

**STORIES OF BEING BACK AT SCHOOL FOLLOWING  
TRAUMATIC BRAIN INJURY (TBI): THE EXPERIENCES OF  
CHILDREN, THEIR PARENTS AND EDUCATORS**

**By**

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## ABSTRACT

### Focus of study and background to the problem

The study focuses on the experiences of children with traumatic brain injury (TBI), their parents and educators of being back at school.

TBI is a major health concern in South Africa (SA). Children who sustain a TBI have significant, but often hidden, disorders which affect their learning and social interaction. The South African government endorses a policy of inclusive education (IE); however, the educational environment is stressed and overburdened. Little is known both internationally and in SA about the children's experiences, and the experiences of their parents and educators.

### Aims

The study has one main aim which is to explore and describe the experience of being back at school of children with TBI, their parents and educators.

### Methodology

A narrative case study design was used, consisting of two cases of 3 participants each (child with TBI, his parent and educator). Children were aged between 10 and 12 years. Data were collected using multiple open ended interviews. Data analysis was a complex and iterative process across 3 levels.

### Results

Results are presented across the levels of analysis. Firstly, six individual participant research stories are presented. Secondly, the emergent themes per participant type are given and discussed and finally a multiperspective combined theme is discussed.

### Conclusion

The experience of being back at school following TBI is a struggle as a policy of IE is expected to be practiced in an unsupported system. The children provided a voice previously lacking in the literature. There was evidence of inclusion being driven from the ground up by parents and educators. Implications of the study for policy makers, rehabilitation and educational professionals are given. A broader view of inclusion is advocated.

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## CHAPTER 1

### INTRODUCTION AND RATIONALE FOR STUDY

#### 1.1 Overview of chapter

In this chapter, the main focus of the study is introduced. The researcher will provide an orientation to the study as well as describe the context in which it is situated. She will present the research question and aims. She will explain the rationale for undertaking this research. An overview of the remaining chapters of this dissertation will follow. Finally, a definition of key terms and abbreviations is provided.

#### 1.2. Orientation to the study

This multi-perspective study explores the experiences of children of being back at school following traumatic brain injury (TBI), as well as the experiences of their parents and educators. Data was collected from two cases, each containing these 3 participants. It focuses on the experiences of these individuals as a means of gaining greater understanding of the process of being back at school following TBI. The study of experience is essential to this topic for two reasons: Firstly, the nature of experience is process orientated in that it requires reflection on past events and consideration of changes over time. Being back at school is a process that the child, parent and educator are undertaking. Thus, being back at school can best be understood by understanding the experience thereof. Secondly, experience has to do with personal meaning making. The subjective realities of those who face being back at school after TBI are best accessed via their experiences. A complete picture of the topic cannot be obtained through objective measures alone.

The current study concentrates on children aged 10 to 12 years who sustained moderate-severe TBI's during the intermediate phase of school<sup>1</sup> and on their return to ordinary school, not specialized education<sup>2</sup>. In South Africa, the children who acquire TBI typically return to ordinary schools after discharge from hospital.

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<sup>1</sup> Schooling in South Africa is divided into 3 phases: foundation (Grades 1 to 3), intermediate (Grades 4-7) and secondary (Grades 8-12).

<sup>2</sup> "An Ordinary School is a school that is not a special school. A special school is one that is resourced to deliver education to learners requiring high-intensity support" (Department of Basic Education, 2010, p.3).

### 1.3 Study context

In South Africa, children under the age 15 years who have sustained a TBI have experiences and needs that are vastly different from those in more developed nations (Levin, 2004; Penn, Watermeyer, & Schie, 2009). Most rehabilitation literature however comes from these developed nations.

The study context will be presented by providing background on the geographical and social contexts of participants, and the health and educational structures of the country in which the research was conducted. This is followed by a description of paediatric TBI in South Africa and a description of TBI in South African schools.

#### 1.3.1 Geographical and social context

South Africa consists of 9 provinces. The Western Cape is one of them. The provinces are divided into a number of municipal districts. The Western Cape has 6 districts which includes the Cape Metro. It is made up of the city of Cape Town, its outskirts and surrounding towns. This study takes place in the Western Cape Metro district. The study participants are drawn from the lower income, impoverished sections of the Cape Metro district. These areas are burdened by overcrowding in informal settlements and in schools. Unemployment, and thus poverty, is rife. Members of these communities are likely to access public health and educational services, due to the aforementioned circumstances. In addition, the communities are plagued by drug and alcohol abuse and the gangsterism and violence that often accompany this abuse.

#### 1.3.2. Health and education structures

In South Africa, health and education are separate departments, both at national and provincial level. They largely function in independent silos and there is little evidence of intersectoral collaboration (Brijjal, 2004; Draper, Pienaar, Parker, & Rehle, 2007). National and provincial level health departments do not provide services in the school context. Similarly, the education departments do not currently provide direct services to children requiring additional therapeutic/rehabilitative support in the ordinary schools. Consequently children who sustain a TBI are thus able to access the health system and receive inpatient rehabilitative care, but on discharge from the hospital there are no such services available for them when they return to school. This is particularly the case for lower income communities as others may access private health care if they

are able to afford it. Payment for public health is on a sliding scale determined by household income.

Although the health department subscribes to a Primary Health Care philosophy with a drive to equal access to health services, on the ground human resources remain severely limited, particularly in terms of rehabilitation staff (Kathard & Pillay, 2013). For this reason, the tertiary hospitals are only able to provide infrequent follow-up appointments which may or may not be attended. This is often due to transport costs involved in accessing these centrally located services which are situated outside the immediate community in which the participants live.

The South African government has chosen inclusive education (IE) as its overriding educational policy (Department of Education, 2001) with the focus being the transfer of children out of special schools into so-called ordinary schools, previously termed mainstream schools. Due to a recognition that at this stage of IE implementation not all ordinary schools will be able to meet the support needs of their learners, the Department of Education (DoE) is piloting another level of school, the full-service or inclusive school. The DoE intends that these full-service schools will be provided with the physical and material resources as well as the staff and professional development that are needed to accommodate children with a range of learning needs (Department of Education, 2001). The long term aim is that all ordinary schools will be full-service in years to come.

In addition, educational policy (Department of Basic Education, 2012) dictates that children may not repeat more than 1 year in a phase (see footnote 1); they are to be progressed<sup>3</sup> “with support” in cases where they do not meet learning requirements for a second year in a phase. This presents a challenge for children with TBI returning to school as they face significant barriers to learning due to the sequelae of TBI. These will be described in detail in Chapter 2. The policy does not make allowance for the additional time these children may need to consolidate learning.

The school year in South Africa is from January to December. Usually, educators teach per grade, meaning that children get a new teacher each year. In some schools, educators are also “subject teachers”, meaning that they teach specific learning areas

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<sup>3</sup> “Progression means the movement of a learner from one grade to the next, excluding Grade R, in spite of the learner not having complied with all the promotion requirements. Progression can be used to prevent a learner from being retained in a phase for a period exceeding four years.” (Department of Basic Education, 2011, p. xi)

to children, e.g. Life Sciences or English, rather than all subjects to one class. Children might therefore have a number of different educators within a school day. In some schools, the children may need to change classrooms with each new subject. This makes providing additional support to those children who need it more challenging, as a larger number of educators need to demonstrate the requisite attitude, knowledge and skills to provide this support.

### 1.3.3. Paediatric TBI in South Africa

TBI is of concern due to its prevalence in South Africa. From a health point of view, violence and injuries have been identified as one of the four main contributors to the national burden of disease, the so-called quadruple burden of disease (Bradshaw et al., 2003; Norman, Matzopoulos, Groenewald, & Bradshaw, 2007). Motor vehicle accidents (MVA's) and violence against children are the main causes of childhood TBI in SA, in that order (Levin, 2004). Pedestrian vehicle accidents have been cited as the single most important cause of injury related morbidity and mortality in South African children over the age of 4 years (Bass, Albertyn, & Melis, 1995). The authors note that morbidity outweighed mortality. As such, mortality figures alone underestimate the burden of disease placed on a country and it is rather the impact of morbidity that must be understood more clearly (Bradshaw et al., 2003). In its description of the experiences of being back at school after TBI, this study assists to fulfil that aim. The issue of morbidity is significant when one considers South Africa's quadruple burden of disease and the chronic nature of TBI with some effects that may worsen over time and into adulthood, as will be described in Chapter 2. It is also a matter of interest for rehabilitation professionals who need to work with survivors of TBI; and more so within this particular context in SA where health and education systems are not conducive to rehabilitation.

Bass et al. (1995) found that the majority of children injured in their study were those en route to or from school, usually closer to home. They noted that high density/informal housing predominated in the areas which formed the catchment area for the hospital in their study. They concluded that socially disadvantaged communities are where the risk of pedestrian TBI is highest. This study draws participants from these communities. Major challenges to pedestrian safety in SA include inadequate road and pedestrian infrastructure, poor street lighting and weak integration of transportation and land-use planning (Seedat, Van Niekerk, Jewkes, Suffla, & Ratele,

2009). Typically, the children in this study walk to school in crowded and busy streets where there is little traffic regulation.

#### 1.3.4. TBI in South African schools

The literature that will be presented in Chapter 2, most of it from developed nations, paints a clear picture of the significant challenges that TBI poses to being back at school. Having described the South African educational structure, the researcher would like to bring into focus the South African school context as it pertains to children with TBI.

Although empirical evidence from SA is sparse, Levin (2004) states that even in the wealthiest section of South African society rehabilitation and educational service provision for children with TBI is lacking. She goes on to explain that in cases where they were not able to return to ordinary school, many children with TBI in the urban areas of South Africa, which tend to be wealthier and have better access to limited resources, are placed in schools for children with special needs, such as Cerebral Palsy or learning disabilities. However, the number of special schools is limited and they are not equipped to manage the unique learning and other needs of children with TBI (Levin, 2004; Penn et al., 2009).

In the rural communities, special schools are particularly limited in number. In addition, educators and learners in ordinary schools in low-income and impoverished communities struggle with overcrowding of classrooms, lack of educational and human resources and infrastructure for running water and sanitation (Levin, 2004). As a result, in these areas children with TBI tend to stay home or are sent to schools where educators have little to no knowledge of their needs. They cannot find their way in the system and struggle to cope with the result that they eventually leave and are cared for at home. In the South African context, the stressed, overburdened educational environment that a child with TBI with unique, complex and hidden needs must re-enter is not one with the capacity to look out for or support him.

#### 1.4 Research question and aims

Given this background, the study therefore seeks to answer the following question:

How do children with a moderate-severe TBI, their parents and educators experience being back at school following the TBI?

The study aims to explore and describe the experiences of being back at school after a TBI from the points of view of

- children with moderate-severe TBI,
- their parents
- and their educators

### 1.5 Rationale

The motivation for this study was derived from the following reasons:

Firstly, the researcher has a clinical interest in undertaking this study. She is a Speech-Language Therapist (SLT) who works on a 4-bed subacute paediatric neurosurgery rehabilitation unit in a state tertiary level hospital. The majority of her patients are from the low-income or impoverished communities as described above. In addition, they are primarily children under the age of 13 years who have sustained a moderate-severe TBI due to a pedestrian MVA. These children are typically discharged home and return to their ordinary school shortly after. They are referred for outpatient follow-up at another tertiary level hospital, as there are currently no SLT's in the community clinics and no government-funded SLT posts at state schools. Following telephone contact, a discharge summary report with recommendations for classroom management is sent to the school principal and educator. The children are also referred to the Senior School Psychologist within their school district with an assessment recommended at about 6 months post-injury, with the purpose of reviewing the academic progress of the child within the ordinary school. In her role as clinician, the researcher has no contact with these children, their families or educators beyond these referrals. She, therefore, does not know what the real life outcome of the TBI looks like further along the rehabilitation continuum which for the majority of children would entail being back at the school they attended prior to the accident.

Secondly, following moderate-severe TBI a child can have a variety of long term deficits in a range of areas, but specifically in the "hidden" cognitive domain. The researcher is aware that these will have an adverse effect on the child's academic performance and socializing at school. The cognitive and cognitive-communicative difficulties are of particular relevance to the researcher in her capacity as an SLT as they relate directly to her field of expertise, affecting learning and communication across multiple levels (e.g. spoken and written language, recall, social interaction). Anderson and Catroppa (2006) importantly note that on long-term follow up of children with TBI, problems not only persisted, but at times worsened. This has implications for

being back at school over time. In addition, the effects of TBI are often described as “hidden” or “invisible”. The children are not obviously physically disabled, nor do they have obvious speech disorders. Rather the difficulties they experience as a result of the cognitive-communicative disorder are misunderstood and misinterpreted as laziness or misbehaving. This study is critical to learn about the impact of these hidden deficits on the children’s experience of schooling, particularly within a strained, under resourced and changed educational system. As an SLT the researcher was interested in the influence of the TBI on the academic and social aspects of the child’s educational experience. However, she recognized that this narrow view of communication and learning, situated at classroom level, would not provide a true reflection of school experience following TBI and that a broader focus open to social and systemic influences was required.

Thirdly, the government of SA is committed to a policy of inclusive education (Department of Education, 2001). However, this ideal has not yet been realised due to various challenges (Engelbrecht, 2006; Naicker, 2006). Referring specifically to children with TBI, Levin (2004) states that, “The likelihood of children with special needs receiving appropriate educational care in these regular [ordinary] schools is remote at this early stage of transformation of the education system” (p.310). The expected result of this lack of support is that these children will not cope and will move from ordinary schools to special schools, a reversal of the inclusive process. Yet little research has been done in this area as will be seen in Chapter 2. A mismatch between the policy and practice of inclusive education in South Africa has been identified – the needs of this population must be recognised and understood if the ideal is to be reached. The study aims to present a holistic picture of being back at school following TBI from the experiences of the children, their parents and educators to inform policy makers. It will provide valuable insights into how inclusive education is experienced on the ground in terms of barriers and facilitators to the implementation of this policy at grassroots level. Policy makers, educational staff and rehabilitation professionals can then be guided in structuring support and resources effectively.

Fourthly, the majority of the children treated in the subacute unit, who present with a wide range of deficits subsequent to their injuries, return to their ordinary schools or will be entering the ordinary school system in future. Within this study’s context the rehabilitation continuum is fractured on discharge from hospital due to a dearth of follow-up services in the community and at school, as previously discussed. The impact of this should be explored by investigating the experiences of those who need to access support services (the children returning to school and their parents) and those

who are expected to provide services (the educators). This is important if meaningful changes are to be made to the systems that are in place and direction given for provision of appropriate support.

Lastly, recent literature recommends further investigation into the experiences of children, their caregivers and educators following TBI (Erickson, Montague, & Gerstle, 2010; Galvin, Froude, & McAleer, 2010; Gfroerer, Wade, & Wu, 2008; Roscigno & Swanson, 2011). Including the voices of all three, both individually and collectively in a multiperspective voice, is the strength of this study and one of the factors that makes it unique. The voice of the child is needed as until recent years it has been excluded from research and there is no knowledge of the experience of being back at school after TBI in children under the age of 13 years. Parents provide a view of being back at school that includes the influence of social and systemic stressors, such as poverty and limited access to health care or service delivery in general. They provide the broader “out-of-schoolroom” societal perspective that the study seeks. The voice of the educator is essential as they provide the first-line of care for the child at school. The study proposes to inform IE policy in SA, thus the voices of the educators expected to put the ideal into practice are salient. The study will present knowledge on their development and how their experience of schooling has changed. The use of a multiperspective voice is important as it gives a comprehensive and multifaceted picture of the experience of being back at school after TBI. What the experience of being back at school after TBI is, cannot be fully known in isolation, but rather in combination as each voice adds its perspective. The study aims to add to a growing body of literature within the field of TBI, specifically from the context of a developing nation with its particular challenges and opportunities. Without listening to the voices of those who are living with the effects of TBI, practice cannot be informed according to best practice principles.

In summary then, school is a critical area of participation for children and is particularly problematic after a TBI. Internationally, there is a small, but slowly growing body of qualitative research examining the experiences of being back at school following TBI. However, the researcher is not aware of any literature on this topic from SA. With its exceedingly high rates of injuries and challenges to the implementation of inclusive education, there is an evident vacuum of voices telling their stories about the longer term effects of TBI within this particular context. Little is known about the subjective reality of the experiences of children, their parents and educators of being back at school following TBI. Yet these are the ones who are expected to implement the vision

of inclusion with regards to TBI where the difficulties are often invisible and misunderstood.

### 1.6 Overview of chapters

In Chapter 2, current and relevant research surrounding the topic will be presented through a literature review, setting the stage for the findings of this study.

In Chapter 3, the study methodology will be described, detailing how the results of the study were obtained.

In Chapter 4, the results from the first and second levels of analysis will be presented. These are the 6 individual participant research stories and categories that emerged per participant type (child, parent, educator) respectively.

In Chapter 5, the resultant themes from the second and third levels of analysis will be discussed in light of and with reference to the current literature on the topic. Strengths and limitations of this study as well as its implications will be highlighted.

### 1.7 Definition of key terms and abbreviations used in this study

#### *Being back at school:*

For the purpose of this study, being back at school refers to the child's return to school following discharge from the subacute rehabilitation ward at a hospital after a moderate-severe TBI. It implies return to the child's premorbid ordinary school. The term intentionally conveys a temporal element, the passage of time. In other words, being back at school is not a once-off event, but rather a process. The majority of children discharged from the rehabilitation ward return to the context of their premorbid ordinary school at the outset. The term includes the concept of participation, as described in the International Classification of Functioning, Disability and Health–Child and Youth version (ICF-CY; WHO, 2007).

#### *Inclusive education/ Inclusion:*

The DoE differentiates between inclusive education/inclusion and integration/mainstreaming. It does not define inclusion, but rather describes it as follows: "Inclusion is about recognising and respecting the differences among all learners and building on the similarities. Inclusion is about supporting all learners, educators and the system as a whole so that the full range of learning needs can be met. The focus is on teaching and learning actors, with the emphasis on the

development of good teaching strategies that will be of benefit to all learners. Inclusion focuses on overcoming barriers in the system that prevent it from meeting the full range of learning needs. The focus is on the adaptation of support systems available in the class-room” (Department of Education, 2001, p.17).

It further views inclusive education within an inclusive system as outlined in Education White Paper 6: Building an Inclusive Education System (Department of Education, 2001). This system aims to include vulnerable learners and to improve the retention of learners in the education system, particularly those at risk of dropping out.

*Traumatic brain injury (TBI):*

In this study, TBI refers to a closed head injury as a result of a MVA, either pedestrian or passenger. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma (Lebby & Asbell, 2007).

*Moderate-severe brain injury:*

Brain injury resulting in a Glasgow Coma Scale (GCS) of <13 (Lebby & Asbell, 2007)

*Parent:*

This is the main carer of the child in question, the person who assumes primary responsibility for the child’s upbringing. In this study, the term further assumes that the pre- and post-injury parents are the same person.

*Ordinary school:*

“An Ordinary School is a school that is not a special school. A special school is one that is resourced to deliver education to learners requiring high-intensity support” (Department of Basic Education, South Africa, 2010).

<b>UNCRC</b>	UN Convention on the Rights of the Child
<b>CRPD</b>	UN Convention on the Rights of Persons with Disabilities
<b>DBE</b>	Department of Basic Education
<b>DoE</b>	Department of Education
<b>DoH</b>	Department of Health
<b>GCS</b>	Glasgow Coma Scale
<b>IE</b>	Inclusive Education
<b>ICF-CY</b>	WHO International Classification of Functioning, Disability and Health-

Child and Youth Version

<b>ICP</b>	Intracranial pressure
<b>MVA</b>	Motor vehicle accident
<b>SLT</b>	Speech-Language Therapist
<b>TBI</b>	Traumatic brain injury
<b>WRD</b>	WHO World Report on Disability

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Overview of the chapter

The literature review will start by presenting the two conceptual frameworks used in this study, namely the International Classification of Functioning, Disability and Health Children and Youth Version (ICF – CY; WHO 2007) and the UN Convention on the Rights of Children (UNCRC; UNICEF, 1989), together with the UN Convention on the Rights of Persons with Disability (CRPD; UN 2006). With these in mind, the definition of TBI, as well as the nature of the impairment, will be discussed. Activity limitations, participation restrictions and environmental barriers will be discussed as they pertain to being back at school following TBI. The focus will then shift to inclusion with qualitative studies describing experiences of participants affected by TBI in general and finally those that deal specifically with participants' experiences of being back at school following TBI.

#### 2.2 Conceptual frameworks for the study

This is a study about the concepts of inclusion, participation and disability as a result of TBI. This study recognises that a complex array of factors within multiple levels (e.g. personal, social, systemic) influence our understanding and experiences of these concepts. As such, the ICF-CY (WHO, 2007) and the UNCRC (UNICEF, 1989), together with the CRPD (UN, 2006) provide beneficial frameworks in which to explore these issues. These frameworks complement one another and will be used to foreground the focus of this study, i.e. the experience of being back at school following TBI.

The ICF-CY (WHO, 2007) is derived from the International Classification of Functioning, Disability and Health (ICF; WHO, 2001), and provides “a universal language...to facilitate the documentation and measurement of health and disability in children and youth.” (WHO, 2007, p vii). It arose in response to the need for a version of the ICF (WHO, 2001) that was tailored to children and adolescents in educational, social and health sectors (WHO, 2007). The ICF (WHO, 2001) was developed in order to describe and classify the functional consequences of various health conditions. It does this by considering health and functioning from the 3 components of body structures/functions, activities and participation. In each individual, these components interact with one other and are influenced by environmental and personal factors

(Andelic et al., 2010; Bernabeu et al., 2009; Tate & Perdices, 2008). Like the ICF (WHO, 2001), the ICF-CY (WHO, 2007) focuses on the individual and his/her particular impairment. The focus is on what the person can and cannot do in his/her environment and why. It views disability as an overarching term for impairments, activity limitations, and participation restrictions. The ICF-CY (WHO, 2007) considers environmental factors either as barriers or facilitators to participation (Bernabeau et al., 2009). Although the component of personal factors has not yet been well classified, the ICF-CY does recognise its influence on functioning and health (Bernabeau et al., 2009).

It is this holistic, multidimensional view of disability that makes the ICF-CY (WHO, 2007) suited to understanding TBI. It is well documented that TBI affects participation (Andelic et al., 2010; Bedell, Cohn, & Dumas, 2005; van Tol, Gorter, DeMatteo, & Meester-Delver, 2011). This is of particular interest to this study as it is the researcher's belief that it is in the school environment where participation restrictions are first experienced by the child and others in his/her community. However, "on its own, the ICF (WHO, 2001) is restrictive as it lacks political clout" (Kathard & Pillay, 2013). Systemic issues such as poverty and abuse, which in South Africa are linked to the country's political history, find no place in the ICF as causes of disability. Kathard and Pillay (2013) argue that the ICF (WHO, 2001) needs to be combined with social or human rights models of disability if a holistic picture of the causes and burdens of disability within the South African context is to be generated. Given the social context of this study, with participants who reside in impoverished and violence-ridden communities, and the systemic problems in the health and education sectors, the CRPD (UN, 2006) and the UNCRC (UNICEF, 1989) were chosen as suitable companion frameworks to the ICF (WHO, 2001), in order to understand how disability is experienced within the South African context.

The CRPD (UN, 2006) and UNCRC (UNICEF, 1989) are written from a perspective of inclusion, of belonging. The CRPD (UN, 2006) focuses on disability and regards this as a human rights issue (WHO, 2011). It argues that people need first of all to be recognized as human and as such have certain inalienable rights, such as the right to education (Ibid.). In addition to its emphasis on government responsibility in upholding the rights of children in all sectors of society, the UNCRC (UNICEF, 1989) holds the family unit in high esteem and specifically recognizes parents as the first line of support for the child. In addition, the convention also underscores the role of the environment in influencing the growth and well-being of children and their families. The South African government is a signatory of both the UNCRC (UNICEF, 1989) and the CRPD (UN, 2006) and consequently recognizes that it has a responsibility to put measures in place

across sectors which will facilitate the inclusion and participation of children with disabilities. The SA government agrees that the education of children with disabilities is a human rights issue (Donohue & Bornman, 2014) and that children have a right to belong, to be part of the world in which they find themselves. It is the researcher's opinion that for children with TBI, the health and education sectors are the key vehicles through which inclusion can be facilitated.

In the education sector, inclusivity has become a pertinent issue with Education White Paper 6 (Department of Education, 2001) translating the CRPD (UN, 2006) into policy within the South African context. Individuals with disability have historically been denied access to education, health and rehabilitation (WHO, 2011). A variety of barriers have excluded them from participation in daily life (Ibid.). Education White Paper 6 (Department of Education, 2001) presents the ideal in terms of provision of inclusive education in South Africa. However, children who have sustained a TBI do not always present with easily recognizable impairments. This makes them particularly vulnerable to exclusion within the education sector. Given what is known about the social context of this study and the health and education systems of the country, some doubt remains as to whether children with TBI are in fact able to access the equal opportunities to learn as put forth in the document.

It is clear that the ICF-CY (WHO, 2007) and UNCRC (UNICEF, 1989)/CRPD (UN, 2006) are suitable frameworks for this particular study which looks at a child's being back in a school environment following an acquired disability (TBI). They complement each other in their understanding of causes and influences on activity limitations and participation restriction brought about by the presence of a disability. While the ICF-CY (WHO, 2011) has a greater focus on the individual and his/her impairment; both frameworks emphasise that the environment can be either enabling or disabling. However, the CRPD (UN, 2006) and UNCRC (UNICEF, 1989) take a stronger socio-political view of disability which complements the bio-psycho-social nature of the ICF-CY (WHO, 2007).

### 2.3 TBI as an impairment: definition, incidence and nature

Currently TBI is reported, in the international literature, to be a major contributor of disability and death in childhood (Ylvisaker et al., 2005). Furthermore, it is estimated that by the year 2020 TBI will exceed many diseases as the main cause of death and disability (Chan, Thuraijah, & Colantonio, 2013). TBI is defined as, "...an acquired injury to the brain caused by and external physical force, resulting in a total or partial

functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention... The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma" (Individuals with Disability Education Act, 2004, as cited in Leiby & Asbell, 2007, p.40). There are no incidence figures for paediatric TBI in South Africa (Levin, 2004); however, an average of 30 children with moderate-severe TBI are treated per year at a subacute rehabilitation unit in one of the state tertiary hospitals in Cape Town.

The fact that TBI is an acquired disorder raises a number of pertinent issues pertaining to the variability of the disability. This has significant implications for the experiences of those effected by the injury, both patient and family. Firstly, the patient is, in most cases, a typically developing individual prior to the TBI (McKinlay, McLellan, & Daffue, 2012) and now presents with a variety of deficits that alter the course of his/her life experience. Secondly, diffuse injury is typical following pedestrian and passenger MVA's. Closed head injuries often have diffuse effects meaning that many areas and therefore functions of the brain are damaged (Dykeman, 2003; Leiby & Asbell, 2007). The third issue relates to the heterogeneous nature of TBI (Rosignano, Fleig, & Knafl, 2014; Savage, DePompei, Tyler, & Lash, 2005; Ylvisaker et al., 2005). The particular resultant picture that a survivor of TBI presents with is influenced by a variety of factors, such as the age of the individual, the nature, severity and site of injury, premorbid personality and ability, as well as family support and functioning prior to the incident and whether necessary services are available or not (Savage et al., 2005).

Despite this variability in outcome, there are some typical deficits following TBI and these have been well-documented. Significantly these deficits can persist for years (Anderson & Catroppa, 2006; Ewing-Cobbs, Fletcher, Levin, Iovino, & Miner, 1998; Fay et al., 1994; Taylor et al., 2002; West, Dunford, Mayston, & Forsyth, 2013; Yeates & Taylor, 2006; Ylvisaker et al., 2005). These can be grouped into cognitive, communicative, social-behavioural and physical deficits (Clark, 1996; Savage et al., 2005; Ylvisaker et al., 2005).

A brief description of each grouping follows:

- Cognitive: Deficits in memory and attention are common. Often it is the executive functions that control the cognitive processes that are the problem and the patient therefore presents as having difficulties with organisation,

planning and judgment. They often have a slow speed of information processing resulting in profound difficulties learning new information.

- Communication: These cognitive deficits are typically tied to communication disorders resulting in a cognitive-communicative disorder. This is characterized by, for example, disorganized discourse, impulsive communication style and slow word retrieval. In addition, language skills can be affected. Receptive difficulties include problems following instructions, recalling what was read, and difficulty with the speed, complexity or amount of information that is presented simultaneously. Expressive difficulties include overuse of vague or empty words e.g. “thing” and “you know”, decreased spelling ability and difficulty writing sentences. Pragmatic difficulties include the use of socially unacceptable words, continuing to talk when others show disinterest, difficulty with turn taking and maintaining topics, talks about unrelated topics. Speech skills, which refers to the production of sounds that make up words, also form part of communication skills. Speech can be slurred, slower, or hoarse sounding after TBI. However, children often recover their ability to produce speech sounds up to their premorbid level of functioning; as such the cognitive-communicative difficulties are often overlooked. The child sounds “normal”; and as a result the hidden cognitive deficits are missed or misinterpreted. The impact of these deficits on a child’s academic learning and social development has been documented and is discussed later in this chapter.
- Social-behavioural: Between 35 and 70% of children have social-behavioural problems following TBI. These deficits are extremely troubling for family, educators and others, often more so than residual physical deficits. The list of typical social-behavioural problems is extensive and includes disinhibition, aggression, immature behaviour, social awkwardness and social withdrawal, depression, impulsivity and over activity, irritability and low frustration tolerance and apathy.
- Physical: These include fatigue, seizures, headaches, weakness and incoordination.

It is evident that children with TBI are a heterogeneous group and show great variability in their individual profiles (West et al., 2013). As such, these children present with diverse difficulties that they may experience at school or home; their cognitive and physical profiles are “patchy, unpredictable” (Ibid.). The long term effects are dominated by cognitive, educational, behavioural and family/social themes (Savage et al., 2005; Ylvisaker et al., 2005). Furthermore, due to this heterogeneity, children with TBI may be classified as having learning difficulties, intellectual and/or physical

impairment. The classification they receive will influence the services they receive, for instance the focus for a child with TBI and physical impairment may be on accommodating the physical impairment with little thought to the underlying cognitive-communication impairment. For this reason, it is argued that the difficulties experienced by those with TBI set them apart as a group and as such they should be able to access specific training and support services tailored for children with TBI (Backhouse & Rodger, 1999; Bullock, Gable, & Mohr, 2005).

The TBI literature is clear that although outcomes are affected by many factors, paediatric TBI has long term consequences and persistent effects (Bullock et al., 2005; Ewing-Cobbs et al., 1998; Ewing-Cobbs et al., 2004; Fay et al., 1994; Limond, Dorris, & McMillan, 2009; Taylor et al., 2002). For a long time it has been thought that that children recover quickly from TBI; however, recent research indicates this is not so (Agnihotri, Keightley, Colantonio, Cameron, & Polatajko, 2010; Babikian & Asarnow, 2009; Bohnert, Parker, & Warschausky, 1997; Hawley, Ward, Magnay, & Mychalkiw, 2004; Lebbly & Asbell, 2007; Taylor et al., 2008). The neurocognitive and other effects of TBI may change in their presentation over time, but deficits persist. As the brain continues to develop into young adulthood, the young brain is particularly vulnerable to the effects of TBI, i.e. the course of neurodevelopment is changed, particularly for the child following severe TBI (Babikian & Asarnow, 2009). Ilie et al. (2014) use the term "lifetime TBI" to describe brain injury that resulted in loss of consciousness for at least 5 minutes or staying in hospital for at least one night. The children on the subacute paediatric neurosurgery ward from which the study participants were drawn have typically been in a coma/sedated for more than 3 days. It is therefore not surprising that research indicates that there is sometimes even a worsening outcome over time, rather than an improvement as parents and educators typically expect (Anderson & Catroppa, 2006; Babikian & Asarnow, 2009; Backhouse & Rodger, 1999; Ewing-Cobbs et al., 1998; Hawley, Ward, Magnay, & Long, 2002; Hawley, Ward, Magnay, & Long, 2003; Hux et al., 2010; Ylvisaker et al., 2005).

The literature is replete with studies which highlight that, despite the devastating impacts of TBI on the individual, it is a largely hidden, misrepresented and little understood condition by professionals and lay people alike (Ashley, 2010; Backhouse & Rodger, 1999; Bullock et al., 2005; Deidrick & Farmer, 2005; Hartley, 1995; Hawley et al., 2004; Hawley et al., 2002; Penn et al., 2009; Schutz, Rivers, McNamara, Schutz, & Lobato, 2010; West et al., 2013). According to Backhouse and Rodger (1999), TBI is often termed the "hidden disability" because the long term consequences involve social and cognitive domains, not those easily seen and typically associated with disability in

the physical domain. The terms “hidden” and “invisible” disability are scattered throughout the TBI literature. Most children with severe TBI have a relatively normal appearance giving parents and educators a false impression of their recovery and functional ability (Schutz et al., 2010). These authors found that there is a marked failure to recognize this hidden disablement with an overwhelming 98-99% of those children who sustained TBI’s being incorrectly presumed capable of resuming their ordinary education, placing this vast number at risk of academic failure and personal maladjustment. West et al. (2013) describe children with TBI as “the walking wounded, i.e. those who do not present with significant physical impairments although they may have considerable cognitive difficulties which are often subtle and may be difficult to recognize” (p.696). In their study comparing outcomes in children following mild and moderate-severe TBI, Hawley et al. (2002), found that school teachers tended to make special arrangements for children who had visible physical injuries, such as fractures to leg, but that “when the injury was invisible, few children had been offered any help” (p.981). As previously mentioned, the full extent of TBI effects, particularly in terms of social-emotional and cognitive capacities, may not be realized for some time (Backhouse & Rodger, 1999).

Schutz et al. (2010) describe this hiddenness as a stereotype error, in which the adults and peers involved with the child with TBI have an incorrect mental representation of what brain injury is. They list 5 misconceptions about TBI: There is a belief that severe brain injury results in very noticeable disabilities, when in fact most TBI symptoms are hidden/silent. There is a belief that brain damage should prevent the child from performing normal tasks, when in fact TBI produces subtle, situational-based errors. There is a belief that brain damage results in physical disability, when in fact children with TBI often look fine physically. There is a belief that brain injury results in bizarre behaviours associated with mental illness, when in fact the TBI symptoms are often difficult to separate from personality problems. And finally, there is a belief that brain injury makes the child stupid, whereas in fact the relatively fluent speech and intact premorbid knowledge base give the impression that the child is intellectually sound. Dykeman (2003) also mentions the existence of “myths” about the effects of TBI. A child’s post-injury disabilities may be missed or misinterpreted as a result of these inaccuracies, i.e. professionals and family do not associate the child’s academic, social and behavioural problems with his/her brain injury. Children may therefore not receive the assistance and rehabilitation services they need (Hawley et al., 2002; Schutz et al., 2010). The presence of any of these stereotypes together with variability of the characteristics presented by children with TBI, may result in a lack of access to the

correct supports and services for the child. This will have a profound impact on their return to school experience.

#### 2.4 Common activity limitations and participation restrictions for being back at school following TBI

Research from developed nations confirms that school reintegration is problematic for children following TBI for a number of reasons (Agnihotri et al., 2010; Bedell et al., 2005; Ehrenfors, Borell, & Hemmingsson, 2009; Ewing-Cobbs et al., 1998; Gfroerer et al., 2008; Savage et al., 2005; Ylvisaker et al., 2005). Dykeman (2003) states that school is an important component of the rehabilitation process for children with TBI and an important area of participation in the lives of children in general. The literature pertaining to returning to school appears to focus on limitations and restrictions which occur in the ICF-CY (WHO, 2007) domains of learning and applying knowledge, and interpersonal interactions and relationships. More specifically, children who have sustained a TBI are at risk for academic failure and they are at risk of social isolation as well as behavioural difficulties. However, before providing an in-depth discussion of these challenges, it is important to point out that it is the very hiddenness of typical TBI impairments that makes it difficult for educators, peers and family members to understand their impact on participation (Sharp, Bye, Llewellyn, & Cusick, 2006). For instance, the “invisible” cognitive difficulties, and specifically cognitive-communicative difficulties, have a greater impact on a child’s reintegration, performance and progress at school than the physical difficulties a child may be experiencing (Ashley, 2010; Hartley, 1995). However, schools tend to focus on accommodating physical disability and not on reducing the activity limitations resulting from the hidden cognitive impairments (Hawley et al., 2004). The World Report on Disability (WHO, 2011) highlights this ironic inequality and explains that not all people with disabilities are equally disadvantaged as children with physical (therefore visible) disabilities currently fare better in terms of school enrolment and participation in school-related activities than those with (the more hidden) sensory and intellectual impairments.

