul>

Source: DOE (2005): Guidelines for Inclusive Learning Programmes, p.72-74.



The study maintains the teacher's understanding of her learners and their local context is a critical factor in the process of developing a flexible, inclusive biology curriculum that: (1) assists to address the low expectations and under-representation of learners with cerebral palsy in biology and related career fields; and (2) attempts to heighten awareness about career pathing for learners with cerebral palsy as an integral part of the curriculum.

However, the barriers listed are not specific for learners with cerebral palsy. A teacher, who has a learner with cerebral palsy in her biology class, does not have sufficient guidance from the document to plan a lesson involving practical experiments. According to the guidelines listed in the table, one of the barriers that learners with disabilities may experience with the Learning Outcome: Scientific Investigations is safety in the laboratory. The guidelines for the teacher states "due to limited motor control / lack of understanding / lack of memory for the correct procedure the student may be at risk of injury" and further suggests 'use of peer/adult support, the use of pictures to enhance safety procedures, and to allow the student more time to complete experiments'. However, the strategies are not detailed enough to assist teachers of learners with cerebral palsy in the biology and science classrooms (see Appendix E for an exemplar of inclusive instructional lesson material).

### **2.3.3 Curriculum and Assessment**

The curriculum also becomes a barrier when learning breakdown occurs through inadequate and inflexible assessment strategies. It is important to keep in mind that inclusive assessment strategies cannot be separated from learning and teaching, and that these strategies together form part of a continuous process (Department of Education, 2005). According to these guidelines, the main purpose of assessment should be to inform and facilitate effective and efficient teaching and learning, and to identify types of support required by learners. It is further suggested that the following

should be considered when selecting assessment methods for learners with physical disabilities:

- The use of an amanuensis (scribe) for physically disabled learners who are unable to record their responses in written form.
- Learners must be allowed to respond to assessment tasks in preferred formats.
- Based on individual needs, learners should receive sufficient additional time to complete assessment tasks.
- Where the assessment tasks require learners to draw, they should be allowed to respond through description. Educators could also make use of alternative questions.

A serious concern is that the guidelines are not specific enough for general teachers who had limited exposure to learners with disabilities. Further, it is not very helpful to advise teachers that “learners must be allowed to respond to assessment tasks in preferred formats” without providing appropriate exemplars. The Guidelines for Inclusive Learning Programmes (Department of Education, 2005) suggest the following general strategies for all learning outcomes:

- Some learners may need to write in a separate venue so that a teacher or trained person assists them to become settled, and to structure the task and time allocation. This could be a temporary arrangement.
- Long assessment tasks could be broken down into smaller chunks, on separate blocks of paper.
- Provide clear deadlines and checkpoints to measure progress.
- Some learners may need minimised visual distractions in the environment.
- Some learners may need to work in short units of time with controlled breaks.



- Demonstrate tasks / activities to learners and provide them with a checklist.
- Emphasise detail / important information through colour coding or isolation.
- For some learners drawings should be embossed or made in such a way that learners can feel them in order to respond.
- Provide visual auditory reminders indicating the amount of time left for activities.
- Inclusive learning, teaching and assessment strategies may be dictated by factors such as time, mode and necessity for substitution.

Although the list seems daunting, teachers will no doubt agree with the recommendations. However, without additional assistance in the form of teacher assistants, the suggestion for separate classrooms will not be manageable. Another concern is that the divide between rich and poor schools will increase as only the more affluent schools will be able to pay for teacher assistants, colour coding, embossing and monitoring. In less affluent areas the teacher will not always be able to do justice to the needs of all learners.

Furthermore, the Guidelines for Inclusive Learning Programmes (Department of Education, 2005) states that the inclusive learning site must have the following in place:

- Audio equipment: audiotape recorders; cassettes; batteries; microphones; dictaphones (headphones are permissible in order not to create a disturbance).
- Video equipment: video-recorders; televisions; video cameras; cassettes; batteries; closed circuit television.
- Assistive devices: FM system1; batteries for assistive listening devices.

- Computers: voice synthesiser programmes; braille printers; braille programmes; back-up systems; headsets / pointers.
- Electrical equipment: cables; power points; extension cables; adaptors.
- Accessible and appropriate venues:
  - Ensure that the inclusive learning, teaching and assessment strategies venue is accessible to all learners and staff (e.g. ramps and wide enough doors).
  - Ensure that bathrooms are close and accessible to all learners while still allowing privacy.
  - Ensure that equipment is accessible to all learners (e.g. pay attention to height of laboratory tables, etc.).
  - Adequate space for equipment and / or extra support staff (e.g. South African Sign Language interpreters, scribes and readers).
- Separate assessment / task completion venue for learners who use equipment which may distract other learners or for learners who need to complete tasks orally.
- Appropriate lighting for different needs (e.g. some learners may need dim light, others bright light).

Teachers will agree with above. However, the requirements are not possible in a low socio-economic area where the school fees of learners hardly cover the running costs of the school. The Guidelines for Inclusive Learning Programmes (Department of Education, 2005) further state that each school must have an assessment team with representation from the different phases, but fails to take responsibility for the training of these teams. In addition, “staff from special schools, special schools as resource centres, full service schools, university professionals and district officials” could train, monitor and support the school teams in the inclusion process. Again, the responsibility is left with the schools and not the Department of Education. Moreover, no mention is made of finances and resources needed to implement these recommendations. Although the initiatives from the National Department of Education are commendable, the reality is that



without adequate resources and training the successful inclusion of learners with disabilities cannot be assured.

#### **2.3.4 Curriculum and Accommodation**

One of the most serious ways in which learners are prevented from accessing the curriculum is through inadequate provision of materials or equipment they may need for learning to take place. Such barriers often affect learners with disabilities who do not receive the necessary assistive devices that would equip them to participate in the learning process. Assistive devices for learners with physical disabilities include, but are not limited to, mobility devices such as long canes and wheelchairs, writers, computers with screen access software, portable note takers with voice synthesisers. Lack of provision of assistive devices for learners who require them may impair not only the learning process but also their functional independence, preventing them from interacting with other learners and participating independently in the learning environment.

The Guidelines for Inclusive Learning Programmes (Department of Education, 2005) suggest educators and education managers address the following in their sites and classrooms:

- Accessible entrances to classrooms, laboratories, libraries, toilets, etc. must be provided for learners in wheelchairs.
- Ramps to accommodate wheelchair users.
- The height of desks, work surfaces and shelves accessible to learners, particularly wheelchair users.

As stated previously, the White Paper on an Integrated National Disability Strategy (Ministry in the Office of the Deputy President, 1997) emphasises that access to appropriate and affordable assistive devices is essential for people with disabilities to exercise their rights and responsibilities, and to participate as equal citizens in society and learning. However, the Education

White Paper 6 and the Further Education and Training Certificate 2008 (indicating the year of full implementation) are silent about appropriate accommodation in the biology or life sciences classrooms. Furthermore, the guidelines are silent about appropriate laboratory furniture and how learners with disabilities, in particular cerebral palsy, will be accommodated in the inclusive life sciences or biology classrooms.

### **2.3.5 Curriculum Adaptation**

The most significant conceptual change from current policy is that mainstream education will be required to change in order to establish an inclusive education and training system. It is expected that as schools become more 'inclusive', the general (mainstream) education classrooms will become more diverse. Therefore, general education teachers will be given increased responsibility with the inclusion of learners with disabilities in their classrooms. One of the major challenges facing inclusion in the South African context is the preparation of general education teachers to accommodate learners with special needs, especially in secondary classrooms.

Morrow (1999) asserts there is a conceptual connection between the content and method of learning, and the 'outcomes' of learning (what is learnt). Furthermore, that:

If the content and the outcomes of learning are conceptually related to each other then the wise choice of content will depend not only on the teacher's sensitive understanding of the local context but also on her conceptual understanding of what she is trying to teach. (p. 38)

For example, grade 10 biology learners have to study a suitable conservation project in their local communities. Learners with disabilities who are from disadvantaged communities, have different perceptions of the 'green environment' as referred to in the curriculum and textbooks. They



had a triple disadvantage. First, as stated before, black learners with disabilities are mostly confined to sub-economic homes where there is hardly any green environment. Second, their particular disabilities limited their opportunities to explore and discover their surroundings as more able-bodied learners could. Thirdly, the apartheid laws have marginalised and silenced them. Furthermore, blacks and the disabled have always received the least funding. Therefore, the teacher's understanding of her learners and their local context is crucial, because as teacher she makes a judgement about her learners' competence and about how best to enable the learners to become more competent practitioners.

In 2001, Kader Asmal, the former Minister of Education, asserted in the preface that the Education White Paper 6 "is therefore, another post-apartheid landmark policy paper that cuts ties with the past" (Department of Education, 2001:5). However, before 1994, the norm has been to approach curriculum development from the point of view of the middle-class, advantaged, able-bodied learners. Therefore, curriculum reform at the time did not afford input from learners with special needs and their biology teachers much attention. Likewise, the availability of adequate and easily accessible resources was not foremost on the agenda. Moreover, even now in the period after 1994, the process of transformation, especially as it relates to learners with special needs and biology education, does not receive much attention.

Education White Paper 6 views the curriculum as one of the most significant barriers for these learners. Furthermore, the same document states that barriers to learning can arise from aspects of the curriculum such as:

- The content (i.e. what is taught).
- The language or medium of instruction.
- How the classroom or lecture is organised and managed.
- The methods and processes used in teaching.

- The pace of teaching and the time available to complete the curriculum.
- The learning material and equipment that is used.
- How learning is assessed. (p. 19)

Furthermore, that the introduction of a flexible learning and teaching curriculum that accommodates different learning needs and styles is a means to overcome the barriers created by the curriculum. Moreover, that the task of the district support team (including curriculum advisors) is to assist educators in creating greater flexibility in their teaching methods and in the assessment of learning by providing illustrative learning programmes, learning support materials and assessment instruments.

The Overview of Revised National Curriculum Statement (Department of Education, 2000:10) claims all learning programmes, work schedules and lesson plans can be adapted to cater for the individual needs of learners and defines curriculum adaptations as any adjustment or modification to:

- Learning, teaching and assessment environment,
- Learning, teaching and assessment techniques,
- Learning, teaching and assessment support material that enhances a learner's performance or allows at least partial participation in a learning activity,
- Structure and number of learning programmes and
- Assessment.

The Guidelines for Inclusive Learning Programmes (Department of Education, 2005:1-7) assert the Revised National Curriculum Statement (RNCS) has several components that are flexible enough to allow for adaptation, and emphasizes participatory, learner-centred and activity-based education. Teachers are encouraged to consider any particular barriers to learning and/or assessment that exist in different Learning Areas and make



provision for these when developing learning programmes. In addition, it is claimed that assessment standards can be broken into finer components and that time allocation for a lesson plan can range from a single activity up to a term's teaching or more time if necessary, depending on the needs of the learner. Further, that time allocation and weightings regarding learning outcomes and learning programmes should vary according to the learner's needs. Moreover, it is encouraging to note that the Overview of Revised National Curriculum Statement (Department of Education, 2000: 12-14) asserts: (i) that the learning outcomes do not prescribe content or method, and therefore, content and methodology could be appropriate for a learner's needs, and (ii) that expectations can be adapted to the abilities of the learner within the framework of high expectations.

#### **2.4 Studies (and programmes) on Learners with Disabilities**

The American Association for the Advancement of Science (2002) reports that a generation ago, career opportunities for learners with disabilities were extremely limited. If they attended schools at all, learners with physical disabilities usually went to special or separate institutions, and programmed into fields 'appropriate' for them. For example, deaf students were often trained to be linotype operators because they would not be bothered by the noise. Blind students were taught to cane chairs or tune pianos. Finishing high school was considered an enormous accomplishment. However, there is sufficient evidence of the importance and value of science for learners with disabilities. Atwood and Oldham (1985) contend that the subject science is the most amenable for learners of all disability categories. Furthermore, Hadary and Hadary Cohen (1978) assert learners with behavioural problems could benefit from science's emphasis on cause-and-effect relationships and on using a systematic approach to finding order in the observed universe. Likewise, Corrick (1981) recommend learners with intellectual impairments could benefit from science because it could

increase their world knowledge and scientific process skills such as observing, classifying, predicting and inferring information. Moreover, Baughman and Zollman (1997) insist that learners with visual impairments could successfully be taught physics principles, e.g. measurement and velocity, by adapting the lab instruments such as meters, timers, balances, and volume cubes.

- **Centre for Studies on Inclusive Education (CSIE)**

The British Centre for Studies on Inclusive Education (CSIE) was established in 1982. The purpose of the Centre was to promote the education of disabled and non-disabled children together in mainstream schools and to end the practice of educating disabled children separately in 'special' schools. The CSIE worked collaboratively with organisations of disabled people, non-disabled practitioners and academics to develop expertise on inclusion of disabled people in mainstream settings, including the development and evaluation of practical tools for implementing inclusive education in schools and early years and preschool settings (CSIE, 2004).

CSIE provides the following ten reasons for Inclusion:

HUMAN RIGHTS

1. All children have a right to learn together.
2. Children should not be devalued or discriminated against by being excluded or sent away because of their disability or learning difficulty.
3. Disabled adults, describing themselves as special school survivors, are demanding an end to segregation.
4. There are no legitimate reasons to separate children for their education. Children belong together – with advantages and benefits for everyone. They do need to be protected from each other.

GOOD EDUCATION

5. Research shows children do better, academically and socially, in inclusive settings.



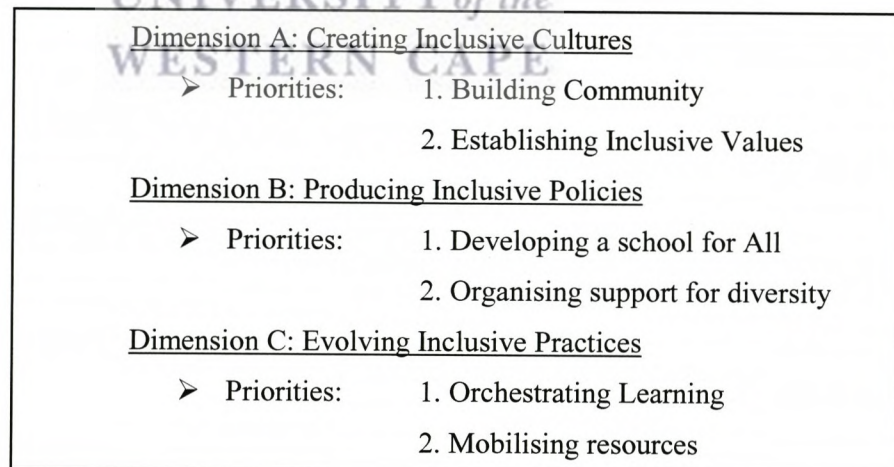
6. There is no teaching or care in a segregated school which cannot take place in an ordinary school.
7. Given commitment and support, inclusive education is a more efficient use of educational resources.

SOCIAL SENSE

8. Segregation teaches children to be fearful, ignorant and breeds prejudice
9. All children need an education that will help them develop relationships and prepare them for life in the mainstream.
10. Only inclusion has the potential to reduce fear, respect and understanding.

In pursuance of the above, the Centre for studies on Inclusive Education explored inclusion and exclusion along three interconnected dimensions of school life: (1) Creating Inclusive Cultures, (2) Producing Inclusive Policies and (3) Evolving Inclusive Practices. The following diagram provides a brief summary.

Diagram 2.1 CSIE Dimensions of school life



Source: Adapted from CSIE, 2004

It is important to note that since 1982 the Centre for studies on Inclusive Education (CSIE) was involved in the exploration and development of inclusive practices. Furthermore, Ainscow (2005) suggests that part of the

way forward for inclusion in the United Kingdom is set in the context of a school improvement initiative known as the IQEA (Improving the Quality of Education for All) that involves university academics working in partnership with networks of schools, in the UK and other countries. The IQEA approach to school improvement emphasises the following features:

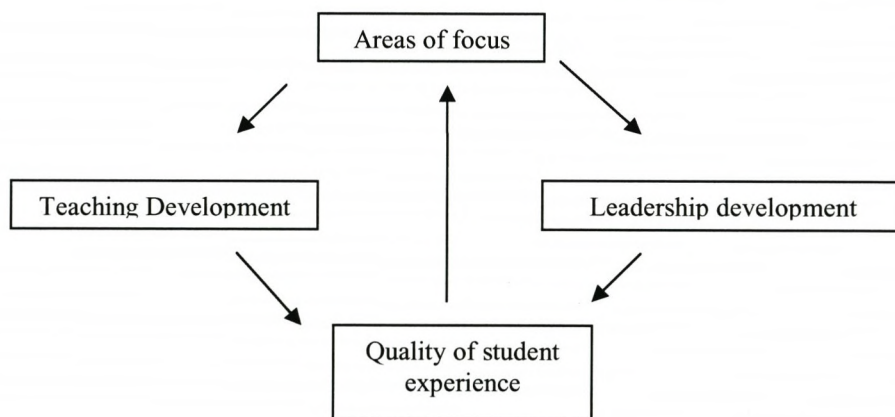
Developments in teaching and learning, through the creation of conditions within schools for managing change successfully:

- School improvement led from within schools, focusing on areas that are seen to be matters of priority;
- Collecting and engaging with evidence in order to move thinking and practice forward, and to evaluate progress; and
- Collaboration amongst colleagues in partner schools, and with IQEA consultants, so that a wider range of expertise and resources is available to support improvements in all of the participating schools. (CSIE, 2004)

The overall framework used to guide these activities is as illustrated in the figure below:

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Diagram 2.2 IQEA approach to school improvement



Source: CSIE, 2004.



The programme encourages groups of staff to: (1) examine the realities of their schools in relation to the four areas outlined within this framework; (2) develop areas of focus that will guide their improvement efforts; and (3) then look more specifically at ways in which teaching and leadership practices can be developed within their schools in order to bring about improvements.

Ainscow (2005) highlights that, at its best, this approach provides endless opportunities for developing new understandings as to how schools can become more inclusive. What are required are groups of stakeholders within a particular context to engage in a search for a common agenda that will guide their efforts. The author further claims that in so doing the members of the group are exposed to manifestations of one another's perspectives and assumptions, and at the same time, a series of struggles to establish ways of working that enable them to collect and find meaning in different forms of evidence. This allows good practices to be identified and shared, whilst, at the same time, drawing attention to ways of working that may be creating barriers to the participation and learning of some students.

- **AAAS (American Association for the Advancement of Science)**

According to the American Association for the Advancement of Science (2002, p.1) ENTRY POINT!, a unique internship program launched in 1996, demonstrates that students with disabilities have enormous career potential to meet the human resources needs of the private and public sectors. ENTRY POINT!, a collaborative project among AAAS, industry, and government agencies is designed to identify, screen and place undergraduate and graduate students with disabilities who are pursuing careers in science, technology, engineering or mathematics fields in paid summer internships. Furthermore, it is claimed to date ENTRY POINT! made more than 350 intern placements, and that ninety-two percent of the ENTRY POINT! alumni are either working in the science or engineering fields or are pursuing degrees in



graduate programs. In January 2002, AAAS published *Roadmaps and Rampways* that profiles 34 students with disabilities who completed at least one ENTRY POINT! internship and went on to graduate school or to pursue a career in science, technology, engineering or mathematics fields. Included in the publication is an account of the difficult journeys all students with disabilities had to travel to reach their goals. A case in point is Robert Hill, who has cerebral palsy, is in a wheelchair with limited use of his arms and legs, and has a 24-hour personal-care attendant. But that didn't stop him from finishing at the top of his high school class in Illinois. Robert is now a mechanical engineer at Boeing in Seattle, Washington where he designs devices for persons with disabilities in his spare time. Robert recalls an early childhood interest in mathematics and science and teachers who turned an interest in science and technology into a career goal. *Roadmaps and Rampways* (AAAS, 2002) claims that students' success can be attributed to the following four critical factors:

1. *Assistive technology*: Computers, software programs, and other assistive technology give students with disabilities full access to the Internet and research resources. This helps level the playing field in both education and professional employment.
2. *Families and communities*: For students with disabilities at every age, family and community support is essential. This support must continue for students who pursue science and engineering degrees and transition from campus to the competitive workplace.
3. *Mentors and role models*: Students with disabilities can face tremendous obstacles. Mentors and role models – teachers, professors, co-workers, or bosses – are pivotal in breaking down barriers and encouraging students to persevere in their chosen disciplines.
4. *Internships*: Students with disabilities greatly benefit from professional internships. They gain confidence in their own intellectual abilities and demonstrate to themselves, and to their



peers that they are valuable contributors. Exposure to competent interns with disabilities helps eliminate employers' fears and dispels prejudice within an organisation.

In addition, it is asserted that the impetus for success of *Roadmaps* students in careers in STEM (Science, Technology, Engineering, Mathematics) can be attributed to the following (AAAS, 2002:6):

- Learners came of age in what was called the 'Tech Generation', when overall growth in the economy was centred on information technology, biotechnology, and related disciplines.
- Changes in the laws regarding accessibility in K-12 and institutions of higher education made it possible for students to enter and /or graduate from high school and college. It is reported that some are pursuing doctorates.
- Learners were determined, smart and highly motivated.
- They had mentors and families willing to go the extra mile to help them.
- They chose STEM fields that value the power of the mind more than physical ability.
- Improved assistive technology allowed them to study, work and deal with their environments.
- They received the support they needed, not only for traditionally defined disabilities, but also for learning and other invisible disabilities, because educators began to understand and accept students learn differently and could be served by new, creative approaches.
- They participated in ENTRY POINT! which helped them prove their value, develop a work history and convince prospective employers that they would make excellent, productive employees.

Moreover, AAAS (2002:16-26) suggests future disability legislation, policies, and initiatives focus on five key areas:

1. Protect and strengthen the laws we already have.
2. Encourage businesses, educators, and health care providers to support the enabling technology that can foster independence.
3. Provide legislative incentives to encourage corporate internships and the hiring of people with disabilities.
4. Improve research on students with disabilities, and their progress in a variety of fields, particularly STEM. The areas identified are:
  - Best practices and critical pathways to student progress.
  - Financial support for students with disabilities.
  - Why students with disabilities either pursue or shy away from STEM careers.
  - The progress of underrepresented minorities with disabilities in education and their progression into STEM careers.
5. Encourage communities, business, and schools to include persons with disabilities in local organisations.

• **DO-IT (Disabilities, Opportunities, Internetworking and Technologies)**

DO-IT, an acronym for Disabilities, Opportunities, Internetworking and Technology, began in 1992. The project is primarily funded by the National Science Foundation (NSF) of the United States of America and the University of Washington at Seattle and aims to increase the participation of individuals with disabilities in science, engineering and mathematics programmes and careers. Burgstahler (1994), director of DO-IT, asserts there are three main factors which cause individuals with disabilities to be under-represented in science, engineering, and mathematics fields: (i) preparation of learners for transition to higher education and the world of work; (ii) access to facilities, programmes and equipment; and (iii) acceptance by educators, employers and co-workers. DO-IT offers summer study programmes, internetworking (access to the internet), mentoring,



special projects and events, and an advocacy programme to raise awareness of opportunities and possibilities for learners with disabilities in science, mathematics and engineering fields.

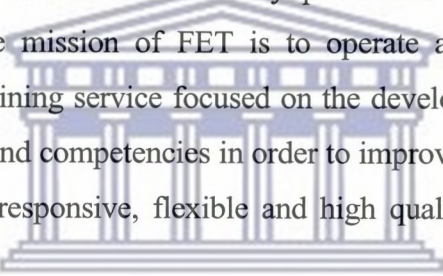
- **A South African Response: Special Schools as Resource Centres**

Skrtic, et al. (1996) assert that inclusion is the new cultural logic that corresponds to the emerging historical conditions of the 21<sup>st</sup> century, and highlight three interrelated levels of reform, namely (i) pedagogical reform at the level of the classroom, (ii) structural reform at the level of school organisation, and (iii) institutional reform (of human service systems generally) at the level of the community. The reported success of international university outreach programmes to re-dress the under-representation of learners with disabilities in science and technology careers (e.g. SNOW, EASI, DO-IT, ENTRY POINT!, etc.) can be attributed to a sound partnership between schools, university research programmes and the business sector. South African university outreach programmes also claimed to improve matriculation results in science, mathematics, engineering and technology, and asserted that this improvement in results will lead to increased access of learners in those career fields (Hartley, 2002; Ogunniyi and Isaacs, 2000). However, the programmes did not include learners with cerebral palsy and other disabilities in the project objectives. In the light of the above, the following section discusses the South African Department of Education proposal and guidelines for special schools as resource centres.

The National Curriculum Statement (NCS) Grades 10 -12 (Department of Education, 2003) asserts the Further Education and Training (FET) band is particularly crucial in terms of providing opportunities for all learners to develop their full potential along the most appropriate pathway and emphasises that all learners must be supported in realising their expectations to enroll for higher studies or the world of work. Further, that for the NCS to become truly inclusive, it is important that all teachers and educators

understand how to review their own understanding of teaching and learning in order to accommodate this new approach. The statement highlights the importance of the notion of inclusivity becoming a central part of the organisation, planning and teaching at each school and maintains this can only happen if all teachers have a sound understanding of how to recognize and address barriers to learning, and how to plan for diversity.

According to the Further Education and Training (FET) Act (Act 98 of 1998), and the Draft National Curriculum Framework, the FET system is aimed at providing access to high quality education and training that offers a wide range of learning options, which will equip learners with the knowledge, skills, attitudes, values and competencies required as individuals and citizens, as lifelong learners and as economically productive members of society. In addition, that the mission of FET is to operate an effective and efficient education and training service focused on the development of intermediate to high level skills and competencies in order to improve the quality of life of the citizens through responsive, flexible and high quality learning programmes, namely:

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- flexible pathways between the education and training sectors, and between the sectors and the labour market;
  - articulation among various programmes, qualifications and providers;
  - accumulation and transfer of credits;
  - recognition of previous self-learning and work experience for credits towards a qualification; and,
  - the provision of guidelines from the NSB for the structure and relationship of programmes and qualifications within FET.