Adequate academic performance is crucial to successful reintegration following TBI (Kinsella et al., 1997). Hawley et al. (2003) state that return to ordinary school following TBI tends to be common and is often taken as an indication by people in the immediate environment that the child has made a good recovery from the accident. Following their study of progress 4-years post-injury, Taylor et al. (2002) concluded that behaviour and scholastic problems fail to resolve over time. Children with moderate-severe TBI re-

enter ordinary education and can often perform at or nearly at their premorbid academic level as they are able to retain prior learning and skills. However, it was found that while many obtain near normal scores on tests in the first year back at school they steadily decline thereafter until they perform below grade-level and stay there with resultant school failure or drop-out (Glang, Ettl, Tyler, & Todis, 2012; Schutz et al., 2010). Ewing-Cobbs et al. (1998) conducted a 2-year longitudinal study and found that despite improvement in scores at the 6 months assessment from baseline, there was no further progress 2 years post-injury; indeed, 2 years after a severe TBI, just under 80% of these children had either failed a grade or received special education assistance. Children who were above-average achievers before the TBI appear to take longer to fall behind, but even these above-average learners eventually underperform (Ewing-Cobbs et al., 1998; Schutz et al., 2010). This research suggests that the activity limitations within the schooling environment were not given adequate consideration. It is expected that this loss of previous academic ability (and failure to catch-up) will have an impact on the experience of participation and inclusion at school for the child, his caregiver and educators. However, it is important to note that the negative effects of TBI on academic inclusion can be counteracted by resources such as family or educator support; appropriate accommodations within the schooling system, and by protection against additional environmental burdens, such as financial hardships or stressful environments (Schutz et al., 2010; Taylor et al., 2002).

A significant part of the participation of children at school involves interacting with friends and other peers. It is recognized that social isolation and loss of friendships are common and persistent outcomes following TBI (Bohnert et al., 1997; Callaway, Sloan, & Winkler, 2005; Glang, Todis, Cooley, Wells, & Voss, 1997; Ilie et al., 2014; Prigatano & Gupta, 2006). The TBI effects hamper the child's ability to engage socially and participate fully (Agnihotri et al., 2010; Galvin et al., 2010; van Tol et al., 2011). However, it is likely that the resultant cognitive deficits and socially inappropriate behaviours typically displayed by TBI survivors (e.g. disinhibition, reduced anger control, memory impairment) are primarily responsible for alienating peers and significant others who are confused by the changed behaviour (Glang et al., 1997). A recent population-based study amongst learners in Grades 7 through to 12 found that students with TBI were more likely to be bullied at school and more likely to be threatened with a weapon (Ilie et al., 2014). The authors caution that these experiences are likely to exacerbate emotional and cognitive difficulties the adolescent is already facing as a result of the TBI (e.g. difficulty paying attention). On the other hand, this research also showed that students with TBI were more likely to victimize others and

engage in violent and other maladaptive and dangerous behaviours. Indeed, aggression is common following TBI and closely associated with depression (Baguley, Cooper, & Felmingham, 2006; Ilie et al., 2014; Nicholl & LaFrance, 2009). Low self-esteem is closely linked to anxiety and depression, and may present a barrier to both social and academic participation. Hawley (2012) found that children with TBI had significantly lower self-esteem than their age-matched peers 2 years post-injury. Hawley (2004) found that 2 out of 3 of the children in her study presented with behaviour problems post-TBI. These difficulties will affect school performance (Hawley, 2004; Yeates & Taylor, 2006). However, Glang et al. (2012) and Hawley (2004) suggest that school children with TBI may develop behaviour problems because they struggle to keep up with class work. They may respond to this inability to cope by becoming rude and disruptive in class or by withdrawing and avoiding school. Hawley (2004) found that behaviour problems in children with TBI are also associated with environmental factors such as social deprivation and parental marital status and inappropriate expectations from parents and educators. Dykeman (2003) lists a number of environmental factors that may also influence a child's behaviours for example, physical factors (the number of children in the class and the intensity of noise); time factors (such as fatigue later in the day); as well as the availability of support for the child. Yet again evidence suggests that activity limitations within the schooling environment were not given adequate consideration. For many children with TBI the result is social isolation. In spite of these challenges which exist for children with TBI to forge and maintain friendships, social inclusion is nevertheless viewed as a valued outcome of schooling, at least for the children themselves. In their study comparing 22 children with TBI with a matched control group on measures of peer adjustment, Bohnert et al. (1997) found that children with TBI are more concerned about losing their friends than about doing well in school work. They are least concerned about how their impairments may have affected their sporting ability. On the other hand, their parents were most concerned about the child's health, followed by their academic performance and then about their ability to make and keep friends.

While each of these limitations has been explored individually, very little quantitative literature is available which explores the interactions between them. Yeates and Taylor (2006) importantly report on the interrelationship between behaviour problems, educational difficulties and their link to additional academic support. The authors found that behaviour problems reported by educators in school are an important predictor of the academic performance of a child with TBI and whether they need special educational intervention. They found that a child's behavioural disturbance (included

items such as aggressive behaviour, rule breaking behaviour, attention problems, social problems, anxious-depressed, somatic complaints, withdrawn) was a strong predictor for classroom accommodations (e.g. special seating, reduced homework, small group instruction), yet behaviour problems did not predict formal academic educational assistance (e.g. special school placement). It was rather the child's academic skills that predicted academic placement. They conclude that eligibility for special education services, as typically provided to children with learning difficulties, is dependent on academic skills, not problematic classroom behaviour (Ibid). Nonetheless, the impairment and resultant activity limitations still need to be managed within an inclusive educational environment. However, it is also clear from the literature that very little academic support or accommodations are offered to children following TBI in the ordinary classroom (Hawley et al., 2002). This lack of support only further exacerbates the participation restrictions which the child experiences within the classroom setting.

## 2.5 Common environmental factors that affect being back at school following TBI: challenges and solutions

The international literature from developed countries speaks to a general lack of support for those affected by TBI on return to school (Gfroerer et al., 2008; Glang et al., 2012; Hawley et al., 2002; Hawley et al., 2003; Hux & Hacksley, 1996). When viewed through the environmental factors proposed by the ICF-CY (WHO, 2007) the most common barriers reported include those pertaining to support and relationships as well as services, systems and policies.

In terms of services, systems and policies, children typically are neither assessed before re-entering school nor followed-up on once they return (Hawley et al., 2002). This is in spite of evidence recommending early and ongoing assessment for behavioural and academic difficulties (Hawley, 2004; West et al., 2013). Hawley et al. (2002) document that special arrangements for learners were made by schools in only 20% of cases. Often accommodations for children focused on keeping the child indoors at playtime and excusing child from PE, both working against participation and both focusing on physical not cognitive symptoms (Ibid.). Suggestions for improving the school environment by way of providing more appropriate classroom specific accommodations and specialised education support are provided in the literature (Ashley, 2010; Dykeman, 2003; Hux & Hacksley, 1996). The fact that educators lack knowledge of TBI in general, lack training in management of TBI in classrooms, and

lack of supportive follow-up has also been well documented in the literature (Deidrick & Farmer, 2005; Hawley et al., 2004; Hawley et al., 2003; Hux & Hacksley, 1996; Schutz et al., 2010). Educator training is encouraged in broad terms (Hux & Hacksley, 1996; Schutz et al., 2010). In addition, continued collaboration between parents, educators and rehabilitation professional working with child with TBI is emphasized as a means of support (DePompei & Blosser, 1994; Farmer, Clippard, Luehr-Wiemann, Wright, & Owings, 1996; Harn, Bradshaw, & Ogletree, 1999; Sohlberg, McLaughlin, Todis, Larsen, & Glang, 2001).

In terms of support and relationships, a general lack of communication among those involved with care of the child with TBI, both from health and education sectors, and the negative effect it has on the child's transitioning back to school and across school years, is documented in the international literature (Ashley, 2010; Backhouse & Rodger, 1999; Deidrick & Farmer, 2005; DePompei & Blosser, 1994; Dykeman, 2003; Farmer et al., 1996; Gfroerer et al., 2008; Glang et al., 2012; Hawley et al., 2004; Hawley et al., 2003; Hux & Hacksley, 1996; Lebbly & Asbell, 2007; Savage et al., 2005; Schutz et al., 2010; Ylvisaker et al., 2001). For instance, studies note that the information about the child's TBI is not being passed on from school year to school year (Ashley, 2010; Hawley et al., 2004; Hawley et al., 2002; Schutz et al., 2010). Hawley et al. (2002) found that current educators were aware of the child's TBI in less than 40% of the cases in their study (207 out of 525). This communication gap is significant, in terms of provision of support for the academic and behaviour difficulties so prevalent post-TBI, as it is noted that "the more remote the TBI, the less likely it is...to be thought of as playing a role in current difficulties... because usually children with even a severe TBI have a relatively normal physical appearance" (Max, as cited in Schutz et al., 2010, p.61). Thus the supportive environment within a school setting which allows for information transfer between teachers appears to be lacking. Hawley et al. (2003) found that parents of children with TBI exhibit significant levels of stress. This was related to receiving little information on TBI and its long term consequences and to experiencing financial or family difficulties. The authors recommend better provision of information, follow-up and support for parents. It is therefore not surprising that DePompei and Blosser (1994) and Glang et al. (2012) report that the strength of the parent-educator relationship is another critical factor influencing the outcomes of the child being back at school following TBI. This relationship needs to be fostered by both parties. Finally, a further contributor to the successful transition from hospital to school is for educators to prepare peers for the return of their classmate (Bullock et al., 2005). It is well documented that peer attitudes to children with disability can either act

as a facilitator or a barrier towards successful inclusion of a child with a disability (Baker & Donnelly, 2001; David & Kuyini, 2012; Rillotta & Nettelbeck, 2007).

## 2.6 Introducing experience through qualitative research: moving beyond the ICF-CY

Thus far in the chapter, the majority of literature consulted has been quantitative in nature. The ICF-CY (WHO, 2007) is most suited to these types of studies. However, in-depth knowledge of the human experience of the impairment of TBI and the attendant activity limitations and participation restrictions as described in the previous sections is best accessed using qualitative methods. Over the past few decades there has been a growing appreciation for these methods of study as an alternative and complementary form of knowing to purely quantitative methods, with researchers seeking the first-hand experiences of participants to better understand the topic under investigation. There is recognition of the fact that the subjective points of view of those who have experienced or are experiencing the topic under investigation can provide the researcher with deep, rich and sometimes novel insights into that topic. In particular, qualitative methods have gained popularity amongst health researchers, specifically those with an interest in disability studies (Farjou et al., 2013; Griffin, Friedemann-Sánchez, Hall, Phelan, & van Ryn, 2009; Hines, Balandin, & Togher, 2014; Kelly, 2010; McLeod, 2011).

In the field of TBI in general, qualitative research both internationally and in South Africa has been dominated by adult studies investigating the experiences of caregivers following their child or spouse's injury with a focus on their stresses, needs and supports (Chisholm & Bruce, 2001; du Toit, Coetzee, & Beeton, 2013; Gan, Gargaro, Brandys, Gerber, & Boschen, 2010; Kao & Stuifbergen, 2004; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2014; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; Leith, Phillips, & Sample, 2004; Marsh, Kersel, Havill, & Sleight, 2002; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000; Prigatano & Gupta, 2006; Roscigno & Swanson, 2011; Wongvatunyuy & Porter, 2005). The experiences of other close family members have also been investigated. Degeneffe and colleagues were interested in the perspectives and experiences of adult siblings of persons with brain injury (Degeneffe & Olney, 2010; Degeneffe & Lee, 2010), while Harris and Stuart (2006) investigated the lived experiences of adolescents whose parents had sustained a TBI. Adults who sustained a TBI have also been included as participants in studies, but far less so (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012; Hyatt, Davis, & Barroso, 2014; Lefebvre, Cloutier, & Josee Levert, 2008; Leith et al., 2004; Liddle et al., 2012). There has been increasing interest in the views of adult survivors of TBI on outcome and the

adjustment to life following TBI (Morris et al., 2005; Nochi, 1998; Roundhill, Williams, & Hughes, 2007; Soeker, 2011). These studies highlighted a sense of loss of self and life from before injury as well as experiences of the negative reactions of others.

In terms of the voices of children being heard in the qualitative literature on TBI, until very recently no research had been conducted with this participant group (Rosignano, Swanson, Vavilala, & Solchany, 2011). The value of including the perspectives of children in qualitative research has gradually gained momentum since the UN Convention of the Rights of Children (UNICEF, 1989) declared that children have the right to express their views freely in matters affecting themselves. Subsequent to this, the World Report on Disability (WHO, 2011) was published which further supports the cause of people with disability. It encourages clinicians, policymakers and researchers to engage with the real life issues facing people with disabilities. Listening to and understanding the voices of the children, and more so, children with disability, in research is critical as a child understands the world differently to an adult (Kortesluoma, Hentinen, & Nokkonen, 2003). Their “self-report may provide a unique assessment of their own experience” (Erickson et al., 2010).

However, within the last 10 years, a number of researchers in the fields of health, disability, rehabilitation and education have begun to investigate the view and experiences of children and young people (Krol, Sixma, Meerdink, Wiersma, & Rademakers, 2014; McCormack, McLeod, McAllister, & Harrison, 2010; McLeod, 2011; Rabiee, Sloper, & Beresford, 2005; Watson, Abbott, & Townsley, 2007; Wingate, 2006). Rosignano et al's (2011) influential paper was the first to use qualitative methods in the field of paediatric TBI. They documented the general experiences of 39 children aged 6-18 years with moderate-severe brain injuries. Despite the challenges involved in accessing the narratives of children with cognitive-communicative difficulties, the authors emphatically state that many of the children can relate their experiences after injury. They found that children were aware of their difficulties and the differences in their functioning but felt that they were essentially the same person. They therefore struggled to understand why others failed to see past their impairments to the person they were. These children also showed that the quality of their new friendships were more important to them than how many friends they had. The children described the challenges of adjusting to this new life and that “everything is such hard work.” In spite of this growing interest internationally, very little research on the experiences of TBI has been done in South Africa; and the existing studies used adult participants (Crewe-Brown, Stipinovich, & Zsilavec, 2011; du Toit et al., 2013; Harris & Stuart, 2006; Mokhosi & Grieve, 2004; Oosthuizen, 2007; Smit, 2006; Soeker, 2011). It is interesting

to note that there have been no published qualitative studies from South Africa that use children with TBI as participants.

Within the body of qualitative literature examining participants' experiences there is a limited number of studies which investigate TBI from multiple interview sources. Most of the studies which did include multiple perspectives sought experiences of the caregiver and TBI patient; in some cases the voices of rehabilitation personnel who worked with patients with TBI in hospital were sought (Fleming et al., 2012; Gan et al., 2010; Gauvin-Lepage & Lefebvre, 2010; Lefebvre et al., 2008; Leith et al., 2004; Mokhosi & Grieve, 2004; Turner, Fleming, Ownsworth, & Cornwell, 2011). However, as the researcher is particularly interested in the experiential research on being back at school following TBI the voices of teachers, parents and children with TBI relating to this area are discussed below.

## 2.7 Experiences of being back at school following TBI: the qualitative research contribution

Being back at school can best be understood by listening to the voices of those affected by the TBI – in fact, it is critical to do so in order to access the rich, valuable information they are able to provide on the subject. Qualitative studies from developed nations have shown discrepancies between the views of students with TBI and their parents or educators (Bohnert et al., 1997; Erickson et al., 2010; Mealings, Douglas, & Olver, 2012). In order to develop a comprehensive, balanced story of school reintegration, it would be necessary to include the stories of all three: children, parents and educators. The researcher assumed that because the child has changed due to their injury and presents with needs that are complex and easily misunderstood, the experience of schooling will have changed for them, their parents and educators. Both would impact on the experience of schooling currently and in future. In keeping with the ICF-CY (UNICEF, 1989) and CRPD (UN, 2006), this study also recognized that factors in the environment would influence the participants' experiences by either challenging (barriers) or supporting (facilitators) being back at school and inclusion following TBI. The qualitative literature around these 3 points (change, environmental factors and a multi-voice perspective) is discussed below.

A changed life, and specifically, the loss of the old life and reconstruction of the new life, is a main theme in the literature for both patients and caregivers following TBI (du Toit et al., 2013; Kao & Stuifbergen, 2004; Morris et al., 2005; Roscigno et al., 2011; Roscigno & Swanson, 2011). Very little has been written on experiences of students

with regard to change at school specifically. In Australia, Sharp et al. (2006) interviewed adolescents with severe TBI who described change in terms of loss of abilities, loss of friendships and loss of certainty about the future. Mealings et al. (2012) found that students with TBI changed their study courses or educational goals. They reported avoiding school and wanting to leave school. In their multi-perspective study on the study skills and accommodations used by college students who had sustained a TBI, Hux et al. (2010) importantly found that the barriers experienced by students and the accommodations they needed changed and evolved for many years after an injury. The experiences of change in terms of schooling from parents' and educators' perspective is not well documented in the literature.

The few international qualitative studies published which describe environmental factors, provide information similar to those given in the quantitative literature earlier in the chapter; however, they provide depth in terms of *how* these factors influence participants' experiences of being back at school and *why* certain factors are perceived as barriers or facilitators, questions that quantitative research is often unable to answer. Mealings et al. (2012) in their review of 8 studies on students' experiences of school reintegration post-TBI found that they experienced barriers to their reintegration as their specific and individual TBI-related deficits, a lack of understanding from important others (e.g. educators and friends) of their TBI and resultant specific needs, and not receiving the help they had requested.

Studies from the UK, US and Australia which included the experiences of parents found that factors such as attitudes towards their child and access to the appropriate services were key environmental barriers. Parents' experiences of their child's TBI were negatively influenced by misinformed responses of the community (e.g. school) to their child and a lack of communication between schools about the TBI when their child transferred to a new school (Hawley et al., 2004; Roscigno & Swanson, 2011; Sharp et al., 2006). With regard to social inclusion, parents of children with other disabilities voiced similar concerns about negative attitudes from peers and professionals (Case, 2000; Leyser & Kirk, 2004). They were also concerned about lack of access to information and services and financial barriers, all of which are significant stressors in the lives of parents of children with TBI (Prigatano & Gray, 2007; Resch et al., 2010; Roscigno & Swanson, 2011). Parents of children with other disabilities also mentioned worries about the quality of teaching and teacher training, but this is not seen in the TBI school reintegration literature (Case, 2000). Students and parents found it helpful when there was effective organisation and planning for school reintegration at a system level, when educators and peers were aware of and educated regarding TBI and where

classroom accommodations were selected and implemented appropriately (Mealings & Douglas, 2010; Sharp et al., 2006). Bernbaum (2007) interviewed, amongst others, educators of children who had sustained severe TBIs. In general, educators sought to accommodate the changed abilities of the learner, but found their lack of knowledge about and experience with TBI as inhibiting. However, in the reviewed literature, the voices of educators were largely absent on the topic of environmental stressors and facilitators.

The mandate put forward by the CRPD (UN, 2006) would suggest that capturing the voices of the people most closely affected by the disability is essential. Yet to date studies on experiences of school reintegration post-TBI appear to have focused on the experiences of adolescents (Hux et al., 2010; Mealings et al., 2012; Mealings & Douglas, 2010; Rodstet, 2008; Sharp et al., 2006). The researcher is unaware of school-reintegration studies with children younger than 13 years as participants. We have no knowledge of the experience of being back at school in the TBI population during the early and middle school years.

The parent provides another important voice to the story of being back at school. On return to ordinary education, parents report concerns about their child's school performance, their behaviour and anger (Prigatano & Gray, 2007). Parents have experienced educators as being resentful of the time it takes to assist their child, claiming the child is misbehaving, as the cognitive deficits are "hidden" (Rosignano et al., 2014). They are not prepared for the immense life changes that their child's condition brings. The family's adjustment to the injury has a direct impact on the child's prognosis (Anderson & Catroppa, 2006; du Toit et al., 2013; Taylor et al., 2008). Rosignano et al. (2014) acknowledge that parental accounts of being back at school are influenced by co-occurring social factors. This point is of particular relevance when the current study context is considered. Parents not only have to learn to cope with a changed child, but continue to face the challenges of financial burden and safety concerns in gang-ridden areas. For this reason it is expected that the family's ability to adjust to the TBI will be negatively impacted by these additional social factors.

In most of the literature on school reintegration internationally the perspectives of the educators are duly recognized. However, the focus in these studies is on the supports and barriers that they experience in the management of the child, not on how their own experience of schooling has influenced their own learning and development trajectories (Bernbaum, 2007; Bullock et al., 2005; Deidrick & Farmer, 2005; Hawley et al., 2004). The researcher feels that this point is worth investigating given the constraints of the current system for educating teachers in the South African context, as previously

mentioned. The voice of an educator is critical as they are primarily responsible for the accommodations which will be suggested for child at school.

## 2.8 Conclusion

In summary, there is a growing body of literature which documents the experiences of individuals with TBI and their significant others. However, despite the fact that return to school following TBI is difficult, there is a dearth of literature which captures the experiences of young children and the significant adults in their environment on being back at school. The existing research is from developed nations. Whilst, the information gathered from these studies is informative it remains limited in that barriers and facilitators to successful inclusion are not fully explored; and the voice of young children with TBI is noticeably absent. What we do know stems primarily from the points of view of adolescents and graduate students and from caregivers and educators. In addition, none of the multi-perspective studies have young children as participants. Finally, the researcher is not aware of any studies which report on the process of being back at school following TBI within the South African context, where young children are included as participants. For these reasons, this research aimed to address these gaps in the literature in this unique, multi-perspective study on being back at school following TBI. The methods used to achieve this will be described in Chapter 3 and the findings will be presented in Chapter 4 and 5.

## CHAPTER 3

### METHODOLOGY

#### 3.1 Aims

The study has one main aim which is to explore and describe the experience of being back at school of children with TBI, their parents and educators.

#### 3.2 Design

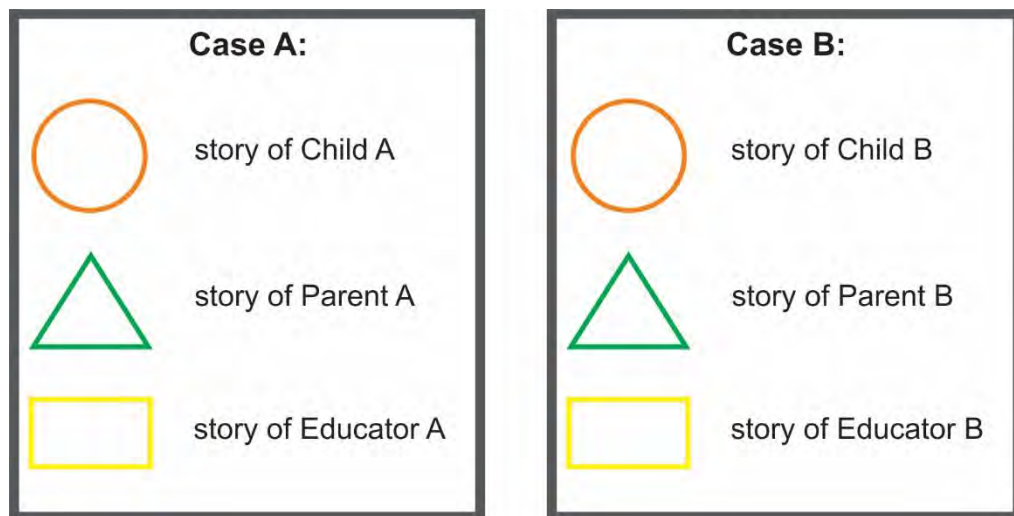
This study focuses on the experiences of individuals regarding a specific event and process in their lives, within a specific context. Experience is the personal meaning individuals attach to an event; it is multi-layered and complex (Clandinin & Connelly, 2000; Polkinghorne, 2005). The exploration of experience is best achieved within a qualitative and interpretive framework.

Qualitative research aims to describe and clarify human experiences (Polkinghorne, 2005). The methods used are flexible and fluid. It therefore allows for the in-depth exploration which is necessary to understand the complexity of subjective experience. It is also a design suited for use with the vulnerable populations as it provides survivors with opportunities to tell their stories and for researchers to hear these in ways that quantitative research never could (Liamputtong, 2009). The child and parent participants in this study are considered part of vulnerable populations, that is, those who are likely to be susceptible to coercion or who experience reduced autonomy, due to physiological or psychological factors or due to economic or educational disadvantage (Liamputtong, 2009; Stevens, Lord, Proctor, Nagy, & O'Riordan, 2010). The children who have sustained TBI are seen as even more vulnerable due to the hidden nature of their disorder, i.e. it is not easily distinguished (Liamputtong, 2009).

An interpretive framework assumes a relativist rather than a positivist ontology. This suggests "there are multiple realities and that researcher and participants co-create, co-construct and co-inform these realities and understandings" (Denzin and Lincoln, as cited in Meltz, Herman, & Pillay, 2014, p.4). It allows the researcher to investigate a topic or event from various angles, "to see life in the round, from all angles... different versions of the same incident." (Rubin & Rubin, 2005). This paradigm is therefore ideal for understanding the experience of being back at school from the perspective of the different participants. A narrative design is reported as the best way to access the personal meaning which is embedded in experience (Polkinghorne, 2005). A narrative approach studies the way humans experience the world (Clandinin & Connelly, 2000)

and is used for understanding the meaning of an individual's story (Ollerenshaw & Creswell, 2002). Narrative inquiry, therefore, is the approach that is taken to this research.

In this study the experience of being back at school following TBI is understood through the stories of child, parent and educator, which together form a single case. Two such cases, Case A and B were studied in the research (see Figure 1). Thus a case study approach which involves the exploration or in-depth analysis of single or multiple cases over a period of time, is also used (Cresswell, as cited in De Vos, Strydom, Fouche & Delport, 2007, p.272). The result is a rich description of the cases.



*Figure 1: Two cases consisting of child, parent and educator participants*

### 3.3. Participants

#### 3.3.1 Study Population

The study relied on the participation of 3 participants within 2 cases to describe experiences of being back at school following TBI (see Figure 1). The participants were the child with TBI, a parent and an educator. The sample was drawn from a population of children who were discharged from the neurosurgery rehabilitation unit the researcher works in and is described in the inclusion criteria. These children were from socioeconomically disadvantaged communities, many of which form part of the so-called Cape Flats.

### 3.3.2. Case selection

As the researcher was interested in understanding the case of being back at school after TBI through the experiences of the child, parent and educator, it was imperative for each case that the 3 individual participants making up that case met the following criteria:

- Willing to participate voluntarily and share their stories
- Information-rich
- Able to participate in view of time needed for in depth interviewing (Polkinghorne, 2005)
- Subscribed to the individual participant inclusion criteria described below

Where any of the above criteria was not met by a participant within the case, the entire case was excluded from the study.

### 3.3.3 Participants within each case

Selection criteria were established meaningfully and strategically with the aim of obtaining participants who are information-rich (Liamputtong, 2009; Polkinghorne, 2005).

#### 3.3.3.1 Child

In order to be eligible to participate in this study the children needed to adhere to the following inclusion criteria:

- Categorised with initial GCS <13 in medical notes as these scores indicate a moderate-severe TBI.
- Back at ordinary school for at least 6 months following discharge from the rehabilitation unit allowing time to experience initial school re-entry as well as progress.
- In the same ordinary school as prior to the injury. This would allow for a better understanding of possible pre and post-injury change. In addition, this study needed to be able to differentiate between premorbid issues and new concerns related to the TBI, which would not be possible if the child has transferred to a new school.
- Aged 10 – 12 years at time of interviewing. This age provided the typical sample facing similar educational expectations and developmental challenges.

In addition, it was expected that children at this age would be better able to reflect on and retell their experiences than younger children.

- Aetiology of motor vehicle accident, either pedestrian or passenger. This is the aetiology of most patients in the hospital's only paediatric rehabilitation unit and would also provide TBI case results that are typical.

The following exclusion criteria were decided upon:

- Injury more than 2 years ago at time of participation in the study. This prevented a larger than 2 year post-injury gap, at which stage the history of the TBI is lost (Ashley, 2010).
- Spinal cord injury additional to TBI, resulting in severe physical impairments. These children are likely to enter special schooling directly post-discharge or are transferred to a long term rehabilitation facility. They thus do not make up the typical case under investigation in the study.
- Prior TBI or multiple concussions (2 or more in 12 months) as this would have influenced prior schooling experiences.
- Premorbidly diagnosed developmental delay or learning disability. This too would have influenced prior schooling experiences. Caregivers would likely have had previous experience with medical and educational professionals and this would impact on their current experience of the TBI and school reintegration.
- Severe dysarthria and/or aphasia, as documented in medical notes. Children with these disorders would likely be transferred to a special school post-discharge. The more subtle cognitive-communicative disorder is typical.
- Participated in previous studies, so as to avoid over-researching of participants and to hear new voices.

#### 3.3.3.2 Parent

In order to be eligible to participate in this study the parents needed to adhere to the following inclusion criteria:

- Primary person responsible for care of child described above and by implication living in the same house as the child
- Same primary caregiver as prior to the injury

### 3.3.3.3 Educator

In order to be eligible to participate in this study the educators needed to adhere to the following inclusion criteria

- Self-identified or identified by the school principal as the educator who knows the child best in order to obtain the needed rich information. This was most likely the class educator rather than a subject teacher.
- A current educator of child described above; in other words they have taught the child for a minimum of at least 3 months to allow time to become familiar if not previously known to each other.

### 3.4 Sampling method

Both purposive and static sampling methods were appropriate to the study and were used.

Purposive sampling is where a particular case consists of the most typical characteristics of the population and the outcome is rich detail about a specific context or subgroup (de Vos, Strydom, Fouche, & Delport, 2005; Polkinghorne, 2005). This study aimed to describe the typical experience of inclusion to school following a TBI and selection criteria were chosen accordingly.

Static sampling is used in that the number of participants was decided on beforehand. However, should participants have lacked the depth of information required to be considered rich sources, the researcher would have had to select another case. In this study, the participants provided a wealth of appropriate data and two cases were used. Each case had 3 informants (child, parent, educator), therefore 6 participants took part in the study.

Source triangulation was used to deepen the researcher's understanding of the topic under investigation (Polkinghorne, 2005). Source triangulation is commonly used in health and social science research (Liamputtong, 2009). It is based on combining information from multiple sources to strengthen or corroborate the data and evolving themes (Ibid.). It is a valuable strategy in this research as it seeks to expose different perspectives of the same reality (Ibid.), providing a multi-voiced and believable answer to the research question. In qualitative research, the "issue is not how much data was collected or from how many sources, but rather whether they are sufficiently rich to bring refinement and clarity to understanding an experience" (Polkinghorne, 2005).

### 3.5 Recruitment strategy

- The researcher obtained permission from the Faculty of Health Sciences Human Research Ethics Committee at the University of Cape Town to conduct the study (see Appendix 1).
- The researcher then obtained permission from the Groote Schuur Hospital Ethics Board to access the medical records of children discharged from the rehabilitation ward from January 2010 to March 2012 (see Appendix 2).
- She created a list of 13 children who fitted the age and time of discharge criteria and pulled their folders to match them to the remaining inclusion criteria. This resulted in a list of 7 names.
- From her experience working with these children and their caregivers, and in consultation with a colleague on the ward who had also treated them, she selected 4 who were likely to be information rich and able to participate in the interview process.
- She contacted parents first by telephone to establish whether they would be interested in taking part in the study or not and whether they would permit their child to participate or not. Following an indication of initial interest, she sent them an information and consent letter by post with an offer to meet and discuss this personally should they wish. She included an information letter for the child as well for the parents to discuss with the child to see whether they would assent to volunteer. One of the parents was isiXhosa speaking. Her English was adequate for everyday conversation. However, the information letter and consent form were translated into isiXhosa and sent with English copies, as the researcher's clinical experience has shown that isiXhosa speakers prefer reading English to isiXhosa, which they find difficult to understand as the isiXhosa translations are often too formal.
- At the same time, the researcher contacted the relevant school by telephone to identify the child's educator and followed this up with an information letter. The information letters and consent forms can be viewed in Appendices 3A-3F.
- All of the participants who were contacted indicated their interest to participate, meaning that the first two cases approached could be used for data gathering.
- Biographical and demographic information about each participant is given in Chapter 4 as an introduction to their stories.

### 3.6 Data collection

#### 3.6.1 Method: Interview

An open ended interview was the primary research instrument as this is a narrative study (Connelly & Clandinin, 1990; Hennink, Bailey, & Hutter, 2011; Polkinghorne, 2005). The researcher's interview style was influenced by responsive interviewing, an approach to depth interviewing used by Rubin and Rubin (2005). This approach fits well into the interpretive paradigm as it recognizes that both the interviewer and interviewee are people with personality, feelings, experiences which will affect the interview. The interviewer is not neutral, but develops an interview style that she feels comfortable with and that matches her personality. At the same time however, she needs to be aware of her own biases and expectations and how these might impact on the interviewee. This reflexivity is essential in supporting the credibility of qualitative research (Liamputtong, 2009) and is discussed further later. Questions during the interview were guided by what the participants said.

Data about experience depend on participants' ability to reflect on and identify aspects of their experience and effectively communicate these through language (Polkinghorne, 2005). Certain adaptations to the open ended interview were required for use with the children in this study in order to facilitate the collection of data that is rich and detailed. As recommended by Lewis (2002), the interview data was supplemented with observational data in the form of field notes. Important information was captured this way in both cases which helped with the interpretation of the linguistic data, for example physical signs of fatigue or enthusiasm (see Appendix 4).

Children with TBI typically present with cognitive-communicative disorders and may thus have difficulties (e.g. topic maintenance, narrative structure and recall of events, interpretation of more abstract language) which hamper their ability to tell their story in sufficient depth (Hartley, 1995; Paterson & Scott-Findlay, 2002; Savage et al., 2005). Bearing this in mind, the following accommodations were used in order to access the children's best story:

- A topic guide (Paterson & Scott-Findlay, 2002; Singh & Keenan, 2010)
- Open ended questions as prompts (Kortessluoma et al., 2003; Lewis, 2002; Paterson & Scott-Findlay, 2002). Specifically, interview questions which tapped into scripts (e.g. What would you tell someone else who had a TBI about...?) in order to facilitate the recall of events and which prompted autobiographical storytelling (e.g. Tell me a story about a time when you...?). The researcher

made note of important words or themes during storytelling to focus direct questioning.

- A variety of visual methods were used to access data in each of their interviews (Bell, 2010). These were tailored for each participant. Firstly, picture cues were used. These have been shown to assist children with learning disability to access and sequence narratives and increase the structure of responses (Lewis, 2002; Rabiee et al., 2005). The pictures that the researcher used were similar to those of Lewis (2002). They were simple representations of the narrative features of person, setting, time and feelings which surround the event the child was trying to tell about (see Appendix 5). The pictures served as a cue to help the child provide more detail about an event or to prompt ideas. Before the interview, the children were familiarised with the pictures and their intended meaning, e.g. person – does this remind you about any people who were with you then? Their use therefore also limited interruptions with questions as the researcher simply showed them the picture and they could continue their story with added detail. Secondly, to assist with story sequencing, a timeline was used along which important points could be plotted e.g. birth, starting school, accident, leaving hospital, first day back. It served as a reference point for what the children told. It was useful for clarification so that the researcher knew where information belonged. It helped contain their thoughts and allowed them to provide more detail about more events. Thirdly, children were encouraged to draw a picture of their first day back at school. This drawing was then used as a trigger for conversation. Using drawings to access information that children might otherwise not be able to express has been used successfully by researchers in childhood speech development (McLeod, McCormack, McAllister, Harrison, & Holliday, 2011).
- Reduced interview length, implemented by alternating talk with activity to keep attention and interest in the interview process, which resulted in multiple, shorter interviews in one sitting (Kortessluoma et al., 2003; Singh & Keenan, 2010). The children's ability to concentrate varied. Short breaks (such as snack breaks) were also used to split the interview into smaller time intervals. External distractions were eliminated as far as possible.
- Singh and Keenan (2010) note that it is important to consider the effects of medication use and times taken. Neither of the children were on any medication.

### 3.6.2 Data collection tools

Topic guides (see Appendices 6A-6C) for child, parent and educator were used during the interview to ensure the aim of the study was covered, but the participant's storytelling was not limited to what the researcher assumed was relevant. A separate form was used to capture specific biographic and demographic detail for each participant (see Appendix 7). This was necessary for purposes of context description and creation of the participant characters so as to increase transferability of the findings.

### 3.6.3 Equipment

An Olympus digital voice recorder – DS-2200 and DS-2100 was used to audio record the interviews. This provided a clear recording of the interview. It freed the researcher to engage fully in the interview. She was able to observe non-verbal cues and make brief notes on points to return to later in the interview. A personal computer was used to store transcriptions and capture the data. Windows Microsoft Office Word 2013 has been used.

### 3.7 Research assistants

The researcher was fluent in English and Afrikaans only. However, in her clinical experience in the hospital, many of the children were isiXhosa first language speakers. One of the cases consisted of isiXhosa first language participants, with varying levels of proficiency in English. With an awareness of the challenges of interpretation and translation in qualitative research, as discussed by Polkinghorne (2005), it was recognized that they would be able to provide their best story in their first language. The parent and child in the case indicated that it would be helpful to have an isiXhosa interpreter present during the interviews. The educator did not feel that it was necessary and chose to speak English. The volunteer service of a 3<sup>rd</sup> year Speech-Language Therapy student was obtained through the university. Though she had no formal training as an interpreter, she had experience in the medical and educational fields due to clinical practicums and was fluent in both isiXhosa and English. Interpreter information and consent letter is found in Appendix 8. Detail of the preparation and interview procedures that were followed to ensure that good quality data was obtained are given later under Section 3.8.3 In addition to the interpreter, a professional isiXhosa/English translator and transcriber was used for the isiXhosa interviews. A

professional English/Afrikaans transcriber was used for the remaining English and Afrikaans interviews.

### 3.8 Data gathering procedures

Informed assent was obtained from the children and informed consent from the adults. Assent and consent forms are shown in Appendices 3A-3F.

#### 3.8.1 Preparation

Prior to conducting first interviews, the researcher practised open-ended narrative interviewing on a child with learning difficulties and a mother known to her in a personal capacity. This helped her prepare for the actual interviews in a number of ways, such as practical use and placement of recorder in the interview setting, practising silence and open ended questions, managing interruptions. In addition, she used clinical opportunities with patients at the hospital and their parents to develop listening and probing skills as an interviewer. The first case was to be treated as a pilot study but the data was rich enough and the topic guide and interview method did not require significant change. Second and third interview opportunities allowed for the researcher to become familiar with the interview technique and rich, in-depth data was captured. For this reason the participants from the pilot study formed part of the main study.

Participants were contacted to arrange for the first interview. These were held in a place and at a time most convenient to them. They were advised to select a quiet and private area to ensure confidentiality, a clear recording and limited distractions. Except for the educators who were interviewed after school hours in their classrooms, all the participants elected to be interviewed at the hospital, rather than at their homes or a public space, such as a community library. This occurred either in the ward therapy room or in the researcher's consulting office. The researcher attempted to eliminate the restriction this physical space might have had on participants' story telling by arranging the furniture away from the therapy space and in a comfortable, sitting-room style. She also provided refreshments to promote the relaxed, visiting atmosphere. One of the parents could not come to the hospital for her second interview. This was then conducted in her home. No time limits were set as interviews were to progress at the participant's own pace. Interview lengths therefore varied with parent interviews tending to be longest. The parents and children were known to the researcher from when they were in hospital. A level of rapport thus already existed between them.

### 3.8.2 Data collection

The following steps were followed during the data collection procedure:

- Biographical and demographic information were captured on a form prior to the interview to provide relevant contextual detail about participants (see Appendix 7). Relevant medical details about the child were obtained from the hospital medical records and also captured on this form.
- One case (child, parent and educator) was interviewed in its entirety before starting interviews for the second case. The interviews were audio recorded.
- In each case, interviews with parents were completed first. This was initially in order to create the opportunity for informal interactions with the child if the parent chose to have the interview in her home, thus allowing the child to become familiar with the researcher again and vice versa (Kortessluoma et al., 2003; Stevens et al., 2010). This purpose was not achieved as interviews were conducted at the hospital; however, the researcher still interviewed the parents first as she recognised them as the cornerstones of the story, the ones who would be able to provide a context or framework for the case from which to listen to the other participant stories.
- Sufficient time was allowed between interviews during the data gathering period to allow the researcher opportunity to review the data and have it transcribed. This was important as a start to initial analysis which then also facilitated the next case interview process. The initial review consisted of repeated listening to and reading of the audio and transcribed interviews. During rereading and re-listening the researcher noted key words and phrases of impact or particular relevance, identified areas of relevance that had been missed and others that required follow-up questioning in the second interviews.
- Prior to interviewing, participants were reassured that there were no right or wrong answers and that their stories were confidential (Kortessluoma et al., 2003). In order to address the expected power imbalance, they were reminded of the researcher's new role as investigator in this situation, that she was not the therapist. She viewed them as the expert on the topic and had come to learn from them. These sentiments were revisited at second and third interviews as well. Their demeanour and posture became increasingly relaxed and they expressed themselves with greater freedom, i.e. spoke longer, provided more detail, initiated topics and directed conversation more, over time. Furthermore, the content of their interviews did not focus on rehabilitative

needs, suggesting they saw the researcher as an interested listener and not as a therapist.

- Interviews were conducted in private by the researcher (Lewis, 2002). An interpreter was present during some.
- All participants were interviewed three times, except Educator B who was unable to continue in the study; he was interviewed twice. This was especially important in light of the researcher's inexperience as a narrative interviewer. Polkinghorne (2005) cautions that narrative interviews need to be more than a once-off occurrence in order to obtain the needed in-depth information. Second and third interviews were conducted as soon as possible after the initial interview.
- In addition to second and third interviews, which were invaluable in helping participants distil their experiences and knowledge, the researcher used a variety of interviewing strategies to gather rich, in-depth stories. These included: reminding participants that they are experts on the topic and that there are no right or wrong answers; initial conversation to become familiar with each other again; allowing participants time to speak; active listening shown in nonverbal communication; limiting interruptions by the researcher; rephrasing and clarifying; prompting; use of silence; minimal note taking; open ended questions; identification of key words or events to return to and focus on (e.g. tell me more about what you thought when..., How did it feel when...?); and showing appreciation and thanks for their time. The children were expected to have difficulty concentrating and completing their stories in a single sitting. Adaptations that were used have been described above.
- During the interview, key words or phrases and issues to follow up on were noted. Detailed field notes were made after the interview documenting the researcher's impressions about the interview. (Polkinghorne, 2005; Stevens et al., 2010).
- Verbatim transcriptions of the interview recordings were made in standard English orthography. A naturalistic approach to transcription was used which captured hesitations, pauses and cultural uses of language due to the importance of individuality and language use in narrative interviewing (Kelly, 2010).

### 3.8.3 Specific data collection strategies for interviews conducted in isiXhosa

The data collection procedures detailed above were used during isiXhosa interviews as well. Both the benefits of affording participants the opportunity to tell their stories in their first language as well as the challenges this posed to rigour of data, particularly as the researcher and interpreter were inexperienced, were recognised. The following additions and adaptations were therefore implemented in order to ensure that quality stories were elicited, with adjustments made when indicated during the process.

- The interpreter was sent the topic guide and questions based on the topic guide ahead of time so that she could prepare for the isiXhosa interview. The researcher and interpreter met before the interview to discuss the case, the topic guide, room set up and interview process. This was to ensure that the sense and purpose of open-ended questions and the aims of the research were understood.
- The interpreter and researcher discussed interpreting options with the participants before the interview. The parent was interviewed first and it was agreed initially to interpret “chunks” of interview, thus allowing her to speak freely without constant interruptions to their flow of thought. At times, she expressed herself in English too. However, she said she was reassured having an interpreter present so that she could explain herself clearly. The value of empowering otherwise marginalised participants by providing means to access their stories in their first language is highlighted. Her understanding of English was good and she was able to correct the interpreter on some occasions when the interpretation deviated from her intended meaning. It was rationalised that the interview detail would be captured on audio recording for later transcription and translation.
- The interpreter and researcher spent time after the interview discussing their impressions about the participants, the content and interviewing method that had been used and changes to make going forward. For example, the interpreter used third person voice in the first interview. The researcher found this difficult to relate to and noticed that the interpreter tended to give her own version of what the participant meant, rather than limiting herself to their words. The interpreter found it difficult in terms of changing language structure “on-line”. It was therefore agreed that she use first person voice instead. These discussions were recorded.
- The interviews conducted with an interpreter were transcribed verbatim in their entirety by a professional isiXhosa/English transcriber. The isiXhosa sections

were then further translated into English by a professional translator, who was also the transcriber, i.e. familiar with the audio content. This word-for-word translation was compared to the interview transcript of the interpreter's English translations during the interview providing a type of data triangulation (see Appendix 9 for an example of the difference in content and therefore benefit of this method).

- This data triangulation (spoken interview with interpreter, translation and then word-for-word transcription) was an effective means of ensuring that the participant's intended meaning and emphasis was understood. The transcriber/translator provided useful feedback on interpreting techniques that were applied in future interviews. For example, she noted that interpreting after every 2-3 sentences was a better technique. It lessened the memory load on the interpreter and would allow the researcher to ask appropriate follow-up questions at the time as the participant's emphasis and meaning would not be lost in the "gist" of paragraph interpretation. Having word-for-word translated transcriptions helped to prepare for the second and third interviews as topics that were not given due consideration in the first interview could be identified and returned to.
- In general, the challenge of an inexperienced researcher and interpreter were managed by: sending the interpreter the topic guide and questions based on the topic guide ahead of time so that she could prepare; meeting before the interview to discuss the case; together reflecting on the interview directly after; the use of a separate professional translator (who also worked as an interpreter) who could provide word-for-word translation and also comment on the interpreting style; second and third interviews to correct and clarify content where necessary.

### 3.9 Data analysis

The narrative data generated from the participant interviews was rich and complex. An iterative, dynamic and multilevel approach to analysis was followed in order to extract the meanings of what was told and to interpret them as deeply as possible. Analyses of interview data for each participant within a case is presented in Table 1. A detailed description follows:

Table 1: Levels of data analysis

	<b>Description of analysis</b>
<b>Level 1</b>	Iterative narrative analysis of interview data resulting in individual research stories/reconstructed narratives for each participant
<b>Level 2</b>	Thematic analysis of research stories resulting in categories and themes per participant type (children, parents, educators)
<b>Level 3</b>	Integrated analysis resulting in multi-perspective voice (final theme)

The first level of analysis was a narrative analysis of individual interview data, also referred to as the process of retelling or restorying (Clandinin & Connelly, 2000; Ollerenshaw & Creswell, 2002). The written transcript of the narrative was read repeatedly in order to develop a sense of what the individual was telling regarding their experience of the child's being back at school following a TBI. The recorded interview was listened to simultaneously. During this repeated engagement with the data, the researcher noted her "gut feel" as to what was important to the participant's story. She crossed out irrelevant sections. She identified narratives/events that they told spontaneously and those that were prompted by the researcher and accorded weight where relevant. She noted the use of emotive language or emotional tone as this links to what is significant for the participant (Kelly, 2010). Pauses or silence and avoidance were highlighted and their meanings considered (Lewis, 2011). She highlighted sections that spoke to barriers, supports and change over time. Using the research question as a guide she crafted each participant's story. The analyses are represented in the form of stories written by the researcher. They are found in Chapter 4.

It was challenging to decide how to represent each participant's voice, whether in first or third person. There are strengths and limitations to both (Kathard, 2009). A particular challenge was the risk of muting the "analytic voice of the researcher" (Ibid., p.31) for fear of "putting words" in the participants' mouths, a challenge that was overcome in repeated consultation with supervisors, reading of relevant literature, engagement with the process of analysis and growth over time. A decision was made to use first-person voice in representing the story to ensure authenticity of the data (Kelly, 2010). A large proportion of the participants' actual sentences were used in the stories. At the same time, certain creative writing techniques, such as repetition, rhetorical questions, using exclamation and italics or using the present tense were used to make the stories

interesting and readable (Kathard, 2009). See Appendix 10 for examples. Another challenge in the restorying was situating the participants' personal narratives within a particular social context, where this may not have been obvious in their telling. However, it is a necessary part of interpretive story writing (Ibid.) as experiences are informed by personal and social factors and the latter need to be evident if the story is to be coherent and transferrable. A simple description of each participant's biographical and demographic information is given at the start of each story in Chapter 4 to situate them in a particular context.

It cannot be overstated that the stories are the researcher's interpretation and understanding of the participants' complex realities and that other interpretations may be equally valuable (Kathard, 2009; Samuel, 2009). This point is critical to understanding and correctly using narrative research. However, to ensure credibility of the researcher's interpretation, the reconstructed narratives underwent member checking. This provided a safeguard against her fear of misrepresentation. Participants were sent copies of the story with a letter of explanation as to the purpose of member checking and what the expectations of them were in this regard (see Appendix 11 for an example). Where possible, a member checking meeting was arranged so that feedback could be given by the participants and the story revised if they found any discrepancies. (Ollerenshaw & Creswell, 2002). Where this was not possible, the researcher was in telephonic contact with participants. The children were both happy with the content of their stories, as was one of the parents, and no revisions were needed. The other parent had minor changes in emphasis that she requested: She wanted more weight given to her experience of indecision when told her child should progress to Grade 5 and to the effect that the bullying and teasing of her child had on her. One of the educators could not complete the study; an objective peer with experience in qualitative research reviewed the interview transcripts and story as an alternate form of member checking. She stated that the story captured the educator's meaning well.

As mentioned, the analysis process was dynamic and iterative. Due to a growing awareness of the complexity of individual experience and the factors that influence it, another phase of restorying was used to refine the research stories/reconstructed narratives. The framework of the ICF-CY (WHO, 2007) was adapted for a detailed categorical analysis per case. It was done by repeated reading of the reconstructed narratives with the research question in mind, identifying relevant elements from each and then sorting these into Personal/Home, Social/School and Systemic/Community categories per case, while at the same time separating those findings into perceived

barriers or facilitators. This iterative process therefore fed back into the research stories and enabled the researcher to better portray the social context by distilling what the critical incidents and factors in each story were, i.e. the research stories were given greater depth and complexity as a result. The iterative nature of the analysis process also prevented a deconstruction of the stories into isolated components which would rob them of their unique power as unified wholes.

The second level of analysis was a thematic analysis based on the stories. This sought commonalities and discrepancies across the participant types, e.g. between children, which were categorised. The resultant categories are presented in Chapter 4. These categories were pondered in the light of each story and the research question. Gradually themes emerged across Child, Parent and Educator participants and combined to answer the research question for each participant type. The themes are presented and discussed in Chapter 5.

At the third level of analysis, an across case analysis had originally been proposed. As the stories were found to be convergent, rather than divergent, this was decided against. Instead, an integrated analysis was done. The voices of the parents, children and educators that spoke from the finished thematic analysis at level 2 were combined to provide a multi-voice perspective on experiences of being back at school after TBI. This resultant theme is also presented and discussed in Chapter 5.

### 3.10 Rigour and trustworthiness

The researcher made use of various strategies at different stages of the research process to enhance the rigour and trustworthiness. Key aspects are discussed under the following headings:

#### 3.10.1 Credibility/authenticity

Credibility was achieved throughout the study by means related to the researcher, the participants and the data.

In terms of the researcher, reflexivity supports the credibility of research findings as the influence of the researcher is recognized and his/her personal biases are made explicit (Liamputtong, 2009). Rubin & Rubin (2005) advocate that interviewers need to be sensitive to their own biases and learn to compensate for these slants. The researcher engaged in reflexive journaling during the study process. She identified biases as a white, English, Christian, educated female and how these potentially influenced the interview setting and her interpretation of the data. These reflections are available on request.

## PEER DEBRIEFING

During a peer debriefing meeting in the data collection stage the researcher exclaimed that “I’m not getting what I want!” This brought to light that she was angling for certain answers to fit with a preconceived result. It made her aware that she was at risk of misconstruing data and of leading interviews rather than staying true and open to what the participants were saying.

Due to her inexperience as a narrative researcher, certain measures were put in place to counter the effect this might have on authenticity of the data and its interpretation. She practiced her interviewing skills by interviewing children and parents before engaging in the actual data collection. Up to 3 interviews were conducted with each participant, so that there was sufficient opportunity for follow-up. She met with her supervisors during the study process who served as sounding boards and advisers. Peer debriefing with an objective colleague experienced in qualitative research was done particularly after first interviews to help her identify insights and problems.

With regard to the participants, credibility was achieved by purposive selection of information-rich participants who were interviewed in a place of their choice, where they were comfortable. Participants were given both time and space in which to tell their stories, allowing for an in-depth exploration of the topic (Connelly & Clandinin, 1990; Stevens et al., 2010). They were reminded before each interview that they were the experts in the field. The intention was to correct a likely power imbalance and instil in them a sense of the value of their contribution. Biographic and demographic information about participants was captured. There was opportunity for repeated interviews, for a type of prolonged engagement, which would further strengthen the participant-researcher relationship and the credibility of the interview data. As the ability to reflect and communicate effectively is critical in narrative research, the specific interview accommodations for children with TBI that are detailed above added to the rigour of the study.

Verbal data were supplemented with field notes that were both observational and reflective after the interview (see Appendix 4). Brief notes were made during the interview. Verbatim transcription of the interviews limited meaning loss. In addition, a naturalistic transcription approach was used, in which pauses and hesitations were recorded, which also contain meaning (Lewis, 2011). The credibility of the isiXhosa interview data was strengthened by having an interpreter present as well as an objective professional translator/transcriber involved. Further consideration for those interviews were described in Section 3.8.3. The researcher engaged repeatedly with these texts and later the reconstructed story to ensure she understood the meaning of what was told by each participant.

Each reconstructed participant story underwent member checking. It is described as one of the most important techniques for establishing credibility (Liamputtong, 2009).

Another critical means of strengthening credibility of qualitative data is triangulation (Ibid.). Source triangulation refers to the involvement of multiple participants or the use of multiple quotations from the data to illustrate themes, both of which occurred.

### 3.10.2 Transferability/applicability

As this study is about personal experience, transferability is not an expected outcome. The research design emphasises and values the complexity of subjective experience and the impact of multiple contextual layers. However, as detailed descriptions of participants and settings are given, the reader will be able to decide whether the findings are transferable to his/her context.

### 3.10.3 Dependability

An audit trail ensures dependability of the study, as decisions made and methods used to reach the findings and conclusions are clearly documented and traceable. This is given throughout the chapter. As an independent transcriber was used, the researcher checked transcriptions for accuracy against the audio-recorded interviews and made corrections where necessary. Other than a few small portions or words marked as “unclear” the transcripts were accurate. She kept records of each stage of the study for verification if needed. These include meeting notes, emails, audio-recordings and transcriptions which are to be destroyed on completion of the study, and analyses done on paper. Aware of her inexperience in qualitative methodology, the researcher ensured that she regularly confirmed with her supervisors the process being followed

and conclusions being drawn. She questioned all aspects of the process and sought answers from her supervisors and relevant literature.

#### 3.10.4 Confirmability

Narrative research by its nature is subjective and open to interpretation. The powerful data and analyses show the complexity and richness of the human story and that multiple meanings can be obtained. This is both the great strength of this type of research and one of its great dangers. The personal role of the researcher in interpreting the data has been stated from the outset. For this reason, a number of recognized measures were put in place throughout the research process to guard against her own biases. These included meetings with objective peer reviewers during data collection and meetings with her supervisors throughout the stages of data analysis.

She also engaged in reflexive journaling during the research process. This enabled her to become more aware of the assumptions, experiences, perspectives and personal judgements she brought to the process. This awareness in turn minimised contamination of the data. She also read studies by other qualitative researchers who made their experiences of reflexivity explicit and so learnt from them (Duncan, 2009; Kathard, 2003). The audit trail, data and analyses substantiate her results, but this in no way excludes someone else from finding something different in the data.

#### 3.11 Ethical considerations

The researcher obtained ethical clearance from the Human Research Ethics Committee (HREC) of the University of Cape Town (see Appendix 1). Based on ethical principles set out in the Declaration of Helsinki (2013):

##### 3.11.1 Respect for persons/ autonomy

Informed written consent was obtained from adult participants prior to interviewing. Participants were all literate. Where necessary, the documents were translated into the participant's first language (i.e. IsiXhosa), with an English version included, as participants indicated that they preferred to read in English. Informed verbal assent was obtained from child participants in addition to proxy consent from their caregiver. Participants were given the opportunity to ask questions or raise concerns about the

study; however, none did. Verbal consent was re-obtained at each contact with the participant. The researcher was aware that her previous role as therapist might unduly influence participants to consent to the study. It was made clear that participants would in no way be disadvantaged should they decline. They would be allowed to leave the study at any time, without providing a reason. All participants, bar one educator who no longer worked at the school, completed the study. The educator in question had participated in two interviews by that stage which were sufficient in terms of richness. Confidentiality was maintained as data was de-identified, i.e. place names were changed and pseudonyms given to participants. Only the researcher and those involved in the study had access to the transcripts. Recordings will be erased upon completion of the study. The study involved a vulnerable population. As it was recognized that participants had given of themselves to the study, reciprocity was achieved by the researcher assisting them by making onward referrals if asked to (Liamputtong, 2009). New hospital appointments were made on behalf of one of the children as they were lost to follow-up and both parents were advised of a caregiver support group that had started at one of the hospitals. In future, she will also report the findings back to them.

### 3.11.2 Beneficence

Participants did not immediately benefit from this study. However, some found it helpful and cathartic to share their stories. Being part of a study in which they were the experts may have given them a sense of control and ownership. They may have found new meanings to their experiences. Recounting traumatic and difficult experiences was expected to affect participants emotionally. The researcher was ready to refer them for professional intervention if necessary, but this was not needed.

### 3.11.3 Justice

No language group was excluded during participant recruitment. Provision was made so that participants could communicate in their preferred language. Participants were expected to be from poor, disadvantaged communities. There was a risk that they would agree to participate in the hopes of receiving some form of compensation. The consent letter and conversation at the first interview made it clear that compensation would only involve transport money, if indicated, and refreshments during the interview.

#### 3.11.4 Reporting

The researcher aims to have the research published in a recognised journal. She also aims to present the findings at conferences, e.g. South African Speech-Language and Hearing Association (SASLHA). She will provide participants with feedback on the findings of the study. They have already received copies of their reconstructed narratives.

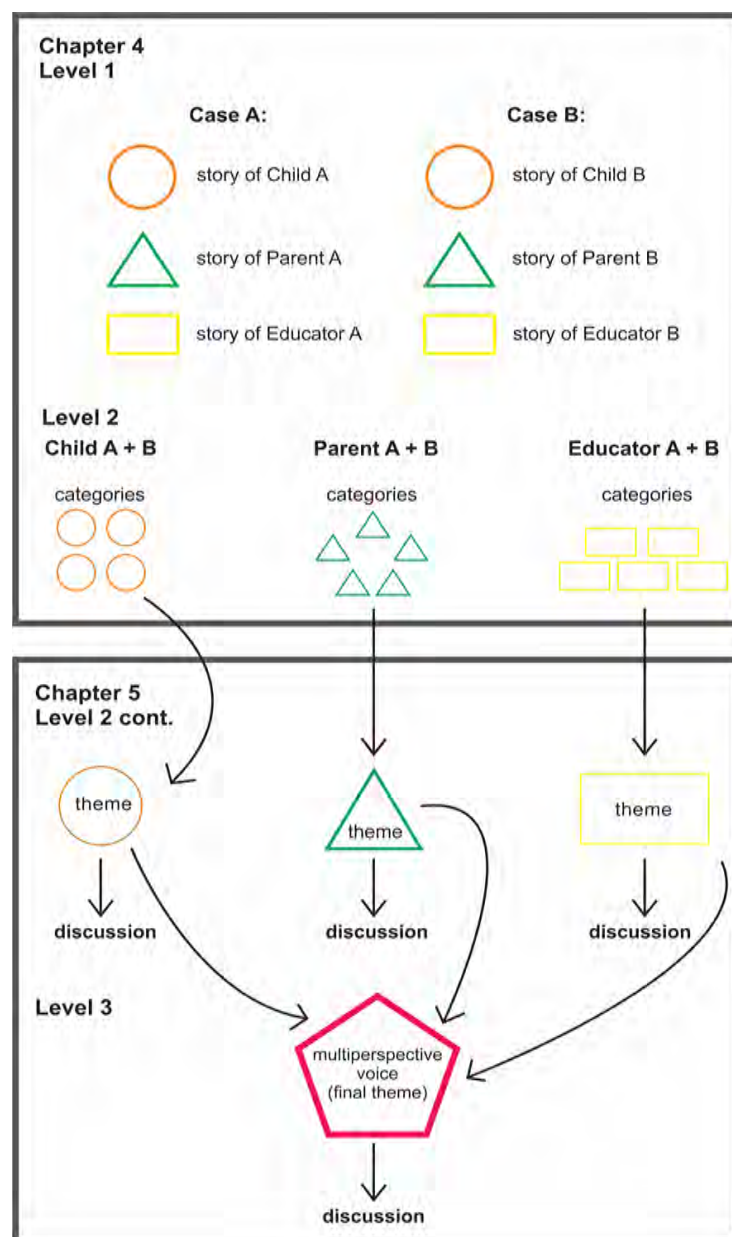
#### 3.12. Conclusion

This chapter presented the study aim and narrative case study design within a qualitative interpretive framework. It introduced the study participants and detailed how the results that will be presented in Chapter 4 were obtained. Strategies used to enhance rigour and trustworthiness were discussed and due consideration given to the conduct of ethical research. The study findings follow in the next chapter and will be discussed in Chapter 5.

## CHAPTER 4

### RESULTS

The qualitative analysis process was iterative, multi-layered and complex. In order to facilitate reading of the results and discussion a “representational map” for Chapters 4 and 5 is given in Figure 2. In this chapter results from the first (i.e. the 6 individual research stories, are presented by case) and second levels (i.e. the emergent categories per participant type) of analysis are presented. The themes per participant type resulting from the second level analyses and the final multivoice theme resulting from the third level analyses will be presented and discussed in Chapter 5.



*Figure 2: Structuring of results and discussion*

## 4.1 Level 1 – Participant stories

The individual research stories from the 6 participants are presented. Firstly the child, parent and educator from Case A and then the child, parent and educator from Case B. These stories were reconstructed from the interview data. They are prefaced with a summary of relevant biographical and demographic detail, a mini biography.

### 4.1.1 Case A

#### 4.1.1.1 Child A

##### Biography

*Mohamed Ibrahiem<sup>4</sup> is a 12 year old Coloured<sup>5</sup> boy, born in 2001. He is in an English Grade 6 class at Rustdene Primary, a co-educational school in Hanover Park, an area in the Cape Flats region of the Cape Metropole. He enjoys playing soccer and computer games. He lives with his mother, 10 year old sister, 8 year old brother and other family members in his maternal grandmother's house a 5 minute walk away from the school.*

*In early December 2011, towards the end of his Grade 4 year at school, he and some friends were playing on the back of a bakkie<sup>6</sup> when it pulled away. He fell off and sustained a severe TBI. He was admitted to the Children's Hospital in Cape Town. CT brain scan showed small left temporal and left cerebellar peduncle contusions, which did not require neurosurgical intervention, and normal midline. A diagnosis of diffuse axonal injury was made. Intracranial pressure (ICP) and Licox (oxygen) monitors were placed surgically. He was ventilated in ICU at the Children's Hospital for 12 days, following failed extubation. Once medically stable he was transferred to the paediatric ward at another hospital in Cape Town for continued inpatient rehabilitation, which included Speech Therapy, Occupational Therapy and Physiotherapy. He was discharged home from there towards the end of January 2012.*

*This is Mohamed's story of his experience of returning to his school after his head injury.*

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<sup>4</sup> Person and place names in all 6 research stories have been changed to protect participant confidentiality

<sup>5</sup> Person of mixed race

<sup>6</sup> A South African term for small truck

## **SCHOOL ISN'T SO NICE ANYMORE. BUT I'M ALIVE.**

### THE ACCIDENT AND HOSPITAL

The accident was in December, in 2011. It was still school time. Nearly the end. I was in Grade 4. I fell off the back of the *bakkie*. My head got hurt. But it's great cos I'm alive.



Picture 1: Mohamed's drawing of himself on the first day back at school, in front of a wall, with a red smile, bright red hair [hair is black] and small red heart. "Just for living," he says.

I was in the hospital over Christmas. For the whole holiday. That made me sad. But Father Christmas came. And then they sang Merry Christmas. They stood at my bed and in the passage. And they gave me presents. To all the kids who were there in the hospital. I was happy. And then they gave us luxuries also, chips, sweets, lollypops. And I got a puzzle.

My brother and sister visited in the hospital. They said, "You must get strong." That was nice. People in the hospital helped me to get better so I can talk. Then after the hospital, I got discharged and I could go home. I just had to go for check-ups still. I play games sometimes at therapy.

I was happy to go home. I looked forward to going to the beach. And to get Kentucky. And Nandos. And Steers (fast foods). I got to go without my brother and sister cos my mom said I missed out when I was in the hospital. My grandpa took us to Strand beach and we swam.

### SCHOOL

Then I got to go back to school in 2012. I was happy and excited to go back to school. I

was going into a new grade. I didn't have to stay in Grade 4. I went into Grade 5. That made me happy.

My first day back at school my friends were happy to see me. They all carried on so. They hopped around, carried on so, looking excited. I was in Mrs Abrahams' class. She's a nice teacher. Some of the kids also wanted to be in her class. She gave us Maths and Maths was fun for us. Then we changed classes. We had to go to other teachers for other subjects. Then it was break and we played outside. We played soccer. I enjoyed playing soccer. I wore my Reeboks to school on my first day back. I didn't have the school shoes yet. I can't wear the Reeboks now anymore unless you write a letter. In the beginning I stayed at school til 10 o'clock, then til 12 o'clock and then 1 o'clock, til after second break. And then the whole day. My friends let me feel happy.

I had good friends from Grade 1 to Grade 4, before the accident. They made school nice for me. Friends make school nice. I only liked 2 subjects though back then. English and Geography. In Geography it's just maps of places and in English you do verbs, adjectives, nouns, pronouns.

The kids who were in my class in Grade 4 stayed in my class. They're still my friends cos we play soccer together and we're in the same class. My friends are Dante, Eloreeze, Jody, Tyrone, Karl. We work together and play games in class when there's no work. Like Dominoes and cards. I like it when we work in groups. Cos you work together. Our teacher puts us in groups and then we do our work. We work on one page together and we talk about it. That was nice and it helped me. We started writing with pens in Grade 5. In the middle of the year.

I like it when we have sports at school. We had a soccer tournament one time. We played soccer and were in a tournament and we won. We played against the Grade 4s. We were in Grade 5. I didn't play this time. I watched how my team played. I stood and watched. It was nice to be there!

School was very difficult in Grade 5. It wasn't so nice as Grade 4. The work is more difficult since the accident. That's what. Before the accident, school was nicer. It is difficult since the accident. Sometimes I finish my work, sometimes I don't. I was happy to go back to school, but it was a bit difficult, the work. It was too much work. Especially the Maths, the sums in the book, were too difficult. I don't enjoy English anymore. It's boring. Homework is *sleg* [bad]. I don't like it. And then there were kids who called me names. They teased me. They let me feel sad, the ones that called me names. They made me sad. They called me "*Dentjies*" because of the dent on the front of my head. I

did nothing and just walked away. But sometimes, I got angry and told my teacher, Mrs Abrahams. She shouted at them. She is a nice teacher cos she is helpful. If the work is difficult then I asked her and then she helped me. I was glad I could ask her for help. The kids teased me in class and on the playground. And then there was the one boy who bullied me. He was eating in the class and I told Mrs Abrahams cos we mustn't eat in the class. Then he said he's gonna get me after school. And then my aunty who lives across the road from school, she told the principal and then they sorted it out at school.

A bad thing happened once. Some of the younger kids and our class were fighting and then they stabbed a *jongetjie* [one of the boys] in his shoulder there in our class. I saw it. He was one of my friends. He's okay now. They took him to his parents. I walked with him. We cried.

Now in Grade 6, I don't need to ask my teacher for help anymore. Also I used to have to sit right in front of the class, near the teacher, after the accident. Now I can sit where I want. My mom helps me a lot with my homework. She helps me with English and Afrikaans and Maths. I like EMS (Economic Management Sciences), Afrikaans, Technology and Natural Sciences. But I don't look forward to high school. I think it's going to be difficult. The work will be a lot.

When I'm big one day I want to be a doctor like at the Children's Hospital. Or a dentist. Or a lawyer, to help people. Like the lawyers we went to see for my accident. They help you after an accident.

I want to tell other children who have accidents that when they go back to school they must look after themselves that nothing happens to them on the road, or playground or at home. Anything can happen to them.

#### 4.1.1.2 Parent A

##### Biography

*Mrs Fatima Ibrahiem is a 39 year old Coloured Moslem single mother of 3, 2 boys aged 12 years and 8 years, and one girl, aged 10 years. She divorced 7 years ago, in 2006. Her ex-husband has a history of substance abuse and lives with his current girlfriend. He does not provide them with financial support, but sees his children some weekends. Mrs Ibrahiem has a good relationship with her in-laws and 16 year old step-daughter. She lives in her mother's house in a cul de sac in Hanover Park, an area in the Cape Flats region of the Cape Metropole. There are 10 family members sharing the 2-bedroom space, including her step-father, and her brother's family. They have a small*

*kitchen and living area and indoor bathroom. Mrs Ibrahiem works as one of the fudge makers at a sweets factory in Muizenberg; the company supply large retailers. She was a supervisor there for a period of time. She makes the 1h30 commute to work 5 days a week by bus. She suffers from high blood pressure and has been trying to lose weight. She attends regular appointments at the hospital for herself and is awaiting an operation for a hernia. Like most people on the Cape Flats, she can speak both English and Afrikaans. She completed Grade 9 at school.*

*Her eldest son, Mohamed, sustained a severe traumatic brain injury following a fall off the back of a bakkie in early December 2011 at the end of his Grade 4 year. He was admitted to the Children's Hospital in Cape Town. CT brain scan showed small left temporal and left cerebellar peduncle contusions and normal midline. A diagnosis of diffuse axonal injury was made. ICP and Licox monitors were placed surgically. He was ventilated in ICU at the Children's Hospital for 12 days, following failed extubation. Once medically stable he was transferred to the paediatric ward at another hospital for continued inpatient rehabilitation, which included Speech Therapy, Occupational Therapy and Physiotherapy. He was discharged home from there towards the end of January 2012.*

*This is the story of Mrs Ibrahiem's experience of Mohamed's return to school following his head injury.*

## **STORY OF CHANGED LIFE**

### **THE ACCIDENT**

I wish I'd known Mohamed was going to fall and I could've prevented it. But I know *mos* it wasn't in my hands. I still cry. It's long over a year since the accident and I cry all the time. I'm his mother. He's my firstborn. It's almost as if I'm the only one who understands what the child's been through. I wish everyone understood his situation that he's in now and all that. It could've happened to any of us, that fall. It was an accident. I'll never forget the day it happened. It was December 2011, nearly 2 years ago, nearly time for school holidays to start. Mohamed was 10 years old. Grade 4 was just about behind him. We'd been to watch the Christmas lights come on in Cape Town the night before. He fell when that *bakkie* [truck] pulled away, him sitting on the back. I was lying sick in bed with gastro and he'd just come in to say goodbye, he was off to play with his friends. He walked out the gate. Next thing, "Aunty, he's been taken to hospital!" "No. He was just here. My boy was just here. He just walked out the gate." They said he wasn't moving. He was just lying there. He couldn't breathe. They saw

him fall off the back of the *bakkie* and he just lay there. And he didn't move. And they ran to help him and they stopped the first car that came past. He was taken to the Day Hospital first. I got him there. He was unconscious; he couldn't breathe by himself. He needed to be rushed to the Children's Hospital. I still look at every ambulance that passes; I want to thank the man who took my child to the Children's Hospital. He got the pipe down to help him breathe; he spoke so nicely to keep my mind calm. "You mustn't worry. He's in good hands. Where we're going now, they'll look after him."