The Further Education and Training Certificate (FETC) for grades 10 to 12 asserts these learning programmes must prepare **all** learners for life and work and that the major factor to be considered is the accommodation of the needs



of learners who experience barriers to learning. Furthermore, that separate learning programmes need not be developed for learners with disabilities, as learning outcome statements will apply equally to disabled and non-disabled learners.

The Education White Paper 6 (Department of Education, 2001:27) maintains particular attention will be given to policies, legislation and frameworks for the school and college system that will provide the basis for overcoming the causes and effects of barriers to learning. In addition “special schools and settings [will] be converted to resource centres and integrated into district support teams so that they can provide specialised professional service in curriculum, assessment and instruction to neighbourhood schools” (p. 29). Further, “central to the accommodation of diversity in our schools, colleges and adult and early childhood learning centres and higher education institutions is a flexible curriculum and assessment policy that is accessible to all learners, irrespective of the nature of their learning needs” (p.31) and therefore new curriculum and assessment initiatives will be required to focus on the inclusion of a full range of diverse learning needs (p.32).

Moreover, the Education White Paper 6: Guidelines for Special Schools as Resource Centres (Department of Education, 2005) states that institutional development is based on the following principles:

- Development activities must be set in the context of whole school improvement in order to achieve the goal of quality education for all learners. The programmes should aim to develop skills enabling the personnel to make the institution responsive to the diversity of learners.
- Teacher education colleges and other agencies working with teacher education, school clusters and individual schools need to network to maximise resources.

- Staff development activities need to aim at facilitating and moving schools towards becoming inclusive schools for all learners.
- Staff training should ensure portability of qualifications, multi-skilling, sustainability, addressing of functional barriers and optimum use of human resources.
- Training should focus on overcoming barriers to learning and development, and should be undertaken within current initiatives so that issues related to 'barriers' will form an integral part of any staff training. For example, curriculum training should be directly linked with addressing diversity in learner population.

Furthermore, the Further Education and Training Certificate-2008 (FETC - 2008) states that the transition from school to work and life is crucial for learners (with cerebral palsy) and suggests that programmes aimed at facilitating this transition should form a priority for education provision for these learners. Moreover, FETC-2008 asserts the learnerships described in the National Skills Development Act of 1998 will provide an important avenue for linking structured learning to a structured work environment, and for providing access routes from learning to work for **all** learners, including learners with disabilities. In addition, occupationally directed programmes should be developed in accordance with the skills needs of industry.

South African attempts at re-dress should learn from the experiences and research findings in the international arena. The 20-year plan, as outlined in Education White Paper 6, acknowledges the challenges and provides valuable pointers for further research. However, the guidelines are silent about collaboration between special schools as resource centres, university outreach programmes and the business sector. Moreover, the guidelines provided in the policy documents are very general, and does not provide any specific strategies for biology teachers. The role of special schools as resource centres should be extended to include programmes on career pathways for learners with cerebral palsy in biology and related fields. A



key objective should be flexible teaching approaches, accommodation strategies and assistive technologies that adequately accommodate learners with cerebral palsy in the biology classroom.

## 2.5 Summary

Chapter two examined the theoretical framework for the study and presented different perspectives on disability and voice as background for the international and South African journey towards inclusion. The historical, socio-political and economic context of teaching and learning of learners with cerebral palsy were addressed, highlighting the struggles learners with cerebral palsy still have to face. Disability as social construct was contrasted with the medical model of disability that have informed teaching and learning in South Africa prior to 1994. The study contends that before 1994, learners with cerebral palsy were socialised and schooled to believe that disability is the problem, and this view has shaped and formed the learners' view of themselves and their possibilities.

Furthermore, education policy documents were examined in an attempt to highlight the curriculum as barrier to learning and development of learners with cerebral palsy - in particular the strategies suggested in the Guidelines for Inclusive Learning Programmes (Department of Education, 2005). The following conclusions were reached. The guidelines do not assist the teacher of learners with cerebral palsy to adequately accommodate learners in the biology and science classrooms. Further, that the suggested strategies are not detailed enough for teachers to develop *inclusive* instructional lesson material. The final section of the chapter discussed the Education White Paper 6 proposal for special schools as resource centres against the background of different international inclusive institutional programmes.

Chapter three will discuss the research design and procedures employed to foreground the voices of learners with cerebral palsy in an attempt ascertain why biology learners with cerebral palsy are underrepresented in careers related to science and technology.





## CHAPTER 3

### RESEARCH METHODOLOGY

Make sure your students understand that they have very important things to contribute regardless of their disabilities. It is so easy for people with disabilities, just like other people who are disadvantaged by the dominant culture, to believe that they don't have anything to contribute.

(Voice of Ron, as quoted by Thousand, et al. 1999:326)

#### 3.1 Introduction

This chapter presents the research design and procedures employed to investigate the under-representation of learners with cerebral palsy in biology and related professions. As stated in chapter one, the main purpose of the study was to listen to the voices of learners with cerebral palsy in an attempt to find out if (and why) they have low expectations of career possibilities in biology, and uncover the various barriers that could have contributed to low expectations and under-representation of learners. The methods and procedures used to obtain and analyse the data collected will be discussed.

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#### 3.2 The Research Design and Procedures

##### 3.2.1 *Research Design*

This is a collective case study of the personalised stories of five former learners with cerebral palsy who attended a special school prior to 1994, highlighting how the experience shaped their future career paths. Stake (2000) identifies three types of case study: (i) an intrinsic case study, (ii) an instrumental case study, and (iii) a collective case study.

- Intrinsic case study

In the intrinsic case study the researcher's primary interest is in understanding a specific case. In this single-case design, the researcher describes the particulars of the case in order to shed more light on the case. The researcher "temporarily subordinate other curiosities so that the stories of those 'living the case' will be teased out" in an attempt to gain better understanding of the particular case (Stake, 2000: 437).

- Instrumental case study

Stake (2000) describes a case as instrumental when the researcher's main interest is in understanding something other than a particular case; the case merely facilitates understanding of something else. The researcher is less interested in making conclusions that are specific to the case and its particular setting than in making conclusions that apply beyond a particular case.

- Collective case study

Stake (2000) defines a collective case study as an instrumental study extended to several cases. The researcher jointly studies a number of cases in order to investigate a phenomenon, population, or general condition. It is believed that understanding the different cases will lead to better understanding about a still larger collection of cases. Advantages are: (i) a comparative type of study can be conducted in which several cases are compared for similarities and differences; (ii) a theory can be more effectively tested by observing the results of multiple cases; and (iii) one is more likely to be able to generalise the results from multiple cases than from a single case. A disadvantage is that the depth of analysis will usually have to be sacrificed because of the breadth of the analysis.

A collective case study was chosen as the number of biology learners with cerebral palsy who attended the particular special school, and completed grade 12, was very small. The aim was to conduct in-depth interviews with



learners who had above average performance in biology, physical science and mathematics and pursued careers related to the three subjects, and to listen to the accounts of learners who had more or less comparable experiences. Three of the participants attended the special school up to grade 7 and thereafter completed grade 12 at a mainstream school. The other two started at age three and completed grade 12 at this special school.

### **3.2.2 Research Procedure**

A qualitative research design was considered appropriate for the purposes of the study. According to Bratlinger, Jimenez, Klingner, Pugagh & Richardson (2004) descriptive information from qualitative studies leads to an understanding of individuals with disabilities, their families, and those who work with them. Furthermore, Bratlinger et al. (2004:196) assert qualitative research designs can “explore the nature and extent to which a practice has a constructive impact on individuals with disabilities, their families, or on settings where they tend to work, reside, or be educated”.

The following stages for critical qualitative research as outlined by Carspecken (1996: 45) were used as guide,

#### **Preliminary Steps**

Stage One: Compiling the primary record

Stage Two: Preliminary reconstructive analysis

Stage Three: Dialogical data generation

Stage Four: Describing system relations

Stage Five: Systems relations as explanations of findings

For the purposes of the study the stages listed above were adapted as follows:

- **Stage one: Monological Data Generation - “Finding our voice”.**

During this stage the researcher collected relevant data about the case without engaging any of the participants in dialogue.

- **Stage two: Dialogical Data Generation – “Hearing our voice”.**

During this stage the researcher compiled profiles and stories of the data collected during qualitative interviews.

- **Stage three: Analysis and explanation of findings – “Breaking the silence: voices and meanings”.**

During this stage the researcher attempted to describe and understand the different themes emerging from the data.

Table 3.1 provides an outline of Carspecken’s research design and the stages adapted for the study.



Table 3.1: Adapted Qualitative Research Design

<b>RESEARCH DESIGN</b>			
Carspecken's stages for qualitative research		Stages adapted for this study	
<b>Stages</b>	<b>Brief description</b>	<b>Stage</b>	<b>Brief description</b>
Preliminary Steps	Creating a list of research questions, a list of specific items for study, and examining researcher value orientation.	<b>Stage one</b> <b>Monological Data Generation -</b> "Finding our voice".	Creating a list of research questions and a list of specific items for study. Examining the researcher's value orientation. Compiling the primary record from document analysis. Description of the site of investigation. Introspective journey of researcher. Observations and class visits.
Stage One	Compiling the primary record through the collection of monological data.		
Stage Two	Preliminary reconstructive analysis.		
Stage Three	Dialogical data generation through qualitative interviews.	<b>Stage two</b> <b>Dialogical Data Generation -</b> "Hearing our voice".	Compiling stories from dialogical data. Generation of qualitative interviews.
Stage Four	Describing system relations.	<b>Stage three</b> <b>Analysis and explanation of findings -</b> "Breaking the silence – voices and meanings".	Analysis of data. Describing and understanding different themes emerging from data.
Stage Five	Using system relations to explain findings.		

Source: Carspecken (1996), p. 45.

## Stage One: “Finding Our Voice” – Monological Data Generation

### *Formulating the Research Questions*

First of all, a list of research questions was created. General questions of interest about the social site of investigation and the problem statement were generated. Carspecken recommends making a list of everything that interest you about the site and the problem to be investigated. The problem identified for this study was the under-representation of black, disadvantaged learners with cerebral palsy in biology careers. The first step was to brainstorm a list of general questions of interest about the social site of investigation and questions about the problem to be investigated - the site of investigation being the biology classroom in the special school for learners with cerebral palsy and other physical disabilities. Although the researcher attempted to generate a comprehensive list, the questions changed as the study progressed. The list included the following:

- Are learners with cerebral palsy interested in biology?
- What are the pass rates in biology for grade 12?
- Do learners with cerebral palsy see themselves as future scientists?
- How do teachers and administrators view learners with disabilities?
- What is the teaching and learning context at the site of study?
- What is included in the curriculum? Who decides on the subjects to be included?
- What career guidance programmes are offered?
- What are the social conditions/ home conditions of learners?

Next, a list of specific items for examination was compiled. The list included:

- The specifications of the social routines of the site of investigation to be studied.



- The specification of documents, laws, media products.
- The specification of participants who will be interviewed.

In the case of learners with cerebral palsy and their under-representation in biology careers, the researcher was interested to find out if there is a relationship between the content and method of learning at the special school, and the under-representation of black disadvantaged learners with cerebral palsy in careers related to biology.

From the two separate lists the research questions were formulated (see chapter one). The next step was to decide what needed to be studied to satisfy the researcher's interests as listed above. The list included:

- To listen to the voices of learners with cerebral palsy.
- Find out if (and why) learners with cerebral palsy have low expectations of career possibilities in biology.
- Uncover the various barriers that could have contributed to low expectations and under-representation of learners with cerebral palsy in careers related to biology.

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A journal of notes on readings and informal discussions with the people at the site was kept in order to assist with explorations of the researcher's value orientations and biases. A primary record was built up through note taking and journal entries. An intensive set of notes was built up for the site of focus and a looser journal kept for observations and conversations made during interactions with learners and teachers at the site.

An attempt was made to describe the participants from the perspective of an uninvolved observer. This was somewhat difficult to do, as the researcher was a resident teacher at the site. The researcher took unpaid study leave for the duration of the field study in order to observe the social routines from the perspective of an 'uninvolved observer'.

### ***Document Analysis***

Meaningful documents were found at the site and their relevance was established. Types of documents and records included grade 12 examination results, learners' education profiles, their medical histories, psychology reports and recommendations, curriculum policy, admission policy, vision and mission of school. The documents were sufficiently described and cited (see following section). In addition, sound measures were used to ensure confidentiality of private documents. The primary record as it has been built up so far was analysed. An attempt was made to articulate and reconstruct linguistically those cultural themes and system factors that are not observable, and up to this point of the research, unarticulated by the participants.

### ***Sites, Settings and Locales, and the Social System: A Description of the Site of Study***

Carspecken (1996) provides the following definitions for sites, settings, locales and systems:

- Social *sites* are specific spatial and temporal regions within society where people interact. Usually, a social site will be characterised by routine activities.
- Social *settings* are tacit understanding reached between actors concerning the type of interaction they will engage in. Settings are not observable and do not depend on a physical surrounding or even the social site within which they are constructed. But settings are usually influenced, conditioned by many factors associated with the physical surroundings.
- *Locales* are patterned activities taking place in areas surrounding a social site. Locales are influenced by the social sites they contain and in turn influence these sites.



- *Social systems* are the result of external and internal influences on action that are very broadly distributed throughout society. They are reproduced through patterned activity stretching across wide reaches of space and time. (p. 37-38)

The site of the study, a special school for learners with cerebral palsy, is described as observed in 2004. Documents and records found at the site were used to describe some of the changes that occurred since 1994, the reference point for the study. The school was first started in the early 1980s in a makeshift building. During the late 1980s the learners and staff were relocated to the present site, a well-resourced facility in a typical township. The school was designed to accommodate learners with cerebral palsy: there are ramps at all the entrances and exits; corridors are enclosed to protect against the harsh cold and wet winters and wide enough for two wheelchairs to pass comfortably.

Most of the classrooms have direct access to toileting facilities. The school library is well resourced. The school has a gym, a large assembly hall and a hostel that can accommodate approximately one hundred learners with disabilities. There is adequate playground space. There are well-equipped speech therapy, occupational therapy and physiotherapy rooms. In addition there is a resident medical sister and nursing sister. The local clinic is approximately five-minute drive from the school.

The biology laboratory is well resourced as the school does its own purchasing. Teachers bought quality equipment. However, the benches are not adjustable and too high for wheelchairs. Furthermore, the gas outlets on each bench could pose a safety risk as the learners may fiddle with the taps. Although the gas output is controlled from the back room, the teacher has to be extra vigilant to ensure that no taps were accidentally left opened when the main gas source is opened. The biology teachers were innovative in accommodation strategies employed. For example, the microscope was

lowered to the level of the learners in wheelchairs in order to include them in all the activities. Various outdoor activities, for example field trips to nature reserves, University Science Departments and cleaning up of rivers all formed part of the outdoor curriculum and proved valuable learning experiences to learners, teachers and outside practitioners. Every effort was made to ensure learners in the biology classroom were included and capable of achieving success.

The school caters for learners with disabilities from pre-school to grade 12. The majority of learners are from poor socio-economic areas. Learners are admitted from age four. Initially the school admitted learners with cerebral palsy and physical disabilities, but in the late 1990s and 2000s learners with learning difficulties were referred to the school. Prior to 1994, therapists and medical doctors played a more prominent role in admissions and referrals. A learner was often admitted more for therapy than academic reasons. At the time of the study there were learners with cerebral palsy and other physical disabilities, learners with learning difficulties (LD), learners with behaviour problems and learners from different language groups, namely English, Afrikaans and Xhosa.

A multi-disciplinary team (speech therapists, occupational therapists, physiotherapists, psychologists, medical staff, and the class teacher) monitors the learner's symptoms and progress when first admitted to the site. This group of professionals with specialities in different areas gather information about the learner's development and keep the parents informed about the learner's needs and problems, as well as the medical reasons for these problems (if known). The multi-disciplinary team make recommendations for treatment and education.

The curriculum committee is comprised of representatives from different sectors in the school. A key objective of the school curriculum committee is to provide teachers and therapists with adequate information and training in



curriculum development, monitoring and control. In addition, to ensure that learning and therapy programmes are realistic, attainable and supportive of the diverse school population. In 1980s and early 1990s the school followed the curriculum offered for a particular race group. After 1994, the school followed the provincial curriculum (for all race groups). The school's first grade 12s wrote the final examination in 1987. Up until 1985 learners had to go to a mainstream school to complete grade 12. At that time mainstream schools were not equipped to accommodate learners with cerebral palsy and other disabilities.

It is reported that when the Provincial Department of Education was approached for permission to offer higher-grade subjects (i.e. for university entrance), the response was that learners with cerebral palsy would not be able to cope. However, in 1987, two learners from the school obtained matriculation exemption (i.e. they qualified to enrol for university degrees), with biology on the higher grade. In 2002 the school entered learners for the national examinations in biology.

At the site of investigation the "medical model" defined to a great extent how the content was presented. Learners were at first exempted from doing mathematics, but that changed since the introduction of the Revised National Curriculum Statement (RNCS). In 2004 all learners at the site did mathematics up to grade 11. However, the curriculum manager admitted that it was a major up-hill battle to convince the teachers and learners.

Career guidance in 2004 was more general and not specific for the biology professions. Two 30-minute periods per week was allocated to Life Orientation (career guidance) for learners in grades 7 to 9. Learners in grades 10 to 12 learner were offered career guidance by a qualified career counsellor for one hour per week. In addition learners attend career exhibitions and encouraged to apply for higher studies at various tertiary institutions. Learners were also assisted to apply for bursaries and loans.



### *Researcher's Introspective Journey*

As suggested by Carspecken (1996), the researcher explored her own value orientations and biases as a preliminary step before entering the research field. All thoughts and feelings were recorded in a special notebook in an attempt to uncover the researcher's biases throughout the research project. In addition thick detailed descriptions of each case were documented. The reconstructions of the introspective journey as researcher provided a reference for the analysis of the mono-logical and dialogical data collected. The reconstructions presented the problem from the point of view of the researcher - an account of how her prejudices and value orientation were shaped by the belief system and social conditions at the site.

The reflections in the journals marked significant incidents on the journey as teacher-researcher in biology, special education and inclusion. The year 1994 (the dawn of the first democratically elected government) was the reference point for the study to track how far learners with cerebral palsy have come. It was encouraging to note that since 1994 learners with cerebral palsy at the special school were more assertive, more aware of their rights, and able to advocate for what they want out of life.

Two interesting cases encountered were Petra and Nancy (fictional names). Petra was a bright, hard-working 17 years old with the same dreams and aspirations as any other teenager. She described herself as a person with diplegic cerebral palsy that mainly affects her walking. Petra mostly uses crutches, and sometimes a wheelchair. She started schooling at the site of investigation in 1987 when she was three years old and has been at the site ever since. Petra received physiotherapy while at school, and also had operations to loosen her tendons. She was one of the top students in her class in mathematics and biology. When asked what she wanted to do after school, she expressed a desire to do forensic science – possibly the influence of television. When the researcher spoke to her in 2004, Petra expressed



doubts about her career prospects. In 2005, when the researcher enquired about Petra, she was told that Petra had dropped out of school before the final grade 12 exams.

Nancy described herself as a person with diplegic cerebral palsy. She has stiff walking gait. Nancy also started at the site when she was three years old. While at school she received physiotherapy and had a few operations on her lower legs to assist with walking. Nancy was a bright 16 year-old at the time and expressed a desire to become a doctor. Like Petra, she was top of the class in biology and mathematics. However, when the researcher spoke to her in 2004 when she was in grade 11, Nancy had changed her career focus to Business Management “because that is where the money was”. Upon reflection the researcher noted that in 2004, ten years after South Africa became a democracy, learners with cerebral palsy still do not continue with careers in biology, science and mathematics. Petra and Nancy both loved biology and mathematics, and were top of their class from preschool to grade 10, yet did not pursue careers in science.

Concern raised by a curriculum advisor proved to be another important marker on the journey. The advisor reported a ‘dilemma’ faced when moderating learner portfolios in natural science at a special school. According to the advisor the standard of work presented in the learners’ portfolios was below the norm, the norm being the work done by able-bodied learners in mainstream schools. However, in the light of the teacher’s explanation that the learner had a terminal illness, the advisor ‘passed’ the portfolio. It appears as if the teacher had a lower expectation of the learner’s performance because of the learner’s physical condition. This incident highlighted the need for adequate training and education for all teachers (and curriculum advisors) of learners with disabilities.

The school visits and observations of inclusive science classrooms in the U.S.A. was another notable signpost on the researcher’s journey. The

classroom observations provided a unique opportunity to compare different districts and schools in terms of time scheduling, accommodation of learners and different inclusion strategies employed. In addition, the visits and discussions with teachers and managers presented an opportunity to hear different views on inclusion, what teachers regarded as beneficial and what challenges remained.

The class visits provided an opportunity to observe how teachers attempted to implement the laws and guidelines governing inclusive education in the United States of America (USA). In the USA the school district determined the type of school programme and availability of resources. Therefore the socio-economics of the local community will determine and reflect the resources and accommodations employed. Learners who need extra academic support have an individual educational programme (IEP) that is jointly compiled by the class teacher, special education teacher, parent and learner. Schools have special education classrooms and special education teachers assigned to individual learners. Learners with IEP's are accommodated in the main classroom (also termed the basic classroom or the inclusion classroom), and at other times the learner is "pulled-out" for individual attention with the special educator.

Moreover, the visits broadened the researcher's view of the challenges and benefits of inclusion and provided an opportunity to compare the USA system with the South African school system. The school visits afforded an opportunity to reflect on curriculum reform in South Africa and learn from different sites, settings, locales and social systems (see Appendix F).



## **Stage Two: “Hearing Our Voices” - Dialogical Data Generation**

During this stage data was generated with the participants. Face-to-face interviews were conducted with learners with cerebral palsy in an attempt to foreground the voices of the learners. The researcher assumed the role of facilitator and conducted qualitative interviews with the participants. The gestures, words emphasised, body language and other mannerisms that added context to the content were recorded. This assisted to isolate and define important categories and themes.

### ***Selection of Participants***

The researcher consulted the examination results and profiles of learners to identify and make the final selection of suitable participants for the study. One of the selection criteria was that the participants should have started schooling at the site in nursery school and finished grade 12 at the special school or at a mainstream school. The learners should have completed grade 12 before 1994, the reference point of the study. The researcher first approached Thelma, one of her ex-learners, who was instrumental in contacting and explaining the purpose of the study to prospective participants. Thelma as ‘go-between’ was critical in securing the permission of the participants.

All the participants are persons with cerebral palsy and came from the previously disadvantaged sector of society. Those interviewed were in their late twenties/early thirties and had work experience or studied at a tertiary institution. The participants were chosen because they had time to reflect on life in school and life out of school, and could give an account of how their experiences at school influenced their career choices.

### *Interview Items*

The formulation and generation of the items for the interview were derived, developed and validated as explained in stage one. The first set of questions was revised to more accurately reflect the essence of the study. The revised set of lead questions was “tested” during informal sessions with Petra and Nicole, teachers and principal at the site of study. Leading questions included:

- How will you describe yourself? Tell me about yourself.
- What does the term disability mean to you?
- What did you most/ least enjoy most about biology and/ natural science, and why?
- While at school, did you consider a career in science?  
If yes, why? If not, why?
- Do you know any scientists with disabilities?
- Can you picture yourself as a future scientist?  
If yes, why? If not, why?

### *Interview Procedure*

The researcher confirmed the interview (time and place) a week before the scheduled date, and re-confirmed an hour before the interview. Before the start of the interview, the researcher explained the purpose of the study and the possible outcomes. A brief overview of the leading questions was provided. Assurance of confidentiality and anonymity were given. The researcher also indicated how much time would be taken for the interview and asked if there were any questions for clarification. Permission was asked to tape the interview in order to ensure that information is accurately reported. The machine was placed in full view of the participant. The researcher offered to stop taping on request, and made it clear that recording is not a pre-condition of the interview. The researcher took brief notes about



the gestures, body language and facial expressions of the participant while the tape recorder was running.

### ***Location of Interviews***

It was agreed that the participant could chose the location where they would be most comfortable. Jason's interview was conducted at his home and Peter's at his place of work. Thelma, Raymond and Jimmy on the other hand chose public eating-places. This could mean that they were not comfortable at home or at their place of work. The location of the interview affected the quality of data received. Rich data were collected from Jason and Peter's interviews.

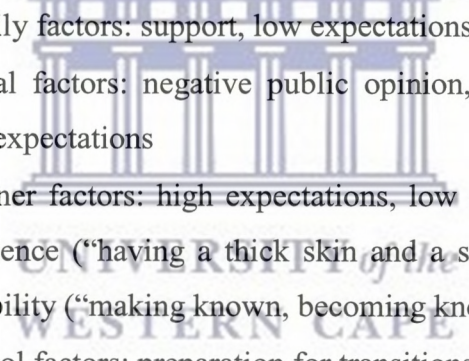
### **Stage Three: "Breaking the Silence - Voices and Meanings": An Analysis**

For the purpose of this study Jason and Peter's stories were foreground to highlight the issues related to the under-representation of learners with cerebral palsy in careers in biology. The accounts from the other learners were used to substantiate Jason and Peter's stories and to provide different insights and points of view. The learners' stories are fore-grounded against the backdrop of voices and reflections of other learners and teachers who were at the site in 2004 when the study was conducted. Bratlinger, et al. (2004:199) asserts that, "these personalised accounts [by the learners] provide insight into how classification [of disability] and [the specialised, separate schooling and] treatment are perceived by people with disabilities and their families" and "by focusing on the participants' personal meaning, qualitative research [is likely to] 'give voice' to people who have been historically silenced or marginalised".

### *Transcribing*

As stated before, a tape recorder was used as backup to the field notes and also served to verify the dialogues (see appendix for excerpts). The researcher transcribed the cassettes, and afterwards asked participants to verify what transpired from the transcripts. Documents and reports obtained at the site were used to correlate the incidents and experiences reported by the participants. In addition, the participants mentioned each other and this also served to verify the data collected. The teachers and principal at the site also confirmed the participants' stories.