## THE HOSPITALS

Mohamed's brain was badly hurt. They said it was bruised all over, but especially the left side. He was in the intensive care unit (ICU) nearly 2 weeks. Two weeks! When at last he woke up in that hospital, I said to him "You passed!" He was a good student. He'd want to know that. They moved him to another ward from ICU. I don't know how many times I told them there his cot was too small. His legs stuck out the other side. I was so scared he'd knock his head! I observed so many things that had changed. Now that time, he couldn't speak yet. He couldn't sit alone either, would hold onto the bed rails. He'd look. He'd nod. He'd give that little smile. He'd point. I washed him. I dressed him. I fed him. We were together every day. My mom was looking after the other two, my little girl and boy; they're a year and then 3 years younger than Mohamed. He's *mos* the oldest, my firstborn. Work could wait. My bosses understood. I had to be with Mohamed.

We became close to the other mothers and their kids in the hospitals. They were going through the same sort of thing as us, fearing for your child, being in hospital. They could understand. All in all we were at 3 hospitals. The Day Hospital on the day of the accident and then the Children's Hospital where he was in the ICU and the other ward. And then he was sent over to the big hospital, to the children's ward. He went because he needed to get all the therapies still, for the arms and legs and the talking. We arranged to visit with the one family from the Children's Hospital over Easter. They were from Oudtshoorn; my people are originally from there. Mohamed was friends with her daughter, Anastasia. She had cancer. When we got there Easter weekend we heard the news her girl had passed on on that Tuesday. Mohamed then thought everyone dies... everyone we befriended at the hospitals. Like Markus. Markus was an older boy but he was also in that children's ward. He had cancer on the brain. He passed away while we were at the big hospital together. Before we got to know Markus, Mohamed wouldn't let me out of his sight. Not even to go smoke. "Mommy's"

going to be away too long!” He was still so dependent on me [*nog so aan my*]. Then he made friends with Markus. “Mommy, Mommy can go smoke if you want. I’m going to stay here with Markus.” And Markus was an only child. After we heard of Anastasia also dying, he asked me “Now what about Siya, Mommy? Is he also going to die?”. “No”, I said to him, “Siya is going to be fine. Markus and Anastasia had something else wrong with them, cancer. You and Siya hit your heads.” It was very hard for us, losing them. We got close on the ward, suffering together. I was glad this year when Kristin, the speech therapist at the children’s hospital, tried to organize that support group for us parents. Even though the accident was nearly 2 years ago, it was good for me to sit between those other parents and to talk. We were only about 5 who pitched. We each spoke a bit about what our kids went through, our experience, how we feel and all that. It was good. Kristin couldn’t keep it up alone though. I miss that now, being together with the other mothers.

We were discharged from the hospital nearly 2 months after the accident. I’d been there with him most of the time. The big hospital started to feel like my home. When we were discharged, I was really happy, really excited, but I also sort of felt, you know, I’m actually gonna miss the hospital. All the kiddies, everyone I met and so. I had to take him back once a week, once every two weeks for outpatient therapy. When we went to the appointments, it felt like we’d never left. Once he was discharged, though, the next big thing was getting back to school. I wanted to see him settled at school before getting back to work.

## LIFE SINCE

### EARLY DAYS BACK AT SCHOOL – IN GRADE 5

In those early days at school, in the February after the accident, we sent him to class for 2 hours, then 4 hours. The therapists at the big hospital had told me it would be good for him if he stayed for short school days at first because he couldn’t concentrate for so long, his brain got tired easily still. They’d also told us he should probably repeat Grade 4, but the school put him through to Grade 5; they said he’d passed Grade 4 at the end of the year. I was glad for that. I was ready to keep him back in Grade 4 cos I was thinking, “The therapists work with children every day, they know what they’re talking about.” But when I got home, everyone shouted, “No, man! Why? He passed Grade 4. Let him go through.” *Sho*, so that made me confused. I’m *mos* the mother, the decision rests on me. So I decided, “No wait, let me go hear what the school says about this. What they have to say.”

I met with the principal and she also called the Grade 5 teacher, Mrs Abrahams. So I explained to them what was going on, how I just want to do the right thing for my child, but I'm in two minds now and don't know what to do. They looked at his profile and they said, "Look, he passed Grade 4 on his own. We'll put him through." So I said to them, "But you must now remember, part of his brain got hurt. He's not gonna be exactly the same." But the principal said, "No, well, if there's a problem, you must just tell us where it is and we can assist him. We'll work on it. But we're going to put him through to Grade 5." She asked Mrs Abrahams how she felt about that and she said, "No, let him come. Let him come. If there's a problem, we'll work on that." And then I felt okay. If that's what the school says, then let's put him into Grade 5.

He was going forward. I just wanted him to get used to it again. Because back to school he had to go! I told Mohamed, "You must tell us when you get tired, *ne*?" Then we could tell how long the days at school should be for him. His new teacher, that Mrs Abrahams, she'd asked me very nicely not to stay too far away. Just in case. Because she wasn't sure she would know how to handle him. I said, "No problem. We have a family friend who lives across the road from the school." I would sit there and wait for him those few hours and then go pick him up and take him home. Oh! I just wanted the time to fly by so that I could go and fetch my child! I kept watching the time. "Just relax!" they said, "Have another cup of tea."

And then there was the one day I was late. I'd fallen asleep. I rushed to the school. When I got there, the caretaker says to me, "He's waiting for you at the office and he's very cross." I gave him a cap to wear to school, for the cut on his head now, to cover it. He was sitting there at the office with that cap pulled down. "Mommy, Mommy said you would be here when I was done. I didn't see Mommy! So I just came to sit here. I thought Mommy wasn't going to come and fetch me anymore." So, I said, "I'm sorry I'm a little late. But here I am now." Oh, he was cross, all the way home. Stalked ahead of me, looking back every now and then. I had to carry his bag for him. And next day, everything was back to normal.

Sometime later, he said to me, "I want to stay at school the whole day. Don't come fetch me, *ne*?" So I said, "Okay, I'm not gonna come fetch you". So I spoke to Mrs Abrahams. "No, it's fine, we can try that," she said, "but still stay close by." Then I said, "No. Ma'am, you have my number. If anything goes wrong, you can call me." I still fetched him every day. She'd come over and say to me, "No, he's okay."

I remember going to the children's hospital for his follow-up appointments after he was discharged and visiting the ward. The nurse asked, "So how's your boy? Is he walking

yet?" I told her, "My child, he's walking, he's talking and he's back in the school." "*Jinne* [gosh], you can just thank the Lord for that," she said. I said, "Yes, that's all we can do".

It was difficult leaving him at school and going back to work. We had been together every day. I'd washed him, dressed him, fed him. And if you've been everyday with your child and your child isn't with you anymore then you miss that child. And you worry for that child. At the hospital, I'd done everything for him, so now you wonder "Can he do it without my help?" I still feel it [back at work]. It was difficult, but I had to go to work. And he had to go to school. We had been together every day. I was back to working long days, leaving when it's still dark in the mornings and sometimes only home after 9pm, because there's so much pressure on production. It's at this sweet factory; I'm a fudge maker. I started up that department. Everyone there comes out of my hands. I'm not the team leader anymore; but I don't mind. That was a strain on me, being in charge. I enjoy my job, though. I wouldn't leave home so early to travel all that way to Muizenberg by bus and get back so late if I didn't enjoy it. And if I didn't have to do it. I'm a single mom with 3 children and the others in the house. There are 11 of us in my mom's 2-bedroom place. Me and my kids, my brother, his wife and their 3 kids, my mom and stepdad. I have to work. Mohamed's dad doesn't help out. It's very difficult. He didn't even visit him in ICU.

I remember there was this time when Mohamed had started staying at school full days and I was back at work full days, that he would miss call me or send me Please Call Me's from my mom's phone. When I got home I told him, "Mohamed, during work time my phone can't be on. Just in case of emergency I'll get a message." Then I tell him, "Please Call Me is for emergencies." So I get a Please Call Me at work and I think there's been another accident or something and I phone home and shout into the phone, "What is it?!" Because it's a message from my mom's phone and she's watching the kids. My mom answers, "What do you mean? Why do you shout?" I say, "Because I had a Please Call Me from you." She says, "It must be that boy of yours again." I say, "Give the phone to him then." He says, "I just wanted to hear Mommy's voice." Or "I just wanted to say Hallo and Mommy must enjoy work." When I get home I tell him, "Please Call Me's are just for emergencies, Mohamed." It is difficult being away from the kids.

I worry about them. We live in Hanover Park, Cape Flats area. There's gangs there by us. Not in our street but they run through there to hide out. Now Mohamed, he likes to go play TV games at a place across the park; it's just this little gravel *veldjie* [field]. I tell him he must tell me whenever he leave the house, where he's going. One day, I'm booked off sick for the week and I hear everyone running and shouting in the street,

“Where are all the kids? The gangs just ran through and they said they’re coming back!” I’ve got my other two kids in the house with me, but where’s Mohamed? It’s like I’m about to lose my mind; I want to rush over that *veld* to see if he’s at the games. I’m scared the gangs come back. I don’t have a number to call the people at that place to check if he’s there and tell them to keep him inside. And then I see him coming, walking with that head tipped and the foot dragging, *lekker* relaxed. I tell him, “Don’t you ever do that again!” He says, “Mommy, Mommy didn’t have to worry. I was just visiting Ricardo next door. Then I tell him, “Then you tell me you’re going to Ricardo before you go! So I know where to find you!” But he still goes off without telling. Because he forgets. Maybe it’s like the attention, where he gets distracted or starts daydreaming now with his homework. He just forgets what he’s busy with, what he should be doing. He forgets he should tell me.

He had a really lovely teacher last year, that Mrs Abrahams, in Grade 6. She’s the one who read a poem at the school concert, the Ten Commandments. Not the ones from the Bible, but about how children should be treated. She supported him incredibly [*gevaarlik bygestaan*] and just let him feel welcome. This is your class. This is your desk. This is yours. And feel at home. You belong here. This is your place. She worked hard to make him feel like any other child in her class. Like I told her at the beginning, when he started back at school, not to give him special treatment because he got hurt. He’s there to catch up. And whatever he needs to catch up, she must give that work to him then I can help him later in the day. And she mustn’t push him, “Do your work!” and all that. We’re *mos* going to take our time here with him. She did all of that. She cares for all the kids in her class; she’s that kind of person. I could relax knowing he was in her hands. The two of us communicated nicely. We sometimes even spoke on the phone. We spoke at the PTA (parent teacher association) meetings too. I’d ask her how is he? How’s he doing in the class? And she’d say to me, “No, I don’t have a problem with him.”

## CHANGES AT HOME

But he’s different at home. He was always a mommy’s boy, you know? He listened. He was the quietest, most well behaved child. He was happy to share with his little brother and sister, with other children. In preschool, he came to me, “Mommy, that girl didn’t have bread, so I gave some of mine.” Now, what’s his is his. If I buy the kids sweets and chips for the weekend, he expects to eat it all up at once himself. “But Mommy, they won’t know, they’re sleeping.” And I must put my foot down and say, “No, that’s

not fair.” He did everything you ask him. But now lately, not always. He doesn’t always listen to me. I have the high blood you know. So I ask him, “*Boeta*, bring Mommy some water for my pills, man.” Maybe he will, maybe he just says “No, I don’t want to”. When he gets like that now, I think to myself, “I’m not going to force you,” and I say to him, “I’m not going to ask you again.” And he gets so angry now; he can’t help it. He knows that too. He says, “It’s just sometimes, sometimes I just get so angry. I work myself up.” He throws this tantrum, screaming out of his throat, lying on the bed and shaking himself so. Just because he was blamed for something he didn’t do. I have to grab him and say, “Must I hit you? Stop it! What is it? You could *mos* have just said it wasn’t you; you don’t have to throw tantrums!” I hope it’s not going to be an ongoing thing, these tantrums. I ask my mom, “Does this happen when I’m at work?” She says, “No.” Now me, I’ve already seen it twice. I can’t take it when he brings up that anger in him; it hurts me so. He wasn’t like that before. And he also tells lies now. He never used to. He was a good boy. He’s taken to playing with matches. I told him, “If I hear again that you’re playing with a lighter or matches then I’ll burn your hand.” That’s what the old people did with us when we were kids; you had to feel to learn. His little brother came the next day to tell me Mohamed’s trying to make a fire. Mohamed shouts, “He’s lying, Mommy! It’s him!” I call the little one. He doesn’t smell like smoke, Mohamed smells like fire. I can’t even tell if he’s lying; he’s so convincing. And he took his Dad’s phone, once when he came to visit, turned out all the screws. And he swore to my face, over and over, that he hadn’t. That weekend when I was cleaning, I find it under the big couch. Screws gone, phone broken. It turned out it was him after all. The others in the house don’t want to understand it [*hulle willie verstaan nie*]. I fell pregnant with him at 28 years. I hadn’t married his dad yet. But Mohamed couldn’t have been more loved from the beginning [*vanuit die dop uit*]. He was a sweet child, a sweet boy. Observant and very neat. Everyone loved him. Since he was born. Everyone still loves him terribly, but he’s different. I worry about him. What will his future be? These changes make things difficult for him with school too.

#### THE CHALLENGES OF TEASING/BULLIES

Mohamed was excited to go back to school after the hospital. And that Mrs Abrahams was wonderful. Then some of the kids at school started teasing him. He wasn’t bullied, but they called him names. ‘*Dentjies*’ because of the dent on his skull from the surgery. And “memory card”. I don’t know why they call him that; kids say things to get you down. He and I, we can’t handle it that they call him names. But I tell him, “Don’t let it get you down. ‘Sticks and stones...’ Turn your back on them and walk away.” But it

was an issue for me, cos it made him angry. Almost like he's a different child. And it made him so he told me he didn't want to go to school anymore. But the teachers spoke to those kids. The teasing stopped for the rest of that year. I wasn't expecting that, you know, the teasing. The kids at home, his little sister and brother, the neighbours' kids, were excited to see him when he was discharged. Excited but also a little scared. He'd been home for weekends while he was at the big hospital, to get ready for discharge, but he couldn't walk or talk then. They'd sit around his chair [buggy] and look at him. I'd be in the kitchen, and hear nothing. So I'd go in and say, "You can talk to him you know? You can point at things and he can show you yes or no. Don't be scared to talk to him, he's still just Mohamed! And then they'd all laugh. I think it's because they were a bit scared. They weren't sure what to expect... they were a bit overprotective. I thought it'd be the same back at school. Thought the kids would be careful with him because they all know he was hurt. But kids don't care if you got hurt. That school is full of bullies. The kids don't care if you got hurt. I was glad the other kids treated him the same as any other child, let him get on with things, but just not the bullies. The bully part I didn't like at all.

One evening, now in Grade 6, we were sitting and chatting. I was helping the kids with their homework. I told Mohamed to go over his books because they were writing a test the next day. He just sat there. I just watched him and I thought, "Something's not right with him." Then he said, "Mommy, there's this boy at school who messes with me every day." I ask, "What does he do to you?" "He says he's going to hit me. I can bring my whole family, he's not scared. I can bring anyone, he's scared of no one." I ask him, "What did he do to you?" Mohamed starts to cry. He tells me, "I just told the teacher he's eating in the class, so she sent him out, cos we mustn't eat in class, Mommy." And after that he said to Mohamed, "You just watch what I'll do to you when I get you outside." Then every day, he shakes Mohamed, pushes him up against the wall. He hasn't hit him yet. But now, Mohamed has this fear the boy's going to do something to him. So I phoned that friend of ours who lives across from the school. She said she'd go speak to the school for me. Next day, my mom takes him to school and the boy's parents are also there. It turns out their boy is a problem child; he's always in trouble at school and trouble at home. He has also been through some trauma though; he was knifed in his back, that boy. After that I ask Mohamed, "Is that boy still messing with you?" "No, Mommy, he's not messing with me anymore."

I saw that boy's mother when I climbed out the bus once after work. I told her about Mohamed and his accident. And told her how he has this anger in him now too. "He gets angry," I told her, "and holds it all in and when it comes out, then, you know what

he does? He throws these tantrums.” I told her I understand what her boy went through when he was attacked. She mustn’t hit him for treating Mohamed like that. I wasn’t angry with her or her son. I was in the hospital where I met so many people. We shared our stories. I realised life doesn’t just revolve around me. I told her I understand, she didn’t send her child off to be a bully and all that. He’s also just got this anger that he’s holding inside of him.

I try to prevent my kids from going down that road. We don’t want our kids to end up in the gangs. Things in our area are getting very crazy, with the gangs. Okay, so the shootings are a few streets away, but you can hear them. My kids hear them then they’re scared. You can feel their hearts, how they’re beating. Then they can’t sleep that night. It’s almost like the shooting’s right here by us. It’s not by us; it’s a few streets away, but it affects them so.

And in our street, there’s this family. Their kids are also these bullies, like at school. There was soccer started in the neighbourhood. All the kids got tracksuits, flasks, and bag with sweets, bandannas. Those kids said to him, “Why did you even get? You don’t even play. We don’t know why you come along. You can’t even kick a ball.” I told Mohamed I would prefer him not to go anymore. I don’t want him to be teased and tempted there. When he’s bigger he can join any team he wants. He asks, “Mommy, if the school starts with soccer can I join there?” So I said, “Yes, then I won’t mind, then you can play, because then there are teachers who can look out for you.” Kids won’t behave like that at the school field. These ones said to him, when he arrived, “You can sit there on the side [of the field] all day; you’re not coming any nearer.” I talked to their mom. I said to her, “Miriam, we don’t want our kids to grow up into *skollies* [drop outs/gangsters]. They must grow up nicely together.” “I’m coming now to talk with you!” she said. But she didn’t come.

That’s why I take my kids away from there on weekends, to their grandparents in Retreat, to get away from those things. Mohamed, he’s so quiet, dead quiet, when he’s teased. He does nothing. I speak to my Maker every day. I try to show my kids that name calling, teasing, it’s actually nothing. If they touch you, then that’s something. If they call you names, just walk away. Listen, turn your back and walk. But if they try touch you, that’s something different. I’m a little bit scared of that. Because Mohamed’s not a child who shouts back or fights back. Like one night, I get home from work, and my mom says, “That child down the road was at Mohamed again today. But then you should’ve seen Broertjie [little brother]. He ran out, down the steps and screams at them, “What are you doing to my brother?! Leave my brother! Go home!” Then he chases Mohamed home. “What are you doing outside? You know what Mommy said

about leaving the house!” The little one’s protecting his big brother. The little one has become the big brother “You’re the oldest but you don’t want to hear! If Mommy said be home by 5 then you want to play outside til 6”.

## THE CHALLENGE OF THE GRADE 6 TEACHER

Last year, when he went into Grade 5, I was so happy because they [educators] cared, they helped him and all that. And in the end he made it through the grade with their help. I remember when I was still fetching him early from the school, some sponsors from Milo [milk drink] were there. When I arrived there and saw this, I said I’d wait else he’ll miss out. They had to jump hoops and things and then dance a shuffle and then they’d get a glass of Milo. Mohamed, he was just sitting there on the side. I ask him, “Why?” And he says, “Cos I can’t shuffle.” One of the teachers was there and she heard him. “Nonsense,” she said, and took him by the hand. “Come, let’s go fetch your Milo.” She was one of the teachers who taught me. She retired at the end of last year. I know quite a few of the old teachers there.

When I went to the school to get his report that week after the accident, they already knew about the accident. My little girl had told them. They came around me and asked, “How are you?” They made a circle around me and prayed. They hugged me. They spoke nicely to me. Even now, 2 years later, when I’m at the school, they see me and come running, “Hello! How are you?” They really care. I *mos* want the teachers to be caring and helpful; where there’s a problem we must *mos* help. But I’m not so sure of his new teacher for this year, now in Grade 6. One of the kids in his class told me he thinks this teacher’s got a problem with Mohamed. At the first PTA meeting of the year I told her he was in an accident a year ago. She told me she hadn’t known that, that she hadn’t been told. She thought he’s just playing around with her. I explained to her we still attend the hospital once a month for therapy. I told her I’d bring a certificate to school every time we go. I told her I hold nothing back at those appointments because the therapists must know, because they’re the ones who must help, they give me advice, how to help my child get better.

She phoned me once to tell me she gave all the kids a task. They’d all finished writing and Mohamed, he was still just at the heading. She wasn’t sure if he was bored with the work or what, but he doesn’t do his work in class, she said. I told her I was glad she told me. I must know these things – I’m his mother! I said I’d talk to him when he got home and find out what his story is. Mohamed told me, “But, Mommy, I didn’t understand.” That’s where I started telling him, “If you don’t understand, lift up your

hand or go to your teacher and tell her. She'll find another way to explain it to you then. But if you don't ask, she won't know." After that call though, she said, in front of the class, "I'm not going to bother to phone his mom anymore because it's like she don't care." I don't know where she got that from! That boy in his class told me. And Mohamed told me. He was angry with me. She had said things about him in front of the class. She twisted the story and she spoke behind my back.

As if I push him forward! I don't want her to treat him like he's 'royal', but don't just look for faults! He's just a normal child! He was injured! He got hurt – I see it every day! Like that anger in him. And, you know, his left hand still shakes. One of his shoes always wears down quicker than the other now because he still walks with a bit of a limp, dragging that left foot. His voice is still not the same; it's that one-toned voice. His head, he holds his head at an angle now. He's changed; I feel like I don't know him so well anymore. Sometimes when he doesn't listen to me, or fights, or lies so, I tell him, "Your head got hurt, not your backside!" That teacher says, "He knows he was in an accident and he's just using it as an excuse." Like he's being lazy and naughty! Just to think she doesn't even try! I don't expect her to have the bond he and Mrs Abrahams had, but I want her to understand him. What he went through. Who he is now. He isn't the same person now.

#### CHANGES AT SCHOOL

His Grade 1 and 2 teacher, she used to say to me, "Mohamed is a very bright boy. He doesn't speak out of turn; he answers promptly when you ask him something; his work is always neat. But sometimes he sits and daydreams. He stares out the window. But he does finish his work." Now, for me, it's like that daydreaming has gotten worse. It's not just staring out the window. It's other things that catch his attention now too. Mohamed sits, then there's his pencil in front of him, now he's listening to the teacher. Now he's going to see that pencil; it's got his attention and he fiddles with it or whatever's in front of him. I told him, "Put everything under your desk. If teacher's talking, I want nothing on your desk." I see it at home. I sit and do his homework with him. He waits. Even if I'm working late, he waits for me. We used to sit in front of the TV and do homework. Now he sits, now he looks up. I've started turning the TV off. "Wait, mommy, wait a bit." I say, "I'm not gonna wait, I'm switching it off cos you must finish your work. You've waited all this time for me to get home, but now you watch TV. We'll do homework without it." But still, there's always something that'll take his

attention. He suddenly sees a little piece of something just lying there and he picks it up, and here he's busy with his work.

At school, before the accident, reading and writing used to be easy for him. With him it was flying colours. Things have changed. He's slower now. He can do the work; it's just slower than he was before the accident. He's become quite lazy to read and his handwriting's very messy now. He doesn't wait to finish listening to you. But it's not that he's actually forgetful. If he focuses and listens, he can remember. I told my mom, "I want to buy him a puzzle book again cos I think those things help them." He can do puzzles so well. I tell him, "If you can do those nicely, you can do other things too. It's just that you, here at the back of your head, you just can't do it the same as other children cos you're slower now. Mmm. Slower. You can be slow, but you can still do it," I tell him.

Near the end of Grade 6 he told me he knows he's going to fail the term. He said he thinks he didn't do so well in the tests. He especially struggled in his Technology and Natural Sciences. For the rest he picked up during the year, like his Social Sciences. I said to him then, "Is that how you feel? We'll have to wait and see, hey?" I can't expect the world of him. I would've understood if he didn't pass. He's not exactly behind, but he's a bit slower. I *mos* told myself, "If he doesn't make it now, then I'll understand why he didn't make it." But I'm satisfied with how he's doing, because he picked up, and yes, he's a bit behind, but he did make it into Grade 7!

## LOOKING FORWARD

He wanted to go to another school. It was at that time they were teasing him; he felt he was different because the kids at school made fun of him. He told me, "I don't want to go to my school, Mommy". He says he wants to go to a special school. Our neighbour's boy, Jarryd, goes to one of the special schools in the area. Now Mohamed, he thinks it'll be nice to be with his friend there. "It's not a school for crazy kids, Mommy." So I said, "We'll see as time goes by. What they say at the hospital, whether we can take you to another school or not." I told his speech therapist, Kirstin, I don't think I want to send him to a normal high school. Because when there's too many children around him, then it seems to me they hold him back. You see, there are more children in high school classes. And already it's difficult for him to concentrate. He'll get so tired. And the youth, they've got things in their heads, you know. Some of them smoke. Now I don't want him with all that. For me, I think it's going to be too much for him. They're also going to be picking on him. I found out about another high school. But Kirstin says

he can't just move. It depends on the Board of Education. He was *mos* assessed at school that first year back by the Educational Psychologist. I didn't get those results. We're going to try and get them and see. It's a bit difficult for me, thinking that he struggles at school now. It used to be easy for him. Thinking about special school – that wasn't the plan. But I must *maar* take it as it comes. We must take every day as it comes. There's no use [*dit baat nie*] fighting it, forcing it, if your child isn't ready. What's your child going to do there in the next grade if he's not ready for it? Mohamed's little sister had to repeat Grade 1. She was too playful still, they said. I was fine with that. We must *mos* now think what is best for the child. And I want for Mohamed to be independent.

But sometimes I think I'm not doing what I need to be doing. I should stop working and be with my kids. I can't, though. I'm mom-alone [*ma-alleen*]. I do it alone. Sometimes it hurts me to think of everything I need to go through on my own. I want to always be there for my kids. But I can't. That's why I try to teach them. About right and wrong. Their dad doesn't even bother. The little one said once, "My dad's dead. I don't have a dad." You mustn't say that; your dad's still alive." "Then where is he that he doesn't worry about us?" "I'm your mother and I worry about you. I'm your mom and your dad together. Don't you remember?" I tell him. I've got my mom who helps me but she's not always well either. And sometimes we're under a lot of pressure at work too. We've got two bosses; the one expect this and the other that. Sometimes they just expect too much from a person. I can't get to the teachers when they want to see me. His Maths teacher, she phoned me and sent a letter, because of trouble with Mohamed. I couldn't just get away from work; they were watching our absenteeism, our performance and all that. So we corresponded with letters. The school gives a message book at the beginning of the year for R7. We use that. And I appreciate it.

I didn't cut myself off from the world after the accident. I'm a hard worker, so I go to work and I come home. On weekends, we go through to visit his other granny and grandpa, his dad's people, and my cousins. The grandpa says he's happy to take me somewhere if I need to go, and they'll look after the kids for me. But at home, it's off to work, and after work, straight back home. I don't go over and visit with this one, and then with that one. I dream of our own place. One day, when his accident money's come through (Road Accident Fund pay-out), I tell the kids, we'll buy our own place.

It isn't easy. It's very difficult. Sometimes I feel like "I can't do it anymore. I can't do it anymore". Then I lie down and just cry. I get those flashbacks from the first day in hospital, from life before the accident, and I cry. I also think to myself, "My child is alive. He could've been dead, but he's alive!" I see how some of the other children who had

accidents turned out when we go to the children's hospital for check-ups. It could've been so much worse. My mom says "You're a strong person." I say, "You all think so. When I'm alone, I cry." It's nearly two years after that accident and still I cry. Those times when things seem to get too much then I just want to quit my work. And be with my children. But I can't. It's not easy but I don't have a choice. I must do it. Without the parents help, a child can't progress, can't go forward. We're their statue, their support. In the same way we support our child, we expect the teachers also to support them. To help where needed and to understand them. That the child can feel, "You want to help me. You don't reject me. You don't make me feel bad." Kids want to be helped. I don't want Mohamed to feel like he's a failure. I was watching him the other day at home – I watch him carefully – and I thought to myself, "Ai, my child was actually really in an accident. It's not a dream. It's the truth."

It's difficult. It's not easy. My child walks, he talks, he's back at school. But I still cry. [*maar ek huil nog altyd*]. Life has changed.

#### 4.1.1.3 Educator A

##### Biography

*Mrs Mertia Abrahams is a 42 year old Coloured primary school educator. She describes herself as a born again Christian. She graduated from teaching college in 1994 and has taught at Rustdene Primary School in Hanover Park, an area in the Cape Flats region of the Cape Metropole, for the 19 years since then. She has taught intermediate phase learners only (Grades 4 to 7) and at time of interviewing had been teaching Grade 5 for 5 years. There are on average 40 learners in her class. She speaks English and Afrikaans; English is the language of learning in the classroom. Her extracurricular activities include coaching soccer, convening the school concert and serving on the Grade 7 farewell and dance committee.*

*She was Mohamed Ibrahiem's Grade 5 class educator during his first year back at school in 2012 after his head injury in December 2011.*

*This is the story of Mrs Abraham's experience of Mohamed's return to school following his head injury.*

## **STORY OF UNKNOWING, EXHAUSTION AND ACCOMPLISHMENT**

### **EARLY DAYS AND EXPECTATIONS**

Mohamed started in my Grade 5 class in 2012. He'd had the accident in December 2011. We get our class lists for the new year at the end of the year before, so I knew Mohamed was coming to my class. The principal let us know he'd been in an accident. I didn't think the accident was so big though; I thought he'd be better when he got to school, when he was out of the hospital. I've been a teacher for 19 years, since 1994, and I'd never had a child with a brain injury in my class. I don't think I knew what to expect, but I didn't expect what I got. I was not equipped to deal with a case like that.

When I saw him that first time, when he came to the class, I realized this child will need lots of attention. He couldn't write. It was like he couldn't manage his muscle groups, the grip. He wrote extremely slow. He couldn't speak properly. He couldn't walk properly. He needed to go to the toilet all the time. It was like we had to start from scratch with him, like he was a Grade R or 1 child all over again. I had been hoping he'd just be able to slot back in. But that was impossible! I noted he needed individual attention. I thought, "He should be at a special school; they're skilled to help him there." He was very fragile at that time, in the beginning and needed all the attention on him. Everything was really just too much for him and he couldn't cope with it at that point in time. I had lots of questions: Will I know what to do? What happens if the child panics? I was scared I would not know how to handle him. Do I have the necessary skill? Will I be able to know if he asks something or do something or show any signs whatsoever? Will I know what to do? I had 40 kids in my class that year. I was worried I would neglect them. Those were my main fears.

At teacher training college I didn't do anything like this, not even a short course on how to deal with a child coming back after this operation or whatever. Yes, I felt equipped to teach children with learning difficulties. We see that all the time. I did some reading up, like the report the Speech Therapist and people at the hospital sent. That was very helpful. I don't remember what they said, but it just helped me to know there were people there to help us. It wasn't just us alone; the assistance was there. Someone else was keeping an eye on this child. They were doing their part. Getting the therapy also gave him confidence, I think. I felt so unskilled, though. I felt I wasn't equipped to help him when I started off with the process. I wanted recommendations on what to do, how to handle him. I wanted to be skilled by professionals, but there aren't therapists to help at the school. We're subject teachers at the school, so the children move from teacher to teacher depending on the subject. So I didn't teach Mohamed for all the

lessons; there were 2 other teachers also. I had him for Maths, EMS (Economic Management Sciences) and Geography - but I was also his register teacher. I think it was also extremely frustrating for Mohamed needing to move from class to class at that early stage. He didn't finish his work and then he'd have to get up to move to the next class, so he just kept getting way behind in his lessons. It was way too much for him. All of us who had him that year, we didn't know how to tackle it.

I knew it was going to be a challenge the minute I saw him, because I thought I won't get the help from the mother. I thought she would be as scared as I was and would leave it up to me, that I wouldn't get any help from her. And if I can't and don't get the help of the mother, then we won't be able to assist this boy. Then this boy will just start on one point and a few months after that he will still be on the same point, because it is senseless for us to give him the necessary support here at school but he don't get the help at home. But, I'm happy to say, Mrs Ibrahiem really went against my expectations! She was so dedicated to him. She brought him to school and waited for him to take him home early in the beginning. So that was also my reason why I also felt I had to come on board to give her the necessary assistance and that, her dedication. She was amazing. I wasn't expecting that amount of support from the mother. I've learnt people tend to have that expectation that teachers will sort everything out, you know. I tend to think that people think we are educated and we know everything. A teacher is a doctor, lawyer, social worker all in one, people think! I think it's sort of the same with church also, the scenario. People expect that they must get their values and Christian beliefs and whatever at church, but it doesn't start there, you see. It starts at home. If you get the help of both the parent and the teacher then it works brilliantly. And she was brilliant from her side, his mother. She helped him a lot, with the writing and all that, when he couldn't cope. She had to go back to work, of course, but so then she would call me, she would answer, she would question, she would whatever. And I would do the same. If he didn't understand, I would call her, I would correspond; we got this diary that we communicate in. Mostly, I'd write about the work that was incomplete, but also about how he was being bullied and later about his aggressiveness. Mrs Ibrahiem came to meet me before he arrived in Grade 5 and explained everything to me; she really did her part, so I felt, man, I had to do mine. I know that this lady must be very tired, because I know she has the other children to look after too, so I decided I will assist from my side. I wanted to help her. It's part of our calling as a teacher, to support. And knowing she was on board, that it wasn't all on my shoulders – teachers, principal, speech therapist - I was ready to face the challenge.

## THE CHALLENGE AND THE SUPPORT

I really didn't think it would be so bad. I had no idea it was so severe. I thought it was just a normal accident, so it will give him enough time over the December holidays, those 6 weeks, to maybe get a programme or be on a programme. When the principal told me Mohamed had had an accident and would be coming to my class, I thought he'd be normal by the time he got to me in January 2012, that he would come back to mainstream and cope magically with his work, be his normal self. But then I got the report from the hospital and his mom came to speak to me and I realized maybe this was bigger than I thought.

There are plenty of challenges working here in my community, I've taught at Rustdene Primary all my 19 years. I went to school here too. This is my area. One of the problems is some children don't do their homework at all. It's not because they don't want to. But maybe rather because some of their parents aren't equipped enough to help them. That is the one problem. So, in our school, our principal started off this programme where we do adult teaching. Before it reaches the child, you must get to understand it first as a parent. It's not that the parents don't want to; they're very much up for it, but they're not equipped to do homework with their kids. Mohamed's mom, now, that wasn't the case with her; she worked hard with him, she'd been to high school. Anyway, so with the Maths programme, for example; we invite the parents to come to the school on a Saturday or whenever and then exactly what we teach the children we go through with the parents to equip them you see? So that they get the idea of what it's all about, so that when the child leaves school at half past two or 3 o'clock, they know how to assist that child. The government made this DBE [Department of Basic Education] workbook available. It's a brilliant book – extra help and homework for the child. So they need to get homework every day. And they need someone who can actually help them with that homework.

Another problem is children not having stationery. Erasers, rulers, whatever. Then the principal or we as the teacher need to buy that so that we can just help the child. You can't blame the child. Due to the high unemployment rate, people don't have money to go and buy, so we sit with those challenges. And just imagine if you have a class of 40 and 15 of them don't have pencils and erasers or rulers what endless problems you will have because it is frustrating and irritating if children don't have and they must ask. That noise level! You can imagine how distracting that is. And then you have children like Mohamed who can't pay attention. That's why most of us just buy for the kids in the class, because we know it's going to happen. We raise funds for these things – sell

snacks and drinks. Because of the high unemployment rate, most of our parents can't even afford to pay the school fees.

We try to make schooling fun for the kids here at our school. There's all the violence in the area. It's continually occurring and that is the reason why sometimes they can't play outside. Because they shoot in broad daylight. Now just imagine a child needing to play, being cramped up in a house, can't play outside, having to sit idle or whatever. Imagine teaching that child. Now they come out to school. They can't sit all these hours. They want to play. That is the reason we need to make school fun for them. Sometimes in the area when they shoot the children are still at school. The principal always advises people, if they are shooting, don't fetch your child, leave them. Because they are safe here. But people, because they panic, they want their children to be at home rather, you see, because otherwise they must walk alone. That has happened to us on several occasions. Where they had to close the school early and children must go home. The principal calls the police so they can escort the children. Even though there's all this violence all the time, and so many other challenges, this thing of a brain injury like Mohamed's is not lost. It's a rare case here. It stands out. It's an extra challenge.

I had an offer years ago to go and teach somewhere else. But because I feel that I grew up here, I know their difficulties. I know what they're going through. I know what it is like to sit in a room, people smoking or doing whatever, gangsters, hearing the gunshots and all of that and you must still study. So there's absolutely nothing that you can tell me about those challenges because I went through it. I didn't hear about it; I experienced it for myself. So, my focus with my kids, is also to tell them that look, there is something better for you out there. I always tell them "If you can dream it, you can do it". It must start with a dream. Because no person must label you. Don't place yourself in a box. You don't place limitations on yourself also. Since those first democratic elections in South Africa when Mandela became president and the apartheid system fell, the lid is off now, you are no longer inside the jar or box, you can explore, you can become whatever or go wherever you want to, but the ball is in your court. That's why I feel I know what they're going through. Don't place limitations, don't blame that and this.

So, yes, a teacher's job is very challenging. I think that is why most people don't become teachers. But this, having Mohamed in my class, a boy who'd had an accident to his head, this was definitely the greatest challenge of my teaching career, even though at first I hadn't thought it would be so bad. I felt like I'd been thrown in the deep end, having never experienced something like that before. Speaking to the mother and

knowing the hospital was there and everything I was more ready to face the challenge. My principal and I have a good relationship. That was also a big help. Mohamed's other teachers and I worked well together. The communication between the principal and the Grade 5 educators was great. We discussed the problems and recommendations, like "He's a slow writer; he might need to come in intervals; let him sit in front of the class near you; keep an eye on him; he often needs to go to the bathroom." I'd explain that I assist him with other learners, a stronger learner. Just ideas of what we could do.

It was very disruptive when he started off, coming at 08:00 leaving at 09:00, then till 10:00, then his mom would fetch him at intervals and so on, the days getting longer until after a few weeks he was staying the whole school day. It was disruptive because I had to deal with him before he left for the day, give him work, talk with his mom. Also, he couldn't cope with the Grade 5 work, with not being able to write, with every being in slow motion. In normal circumstances, a learner can write half a page in a 30 minute lesson. For him, he could do one sentence in that time. So, my planning had to change completely. I needed to give him a different lesson to the others; he wasn't part of them yet. I had to start with the basics first, have him write the work down, but then also give him extra activities. I had to prepare his hand-outs in advance. He needed this extra work to try and bridge this challenge.

He really needed a lot of attention. I would take 10-15 minutes of a lesson to focus on him, before I would move over to the others. And sometimes I had to help him to write. That's why I had him sit right in front of the class. At intervals I would ask him to come so I could assist him. After school I'd ask him to come if the work wasn't completed. Just to guide and assist him. That's what I would do all the time. It was exhausting (uitputtend). I love to do the one-on-one teaching. As teachers it's important to us and we always do it. But I had 39 other learners to think of also. If you sit with the one child all the time, the other children will get frustrated if they call on you. I think now it would have been a good idea if I requested that the school employed a parent assistant, someone to help with all that extra work. But, as I say, it was a new thing for me then. I didn't know. But I had this very helpful child sitting next to him that would always assist him. Now if he was in a special class, I thought, where there are only 10 learners, then he could get all that attention that he needed. But I wanted to help him, I wanted to make him a priority, for his mother's sake. He was a lot of work and it was tiring, very tiring. I had to sacrifice my intervals and that. But I just wanted to help his mother, man, knowing her circumstances and everything. This is the least we can do as teachers.

He needed all this attention, but we didn't want to treat him like a prisoner; we wanted to show him he is quite normal, there's nothing wrong with him. But the children would

make fun of him, make him sad and he would cry. And I think that was one of the reasons he was aggressive later on. He was weak in the beginning and couldn't fight back, so he kept it all in, that frustration and anger. Then later, he was stronger and could fight back, defend himself. He got frustrated when he couldn't complete his work or do a problem within the duration of time he was given. I could see the clear frustration on his face, having to turn around and check and look at his friends books, seeing that they are completed. I don't think he liked it if all the attention was focused on him and the children could notice that of course and make fun of him. I think that also made him aggressive. That was a main concern. But also, if I left him so that I could focus on the other children and he couldn't manage the work, he became aggressive too, not knowing what to do. I had to keep an eye on him for that. And also, in the beginning, he would give up easily. If I was standing behind him, he'd carry on, but I noticed if I walked away then his mind would wander. I would have to stand behind him and say "Come on Mohamed, carry on with your work!" Especially with Maths and English. We felt, if we stand here behind him, then he'll do his work. But I would also often stand and watch him without his knowing. I didn't want him to think that I'm a policeman.

When he stepped into the class early in the year his peers made fun of him. The kids would walk like him, with a limp, or speak slowly like him. And it was very embarrassing and humiliating for him. The principal with the Grade 5 teachers would counsel those children not to make fun. But after a while they got used to him. He was just a normal learner. They knew what to do, they knew the drill already. He didn't come to school the first day of the school year; he started off a few days after that so it gave us a chance to try prepare the children and explain to them what had happened to him the previous year when he'd fallen off that *bakkie* and hit his head ending up in hospital. They made fun, but I spoke to them. I had lots of conversations with them in the mornings before we started our lessons. How to respect children and how to do this and how to cope with that and not to make fun. I always read them that story about the fruit bowl; they are like a lovely fruit salad, I tell them. If you're part of a lovely fruit salad, pineapple can't say to strawberry, I'm most important because I give colour. Or paw-paw can't say whatever. You are all precious and unique and make up this lovely fruit salad. I think those morning briefing sessions helped to minimize the teasing and bullying. You're going to always get those children who exploit a situation, but as time went along, as they say, "Time heals..." I told Mohamed, "If anything occurs, you come and report it and we can solve it." Gradually he reported less and less, and I also noticed the bullying less and less.

It was very sad for me in the beginning to see that the children made fun of him despite these briefing sessions I had with them in the mornings. At one time I was wondering about him, "Must I keep you in staff room? Must I keep you in the class?" so that he's not on the playground with the bullies. But then I thought that, no, he needs the fresh air and he needs to be with his friends. Bullying is a big problem in general at schools. We've got this bullying thing every single day and we've got to deal with it. We address it in Life Skills lessons. There's this brilliant book by the Department of Education. It teaches the kids about anger, what causes it, how to manage it. They have to write assessments on this. How to cope with your emotions, how to deal with situations positively, like walk away or talk to your teacher. This book is used nationally. It's very good. So, we deal with it in Life Skills, we give detention, and we have those morning briefing times as well. I would take that time religiously every morning to speak to them, not specifically about Mohamed, but in general about accepting each other, how to cope with teasing etc. How we area Rustdene Primary family. How the person next to you is your brother or sister. That is the reason in the morning, after our prayers, I would do a greeting and they must make eye contact with each other and say "I'm so glad to see you this morning." I've always done this when I teach, but having Mohamed in the class I did it religiously. It made me sad. He had to cope with the bullying besides not being able to write and speak and run properly. And I mean, I can defend him in the classroom, but not on the playground, not outside. If there's one thing I hate as a teacher, it's a bully. I can take a naughty child but not a bully. Watching programmes on TV and reading papers and magazines you always find what this bullying does to a child, how it scars them for life. So I always tell the children that if there's a bully they should report them. They can write it on a paper or in their journal, whatever, just inform me. I won't deal with that child in front of the class, but that child has also got a problem. So we need to reach out and help that child.

I questioned myself a lot during that year with Mohamed in the class. I was often unsure and uncertain. Am I doing the right thing for him? Am I giving him too much attention, costing the other kids? I talked with my husband about that. Am I being too strict with him, putting too much pressure on him? He developed a low self-esteem. I could see frustration on his face when he couldn't do something. Will he ever get there? Am I expecting too much? I would stand and watch him from a distance, keeping an eye on him. Should he be in mainstream? I thought to myself, "They made a mistake sending him here, he should've been at a special school." He needed some pre-mainstream school programme or something before they just threw him into the mainstream – a time to help him to cope with things, like the writing. I thought, "They

should have worked with him first, given him individual attention, get him to strengthen in that area of writing.” Then maybe he could’ve come back. Just so that he can become more confident. I didn’t realize that there *aren’t* any places like that for a child like Mohamed.

## ACCOMPLISHMENT

That whole year, every day was a challenge. I took each day as it came because I didn’t know what to expect. By the middle of the year though, so by June, I wasn’t scared anymore. We had settled. He had become more relaxed. Everyone was more relaxed. He and the children were accepting the disability. When he got here in 2012, I was shocked and scared, likewise the children. But with all the morning sessions, they started to accept and treat him like normal. I wasn’t fearful that he would go into a panic. I had decided to let him develop at his own pace, not at my pace or the classes pace. His drawing and sketches were better. His writing was slow, not quite there yet, but better than at the start! And his speech had definitely improved. It was a slow pace of improvement, but he was getting there. Man! To tell you, when he stepped in here...! Time heals. I started to realize there was nothing wrong with him actually, one just had to take him right back to basics. And he started to cope.

A lot is because I think his mom had all the patience in the world with him. She brought him to class, he was very regular, hardly absent at all. She guided him and helped him with his homework. She was on the ball.

I think it was the right thing sending him to mainstream. Because he helped himself also. He wanted to do it, the fact that his mother was pushing him, the fact that the hospital from their side and the teachers from their side... it showed him he can. And his peers also – he started to learn from them also. I can honestly say, children like that, they need the help from the different sources: Hospital, mother, school.

Mohamed’s still very slow, but he’s coping now. He’s not where he started off; he improved a great deal. He’s able to write more sentences on a page, not just that one. He can sit on his own, not needing the stronger learner to sit near him. From watching him, I can see he’s quite normal now; he can run, he can speak properly and he is really coping. I don’t remember that he was ever seen by an Educational Psychologist. He also enjoys the extracurricular soccer and cricket. I coached him with the soccer. He was very fond of it. The principal allows them to play interclass soccer matches after the exams. We were “Holland” and he was part of those matches by September, the third term. We wouldn’t give him full games to play, just a few minutes, so 5-10

minutes before full time we'd allow him on. All of this as a means of helping his self-esteem, to make him feel part of the class. And he loved it so much! Oh my word! He was screaming and shouting for his team there on and off the field. We didn't want to treat him like an isolated case, like some disability-child, because we thought it would hamper his self-image. So this was one of the means we tried to treat him like the other kids, tried to boost his image. He definitely became more confident as the year progressed. The kids don't tease him anymore. In fact, it got so they would come to tell me of things he was able to do, "Miss, Mohamed did this and that." I never saw him hit a child for teasing him, but the other children reported it, swearing back, hitting back, fighting back. He was not a child who would easily lie, so I'd ask him, and he'd say, "Yes, I did, Miss, but because they..." It was his way of standing up for himself then. So I thought, "Okay, you've become stronger." I saw once when we had to go down to the hall for Arts and Culture, I saw the children wanted to tease him, call him names, but he didn't cry and turn back. He faced up to the problem and made eye contact with them. I thought, "Okay! Well done! You're getting there." He was getting stronger. The things I was teaching them in the morning brief, he was learning and trying. "I'm not going to cry and turn around. That won't solve the problem. I must stand up to the challenges. Do it myself." It was nice. It was really nice to see. In that case, a real sense of accomplishment.

At the beginning of the year, I wondered if he shouldn't be in a special school. Then my thinking was that he would need to repeat the grade. But there was no need to. He was ready to progress to Grade 6 at the end. He'd met the academic requirements. With any of the children, it is nice to see when they come into your class and you feel sorry for them because they can't cope with the work in the grade; but then you see the progression over the year until the end when they step out. It's lovely to see. To be able to say, "Wow, they really achieved that by the end of the year with this challenge or that." Even more so with Mohamed.

But I think he'll still need the extra help besides school and the extra lessons, like from the hospital and at home. I'm comparing him to what he was like before the accident. I had a small interview with his Grade 4 educator to find out a bit about him before he came to my class. She had told me he could cope well in Grade 4. So, I think I was judging him on how he used to perform and compared him with other children. He improved a lot in Grade 5, but in Grade 4 he was a better learner than so and so, so I expected him to be better than that learner again. I wanted that to happen. But it will take time of course. He was an average learner that could cope with his work, said his

Grade 4 teacher. So that was my expectation for getting him through Grade 5. But he wasn't there yet. Much better. But not there yet. There's still room for improvement.

For me, the pure joy in the end, though, was to see him be a better learner than when he came into my class. I really thought that this child will never make it, but, I mean, miracles do happen. God specializes in dreams and miracles. I love challenges – you can learn a lot. Especially if it's something you've never come across. Look, when you start any process, it's a humongous challenge; you don't know what to expect, you don't know how to react. But you learn a lot. I won't say I'm ready for the next challenge just yet, but really just the fact that you can be there and help the child, I feel that is a great accomplishment.

#### 4.1.2 Case B

##### 4.1.2.1 Child B

###### Biography

*Simphiwe Dyasi is a 12 year old isiXhosa speaking boy, born in 2001. He is a Grade 6 learner at Wandisa Primary School, which is an inclusive co-educational and English medium school in Khayelitsha, a large Black township in the Cape Metropole. He enjoys Maths and singing and recording songs with his friends. He lives in an informal dwelling with his parents and 4 other siblings, aged 21, 19, 15 and 4 years of age. It is a ten minute walk to school.*

*Simphiwe was knocked over by a car in September 2011 towards the end of his Grade 5 year at school. He sustained a severe traumatic brain injury. He was admitted to the Children's Hospital in Cape Town. CT brain scan showed a small left anterior temporal extradural haematoma and overlying left temporal skull fracture requiring neurosurgical intervention (craniotomy and evacuation). He was in ICU for 2 days. He was transferred to a nearby hospital for inpatient rehabilitation a week later where he received Speech Therapy, Occupational Therapy and Physiotherapy. He was discharged home from there in mid-October 2011 and returned to school for the rest of that year.*

*This is Simphiwe's story of his experience of returning to his school after his head injury.*

## **I LOVED SCHOOL BUT NOW IT'S DIFFICULT**

I loved school. Before the accident in Grade 5 [2011], I enjoyed all the work and was *really* good at it. I used to come first in Maths, English and Xhosa. I never, never failed anything. But things are different now at school. Now, after this accident.

I *wanted* to go back to school after the accident. I couldn't wait! I liked working hard. I liked school. There was only a little bit of school at the hospital for us kids. Not a whole school day. So I couldn't wait to go back to my school. But also I was worried about going back to school, to my Grade 5 class. I was afraid the children would make fun of me because of my operation. It was better than I expected! On my first day back, my class threw me a welcome back party. This was really nice! They brought money to class and then bought a cake, drinks, chocolates, biscuits, all that kind of stuff. It was all done with my teacher, Mrs Luthu, there. It was fun. I couldn't believe it was me who had come back from the hospital, that it was me who had an accident and was here now. I couldn't believe that school could be fun like it was before I got run over by a car. I could see my teacher and friends were happy that I was back because they threw this party for me. I was happy that children in my class cared about me. Most of the kids in my class were nice. But some of the children weren't nice. They didn't want me to come back. They didn't think I would come back from the hospital. They thought I was going to die. And then they did not want to give money for my welcome back party. So when the other children still did give money, these ones were upset. I remember:

*When I get in the door of the class the other kids stand up and clap! But those kids they just sit there and watch me. And then they just say "tsk!" and shake their hand. They don't really want to do the welcome back. My friends in the class bought the cake for me and they put it out; the other kids they just leave then when we have the cake, they just go out of the class to the bathroom.*

They weren't interested in me or my party. Those kids have never liked me. Even before my accident, when I want to borrow something from them, they say "Go away. I don't have it." When my friends borrow me stuff it shows that they really wanted me back. I was also right about being teased. There was a boy who teased me when I got back to school. He made fun of me because of the scar on my head from the operation. He said I had a sack on my head, and train tracks. I teased him back and called him "custard" because he had a problem with his eye that looked like custard or wax. I want to tell people they must not tease because you don't know what's going to happen tomorrow.

You see, after my accident, I have some problems now. I get headaches and start to feel dizzy. It's more bad when it's hot. I have to sleep and not play too much. My energy just runs out and I don't want to do anything. Then the teacher says I must go home and I feel upset. I don't want to miss work! It is difficult to keep up. Work goes too fast now. I want to keep up! On my first day back, my mom took me to school. I had to leave early, go home at 10:00. I didn't like that, leaving early in the beginning, because it made me miss stuff. My mom and teacher thought that I was getting tired, but I wasn't. My work is important to me! I don't like to miss work. So, when I get the headaches or dizziness, I stay in class if I can and just keep myself busy then.

The headaches make me angry because I won't be able to do well in school if I have them. They make me not be able to focus. My homework is easy if I can listen in class and then go and do it at home. I must listen more carefully in class now than before the car accident. If I listen carefully then I can remember the homework questions when the teacher says them and I can go home and do the homework better. The way to listen carefully is I mustn't be disturbed. I don't want anyone to disturb me when I am sitting listening to my teacher. When the kids make a noise then I just stand up and say "Shhhhh!" The kids look at me and go "WOOaaaah!" like I'm pretending to be the teacher or something. I just ignore them then! Sometimes my teacher helps me when they make a noise and tells them to keep quiet.

You see, the problem is that before I got run over by a car, I couldn't fail. I never failed. I just passed before. Before I have the accident then everything goes right. But now! ... Now after the accident, in Grade 6, I don't pass in the same way as I used to. My marks aren't so good anymore. I got a code 4<sup>7</sup> for Xhosa, a 3 in English and only a 2 in Maths. I didn't pass my Maths! I don't do as well as I used to. That makes me sad. I get upset because I see all these kids passing Maths and I used to be Number 1. I used to pass Maths very well and no one would be able to pass Maths more than me in the class and so now I can't do the same thing I used to and I don't know why. I just don't know why! The Maths, it's more difficult to understand. So I can't keep up. The teacher's onto the next one there, and I'm trying to understand this one here. Everything is more difficult! Everything takes more time!

The worst was when I failed Grade 6. I repeated it. They told me I repeated because I was in the hospital for such a long time I didn't get to learn other things, so I was behind. I was very worried that time when we were getting the reports at the end of Grade 6 [2012]. Mr Magoda is my Grade 6 teacher. He said he was busy doing my

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<sup>7</sup> Scores are from 1 to 7 and represent a percentage range, with 7 being the highest and 1 the lowest

report, he was writing it, but I saw the other kids had got their reports already. I started sulking because I was upset. Why couldn't I get mine? There must be something wrong! I never saw my report in the end. Only when we went home for the holidays, to our family in the Eastern Cape, that's when my mom told me that I'm going to have to repeat Grade 6. She asked if I wanted to repeat and I said, "No!" I was very upset and sulking when she told me I must repeat. I remember she asked me not to cry. She said the therapist at the hospital said I could go to Grade 7 only in June the next year [2013]. So then we waited and then when the school year started nothing was said to me about what was going to happen. So we didn't know what was going to happen. And then I just stayed in Grade 6. I just stayed there. No one said anything more to me about Grade 7. My friends moved to Grade 7 and I stayed in Grade 6. One other child also failed Grade 6, like me. I was friends with him that second year in Grade 6. The other friend was a child who had something wrong with his eye. He was playing soccer, then he looked in the sky and when he looked down again he couldn't see. So he went to the hospital and when he came out he was in my Grade 6 class also. I started to write songs in Grade 6 and these guys wanted to sing with me. They like my songs. But my old friend, Asenathi, doesn't want to sing with them. He's a friend who went up to Grade 7. He stayed my friend. Mostly, I stayed friends with my old friends who went to Grade 7. But so with these guys in Grade 6, we run and play Ndize (hide-and-seek) at break. We eat together. I think a friend is maybe someone who likes you the way you are.

So I was not happy to repeat Grade 6, but I have some friends. And at least I was with Mr Magoda again. Mr Magoda is a nice teacher. He's taught me for two years. He doesn't hit the students when they haven't done their work. He just warns them and then tells them to do it now in the class. He also gives me time. It helps if they give me more time. School is difficult now. Because I am not too fast when I write the tests. Extra time to write makes it better for my schoolwork. He also helps me because he encourages me and says "You can do it, you are very good" and once he starts saying that then I start to feel proud and I can try to do my best. And this year, when the other kids see that the teacher says I can do it, so they start saying, "Ok, Simphiwe does actually know about the Maths" so they come and work with me and we help each other and we work together. When they don't know something they ask me. When I don't know something, I ask them. I ask, "Do you know this question?" and they will say if they know it. I ask my friends for help. If they don't know, I try it myself and answer it on my own. I take a scrap of paper and I practice on my own on the side. I still love Maths. It is my favourite subject. We do things called "values" and "nearest to", like

“round off to the nearest 100, nearest 5, nearest 1000”. I think I’m doing well in it this year.

I want to be a singer one day and record my songs. I didn’t used to sing. It’s what I do with my friends now. I write my songs. My friends write theirs. Then we go in my bedroom and we teach our songs. There are 4 of us in the band, me and 3 of my old friends in Grade 7, Asenathi, Bongsi and Liyasakha. We just started one day. I was listening to the radio and I thought, “I like music.” So I told my friends, “Come on, guys! Let’s sing now! We must sing in a band!” So we got paper and we wrote songs. So, I started this group. We called our group CEN, for Crazy Evil Niggers. We sing hip-hop. The beats are on the phone. It’s special beats we get at the studio there near my house. We record at that studio. But the guy there he tells us to finish our homework and focus on the schoolwork first, then we can come record. The music sounds so good! When I’m in the bedroom, I just sing!

#### 4.1.2.2. Parent B

##### Biography

*Lindiwe Dyasi is a 39 year old mother of 5 boys, ranging in age from 23 years to the youngest of 7 years. She is able to communicate in both isiXhosa and English. She and her husband are unemployed. They live in an informal settlement in Khayelitsha close to one of the main highways near the Cape Town International Airport. They all live together in a 3 room shack/informal dwelling consisting of 2 bedrooms and a kitchen/lounge area. The family use communal toilets. They share electricity with other dwellings in the area and do not have running water. Their extended family are in the Eastern Cape Province of South Africa. Lindiwe completed Grade 12 at school but did not pass. She attends a local Apostolic Church in Christ. She started experiencing occasional stress-related migraines and high blood pressure in the past few years.*

*Her 12 year old son, Simphiwe, was knocked over by a car in September 2011 towards the end of his Grade 5 year at school. He sustained a severe traumatic brain injury. He was admitted to the Children’s Hospital. CT brain scan showed a small left anterior temporal extradural haematoma and overlying lying left temporal skull fracture requiring neurosurgical intervention (craniotomy and evacuation). He was in ICU for 2 days.*

*He was transferred to a nearby hospital for inpatient rehabilitation a week later where he received Speech Therapy, Occupational Therapy and Physiotherapy. He was discharged home from there in mid-October 2011 and returned to school for the rest of*

that year. Lindiwe was with him throughout his hospital stay. This is the story of her experience of Simphiwe's school reintegration.



Picture 2: A quote for Mrs Dyasi

### **STORY OF FINDING JOY IN A CHANGED LIFE**

Before Simphiwe's accident in September 2011, there were no problems with him. But he came out of the hospital as a child who wasn't quite right. There were things different with him. He was hit by a car. He was coming home with friends after school. They were taking the long road home for some reason. That's when it happened. I saw him when he was lying there in the road and I didn't have hope that Simphiwe would be fine. I saw him in the ICU at the Children's Hospital and I thought that Simphiwe would not be able to walk. Then I saw him struggling to walk in the therapy at the big hospital and I thought, "He's going to walk, but not well." I stayed there with him at the hospital, trying to help him with everything. He needed help with everything. Talking - he was talking very, very slow. I didn't think he was going to talk normal again. Going to the toilet - I was worried how would he cope at home? You have to cross the road to go to the toilet. He needed help with everything. How will we cope with him? It is going to be a big struggle. And what about going to school? So, he came out of the hospital quite better, but he was a child who wasn't quite right.

### **FEARS AND UNCERTAINTIES**

He had been a very good learner before the accident. That is why I think he was promoted to Grade 6 in 2012, because he had been a very good learner before, in Grade 5. Before the accident, his teachers knew him to be a good student. He was a hard worker. He was well-behaved. He was very good at Maths. Maths was his subject! No one did his homework for him at home. He would get home from school, throw his bag aside and do his homework. He would get help from his brothers when there was something he didn't understand, "*Bhuti* [brother], what is this? I don't understand this thing?" Otherwise he knew his Maths very well. He was fluent in English too. No one spoke for him. When I saw his reports, I was very, very, very pleased about him because he is a good child at school. The teachers would call us parents in once a

month or so to tell how our kids are doing. They'd put out the books and tell us "Your child is good with this; he's suffering with this", but with Simphiwe I saw at these meetings he was doing very well. He did his homework very, very, very fine. He was just a good learner. He went to school each and every day. Even if it's raining, Simphiwe is at school.

After the Children's Hospital, he moved to another hospital in Cape Town for more therapy. He left that hospital in October 2011 and stayed at home about two weeks. I took him to school in November, back to his Grade 5 class. But he wasn't doing well at school because of his condition after the accident. I wanted him to go to school so he wouldn't just be at home thinking about what had happened. I wanted him to go to school so he can mix with other children and forget. He can play there and forget what's happening to him.

I also didn't want him to be isolated from the other children, because when he got back home from the accident, he was suspicious of people, thinking everyone is talking about him. I'd just be talking with my neighbour, Thandeka, and she would scratch her head, then he'd start crying, "I saw you! Don't say I'm mad! I'm not mad. I saw you scratch your head like this." Or if people are talking, he'll say, "No, don't whisper! Why are you talking about me?" And then he cried a lot. I tried to talk to him, "My love, are you all right? It's too soon after the accident. So as the time goes on, it's going to be okay. Don't stress yourself." But then he says, "No, I saw you with Thandeka! Thandeka thinks I'm mad! I saw her!" So, I saw that he thought he was mad because of his sickness [injury] and I wanted him to forget this and not be isolated. Also, the laughing. He could come in while we are watching TV at home and just start laughing non-stop. He doesn't stop laughing. I don't know if that is normal or not. Is it normal? The way he bursts out laughing is incredible. He just laughs. You don't know what caused it. He laughs until he doesn't feel like it anymore. He just laughs and cries the whole time. When he feels the need to cry, he could cry for an entire 5 minutes and then he just starts laughing again.

These are the things that have started happening after the accident. I don't know if that is what caused all this. Did the accident cause all this? He also doesn't listen now when you tell him "no". I mean, when he does something wrong you have to tell him "no" about 10 times before he actually hears you. You could even end up raising your voice and he must see you're irritated before he actually stops and listens. So, we see Simphiwe's not all right, but we thought, as time goes on he's going to be okay. But the time is real slow. It is really, really *slow*.

I knew the teachers know everything about Simphiwe, how he was before the accident, and what his problems are now, and they do understand. So, I thought it would be okay at school for him. But sometimes also if the other pupils in the class are talking their own things, then Simphiwe just stands up and says, "I'm going to fight with you! I hear what you are saying!" Then the teachers have to calm him down, "No, Simphiwe, they are not talking about you. They're just talking about themselves. So don't stress yourself." And then they take him out to the office and they just talk to him and he becomes calm. But after a few weeks back in Grade 5, the teachers said to me that no, he must stay at home for a while and he can take homework to do there, because he can't mix with other children because he's just crying a lot. But he didn't want that. He wanted to go to school. I also didn't want him to stay at home, like I've said. But he stayed home for the rest of that year and he did his assignments and his exams at home for Grade 5. So I had to watch him and help him. I did it all. It was my responsibility.

I was hoping school would help him to not think so much about the accident. He was now scared to cross the road, even for me to cross. If he saw a car, he'd just say, "Mama, don't! Don't cross the road! There's a car there!" He'd be crying, "No Mama, don't go. Send someone else to the shop because the car's going to hit you!" And you see, also, we don't have the toilets in our home, so we go across the road. So I had to go with him every time he needs to go, help him across the road, wait and then walk back with him again. It was difficult, but I kept talking to myself that he's going to be all right: "He's going to be all right, he's going to be all right, he's going to be all right." Because he is alive and as time goes on after the accident he's going to be all right. I really believed that it's going to be okay.

I wanted him to come to his sense again. Like normal. That's why I wanted him to go back to school. I thought, he's going to learn a lot at school. As he sits listening to the teacher with the other children, his mind will come back, that it will get to a point where his brain is back to normal. And then as he mixes with the other children, playing with them, he will remember he missed the kids from school and think "Now I am here with them", and that will also help his mind to come back. If he's just at home, he cries, worrying about what the kids will say, that they will think he's stupid since he had the car accident, that they will tease him about his operation as children like teasing. All these things prompted me to want him to be back at school and not to be at home.

So he only went back to school again in 2012 and they put him into Grade 6. I remember him saying, "Mama, I don't want to just sleep here at home. I want to go to school! I'm not sick!" I was very excited about that. But he struggled in that new grade,

Grade 6. He often lost his memory; then he'd come right sometimes. I mean, he was constantly on and off – unpredictable. His teachers told me sometimes, "I give Simphiwe some work now and he understands it, but when he goes out for break and comes back he will have forgotten it". Even at home he's like that. When you send him for something at home you have to repeat it over and over, because Simphiwe needs to be reminded all the time.

Also, Simphiwe had a tendency to fall asleep at school after the accident. His mind got tired very quickly and his teachers often asked for him to be taken home. They would call and I'd walk to go fetch him. He suffers from persistent headaches at school too. Especially when it is hot during the summer, then he has the headache problems. I don't understand what's going on. What's going on? It was so bad, from the heat I think, that he had to repeat the year, repeat Grade 6. The English he could do so well before has now disappeared. It just disappeared after some time. He used to be so good with Maths, but now he struggles a lot with it. Things he used to know have just disappeared over the time. I don't understand what is happening. What is happening?

And you know, Simphiwe needs to be watched over, because he could even hurt himself. He doesn't reason that he mustn't touch something because it's hot and he could burn. You need to know where are the best places that you can send him, that are safe, because he doesn't cope well with a lot of things. You can't send him to places that are dangerous. And there is very much danger here where we live. There is gangs and drugs. People get killed. Even, one of my sons is into the drugs and the gangs. He got into trouble with the police, him and those gangsters. They did a really bad thing. It causes me too much stress. I am going to send that son of mine back to the Eastern Cape, to his father's family, to get him away from here.

When he started going back to school after the accident in November I was worried about him walking home, because I knew he gets so tired. What if he collapsed on the road, so who was going to help him there? At least he does not cross a fast road. So I would estimate the time and then go to the school and take him from school. The next year, I made the plan and gave my number to his Grade 6 teacher, Mr Magoda, and said when school is out he must phone me and then I will go and pick him up and take him back home. I was also so scared about the sun, because he collapsed twice in the heat. So I tried to buy him a cap, but the cap was too tight, he said it made his head sore. So then I got him an umbrella.

I was also thinking at that time how he would mix with the other kids, having had this big operation and now his mind doesn't think well. He's still getting better. He's still

getting better. I got reports about the other children at his school who used to tease him. They used to laugh about the operation, call him names, like “train tracks”, because of the stitches. It upset him a lot and he’d come home crying. They don’t tease him anymore though. I went to the school and told the teachers. The teachers spoke to those children. They said an accident could happen to anybody.

At the end of that year of the accident, of 2011, we all went to the Eastern Cape for a few months to stay there. We go whenever we can, usually for holidays and funerals, like for my cousin’s sister who was sick and then my brother’s son who was in an accident. Both were in one year. My husband’s family and my family are from townships close to Umtata, the capital city of the Eastern Cape. Our villages were neighbours. So we grew up together there in the rural areas. We moved to Cape Town for work. But we haven’t found any. My mother-in-law is also down in Cape Town, but the rest of our families are in our home villages. My parents have passed on. And my brother. But my sister-in-law, it is good to visit her. She works at the hotel in my town. Life in Eastern Cape is good; it’s very good. It is good to visit and nice to be with the family. Sometimes you need to talk to someone but the family is far from you so it’s nice to be together and you can share all the things you have inside to share. So, after the accident, it was good to be close to our family.

Simphiwe had dates to see the doctors and therapists at the Children’s hospital again, but after the first follow-up ones we missed those appointments, because my husband was not working. So we did not have money for the transport to go there. I didn’t get another date for the follow-up appointments, so we didn’t go there again. I was scared to go and find out new dates because I’d missed them. I’d missed too many appointments. And it was a long time. So I didn’t know what I was going to say to them for why I didn’t go. So, in two years since leaving the hospital the first time, he hasn’t been to see the doctor or the therapists. I’ve been trying my best on my own. I tried to help.

#### FAILURE, RESPONSIBILITY AND SUPPORT

With all these challenges I must say his Grade 6 teacher, Mr Magoda, has been brilliant. He is a very brilliant teacher. Simphiwe doesn’t want our help at home with his homework. It’s like he thinks he knows the work, even though he does it wrong. He has told himself that he knows the work and he goes with that even though he is doing it wrong. He doesn’t seem to understand that things are no longer the same as before. Even if it’s wrong, he takes it to the teacher as it is. I don’t feel good that he doesn’t

know he's wrong. His teacher then shows him the right way with his homework. He takes help from the teacher somehow, but with us, his family, he's told himself that we think he's stupid. Mr Magoda knows the situation at home, that he doesn't want our help, especially with Maths. So the teacher decided that when it is time for break he must take Simphiwe aside and teach him the Maths again. He shows him and teaches him and then he understands. The problem is just that he forgets it by the next day. But Mr Magoda says he will keep trying, even if he has to repeat it 5 times, he doesn't mind.

He wants Simphiwe to stay in his class, not to change schools, because he says he knows Simphiwe, he is used to him and he wants to help Simphiwe to understand. You see, a lady phoned, I think she was a social worker or something. I don't know. I'm not sure from where she was, but she phoned me and asked how Simphiwe is doing at school. And is he at the same school as he was the year before? So I told her. She said he wasn't supposed to stay at that school; he should be at a special school for children with his problem, whose minds are slow. I was shocked and I didn't ask anything, but Mr Magoda must have heard about this, because that's when he said please not to let Simphiwe change schools, because they'll know nothing about him, they'll just move him on to the next grade without him understanding anything, and Mr Magoda doesn't want that to happen. He asked, "Leave him in my class, because I will work with him until I see that he is coming right and is ready to be moved on to the next grade." I'm not sure what all they spoke with the social worker, but my agreement is now with the school that he will stay there until he passes standard 5 [grade 7].

Mr Magoda used to call me each and every two weeks to explain to me how Simphiwe was doing in class and what the problems are – he likes to sleep, he doesn't always understand what the teacher is saying so he struggles but is trying his best, things like that. It was great to have that participation with the teacher all the time; it made me want to participate with the teacher. Sometimes the teacher and I would sit down and he'd talk with me until I understood. That made me really happy, because his teacher understood what sort of a child Simphiwe is now and he liked working with me as a parent, including me. He explained to me what help he wanted from me as a parent, to make sure Simphiwe didn't play too much in the neighbourhood but had time for his homework. "We can work together in that way," he said. I see from talking with him that Simphiwe's teacher understands my child and that he sees the reason why Simphiwe is the way he is at school is not because he is stupid, rather just that he had a problem. So I like that. He *understands* my child the way I understand my child. That gives me great joy.

As I said, he really struggled in that Grade 6 year in 2012. He had to repeat it. That was a very, very difficult time. He thought he was doing well; he thought he was going to pass. "Mama, I wrote the exams well." But I had been seeing all the problems through the year. It was difficult for his teachers to tell him that he had failed. All the other children got their reports at the end of the year. He came home and said, "Mama, I didn't get my results. The teacher said I should bring my parent."