The interviews were transcribed and common themes identified. The following themes were highlighted:

- 
- Family factors: support, low expectations/ high expectations
  - Social factors: negative public opinion, stereotypical attitudes, low expectations
  - Learner factors: high expectations, low self esteem, depression, resilience (“having a thick skin and a strong heart”); views on disability (“making known, becoming known”)
  - School factors: preparation for transitions, “time out, time lost”, career guidance

During this stage explanations for the experiences and reconstructions were suggested, drawing from the successful cases and stories encountered in literature and practice. Every attempt was made to represent the stories of the participants sensitively and fairly and to ensure confidentiality (see Appendix C for excerpts from Jason's transcript).



### 3.3 Data Analysis: Credibility Measures

The researcher was the biology and mathematics teacher at the site of study for more than 10 years, and was fairly familiar with policies and procedures at the school. The staff at the site readily accepted her in the 'new' role as researcher. The participants also accepted her in the role as researcher because they were aware that the researcher was a biology and mathematics teacher at the special school.

Lincoln and Guba (1985) suggest that for the purposes of a qualitative study it is more appropriate to use the following terms to discuss credibility measures during data analysis:

- *credibility* instead of validity, i.e. how did you attempt to establish the constructed realities of the participants and those realities perceived by you as researcher
- *transferability* instead of external validity, i.e. the extent to which the findings can be applied to other situations
- *dependability* instead of reliability, i.e. the stability of data over time or the extent to which findings may be replicated
- *conformability* instead of objectivity, i.e. authenticity or trustworthiness of views of all the stakeholders ( p. 219)

Lincoln and Guba (1985) advise the following measures will increase the degree of credibility: prolonged engagement in the setting, persistent observation, triangulation of data, peer debriefing. In this study the following measures were used to attempt to establish the constructed realities of the participants and those realities perceived by the researcher:

- Records and document analysis
- Personal reflections
- Field notes
- Informal discussions

Two types of data were collected: (i) *monological* data, i.e. records and document analysis, researcher value orientation, reconstructive analysis and observations, and (ii) *dialogical* data, i.e. qualitative interviews with the participants. The data collected through informal discussions, observations and document analysis at the site served as a tool to validate the data collected during the interviews. The researcher confirmed transcripts and field notes by comparing and contrasting them with information gathered by monological data generation.

Data collection at the site of investigation posed some difficulties. The researcher decided to collect the data over the period of a school year. The records and documents identified in stage one of the research design were collected during the first term of the school year. Throughout the study the researcher kept a reflective journal where she noted her experiences as qualitative researcher. Included were personal reactions, modifications of theories, questions, assumptions and expectations. This formed the reconstructive analysis of the study.

During the second term the researcher took study leave in order to compile the primary record, analyse the records and documents collected at the site, and formulate the research questions. This provided an opportunity to visit the school and observe the settings as an “uninvolved observer” (Carspecken, 1996). This was the more difficult part. However, the fact that the researcher was not “officially” part of the school eased the way for closer observations, reflections and more relaxed discussions with members of staff. The data collected during this stage, together with the information gathered during the overseas class visits, provided valuable insight for the development of the interview questions.

The interviews were conducted during the second and third term. One of the difficulties of being a teacher-researcher is that the current learners were too close to the researcher. For that reason it was decided to interview former



learners who were mature enough to reflect honestly on their experiences at the special school. The participants selected were former learners with cerebral palsy who had attended the site before 1994.

As the study progressed, the initial assumptions and expectations were shaped and changed according to the information collected and analysed at different stages of the process. The participants reviewed the information gathered during the interviews to ensure accuracy and to minimise misunderstandings of meanings.

To increase transferability, the researcher provided a thorough description of the site, settings and locale of the site of study. In addition the researcher compiled “thick descriptions” of data collected during stage one and two of the design (Lincoln & Guba, 1985; Carspecken, 1996).

In order to increase dependability or the stability of data over time, careful recordings of the details of each stage of the process were kept. These details could be used in what Lincoln and Guba (1985) called an inquiry audit, which can assist the researcher to trace back in the event of a misinterpretation of data. Changes can then be made to restore dependability and confirm that procedures were followed fairly and correctly. Finally, the examination records and profiles (teacher-, therapy- and psychology-files) confirmed the trustworthiness of views expressed by the participants.

#### **3.4 Ethical Principles Adhered to During the Research**

Permission was obtained from the education department to conduct research in the school in their jurisdiction and was agreed that a copy of the completed study will be delivered to the Department of Education. Secondly, permission was obtained from the principal of the selected school (see appendix B). The learners were given consent and confidentiality forms

before the interviews were conducted, with an explanation of the purpose of the study attached (refer to appendix A). Permission from parents was not required as the participants were over the age of 18. Anonymity and confidentiality were assured in all cases. The researcher transcribed the audiocassettes and field notes (see examples in appendix C and D).

### **3.5 Summary**

The study is based on the premise that the voices of the learners and the stories they tell are central to the process of curriculum development. Learners with disabilities have their own stories to tell about physical suffering and pain they endure, and the socio-economic and political challenges they face as they battle against real and imagined obstacles.

The study was an attempt to foreground the voices of the participants that were interviewed, against the background of the historical, political and social realities of their classroom or school environment. The stages described in the research procedure were designed to bring the voices of black learners with cerebral palsy from the margins to the centre.

In addition, the chapter provided a detailed account of the presentation of the problem from the point of view of the researcher, an account of how her prejudices and value orientation were shaped by the belief system and social conditions at the site.

In chapter four the results and findings of the study will be discussed.



## CHAPTER 4

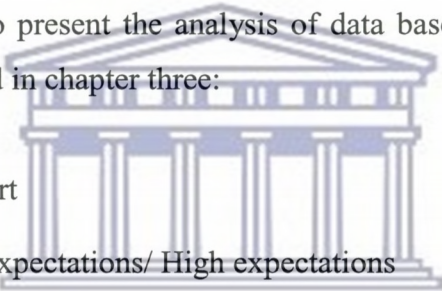
### THE RESULT

If you want to know me, then you must know my story, for my story defines who I am. And if I want to know myself, to gain insight into the meaning of my own life, then I too, must come to know my own story.

(MacAdams, 1997:11)

#### 4.1 Introduction: Breaking the Silence

The study attempted to foreground the participants' early lives to ascertain what might have influenced them to be what they are today. The focus of this chapter is to present the analysis of data based on the following sub-themes identified in chapter three:

- 
- Support
  - Low expectations/ High expectations
  - Negative public opinion and stereotypical attitudes
  - Resilience (“having a thick skin and a strong heart”)
  - “Making known, Becoming known” – awareness of disability
  - Preparation for transitions
  - “Time out, Time lost”
  - Career guidance
  - Views on special schools

## PART ONE

The participants who shared their stories all attended the site of investigation and started their schooling at the site at approximately age three. Fictitious names were used to protect the identities of the participants.

### 4.2 Profiles of Participants

- *Profile of Jason*

Jason (fictional name) was 27 years old at the time of the interview in 2004. He started at the special school when he was four years old. He describes himself as a learner with cerebral palsy and hydrocephalus. When Jason talks about his love for science and math his face lights up and he becomes animated. He relates that he was interested in science from an early age, always trying some or other experiment at home. He was a bright student, top of the class since he started grade one. Jason left the special school in grade 8 to attend a mainstream school. He talks about the struggle to adapt to the way of doing things in a regular classroom. But, as he says, he worked extra hard to fit in. In grade 12 Jason became ill after the June examinations and was advised not to write the final examination. After that episode the doctors advised him not to continue with any further studies, fearing that the concentration would be detrimental for the build-up of pressure on his brain. After a year of “rest” Jason continued his academic career and enrolled at the technikon, but his illness prevented him from successfully completing the programme.

- *Profile of Peter*

Peter (fictional name) was in his early thirties at the time of the interview. At that time he was the chief executive officer (CEO) of a Black Economic Empowerment (BEE) company. Peter describes himself as person with tri-



plegic cerebral palsy. He started the special school at age three and finished grade 12 at the site. He was the first learner to obtain an exemption (pass that qualifies you to study at university), with biology and mathematics. After grade 12 Peter went to university and completed a B.Com degree. He was busy with his MBA at the time of the interview. Peter was chairperson of the Student Representative Council (SRC) while doing his undergraduate courses at university. He was also part of the Task Team for Persons with Disabilities. Peter admits that at first he did not see himself as disabled and did not want to be labelled as such. However, today he recognises that his acknowledgement of difference was an important part of his journey.

- ***Profile of Thelma***

Thelma (fictional name) was 30 years old at the time of the interview. She describes herself as a person with diplegic cerebral palsy. Thelma started schooling at the site at the age of three in 1975 and finished grade 12 in 1989. Even though she was the eldest and first in her extended family to finish grade 12, her family did not consider this an achievement at the time. After the final examination she stayed at home for ten years because her parents were concerned about her using public transport. During the week she helped her father prepare products to sell at his store. Thelma regards those ten years as wasted years.

- ***Profile of Raymond***

Raymond (fictional name) describes himself as a person with diplegic cerebral palsy. He says he uses a wheelchair for “convenience” and sometimes to “exploit the pity factor”. Raymond started schooling at the site when he was three years old. When he was in grade 8 he was transferred to a mainstream school. Raymond completed grade 12 at the mainstream school and registered for a degree in medicine “because his results in maths, physics and biology were acceptable”. However, he did not complete his first year. Raymond changed his course of study, but did not complete that

programme either. At the time of the interview he was the manager of an organisation for people with disabilities.

- *Profile of Jimmy*

Jimmy (fictional name) described himself as “a right hemi, bi-polar, that takes 40 tablets a day, attempted suicide four times by age twenty, and flat-lined at the last attempt”. Jimmy started school at the site when he was three years old. He left the special school to continue grade 8 at a mainstream school. Jimmy completed grade 12 with “good marks” in mathematics, physical science and biology. After grade 12 he went to university, but only did not complete his second year. Jimmy described his schooling years as being a “latch-key” kid, typical for the socio-economic area where he grew up. He had to fend for himself in the afternoon as his mother had to work to keep him in school. He does not mention his father. At the time of the interview Jimmy had a job.

#### 4.3 Stories and Voices - “Breaking the Silence”

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JASON'S STORY

Jason (fictional name) was a bright student, the top achiever in his class. When he talks about his love for science and mathematics, his face lights up and he becomes animated. He relates how he was interested in science from an early age, always trying some or other experiment at home. According to Jason:

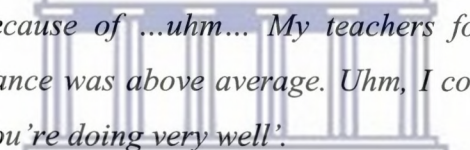
*I loved biology. I really liked science and math from primary school years. I used to investigate things all the time and try and figure out how things fit together.*



Jason is what Costa (1995) describes as a “potential scientist”. Like any other young child of his age, Jason was curious about nature and how things work. Jason’s home and school life clearly fostered an early love for science and shaped his view of becoming a scientist.

- ***Specials Schools and Low Expectations***

Jason’s teachers and guidance counsellor suggested that he attends a mainstream school after grade 8. When asked why he decided to leave the special school, Jason stated clearly that it was not because the special school did not offer physical science up to grade 12. He left primarily because his teachers and guidance counsellors believed that he could make it in the mainstream. Jason had a very high regard for his teachers, as became evident with all the participants. Jason claims:



*I left because of ...uhm... My teachers found that my academic performance was above average. Uhm, I couldn't tell. .... They just said: 'You're doing very well'.*

One of the reasons offered as explanation, was that the special school will “not be able to challenge [him] fully” and “might waste [his] potential”. The mainstream classroom was posed as “the learning institution that will challenge you fully”. As Jason recalls:

*...[the teachers and guidance counsellor said] maybe you should try and aim for a learning institution that will challenge you fully, because we will not be able to challenge you fully and we might waste your potential.*

The teachers alluded that the special school curriculum at the time was somewhat inferior to that offered in the mainstream. For Jason, who clearly had high expectations of a future career in science, this information must

have been shattering. The school and teachers that were his “home” so to speak since the age of four, was “wasting his potential”. As he recalls:

*... it was more a case of: ‘Look, we [the teachers] think you should really try and challenge the mainstream environment’, you know. ‘Be a guinea pig, even, in a way’. So, in a way I was very, very ... kind of gunning for it... I think, uhm, maybe [name of psychologist] would have had a huge say in that ... and the other therapists and teachers involved all said: ‘Let’s see what happens. You could actually give us some valuable insights as to what happens when you go from this foundation into the mainstream arena where they haven’t really begun to think about disability’.*

Jason rationalises the decision that he should leave the “comfort of the special school” for the unfamiliar mainstream environment by taking the view that he would be a pioneer, the person who will actually help the special school to improve. Upon reflection, he still regarded the fact that he was a “guinea pig” as not “a big issue.” For Jason, the key issue was the high expectations of others, namely his teachers, the school psychologist and therapists. He wanted to make them proud and therefore left the special school for the mainstream secondary school. However, this event clearly raised questions in Jason’s mind about the teaching and learning context at the special school. Jason compares the special school and the mainstream classroom and concludes that the mainstream school was better. In the following extract he provides evidence for his claims.

*Uhm, I think at [the special school] they didn’t even look at the concepts. I don’t even think they went there. I don’t think they did very much basic geometry with us, to the extent where they introduced the little ideas that you should have picked up on. And I know this because my classmates at [mainstream school] were picking it up and I wasn’t. So, they must have been taught those concepts.*



Jason was the top of the class in the special school when he was advised to continue his education in the mainstream, but he soon realised that top of the class is relative. In the mainstream classroom it soon became evident that there were gaps in his knowledge. At this stage Jason rightly diagnosed that the problem was with the system of teaching and learning, and not with him. He knew that if he had received the same teaching as the others in his class, he would not be experiencing problems.

Jason does not mention any support from the teachers and therapists at the special school who asked him to “give [them] some valuable insights” as to how learners with cerebral palsy cope in the mainstream. Jason admits that it took him three years to “get up to scratch”. It is evident that the absence of adequate preparation for transition impacted on Jason’s crucial first three years in the mainstream. He had to struggle and battle alone in this new physically unfriendly environment. Furthermore, Jason feels that at the special school they were not required to reflect upon their difference. His choice of words is very illuminating: “it was almost normal”, indicating that the situation was not normal. When he came face-to-face with the stark realities of the “outside world” (Jason’s phrase), he was not adequately prepared to deal with it. Regardless, Jason chooses not to remember any negative experiences at the special school. The only incident he recalls is getting in “trouble” with teachers, but only because he was bored.

*Least enjoyable... Uhm... I don't remember really... But, I might have gotten into trouble with teachers. Because I would always ... I would possibly distract the teacher from doing her job. I would.... I think I might have been the type who would be chattering away when everyone else is struggling to learn, possibly. And, either disrupting my classmates or disrupting the teacher, or tries to teach the teacher... which was very naughty. [Laughs] But that was definitely the case or an indication that I needed more stimulus.*

The inclusion of learners with cerebral palsy and other physical disabilities does not only refer to the physical accommodation, but also the academic progress of the learners. Jason was clearly bored at that time and the recommendation that he should attend the mainstream probably came from the class teacher.

- ***“Making Known, Becoming Known”***

Jason describes himself as a learner with cerebral palsy and hydrocephalus. He related how he became aware of being different or aware of his disability.

*I started out at [site of investigation] in primary school...no, in pre-primary (nursery school), at the age of four. So all my classmates had some sort of cerebral palsy. And, so it didn't really seem strange. Someone limped and someone had a funny hand, someone had a funny arm, someone spoke differently, or looked different. Because ...that was just us accepting it as is. This was how we are.*

Segregated schooling often relayed a false sense of security. Jason and his friends were made to believe that they are the “same” - all of them had “*something funny, spoke differently, looked different*”. In this atmosphere acceptance was easy. In the special classroom Jason somehow did not feel as strange as when he was in his neighbourhood where he was the only one who “looked different”.

*And,...and then...being at [site] for my primary school years, [disability] didn't become an issue, because everybody else also had some kind of physical thing (emphasised word) and sometimes non-physical thing (emphasised word) that they just had to deal with...*

Jason clearly had a very supportive family that did not make him feel different in any way. He seemed to be oblivious to the fact that he looks



different. It was only when his friend drew attention to his difference, as Jason puts it, “noticed a strangeness”, did he become aware that his disability and difference was an issue for some people. Jason “became known” at a very early age, but he only internalised and made sense of his difference at a later stage in his life.

In the following extract Jason recalls how he “became known” and in turn decided to “make himself known”.

*Where it started... Where I started becoming aware of a difference as such was that my friends in my neighbourhood...uhm...my next door neighbour, being one of my first close friends...he has since emigrated...We knew each other since we were about two or three years old. He doesn't have cerebral palsy. So, he and I grew up...and as we grew up...uhm ...he would notice that there's something strange about me... and this [strangeness] was my, my...physical movement, ...uhm...but...he didn't raise any issue about it...*

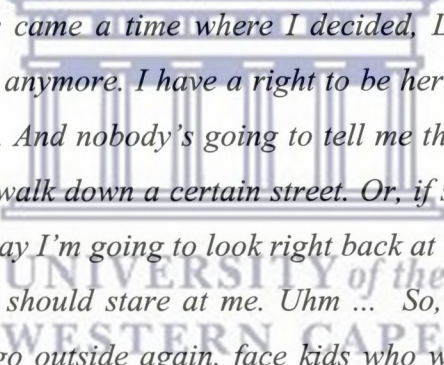
But, Jason soon came to realise that not all children were as accepting as his friend. He was harshly introduced to the unkindly face of the non-disabled.

*And, as I got older...uhm ... I started becoming self-conscious; especially around the neighbourhood...uhm... So, the kids around here would sort of look at me and I would get these funny names and ...insults, if you want... and that was difficult to deal with.*

Society constructed our perceptions of what is normal. Anything or anyone who differs from the “norm” is treated with suspicion. Young children learn this very early in life. Jason had to learn to “defend” himself against the taunts and abuse of the children in the neighbourhood, and make himself known. Jason learns at this early age that who he is and what he represents is not what society can accept. The children in the neighbourhood reacted in

the way they have been socialised, namely that there must be something wrong with the person who does not conform to the “norm”. They responded in the way most children do when they are in a group, they start taunting and calling the outsider “funny names”. This incident left an indelible mark on Jason. After more than twenty years it is as if he can still hear the insults and funny names.

At first Jason was devastated by the name calling and labelling, so much so that he did not want to go out. He became a prisoner in his own neighbourhood, because he could not bear hearing the “funny names” and taunts. Jason remembers that “*there was a time when [I] would say, yah, I don’t like this, and I don’t want to go outside*”. But his resilience and strength of character becomes evident in the following extract:



*But there came a time where I decided, Look, I’m not taking this nonsense anymore. I have a right to be here, and I’m going to stake my claim. And nobody’s going to tell me that I can’t be in a certain place or walk down a certain street. Or, if someone looks at me in a certain way I’m going to look right back at them, because I don’t see why they should stare at me. Uhm ... So, that strengthened me to literally go outside again, face kids who wanted to taunt me, taunt them back, and basically take back my power. And just say: Look, I have a right to be here and I don’t really care what you think about me anymore. So, either leave me alone...uhm...or I’m going to stick it to you...Uhm...And I didn’t...I wasn’t one for physical violence.*

But as Jason admits, “*that took a couple of years to develop*”. Making himself known as a person in his own right took much courage. Later on in the interview he relates how he “became known” as being different in the mainstream classroom. He emphasised words to show his embarrassment and discomfort.



*But I actually got sick in my first three months at the school. I had a “cephalous incident”. That was a shock to my class teacher. And ... uhm ... I was then finally EXPOSED (emphasised) as in what I was about to the ENTIRE CLASS (emphasised).*

It was interesting to note his choice of words “what I was about”. This highlights that Jason had, to certain extent, accepted his difference. But his classmates had not fully realised what Jason’s difference meant. He talks about the “shock” of his class teacher, who clearly was not fully prepared to cope with the realities of Jason.

*So, there was the start of now being fully exposed, in a way, to the outside world ... taunts of children ... and steeling myself against it. And just saying: Look, I have to get on with this, get on with my schoolwork, and get on with enjoying the mainstream world...uhm...where we are not really protected from anything.*

That incident was also the end of innocence and childhood. Jason had come face-to-face with the cold and unforgiving “outside world”. He refers to “not really [being] protected” in this “outside world”. This incident highlights the many battles learners with cerebral palsy have to overcome.

Jason remembers his years at the special school as very enjoyable. He remembers that he was one of many with disabilities. Sameness was equated with comfort and security.

*Uhm... The most enjoyable was that ...uhm... in terms of my peers and friends... everybody was at the same level. Everybody had some kind of cerebral palsy. There was nothing unusual about the fact that this guy limps, or that guy ‘looks’ this way. So, we just got on with each other. ... uhm ... It was never an issue. It was never raised. There was never any kind of taunting about it...I mean, people would tease each other, but it was never because the person walked*

*funny. Uh ... And ...we could just actually be children and not ever actually have to be conscious about having something that wasn't in the majority of people around us. So, that was great. You could actually just be a child and go through the phases of growing up... and getting into trouble...and meeting friends ...and, you know ...it was almost normal, ... because there was never any reflection on it.*

It is interesting to note that Jason says, “...it was almost normal” when referring to the special school classroom. His next remark, “because there was never any reflection on it” seems out of place. However, the fact that nobody in the special school talked about disability, although everyone is aware of it, underlines that learners with disabilities are socialised to compare themselves with people who can walk and talk without difficulty. In other words, able-bodiedness or ableism is the “norm” that learners with cerebral palsy have to strive towards. Jason’s account seems to echo Davis (1997:1) that “we live in a world of norms. Each of us endeavours to be normal or else deliberately tries to avoid that state”.

Another encounter that Jason remembers is when he was working as a tele-consultant. He recalls that the environment was “*tougher than [he] thought*”. He was 23 years old at the time and his co-workers averaged 19 years of age. Jason describes them as “*still kind of competitive and not really accepting*”, and he had to make himself “*known*” all over again. Jason recalls his thoughts at the time: “*... and I’m like ...ooh... I’d have to do all this all over again now (sighs)*”, an experience that left him very distressed and depressed. He had to see a therapist to help him cope. The specialist gave him very good advice.

*Uhm...and, I needed help. So I went to speak to a specialist who was recommended. And this gentleman gave me good advice about ... uhm ...how I see myself and how I see ... how I think other people relate to me. And he said to me essentially: Look, you are you, okay?*



*If other people have an idea about you, that's their problem. As long as you don't mind ... and, like things about you - that's what matters. And, if you think that ...uhm... for a while, even if you have to be a little bit aggressive about it, you do that. But, you will eventually temper away the aggressiveness, and you will find that you actually now just got more of a command about how you present yourself. And, you then will survive at work...*

At age 23 Jason was helped to make sense of his difference. The advice from the therapist was very important. He was told that he was “okay”, and Jason somehow came to understand that the problem was not with him but with how others viewed him.

- ***“Time Out, Time Lost”***

He recounts the barrier of “time lost” that is part of the life of a learner with cerebral palsy. Losing out on teaching time meant that he had to work twice as hard when he came back. Jason attributes the success in “catching up” to his technique of unpacking concepts.

*By the time I came to grade 10, I had had two surgical incidents. I had a surgical incident in grade 8, a hydrocephalus incident, which took me out of school for about two weeks at least. Uhm ... And there I had to now catch up with concepts, that's besides the physical recovery ... and hopefully remember what I had been learning, because there's brain trauma... Somehow I would forget. [But] somehow that wasn't the case and I was able to just pick it up, stumble a bit and then start running again.*

Losing time is but one of the challenges. The physical recovery and discomfort of being in hospital bed is more acute in the mainstream

classroom. Many learners with cerebral palsy try to make light of the embarrassment they must have suffered.

*In grade 9 I had orthopaedic surgery that took me out of the game for well [six weeks] ... The orthopaedic surgery happened during the mid-year holiday, but what happened then was, I ended up being shuttled...um...physically carried around the school by two classmates. So, here is the thing where I'm really self-conscious... I had my legs in plaster from my ankles to my hips, and I have to sit with the stuff on for another three weeks, because holidays were only three weeks long itself. So I get chartered around school, people are looking at me, it's freezing cold and I've still got to concentrate through every single class.*

Although Jason recognises the importance of the operations, the embarrassment and discomfort of being “shuttled” and carried distracted from learning.

*So, there again it was distracting, it was at a time when my concepts in maths and science were not that great yet, ... and somehow I was still trying to unpack things.*

Jason was grateful that by the time he fell ill again he had mastered much of the content. This is the routine that learners with cerebral palsy have to become used to. Time out of class means that they have to make up for the time lost.

*In grade 10, the transition period, I fell ill again with hydrocephalus problems ...uhm... but I think just enough work has been done in my math concept building and science concept building so that I was still able to pass the math and science that year. So, I was now able to use the technique, break down the concept ... uhm ... try and see where it fits in, work it out, check your answer, check a worked*



*example, [ask] does the method look remotely the same? Yes. So, there in fact, all they were giving us made sense, because I was latching on to the concepts. I was able to figure out the little concept and attach it to the big concept and finish off the calculation; because, the answer was not what they [teachers] was looking for, they were looking for your method, how did you get to this answer...*

Jason found a “technique” of deconstructing and reconstructing the content. He also discovered that how you get to the answer was more important than the answer itself.

- **Support**

Jason has a strong family support structure. Support from parents and classmates were important factors for his “survival”. According to Jason, his *“parents were very supportive. Uhm ... My whole family was very supportive...uhm...and teachers at [mainstream school] were very supportive. And so I managed to kind of get on with that”*.

Jason remembers: *“I also had a close friend in class with me who I’d met two years before through friends of my parents. He is not disabled. Uhm... He was also very supportive of me.”* And, when he first came to the mainstream school the *“class was very supportive from very early on, which was an incredible experience. And we were all 13 years old”*. When he became ill in class he remembers, *“They [classmates] all rallied around me...uhm... and, tried to understand what I was about”*.

- **Preparations for Transition**

Jason had a triple transition to contend with. First he had to deal with the transition from primary to high school. Second, the transition from the special school to a mainstream school and thirdly, the transition from a

small contained special school classroom to a large mainstream classroom. Jason relates the change in terms of the difference in teaching and learning. He recalls that learners at the mainstream school were given “formulas” to solve problems in mathematics which he wasn’t taught at the special school. But he also remembered that the teachers at the mainstream school could mistake a learner’s underperformance for incompetence and not take the time to find out why the learner is struggling. In a smaller contained classroom, the teacher would have picked up if he struggled. In the special school the teacher would have used Jason as yardstick to see if the lesson was successful. This was different in the mainstream. The teacher did not know his potential and he had to compete with 30 plus learners for the teacher’s attention. According to Jason:

*[In the mainstream] ... you are ... you are being groomed to think in a certain way, sort of like a formula, let's say. There's a process or a formula that you are taught to start using...uhm... If it's geometry and you need to understand a rectangle, there's a way to do it, called a theorem. A theorem has steps... So if I don't understand the steps of a theorem that are given to me, I will never be able to apply the concept to a test question. And if the teacher doesn't know that I'm misunderstanding the theory, then he's never going to know why I can't get the sum right. If he doesn't get it that I simply cannot imagine or visualise this 'thing', then ... and how this 'thing' fits together, then ...uhm... (sighs) ... no amount of ...of lesson is going to change it.*

Jason is a reflective thinker. Reading though the extracts, it is evident that Jason thinks and ponders about the way he learns and the way teachers teach. In the above extract it is clear that the teacher’s understanding of Jason’s problem with understanding is crucial in the teaching and learning context. As Jason points out, the teacher must find out why the learner is not grasping the content and get to the root cause of why he [the learner] is not getting the sum right. Wiggins and McTighe (1998:175) cautions that



teachers are “in danger of misunderstanding what students need to understand” and suggest teachers do “misconception checks” where learners are presented with common or predictable misconceptions about a concept or process. The learners are asked if they agree or disagree, and have to explain why they agree or disagree (Wiggins and McTighe, 1998: 167).

- ***High Expectations***

Although he was a bright student, Jason admits that at first he had to struggle to adapt to the way of doing things in a mainstream classroom. But, he worked extra hard to fit in. He recalls that he had no problems with biology. According to him:

*And, there I did very well at biology, struggled a bit with my physics – conceptually... And it took a lot of remedial attention from my physics teachers and my math teachers to get me up to scratch... because a shortcoming I had was ...uhm... abstract comprehension... Uhm... I struggled with geometry specifically and then going into physical science again where anything related to spatial awareness was concerned ... was a battle for me to get used to it. Eventually I did. But it took about three years of knocking my head against the wall, so to speak.*

Jason was also very aware of what his problem was in mathematics. This definitely helped the teachers to focus their interventions accordingly. While reflecting on his “struggles” in the mainstream, Jason had the following advice for primary school learners and their teachers:

*Something that primary school kids need to do is (and spend quite a bit of time with) ... uhm... is geometry in math, uhm... literally... Concepts in math like algebra and, even maybe trigonometry, should be fairly easy for a child to grasp. But they're going to struggle with many aspects if they don't have geometry and*

*spatial awareness sorted out carefully. So, even if it means doing the same and ... doing similar type of exercises and changing those exercises for seven or more years for the child's primary school career. That would be the key... Because that [addresses] a lot of how they think ... uhm.... And even beyond science, I think... Uhm... Somehow the geometry seems to fit into other parts of your life, and ...I mean...Let's imagine trying to... uh... build a house... and if you don't have a spatial awareness, then you're not going to figure out how you'd like your living space to be. So even planning your future life is going to depend on these basic concepts.*

Jason identified the following key issues:

- Teachers should spend enough time with concepts formation.
- Learners should be given similar types of exercises in order to grasp and apply the methods, processes and techniques of problem solving.
- Teachers should integrate as much of the learning programmes so that learners see the application e.g. of geometry concepts when they have to build a house.

Key factors that made Jason persevere against all odds ("it took about three years") were "remedial" attention from his physics and mathematics teachers. According to Jason:

*Each teacher that I got between grade 8 and grade 10... because, only after grade 10 did I start catching up on the concepts... Each teacher, uhm... In fact I think it was the same teacher for grade 8 and 9, and a different teacher for grade 10...The two of them kind of figured out that I was not grasping the way they were giving it to the other kids. So they tried to give it to me a little differently. And tried to keep it simple and introduce the minor concepts before they introduced the major concepts. So, the little pieces actually, when they were put in, helped me to understand how this whole thing*

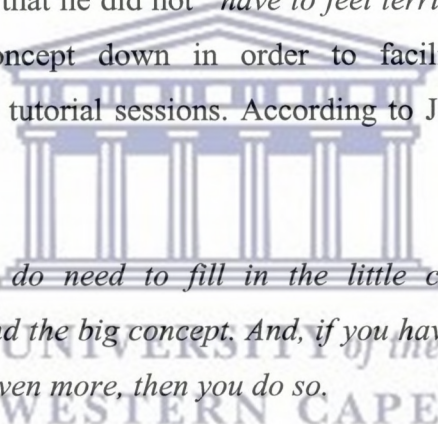


*works. I also needed to go for tutorial sessions... uhm... for at least two years. ... In fact, I think, even three years, from grade 8 to grade 10 - once a week, to once every two weeks. And, this gentleman, he was also one of the teachers. He was a senior teacher offering classes at [mainstream school], and he also tried to understand why I was misunderstanding. And in fact he said: "Look, your misunderstanding is not uncommon. So, you don't have to feel terrible about it. But, you do need to fill in the little concepts before you can understand the big concept. And, if you have to break down the little concept even more, then you do so." So, that [technique] I used in math. I went on to use that in physical science as well ... uhm ... so that for me was the clincher. Here's a concept. Fine. What are the parts of the concept? Look at each part as a little block. Do you understand the little block? Okay. Now look at the other little block. Do you understand that? Fine. Now, put all the little blocks together. Because you understand what concept each little block represents, NOW (emphasised) do you understand the major concept? Yes. But, [the problem is that] I cannot get the big concept which might seem simple to the teacher; I cannot get that concept and be expected to understand the [work].*

It was important that Jason had the same teacher for two consecutive years because the teacher "kind of figured out that I was not grasping the way they were giving it to the other kids. So they tried to give it to me a little differently." According to Gagné (1985:128) Jason was 'not grasping' because "the subordinate rules or concepts" were not known and therefore he could not understand the main topic. The important point is that the teacher took time to understand why Jason was misunderstanding and had the courage to teach him "differently". This is clear evidence of differentiation of teaching and learning. What is commendable is that the teachers did not make Jason the problem, but realised that the way they were teaching was a problem for Jason.

The teachers were courageous enough to try new and different methods. According to Jason they “*tried to keep it simple and introduce the minor concepts before they introduced the major concepts. So, the little pieces actually, when they were put in, helped me to understand how this whole thing works.*” The teachers presented Jason with a method that made sense: from bits and pieces to the whole, the big picture. Jason applied this method to all his subjects.

The teachers also introduced extra sessions for Jason. For two years he attended tutorials, “once a week, every two weeks”. The teacher in the tutorial classes “*also tried to understand why [Jason] was misunderstanding*” and reassured Jason that his “*misunderstanding is not uncommon*” and that he did not “*have to feel terrible about it*”. The idea of breaking the concept down in order to facilitate understanding was reinforced in the tutorial sessions. According to Jason, the teacher advised the following:



*But, you do need to fill in the little concepts before you can understand the big concept. And, if you have to break down the little concept even more, then you do so.*

The teacher advised Jason to break down the big concepts to the specifics, which Jason refers to as the smaller blocks. What the senior teacher was trying to do corresponds with Gagné’s (1985) learning hierarchies.

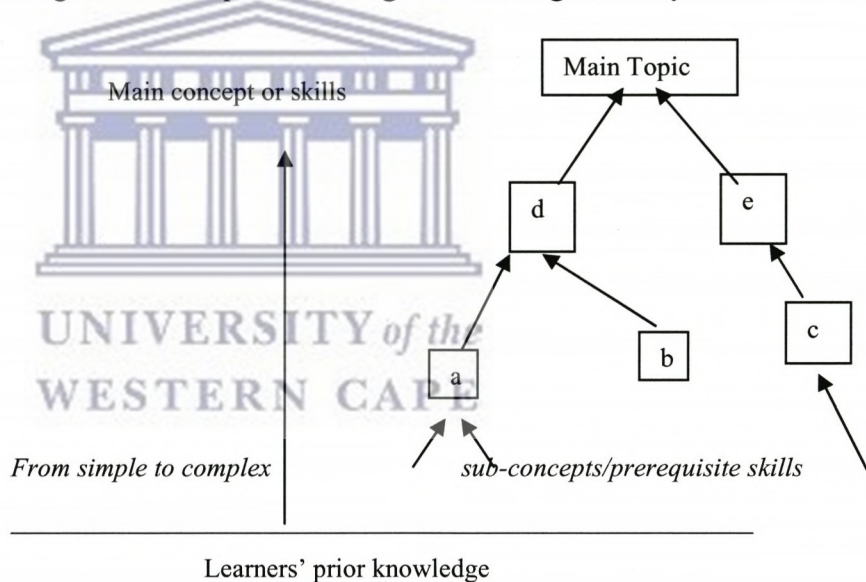
According to Gagné many subjects taught in schools have an organisation that can readily be expressed as a learning hierarchy. The learning objective may be shown to be composed of prerequisite rules and concepts. Learning is therefore a matter of combining these prerequisite skills - the learner’s prior knowledge of learning that took place a while ago. Gagné’s (1985) asserts:



...two or more concepts may be prerequisite to (and in this sense subordinate to) the learning of a single rule. Once the latter is learned, it may combine with another rule, and so on. The entire set of rules organised in this way, forms a learning hierarchy that describes an on-the-average efficient route to the attainment of an organised set of intellectual skills that represents “understanding” of a topic. (p.128)

The following figure is a diagrammatic representation of Gagné’s learning hierarchy. The letters a-e represents the prerequisite concepts that must be in place in order to understand the main topic.

Diagram 4.1: Adaptation of Gagné’s learning hierarchy



Source: Gagné’s (1985, p.276)

Jason found a coping mechanism, a way to make sense of the content in the different classes. He relates how he mastered concept formation, a technique that he still applies today. This presented the breakthrough for Jason. He relates: “so that for me was the clincher”. Jason used the technique in mathematics and went on to apply the method in physical science as well.

Jason described his method as follows:

Step 1: Here's a concept. Fine.

Step 2: Ask yourself the following question:

What are the parts of the concept?

Step 3: Look at each part as a little block.

Step 4: Look at each little block separately.

Do you understand this little block? Okay.

Step 5: Now look at the other little block.

Do you understand that? Fine.

Step 6: Now, put all the little blocks together.

Step 7: Because you understand what concept each little block represents NOW (emphasised):

Do you understand the major concept? Yes.

Gagné states that a learning hierarchy is the successive application of an analysis for each concept or skill and its subordinate skills. According to Gagné (185: 272):

The process of analysis may be continued on each of these prerequisite skills so as to reveal rules or concepts that are in turn subordinate to these. In general, the analysis is conducted by asking the following question about each skill: 'What [skill] should the learner already know how to do and be able to recall when faced with the task of learning the new rule, the absence of which would make it impossible for him to learn the new rule?'

Jason's description echoes Gagné's account. Jason interrogated each "block" or concept before moving on to the next. He talks about the "trick", something you can teach anyone. This involves "unpacking the concept".



According to Jason:

*Well, it is what I've been taught to do to try and understand things. In order to try and understand this huge idea, break it down into smaller pieces and then put it back together...That's how I've managed to get through, let's say grade 10, grade 11 and grade 12, where your basics after grade 9 stops and now you start doing application.*

Jason could apply the method across disciplines, i.e. mathematics to physical science, and even history.

*For the next three years in maths, in science, in English, in history, in all your subjects, you now start doing applications from grade 10 to grade 12. If you haven't mastered the basics, you're going to have a real battle doing all the applications ... uhm... because the thing was... If I look at my history mark ... my history mark was quite good... uhm.... Because I like the story behind the incident and ... our history teacher, who was my class teacher for four years from grade 9 to grade 12, he encouraged us to break down the concept, to think about why it happened, whether it was Pearl Harbour or whether it was...uhm... the Great Trek or whatever, you know, [ask yourself] why did it happen, what were the parts of it. Now let's put all of the parts together. Right. Now, think about this in your own mind. Now write about it in your own words. Uhm...so, my little ideas eventually became a common theme that my history teacher was using. Uhm... My physics teacher, who would knock my head against the wall, not literally, ... but was trying to get me to understand things, ... eventually realised that the only way I was going to understand physics is if he will quietly get me to break down the concepts into smaller pieces and then try and apply it to the bigger concept. So that enabled me to build up my physics mark.*

*Uhm ... I have no idea why I didn't struggle with biology. I can't say. Uhm...Biology just seems to gel with me... Uhm...*

Jason has mastered the technique of deconstructing and reconstructing concepts and applied his technique to other subjects. His physics teacher took time to assist Jason and showed him how to break the concept into smaller pieces and then apply to the big concept or what Wiggins and McTighe (1998) calls the "big idea".

Jason had a method to approach problem solving, but there was still a problem. Jason did not always get a YES to step 7. According to Jason:

*But, [the problem is that] I cannot get the big concept which might seem simple to the teacher; I cannot get that concept and be expected to understand.*

As Wiggins and McTighe (1998:175) assert: "It is a humbling but true fact that the best curriculum design may fail with a particular group of students." Jason understood the method and could apply the technique, but in some cases he could not grasp the big concept. Wiggins and McTighe (1998) advises:

This is the great irony of teaching. At times, being observant and silent is the best way to teach, because it allows us to listen for weak insights or misconceptions that may inhibit student understanding. To teach for understanding, then, we as educators also must be aware of how our teaching habits can undercut learning. (p. 175)

Jason's teachers did much to help his understanding and build his confidence. However, it seems as if all their efforts were not enough for Jason to overcome all the hurdles.



- **Mainstream Schools and Low Expectations**

Jason talks about the struggle to adapt to the way of doing things in a regular classroom. When asked if he thought that his disability had anything to do with the struggle to conceptualise, he says that at first he thought so. He relates that teachers at the mainstream school alluded to that being a possible reason.

*Well, it's a case of, yes, because I'm cerebral palsy, [and] there was a blockage in terms of abstract thinking. That was definitely commented by my teachers... at [mainstream school]. [They thought] possibly the cerebral palsy generated a block in abstract thinking. They thought so. They couldn't prove it. They were just thinking... And...*

Teachers believed that the cerebral palsy could be a reason even though Jason was not the only one in class who didn't understand. The teachers had no reason to believe that there is any correlation between Jason's disability and the fact that he was experiencing difficulty with mathematical concepts. However, the teachers made Jason believe that his disability was the problem. When asked what he believed at the time, Jason admits that he believed that being cerebral palsy could be a possible reason, but while reflecting he recalls that the system of teaching and learning at the special school did not prepare him sufficiently. It seems as if Jason believed that the teachers at the special school had a low expectation of what could be expected and therefore Jason was not really challenged academically.

*The thing is I sort of understood things and then all of a sudden I couldn't take the process to it's logical conclusion. And I thought, look, it must be the cerebral palsy. I'm kind of understanding what the teacher's saying, but I cannot get to the end. What's stopping me from doing this? But I also remember.... what might have been missing from the [site of investigation] was that I didn't have to take*

*the concept to its conclusion. I didn't have to push myself to thinking to that point. So, whereas, just say for argument's sake, one of my classmates was a bit lazy, that's why he wasn't pushing himself. Okay, but my classmate was on the ball, she's fine, and she knows exactly where she's going. And it's because she's actually picking up what the teacher's saying and she's applying it. My problem was I struggled initially to apply because I was never required to do that ... I've heard that ... I've heard that ... uhm ... that if you have cerebral palsy, there's a built-in intellectual deficiency. Uhm, I don't know how true that is. I suppose its true. Uhm. I don't know if it's just an assumption, a true assumption... or if it's actually proven. But, uhm, that definitely for me was apparent that I had this abstract block.*

It is very important that teachers refrain from voicing their concerns where the learners can hear them. As Jason's account illustrates, he "heard" that teachers thought cerebral palsy could be a reason or explanation for his difficulties. Jason also "heard" that "if you have cerebral palsy, there's a built-in deficiency". None of the claims were substantiated, but the doubt was cast in Jason's mind.

- **"Overcoming Formidable Odds"**

Jason finished grade 12 in 1994 at the mainstream school. However, he became ill in his matric year and had to undergo an operation.

*Yes, this was in matric. This was 1994. After this difficult, ur... fairly debilitating surgery, and ... I didn't feel myself... and[name of doctor] said, well, maybe it's due to the surgery being a bit difficult. There was an incident while I was under surgery and I might have sustained a bit of shock on the table ... on the operating table...uhm... but I managed to recover, went back to school, didn't*



*feel myself and within a few weeks I started realising that something was amiss...*

Jason had to face the challenge of making up for the “time lost” while he was in hospital. But he did not recover as in the past. His parents first realised that Jason was not coping and consulted his doctor. Something must have gone wrong during the operation that left Jason with short-term memory problems. According to Jason:

*And up till now we still do not know what had gone [wrong], but what the outcome was... that the hydrocephalus was under control and, in fact, hasn't been a problem since then. BUT, (emphasised) in a matter of weeks my memory did not recover... my short-term memory... and it stayed a problem for a number of years after that. And even now it's still a bit dodgy. I still can't remember things that, well, that I've done maybe a few days ago. Back then, for example, I couldn't remember what I had for breakfast ... and that happened for months ... I just couldn't remember little incidents during the day... uhm ... (he hesitates)*

Jason went into a state of depression. However, he was determined to continue with his matric exams. He went back to school and wrote the September examination, but “predictably it didn't work... none of the papers really worked.” He only passed his language papers. He failed mathematics, physics, biology and history. He went back to the doctor, who advised that he not write the November examination.

*[Name of doctor] said: “Look, there's obviously a problem here and it's putting you under a tremendous amount of stress...and I suggest that you not write the final, that we will have to speak to your teachers, your school principal at [mainstream school], and the Education Department and try and work out what we're going to do for you... let's say by next year.”*

Jason was determined to stay and attend all the classes until the grade 12 learners left school to prepare for the final examination. He recalls that the teachers were very supportive and “*now understood what the problem was, sort of understood that I just could not grasp and hold information, so they didn't push me*”. The Education Department awarded his matric certificate based on his performance in June.

*And then we submitted information to the Education Department and they were willing to consider ... uh... granting me a senior certificate based on three years of work that I've done, based on the fact that I'd worked exceptionally hard in grade 10 and grade 11... uhm... and had a consistent track record for those two years of improving in all subjects. And, that I'd actually passed every single exam in June of my matric year, which was effectively more than 50% of the content for the year...uhm ... and, with that they [Education Department] were willing to grant me a Senior Certificate.*

Jason, however, still thinks that he did not “pass in the real sense”. The note of disappointment and failure (in his voice) was clearly evident. He felt as if he was “robbed” of seeing his name in the paper.

*Well, then...uhm... I was sort of half-relieved and half-disappointed. I was in fact ... I felt like I'd let myself down. On the one hand I was allowed to pass, but ... I was actually very disappointed that I was not allowed to challenge myself the way every single matric has to bite their nails to hope they pass the Senior Certificate exam, because it's like... It's like ... a line that you have to cross. You cross that line and now you are actually out of school and in the adult world. You've actually crossed ... uh ... some kind of major barrier, which everybody felt fantastic about. Uhm ... And I didn't get that feeling. But, fine. I was ...I ended up being an adult anyway. I ended*



*up being 18 by the end of the year, getting a matric and now having to figure out what to do next.*

After the operation the doctors advised that he put his studies “on hold” as it might be detrimental for him and cause pressure to build up on his brain. It was clear that Jason had high expectations about his future. During his matric year he applied and was accepted to further his studies in microbiology at university or technikon.

*By June of 1994, before I took ill, when I'd finished writing the [June] exams, I knew every single exam had gone off brilliantly. And I thought right, application for [name of university] and [name of technikon] are in. I'm going to apply for first choice of microbiology at university, 2<sup>nd</sup> choice mechanical engineering at university. And at tech my 1<sup>st</sup> choice is probably going to be mechanical engineering, and 2<sup>nd</sup> option would have been biotechnology at tech. Uhm... Why I chose tech is because they had then already quite an impressive track record in those two departments. We [Jason's family] knew people instructing in those departments... My parents knew people instructing in those two departments, so I thought, okay, those are good options...*

His disappointment when his dreams were shattered was almost palpable. He recalls: “And ... those plans did not materialise.” When asked if it was because he was not accepted into the programs, he mentioned that “others” made choices for him.

*[Plans] didn't materialise, because I chose NOT (emphasised word) to study in 1995... Well, I shouldn't say chose. I should say it was recommended to me to choose not to study in 1995. My surgeon said: “Look, I REALLY (emphasised) recommend that you go on a gap year”, you know. “Do nothing. Just relax. It's been an*

*exceptionally stressful year, beyond what most matrics go through. Relax. Take it easy. Do absolutely nothing. Don't even think of working. You may be 18 years old and in line for trying to hunt for a part-time job. Don't even bother doing that. Just take it easy", which sounded like a lovely idea...*

Upon reflection, Jason rationalised his condition and choices yet again. He justifies that the decision taken by his parents and doctor was the right decision, because:

*In any case, I actually became quite depressed when the realisation hit me that I'd had a huge knock in my life. But, after a week I was gnawing at my nails because I was bored... But, uhm ... but, I ... just had to ... my parents had to accept that, look, I have to take a break. I had to recover. If I'm going to push, then I'm probably going to end up much worse.*

This situation was clearly not what Jason regarded as in his best interest. He was torn between listening to the advice of the “experts”, and his own voice. Jason had adults and “experts” making decisions for him throughout his life – decisions about operations, his friends, where to school and when to attend school. Moreover, the view of disability as impairment is evident in the way Jason, his parents and medical doctor approached the situation. All his life Jason was made to believe that he had to listen to his body, even though he might be feeling something else. For example, in this case, he was advised to rest. But, as Jason recalls, “I was gnawing at my nails because I was bored”. When he said that his parents “had to accept” what the doctor said, it became clear that his parents might not have agreed with the doctor. But, that is the fine line that people with disabilities have to tread.



Jason's situation highlights the struggles and difficulties learners with cerebral palsy have to overcome to prove themselves. His despair is still evident in his tone of voice, although this happened almost ten years ago. This incident, which was not of his doing, left him 'demolished'. Serious counselling sessions were needed to build up his self-esteem.

*After building myself up, trying so hard to build myself up for the previous five years, I was back in a position where I'd have to start from scratch. I'd have to prove to people what I could do; I'd have to ... uhm ... build up a track record again, 'cause I felt like I was demolished ... uhm ... and that I just felt awful. And I felt awful for the bulk of 1995. I had to go for counselling, for serious counselling...uhm ...because I was really... I'd hit absolute rock bottom. Uhm... And ... the counselling sort of brought me back to the present and to what could happen in future, if I just took it slowly.*

However, Jason was determined to continue with his studies in science. He applied and was accepted for mechanical engineering at technikon in 1996. He chose technikon because he thought it would be less stressful, but discovered differently. Jason chose the institutions for their academic track record and not necessarily for their policies regarding inclusion and disability. As Jason discovered, tertiary institutions did not have any policies in place to accommodate learners with cerebral palsy. The institutions did not have much practice in working with learners with cerebral palsy. The lecturers did not know what needed to be done, or how to do it. Much of Jason's academic experience at technikon was trial and error.

Jason displayed the same anxiety and fears as the “normal” first year students.

*... and [I] was as scared as any other first year[student] to go to that HUGE (emphasised word) campus, and ... uh ... get stuck into this nitty gritty of... uh ... world of metals and machinery, and ... uhm ... and ...uhm ... really, you know, just get to know this thing.*

Jason was always ready for the challenges life put to him and ready to try his best. It is this attitude that keeps him going. This perseverance is an attribute displayed by all the participants in the study. Jason tried technical drawings even though he did not have any schooling in this subject. He failed the subject.

*And do one or two things, which I wasn't really ...uh ... comfortable with. Like, for example, technical drawing. I had very little exposure to it...uh ... except for a little bit of experience at [site of investigation] in the woodwork class. Now you go to Tech and one of your subjects for a semester is technical drawing. And [I] did hopelessly at technical drawings for the semester, and flunked it, of course, uhm, but passed six out of the seven subjects, uhm, although some were 'just passed', and some were 'sort of okay'. Some were just 50% and some were about 60%. And, so that was not too bad. I could live with that.*

Jason set high standards for himself from an early age. At the special school he was always the “best”, the one against whom others measured themselves. Therefore, when he started to “struggle” academically, his parents approached the lecturers and asked for assistance. Jason’s parents believed that he was capable of better academic performance, as his track record proved. However, at that time concessions and accommodations for learners with cerebral palsy were not considered a right. Thus Jason talks



about an accommodation that today is considered normal practice, as an ‘arrangement’- as if it is something illegal and distracting from his academic performance.

*But, uhm, my parents and I discussed this issue with the head of department ... and they [his parents] said, look, can't we make some kind of arrangement that [our son] does not do a full roster of subjects for the second semester...*

The lecturers agreed to change Jason's programme.

*So, instead of doing seven subjects in my second semester, which included re-doing drawings (I had to re-do drawings), I could go onto, e.g. uhm ... mathematics second semester and two other follow-up subjects ... uhm ... relating to materials and fluid mechanics in the second semester. "And we see how that goes", he [the lecturer] says.*

However, Jason does not mention any other support from the lecturers. Only after two years does the lecturer attempt to assist Jason.