I immediately went to his school because I thought maybe there were subjects he hadn't written. When I got there the headmaster was there with Mr Magoda. Simphiwe was standing outside the room with his friend. 'I'm going to get my report now. I'm going to pass!' We could hear them talking outside. The headmaster said, "Parent, Simphiwe's results are not very good. We are aware of his situation and we couldn't just give him his report with all the other children standing around. What should we do? Should we give it to you?" He showed me Simphiwe's results, 1's for English and Maths. He said, "With these scores, he has failed, Parent. I don't know how we can do this because he is failing, but we can maybe pass him." Then Mr Magoda said, "No, we cannot do that. It will not be good for the learner. He must repeat. He must have a chance to get all the work" and so they crossed out the pass and wrote there FAILED. They failed him. "Now how can we talk to him, Parent? How can we tell him this?" They were so scared to tell him! "No! I don't know!" I said. Simphiwe was waiting outside anxiously for me to come out with his report! Then I couldn't say, "My child, you didn't get your results because you failed." I was very, very, very sad. I cried inside the classroom. So I said, "Teacher, please keep this report. I will not take his report with me. I cannot tell him that he has failed. He is very sure he passed. I must wait. I will go back home and trick him, so that I can find the right time to tell him. I will say that the therapists at the hospital requested the report and will fax it to me another day." So I told him that and I said "but you passed." Then he jumped there, up and down, "Yes! I told you that I'm going to pass!" So, that was how I got out of that situation. I mean, I was not strong enough to tell him.

We came home and his father said "No, we're going to celebrate for you. You passed. So we're going to do something for you." Then we just bought something, drinks, everything, snacks, and we celebrate for him. But you know deep down that he has not passed. But you just want him to enjoy.

We went to the Eastern Cape again for the holiday that year over December. Eventually, that was where I told him. It was so difficult. Each time hearing him tell his friends he has passed. Pffew! It was very, very difficult. I just cried that whole day, the whole day. I regretted having to tell him that he failed. But I had to do it. "Simphiwe, the

therapist phoned me and they said, no, you must repeat again because they saw something there.” He just cried continuously. I said to him, “Young man, you know you are not like other children. Even if you fail, the other children will understand because you were injured.” That was painful, very painful, because Simphiwe is not clever but he’s a hard worker. But he’s not that same – before the accident and after the accident, there’s a difference.

The school said they would promote him to Grade 7 in June of 2013. So he accepted it that way. But in the January 2013 when he went back to school and they called the ones who passed and were going on to the next grade, he could not accept it. He cried all the time. That whole week when the schools were opened, he was not ok. Eventually he accepted it. I mean, by 6 months later he had already accepted that he had to repeat Grade 6. The school called him in and sat him down and explained to him, “Simphiwe, you haven’t failed because you are stupid. We know how you were performing before your accident. So this happened after the accident. So you had a head injury, so you are not able to grasp everything. That’s why you failed.” It was really difficult for me to break the news to him of failing. But I tried my best to do it because I had to do it. I had to do it. There was no one else who could have told him besides me. His father would not have been the best person, because every time we think or talk about anything concerning Simphiwe, he can’t handle it. Simphiwe accepted that he had to repeat because of his accident. But still, at the end of that year, when his friends were going to be graduating to high school without him, he said, “No I’m not going to that graduation. I will cry if I go, Mama. Because I was supposed to be there!”

Since the accident, I have been in charge of looking after Simphiwe. That is just how it is. I showed my family how we should change in treating Simphiwe after the hospital. I had stayed with him there, so I was able to watch his progress and even how the therapists spoke to him. They had a tendency to do everything slowly with him, and be patient and let him take his time, not shout at him. I do not complain about it, because I have to do it. But I have a strong support system with my own children and with the community. Especially when I’m not around, they look out for Simphiwe. Because when I’m home, I take the responsibility... For example, playing outside. When it’s hot he shouldn’t really play outside because if he’s in the sun too long, his complexion goes very dark and we won’t get any sleep because he has a big headache and we have to get Panados [headache tablets] and all that to attend to him. But I let him play outside a bit, because he’s only just a child. But then I must call him back inside sooner. So, his older brother when I’m not home, will take that initiative to ask him to come back inside.

And everyone in the community is fine. I mean, they are really a bunch of people that care. They even look after him on the roads. When they see him by the road, they will call out to him.

#### KNOWING JOY IN A CHANGED LIFE

When he was 11 years old, I thought Simphiwe was going to pass Grade 12 on time, at age 18 years. He was such a good learner. Now I don't know, because *everything* is different for him. When will he finish school? Now I just want him to finish Standard 5 [Grade 7] and then we will think further. I know that I don't want a school that he is going to have to travel in public transport by himself. I want a school that is going to have its own transport. And a school that can understand his situation. Like Mr Magoda understands his situation. I am very scared to think about high school. I don't know. Which school will be good for him? Which school I can take him to? But let him first finish Standard 5...

My good memory is that my Simphiwe is doing well now in this second year of Grade 6. He has time to understand the work. I saw him lying on the road. I didn't think he would walk fine, like now. Or talk normal again, like this now. You know, he's doing his music? He's very busy with that. He's writing songs, doing music. He started with his friends, four of them. One who was with him at the accident. They started music and I was happy for them. He tried to play soccer but when he's on the playground he's feeling dizzy. And so he doesn't fit. What is nice about the music is I love to see him happy! He likes music very much! And I was happy for him. And then I tried to push him so that he maybe can get a talent for the music. I thought it could be a strength for him. Because schoolwork is not so easy anymore, especially Maths. He's struggling in school with everything but especially Maths. So I wanted to see what other talent he's got. Then I saw his singing. So then I was very, very, very happy for him. There was hope that he could use that talent. He was very, very good "Ah, here's a chance!" When he's finished his homework and assignments, he takes this book with his songs in. I ask him, "What are you doing?" "No, I'm just writing my song, Mama". "Ai, you are busy, my love," I say. "Yes! I want to write another one. I ask you for R10, Mama, so that I can go to the studio with this." He and his friends go to the studio and pay so that their song can sound professional and good. They are making a CD. So, I'm very happy about him. I am very, very happy. When I heard his voice there with that song, he's rapping and rapping – I was very, very happy. Simphiwe, he was singing!

#### 4.1.2.3 Educator B

##### Biography

*Mr Magoda is a 42 year old isiXhosa-speaking gentleman who has been a teacher for 14 years since 2000. He can also speak English. He has taught at Wandisa Primary School, an inclusive school in Khayelitsha, a large Black township in the Cape Metropole, since 2003. He has been a Grade 6 educator all that time. He is a Christian. He is a member of the school governing body and coaches athletics and soccer at the school as well. Wandisa Primary school is an inclusive school. Mr Magoda has on average 30 learners in his class. He was Simphiwe Dyasi's Grade 6 educator in both 2012 and 2013, the first two years after his head injury.*

*This is the story of Mr Magoda's experience of Simphiwe's return to school following his head injury.*

#### **STORY OF UNKNOWING AND OF GROWING**

When Simphiwe came to my Grade 6 class in 2012, I wondered why he'd come to me. He is a child who was in an accident and had a head injury. I didn't have any experience working with a child with a head injury; I didn't know what to expect. I told myself that it is probably a lot of work that I will have to do. I'd had a child who got fits before. And then one who was being abused at home; that one was out of my league and the social worker got involved. And then a child who had bad eyes and needed to wear glasses but didn't want to. I didn't know Simphiwe from before; now I had to get to know him from the start. Why did the school give this child to me? What criteria did they use to give him to me? He'd been out of school for 3 months near the end of Grade 5. Did he complete the syllabus? I wondered, "Why did he pass Grade 5? How will Simphiwe cope this year?" I had many questions. I didn't know the answers! But he was coming to my class. And I knew nothing about him or his head injury or how to handle any of it in the beginning. I saw him for the very first time when he came into my class at the beginning of 2012.

#### **IN GRADE 6**

His mother, Mrs Dyasi, made contact with me that first day of school. I was glad she spoke with me as I hadn't gotten information from, Mrs Luthu, his Grade 5 class teacher. At least, I would've liked a proper report as to what happened with the car accident and with his learning after. Mrs Luthu just told me he was in an accident. No

other information. She didn't give me copies of the hospital reports. She said she didn't have them; she forwarded his school profile to someone. And his parents said they had sent everything to the lawyers (Road Accident Fund). That really was very unfortunate, not having all that information about him. So, I didn't know what happened with him when he came back to school in Grade 5 after the accident. Was he coping in the class and learning or did they just push him through to Grade 6? I didn't know what kind of a person he was before his accident, like how he was in terms of his behaviour? What was his progress at school? I don't know if he wrote all or part of his Grade 5 exams or even how he did. I know one of the Grade 5 teachers gave Simphiwe's older brother some work to take home to him to catch up, I think. I feel I could have done better for him if I'd known a bit more before.

I would think that Mrs Luthu could have gone with him and the other learners in her class into Grade 6. Sometimes we can do that in Primary School that the teacher moves up the grades with the children. I would've thought they should do that in this case. Because at least she knew him better, how he was before, how to handle this situation. But I heard the Grade 5 teachers saying that "Now this learner is going to be a problem to us. Since he got this head injury, this learner is going to be a problem. Let this learner not be our problem". And so I think they pushed him on into Grade 6.

So, yes, I was glad his mother came to speak to me even though I was very busy with administration then. She made me aware of looking after him when he started in my class. She said she wanted to speak to me to tell me about Simphiwe and the problem with his head. She wanted to tell me how he is supposed to be protected. She asked me to tell his friends that whatever game they're playing they must not hurt his head. But I can't always be with the learners. At break, I have meetings to attend or something like that. And she even said to me how to discipline him. So, because of these comments from her, I said to myself that this learner has a head injury and something like that must be respected. So now I knew a bit better how I must pay special attention to him, for instance whenever he plays. But I also thought, I mustn't treat him specially; I must put an eye on him [*keep an eye on him*], but not treat him specially. And I saw I must make sure that we work hand in glove with his parents. That's why I was always making sure that I call his parents. We can work together, because I cannot work by myself alone. In order to deal with Simphiwe's situation I must not leave his parents behind, I must keep them informed of his progress and problems. We must work together in order for him to perform.

Even though I didn't know him from before, I could quickly see that Simphiwe had some problems. The speech, his speaking, was a little slower, like someone who is

tired. It was difficult to hear what he was saying exactly. I found out that he is restless. His mother told me he sometimes feels dizzy. Then he says, "Teacher, I'm feeling dizzy." Sometimes I found out that he is tired while you are teaching him and he will just fall asleep in the classroom. Maybe his mind does not want to take in too much but he does not want to say to me that now he is tired. But also, he often likes to take a break outside. But I say to him, "No, you just came in from break. Why do you want to go again?" I said that but I still allowed him to go out, because of his problem with his head. I didn't want to cause damage. So he needed lots of rest in the beginning and then he'd ask one of his friends to take him home when he woke up. It was also difficult because you must not leave him behind in the work; you must make sure that you get him to be involved. You must not exclude him from the other learners, but you must also know that he's got the problem of this nature.

Giving him this attention, I heard some of the children gossiping that I'm treating him differently to them. They think you are showing favouritism. As an adult you can't let those things discourage you. Kids can say anything they want to. You ignore those things, because you've got this achievement you want to achieve, helping this child Simphiwe get through the year. The kids take extra notice of Simphiwe then, even minor things. They say to you, "Teacher, he's being naughty, but you're not doing anything to him", like I would discipline them. You have to devise other ways for him; you need to treat him as a doctor's case, you see. His mother had spoken to me about disciplining him at the beginning of the year. I was worried if I do the corporal punishment, he will faint and then I will lose my job. Especially with his dizziness. I had a fear that I would hurt him in some way that would damage him. I didn't know. And how do you explain that to the Department of Education? The Department are saying "Do away with corporal punishment."

Some of the learners are aware of Simphiwe's situation, of the accident, but when you are implementing these things, they think that you are treating them differently to him. It haunts me that they misunderstand, misinterpret what I am doing. He is getting special treatment, but I'm not meaning to show him favouritism. He needs that help. And for Simphiwe, being treated differently, or actually for any child being treated differently because of a special need, you must be open with them about why they are getting this attention. You must explain that you are not doing this to embarrass them but to help them and that his parents agree. You don't want to embarrass them in front of other learners. He might think, "Am I a slow learner? Am I different from other people?" And you can read on his face then that he is not happy with that. But then I discuss with him and say "I am trying to help you because you had this and this in the head in Grade 5.

It's not that you are different from other people but you are having this problem and you know it because you used to tell me you were going to the doctor. You are not 100% well." I said this to him so that he could understand the attention and behave a little bit better. For an example, he is rough. When they play he is very rough, so I said to him, "Hey, you must not be so rough because you've got this problem with your head." And also, I've observed that when he is angry it is frightening because you think he might faint. When you tell him something trying to discipline him, then he gets angry.

Another thing is the workload. The workload in Grade 6 is more than in Grade 5. I sometimes felt pity for Simphiwe in the beginning because he had to cope with more subjects in Grade 6, more learning areas. They have 6 in Grade 5 and 9 in Grade 6. And I think that was too much for him. It was difficult for him to keep up. For instance, when he's dizzy, I cannot keep him here at school, I must send him home. If I send him home, then he's missing learning. And as teachers, we each want the children to excel in our learning area. So we sometimes overload him with work, I think. Maybe that makes him dizzy? We sometimes maybe forget that there's a learner of Simphiwe's calibre in your class; you just want to finish the work, to get through the syllabus. So, maybe we overload him sometimes with work and he gets dizzy, then you just leave him. You must be flexible in that situation. It's difficult because you must change your style. You change that, you try that and you do that. When you're planning your lesson, when you're giving your lesson, all the time, you must have this picture of Simphiwe before you. Then you can sort of remember, *eish!*, there's this learner in my class. I must accommodate him. Always accommodate him.

You must be sober minded when you are planning your work so that you are able to cater for him as well. It takes up a lot of time. I'm an experienced teacher. I can do my lesson preparation in about 10, 30 minutes in the evenings usually. But now with Simphiwe, he is challenging me now, so therefore I must put in some extra time. Go the extra mile. It takes some of my holiday time, some of my quality time. But it's my choice to do it, nobody forces me. I did take this burden on my own, this burden to help the boy. So I said to myself, this is my burden, I'm gonna do it. I put him to sit next to me in class so that I could always have my eye on him when he's doing his work. So that I can iron out any problems. I must make sure that I don't just give them some work and sit here and read my newspapers. I must make sure I sit here close to his desk, or stand there behind him and see how he is doing. And when he brings his work, I must make sure I give that special, individual attention. Not like, for instance, give my corrections on the board and say, "Question A is done like this." I must rather go to him and say, "No, look here, you could have said here, and you could have said

here.” That kind of attention. Not just generalize. I must make sure that I bring him closer to me.

You must focus more when you have a learner like Simphiwe. He had to do extra work that first year in Grade 6 because of bad results; he missed those months of school when he was in hospital. And the pace that he was moving was not the same pace as that of the other children. He worked slower. So, for instance, you must not give him a load of work. Give him a little, a piece of work. For instance, we’ve got 10 sums to do, then you must give him 3. You mustn’t give him extra work. Then, as time goes by, you give him another 2 and you see how he copes. So he needed that intervention of extra help, extra work to help him catch up. He’s slower, but he’s very good at Maths, because it’s all about practice. It’s not about studying, about storing up all this information. If you’ve got a formula, you can do all these 10 sums. It’s different to Social Sciences, for example, where you have to grab all this information from page 99 to 200. It’s too much for him. Too much for him. And see, if he’s in this school, Wandisa, it’s an inclusive school, not a special school where they will take things slowly, so he just has to deal with that situation.

When the school screened him after the accident, we must have said, “No, he is coping.” I do not think he belongs in a special school. He didn’t ever need to go to the LSEN<sup>8</sup> (learner support, previously remedial) teacher, because he can read and write. He’s got a very good handwriting. He can read. He can write. So he is coping anyway. Some children who *don’t* have brain injuries are going to the LSEN teacher. They have those learning difficulties. But still, it’s a challenge to have a learner of his calibre in an inclusive school. It’s a challenge in the sense that maybe we are not trained to deal with learners of Simphiwe’s calibre. You need to develop a second skill within you to deal with a learner like him, because you do not have a trained skill. It’s a challenge in that manner. But it’s funny, because even these learners that are normal, they are challenging as well! Simphiwe can do Maths better than some of the normal learners. Then I wonder, “What is wrong with these other learners? Simphiwe can perform better than them! Now what is going on? Is it a social problem? A social economic problem?” So, what I understand now is that there are challenges with these normal learners. They are a challenge on their own. And then a learner of Simphiwe’s calibre is another type of challenge. I guess it depends what kind of teacher you are, but it’s not at all easy to have a child like him in your class. His challenge is this: all the extra work, adjustments and time you have to put in for him. Otherwise, he is just a normal child generally. An ordinary child.

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<sup>8</sup> In the Western Cape, the aim is to have one learner support teacher for every 2 schools

Communication with all the stakeholders is important when you are dealing with a learner like Simphiwe. Everyone must be involved to help you to deal with his problem. You know, no one followed up on Simphiwe once they'd accepted him back to our school? No one paid attention to his issue, not the principal, the management of the school. They should have made some provision when they accepted him back, even if they thought he would be coping. They should have come to find out "Simphiwe, how are you doing? Is the teacher doing well with you? Do you get some support?" and stuff like that. But no one did. It was my burden.

The other learners were a big help. I found out it's important to work with them, to include them. Sometimes you want to make more of group work than individual work. To support Simphiwe. Sometimes more of the activities needed to be group activities just to support him. One must not give him always individual work. Sometimes you find out that the learners understand other learners better than they understand you. And the learner finds it easier to ask for help among his colleagues, to say he didn't understand something, rather than being singled out in front of the whole class. But you can't just put anybody in the group. As a teacher you know your learners. So you put him in a group with the child who is patient, the child who specializes in a certain learning area that he is struggling with. That did help him.

Last year, in 2012, there were other teachers involved too. I was his Grade 6 class teacher, but he had different teachers for different subjects. So I said to these other teachers, "Let's try to work together and give him support." It's not just for me to do, as his class teacher, all of us must be on board in this situation. I try to motivate them not to abandon Simphiwe, that one day he will be all right. Because maybe sometimes they are getting sick about his situation. But some of them, they do give him support. So, you know, it's tiring sometimes, keeping people involved and communicating. His Grade 5 teacher did not want to cooperate with me in terms of giving information about his learning and behaviour in her class. She didn't even give me his books to see how he'd been doing with her. It's sometimes like that here. Sometimes we as teachers, as staff members, we are selfish. But you don't dwell on that, when a teacher doesn't want to support you in terms of this kind of learner. Maybe Simphiwe could have passed Grade 6 if I had that information from Mrs Luthu. Maybe. Or maybe she could've done better with him than I did because she knew him better. And then maybe he could have passed Grade 6.

## FAILING GRADE 6

I was scared to tell him that he was going to fail Grade 6. I was scared he was going to get a shock and faint. That he would get so angry and faint. Because he could see that his friends passed, so obviously he's going to pass. Simphiwe was not doing well though. His mother was worried about Simphiwe failing so she wanted to say to me, "He must pass." And I said to her, "By doing that I'll be killing him. He's going to become a drop out. It will be tougher in the next Grade and because it's a problem of the brain injury it will affect him more." But now, if he passes on his own, it will be better for him. He will move smoothly and it won't affect him psychologically.

His mother was worried and I was scared to tell him he failed, because most of his friends passed. He was the only one who failed. But his mother was not caught by surprise at this news he must fail; I was communicating with her all the time through the year about Simphiwe's progress. It is difficult when parents see things differently at home than you see them at school, but in his case they saw the same problems. Some teachers, they would pass a learner like Simphiwe on. They say, "Uh-uh, man, this year was a tiring year, because Simphiwe was in my class. Next year he must go. Even if he doesn't perform, he must go. Because it is strenuous work." But I don't think it's wise to do that.

So, when he failed last year I didn't want to tell him. I didn't even want to give him his report. I was worried that if I told him something that was going to be a surprise for him then he is going to faint. Something in the head is very dangerous. I was giving all the other kids their reports. I could see by the way he was looking at me when he asked for his that he was going to cry. So I decided it was not for me to tell him what was going on. He must go home, sit down with his mother and then his mother must find a way of telling him. So I called her. I gave all the other kids their reports. He was very cross and angry. He was sitting there and he asked me, "Where is my report?" And I said to him, "Your mother must come and take your report." I could feel that he is anxious. He wanted to know. Why is this teacher not giving me my report? Why can the other children open theirs? Why does he want to call my mother? So he was sceptical about what was going on. Then his mother came and I told her, "This gentleman has failed." She said to me, "Hey, I don't know how I'm going to handle this situation, because this man, sometimes when he is angry or shocked he faints." At this point, he was standing outside the door and wanted to know what's going on. His mother said to me, "Tell him that the report went to the doctor." So I told him. I don't know how his mother handled it after that. But I told her she must not hide that he failed. At the end of the day he must know that he didn't pass. And I also said to her that when Simphiwe comes back to

school in 2013 I will make sure he is in my class, since I know his situation now. I said that I didn't want him to be in another teacher's class, so I can deal with the situation at a very close range. I believe that is why he got the results he has now at the end of 2013, because he came back to the same teacher who was teaching him in 2012.

#### IN GRADE 6 AGAIN

This second year in Grade 6, in 2013, is good. Now I know how to handle him, how he was the year before, what the difficulties were I've experienced with him, how to change my style to accommodate him... In 2012, it was not easy for him. But at least this year he is quite coping. He's actually getting quite good results. He is good in Maths and his scores in general have gone up. He's with a teacher who knows him. This time I'm his only teacher; I teach them all their learning areas. It helps him to get the special attention. Initially it was very difficult for me to deal with him, but now I can understand his position. He still gets tired and loses concentration. The progress in his schoolwork was very slow, but it's improving now. And his behaviour is better, quite normal now. He looks normal. He's behaving like a normal person, like any other learner. It's not a scary situation anymore. Just the progress in his school work is a bit slow.

And his parents' cooperation is also important. Every time I'm having a problem with Simphiwe and his behaviour I'll call her and she does respond. And what I did with his homework, I would write at the bottom that she must leave a comment about the work. That way I could see if anyone at home is assisting him. That cooperation from his parents really helped me to get the good results he's getting now this second time round in Grade 6.

There was a quarter [term] though when they didn't play their part. Simphiwe was being absent too much that term. Maybe only 2 days a week he would come to school. He used to bring letters from the doctors if he was off but now there was no reason. Work was very busy that quarter with the annual national assessments (ANA). That's when people from the Department of Education come to check the Grade 6 and Grade 3 pupils. I had very little time to communicate with his parents and find out what was going on. He was absent for those National Assessment days. He was supposed to be present; those tests are very important. Maybe he thought that those tests are very challenging and so he stayed away. The tests are challenging, because they are national, not only for Simphiwe but for all the Grade 3 and 6 learners in South Africa. So, that was not good, when his absenteeism went up like that with no explanation and

I didn't have time to contact his parents. That contact with the parents is important. We need to keep that communication. But I think they should have also played their part; the communication is not supposed to be initiated by me only but by both of us.

So this year was better but still had its challenges. It disturbed me when he was absent so much. I felt like he's dragging me backwards after all the work I've done with him, all the effort I've put in! I hoped I didn't have to start all over with him again, all the spade work. I didn't think I'd have to, maybe just iron some few things out and get his parents back on board, but I was worried about that. I knew he was still going to be a child who needed a lot of attention and extra work from me this second time in Grade 6. But I saw that he is a child who is eager to learn, he really wants to study, he really likes school. He's just got the problem of the head injury. He didn't cause it himself. It was an accident. So I just wanted to help him, I wanted him to be in my class, even though I knew it would be a challenge still. I wanted for Simphiwe to achieve his goal because I could see he is not blank. Also, I felt he was my responsibility given to me by the Lord and if I passed him on to another teacher, in the eyes of the Lord I would be judged. I'm the person who was supposed to help him because I know his problem. If I just passed him to another teacher, maybe that teacher will also not be able to help him in the beginning because they have to start over, and so he will fail Grade 6 again, and again be pushed through because the teacher will say, "This child is a problem. I don't want this child in my class." And they will pass him on to another teacher and Simphiwe will see, "Hey, I'm being made a ball here. These teachers they are not willing, not ready, to help me." And he will become a drop out.

It makes me happy to see his success after all the effort I've made. All I've done to help him. It gives me joy. It makes me happy and I am proud that he is doing well now. And I'm proud that I was on the right track. And I didn't give up when things were difficult. His parents also, I am sure they will be happy that I said he should repeat the standard, that he must pass on his own, not just be pushed through to the next grade. They will be happy that I took him into my class again and didn't let him go to any other teacher, who would have to start from scratch getting to know him, start the spade work, all over.

So, Simphiwe's next stage is going on to Grade 7. And at least I can say he is fit for Grade 7. Yes, he will make it for Grade 7. And not just because of the Department of Education's rule that the learner can't repeat twice in a phase. He will pass because he is ready.

It was a very difficult decision for me to make him fail Grade 6, because people were saying, “No, just let him go. Then the learner will be happy.” And I could see how upset he would be to get the news of failing. But I was thinking of his future. But now, now he’s a happy man. And he will be even more happy when he sees that next year he is going to Grade 7!

## GOING FORWARD

But you know, you can’t just say, “I’ve done well this time and so Simphiwe can stand on his own feet.” You’ve got to keep all the stakeholders involved. Like how things were difficult when I lost contact with his parents this year. You’ve got to keep watching him, keep helping him, keep everybody informed at all times. So, even though Simphiwe does well now in Grade 6, it does not mean I have now finished my work. Since I am the person who knows his situation I must also inform the Grade 7 teacher and the parents they must then also when he starts Grade 8 inform that teacher. It must be something that is continuous, this communication about Simphiwe, until his situation is improved. He’s a minor, a kid, he needs to be looked after. Teachers must do this for all their learners, but with Simphiwe, you need to go the extra mile. You need to put in more effort with someone like him.

I’ve learnt now that in a situation like this with Simphiwe, you are not just a teacher, whereby you teach English, Maths, Science and that’s your profession. You’re more than a teacher now with a child like him. You are like a parent, you are like social care. You have to look at other issues too, not just the teaching.

I look at all my children differently now. It is important to know everything about your learners. Not just their name and surname and where they stay. So that when they have a problem you can know how to help. You must know them – what they like, don’t like, what their allergies are. You know, sometimes you can eat something and you see the learner looking at you and you think, oh, he’s hungry, so you give some food to that learner, but then the learner is allergic to it and you get in big trouble. So, I’m saying I realize you need to look at your learners more holistically. Also some learners are not physically challenged. But you find out they’re having problems at home. Social economic problems. That can be almost equivalent to physically challenged problems. Because that child you can see is psychologically disturbed. So I’ve got to pay attention to that particular learner too, find ways of helping that learner. Simphiwe’s kind of problem opened my eyes to many different things. I look at the children differently now to how I did before.

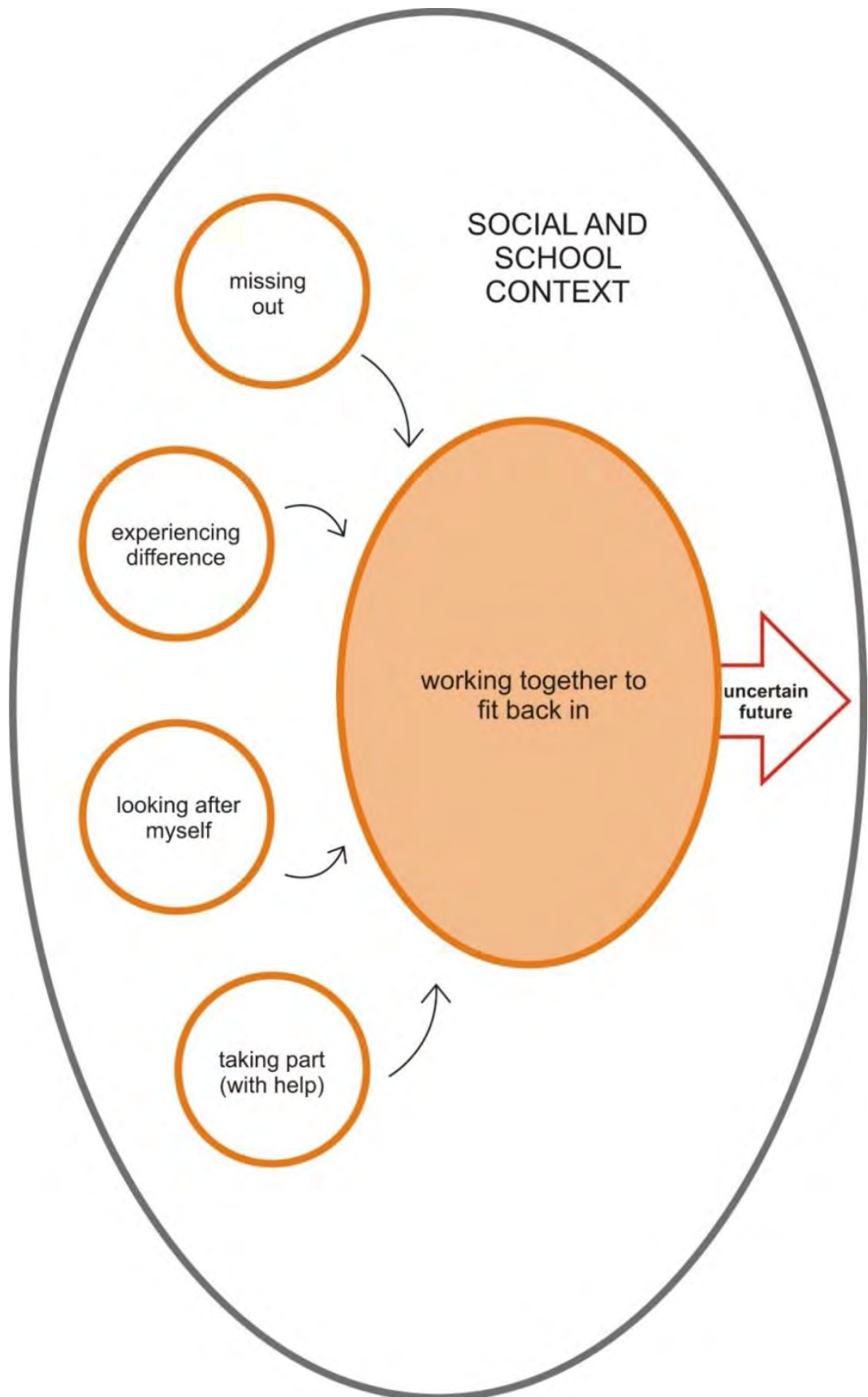
Having Simphiwe in my class was a big challenge. But I enjoy challenges and I learnt skills. I'm a fighter and a winner. His report this year, showing that he can go on to Grade 7, is to me an achievement.

#### 4.2 Level 2 – Categories per participant type

The children, parents and educators provided rich data on returning to and being back at school following TBI. Their stories relate their individual experiences and the barriers and facilitators to inclusion, as they perceived them. Thematic analyses, as described in Chapter 3, were done to reach the essence of their experiences. Facilitators and barriers to inclusion were identified/extracted during this process. The researcher will first present the results from voices of the children, then the parents and finally the educators. Selected excerpts from the individual stories will be presented to support the category findings which are illustrated in Figures 3, 4 and 5. The excerpts are not an exhaustive list. The resultant theme that emerged from the synthesis of these categories will be presented and discussed in Chapter 5, again with the children first, then the parents and finally the educators.

##### 4.2.1 Categories emerging from the children's stories

Following thematic analysis of their stories, 4 categories emerged which relate the children's experience of being back at school. These were labelled "Missing out", "Experiencing difference", "Taking part [with help]" and "Looking after myself" (see Figure 3). These categories combined and the resultant essence of the children's experience of being back at school following TBI was encapsulated within the theme of "working together to fit back in". The children note the passage of time and possible impact of the TBI on future schooling, hence "uncertain future". Their stories are told within particular school and social contexts which influence their individual experiences. Systemic issues are not recognized directly by the children, and thus not captured in Figure 3; however, their impact on the children's contexts is implicit. Each one of the categories is explored in more depth below.



*Figure 3: Children's experiences of being back at school following TBI*

#### 4.2.1.1 Category 1: Missing out

The children were conscious of missing out from both social and academic activities as a result of the TBI. Mohamed relates missing the school holiday due to hospitalization. The fact that he included this in his story highlights the importance children attach to experiences which are shared with friends which, can be retold to classmates in the new term/year. Not having these shared holiday experiences resulted in his perception that he was “missing out”. For Simphiwe, he missed out on progressing into a new grade with his friends as he had to repeat Grade 6. *“The worst was when I failed Grade 6... My friends moved to Grade 7 and I stayed in Grade 6.”* This longer term effect of the TBI on academic outcomes meant that future shared experiences with his current friends had been eliminated.

Simphiwe was acutely aware of the physical difficulties, such as dizziness, headaches and fatigue that made him miss out on schoolwork. He explains: *“...after my accident, I have some problems now. I get headaches and start to feel dizzy. It’s more bad when it’s hot. I have to sleep and not play too much. My energy just runs out and I don’t want to do anything. Then the teacher says I must go home and I feel upset. I don’t want to miss work!... Work goes too fast now. I want to keep up!”*

The children’s stories show that residual cognitive and physical deficits were barriers to participation in learning as well as social activities. These caused them to miss out on full school days engaging with peers and learning new academic skills and thus affected their experience of school after injury.

#### 4.2.1.2 Category 2: Experiencing difference

The children recognized that they were different and were treated differently after the injury. Differences were felt in appearance, personal ability and academic achievement.

Both children had clear recollections of being teased and bullied due to physical scarring: *“There were kids who called me names. They called me ‘Dentjies’ because of the dent on the front of my head.”* *“He said I had... train tracks.”* In addition, both children described the help and support they received from their parents and educators when they were teased, which acted as facilitators to inclusion/reintegration.

Both children experienced a marked change in their experience of schooling in general and of learning in particular before and after the accident. The change is described almost as a complete about-face: *“Before the accident, school was nicer. It is difficult since the accident.”* and *“Before I have the accident then everything goes right. But*

*now! ... Everything is more difficult! Everything takes more time!*” Simphiwe also found that *“I must listen more carefully in class now than before the car accident.”* The differences in their learning are a result of the cognitive-communicative disorder that is typical following TBI, for example, slower processing speed and difficulty with auditory comprehension of longer utterances (Hartley, 1995).

Despite this clearly negative comparison of school before and after the head injury, the children were able to note positive changes in their ability over time. Their observations were linked to people and practices that facilitated their inclusion/reintegration, indicating that the children have awareness/insight of what helps or hinders them. For instance, Mohamed noticed that he no longer needed to ask his teacher for help with difficult work anymore. He could also sit where he wanted to in class, not only in the front, near to her. Simphiwe realized *“It helps if they give me more time... Because I am not too fast when I write the tests.”*


“Experiencing difference” is a category that encompasses a large range of changes across self and schooling in general. Although many of these are negative, the children are aware of the positive influence of the teachers in the environment. Simphiwe, for example, explains why he feels supported by Mr Magoda: *“He also gives me time. It helps if they give me more time... He also helps me because he encourages me and says “You can do it, you are very good “*



#### 4.2.1.3 Category 3: Looking after myself

The two children who participated in this study took responsibility for their own reintegration, finding significant, though seemingly small, ways to manage the challenges they now faced. For example, Simphiwe describes quietening the class so that he can listen better as he knows he needs to. *“I don’t want anyone to disturb me when I am sitting listening to my teacher. When the kids make a noise then I just stand up and say, Shhhh!”* Mohamed used ignoring or reporting as methods to handle the children who teased him. *“They teased me. I did nothing and just walked away. But sometimes I got angry and told my teacher.”*

The researcher did not find literature addressing this area in children with TBI; however, literature on young people and adults with TBI describes the importance of self-advocacy (Hux et al., 2010; Ylvisaker et al., 2005). The children display an awareness that you need to care for yourself and provide examples of this self-advocacy at school.



#### 4.2.1.4 Category 4: Taking part [with help]

The children spoke to both academic and social participation, the areas of fall-out following TBI described in the literature. There was a definite sense in which inclusion, feeling and being part of the peer group, was valued, rather than simple reintegration, i.e. being physically present in the school environment. Their words indicate that this inclusion is not possible without the contribution of others.