*And then the head of department, who was now actively trying to keep contact with me, (and one or two of the lecturers, who were actually trying to pay attention to my progress now), he said: "Look, I know where you're going. I quite frankly don't mind if you do two subjects a semester until you finish the course. It's up to you.*

Again, Jason is made to feel that the ‘accommodation’ is not acceptable academic procedure: “And we’ll make a special arrangement.” It is clear from Jason’s account that the lecturers did not know how to accommodate Jason. They told Jason that his progress is “up to you” and somehow created the impression that failure would also be his fault. The lecturers come across

as very patronising and left Jason with the impression that they were doing him a favour: “*So, if need be, we’ll take more time for you. It’s up to you. And you have my blessings*”.

Jason viewed himself as a failure - academically and socially. When he compared his progress with his friends’, he talked about “trying to grasp” first year content while his friends are entering their second year.

*On the other hand, socially, my friends are getting on pass their first year at varsity. Some are already in their second year and some are finishing their second year... because some had started in 1995 - done well, [and] gone on to 1996 - done well, got to 1997 and were in their last under-graduate year and roaring to go. And here I am, you know, trying to grasp first year level subjects still.*

He mentioned again that something must be wrong with him, and not the system. Jason compared his progress with that of his friends who were in grade 12 with him and thought he was “stuck” - a failure. The work that he loved in his early years became a burden, a hurdle that he had to overcome. It seems as if the joys of learning and discovering had gone. Success, for learners with disabilities, should be defined differently. Learners with disabilities (and their teachers) should compare their progress with where they were yesterday, and not so much with how they measure in terms of the progress of the rest of the group. As is evident from the next extract:

*So, again it is a case of: Gee, I’m not progressing... Gee, I’m hanging back ... What’s wrong with me? You know, I was at par with these guys. We used to compete to see who got the most A’s [symbols] in matric (grade 12) and grade 11. Now, where am I? I’m stuck.*



After the long struggle, he “finally” passed the three subjects. The relief was evident in Jason’s voice. Jason’s hopes were raised.

*And, uhm ... So, 1997 meant for me that I could only do three subjects. I had to re-do two subjects again and I could now progress from drawings to computer drafting, which is the next follow-up. So I started computer drafting in 1997, for the semester; did the materials and fluid subjects again - passed the three subjects - and now I felt great. [By] June of 1997 I had now finally gotten through all (emphasised word) three subjects that I started. [I thought that] something might be working. I now realised [that] maybe three subjects is the way to go. So ...uh... the next phase of 1997... of 1997 is ... I have to do a subject called Thermodynamics. I think I had to do a communication subject at level two. So again I had about two or three subjects.*

The year 1997 seemed to be a better year for Jason. He had an opportunity to work as an assistant in the computer lab, an experience that proved invaluable to his personal and social development. He had an opportunity to work with other learners who were not disabled - and they accepted him. Jason thrived in that environment.

*But now I was also working in the laboratory. So, my days were absolutely (emphasised) filled helping people doing various things in the lab, maintaining the equipment,... uhm ...checking on the printer, checking with the laboratory administrator what he needed me to do with regards to [the] machines ... so, I was learning something quite secondary there. ... So, that was great. So now I was really ... was getting a feel for how to work these machines. And so I was finding that being an assistant was good.*

However, Jason still experienced difficulty with his academic work. As he recalls: *“I was struggling again with academic content and ...uhm ... that wasn't good.”* His confidence was built up by being able to help students who accepted him for his expertise, but on the other hand his struggles with the learning material lowered his self-esteem. It is clear that Jason thought there was something wrong with him and not the system. His despair is evident. Jason decided to take a break from his studies. His choice of words was very illuminating:

*Let me stop now. Let me just stop studying by the end of 1998. Let me stop studying, let me take a break; let me find a part-time job sometime in the New Year. But for now, I'm taking a break. I've got some money. I can go and have some fun and I'm now just going to stop... uhm... and that was at the end of 1998.*

In 1999 he worked as an assistant in the school library. His job entailed starting a computerised database. He sound quite proud of himself that he could assist the librarian to figure out *“how to make the system more efficient”*. Jason describes his experience in the library as *“very interesting, very interesting time – again”*. There were clearly more gains from this stint in the school library. Jason recalls that he had *“better social relationships with a lot of people”* and that he *“felt a little less like an outsider now”*.

Another important breakthrough came when he accepted as gift a series of sessions in alternative healing. Although he hated *“ people handling my toes”* he *“enjoyed it so much I went for more sessions...and it [alternative healing] started helping me ‘let go’ of things bothering me consciously”*. Jason enrolled for a part-time course in alternative healing. He recalls that the content was anatomy and physiology, content he remembers from school biology. It is evident that he was doing something he loved. Jason relates how he felt at the time:



*I think it's because the content had been cemented in my memory through high school. Because a lot of the physiology content you might learn in high school biology from about grade 10 to grade 12. So, some of that was memory based ...especially the detailed physiology, I actually had to learn and somehow I was actually able to learn it again. And remember it! And write it in my own words when I was questioned during the monthly test sessions. At the end of it all, 18 months later ...uhm ... in mid-2001, I had to write the final exams, which was a two-hour theory exam and a half an hour practical exam. And, there again it was a case of ... then it was a case of the whole of 2000 [work] stuffed back into my head.*

Jason does not recall having problems with his memory. He remembers that he “*was astounded that the memory worked; the understanding of combinations of afflictions and how you should treat it*”. He attributed his success to the way the course was structured.

*It was one small batch of information a month. So, let's say we were talking about the skin. That's all we will discuss ... think about and discuss for a month. We discussed it at the seminar. You have to read up in a physiology textbook about it, uhm... follow the course outline and write it off next month. That happened for each of the modules: nervous system, skeleton, digestive system, the works.*

Jason also mentioned the following factors that contributed to his success: continuous assessment, peer evaluation, regular feedback and practical hands-on experience. He qualified as a practitioner in 2001. The achievement meant much to Jason. He described it as follows:

*It felt incredible. I thought: Wow, I'd got to do something! I have a major interest in biology on the one hand, and people contact on the other.*

Jason described the course as the “*coming together of these two things that I enjoyed doing*”. The achievement in alternative healing encouraged Jason to apply for a course in microbiology at university. The following year he enrolled for the bridging course. This entailed four half courses for the year. By the end of the first quarter he was experiencing problems. According to Jason:

*I could feel problems. I wasn't ... wasn't really adjusting too well to the vast amount of work thrown at us - even doing half-courses. You had a full day, every day, doing all four subjects: doing a tutorial or a practical every single day, except Friday.*

- ***High Expectations/ Low Expectations...***

Jason admits that being back at university was an adjustment and that the day was very long. Jason again believes that he is the problem: “...*Very, very long workday...uhm... and I'm sure that was what probably made me take strain with regards to memory*”. Although he attributed his success in the alternative-healing programme to the way the course was structured, he did not question the way the university course was structured. He states that “*by the end of the first quarter I had to ...uh ... beg ... that I could drop two of the subjects*”. Jason believed that he had to change to fit in with the system and was grateful when “*the two lecturers concerned noticed that I was having a major problem and ... uhm ... said to me: 'Well, uhm, maybe you should...uhm ... drop at least one subject'*” (He started to speak slower). Although the lecturers saw this as the best solution, Jason interpreted it differently. There was a note of resignation in Jason's voice when he recalled that he had to “*stop [doing] math*”. It was almost as if he failed grade 12 all over again...



Jason's story echoes what the American Association for the Advancement in Science (2002) relates about the accounts of students with disabilities in science, mathematics, engineering and technology career pathways:

For many students, the science/math/technology pipeline is well defined: Select a major, complete the coursework, [and] receive a degree. For students with significant disabilities, there are additional battles. From the very beginning, the students and their families must sustain high expectations, often against formidable odds. The medical, educational, and employment establishments are quick to suggest low expectations for education and careers. Even when those barriers are broken, negative public opinion is always present with stereotypical concepts, which are usually very limited, of what a person with a disability might do. Students need to have a thick skin and a strong heart to convince the wider world that what is considered impossible is indeed possible.

Jason's had constant struggles with his health throughout his school years. However, despite the setbacks and time lost he remained focused on his goal, namely to study microbiology. In the midst of insurmountable conceptual difficulties and the disdainful gaze he endured at the mainstream school, Jason made it to grade 12. His resilience and determination to achieve against all odds is what characterises Jason as a person. At the time of the interview he was still enrolled in a higher education programme in microbiology. However, in 2004 Jason still encountered an education system that expected **him** to change and fit in.

## PETER'S STORY

Peter (fictional name) describes himself as a 'tri-plegic'. He relayed with pride that at first the therapists at the site did not know how to classify him because he did not fit any of the textbook descriptions at the time. He suggested to his physiotherapist that if a diplegic means that your legs were affected, a hemi-plegic means that one arm and leg at same side of the body were affected; therefore he should be a tri-plegic because both his legs and right arm were affected. That account also describes Peter's journey through life, always welcoming a challenge.

At the site Peter is remembered for his leadership skills and creativity (he was awarded the principal's award for creativity and innovation). His teachers also remember him as the boy who was always running, falling, dusting himself and proceeding to run again. When reminded of this, he said that describes his philosophy in life: "Failure is not the falling down; failure is the staying down".

- ***High Expectations***

Peter started school at age three and finished grade 12 at the special school. He was the first learner to obtain an exemption, a pass that qualifies you to enter for a university degree. Peter was busy with his masters' degree at the time of the interview. His comments on the reaction of the audience at his graduation underlines that academic achievements by people with disabilities are still not regarded as the norm.

*When I got my undergraduate degree the crowd applauded for my achievement. And that was fine. But, I only really saw the impact as to what I did when I got my honours and I walked across the stage and the crowd went ballistic. And I thought, okay, why are you...? And I began to realise [my achievements]. And hopefully at the end*



*of 2004/ March 2005 when I get my masters... maybe there will be pandemonium in the hall. So, that will be quite interesting to see that kind of progression of my academic studies.*

Peter had very positive career experiences. He had a university degree and his positive outlook on life contributed greatly to his achievements. When asked how he accounts for his success, he answered:

*I think it's a question as to where you see yourself in relation to society. You have two choices, either to spiral down to the negativity or rise above ... uhm... and move beyond that negativity. Uhm...Do I see myself as rather having been part of what society expects of me? Or do I want to rise above it and actually beat society at its own game in terms of how it [society] perceives me?*

Peter's view on life and disability is in contrast to the way in which he was schooled. He spent his entire school career at the special school where the view of disability was that disability is the problem. Peter has clearly broken out of that way of thinking and was questioning the label and limitations society tried to put on him. He was one of the few learners who were at the special school before 1994 who succeeded in "beating society at its own game".

- ***"Making Known, Becoming Known"***

Peter was chairperson of the student representative council while doing his undergraduate courses. He was also part of a governmental task team for persons with disabilities. Peter admits that while he was at school and an undergraduate at university he did not think of himself as 'disabled'. He was a university graduate when he became aware of his difference and what it meant to describe himself as 'disabled'. However, today he recognises that his acknowledgement of difference was an important part of his journey.

Society expected less from people with disabilities. He wants to correct that view. According to Peter:

*Before I went to join the task team on disabilities I didn't see myself as a person with disabilities. And only once I ... and only before I left to go to join [the task team] did I begin... say six months before then ... did I begin [to think of myself as disabled]. And I would say the turning point was me getting a parking disc. It was then that I myself recognised the fact that I had a disability. And, that I'm not privileged, but have a right to certain special treatment or privileges in terms of the parking or accessibility issues.*

Before he joined the task team Peter would not have dreamt of applying for a parking disc that clearly identified him as a person with a disability. At that time he believed that the 'label' defined who you are and what you will become. The change for Peter was when he realised that the 'label' society puts on you does not define who you are. You define who you are, and being a person with a disability is part of how you define and describe yourself.

Peter read extensively on disabilities and his work in the task team provided valuable insight into how society views disability and possibility. He was very aware of people with disabilities who have reached great heights in the science and technology professions. He mentioned Stephan Hawking, Lucian Professor of Mathematics at Cambridge University, a post once held by Isaac Newton. Professor Hawking has the progressive neurological disease amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease. Hawking is almost immobile, has a 24-hour personal-care attendant, and has barely intelligent speech, yet he has a brilliant career in science. Stephan Hawking communicates and writes by selecting words from a computer monitor with small hand, head, or eye movements and sending the text to a speech synthesizer.



According to Peter:

*Another dimension to the whole issue of people with disabilities regarding ... the ... I would say ... progression within math and science, is the whole issue of high function and low function. And then the whole issue with high output and low output. So you have variables. You can do a matrix, where on the one axis you have functionality – high and low, and on the Y-axis you would have a combination of those four, which would give you interesting possibilities. Now, in a typical, stereotypical, scenario there's still the debate raging about high function/low function versus high output/ low output... And we would bring forth the case study of someone such as Stephen Hawking, Professor Stephan Hawking ...uhm ... professor of Geophysics at Cambridge University, and say there is a low function, but [also] a brilliant high output. Although he's probably one in a billion within the able-bodied context, let alone probably one within ten billion within a disability context - at the most.*

Peter uses Stephen Hawking as an example of a person with physical disabilities who reached great heights in the field of physics. He points out that society wants us to believe that a person like Stephen Hawking with 'low function', meaning limited physical mobility, will have a 'low output' in terms of academic achievement. Yet, Stephan Hawking has 'gone against the grain' (Peter's words) and 'beat society at its own game'. He proved that low function or limited mobility can mean high output, in his case high achievement in the field of physics.

Peter also talks with pride of his friend who, like Stephan Hawking, has 'low function'. His friend became the first black, disabled chartered accountant (CA) and equally demonstrated that 'low function' can also

mean high academic achievement, in this instance, high achievement in a mathematics related field.

*Our former colleague and friend last year was the first black CA with a disability. Uhm. He's probably my case in point. He has muscular dystrophy [and] he has limited mobility, uhm... He has to be wheeled around, and he takes about five minutes to get out of a wheelchair parked right next to a seat. Yet, he has just passed his board examination ... The point being that when you look at him it's perceived that he might not have those numeracy skills, but when you analyse him deeper, you realise that he has that numeracy skills. Uhm ...*

Peter mentions two examples of persons with disabilities who in his opinion “went against the grain” and challenged society’s view of what is possible for people with limited physical mobility. Peter points out in the extract that we often judge people by appearances. Stephen Hawking and his friend, with their limited mobility, would not normally be considered as able to achieve in the field of physics and mathematics. However, both of them disproved societal views of what is believed to be possible for persons with limited mobility. As Peter points out, both of them became high achievers in the field of science and mathematics.

Peter brings the discussion back to persons with cerebral palsy, who like persons with Gehrig’s disease (Stephan Hawking) and muscular dystrophy (his friend), have varying degrees of mobility depending on the type of cerebral palsy.

*And coming back to the person with cerebral palsy... you might look at a person [with cerebral palsy] and judge a book by its cover and say the psychological perception of that person is that that person*



*does not have the ability, competence, capacity to do numeracy skills.*

People with cerebral palsy are not generally considered as capable and competent in mathematics. But, like Stephan Hawking and the chartered accountant Peter mentioned, persons with cerebral palsy are competent and able to achieve in the field of mathematics and science. Peter remarked that your quality of life is as much an acceptance of who you are and how you respond to the way society views you: *Do I see myself as rather having been part of what society expects of me? Or do I want to rise above it and actually beat society at its own game in terms of how it [society] perceives me?* Peter highlights that society's view of disability plays a major role in how persons with disability view themselves. And this is an ongoing battle that they have to face every day of their lives.

- ***Low Expectations***

Peter's experience in the government sector also provided him with a different view of how persons with disabilities become entrapped in the cycle of lowered expectations:

*What we've realised... uhm.... And I teasingly joke about it in training about Diversity and Disability, but it's a reality and maybe I'll explain from a ... humorous point of view... and we can deconstruct the practical implications thereof. If we look at where society is at, and I had the privilege of, to a certain extent, look at international models as well, and the South African [model] is very similar to international models in terms of the way we look at disabilities, but even more so because of apartheid. And part of my joke and analysis is around that. If you started from a zero base and you say fine, society discriminates or indoctrinates or disadvantages your thinking from a basis of ... from a racial basis, and if you*

*happen to be black – it's minus 33⅓ %. If you happen to be a woman, it's another minus 33⅓ %. We're in negative territory. And, if you happen to be from a rural area, it's minus another 33⅓ %. That's 100% that you're already disadvantaged in terms of trying to start off into society. Now, if you happen to also have a disability, you're totally stuffed. So, what are we saying there?*

Peter points out that disability issues are often the last on the political, social and economic agendas of policy makers. This highlights the obstacles people with disabilities have to overcome to be heard. This view of disability influenced how persons with disabilities considered their chances of being able to succeed in the field of mathematics and science.

*When you look at how our able-bodied people generally look at math and science, as documented by the Department of Education, there's a real lack or shortage [of persons with disabilities in mathematics and science professions] ... caused by a fear factor, by able-bodied persons, but even more so by people with disabilities. And it's probably one of two or three scenarios; (1) the fear of actually succeeding against the grain, (2) fear of not succeeding in terms of maths and science (and I can give a personal experience as well), and (3) to a certain extent the fear of being a self-fulfilling prophecy, where because of your disability there are other reasonable accommodation issues which just blurs the high intensity of studying ... the requirements that a subject such as math and science requires of a student or learner.*

As Peter points out, he had doubts about succeeding in mathematics at university. He questioned his academic ability as far as mathematics were concerned and regarded the first year pass in university mathematics as far as he would be able to go. But, reflecting on that time, Peter thinks that he might have been able to carry on with mathematics at university. At that



time he feared that he might not succeed (his third point) and become “a self-fulfilling prophecy” where the “high intensity” of studying and the reasonable accommodation proved to be too much. According to Peter,

*For example, in my case I could only progress up until 1<sup>st</sup> year maths at university. I wouldn't have had the capacity to progress beyond that. Perhaps, also I didn't find the subject interesting, exciting...yet, maybe my intellectual capacity could allow it, but I didn't know that when I was at university, because of various societal factors. So I had to be content with basically a passing grade in terms of a D (symbol) – a pass at a statistical analysis level for 1<sup>st</sup> yr university maths. Although maybe now, looking back, in retrospect I would possibly have the emotional maturity, and intellectual maturity probably as well, to possibly have progressed further, but ... I have chosen other careers.*

Peter believed that after 1994 learners are more assertive and that they advocate more actively for their rights. He partly thinks that Outcomes Based Education (OBE) might have contributed to the way learners view themselves.

*The unfortunate consequence of information and education... is that if you look at people who are not that educated and who are maybe still sitting in protective and sheltered workshops versus people in mainstream society, there's an interesting dichotomy. Because people in mainstream society can either take up their rights and fight/ champion their cause on behalf of themselves and the people who are not in mainstream, or they can totally ignore rights and just consider themselves as 'able-bodied', and... uhm... progress...[It] will be interesting to see how the next wave of persons with disability, and I suppose people with cerebral palsy, as well, ('cause that's the most visible disability of the group of disabilities), how*

*they come through in terms of their confidence, their assertiveness, their achievements and their progress.*

Peter divides people with disabilities into two groups, the 'educated' and 'uneducated'. The 'uneducated', according to Peter, is normally found in sheltered workshops and protective employment. This group has limited access to information, and therefore often not able to advocate for their rights. They are dependent on the 'educated' disabled to campaign on their behalf. According to Peter, this is a direct result of segregated schooling and teaching that characterised the period prior to 1994. He wants to believe that the outcomes-based education introduced after 1994 will have a different outcome. And he wants to believe that learners will become more assertive and more demanding of their rights as disabled persons.

- *View of Special Schools*

Peter regarded the primary school teachers at the special school as 'paternalistic'. He mentions that his high school mathematics and science teachers treated him as 'normal', meaning that they expected him to work as hard as a non-disabled learner in the mainstream school. In contrast, the primary school teachers had low expectations of learners with disabilities and did not challenge them sufficiently. Peter also admits that his accounting teacher at the special school influenced his career choice. When asked about the career guidance he received at school, Peter laughed out loud. When asked if the career guidance had any influence on his career choice, he simply answered "no", and laughed. He remembers that the career counsellors at the special school did not pay much attention to careers in biology, physical science and mathematics for learners with cerebral palsy. At the time of the interview, Peter was aware of people with disabilities in careers in science, mathematics, engineering and technology. He has now become an active campaigner for learners with cerebral palsy to pursue careers in science and technology.



Peter also refers to the inadequate training of teachers to accommodate learners with differing abilities. According to Peter, if the teacher subscribes to the medical view, namely that the problem is with the learner, the teaching and learning context will reflect the limited possibilities for learners with disabilities. However, if teachers consciously set out to “make high achievers” of all the learners, including those with cerebral palsy, then the teaching and learning contexts will reflect those views. According to Peter:

*[It] depends on how teachers are educated and what they're exposed to at university ...Do they have a 'norm-society' paradigm when they go into teaching, or do they have a 'uitskieter' (high achiever) mentality towards the teaching, and say: 'No, we want to make 'uitskieters' (high achievers) out of say 9 out of 10 of these kids as far as possible ...uhm ... and then that becomes the norm, as opposed to 1 out 10 [becoming an "uitskieter"] as a case study or statistical analysis.*

Peter's account confirms to a certain extent what Morrow (1999) asserts, namely that the outcome of our teaching is a product of the method and content of teaching.

- ***Support Structures***

Peter had strong support structures. His parents were divorced when he was very young. He grew up in the care of his mother and grandmother. He attributes his success to the fact that his mother treated him as an “able-bodied” person. On the other hand his grandmother was more protective. Peter had as strong church upbringing where he was also accepted and treated as “normal”.

*And that's very important because your social basis, for example, within your home environment...if there's a stable home environment ... [that will] assist in the learning journey of that learner.*

Peter's strong family support structure was a critical factor in his academic development. As pointed out in the following extract, it is important for the learner with cerebral palsy to have a family that believes in him.

*... (1) how does the family regard the learner or the person as a child within the home, and (2) how does he or she [learner] see themselves and (3) what are the socio-dynamics between them [parents and learners]. Do the parents or guardians regard the learner as a 'special child', or do they regard the learner as an able or normal child? And, they [parents] must then have accepted the responsibility of extra studying, extra tuition that needs to be done, etc, etc.*

Peter was fortunate that he had a family who viewed him as special and at the same time as able and capable to become whatever he dreamed of becoming. According to Davis (1997:1) "we live in a world of norms. Each of us endeavours to be normal or else deliberately tries to avoid that state...To understand the disabled body, one must return to the concept of the norm, the normal body". Learners with disabilities, and their families, come to learn very early in life that societal norms and views of disability influence and shape their perceptions of themselves.

- ***Women and Disabilities: A Triple Disadvantage***

Peter claimed to be a champion for women's rights, more so if the woman happens to be black and disabled. When asked why women with disabilities,



and in particular women with cerebral palsy, sometimes don't achieve in the field of science and maths, he answered:

*... women themselves, to a certain extent, perpetuate that cycle by believing and reinforcing that stereotype [by] saying, yes, we will accept this, [we will] be subservient, uhm ... and we will not go for the mathematics or the physics ... uhm ... positions. My director at [name of institution] has her masters in biophysics... that would be another "uitskieter" (high achiever) or someone going against the grain of black women with disabilities, who didn't let the stereotype that society is trying to enforce hold her back.*

Peter refers to his director, a black woman with disabilities who has achieved against all odds. He admits, however, that there are not many examples of women with disabilities who have achieved in science.

- ***Stereotypical Attitudes / Negative Public Opinion***

Peter maintains that the under-representation of learners with cerebral palsy is linked to the fact that they don't want to admit, even to themselves, that they are disabled or different. He reiterated that it is important for learners with cerebral palsy to admit that they are disabled, even though society views them in a negative light. Until such time when learners with disabilities accept that societal views should not define nor confine them, they will remain "trapped" in the cycle of negativity and low expectation.

*A friend of mine, a colleague, [name], he says that in person, society accepts you with a stereotype. You're reminding them of their worst fears ... of what they can become, [when] the concept of cerebral palsy kicks in... yah ... so, to a certain extent, that kind of messes with the mind on both sides.*

Leicester (1999) agrees that persons with disabilities, and especially persons with physically disabilities, often remind non-disabled people of the fine line between ability and disability. These fears often shape the way non-disabled people respond to people with disabilities, and in turn explains why the disabled often remain reluctant to accept their disability and difference.

- ***Role Models and Mentors***

Peter believes that role models and mentors are an important part of the academic and social development of learners with disabilities. However, many successful persons with disabilities do not share his view. When asked if the expertise needed will come from the “uitskieters” (achievers), and if they should they become role models, he answered:

*There are advantages and disadvantages about that. Let's look at some of the disadvantages ... and it comes back also to those involved in mainstream society, just generally, and related to this discussion, you can isolate those ones involved in mathematics and science related careers. Uhm, yes, [firstly] it's role models. It's positive reinforcement, secondly. Thirdly, it shows triumph of the human spirit... uhm ...It comes back to how it's [mentoring] done. If it's done [in a] realistic manner ... to say the person has progressed to this point, but these have been the stumbling blocks, or the growing pains, the hurdles that the person had to overcome through life as part of the journey [then it will work]... uhm ... Because, the flipside of that is, it could go to certain people's heads, where they become totally full of themselves, arrogant... We had some of those in the Disability Sector already that have now been put onto a pedestal, who sometimes see themselves as "I've arrived". And it sometimes happens in the Black Culture as well, and in the Woman's culture. And they say: "I've arrived; I'm now part of the 'in-crowd'. And they forget about the millions who are still waiting on the*



*government's disability grant, on that 'DG'. Versus those who are also saying: Is there a mentorship, or ... is there a through-flow from that level of person who 'has arrived', who 'role –models' to this ... uhm ... and [what is] the mechanism?*

Peter reminds us that a person with disabilities is like any other person who allows fame and attention to “go to their heads”. After reaching their goals in life, persons with disabilities soon forget about the “millions” who are less fortunate and who depend on the “achievers” to be their “voice”. Peter has taken on the responsibility of being a mentor and role model.

*...A clear example, on a personal level, is a chap from [site of investigation], [name] who left for [name of college]. We have a little informal mentorship programme going now ... and I have that social contact with him, where I teach him certain skills and competencies from a financial point of view and all that, [provided] that he passes it on to somebody who is now still in grade R or grade 1 at [site of investigation]. And when that [person] is perceived to have “arrived”, then they must just do the same [for someone else]. So, yah ...*

Peter highlights the importance of successful professionals taking the time to invest in just one learner with disability. The success of the mentoring will mean the start of a chain of learners who inspire and encourage each other to believe in themselves and “go against the grain”.

## RAYMOND'S STORY

Raymond (fictional name) describes himself as a person with diplegic cerebral palsy and said that he uses a wheelchair for “convenience” and sometimes to “exploit the pity factor”. This account resonates with Priestly (1999:99) citing Low describing how students often found it necessary to revert to a ‘disabled identity’ in order to negotiate the disabling barriers in a mainstream campus. Thus, ‘In order to achieve a non-disabled identity, students with disabilities must successfully negotiate a physical environment which in its inaccessibility isolates them from interaction with others, emphasising their disabled identities.’ The author asserts children “were able to skilfully manipulate disabled identities when they thought it would work to their advantage.” Raymond admits that, depending on the situation he still negotiates between two identities.

Raymond started schooling at the site when he was three years old. He left the special school in 1982 when he was in grade 8 at the recommendation of his teachers and guidance counsellor. It was suggested that he leaves at that time to allow him enough time to adjust to the mainstream before he writes his grade 12 examination. Raymond recalls that promoted from grade 6 to grade 8, a decision he recounted to not have been in his best interest. The ‘promotion’ meant that when Raymond joined the mainstream class he was a year younger than his peers. He had to adjust to a new environment where he was not only the new boy in the class, but also looked visibly different and was a year younger than his peers. This decision, though with good intentions, definitely added to the difficulties Raymond experienced at the mainstream school.

Raymond had many operations on his legs when he was younger, so being in hospital was almost a ‘necessary inconvenience’ that he has come to accept as part of his life. However, he chose to speak about the following



incident because it coincided with the move to a “strange” school and also when his mother became ill.

*That [operation] was a very stringent learning curve for me. At the same time that this was happening, my mother became severely ill. And the shackles that held me behind...Mommy's little boy... weren't there...and I had to cope on my own. I became street-smart, but at the same time became severely depressed. I orchestrated failing... I had to chose which subjects to fail. [I] decided to fail biology and physics...failed with a H symbol, and in other subjects I got A's, but I was depressed. I couldn't cope with my environment...*

It seems as if the teachers at the mainstream school were oblivious to Raymond's state of depression. He does not mention any time when the teachers intervened. In addition, it appears as if the special school did not adequately prepare for Raymond for the transition to the mainstream.

Raymond was clearly looking for attention, but the teachers did not “hear” his cry for help. But, because Raymond was “first in class”, the teachers felt that they had no reason to be concerned about him. In grade 11 he suffered severe depression, but despite all these setbacks and challenges, Raymond completed his grade 12 at the mainstream school. He enrolled for a degree in medicine “because his results in maths, physics and biology were acceptable”. However, he did not complete his first year. Raymond changed his course of study, but again was not successful. He views that experience as “being a failure”, even though at the time of the interview he was a successful businessman, had a wonderful wife and three sons.

- ***“Making Known, Becoming Known”***

Raymond related how he “became known” to his classmates in the mainstream classroom. Like Jason, he became ill in the first year at the mainstream school.

*I had a [setback], which happened instantly. I went to the doctor, he sent me to hospital and said don't worry. They start cutting me up... In the end I had what I call open-heart surgery, but it wasn't that bad. I was in the heart ward and there they [patients] dropped like flies. It was quite fun: I was on morphine, [and] could play with the respirator.*

Raymond refers to the incident as a ‘setback’ and talks about his time in hospital in a matter-of-fact, light-hearted way - hiding his true feelings. It also seemed that “becoming known” is an ongoing process for persons with disabilities. When Raymond talked about his first job as a manager of other people with disabilities, he refers to that experience as “significant in my development”. He recalls that even though, as he states, he “had all the credentials [to be a manager]”, the employer had a problem with him being disabled. As he recalls, the employer had a problem with a disabled person managing other disabled persons and therefore paid him less than the previous manager.



## THELMA'S STORY

Thelma (fictional name) walks with a noticeable difficulty. At the time of the interview she was employed, busy learning how to drive and determined to own a car. Thelma recalls that when she was at [site of investigation] she believed the career guidance counsellor and her teachers when they told her there were not many career opportunities for her to explore. At that time no one at school talked about scientists with disabilities. However, at the time of the interview Thelma was aware of a chemical engineer who uses a wheelchair, also of two girls with physical disabilities who were studying to be nursing sisters.

Thelma is more assertive of her rights and says that career guidance or career pathing should not wait until grade 11. It should start with the learner's first step, and should be broadened to include the family, the community and the whole school. She admits that at the time when she was at school, she was concerned that she would be an 'inconvenience' if she insisted on appropriate resources and assistive technologies. But today (speaking for learners with cerebral palsy) she knows that she has a right to ask for what she wants to do, and have a right to ask that teachers and guidance counsellors steer her in the direction she chooses. Furthermore, she asserts that from the time when she was at school until now, the mindset of the disabled has changed dramatically. Now the disabled say: "I deserve this", and "This makes me happy."

- ***"Making Known, Becoming Known"***

Thelma described herself as disabled and different. She refers to the labels society assign to persons with disabilities and admits that she was "trapped" by the labels for a very long time. However, she now carries the "label" proudly.

Thelma asserts:

*I see myself as (name), female, daughter, sister, [a] potential wife, unique, one of a kind. [I] won't change anything. Ten years ago, yes. But, not now....I look different, walk different, does not blend in a crowd. But why must I? Which law says I must? ... Society contributed to how I see myself. [I] was told that I look different, was labelled [as different], family also contributed to how I see myself. [Their actions] were maybe out of concern [for my welfare], but they [family] acted mainly because THEY (emphasised) believed it was in my best interest.*

When asked what the term disability means to her, she answered:

*People talk about normal? What is normal? It is relative. The pre-fix 'dis' means 'not'...therefore, 'not able'. Analyse the 'not able'...In my opinion, I do not agree... Would rather say, 'do differently'... This does not mean the same as 'not able to'. [I] do not like the word 'disabled' because of the analysis I mentioned. But if I think of the words that were first used, such as 'cripple', 'retard'... and I compare that [to disability], then [the word] disability is more acceptable.*

Thelma echoes Davis' (1997) view that 'we live in a world of norms'. However, she has come to realise that "normal" is a relative state of being. What is more important is that you accept yourself as a disabled person. After a long journey, so to speak, Thelma has accepted that to be disabled does not mean 'not able to', but to do differently.

- **High Expectations**

Like all the other participants, Thelma enjoyed biology. She describes her experiences as follows:



*I enjoyed biology... very interesting, relevant ... about everyday life experiences. Biology is part of you. ... I enjoyed subject overall... found out that it is a difficult subject.*

However, she did not consider biology as a career path. Added to that, teachers and career guidance counsellors did not encourage learners with cerebral palsy to pursue a career in biology or science.

- ***Views on Special Schools***

It is clear that Thelma regarded the teaching at the special school as lowering the expectations of learners with cerebral palsy to pursue careers in science, mathematics and biology.

*We did very few experiments, and maybe [I] did not have enough exposure in this area. [When asked] the teachers just said the school does not offer physical science. Maybe because teachers felt the learners do not have the potential.... But the teachers could not see the benefit for learners, because... For example, if a teacher offers a subject to ten learners and in the group there is one that displays potential... I ask myself the following question: Will the teacher stimulate and steer the learner in that direction, or limit him?*

Thelma raises an interesting question about the teacher's willingness and ability to differentiate effectively. She questions whether the teacher in the special school with a relative small group of learners (she mentions ten) will stimulate the one learner in the group that shows potential. Thelma also pointed out that not many experiments were done and to her mind she did not get enough exposure to the subject. It is evident from Thelma's response that she perceives "doing science" as only about "laboratory work".

## JIMMY'S STORY

- *“Making Known, Becoming Known”*

Although Jimmy (fictional name) at first described himself as “a right hemiplegic, bi-polar, that takes 40 tablets a day, attempted to commit suicide four times by age twenty, and flat-lined at the last attempt”, he regarded himself as disabled and comfortable with his disability. He recalls that while he was at school there was a saying that disability is special. Then he did not know what it means, but today he lives it. However, he admits to bouts of depression. At 34 he still gets angry “when someone looks at him funny, laughs at the way he walks”. He reacts by balling his fists and “talking back”. This is an indication to him that “society has not accepted him for who he is, still only sees that he is different and reacts to [his] difference in a negative way.”

- *High Expectations*

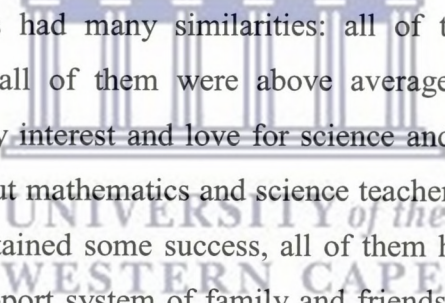
Jimmy started at the special school when he was three years old, and like Jason and Raymond were advised to continue grade 8 at a mainstream school. He finished grade 12 with “good marks” in mathematics, physics and biology. After school he went to university but only completed two years at university. However, at the time of the interview he was leading a full productive life and knew what he wanted out of life. His medical history made him appreciate life and living. His philosophy is “to do today because you don’t know if you will be around tomorrow.” At the time of the interview he had a “nine-to-five” job. He regarded life as valuable and wants to contribute to society. That, he says, is the driving force in his life.



## PART TWO

### 4.4 Voices and Meanings - An Explanation of Findings

This study was an attempt to foreground the voices, case studies and reconstructions of the participants against the background of the historical, political and social changes at the site of investigation, using 1994 as reference point. The participants choose a particular story to tell, their story of how they make sense of their lives now, in the present. These stories are their 'right stories', the story that gives them identity, the story that they find valuable to their sense of self. Each account is a unique story, a unique journey travelled. Despite formidable odds that they had to overcome, all the participants displayed courage, perseverance, tenacity, resilience and optimism.



The participants had many similarities: all of them were persons with cerebral palsy, all of them were above average achievers, all of them reported an early interest and love for science and mathematics, and all of them talked about mathematics and science teachers who inspired them. All of them have attained some success, all of them had jobs, and all of them had a strong support system of family and friends. In addition, all of them became aware of disability rights when they were in their twenties and related specific instances when they advocated for their rights and place in society. But, as the accounts of the different stories reveal, these similarities do not define nor confine them.

The stories highlighted the philosophies that defined each participant in a unique way. Peter stumbles and falls all the time. Even in his adult life he stumbles and falls over his own feet. But, as Peter says, 'Failure is not the falling down; Failure is the staying down'. Peter took what happened to him every day as person with a disability, and translated the experience into a philosophy that aptly describes him. Thelma too says: 'I deserve this. This makes me happy'. She has come a long way from the learner who at school

did not want to “inconvenience” her teachers. And Jimmy’s philosophy: ‘To do today because you don’t know if you will be around tomorrow’, defines who he has become. He had attempted suicide and knows how fragile life can be. This general disposition towards adversity and perseverance runs through the accounts of every participant. All of them displayed a remarkable ability to ward off the trivialities and stereotypical attitudes of the non-disabled. Even those who seemed to have failed have shown characteristics of the valiant. There is the boldness of Jason, Raymond and Jimmy leaving the “comfort” or “protective” zone of the special school to the mainstream secondary school where the reality was “survival of the fittest” so to speak. Their voices become less bold when they relate their struggles with ill health, battles with operations, bouts of depression, and become mere ‘whispers’ when they talk about the humiliation of being carried around by their fellow learners.

- ***Disability and Difference: “Making Known, Becoming Known”***

The experience of “becoming known, and making known” determined how the participants viewed themselves in relation to others, their quality of life and the contribution they could make to the communities where they lived. It is evident from the individual accounts that their parents and teachers did not assist to help them reflect on their difference or help them celebrate and become comfortable with their disability. This clearly had a negative effect on their future career paths.

Jason was harshly awakened to how society viewed his difference. He talked about “the taunts of the children” and having to “steel” himself to face them. Again, there was no mention of his parent or teacher helping him face the battle, so to speak. The special school “where everyone has some sort of disability” provided a false sense of security, but only from eight in the morning to three in the afternoon. Jason remembered at the special school “they never had to reflect on their differences”. When he arrived at



the mainstream school he was ill prepared for the stereotypical attitudes and behaviours of the so-called “normal” learners and teachers. Raymond and Jimmy expressed the same sentiments.

Jason, Raymond and Jimmy were the only learners with cerebral in the mainstream classroom (and in the whole school) when they started in grade 8. They had to adjust to the mainstream classroom and building that was not physically equipped for learners with cerebral palsy. They were forced to suffer all kind of indignities. There were these young adolescents being carried up the stairs, emphasising their helplessness and dependence. Jason uses the word exposed (emphasised word), highlighting how vulnerable and alone he must have been. It was only in his early twenties that Jason received sound and useful advice from a counsellor on how to deal with and accept his difference.

- ***Low Expectations/ High Expectations***

The findings showed that learners often viewed their lives through the teacher’s lens. However, the teacher’s perspective at the time was shaped by the views of a medical model of disability, shaping their view of learners with cerebral palsy in a particular, limiting way. This perception of disability informed the context of teaching; the way learners were taught, what the learners thought was possible and shaped the outcome of teaching and learning.

None of the learners who shared their stories completed tertiary education programmes in science related careers, despite having expressed an early interest in science, biology and mathematics. The voices of learners in this study complement the findings by Alston and Hampton (2000) that the absence of professionals with disabilities in the workplace and an absence of learners with cerebral palsy in biology classes can discourage learners from entering these careers.

All the participants referred to the absence of specific career guidance in biology and science fields for learners with cerebral palsy. Alston, Hampton, Bell and Strauss (1998) found that rehabilitation counsellors (career guidance teachers) perceived learners with disabilities as lacking the educational skills required for careers in science, mathematics and technology and based on this perception, recommended careers other than science, mathematics and technology for learners with disabilities.

- ***Learners with Cerebral Palsy: Potential Scientists***

Costa (1995: 314) describes the following model for ‘understanding how students’ responses to science are related to the degree of congruency between their worlds of family and friends and the worlds of school and science’. Students are categorised into five distinctive patterns of behaviour regarding the relationship between personal experiences and success in school and science:

1. *Potential Scientists*

World of family and friends are congruent with worlds of both school and science.

2. *“Other Smart Kids”*

Worlds of family and friends are congruent with world of school but inconsistent with world of science.

3. *“I don’t know” Students*

Worlds of family and friends are inconsistent with both school and science.

4. *Outsiders*

Worlds of family and friends are discordant with worlds of both school and science.



### 5. *Inside Outsiders*

Worlds of family and friends are irreconcilable with world of school, but potentially compatible with world of science. (p. 316)

Costa (1995:317) asserts that learners experience many pathways into the world of science, and describes a “potential scientist” as a learner whose “worlds of family, friends and school are congruent with the world of science”. Jason in particular fits the characteristics of “potential scientists” as described by Costa, namely curiosity, confidence and self-motivation. Costa (1995) contends further:

Numerous factors perpetuate negative experiences of students in science classes, including different cultural values and norms; different ways of viewing society; basic ignorance or fears of the system on the part of the students; and possible prejudice on the part of counsellors, teachers, and administrators. These issues are not always considered when we evaluate and prescribe for school science. What goes on in high school science classes is somehow considered independent of the adolescents’ worlds, as though students leave their personal life at the door of the classroom and take it up again like a backpack when they leave. In reality, the personal worlds of adolescents colour their response to and engagement in science.

The participants in this study echo the above sentiments. All of them reported low expectations of teachers and career counsellors of career possibilities in biology and science for learners with cerebral palsy. In addition the biology classroom did not reflect the personal world of the adolescent with cerebral palsy and therefore failed to assist their engagement in science.

Furthermore, Jason's journey echoes Costa's (1995) findings:

Because science is personally important, one bad experience is not going to deter these students from their goal of a scientific career. Their interest in science is reinforced outside of the classroom, whether through friends, part-time employment or a toy chemistry set. They are willing (and expect) to work diligently in science, and they intrinsically enjoy the subject matter. (p. 319)

Jason had many bad experiences and had to overcome numerous battles with illness, "time lost", low expectations of teachers, taunts of children and struggles with conceptual difficulties. Yet, these "bad experience" did not deter Jason. At the time of the interview he was studying microbiology at the university.

Aikenhead (2001) proposed an additional category, "I want to Know" to Costa's (1995) five-category scheme and refers to the borders and world views learners have to negotiate:



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1. *Potential scientists*

Smooth border crossing that lead to an in-depth understanding of science. Their self-image and lifestyle resonate with the world of Western science.

2. *"I want to Know" students*

Adventurous crossings that lead to a modest yet effective understanding of science (there are hazards, but students want to know). Their self-image and lifestyle resonate with the world of science, but the intelligibility, plausibility, or fruitfulness of Western science concepts is often a challenge to them.



### 3. *Other smart kids*

Easily managed border crossing but with no personal interest in pursuing science. These students do not fit the self-image and lifestyle they associate with Western science, but they do have strong self-esteem and self-perceptions related to academic success.

### 4. *“I don’t know” students*

Hazardous border crossings into a superficial understanding of science (there are hazards, but students do not want “to look stupid” in the eyes of their peers or teacher). Science does not fit their self-esteem or their lifestyle, but they have enough self-esteem and self-perception to persevere.

### 5. *Outsiders*

Impossible border crossing that lead to dropping out, physically or intellectually. Science fits neither their self-image nor their lifestyles.

### 6. *Inside Outsiders*

Impossible border crossing due to institutional discrimination in spite of personal interest in understanding science. (p.186)

Peter fits Aikenhead’s “I don’t Know” category. Peter talks about his “fear of not succeeding in terms of maths and science”. He had doubts about succeeding in mathematics at university and regarded the first year pass in university mathematics as far as he would be able to go. At that time he feared that he might not succeed. He rationalises by saying that he did not find the subject interesting, and therefore he chose a career in accounting. This decision underlines Aikenhead’s definition of “I don’t know” students: the possibility of failure and ‘looking stupid’ in the eyes of his peers did not fit Peter’s self-image and lifestyle. However, Aikenhead has not taken into account that learners with cerebral palsy also have an added concern: their ‘disabled bodies’ do not fit the image that society has of scientists.

Although the participants displayed an early interest in science and a desire to pursue a career in science and technology, they seemed to have become ‘inside outsiders’ due to societal discrimination and stereotypical attitudes towards people with disabilities. Costa’s (1995) and Aikenhead’s (2001) categories did not include the added “worlds and views” that learners with cerebral palsy have to negotiate and transition. Learners with disabilities have to negotiate and overcome the world of the non-disabled and disabled and stereotypical social and cultural constructs of disability. It would be interesting to see where Costa and Aikenhead placed the black, disadvantaged learners with cerebral palsy interviewed in this particular study.

- *Towards an Inclusive Biology Curriculum*

Costa (1995:330) asserts, “Science educators need to improve practice as well as impact policy. Curriculum should involve learners in active reflection of how science makes a difference in their lives and society.” First of all, Jason’s experience with the children in his neighbourhood and the learners in the mainstream classroom highlights the importance of an inclusive curriculum that assists non-disabled learners to unlearn prejudices about those with disabilities, uncover stereotypes and value diversity. The biology curriculum should (i) facilitate an understanding that ‘equality of treatment’ is not always equivalent to ‘sameness of treatment’, and (ii) advocate a ‘disability awareness’ that highlights understanding of the ‘ways in which disabled people are devalued and denied their rights’ (Leicester, 1999:23-4).

Secondly, the inclusive biology curriculum should assist learners with cerebral palsy (and their teachers) to understand and successfully negotiate the different “worlds and views” of science - the worlds of family, friends, school and society.



According to Costa (1995: 331):

Science educators should get involved in school reforms that focus on breaking down barriers between student's worlds of family, friends, schooling, and science. A beginning would be to provide all teachers with an understanding of the other worlds of students through in-services on at-risk students and student diversity.

There is an added challenge for learners with cerebral palsy, and their teachers. Costa (1995: 330) suggests that science courses be organised around a central question: 'How does chemistry (or biology, or physics) impact my personal life and society?' In the inclusive biology classroom (with learners with cerebral palsy), the question could be extended to ask learners to reflect how, for example, biology and the study of the skeleton impact on their understanding of disability and difference. Or, learners could be asked to relate how the success story of a person with cerebral in biology related professions impacted and influenced their journey to become scientists. Chin and Chia (2004:721) assert, "anchoring instruction around such human stories could bring about a better appreciation of the place of science in contemporary life, and signal to students that the questions and answers that arise in their daily experiences are valued".

There is an added challenge for teachers of learners with cerebral palsy "to make teaching more effective by situating syllabus objectives in real-life contexts, especially in daily life examples that students can relate to" (Chin and Chia, 2004, p.721). In the inclusive biology classroom teachers need to relate scientific concepts to the real-life experiences all learners.

#### 4.5 Summary

The experience of listening and writing the stories of learners with cerebral palsy provided a glimpse of learners' lives and offered a chance to view the world through their eyes, the world of school and the world of work. In addition, the experience helped to foreground the researcher's prejudices and assumptions as teacher of learners with cerebral palsy. Moreover, the study presented an opportunity to share in the successes of some of the learners, and the continued pain they still experience. The researcher was challenged to rise above and beyond the trauma of the "case" and to hear the voice of the participant, to uncover the pain and see the potential that was stunted. The process provided the researcher a chance to re-look at self, at her practice, and to admit that she often did not like what she saw. The voices and stories told were indeed powerfully educative and liberating.

The case studies highlighted the struggles and triumphs, providing a compelling snapshot of the journeys of young persons with cerebral palsy. The interviews provided a glimpse into the inner cognitive world of the learner with cerebral palsy, a portrait of each one interviewed as a unique individual, each with their own dreams and aspirations, each with their own stories of pain and exclusion. Chapter five draws on the results and findings and offer recommendations for policy, curriculum development, instructional practice and future research.



## CHAPTER FIVE

### CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

...with opportunity, people with disabilities do not only shine but find their definition as talented members of society who can place their mark of excellence in our competitive world...When the burning flame of spirit is ignited, it can light up and transform any life, no matter the circumstance.

(Zulu, 2004:19)

#### 5.1 Introduction

The ten years of democracy should have been a celebration for **all** South Africans. Yet, in the area of disability there is still not enough reason to celebrate. Lack of resources and low expectations remain the major barriers to developing the science and technology potential of the country. The study was premised on the assumption that there is a conceptual connection between the content and method of learning, and the 'outcomes' of learning (what is learnt), and that the origin or root of negative attitudes and low expectations shown towards learners with cerebral palsy could be traced to this crucial interface. This study was an attempt to find out if the under-representation of black, disadvantaged learners with cerebral palsy in biology careers is in any way linked to the method and content of teaching and learning in special education. In addition, the study attempted to identify and uncover the barriers that prevented learners with cerebral palsy from pursuing careers in biology and related fields.

In pursuance of aim above a group of learners with cerebral palsy were interviewed. The purpose was to listen to their voices and pull their views together to inform practice. Based on the outcomes of the interviews, the following conclusions have been reached:

1. The support from parents, teachers and medical staff was critical for success of learners with cerebral palsy during their school careers.
2. Teachers in special and mainstream education were not adequately prepared for disability and difference in the biology and science classrooms.
3. The low expectations of teachers, parents and academics in higher education often countered and minimised the high expectations of learners with cerebral palsy to pursue careers in biology and related fields.
4. The school curriculum at the time did not prepare learners with cerebral palsy for the mainstream, higher education and world of work.
5. The lack of assistive and adaptive technology, inclusive accommodation strategies and limited exposure to adequate laboratory facilities played a part in creating low expectations of careers in biology for learners with cerebral palsy.
6. The absence of role models and mentors of people with disabilities in professions related to biology, appropriate internships and learnerships in biology and related career fields added to learners with cerebral palsy not attaining their dreams and goals of becoming scientists.



## 5.2 Implications for Policy, Curriculum Development, Instructional Practice and Research

This study was conducted with a limited number of former learners from a typical 'township' special school. All the participants were learners with cerebral palsy. Given these limitations, generalisations should be made with prudence and the applicability of the outcomes of the study to the teaching of biology or any other subject would of course depend on the goal in view. However, the study highlighted the following implications for policy, curriculum development, instructional practice and research.

### • *Teacher Training for an Inclusive Biology Classroom*

A major concern to all teachers is time: time to make individual accommodations, time to set up labs and take down labs, time to manage student behaviour, time to deliver a lesson, and time to assess progress. Furthermore, teachers will be expected to know how to identify and implement special adaptations for learners with disabilities. Rapp (2005) asserts:

Each year, teachers are faced with a task that is becoming increasingly difficult – meeting the educational needs of all students. ...Class sizes are increasing, and the backgrounds of the students in those classes are becoming more diverse. The move towards inclusive education, the societal respect for and celebration of diversity, and the recognition of multiple intelligences and learning styles all emphasise the complex heterogeneity of our students. We as educators need to move towards more innovative, collaborative, student-centred practices, particularly for students with exceptional needs. (p. 297)

Teacher training programmes should draw on the experience of biology teachers at special schools to assist with programmes to address the fears

and misconceptions mainstream teachers might have of learners with disabilities in science classes. Furthermore, biology teachers in mainstream and special education should work together to prepare innovative, inclusive instructional material to assist with full inclusion in the mainstream classroom (see Appendix E for an example).

Teacher training programmes should explore *on-line classrooms* where the participating teachers can reflect on the process of inclusion, and will hopefully become a forum for teachers to talk about and comment on how they approached inclusion in the biology classroom. The accounts of the interactions in the different classrooms could be organised into a networked curriculum database of case studies as used as reference for teachers in the mainstream classrooms.