Positive academic experiences were supported by group work which created opportunities to work together with peers. *“I like it when we work in groups. Cos you work together... it helped me.”* The children appreciated being able to ask friends for help with work and valued being able to reciprocate. They also depended on parents for assistance with homework and were glad when their educators were willing to help them by accommodating their learning needs or answering their questions.

In terms of social inclusion/participation, educators and peers made the children feel happy and cared for by the way they welcomed them back to school after the injury, throwing a welcome back party and making a fuss of them. Both children emphasized these first-day-back experiences in their stories. *“My friends were happy to see me. They all carried on so...”*. Being included in extramural activities, even if the role was small, fostered a sense of belonging. *“I like it when we have sports at school...I didn’t play. I watched how my team played. It was nice to be there!”* Simphiwe and his friends found a new activity, recording music, to enjoy together.

In order to participate fully, to belong, or be included, the children depended in a large part on their educators, peers and family and their willingness to adapt and assist.

#### 4.2.2. Categories emerging from the parents’ stories

Following thematic analysis of their stories, 5 categories emerged which relate the parents’ experience of their child’s return to school. These were labelled “Adjusting expectations”, “Shouldering the burden”, “Not knowing”, “Needing (and receiving) support” and “Seeking understanding for my (changed) child” (see Figure 4). These categories were combined and the resultant essence of the parents’ experience of being back at school following TBI was encapsulated within the theme of “struggling with change in an unsupportive system”. The time line serves to highlight that this struggle continues throughout the child’s school career. In many ways the cycle of burden for parents starts again with the new school year, new educators, and/or new school. Recognition of the long term and extra burden of care on parents of children

with TBI is recognized in the literature, with Backhouse and Rodger (1999) describing the experience as “war weariness” (p.107) and Nelson, as cited in Bedell et al. (2005) as “mothering ‘plus extras’” (p.281). The parents’ experiences cannot be separated from the systemic and social contexts within which they occur.

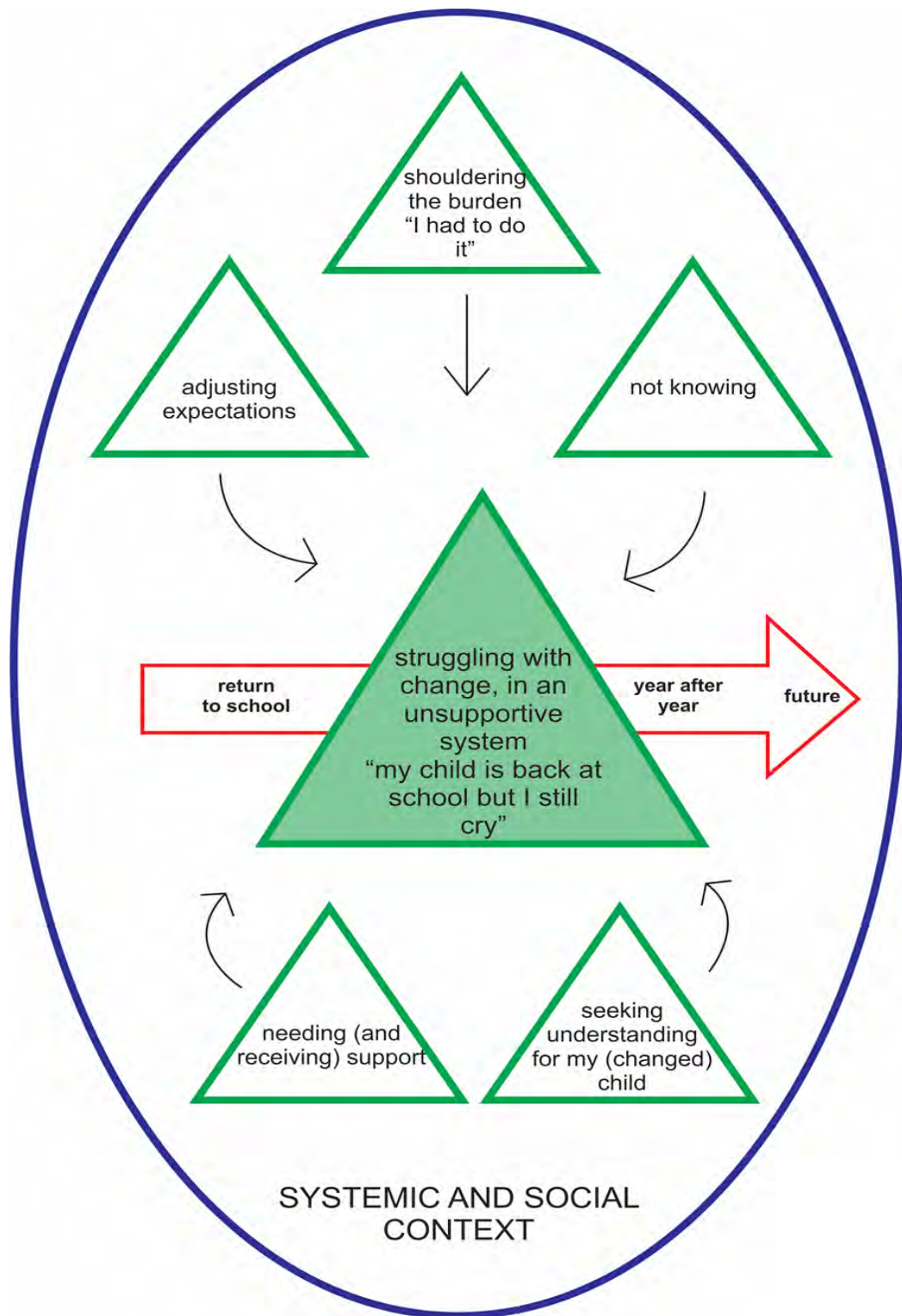


Figure 4: Parents’ experiences of being back at school following their child’s TBI



#### 4.2.2.1 Category 1: Adjusting expectations

The parents' stories tell of the process of coming to terms with the shock of the TBI and adjusting to the changes it wrought in the lives of their children. They tell of grieving over these changes, most notably the cognitive and behavioural changes. Mrs Ibrahim notices that Mohamed is "*slower now*" and that "*it's like that daydreaming has gotten worse.*" Mrs Dyasi finds that Simphiwe "*needs to be watched over because he could even hurt himself.*" The grieving is tempered by a sense of gratitude that their child is alive and the recognition that "*it could've been so much worse*", as Mrs Ibrahim explains from her experience of meeting children with severe disabilities after TBI at hospital follow-up appointments. They were terrified their child would die and then elated that they would live and recover. "*I didn't think he would walk fine, like now. Or talk normal again, like this now.*"

However, the realisation slowly dawned that certain differences would persist. Both parents considered the implications of these differences for their child and struggled to reconcile the pre-injury hopes and expectations they had for their child's future with the child's post-injury abilities. Mrs Dyasi reflects that "*When he was 11 years old, I thought Simphiwe was going to pass Grade 12 on time, at age 18 years... Now I don't know, because everything is different for him*" and Mrs Ibrahim states, "*Thinking about special school, that wasn't the plan.*"

Accepting that their child would find schoolwork difficult and consequently looking for new avenues for achievement, such as Simphiwe's musical talent, were evidence of adjustment in the parents' lives.



#### 4.2.2.2 Category 2: Shouldering the burden

The weight of responsibility placed on the primary caregiver comes through forcefully in the parents' stories. Quotes such as "*I did it all. It was my responsibility*" and "*I'm the mother. The decision rests on me*" are not difficult to find. Their care-giving burden(s) crossed the boundaries between home and school life, i.e. in both environments they experienced added responsibilities as primary caregiver for their child. The social context of financial impoverishment and gang violence adds to this weight. Mrs Ibrahim describes her fear one day at home, now compounded by her son's new vulnerability: "*But where's Mohamed? It's like I'm about to lose my mind!...I'm scared the gangs come back...He still goes off without telling. Because he forgets.*"

Furthermore, it is not a short-term burden, but rather one that will be borne year after year, as parents advocate for their children at home, in their neighbourhoods and at school, as Mrs Dyasi and Mrs Ibrahim explain: *“Since the accident I have been in charge of looking after Simphiwe. I showed my family how we should change in treating Simphiwe after the hospital.”* and *“At the first PTA (Parent Teacher Association) meeting of the year, I told her [child’s new teacher] he was in an accident a year ago... she hadn’t been told.”* Many studies bemoan the lack of transfer of information about the child’s TBI between educators within a grade and between educators across grades (Ashley, 2010; Hawley et al., 2002; Schutz et al., 2010).

The usual daily parental responsibility for teaching their children academic and interpersonal skills falls on these parents with added weight in light of the acquired learning difficulties and social challenges following TBI. For example, Mrs Ibrahim describes how she found ways of motivating Mohamed to study for tests when he was overwhelmed by the amount of work or how she noticed and managed his distractibility during homework. She also explains how she now had to talk with him about being teased and bullied.

In the same breath, with this enormous responsibility on their shoulders, having their child back at school gave parents a sense that things were going to be okay. They placed a great amount of hope in the normalizing effect of being back at school. Mrs Dyasi, for instance, describes this by saying *“I wanted him to come to his sense again. Like normal. That’s why I wanted him to go back to school... As he sits listening to the teacher with the other children, his mind will come back, that it will get to a point where his brain is normal...and then as he mixes with the other children, playing with them... that will also help his mind to come back.”*



#### 4.2.2.3 Category 3: Not knowing

The experience of “not knowing” permeated the parents’ stories. Their experiences indicated that they lacked knowledge of TBI, its effects and management on personal and systemic fronts. Mrs Dyasi noticed significant changes in Simphiwe’s behaviour, but confessed to not knowing whether the head injury was responsible or not. She reports having learnt some things about TBI management from therapists at the hospital, but further education and follow up was clearly lacking. She explains, *“We did not have money for transport to go [to the follow-up appointments at the hospital]... I was scared to go and find out new dates...I didn’t know what I was going to say.”* This description illustrates the failure of a system to meet the rehabilitation needs of its

people. Societal factors of poverty and a history of inequality as well as lack of appropriate and accessible support services at the school and community health facility are highlighted.

Additionally, the parents indicated that they were at a loss about how to access and engage with the information provided by the available services. Mrs Ibrahim describes not knowing which course of action was best to take for her child, especially in the face of two competing professional opinions, that of the hospital therapists and that of the school. *“I explained to them [the educators] what was going on, how I just want to do the right thing for my child, but I’m in two minds now and don’t know what to do [in terms of keeping him back in the Grade or not].”* Mrs Dyasi faced a similar challenge of needing to decide, with inadequate knowledge, between the opinions of disagreeing professionals. *“I’m not sure what all they [the educators] spoke with the social worker, but my agreement is now with the school that he will stay there until he passes Standard 5.”* These two quotes are indicative of a systemic breakdown in communication between parents and health and education professionals. Furthermore these experiences illustrate the emotional burden this places on parents.

Parents realized that future schooling for their child had become very uncertain, an experience reported on in the literature pertaining to parents of children with TBI (Prigatano & Gray, 2007; Roscigno et al., 2014). They did not know how to navigate through the options which were available to them. Mrs Dyasi said, *“I am very scared to think about high school. Which school will be good for him? Which school can I take him to?”* They also report not knowing where to turn for advice or which procedures to follow. Mrs Ibrahim says, *“I found out about another high school, but [the speech therapist] says he can’t just move. It depends on the Board of Education.”*

The parents’ stories of navigating these many uncertainties, largely on their own, not only highlight a system that lacks appropriate and accessible services, but also alerts professionals to the absence of, or breakdown in, communication between role players. These present significant barriers to the child with TBI’s return to school.



#### 4.2.2.4 Category 4: Needing [and receiving] support

The parent stories highlight the fact that they have many support needs, for themselves and for their child with TBI, from the time of school re-entry and throughout the years that follow.

Both parents acknowledge the supportive value of parent-educator partnerships. They repeatedly stated their appreciation of the educators who spent time in conversation with them about their child. This regular, interested communication fostered the development of a partnership that can be identified as a critical facilitator of inclusion in these stories. Parents experienced this relationship as a significant support. Mrs Dyasi describes how *“Mr Magoda used to call me each and every 2 weeks to explain to me how Simphiwe was doing in class and what the problems are. It was great to have that participation with the teacher all the time.”*

Absent from their stories is any mention of top-down support in the form of educational policy and procedures. This is an indictment on the practice of inclusion in South Africa, but the country’s literature on the topic provides many examples of the barriers currently experienced with inclusive education (Engelbrecht, 2006; Levin, 2004; Mashiyi, 2014; Swart & Oswald, 2008). While in hospital, parents received a measure of support from therapists in terms of learning about TBI and management thereof; one therapist started a support group for parents. However, there was little support available within the education system when challenges were experienced at a classroom level. It can be argued that the lack of appropriate support of this nature is a major contributor to the parents’ experience of “not knowing” and “shouldering the burden”.

As a result, the emotional and practical support parents needed was received at personal and social levels from family, educators, community members and other parents of children with TBI. Personal faith was also mentioned as a source of support. Mrs Ibrahim recalls the care and concern she experienced from Mohamed’s teachers towards her after the accident and over the years since; her detailed description signifies the deep impression this consistent show of support made on her. Mrs Dyasi expresses how neighbours take responsibility for looking after Simphiwe when she is not at home. Mrs Ibrahim remembers attending a hospital support group once and reported that *“Even though the accident was nearly 2 years ago, it was good for me to sit between those other parents and to talk.”* This statement also emphasizes that parents of children with TBI require long-term follow-up and support.

This theme highlights that parents need long term practical, informational, as well as emotional supports in order to better facilitate their child’s recovery and inclusion, and their own coping. By locating the support at the individual and community, they inadvertently reveal the vacuum of systemic support.



#### 4.2.2.5 Category 5: Seeking understanding for my (changed) child

The parents wanted their child to be understood, to be treated as any other child, but at the same time to be looked out for with their special needs. Both parents experienced this understanding from their child's class educators. Mrs Dyasi said she could “*see from talking with him that Simphiwe's teacher understands my child and that he sees the reason why Simphiwe is the way he is at school is not because he is stupid... He understands my child the way I understand my child.*” Mrs Ibrahiem noticed how Mohamed's educator worked hard to make him feel welcome and like any other child in her class.

However, they also experienced a lack of understanding from some educators and from the children who teased and bullied. Mrs Ibrahiem recounts, for example, the educator who felt that Mohamed was using the TBI as an excuse not to complete his work. Unfortunately, this ignorance is reported all too often in the literature (Glang et al., 2012; Hawley et al., 2002; Roscigno et al., 2014). This lack of understanding was a great source of tension for Mrs Ibrahiem due to the unwelcome attention Mohamed received and the subsequent unhappiness it caused him. She also describes the effect of the teasing on him, how he wanted to move to a different school. This lack of understanding, from its various sources, is identified as a barrier to inclusion.

#### 4.2.3. Categories emerging from the educators' stories

Following thematic analysis of their stories, 5 categories emerged which relate the educators' experience of school reintegration. These were labelled “Lacking support”, “Not knowing”, “Finding support”, “Supporting inclusion” and “Growing professionally” (see Figure 5). These categories were combined and the resultant essence of the educators' experience of school reintegration following TBI was encapsulated within the theme “struggling with the challenge to include in an unsupported system”. The fact that the child is in their class for only a year or two before moving on was seen to be an important influence on their experiences. These temporal features are indicated by “pass the baton”. This element of change is not mentioned in the literature. In addition, their recognition that continued future support for the learner is necessary is particularly relevant considering the chronic nature of TBI and likelihood of worsening academic and social performance detailed in the literature (Ewing-Cobbs et al., 1998; Taylor et al., 2002). Their personal and professional background and beliefs were seen to be critical to their stories and underpin the categories “finding support”, “supporting inclusion” and “growing professionally”. Swart and Oswald (2008) write an inspiring

paper which touches on these points. The systemic and social contexts in which the educators work greatly influenced their experience and underpin the categories “lacking support” and “not knowing”.

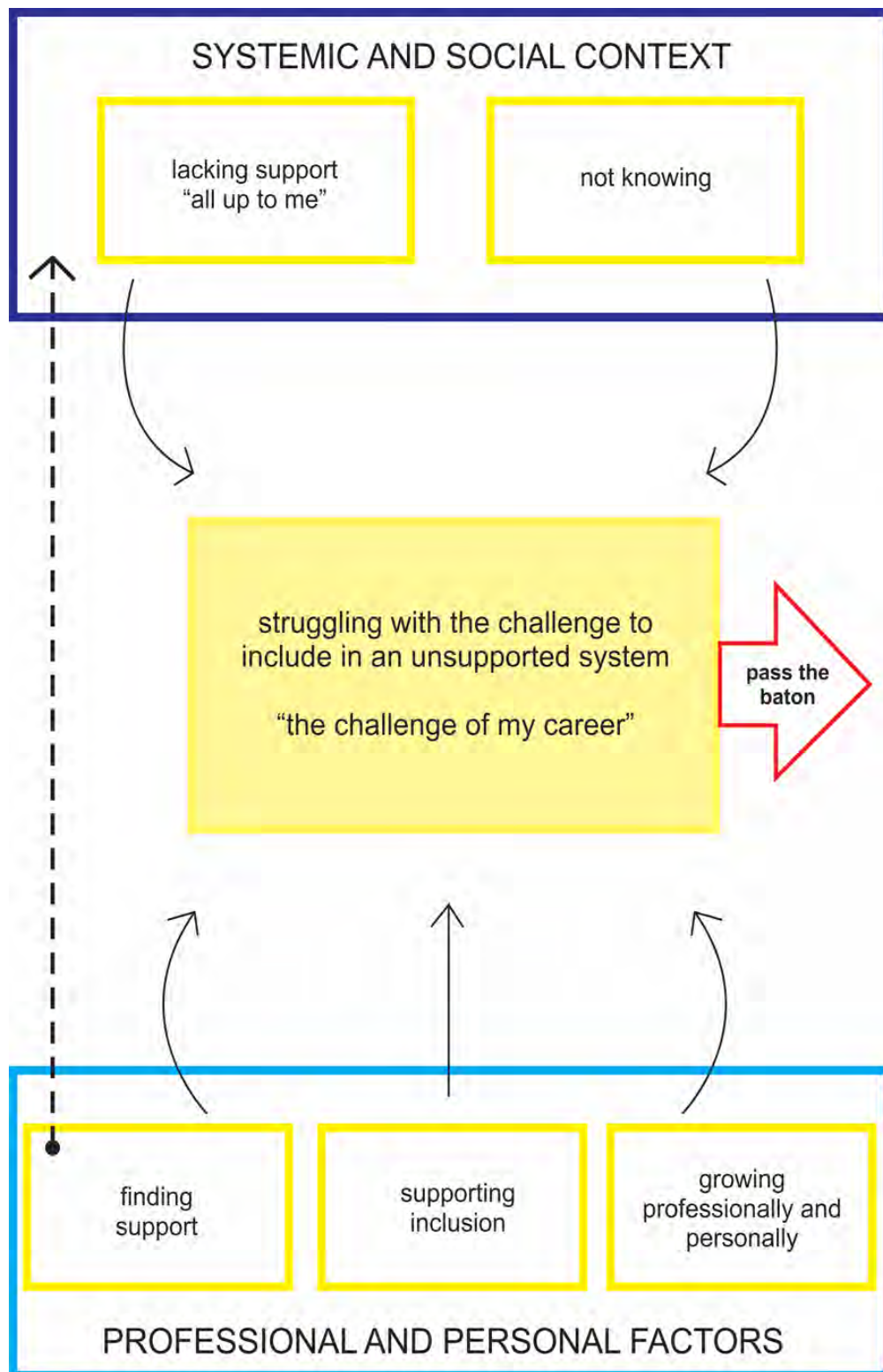


Figure 5: Educators' experiences of being back at school following a learner's TBI

#### 4.2.3.1 Category 1: Lacking support

The educators received very little to no top-down educational information and support in terms of reintegration and inclusion, despite the significant demands placed on their time and professional skills by the child with TBI. For example, there was no talk of training in management of a child with specific TBI needs; no mention of a classroom assistant; they were not made aware of referral pathways or potential interventions, e.g. educational psychology, and if these recommendations were made, the educators were not informed of outcomes. In addition, they were unclear on the school's policy for acceptance and progression of the learner. The educators' stories present a picture of the general lack of support and resources in inclusive education in general in South Africa as described by Donohue and Bornman (2014). It would appear that the success of a child's inclusion in the South African context is largely dependent on the individual educator's skill and personal will.

The educators acknowledge throughout their stories how challenging it was to do their best for the child without adequate assistance, from both a human resource point of view (*"I think now it would have been a good idea if I requested that the school employed a parent assistant, someone to help with all the extra work"*) and from a systems/procedural point of view. They took it upon themselves to liaise with and support the other educators as there was no case manager assigned to the child (*"You know, no one ever followed up on Simphiwe once they'd accepted him back to our school? No one paid attention to his issue."* And *"It's tiring sometimes, keeping people involved and communicating [about his case]."*) This lack of procedure and accountability is a serious barrier to inclusion. As a result, the success of the child's school reintegration is thus dependent on the educator. Consequently, it is a luck-of-the-draw, or type of Russian roulette, as to which educator the child ends up with. Will it be one who will take up his case? Or one who will take little responsibility for his progress? The educators who participated in this study were of the positive, proactive type. Their stories, however, also tell that this support is not given by all educators.

Both stories call to attention the fact that the child with TBI needs time-consuming, special consideration and one-on-one attention, a luxury that is scarce in classrooms of up to 40 learners. *"I'm an experienced teacher, but now with Simphiwe... I must put in some extra time. It takes some of my holiday time, my quality time. But it's my choice to do it."*

The educators both reiterated that they lacked training support. This feeling of being ill-equipped is seen as a serious barrier to inclusion as it is likely to influence the

educators into thinking that special schools would be able to do better by the child. This separatist, rather than inclusive, mind-set is not in the best interest of the child. Mrs Abrahams describes her sense of inadequacy: *“I was not equipped to deal with a case like that... I thought ‘He should be at a special school; they’re skilled to help him there.’”* Mr Magoda admits that even at his inclusive school it is a challenge to have a learner with TBI because *“we are not trained to deal with learners of [his] calibre.”*

South African inclusive education policy acknowledges the necessity of sufficient educator support for inclusion to work in practice (Department of Education, 2001). These two stories show, however, that this support is not yet part of the educators’ experience.

#### 4.2.3.2 Category 2: Not knowing

The educators were overwhelmed by the fact that they felt unskilled, untrained and inexperienced in TBI. *“I didn’t have any experience working with a child with head injury; I didn’t know what to expect.”* Mrs Abrahams commented that the other educators felt the same. *“...he just kept getting way behind in his lessons. It was way too much for him. All of us who had him that year, we didn’t know how to tackle it.”* They tell of the many questions they had for which there were no answers. *“I had lots of questions. Will I know what to do? What happens if the child panics? I felt so unskilled. I wanted to be skilled by a professional.”* This lack of experience and exposure to TBI in the classroom is interesting in light of the fact that they had both been teaching for many years in communities where head injuries are common (Bass et al., 1995; Semple, Bass, & Peter, 1998). One possible explanation is that they had previously taught children with TBI but were not informed of the child’s diagnosis. Research shows that the history of TBI is not associated with academic or behavioural problems that arise later in the child’s school career (Schutz et al., 2010). Had they taught children with TBI but not been informed by the educator from the previous year? This failure to transfer information into the next school year is noted in the literature (Hawley et al., 2002; Schutz et al., 2010). Whatever the reasons may be, these educators experienced a deep sense of inadequacy due to not knowing.

Not knowing also relates to their belief that it was a challenge not having known the child prior to his injury. *“That was really unfortunate, not having all that information about him...I feel I could’ve done better for him if I’d known a bit more before.”* This suggests that the educators feel they would have better been able to facilitate school reintegration with adequate premorbid information from a previous educator or

interaction with the child in class or extramurally prior to the injury. This feeling does not appear to be documented in the literature; however this is an important part of these educators experience. One possible explanation for this perception may be because they feel so unsupported that not knowing the child from before the accident becomes an additional “unknown” in their world which is already filled with uncertainty.

#### 4.2.3.3 Category 3: Finding support

Despite an obvious lack of support in terms of inclusion policy and procedure, the educators described how they were able to find support, in their words “help”, for themselves from the child’s parent, from other staff and professionals and from the other learners in their class. *“The other learners were a big help. I found out it’s important to work with them, to include them.”*

The value of team work in facilitating a child’s reintegration to school is emphasized in the educators’ stories. Both educators highlighted the supportive nature of being part of a team when managing a child with TBI. Mrs Abrahams describes the value of continued liaison with the health professionals who treated Mohamed *“...it just helped me to know there were people there [at the hospital] to help us. It wasn’t just us alone...someone else was keeping an eye on this child.”* Mr Magoda explained how the parental support he experienced facilitated Simphiwe’s academic reintegration. *“That cooperation from his parents really helped me to get the good results he’s getting now...”*

As with the parents’ experience of support, it is important to note that the educators themselves were actively involved in setting up their own support networks. It is therefore clear that they placed immense value on the practical, informational and emotional support which they received.

#### 4.2.3.4. Category 4: Supporting inclusion

The educators in this study were motivated and dynamic individuals who accepted the challenge of having a child with TBI in their class, despite their sense of inadequacy and real lack of training and support. They worked hard to make the child’s reintegration a success. This again speaks to a certain *type* of educator who may be more suited to facilitating a child’s being back at school (Swart & Oswald, 2008). They supported the child’s reintegration in a number of ways.

Firstly, they recognized that returning to school for the child involved both academic and social inclusion and worked hard to facilitate this process. Academically, the child needed maximum support. For example, Mr Magoda said that *“[Simphiwe] needed lots of rest...it was difficult because you must not leave him behind in the work; you must be sure that you get him involved. You must not exclude him from the other learners but you must also know that he’s got a problem of this nature.”* Mrs Abrahams noticed *“...if I walked away then his mind would wander... I would often stand and watch him without his knowing. I didn’t want him to think that I’m a policeman.”* Socially, the child needed opportunities to interact. The implication, recognized and applied by the educators, was not to exclude them from everyday school activities. *“I coached him with soccer...5 to 10 minutes before full time we’d allow him on... as a means of helping his self-esteem, to make him feel part of the class. This was one of the means we tried to treat him like the other kids.”* Mashiya (2014) explains that exclusion from sports is one of the issues that affect children most. *“At one time I was wondering about him, ‘Must I keep you in the staffroom [at break]?’ so he’s not on the playground with the bullies. But then I thought, ‘He needs to be with his friends.’”*

Secondly, by trial and error over time, they developed classroom accommodations and adaptations to their teaching styles which supported the inclusion of the child with TBI. *“My planning had to change completely. I needed to give him a different lesson to the others... he needed extra work to try and bridge this challenge.”* *“Sometimes more of the activities need to be group activities to support him.”* These educators graduated before inclusive education had become policy in South Africa. Despite this, they intuitively put into practice a number of principles of inclusive education. *“I thought ‘I mustn’t treat him specially. I must [keep an eye on him] but not treat him specially.’”* Mrs Abrahams reported: *“He needed all this attention but we didn’t want to treat him like a prisoner; we wanted to show him he is quite normal”* and *“I had decided to let him develop at his own pace, not my pace or the class’s pace .”*

Thirdly, they recognized that inclusion required a coordinated team effort and were ready to accept and facilitate that interaction. *“I can honestly say that children like that, they need the help from the different sources: hospital, mother, school.”* The value of this notion of continued collaboration between the role-players in a child’s being back at school is supported in the literature (Farmer et al., 1996; Glang et al., 2012; Savage, Pearson, McDonald, Potoczny-Gray, & Marchese, 2001; Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007).

Finally, they supported being back at school by recognizing the long term impact of TBI on the child’s learning and therefore the necessity of effective transitioning to the next

school year by liaising with the new educator. *“Even though Simphiwe does well now in Grade 6 it does not mean I have now finished my work... I must inform the Grade 7 teacher...”*

#### 4.2.3.5 Category 5: Growing professionally and personally

The literature focuses on the child’s development and progress on return to school but is largely silent on educators’ experiences of their own personal and professional growth. These educators’ stories, however, were full of the sense of accomplishment they knew and the professional growth they experienced in knowledge, skills and development of self as an educator. There is a clear progression in their stories from fearful and uncertain to experienced and accomplished. *“Now I know how to handle him... how to change my style to accommodate him.”*

This change however, was fraught with challenges. They described their experience of having a child with TBI in their class as the challenge of their careers. This was despite having more than 30 years of experience as teachers between them. Mrs Abrahams said *“That whole year every day was a challenge. By the middle of the year though... I wasn’t scared anymore.”* Mr Magoda adds *“Having Simphiwe in my class was a big challenge. But I enjoy challenges and I learnt skills.”* Their personal values and beliefs are considered to be important drivers of their growth and therefore the success of the child’s reintegration. In addition, they provided examples of times of professional reflection which was necessary for growth. For example, Mrs Abrahams reports discussing with her husband the difficulties she experienced attempting to divide her attention between the rest of the class and Mohamed.

Mr Magoda’s professional growth is particularly telling as his educational outlook changes from separatist to inclusive *“Simphiwe’s kind of problem opened my eyes to many things. I look at all my children differently now... I realise you need to look at your learners more holistically... So what I understand now is that there are challenges with these normal learners. They are a challenge on their own. And then the learner of Simphiwe’s calibre is a different type of challenge.”* It is argued that “inclusion” implies an exclusion based on an assumption of the norm of the dominant culture, in this case, children without TBI (Graham & Slee, 2006). Mr Magoda’s reflection on his experience leads him to the realisation that each child has certain difficulties requiring attention, that there is no “normal”, and that every child needs to be “included” in their school environment. This sentiment is supported by Peters (2004) who states that “every child has unique characteristics, needs” (p.12).

## CHAPTER 5

### DISCUSSION

In this chapter, the results from the second and third level analyses are discussed (see Figure 2). At the second level, the resultant theme from the thematic analyses of the research stories is presented per participant type (child, parent, educator). The themes describe the experiences of being back at school after a TBI. At the third level, the multiperspective voice combining children, parents and educators, is presented and discussed as the final theme. The chapter concludes with the implications of this study for practice and future research as well as the study's strengths and limitations.

#### 5.1. Level 2 – Themes per participant type



##### 5.1.1. The children's theme: "Working together to fit back in"

The children's experiences of being back at school following TBI are encapsulated in the theme "Working together to fit back in" (see Figure 3). Sharp et al. (2006) in their study of adolescents with severe TBI returning to school identified the challenge of "fitting back in" as central to their experiences. It is important however, to point out that the children's stories may be different in a different social and school context.

Whereas a large part of the parents and educators experiences consists of "struggling" against the education system, the children's stories have less of a sense of this individual burden and more of a sense of supportive environment with cooperative solutions. The critical role the specific parents and educators in these cases play as buffers to failure and exclusion cannot be overemphasized at this point. The school system in South Africa is organized in such a way that children may interact with several educators in a day as they move from class to class depending on the subject being taught. The child with TBI therefore needs to deal with new teachers and new subject matter within a day and each new school year. The support that parents and class educators offer the child by ensuring regular liaison across staff members is critical. Literature supports the important role of parents and educators in supporting school reintegration following TBI (Backhouse & Rodger, 1999; DePompei & Blosser, 1994; Hawley et al., 2004; Mealings et al., 2012; Savage et al., 2001; Sharp et al., 2006). The amount of support the child will receive when back at school is also important, as the literature provided in Chapter 2 shows that they will lag behind over time.

The children find themselves needing to adjust to, rather than struggling against, the changes in themselves and in people's responses to them. In agreement with literature in the field, their stories do highlight that extra work is required now that they are back at school, both academically and socially (Gauvin-Lepage & Lefebvre, 2010; Mealings et al., 2012; Mealings & Douglas, 2010; Rodstet, 2008; Roscigno et al., 2011; Sharp et al., 2006). There appears to be an awareness that their success is at least somewhat dependant on their efforts. However, this is counterbalanced by their recognition of the help they receive from others, most notably their educators and friends. There is little written about this tension between autonomy and accepting help that is needed. Where mentioned, the evidence is one-sided and focusses primarily on the TBI survivors' reduced self-awareness and how their perception of ability differs from that of their family or educator (Bohnert et al., 1997; Gauvin-Lepage & Lefebvre, 2010; Prigatano & Gray, 2007). This disjuncture did not obviously stand out within these cases, possibly because deficits were not the focus of the study and therefore used by participants as examples only. The literature confirms that in general children with TBI have an increased reliance on others (Bedell et al., 2005; Mealings et al., 2012; Roscigno et al., 2014). In addition, it is noted that adults in the environment sometimes over-accommodate for learners (Hux et al., 2010). The stories which these children shared show that there is a need for guarded and guided autonomy (Mealings & Douglas, 2010). Clearly, striking a balance between growing independence and autonomy and providing the necessary special support is pivotal for the success of school reintegration following TBI.

Their stories also show positive changes over time as they learn to assert themselves in class and playground situations. Consequently they report that as their assertiveness increases, they come to rely less on external support. The relationship between support and assertiveness has not been well documented in the literature. In a study involving children with multiple disabilities, the authors found that classroom aides tended to hamper student participation by providing excessive support (Giangreco, Edelman, Luiselli, & MacFarland, 1997). One possible explanation for the lack of research is the fact that the majority of published studies interviewed older TBI survivors at later stages post-injury. The fact that the individuals were at life stages where greater independence is expected by society and that more time had passed since the injury allowing for more opportunities to experience challenges and failure could be factors which contribute to this difference. This implies then that unless these positive changes can be maintained and expanded on, the child participants' perceptions and experiences may become more negative as time progresses.

Furthermore, Mealings et al. (2012) recognize that the age of the story teller has an important influence on what is told. There have been no studies internationally or in South Africa that focus on this age group of the child in the intermediate phase of school. This finding raises the issue of early and continued intervention for successful school reintegration. If children with TBI and their educators and parents are supported throughout the initial phases of the child's return to school, as well as at critical periods in the future school career, might this change the expected outcome? Is this a critical age for intervention, when parents and educators "naturally" provide more support due to the younger age of the child?

Despite the experience of these positive changes, the children are aware that learning is more difficult now and they show concern for the transition to high school. There are no studies focusing on the perspectives of this age group, but concerns regarding the future, often in terms of university and employment opportunities, are commonly voiced (Hux et al., 2010; Mealings & Douglas, 2010; Sharp et al., 2006). The literature on TBI indicates a questionable future prognosis for these children at school. As will be discussed later, their chances for progress at school are considered to be at even higher risk due to the unsupported system of "inclusion", a system in crisis, they are forced into in South Africa.

Inclusive education depends on the notion that all children should learn together (Peters, 2004). This study shows that from the child's perspective schooling involves both academic and social participation. This is in agreement with international research which describes participation at school as consisting of both academic achievement and social interactions. Mealings and Douglas (2010) explains that success at school relies on social competence and personal well-being, a sense of feeling "accepted and part of the school community" (p.14). The children in this study are cognizant of the value of various accommodations used to support them in their classroom learning; helping them to participate with their peers; as well as the value of being included in sporting events; and of playing with their friends. Thus the theme "working together to fit back in" reminds educational staff and allied health professionals to maintain their focus on the holistic inclusion of the child into his/her learning environment.



#### 5.1.2 The parents' theme: "Struggling with change in an unsupportive system"

The parents' experiences of their child's being back at school following TBI are encapsulated in "Struggling with change in an unsupportive system" (see Figure 4). The parents in this study, as in the international literature (Prigatano & Gray, 2007;

Roscigno et al., 2014; Roscigno & Swanson, 2011) made regular reference to the cognitive, behavioural, and physical changes in their child. In addition, they describe the negative effect this had on their lives as parents in terms of increased burden of care. The parents struggled with this change in their normal day-to-day responsibility as much as they struggled to adjust to the changes in their child. The burden in this study is amplified because the social contexts in which their stories take place feature significant financial pressures as well as the daily stress of living in a gang-ridden area. Other research in the field agrees that parental experience of school reintegration cannot be separated from the rest of the parent's life – their life affects and is affected by the TBI (Bedell et al., 2005; Hawley et al., 2003; Roscigno et al., 2014; Roscigno & Swanson, 2011).