Teacher training should also include *career development teams* comprising of the biology teacher and the life orientation teacher. One of the learning outcomes of the curriculum for biology/life sciences is the exploration of career pathways. Biology teachers do not have time and are not adequately prepared to make links with science content and industry-related careers. The biology/ life orientation teacher-teams can work together with the relevant universities and industry to design career pathing for learners with cerebral palsy. These teacher teams could plan, organise and conduct local, on-site workshops to assist both to develop innovative ways to heighten awareness of careers in biology/ life science for learners with cerebral palsy.

The study also highlighted the importance of *specialised laboratories* that offer access and safety for learners with cerebral palsy. The special school as resource centre could become the place where teachers in mainstream classes can train and workshop inclusive settings for the biology practical classes.



- ***Development of Appropriate Learning Materials***

The study also points to the need for the development of an *employability portfolio* to facilitate career paths for learners with cerebral palsy. The employability portfolio could offer learners the opportunity to foreground their “voice” against the background of all the tasks. Regular sessions with the career developer should be arranged to track progress. Learners can reflect on their own interests and abilities as well as career and entrepreneurial options as they move towards finalising their choice of a career.

- ***Preparation for the World of Work or Higher Education***

The study also highlighted the importance of *role models and mentoring* for learners with cerebral palsy. Alston and Hampton (2000) suggest that in order to address the issue of shortage of role models, schools should establish a mentoring system with local universities that have learners with cerebral palsy majoring in biology, and with local employers who have employees with disabilities working in biology settings. Learners could ask mentors basic questions, for example questions about logistics, mechanics, concerning accommodations and adaptive technologies. Mentors could also share strategies for handling low expectations from teachers and parents, as well as negative attitudes of employers and fellow workers. In addition, the school should arrange visits to university and technikon campuses to broaden the teachers’ and learners’ thinking about possibilities for careers in biology. Likewise, visits to workplaces to observe people with disabilities performing at their job sites could allow teachers and learners to see learners with cerebral palsy making the transition from school to biology career fields. In addition, video recordings of learners with cerebral palsy in tertiary programmes and the workplace can be used.

Another implication that the study points to is that the role of special schools as resource centres (SSRC) should be extended to accommodate

training for career pathways for learners with cerebral palsy in biology and related fields. The special school in its new role should become the formal link between the institution of higher learning, the neighbouring schools, government sectors, and industry. Special schools could, together with mainstream schools, design and develop *programme-to-work linkages* that focus on career pathways for learners with cerebral palsy in science and technology professions.

The key objective is to form *partnerships* with the Department of Education, Higher Education Institutions, Further Education and Training (FET) colleges and the private sector in order to assist Government to address the under-representation of learners with cerebral palsy in biology and related careers. There are many spaces within the FET-2008 curriculum for university outreach programmes to work together with teachers and curriculum planners to develop careers pathways for learners with cerebral palsy within the science and technology related professions.

• ***Research and Resource Development***

Inclusion is a process. An important part of the process is the documentation and management of the change from special education to inclusive education. The study highlighted the importance of research and development of the following as critical for a truly inclusive biology curriculum:

- Teacher/ assessor training modules that includes printed materials and collateral multi-media courseware that articulates how content in various subject fields can be explored and linked to science career pathways.



- Science teaching and learning programmes incorporating print and online materials that focus on biology careers for learners with cerebral palsy.
- Resource manuals that provide insight as to how materials can be adapted to include learners with cerebral palsy in biology and related fields. Examples of a Students' Abilities Profile and the Four-Step Accommodation Model (see Appendix E) could be included. Also, an index on assistive technologies and useful websites for the teacher to explore.
- Case studies of success stories and role models of professionals with disabilities in biology and related careers.
- Studies of successful Inclusive Institutional Models and Programmes.



### 5.3 Recommendations

In the light of the study and the discussion above the following recommendations are made for future research:

- **Extend research on black, disadvantaged learners with cerebral palsy.**

The aim should be to include learners who attended this special school and matriculated during the period 1994-2004. Also, the voices of teachers, school managers and curriculum planners in special education and the mainstream before and after 1994 should be listened to. In addition, the voices of parents of learners with cerebral palsy should be heard.

➤ **Document case studies of professionals with cerebral palsy in the higher education and the workplace.**

The myths and ignorance surrounding the abilities and capabilities of people with disabilities could be countered with proper documentation of case studies of success stories of people with disabilities in careers related to biology and science.

This study was an attempt to start a discussion on the state of affairs and what can be done to attain a wider vision of a full inclusive system of education within the present school setting. In order for this to happen, there will have to be a significant paradigm shift in various sectors. Firstly, teachers of learners with disabilities will need to be re-trained to deal with diversity and associated challenges. Their belief about what role they ought to play in the new dispensation of a democratic South Africa and what learners are capable of will have to change. Secondly, learners with disabilities will have to change their perceptions of what is possible and what they are capable of becoming. Last, but not least, the challenge is to design and develop an inclusive biology/ life sciences curriculum that will assist learners with disabilities to participate in all the processes of a democratic society.



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**APPENDIX A**  
**Information and Informed Consent Document**

TITLE OF THE RESEARCH PROJECT:

Voice, Disability and Inclusion: A case study of biology learners  
with cerebral palsy

RESEARCHER:

E. Johannes  
Doctoral student, University of the Western Cape

SUPERVISOR:

Prof. M.B. Ogunniyi  
School of Science and Mathematics Education  
University of the Western Cape

**DECLARATION BY THE PARTICIPANT:**

I, ..... (name), hereby confirm that I was invited to participate in the abovementioned research project.

The following aspects have been explained to me:

- **Purpose and key question** is to determine whether biology learners with cerebral palsy have low expectations of future careers related to science and technology.
- **Procedure:** Qualitative interviews will be conducted with learners with cerebral palsy who have attended special schools.
- **Possible benefits:** A possible outcome is the design and implementation of a model for career pathing in biology and science for learners with cerebral palsy.
- **Confidentiality:** The researcher will ensure that all information that is obtained during the course of this study will be kept confidential. The privacy of the participants will be ensured by not using their names, and that information will be treated as confidential and that no personal information will be disclosed.
- **Access to findings:** The findings of this study will be made available to all those who participate.

- **Voluntary participation/ refusal/ discontinuation:** Participation in this study is on an entirely voluntary basis. All potential participants have the right to refuse to participate without needing to supply a reason. Also, the participants have the right to withdraw or discontinue their participation in the research project at any stage.

The information above was explained to me in my home language (English/ Afrikaans). I was given the opportunity to ask questions and all these questions were answered satisfactorily.

No pressure was exerted on me to consent to participation and I understand that I may withdraw at any point without penalisation.

Signature of participant: ..... Date: .....



**STATEMENT BY RESEARCHER:**

I, ....., declare that

- I explained the information given in this document to ..... (name of the participant);
- he/she was encouraged and given ample time and space to ask questions;
- this conversation was conducted in English/ Afrikaans and no translator was used.

Signature of researcher: ..... Date: .....



## APPENDIX B

### An Example of Permission Letter

[Date]

Dear Sir

**RE: Request to conduct research**

I am currently registered as part-time student in the doctoral program in the faculty of Science Education at the University of the Western Cape. My research interest is the under-representation of biology learners with cerebral palsy in careers relating to science and technology. I successfully applied to the Western Cape Education Department for approval to conduct research at schools in your district.

The purpose of the study is to determine why biology learners with cerebral palsy have low expectations of career possibilities in science and technology, and to uncover the various barriers that may have contributed to low expectations and under-representation of learners with cerebral palsy in those careers. It is expected that the results of the research might provide pointers towards an inclusive biology curriculum that will redress the under-representation of learners with cerebral palsy in science and technology related professions.

I trust that my request will meet with your approval. Please do not hesitate to contact me should you require any additional information.

Yours in Education

.....

## APPENDIX C

### Excerpts from Jason's interview

[I]: *Tell me about Jason...*

[J]: Okay. At the moment, I'm 27. I've been working as a learner. I started a learnership project and ... uhm ... Before this I've been attempting to study at tertiary level in microbiology. That was ...uhm... real goal for me since my high school years. I loved biology. I really liked science and math from primary school years. I used to investigate things all the time and try and figure out how things fit together. So, even at [special school], I was very into how things work... and ... that carried on into high school. And, there I did very well at biology, struggled a bit with my physics – conceptually... And it took a lot of remedial attention from my physics teachers and my math teachers to get me up to scratch... because a shortcoming I had was ...uhm... abstract comprehension... Uhm... I struggled with geometry specifically and then going into physical science again where anything related to spatial awareness was concerned ... was a battle for me to get used to it. Eventually I did. But it took about three years of knocking my head against the wall, so to speak. ... Until I could definitely say ... Something that primary school kids need to do is (and spend quite a bit of time with) ... uhm... is geometry in math. Uhm... Literally [spend time with] concepts in math like algebra and, even maybe trigonometry, should be fairly easy for a child to grasp. But they're going to struggle with many aspects if they don't have geometry and spatial awareness sorted out carefully. So, even if it means doing the same and ... doing similar type of exercises and changing those exercises for seven or more years for the child's primary school career. That would be the key... Because that [addresses] a lot of how they think ... uhm... And even beyond science I think... Uhm... Somehow the geometry seems to fit into other parts of your life... And ...I mean...Let's imagine trying to... uh... build a house... and if you don't have a spatial awareness, then you're not going to figure out how you'd like your living space to be. So even planning



your future life is going to depend on these basic concepts. Uhm...And being at [mainstream]...

[I]: *When did you become aware of being different, [aware] of your disability? ...*

[J]: Okay. I started out at [special school] in primary school...no, in pre-primary (nursery school), at the age of four. So all my classmates had some sort of cerebral palsy. And, so it didn't really seem strange. Someone limped and someone had a funny hand, someone had a funny arm, someone spoke differently, or looked differently. Because ...that was just us accepting it as is. This was how we are. Where it started... Where I started becoming aware of a difference as such was that my friends in my neighbourhood...uhm...my next door neighbour, being one of my first close friends...he has since emigrated...We knew each other since we were about two or three years old. He doesn't have cerebral palsy. So, he and I grew up...and as we grew up...uhm ...he would notice that there's something strange about me... and this [strangeness] was my, my...physical movement, ...uhm...but...he didn't raise any issue about it...And, and then...being at [site] for my primary school years, [disability] didn't become an issue, because everybody else also had some kind of physical thing (emphasised word) and sometimes non-physical thing (emphasised word) that they just had to deal with... OK...And as I got older ...uhm... I started becoming self-conscious; especially around the neighbourhood...uhm...my parents were a bit scared of me using public transport. So, most of my close friends were in this [area]. I would get taken to [them] or they would come pick me up, their parents would come pick me up. So, the kids around here would sort of look at me and I would get these funny names and ...insults, if you want... and that was difficult to deal with (hesitates...) There was a time when I would say, yah, I don't like this, I don't want to go outside...uhm... but, what helped me really was...First of all, my friends were a great support. We all teased each other, but they never rejected me because of whatever was different between us. So, that strengthened me to literally go outside again, face kids who wanted to taunt me, taunt them



back, and basically take back my power. And just say: Look, I have a right to be here and I don't really care what you think about me anymore. So, either leave me alone...uhm...or I'm going to stick it to you...Uhm...And I didn't...I wasn't one for physical violence. But there came a time where I decided, Look, I'm not taking this nonsense anymore. I have a right to be here, and I'm going to stake my claim. And nobody's going to tell me that I can't be in a certain place or walk down a certain street. Or, if someone looks at me in a certain way I'm going to look right back at them, because I don't see why they should stare at me. Uhm. That took a couple of years to develop...

*[I]: And now?*

[J]: I sort of had to use that "technique" very much when I left [special school]. Went to [mainstream] where I don't think anyone else besides me had ...uh.... C.P, uhm, cerebral palsy. And again [I] had to keep building up on that [technique], almost like a defence mechanism. But again I had ... I entered into a class where ... I don't know how it happened, but the class was very supportive from very early on, which was an incredible experience. And we were all 13 years old. But I actually got sick in my first three months at the school. I had a "cephalus incident". That was a shock to my class teacher. And ... uhm... I was then finally EXPOSED (emphasised) as in what I was about to the ENTIRE CLASS (emphasised). But, they all rallied around me...uhm... and, tried to understand what I was about. I also had a close friend in class with me who I'd met two years before through friends of my parents. He is not disabled. Uhm... He was also very supportive of me. So, there was the start of now being fully exposed, in a way, to the outside world. Taunts of children ... and steeling myself against it. And just saying: Look, I have to get on with this, get on with my schoolwork, and get on with enjoying the mainstream world...uhm...where we are not really protected from anything. And... uhm... my parents were very supportive. Uhm ... My whole family was very supportive...uhm...And teachers at [mainstream] were very supportive. And so I managed to kind of get on with that.



....

[J]: This was at [mainstream]. Each teacher that I got between std 6 and std 8... because, only after std 8 did I start catching up on the concepts... Each teacher, uhm... In fact I think it was the same teacher for std 6 and 7, and a different teacher for std 8... The two of them kind of figured out that I was not grasping the way they were giving it to the other kids. So they tried to give it to me a little differently. And tried to keep it simple and introduce the minor concepts before they introduced the major concepts. So, the little pieces actually, when they were put in, helped me to understand how this whole thing works. I also needed to go for tutorial sessions... uhm... for at least two years. ... In fact, I think, even three years, from grade 8 to grade 10 - once a week, to once every two weeks. And, this gentleman, he was also one of the teachers, he was a senior teacher offering classes at mainstream, and he also tried to understand why I was misunderstanding. And in fact he said: "Look, your misunderstanding is not uncommon. So, you don't have to feel terrible about it. But, you do need to fill in the little concepts before you can understand the big concept. And, if you have to break down the little concept even more, then you do so." So, that [technique] I used in math. I went on to use that in physical science as well ... uhm ... so that for me was the clincher.

Here's a concept. Fine.

What are the parts of the concept? Look at each part as a little block.

Do you understand the little block? Okay.

Now look at the other little block. Do you understand that? Fine.

Now, put all the little blocks together.

Because you understand what concept each little block represents NOW (emphasised) do you understand the major concept?

Yes

But, [the problem is that] I cannot get the big concept which might seem simple to the teacher; I cannot get that concept and be expected to understand the [work].

[I]: How was it at [special school]?

[J]: Uhm, I think at [special school] they didn't even look at the concepts. I don't even think they went there. I don't think they did very much basic geometry with us, to the extent where they introduced the little ideas which you should have picked up on. And I know this because my classmates at [mainstream] were picking it up and I wasn't. So, they must have been taught those concepts. ... Uhm ...

...

[J]: Yes. Yes ... I unpack the concept...

[I]: *What is it [that] you do?*

[J]: Well, it is what I've been taught to do to try and understand things. In order to try and understand this huge idea, break it down into smaller pieces and then put it back together.

...

[J]: That's how I've managed to get through, let's say grade 10, grade 11 and grade 12, where your basis after grade 9 stops, and now you start doing application. For the next three years in maths, in science, in English, in history, in all your subjects, you now start doing applications from grade 10 to grade 12. If you haven't mastered the basics, you're going to have a real battle doing all the applications ... uhm... because the thing was... If I look at my history mark ... my history mark was quite good... uhm.... Because I like the story behind the incident and ... our history teacher, who was my class teacher for four years from grade 9 to grade 12, he encouraged us to break down the concept, to think about why it happened, whether it was Pearl Harbour or whether it was... uhm... the Great Trek or whatever, you know, [ask yourself] why did it happen, what were the parts of it. Now let's put all of the parts together. Right. Now, think about this in your own mind. Now write about it in your own words. Uhm...so, my little ideas eventually became a common theme that my history teacher was using. Uhm... My physics teacher, who would knock my head against the wall, not literally, ... but was trying to get me to understand things, ... eventually realised that the only way I was going to understand physics is if he will quietly get me to break down the concepts into smaller pieces and then try



and apply it to the bigger concept. So that enabled me to build up my physics mark. Uhm ... I have no idea why I didn't struggle with biology. I can't say. Uhm...Biology just seems to gel with me... Uhm...

...

[J]: The thing is there are also a lot of concepts [in biology], and a lot of content. Which is different to physics. Physics has a little bit of content that you apply and modify over and over. But, biology has quite a bit more content that you've got to think of and use for a lot longer ... uhm ... even in high school ...uhm ... and I don't know how that worked. It somehow just worked, that I just somehow managed to grasp the concept, stick it in memory...uhm ... put all the other concepts with it, like when you ... when you were required to know ... to just basically remember the content around something. Whether it's the liver or whether it's how a plant cell works or something like that ...uhm ... you did need to understand it, which would make it much easier to remember. And at the time grade 10, grade 11 and grade 12, I had had... By the time I came to grade 10, I had had two surgical incidents. I had a surgical incident in grade 8, a hydrocephalus incident, which took me out of school for about two weeks at least. . Uhm ... And there I had to now catch up with concepts, that's besides the physical recovery ... and hopefully remember what I had been learning, because there's brain trauma... Somehow I would forget. Somehow that wasn't the case and I was able to just pick it up, stumble a bit and then start running again. In grade 9 I had orthopaedic surgery that took me out of the game for well... The orthopaedic surgery happened during the mid-year holiday, but what happened then was, I ended up being shuttled ...ur...physically carried around the school by two classmates. So, here is the thing where I'm really self-conscious... I had my legs in plaster from my ankles to my hips, and I have to sit with the stuff on for another three weeks, because holidays were only three weeks long itself. So I get chartered around school, people are looking at me, it's freezing cold and I've still got to concentrate thought every single class. So, there again it was distracting, it was at a time when my concepts in maths and science were not that great yet and somehow I



was still trying to unpack things. In grade 10, the transition period, I fell ill again with hydrocephalus problems ...uhm... but I think just enough work has been done in my math concept building and science concept building so that I was still able to pass the math and science that year. So, I was now able to use the technique, break down the concept ... uhm ... try and see where it fits in, work it out, check your answer, check a worked example, [ask] does the method look remotely the same? Yes. So, there in fact, all of sudden these mysterious worked examples that the math and physics teachers were giving us made sense, because I was latching on to the concepts. I was able to figure out the little concept and attach it to the big concept and finish off the calculation; because, the answer was not what they [teachers] was looking for, they were looking for your method, how did you get to this answer... And there's probably three ways to do it. So, [the question is] how did you get there ... at the end of it...

...

[J]: well, I shouldn't say chose. I should say it was recommended to me to choose not to study in 1995. My surgeon said: *"Look, I REALLY (emphasised) recommend that you go on a gap year"*, you know. *"Do nothing. Just relax. It's been an exceptionally stressful year, beyond what most matriculants (grade 12s) go through. Relax. Take it easy. Do absolutely nothing. Don't even think of working. You may be 18 yrs old and in line for trying to hunt for a part-time job. Don't even bother doing that. Just take it easy"*, which sounded like a lovely idea... But, after a week I was gnawing at my nails because I was bored... But, uhm ... but, I ... just had to ... my parents had to accept that, look, I have to take a break. I had to recover. If I'm going to push, then I'm probably going to end up much worse. And, in any case, I actually became quite depressed when the realisation hit me that I'd had a huge knock in my life. I had had a huge knock to my confidence, my self-confidence, uhm ... and I was ... I was ...uhm ... After building myself up, trying so hard to build myself up for the previous five years, I was back in a position where I'd have to start from scratch. I'd have to prove what I could do to people; I'd have to ... uhm ...



build up a track record again, 'cause I felt like I was demolished. ... uhm ... and that I just felt awful. And I felt awful for the bulk of 1995. I had to go for counselling, for serious counselling...uhm ...because I was really... I'd hit absolute rock bottom. Uhm... And ... the counselling sort of brought me back to the present and to what could in the future if I just took it slowly. And, so by September 1995 I applied to technikon for mechanical engineering. I thought, look; let me see if the technikon environment is a little less stressful than the university environment, which of course is not the case. Technikon is not less stressful than university; it's just that the applications are directed differently. We do just as much theory by suggestion; it is just not all there in book form. So I went on to start mechanical engineering at tech.

...

[J]: Oh... The memory problem somehow didn't affect me while I was doing the modulated course. It was one small batch of information a month. So, let's say we were talking about the skin. That's all we will discuss ... think about and discuss for a month. We discuss it at the seminar, you have to read up in a physiology textbook about it, uhm... follow the course outline and write it off next month. That happened for each of the modules: nervous system, skeleton, digestive system, the works. So it seems that modulated, small amounts of information worked for me. And it was really in one area – anatomy and physiology. And the [alternative healing] training is very practical. It's literally hands-on. We'd work on each other's feet during the seminar as part of the seminar day/afternoon. We'd do a session working on each other's feet. And you and another student would exchange notes on how your technique was going and [how] you would work it... There were about 14 of us in the class... uhm ... and we'd exchange notes on what we were doing right: "That wasn't so good. No, don't do that this way. No, she showed us to do it that way. Do it like that". So, I was getting feedback from another person constantly in that period of instruction. I was getting an idea of how to go forward. And then, between the seminars I would have to practice at home to try and hone the skill. So, I would just



read the textbook, read the notes, work on the practical application... uhm ... and at the same time develop the listening technique - which I developed over about two years – which is part of our work. You got to try and develop how to do a case study, try and develop how to handle a client. And there was a bit of instruction on that, but a lot of it you had to absorb and use, and try and figure out whether or not it's working. So, that was interesting as well. And ... we only did a full-on seminar on that the following year. But, in the meantime we had to, at a lower level, figure out how to do this. By the end of that, somehow, I managed to pass the courses. I think it's because the content had been cemented in my memory through high school. Because a lot of the physiology content you might learn in high school biology from about grade 10 to grade 12. So, some of that was memory based, and some of that was .... Especially the detailed physiology, I actually had to learn and somehow I was actually able to learn it again. And remember it! And write it in my own words when I was questioned during the monthly test sessions. At the end of it all, 18 months later ... uhm ... in mid-2001, I had to write the final exams, which was a two-hour theory exam and a half an hour practical exam. And, there again it was a case of .... Then it was a case of the whole of 2000 [work] stuffed back into my head. Thinking about it and working on it for most of the half of 2001, and then finally trying to write off everything as a full batch of modules and knowledge in June 2001. ... That was a ... I hadn't been that nervous in a long time. But, I actually got through it. I was astounded that the memory worked ... the understanding of combinations of afflictions and how you should treat it .... Uhm... the analysis of that... My physical exam, half an hour hands-on practical exam, worked well. My technique was found adequate ... and somehow I managed to pass it. (nervous laugh)

...

[J]: Yes. I thought, well ... I was very, very, very interested to check whether or not I could finally get back into this. So, I thought, look, I was doing this course ... I was doing it for two years. It was quite an exercise, but I got through it. Let me try again. But, now I have to do a bridging



course for a year which involved doing four half courses for one year. And this is for people who have either had some difficulty in school in terms of handling concepts, and the minimum pass you needed for all the subjects was a D [symbol]. All the maths, physics, biology and chemistry – you had to have at least a D at the end of your grade 12 year- and then that’s how they considered you [for the course]... because all of us were below the point-score to get into microbiology the conventional way. ... Uhm ... And [I] got in. In the first semester, by the end of the first quarter, which was around about April, I could feel problems. I wasn’t ... wasn’t really adjusting too well to the vast amount of work thrown at us - even doing half-courses. You had a full day, every day, doing all four subjects: doing a tutorial or a practical every single day, except Friday ... So your day ended. As a certainty your day would end at 4:30 everyday. So that was a big adjustment all over again. A very, very long workday ... uhm... And, I’m sure that was what probably made me take strain with regards to memory. By the end of the first quarter I had to ...uh ... beg ... that I could drop two of the subjects. ...Uhm ... The two lecturers concerned noticed that I was having a major problem and ... uhm ... said to me: “Well, uhm, maybe you should...uhm ... drop at least on subject.” (Jason started to speak slower) I ended up stopping math... (Note of resignation in his voice)

## APPENDIX D

### Excerpts from Peter's Interview

[P]: What we've realised... uhm.... And I teasingly joke about it in training about Diversity and Disability, but it's a reality and maybe I'll explain from a ... humorous point of view... and we can deconstruct the practical implications thereof. If we look at where society is at, and I had the privilege of, to a certain extent, look at international models as well, and the South African [model] is very similar to international models in terms of the way we look at disabilities, but even more so because of apartheid. And part of my joke and analysis is around that. If you started from a zero base and you say fine, society discriminates or indoctrinates or disadvantages your thinking from a basis of ... from a racial basis, and if you happen to be black – it's minus 33 $\frac{1}{3}$  %. If you happen to be a woman, it's another minus 33 $\frac{1}{3}$  %. We're in negative territory. And, if you happen to be from a rural area, it's another 33 $\frac{1}{3}$  %. That's 100% that you're already disadvantaged in terms of trying to start off into society. Now, if you happen to also have a disability, you're totally stuffed. So, what are we saying there? When you look at how our able-bodied people generally look at math and science, as documented by Department of Education, there's a real severe lack or shortage ... caused by a fear factor by able-bodied persons, but even more so by people with disabilities. And it's probably one of two or three scenarios; (1) the fear of actually succeeding against the grain, (2) fear of not succeeding in terms of maths and science (and I can give a personal experience as well), and (3) to a certain extent the fear of being a self-fulfilling prophecy, where because of your disability there are other reasonable accommodation issues which just blurs the high intensity of studying ... the requirements that a subject such as math and science requires of a student or learner. And that's very important because your social basis, for example, within your home environment...if there's a stable home environment and basis in a normal able-bodied learner, [that will] assist in the learning journey of that learner. More so if there's extra pressures placed on the learner because the learner happens to have a



disability and that socialisation, or what some of my colleague's refer to as the psycho-social analysis of the whole thing, is that (1) how does the family regard the learner or the person as a child within the home, and (2) how does he or she see themselves and (3) what are the socio-dynamics between them. Do the parents or guardians regard the learner as a 'special child', or do they regard the learner as an able or normal child? And, they [parents] must then have accepted the responsibility of extra studying, extra tuition that needs to be done, etc, etc.

...

Another dimension to the whole issue of people with disabilities regarding ... the ... I would say ... progression within math and science, is the whole issue of high function and low function. And then the whole issue with high output and low output. So you have variables. You can do a matrix, where on the one axis you have functionality – high and low, and on the Y-axis you would have a combination of those four, which would give you interesting possibilities. Now, in a typical, stereotypical, scenario there's still the debate raging about high function/low function versus high output/low output. And we in the business context and the social context, because there's a debate between the two dogma's – being the social model versus the medical model- we would bring forth the case stuffy of someone such as Stephen Hawking, professor Stephan Hawking, ...uhm ... professor of Geophysics at Cambridge University, and say there's a low function, but [also] a brilliant high output. Although, ... He's probably one in a billion within the able-bodied context, ... Let alone probably one within ten billion within a disability context, at the most. And that's very interesting to look at and say: Let alone is Stephan Hawking not only within the able-bodied context and extreme on the statistical range of personalities that could progress [in terms of science and maths] ... Then, you need to say: well, firstly, within the south African context, there are issues in terms of urban versus rural PWD (people with disabilities), and that the aspirations of PWD in that context, are saying: well, can we aspire to become proficient and competent within maths and science? Uhm ... And, the psychology of the



learner is very important. They are within two levels: (1) the home environment, and (2) the school environment. If there's a balance between the two [levels], then the person is socialised and integrated, to a certain extent, into society and taken [up] into society as an equal citizen. The chances of them being assimilated into ... or finding an affinity for maths and science as a subject that is fun, and not something that is tedious, is... would be much higher, because (1) the psychological barriers and walls are broken down, and (2) the confidence level of the person is so much greater. The flip side of that is, of course, the attitude of a person. A learner mustn't have the illusion... of confidence that he or she can achieve in maths or science, if their academic or intellectual capacity – and that's calling a spade a spade – cannot progress beyond a certain level. For example, in my case I could only progress up until 1<sup>st</sup> year maths at university. I wouldn't have had the capacity to progress beyond that. Perhaps, also I didn't find the subject interesting, exciting...yet, maybe my intellectual capacity could allow it, but I didn't know that when I was at university, because of various societal factors. So I had to be content with basically a passing grade in terms of a D (symbol) – a pass at a statistical analysis level for 1<sup>st</sup> yr university maths. So, that was ...although maybe now, looking back, in retrospect I would possibly have the emotional maturity, and intellectual maturity probably as well, to possibly have progressed further, but ... I have chosen other careers. So, very often learners going into adulthood and choosing careers, even where maths and science are not involved, put themselves at a disadvantage - to a certain extent ... uhm ... because numeracy and numerical skills are one of the building blocks of survival within a societal context.

...

...

[P]: I think that the issue about me speaking about our achievements or what we've done, and being realistic about it as well, is not so much the issue about boasting or bragging – and you can quote me on that- but it is about marketing ... it's to a certain extent a combination of being proud and



humble. I've now said this publicly, for every success story there's thousands of people who are waiting on a disability grant. And that's where the connection comes in, and where we need to tie in active involvement in the economy versus the NGO (non-governmental organisation) mentality; a begging bowl versus a "we can do it for ourselves". Maybe that's the magic of the company to a certain extent. Of all the companies starting where we are, we are competent and we have a capacity to work with, e.g. we have numeracy skills, uhm. We have the ability to put business plans together, to put teams together, competent teams together, and work with other people, even if they are able-bodied, uhm, who also have acumen towards numeracy and a financial understanding. So I think that is my ...my understanding comes from that. And I could see this from when I was in government, to certain extent, that there was this resistance to, even from able-bodied people, to come together as government departments to assist disability sector in advancing, e.g. in education [issues]. There was a certain advancing, but also there were certain areas in education that went against [Education] White Paper 6. Uhm... And we don't want disability at the end of the day to loose out. .... But the point being that we talk to each other and we encourage each other. That's why we agree ... on the one level, from an organisational level, build companies and then the second part is bringing OUR people from a management level, with strong mathematical or financial skills, into that kind of management and manages those companies. Uhm... And another pet passion is the issue of black women with disabilities who have numeracy skills. If you think of the percentage of people with disabilities generally, and their level of competence in numeracy, ... it's probably a fraction of a percent. Given the fact that let alone, of the one percent of PWD, 48 000 people are involved in mainstream economy. You can say a fraction of that, it would be a tenth, maybe 4800 on average, that are numerate...whose numeracy skills are quite high in terms of post-grade 12...uhm...let alone in terms of the black component of it, and than the women component of that [fraction]. So you can end up with e.g. only 48 women, black women with disabilities – as a



rough estimate ... as to education trends...uhm...because there's going to be dominance, unfortunately so a societal dominance of white males, then black males coming through which will outnumber, to a certain extent women with disabilities ...and it comes back to then the psychological effect of where women see themselves in the disability sector. And it has effects in the leadership structures as well, that there are more males involved in these structures, generally, than women. Even on the women's side, two years ago, e.g. the women's association of [name of organisation] ... uhm... they had leadership problems. There was a void in the leadership with people being taken up into parliament and all that, and there were no leadership structure. So you have a good core of top leaders and ...it's the same that [name of organisation] went through. But you don't have a good second tier leadership base. And you could look e.g. then of the leadership base which are in women structures, black women ... are there any of them that are numerate? And those who probable are numerate, they probably don't recognise themselves as being persons with disabilities, in terms of the psychological ... uhm ... make-up of themselves. And that's why mainly... Before I went to join the Task Team, I didn't see myself as a person with a disability. And only once I... and only before I left to go to join the Task Team did I begin... say six months before then ... did I begin. And I would say the turning point was me getting a parking disc. It was then that I myself recognised the fact that I had a disability. And that I'm not privileged, but have a right to certain special...uhm... treatment of privileges in terms of the parking or accessibility issues. ..Uhm... And you need to ask ... There are women out there who are numerate, black women also, women who have disabilities, ... uhm ... especially probably some even more so in terms of physical disabilities, and even cerebral palsy... They see it, but yet they don't see it...and it comes back to us and that's why maybe I can "boast" more strongly about achievements of persons with disability because I don't have ... uhm ... two things, well probably; (i) the baggage of the past, and (ii) the garbage of the past. Let's explain. The baggage is what you come with from the past and the garbage is any nonsense in terms of



negative nonsense that you've accumulated as you've gone though... uhm ...

[I]: *There's also something else you said about women with disabilities, and in particular women with cerebral palsy...sometimes they don't achieve because they don't believe they can achieve in the field of science and maths? Is that what you said?*

[P]: Yah... It goes back to the joke at the beginning of the interview, where males have dominated women in a paternalistic manner ... uhm ... and have done them an injustice. And that women themselves, to a certain extent, perpetuate that cycle by believing and reinforcing that stereotype [by] saying, yes, we will accept this, [we will] be subservient, uhm ... and we will not go for the mathematics or the physics ... uhm ... positions. My director at the Task Team, uhm, [name] she has her masters in biophysics, plants and that...yet she didn't use that skills and accomplishments after she did her masters. She became a director of a general government department. But, yah, ... so, uhm, yah ...It would be quite an interesting example, how someone coming from nowhere, go into zoology and chemistry and does her thesis on that... What kind of skills are needed in terms of that and ...uhm ... that would be another "uitskieter" or someone going against the grain of black women with disabilities, where she didn't let the stereotype that society is trying to enforce, hold her back. So, yah...

[I]: *Do you think [their under-representation] is linked to what you mentioned earlier, that sometimes they don't want to admit, even to themselves, that they are disabled or different? Is it important for people with disabilities to admit that?*

[P]: Yes and no. Even goes to the fact where I referred to able-bodied society, where I said [the] disability [sector] now, in terms of the Government Employment and Equity Act, we are at [the place] where Women's [Rights Movement] were 10-15 years ago, where women did not want to achieve and progress for the sake of being women, they wanted to do it on merit. For the person with a disability, who happens to be a woman, who happens to be black, even more so. [It is true] that [they say] you have



to achieve and work maybe twice, three times as hard ... uhm ... as my able-bodied counterpart, because I happen to have a disability, I happen to have special needs, ... uhm ... and ... thereby will progress, but I will not recognise the fact [of my disability] publicly. There are a whole lot of other issues in terms of baggage that can be attached to that. Which as a black woman with a disability [she] might not necessarily have... But, I cannot speak for them. I'm just surmising. She wouldn't necessarily have the baggage, but society could have the baggage. A friend of mine, a colleague, [name], he says that in person society accepts you with a stereotype. You're reminding them of their worst fears ... of what they can become, [when] the concept of cerebral palsy kicks in... yah ... so, to a certain extent, that kind of messes with the mind on both sides. So, ...uhm ... yah ... that ties in with the gender and disability and black [race] stereotypes that they, the black women with disabilities, [should] not reinforce, that they look at themselves in terms of [their] self-image and say: Am I just an individual who is gender-less, who is colourless, and is able-less? Because there is a report on racism, sexism and able-ism ... so, if those three [issues] are totally neutered, ... just as a human being, then I will progress just as a human being, and ... [then] the fact that I happen to be black and the fact that I have a disability, is pure co-incidence. Why would [society] not rather emphasise the achievement instead of the co-incidences? Uhm ... so, I don't think we [the disability sector] will crack out of it as easily as race and gender have done. We'll probably take 20 – 25 years... and I'm ... very pragmatic about that. Maybe I'll be able to eat my words in 10 – 15 years time ... uhm ... but I think realistically, [it will be] 20 years before we break out of that kind of stereotype ... and also, because of the current generation. They would then be in the adult population, and the “uitskieters” or anomalies would be more common and more of the norm, than the unusual or against the norm ... uh ...by that generation, I think. And, there will be more integration into society, yah.

[I]: *Tell me about career guidance at the special school...*

[P]: Pardon? ...[laughs]



[I]: *Your career guidance at school...*

[P]: [laughs out loud]

[I]: *Did [career guidance teacher] have any influence on your career?*

[P]: No [laughs]

[I]: *Is there anything that you would have liked to change?*

[P]: Yah ... I think that ... exposure of students these days should become more realistic, uhm, and not that protected ...well, it [career guidance] is really like that. But it [career guidance] should become more exposed... And there you have a problem with what a teacher sees as an ambition or drive, and aspiration of a learner, uhm ... In terms of the [latter] the teacher will probably say: 'No, my child. You cannot progress beyond this level'. And the learner says: 'No, I think I have the competence. I have the ability to progress beyond that level' ... but... I can mention my family as an example. Take the university and technikon for example. [*Peter's family did not think he would make it at university*]. Uhm, and that can apply to teachers ... and depends on how teachers are educated and what they're exposed to at university ... uhm... and what ... Do they have a 'norm-society' paradigm when they go into teaching, or do they have a "uitskieter" (high achiever) mentality towards the teaching, and say: 'No, we want to make "uitskieters" out of say 9 out of 10 of these kids as far as possible ...uhm ... and then that becomes the norm, as opposed to 1 out 10 [becoming a "uitskieter"] as a case study or statistical analysis. So, yah ... so that is where I think the educators come in ... and ... now, basically, it comes back to a certain extent... coming back to Education White Paper 6 ... how does the community and society then perceive that school... uhm ... For example, a school like [*site of investigation*] ...

## APPENDIX E

### An Exemplar: Inclusive Instructional Biology

➤ *To test for the presence of starch in a green leaf*

The teacher follows two stages to assist with the inclusion of learners with cerebral palsy. The stages are as follows:

Stage 1:       The Ability Profile for all the learners.

Stage 2:       Accommodation of all learners.

*Stage 1: The Ability Profile for all the learners*

This is a tool that assists teachers in breaking down the individual components of the experiment. The best solutions for maximising participation come about when the learner and the teacher work together to develop creative alternatives for challenges faced by students with disabilities. The teacher is asked to briefly describe the student, the classroom or lab environment, equipment or supplies needed. Also, in addition to the physical, sensory and cognitive skills needed for the task, to list available professional and external resources, and possible accommodations. The following list is provided as guide.



## List of Physical, Sensory and Cognitive Issues and Challenges

Physical Issues	Sensory Issues	Cognitive Issues
<p>Think of the required physical aspects of the task. What will make the environment accessible, keep the student safe and allow him/her to be an active participant? What lab equipment must be manipulated?</p>	<p>Think of room temperature, noise, fumes, dust, odours, and allergies. Also consider the ability to speak and/or communicate, and the visual aspects of the task or assignment.</p>	<p>Is the assignment done with a group, partner or individually? What memory and communication skills are needed? What is the level of complexity of the task?</p>
<p>lift/ carry                      stamina / endurance                      push /pull                      knee / squat                      reach                      repetitive tasks                      fine motor: pinch / grasp                      fine motor: manipulate / manoeuvre                      gross motor                      sit in chair                      walk / stand                      balance                      bend / twist                      stoop / crouch                      other</p>	<p>vision                      hearing                      touch                      smell                      taste                      oral communication                      temperature                      fumes                      external stimuli                      lighting                      other</p>	<p>short term memory                      long term memory                      task complexity                      reading                      writing                      spelling                      string of numbers (Math)                      paying attention                      visual, auditory, or kinaesthetic learner                      self-esteem / advocacy issues                      behaviour issues / acting out                      other</p>

Source: DO-IT resource manual (2000)

The biology teacher, learner, parent, therapists, doctor and psychologist will jointly compile the profile when the learner is first identified at the beginning of the year.

Adapted Learner Ability Profile

<b>Learner Ability Profile: Thandi</b>		
<p><b>Narrative:</b></p> <p>Thandi is a 16 year-old who has had cerebral palsy since birth. She uses a wheelchair for mobility and has significant fine motor control difficulties. She is quiet in class but very friendly. She has difficulty expressing her thoughts verbally, but can be understood when she speaks slowly. Her family is very supportive of her participation in all school activities. She needs extra room to manoeuvre her wheelchair. Additionally, she needs a large flat surface for experiments that is lower and that allows 29° of clearance underneath. Her chair should be facing the board so she does not have to turn her head. A mirror above teacher demonstrations would be helpful. Group work or work with a partner is best for Thandi. The group should allow her to participate to the highest degree possible. Some instruction by the teacher to the group would be helpful to assure maximum participation.</p>	<p><b>Task / Assignment</b></p> <p>Learner will be actively participating in biology classroom and lab experiences, including lab manipulation</p>	
	<p><b>Equipment:</b></p> <p>Write down lab equipment, protective clothing, chemicals, etc.</p>	
	<p><b>Environment:</b></p> <p>Will there be fumes, odours, dust, temperature, noise, group-work?</p>	
<p><b>Physical challenges</b></p> <p>Lifting</p> <p>Fine motor, pinch, and grasp</p> <p>Walk / stand</p> <p>Difficult to turn head</p>	<p><b>Accommodation Needed</b></p> <p>Practice lifting small objects / loads</p> <p>Provide modified physical exercises stressing strength and fine motor enhancement</p> <p>Monitor closely in lab and note the increased ability in above physical areas</p> <p>Lab area / desk must be accessible</p> <p>Need a lab partner</p> <p>Group should take time to allow slower verbalisation</p> <p>Hold high expectations for quality of work completed</p> <p>Allow assistance with manipulatives</p>	<p><b>Options and Resources</b></p> <p>Special attention to social skills</p> <p>See doctor regarding stamina, safety issue</p> <p>Physiotherapist/ PE teacher</p> <p>Work with IEP team to create a modified PE class</p> <p>Determine vendors of modified lab equipment and furniture</p> <p>Determine computer software for word processing and voice activation such as Dragon</p>



	<p>Needs a lap-desk for microscope and a taller or extended eyepiece</p> <p>Sit to allow talking to her at eye-level</p> <p>Instruct in her line of vision. No sudden location changes</p> <p>Needs more time for labs to set up</p> <p>Needs more time for writing on test</p> <p>Provide a scribe for some tasks</p> <p>Provide a note-taker for some labs would help</p>	<p>Dictate</p> <p>Determine options to increase self-reliance and independence</p>
<p><b>Sensory challenges</b></p> <p>Thandi has no sensory challenges</p>	<p><b>Accommodation Needed</b></p>	<p><b>Options and Resources</b></p>
<p><b>Cognitive challenges</b></p> <p>Long term memory</p> <p>Task complexity</p> <p>Reading</p> <p>Writing</p> <p>Spelling</p> <p>Self-esteem / advocacy issues</p>	<p><b>Accommodation Needed</b></p> <p>Shorter reading time</p> <p>Breaking down assignments</p> <p>Allow extra time on tests</p> <p>Praise accomplishments</p>	<p><b>Options and Resources</b></p>

Source: DO-IT resource manual (2000)

### *Stage 2: Accommodation of all learners*

During this stage the biology teacher answer the questions as outlined in the Four-Step accommodation model (Adapted from DO-IT, 2000)

#### Step 1: What does the task or assignment require?

The teacher breaks down all of the components of the experiment. By analysing and evaluating the task thoroughly the teacher will be able to determine how best fully and effectively include a student with a disability.

#### Step 2: What physical, sensory, and cognitive skills are needed?

The teacher is required to compare the task requirements to the physical, sensory, and cognitive skills needed to successfully complete the experiment and separate the “real” requirements of the task from the “fictional or perceived” aspects of the project. The teacher should also consult the learner about ways to solve a unique problem or task.

#### Step 3: What components of the task require accommodation?

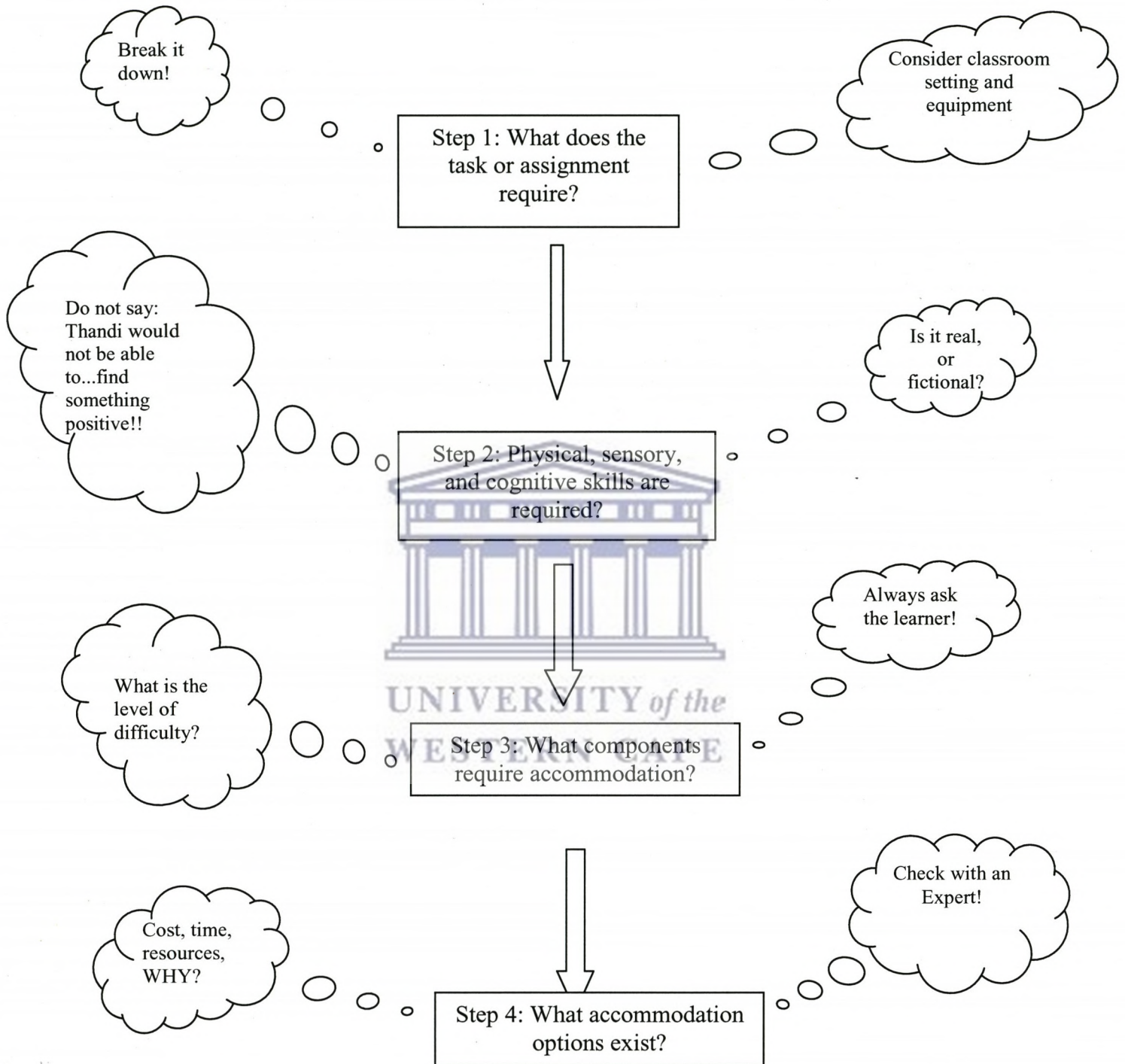
Once the task has been analysed and the skills needed identified, the teacher has to determine what accommodations may be needed. The teacher has to determine the level of difficulty of the project and determine how best to make an accommodation to create an inclusive environment for Thandi. It is very important to first check with Thandi to determine what she perceives as aspects of the experiment in which she may need an accommodation or assistance.

#### Step 4: What accommodation options exist?

After the accommodations have been determined, the teacher has to identify what resources exist for providing the needed accommodation. This is a time when other staff and professionals who have expertise in a specific area can be called on to provide input. The cost and time required for the accommodation are variables that may also be weighed in determining an effective accommodation. The teacher is encouraged to use the most readily available resources in making accommodations.



Four-step accommodation model (adapted: DO-IT, 2000)



The teacher then summarise the accommodations for the whole class according to the four steps.

⇒ To Test for Presence of Starch in a Green Leaf

(Adapted from DO-IT Four-Step Accommodation Model)

*STEP 1: The task requires...*

- following directions/ instructions
- working in a team/ group
- following safety procedures
- using a Bunsen burner
- writing down observations

*STEP 2: The physical, sensory and cognitive skills required include the following challenges:*

Physical challenges:

- fine motor grasp/ pinch/ manipulate
- gross motor
- stand/ walk

Sensory challenge:

- oral communication
- listening
- vision

Cognitive challenge:

- reading
- writing
- attention span
- complex thinking
- behaviour that ensures safety

*STEP 3: Components of the task that require accommodation*

➤ The following learners will need physical accommodations:

- Jacob and Thandi need help with fine motor movements, e.g. when folding leaf into test-tube; removing test-tube from beaker with boiling water; manipulating the pipette.



- Check if John needs assistance. His fingers on left hand tend to become stiff.
  
- Check with learners if they need assistance with sensory accommodations
  
- Cognitive accommodations for whole group:
  - Stop at regular intervals to consolidate processes, results and conclusions.
  - Remind learners to be extra careful – draw attention to safety regulations on notice board.

*STEP 4: Accommodation options that exist: (Check with learners!!)*

- Assign lab partners that complements each others strengths and abilities



## APPENDIX F

- *School visits in the United States of America - different sites, different settings, different locales, and different social systems*

The first school was a typical inner-city school with a diverse learner population. Teachers were divided into teams and each team assigned a resource educator (special educator), depending on the number of learners with special needs in the group. There were no learners with physical disabilities in the academic programme. The researcher had an opportunity to observe a grade 7 Science Inclusion lesson on the speed of sound. There were 14 learners in the class. The science teacher presented the lesson, while the special education teachers took additional notes. The special education teacher noted difficult concepts and terminology. At end of lesson the learners were given an assignment to do in class. During this time the special education teachers assisted the learners who have been identified as special education learners. Each learner had an individual educational programme (IEP) that outlined the type of support required. When asked, the subject teachers approved of the inclusion of all learners, however, the special education teacher noted that there were too many learners in the class needing support and that she could not assist all of them.

The second school was situated in a more affluent area, with the middle school and high school in the same building. On the day of the visit the grade 6 classes combined for cumulative testing. There were 27 learners in the group. The basic classroom had 17 learners with diverse learning needs. Three resource teachers assisted the class teacher with language arts, mathematics and reading. There were no learners with physical disabilities in these classes. At the high school, ninety-four of the nine hundred learners were identified as learners with special needs. The school had four resource teachers (also known as special educators). There are “pull-out” sessions where learners who need support are taken out of the main class to receive



individual attention from the special education teacher. Learners identified as in need of special education go to the special education classroom with their assignments and tasks.

The researcher also had an opportunity to interview an elementary school teacher. The school was situated in a rural area. Sharon (fictional name), a grade five teacher at the school, described the school as full inclusion school that “regressed” in recent years, meaning that the school went back to the pull-out system. Sharon had 26 learners in her class. A special education teacher co-teaches the class. Seven of the learners have been identified as special education learners. One has cerebral palsy, another learner has a physical disability plus a learning disability, and the other five are all classified as having learning disabilities. The special education teacher took the learners with disabilities out of the general classroom for tests and reading, and modified all readings include in assignments and tasks.

Sharon seemed to cope well with the inclusion of learners with disabilities. She allowed a learner to use a tape recorder for written assignments, which she then transcribed and assessed. She did not regard this as extra work, emphasising that it is important for the teacher to be organised or “extra work” will feel like a burden. During the mathematics periods she has the full class - full inclusion as she terms it – and good classroom management skills are needed during this time. Sharon confirmed general teachers do need special education teachers to assist them during their first year with learners with disabilities in order to learn and gain experience with classroom management and modification of tasks and assignments.

According to Sharon teachers welcomed any in-service/ professional development courses addressing inclusion and inclusive practices. Sharon recalled that the year the community eye doctor presented a very informative session on eye care and addressed questions that she did not think about. Sharon asserts special education teachers could do more in-

service training with general teachers and provide strategies and concrete examples. New staff, especially those straight from college, would benefit enormously.



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