Parents found support from family, neighbours and certain educators. Input from schools and educational services was only mentioned in terms of confusion, e.g. lack of knowledge on who to contact or what procedures to follow. One is left with the impression of parents blindly attempting to navigate educational and health systems. Parents knew their child needed help and they wanted help for themselves but did not know where to go to access this support. Mrs Dyasi placed all her hope for her child's recovery in his return to school. It was her belief that "they" would know what to do and simply being at school would make him "normal". Having the educator's perspective we realise that this was far from the truth. The educator felt unskilled, untrained and inexperienced. No-one at the school followed up on Simphiwe's support needs despite the school being an "inclusive" school. The educator reported that they did not have the resources needed to assist a child with TBI. Simphiwe returned to a school that was not resourced and not ready. From the literature on inclusion in South Africa, it is likely that this is the case at the majority of schools (Donohue & Bornman, 2014; Levin, 2004; Mashiya, 2014; Meltz et al., 2014; Naicker, 2006). Similarly, parents did not mention any resources in the community that they could access; indeed it is suspected that there are very few if not none and mention of rehabilitation support from the hospitals was limited. The system is experienced as unsupportive, as it provides none of the support they needed, particularly in terms of practical information.

Therefore the current government systems designed to be supportive are in reality, the reverse. Policies for inclusion are in place, but there is no clarity on how exactly this should be accomplished nor is there political will to finance this (Donohue & Bornman, 2014). In addition, intersectoral collaboration between the Department of Health (DoH) and Department of Education (DoE) is also sorely lacking, with no policy in place to direct hospital to school transitioning in an organized fashion as recommended in the

literature on returning to school following TBI (Ashley, 2010; Clark, 1996; Glang et al., 2008; Sharp et al., 2006). Parents remain uninformed about what support is available for them to access largely because there is very little available at a systemic level. Consequently, parents of children with TBI who do not find positive individual support from educator and family relationships as these parents did are likely to be in dire straits indeed.

The UN Convention on the Rights of Children stresses that family and parents should be the first line of intervention and support for a child (Peters, 2004). The parents in this study show time and again how they were that, despite struggling to achieve this in a system wholly lacking in top-down support. This study raises the profile of parents as cornerstones to successful inclusion. It shows that schools cannot plan for inclusion in isolation, i.e. without the vital contribution of parents. Learning, not the child's mere physical presence at school, should be the focus. This learning occurs both inside and outside school. Having highlighted the role of parents in facilitating the success of their child's being back at school (Bedell et al., 2005; Glang et al., 2012; Yssel et al., 2007), the study further proclaims the desperate need parents of children with TBI have for assistance on a number of levels, not least the navigation of an as yet unsupportive school system. This is of particular significance within the South African context, where their ability to support fully the learning of their child may be compromised by additional financial and social burdens such as poverty, unemployment, community violence and substance abuse.

### 5.1.3 The educators' theme: "Struggling with the challenge to include in an unsupported system"

The educators' experiences of school reintegration following TBI are encapsulated in the theme: "Struggling with the challenge to include in an unsupported system" (see Figure 5). South African DoE policy is one of inclusion. However, Donohue and Bornman (2014) deliver scathing commentary on the insufficiency of the policy due to its lack of clarity for implementation in terms of guidelines, incentives and directives to educators. As a result of this ambiguity, very little has changed at a classroom level, with resources largely remaining as in the days of segregated/special education (Engelbrecht, 2006; Levin, 2004; Naicker, 2006). This contributes to the perception that making the actual practice of inclusion in South African schools a reality is a seemingly insurmountable challenge.

Not only does the system not support inclusion, it also does not support its educators (Donohue & Bornman, 2014; Mashiya, 2014; Naicker, 2006). Indeed the educators in this study explicitly mention the lack of resourced support for the children and themselves, despite one of the schools being classified as an inclusive or full-service school, which implies that the school should have physical resources and professionals who provide consultative support to learners and educators with a variety of support needs. This is evident in the lack of physical and educational resources for learner support, e.g. teacher assistants, graded workbooks. It is also evident in the lack of specific educator support, e.g. training in management of the disability, knowledge of procedures and referral pathways. Literature emphasises the lack of and need to supply educators with information about and training in the field of TBI and inclusive education (Donohue & Bornman, 2014; Glang et al., 2012; Hawley et al., 2004; Mashiya, 2014; Sharp et al., 2006). Peters (2004) explains that educators need more than workshops and in-service training regarding inclusion. She explains that they need time to develop confidence and coping strategies and that this occurs best within the context of continuous classroom support. The experiences of the educators in this study demonstrating professional growth and increased confidence over time support Peters' view.

The educators' initial responses to the children indicated a default mind-set of "segregation", as they felt the child belonged in a special school, or at least in a bridging programme prior to returning to ordinary school. This "hand the child over" approach is likely to be a result of the educators feeling unskilled, untrained and thus ill-equipped to assist the child appropriately. It also suggests that the theory of inclusion has not filtered down from the policymakers in government to those who need to bring it to life in the school setting. It appears that the issue of lack of training in graduate programmes is being addressed, as Mashiya (2014) found that recent graduates are better equipped within themselves to apply inclusive education principles in class whereas older educators, such as those in this study, did not receive this inclusive education training at college. This insufficient support means that social justice is not done; children do not receive the fair and equal education the policy promises them and their parents (Ibid.)

The systemic/departmental support that the educators in this study do mention is limited, fractured and does not carry through to daily classroom management. International studies have shown that the provision of systemic support varies and, when available, is often not accessed by educators, for example, a statutory assessment of special education needs (Hawley et al., 2004; Mealings & Douglas,

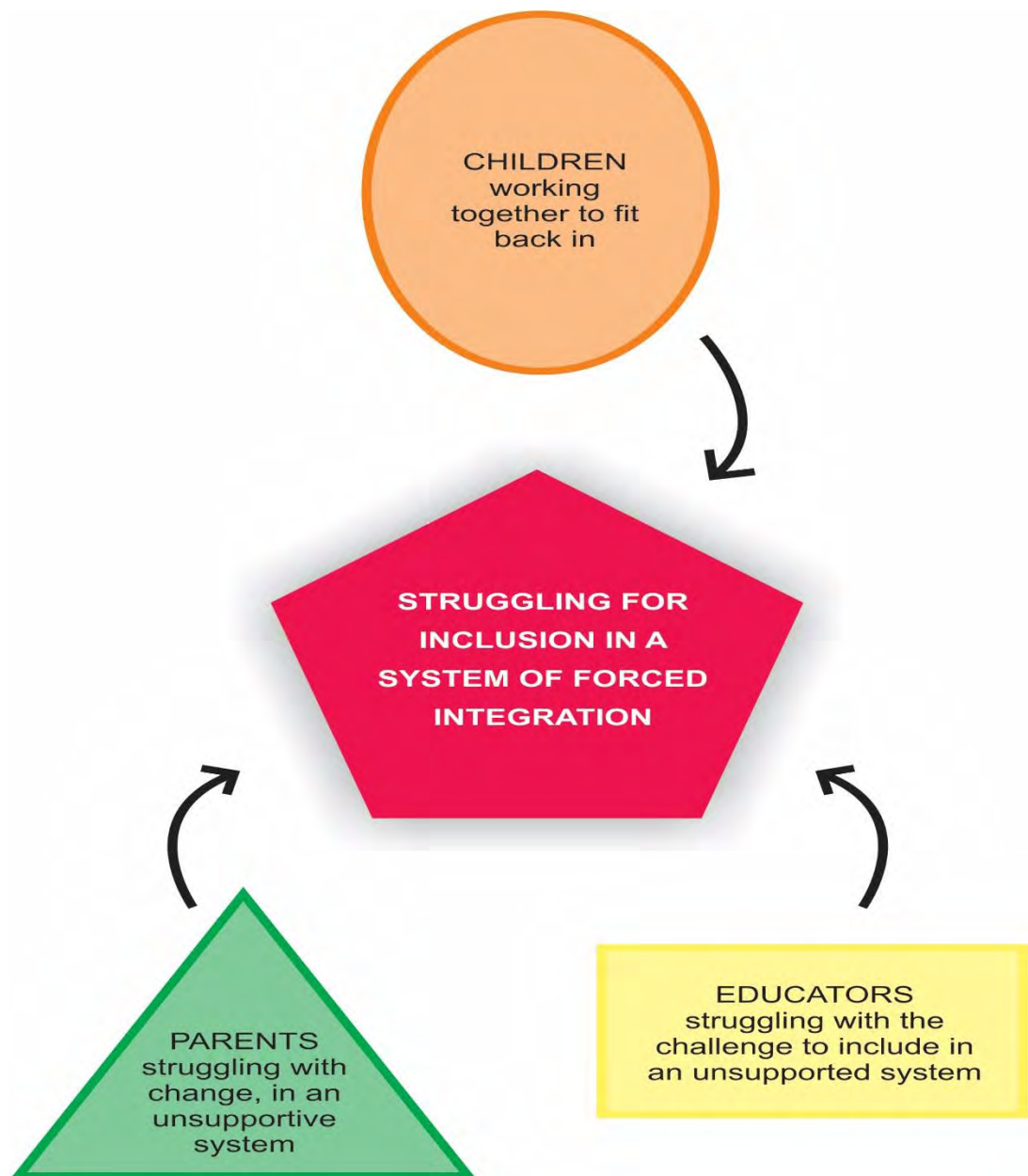
2010). The educators in this study work within an unsupported system that purports to uphold inclusive educational practices, without supplying the resources teachers need in order to successfully implement inclusive education. This makes the challenge of TBI in school that much greater, and the educators' stories vividly illustrate this point.

Nonetheless, despite these barriers to inclusion, and despite the unsupported educational system pulling them in the opposite direction, towards segregation, the educators actively engaged with the process and intuitively worked towards inclusion. Their stories are replete with examples of how they tackled the challenge of supporting these children with very specific and varied educational needs to facilitate their return to ordinary education. This raises a question about whether or not there is a certain type of educator who is better suited to enabling a child's inclusion into ordinary school. Mashiya (2014) and Donohue and Bornman (2014) allude to this by stating that educators with positive attitudes who are willing to teach learners with a range of needs and abilities are needed for successful inclusion. Swart and Oswald (2008) describe the types of educators who embrace the challenges of inclusion and how they develop themselves independently by seeking external assistance from others. Meltz et al. (2014) recognize the importance of belief systems and acknowledges that beliefs can impact service delivery. Furthermore, they state that individual perceptions play a role in change towards inclusive practice or, on the other hand, resistance to that change. This study's educators are individuals who value diversity, enjoy challenges, are empathetic, flexible, have a sense of moral obligation and are described as caring by parents and learners. The available literature and data from this study point to the fact that there are educators who can drive inclusion from the ground up and that these persons need to be strategically selected and then supported.

The stories of the educators speak to a lack of organized support as a great barrier to inclusion, but also show how the application of IE can begin in an unsupported school setting. In their stories they demonstrate some of the practical means by which the goals of IE can be achieved, e.g. parent-educator partnership (characterized by regular communication); liaison with other educators and transfer of information to the next year; adapting workload and tasks so that the child is allowed to move at his own pace; monitoring the child "from a distance", and using other learners as peer supports. These educators are an excellent example of how to mitigate exclusion by the way they interacted with the children and families they served (Mashiya, 2014).

## 5.2 Level 3 – Multiperspective voice (final theme)

The resultant themes from each rich, in-depth perspective of the children, parents and educators speak to the experience of being back at school following TBI in the Western Cape. Through an iterative, reflective process, these 3 themes were merged to create a final, holistic and multi-voice theme: “Struggling for inclusion in a system of forced integration” (see Figure 6).



*Figure 6: Multi-voiced theme emerging from the 3 participant types*

This study asked the question “How is being back at school after a TBI experienced by children, parents and educators?” The multi-voiced answer that is given tells of an experience of struggle in a system that, in practice, is unsupported and therefore unsupportive of inclusion. The complexity of this struggle is shown in the joining of these voices. The children face social and academic struggles, the parents a long term struggle with the system and the educators a professional struggle. The experience is largely a negative one of forced reintegration, although there are points of hope and progress within each of their stories. This finding will be discussed in terms of the major barriers and facilitators to being back at school which were experienced by the participants.

The major barriers to inclusion highlighted by the participants were the systemic factors in the environment and the child characteristics which arose as a result of the TBI. These are considered in light of the UN Convention on the Rights of People with Disabilities (CRPD; UN, 2006) and the ICF-CY (WHO, 2007) respectively.

One of the important systemic barriers to inclusion which was reported by the participants is the socio-economic context in which these participants live. Financial burdens and unemployment, gang violence and drugs, all serve to place additional pressures on the parents, educators and children with regard to being back at school. Learning does not happen at school only. Children receive homework to do which parents may or may not be able to help with. The children reviewed lessons at home, needed to interact with friends and bullies in the street. It is clear from the stories of the participants that the experience of being back at school cannot be divorced from their personal/social environments. Furthermore, their stories show that being back at school involves a child’s learning across place domains. However, the impact of the socio-economic environment on the child, parent and educator’s experiences is not often considered in the literature on inclusion. Instead, the focus is on the school, and not on the broader environment in which the child lives and learns (Meltz et al., 2014; Ntombela, 2011; Prinsloo, 2006; Walton, Nel, Hugo, & Muller, 2009; Walton, 2011). The ICF-CY (WHO, 2007) and CRPD (UN, 2006) see the impact of the environment and the society in which a person lives as instrumental in enabling or disabling them. In their study, Yssel et al. (2007) align themselves with this position by recognising that inclusion involves more than placement in an ordinary classroom, but rather that “every child... belongs in the mainstream of both school and community life” (p.2). The current study shows that inclusion is not isolated to the school setting. It calls for a broader view of inclusion which includes the home and social contexts.

The combined voice of the participants in this study tells of an absence of integration between the health and education systems. It was keenly felt in the lack of communication across levels. Levin (2004) points out that there are no state-run post-discharge services currently provided for children with TBI in South Africa; this despite the complexity of problems post-TBI and the status of injury as contributor to the national burden of disease (Department of Health, 2011). The children in this study had access to rehabilitation services in the hospital but the long term supports, essential at school level, were absent. Glang et al. (2012) report a similar challenge in the US, stating that children with TBI and families receive little to no support from health and community agencies. Furthermore, communication between the Departments of Health (hospital staff) and Education (school staff) was minimal in these stories. Parents and educators struggled with accessing the necessary supports within the child's current schooling and received very little support when investigating future schooling options. They did not receive information they needed and did not know where to access it. A clear intersectoral gap between the DoH and DoE is highlighted with the departments functioning in silos. Both national and international literature on paediatric TBI raise the issue of this gap and emphasise that medical and educational facilities and departments need to work as complementary partners in an integrated fashion to achieve better outcomes (Lash & Scarpino, 1993; Penn et al., 2009; Savage, 1997; Ylvisaker et al., 2001). In addition, the children themselves were kept in the dark regarding matters concerning them. Transparency in terms of responsibility, accountability and referral pathways was absent, leaving educators and parents floundering in a sea of the unknown. In spite of this the child and parent still needed to navigate between these disintegrated sectors. The efficacy of this approach to service delivery is rightly brought into question. The CRPD (UN, 2006) argues that disability is a social construct resulting from the systems put in place by the able. It maintains that basic human rights, such as the right of children to education, can only be accessed equally when there is integration across systems.

Speech-language therapists are at home both in the hospital and school settings. As such, they are ideally situated to facilitate this intersectoral collaboration and assist with the transition between rehabilitation unit and school (Harn et al., 1999). With their training in acquired communication disorders, cognition and language and learning skills, they could be a valuable team member throughout the child's school career. They could fulfil multiple roles including acting as consultant to educators, providing intervention to children and possibly even fill the role of case manager currently inhabited by the overburdened parent. However, the lack of support from rehabilitation

professionals during the process of being back at school is clearly articulated in the participants' stories. International studies on the topic repeatedly recommend collaboration between educators, family and rehabilitation professionals as best practice (Harn et al., 1999; Savage, 1997; Sharp et al., 2006). Lack of integration between health, rehabilitation and educational support services post-discharge means that the burden of care for the child with TBI falls to the parent; and in the school system, to the educator (Glang et al., 2012).

The term "forced integration" is used in this final theme as the child must return to school and there is no choice as to where that will be and what services will be available. It is forced integration for the educator as he/she must attempt to provide inclusive service while wholly unsupported by the educational system. The child may therefore physically be present at school, but this study makes it apparent that this does not necessarily mean that the child is being "included". In these stories, the education system is portrayed as both unsupported and unsupportive. The IE policy-practice disjuncture in South Africa is described in various studies (Donohue & Bornman, 2014; Mashiya, 2014; Naicker, 2006; Swart & Oswald, 2008). Jansen, as cited in Donohue and Bornman (2014) explains that South African policies are often passed as a political gesture instead of for their practicality, thus policies which are unclear are adopted and there is no system of accountability for their implementation. Furthermore, the authors further cite a lack of finances and a lack of trained educators as reasons for the failure to successfully implement IE policy. Meltz et al. (2014) concur and state that despite Education White Paper 6, "IE practice is not happening consistently or at all in South Africa" (p.2). Without the necessary support, the burdens associated with implementation (clearly described by the parents, educators and children in this study) soon overwhelm educational staff who then revert to a segregated model of service delivery (Donohue & Bornman, 2014). This was evident in the educators' stories, particularly during the early stages where they were feeling vulnerable and overwhelmed by the challenge facing them. While they did not practice segregation (rather the opposite), the struggles they faced in trying to include the child made them think, at times, that segregation, i.e. return to a special school system of education for children with additional support needs, was a favourable option. This unsupported system of inclusion results instead in a system of "forced integration" (see Figure 7). It is clear that within the unsupported system children do not have equal access to education, as the UNCRC (UNICEF, 1989) promotes.

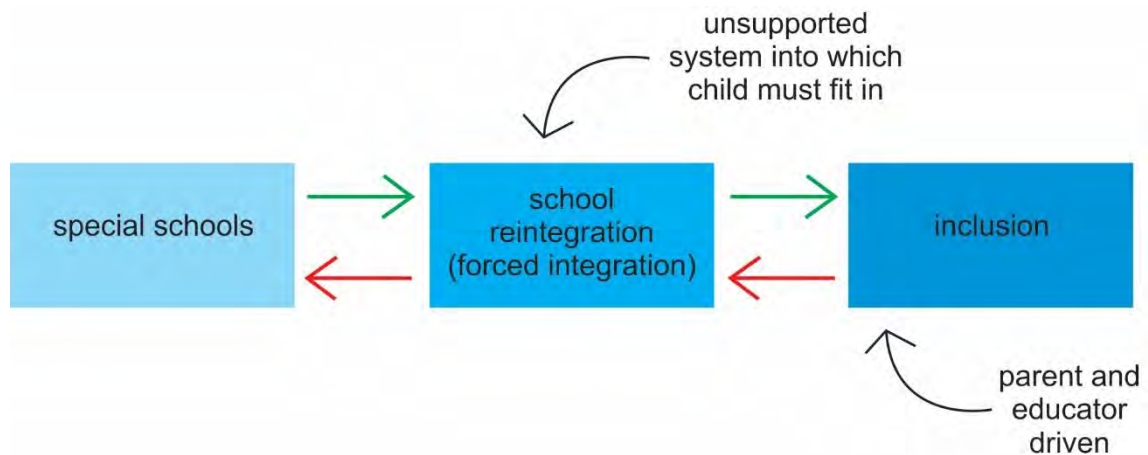


Figure 7: A system of forced integration: reversal of inclusion

In keeping with IE policy, Education White Paper 6 (Department of Education, 2001) promotes a flexible curriculum which can be adapted to individual learner needs; however, in practice educators tend to follow the same curriculum, so it is up to the child to make adaptations rather than accommodations being made to teaching methods and materials. Education White Paper 6 (Ibid.) encourages educator upskilling through training on managing diverse classrooms and educator support by developing roving teams of professionals available to provide educators with any consultative help they might need. Were this policy translated into practice, the educators in this study would have told a different story, one in which they acknowledge the felt support they currently lack. However, the educators make numerous references to their lack of knowledge and skills pertaining to inclusive education. Educators will struggle to meet the challenge of inclusion without adequate human resource support and assistance in adjusting syllabi. In true inclusive practice, any child, with any difficulty (indeed, as Mr Magoda recognised, all children have support needs) would be accommodated. It is recognized that for IE to be implemented successfully in any country, educators must have positive attitudes and receive appropriate training and adequate support. Donohue and Bornman (2014) acknowledge that many countries have struggled to bridge this policy-practice gap in IE.

The changes to a child's physical, perceptual, cognitive and communicative abilities as a result of TBI are also perceived as barriers to inclusion within the context of the unsupported South African educational system. These impairments at a body structure and function level interact with systemic factors in the child's school and social contexts mentioned previously and serve to reinforce the notion of difference. Impairments to body structures and functions affect the child's ability to participate in classroom

activities in the same way as their peers. The nature of these differences and how they impact participation and reintegration are discussed below. Firstly, the fact that the cognitive-communicative impairments, such as reduced attention and concentration, are not visible contributes to the “hiddenness” of the disability. Without transfer of information about the TBI to new educators, the child is at risk of being labelled “naughty” or “lazy”, as was the case with Mohamed. Secondly, this barrier is exacerbated by the chronic nature of TBI. The child will never “recover” fully. Deficits will persist over the years, meaning that participation and inclusion is not a once-off matter occurring at return to school, but requires long term input throughout the child’s school career (Savage et al., 2005; Taylor et al., 2008; Ylvisaker, Feeney, & Mullins, 1995). The time element is critical in understanding paediatric TBI as it has implications for the planning of service delivery and structuring of resources. It also has classroom level implications described in the following point. Thirdly, children with TBI will continue to face difficulties learning new information and due to various cognitive deficits (slower processing speed, impaired concentration) they will take longer to complete tasks. The educators’ stories emphasized that managing a child with TBI at school is extremely time-consuming. These barriers need to be considered and curriculum adaptations made and adequate support provided. Finally, the socio-behavioural difficulties that children with TBI can present with, discussed in detail in Chapter 2, have been shown to impact on the quality of their previous friendships and also limit their ability to make and maintain new friendships. All participants described situations in which the child was teased and bullied. Bullying is a systemic problem in South African schools (Greeff & Grobler, 2008; Liang, Flisher, & Lombard, 2007). Children with TBI are particularly vulnerable to bullying because of differences in ability and possibly also in appearance. As discussed in Chapter 2, this can lead to emotional withdrawal or increased aggression both which would hamper a child’s social and academic reintegration. As has been stated repeatedly in this study, successful inclusion is dependent on a sense of belonging and of social acceptance. The stories of these participants foreground the effects of TBI and provide concrete examples of how these present a barrier to academic and social inclusion.

In spite of the number of barriers highlighted by the participants some facilitators are also present. The facilitators to inclusion were notably found at grassroots level and importantly extend to both school and home environments. Four facilitators are apparent namely parents’ perseverance; educators’ skills in scaffolding independence and belonging; the development of partnerships; and the participants ability to access to support from their own environments.

The role of the parents in this study was of inestimable value in facilitating inclusion and provides evidence for the UNCRC (UNICEF, 1989) statement that parents are the first line of support for their children. Other local and international studies have emphasized the role of parents in inclusion (Bedell et al., 2005; Yssel et al., 2007). Parents fulfilled this role in many and varied ways: assisting their children with homework, attempting to solve problems of bullying and dizziness, supporting their children through times of failure, observing their child and adapting their way of interacting with them, taking responsibility for teaching educators, family and community members how to handle their child. In so doing, they were bridges across the school-home divide, promoting learning and belonging in both environments. This study shows that inclusion includes the parents, both in their indispensable roles as facilitators of inclusion and in recognizing the immense need they have of support. It could be argued from this study that it is they, rather than the children, who are most unsupported and neglected in the process of being back at school following TBI.

The skill of the educator in striking a balance between providing assistance and allowing the child autonomy is a facilitator that the children repeatedly refer to and that studies recommend (Giangreco et al., 1997; Glang et al., 2008; Hux et al., 2010; Mealings & Douglas, 2010). The children's stories show that they felt less different, i.e. more included, as their independence and sense of belonging increased. From the educators' stories it is seen that this skill lies in part in their ability to adapt continually the child's workload and level to allow for encouraging success tempered with motivating challenge. This strategy of scaffolding work load and complexity is critical in the rehabilitation of children with TBI (Ashley, 2010; Glang et al., 2008; Lebbey & Asbell, 2007). Both children and educators experienced the inclusionary value of engaging with classmates, in schoolwork, e.g. group work, and socially on the playground, e.g. sitting with friends, or playing soccer. The role of peers in facilitating being back at school is recognised (Glang et al., 1997). Being able to participate in after school activities with friends from school, such as Simphiwe's singing, also fostered a sense of belonging.

Another major facilitator to the child's successful school reintegration was the development of strong parent-educator partnerships, initiated and maintained by the individuals themselves. This included parents meeting with educators before the child returned to school to inform them of specific needs and management strategies, educators communicating regularly with parents, telephonically or in written form, and showing mutual respect for the role each was playing in the child's return to school. Many authors document the need for parent-educator interaction and the negative

impact on being back at school where this breaks down or is not possible (Bedell et al., 2005; DePompei & Blosser, 1994; Glang et al., 2012; Roscigno et al., 2014; Savage et al., 2005; Sharp et al., 2006). The formation of this collaborative partnership is seen as critical to inclusion, providing a strong safety net in an otherwise unsupported system. The adult participants in this study each describe a sense of security they felt knowing that they were not alone in the challenge. Each stated that it gave them courage to persevere. The study shows that it is currently the parent and educator and the strength of the relationship between them which strongly support the process of the child being back at school (see Figure 7).

Parents and educators were unsupported by the system; however the informal support that they did access enabled them to continue in their respective roles. Parents experienced emotional support from talking with other parents of children who had sustained TBIs in groups started at the hospital. Conversations and visits with family members were also beneficial. The assistance of members of the community lifted some of the responsibility from parents as they knew their child was being looked out for. Gan et al. (2010) document similar categories of support needs for parents, i.e. peer emotional support and respite care, but describes these in terms of formal services offered. Rehabilitation and educational professionals should assist caregivers in identifying the informal supports available around them, especially in South Africa where formal services are lacking. Educators reported that their relationships with certain colleagues encouraged them. The role of informal support is not typically seen as a facilitator to inclusion as many of the individuals who provide this type of support are removed from the school environment, yet this study shows that this type of support is indeed beneficial and should be considered seriously.

The study participants describe the struggle of being back at school after a TBI. It is a complex challenge with barriers to inclusion across personal and systemic levels. Facilitators to inclusion were mostly found at grassroots levels and surprisingly across school-home-community environments. Despite these supports, it is the struggle that is dominant in the stories.

### 5.3. Implications

This study shows that parents, educators and children experience inclusion following TBI as a struggle of forced reintegration. They highlight numerous barriers and facilitators to inclusion. These results have a number of implications which will be of

relevance to policy makers, rehabilitation and educational professionals and researchers. They are provided below.

- In terms of IE policy, the study shows that inclusive education is not being successfully implemented. IE policy needs to be clearer in its procedures and practices (Donohue & Bornman, 2014) so that the systemic support that is currently absent can be cultivated and that the educators who need to apply it at classroom level have the necessary knowledge and skills to do so.
- The study highlights the numerous opportunities for educator training. They need training and support, both theoretical and practical, short term and continued. SLTs working in the field of TBI could be a valuable resource to educators in this regard.
- There are implications for practice in terms of participants' visions of the future. It is clear that the process of being back at school following TBI is long term, fluid and dynamic. It needs monitoring and support over time. The study showed that each participant type has support needs that vary over time. There therefore needs to be a clear delineation of roles and responsibilities by the DoE regarding the process of being back at school in order to make it as effective, supported and seamless as possible.
- The question is raised as to whether schools and policy makers need to identify a type of educator who would best pioneer inclusive practice for children with TBI. An inclusion path across school years could be established initially, ensuring transfer of communication from one year to the next, providing a successful and thus motivating example of inclusion to other educators.
- The study also shows that inclusion is not restricted to the school ground. The participants' experiences were across home, school and community contexts. Those environments are interrelated places of learning for children. The barriers and facilitators experienced across these contexts need to be addressed for inclusion to be successful.
- There is a communication gap between the DoH and DoE that must be addressed, as the child with TBI leaves a medical facility and re-enters a school. There is a great opportunity in South Africa for rehabilitation personnel to act as advocates for the child and family (Backhouse & Rodger, 1999), as this does not yet happen in practice. There is much room for collaboration between DoH and DoE in cases involving TBI (Glang et al., 2008). SLTs are uniquely situated in terms of places of work, i.e. hospital and school settings, to assist with the support of inclusion, particularly in bridging this intersectoral.

They have a unique skill set in their understanding of rehabilitation, TBI and the complex nature of communication (receptive and expressive language, both written and spoken) and its relation to learning and are therefore able to address specific barriers to social and academic inclusion.

- In terms of support to parents, absent from the literature on IE, this study identified parents as lasting drivers for inclusion. Parents advocate for their child and assist educators by giving them information about TBI and its management at home. However, they are also the most unsupported. Policy needs to recognize the role parents play in inclusive education and propose ways of supporting parents by making information on school policy, communication pathways and referral systems accessible to them. Policy makers and educators should include the establishment of parent-educator partnerships in their planning. The value of support groups for parents are again emphasized. SLTs could ideally set these up.
- Children with TBI can return to school after the injury. They need maximum academic and social support initially and continued monitoring as the year progresses. The focus should not be reintegration, i.e. physically occupying a seat in class, but rather inclusion, i.e. the sense of belonging, both academically and socially. This can be achieved by striking balance between providing support and granting children autonomy.
- The parents and educators are identified as remarkable resources for inclusive practice. Their coordinated efforts show how inclusion can be developed from the ground up.
- Parents and educators valued the emotional support they received from varied sources. Rehabilitation professionals and senior school staff need to be aware of and find ways to encourage the development of these lesser known facilitators to inclusion, thus providing critical support for those at the coal face of inclusive practice.
- According to the researcher's knowledge, this is the only qualitative South African study on the experience of being at school following TBI. Despite the high levels of TBI in SA, and sufficient recognition that injury and violence form one of the arms of the quadruple burden of disease in the country, there is a dearth of research on TBI in South Africa. Further research in the field, both quantitative and qualitative, is sorely needed in order to raise the profile of TBI so as to advocate for the necessary support. It is also the only international study focusing on the experiences of return to school following TBI in this age group, as well as the only study that included the voices of parents, educators

and children, giving equal weight to all three. There is therefore a need for additional multi-voice studies on school reintegration following TBI as they provide a rich, complex picture of reality that would be missed in a study from one perspective.

#### 5.4 Strengths and Limitations

The study consisted of two cases which were specific to a context. Other cases might raise different points of relevance. The influence of social context on participants' experiences is noted throughout the study. In addition, the methodology used may have only attracted those participants who are positive in their approach and actions. Critically, however, they were information rich and motivated and the information gained from the participants provided valuable insights into both the barriers and facilitators present within this context. The study in no way purports to generalise the findings to all child survivors of TBI, their parents and educators.

IsiXhosa data might have been limited in depth and accuracy due to the researcher's inability to speak the language and the researcher's use of an interpreter instead. Measures described in Chapter 3 were put in place to minimize these limitations. The stories that emerged were detailed and robust. Participants corroborated the findings during member checking.

A strength of the study was the use of specific adaptations made to the interview process as described in Chapter 3. In spite of the challenges to interviewing children with TBI, the children were able to provide sufficiently detailed interview narratives for analysis.

The interpretive design used means that the study is vulnerable to researcher bias and subjective interpretation. Other researchers may look at the same data and provide different categories and themes. Although this can be viewed as a limitation, it is also an inherent strength of this study. It is flexible and as it allows for multiple interpretations, and does not limit truth, it recognizes the validity of subjective realities and therefore is able to learn from them. However, sufficient measures were used to address personal and professional biases and assumptions as described in Chapter 3, such as member checking. The results speak to the international literature on the topic but also provide some novel information. This supports the trustworthiness of the study.

## 5.5 Conclusion

The study aimed to explore and describe how children, parents and educators experienced being back at school following a moderate-severe TBI. It did so by combining the voices of those most closely affected. This information was presented as detailed in individual research stories and the thematic and integrated analyses. The multivoice description of the experience of being back at school following TBI found that it is a struggle. This was largely due to the fact that there is an expectation that a policy of inclusive education will be practiced in an unsupported system. What the participants experienced was described as “forced integration” rather than true inclusion. There was evidence of the possibility of inclusion being driven from the ground up by parents and educators. However, the overriding picture unfolded of the struggles that the children, their parents and educators faced as they worked at being back at school, worked towards inclusion. The study shows that the policy and practice of IE in schools remain disjointed and that there is minimal intersectoral collaboration. The study is relevant as it speaks to the current situation in SA, both from health and education point of views. It shows health and educational professionals what is missing in terms of providing a co-ordinated service for children with TBI and their families, but also what is possible when key stakeholders partner together to promote successful inclusion.

## REFERENCES

- Agnihotri, S., Keightley, M. L., Colantonio, A., Cameron, D., & Polatajko, H. (2010). Community integration interventions for youth with acquired brain injuries: A review. *Developmental Neurorehabilitation, 13*(5), 369-382.  
doi:10.3109/17518423.2010.499409
- Andelic, N., Sigurdardottir, S., Schanke, A., Sandvik, L., Sveen, U., & Roe, C. (2010). Disability, physical health and mental health 1 year after traumatic brain injury. *Disability & Rehabilitation, 32*(13), 1122-1131.
- Anderson, V., & Catroppa, C. (2006). Advances in postacute rehabilitation after childhood-acquired brain injury - A focus on cognitive, behavioral, and social domains. *American Journal of Physical Medicine & Rehabilitation, 85*(9), 767-778.
- Ashley, M. J. (Ed.). (2010). *Traumatic brain injury: Rehabilitation, treatment and case management* (3rd ed.). Florida: Boca Raton.
- Babikian, T., & Asarnow, R. (2009). Neurocognitive outcomes and recovery after pediatric TBI: Meta-analytic review of the literature. *Neuropsychology, 23*(3), 283.
- Backhouse, M., & Rodger, S. (1999). The transition from school to employment for young people with acquired brain injury: Parent and student perceptions. *Australian Occupational Therapy Journal, 46*(3), 99-109.
- Baguley, I. J., Cooper, J., & Felmingham, K. (2006). Aggressive behavior following traumatic brain injury: How common is common? *The Journal of Head Trauma Rehabilitation, 21*(1), 45-56. doi:00001199-200601000-00005 [pii]
- Baker, K., & Donnelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society, 16*(1), 71-85.
- Bass, D., Albertyn, R., & Melis, J. (1995). Child pedestrian injuries in the Cape metropolitan area - final results of a hospital-based study. *South African Medical Journal, 85*(2), 96-99.

- Bedell, G. M., Cohn, E. S., & Dumas, H. M. (2005). Exploring parents' use of strategies to promote social participation of school-age children with acquired brain injuries. *American Journal of Occupational Therapy, 59*(3), 273-284.
- Bell, S. E. (2010). Visual methods for collecting and analysing data. In I. L. Bourgeault, R. Dingwall & R. G. De Vries (Eds.), *The SAGE handbook of qualitative research methods in health research* (pp. 513-535). Thousand Oaks, California: SAGE Publications, Inc.
- Bernabeu, M., Laxe, S., Lopez, R., Stucki, G., Ward, A., Barnes, M., . . . Cieza, A. (2009). Developing core sets for persons with traumatic brain injury based on the international classification of functioning, disability and health. *Neurorehabilitation and Neural Repair, 23*, 464-467.
- Bernbaum, C. (2007). *School reintegration following traumatic brain injury in children and adolescents*. Published Doctoral Thesis, Walden Univeristy. Available from ProQuest. (3277942).
- Bohnert, A. M., Parker, J. G., & Warschausky, S. A. (1997). Friendship and social adjustment of children following a traumatic brain injury: An exploratory investigation. *Developmental Neuropsychology, 13*(4), 477-486.
- Bradshaw, D., Groenewald, P., Laubscher, R., Nannan, N., Nojilana, B., Norman, R., . . . Johnson, L. (2003). Initial burden of disease estimates for South Africa, 2000. *South African Medical Journal, 93*(9), 682-688.
- Brijlal, P. (2004). The school: A viable educational site for interdisciplinary health promotion. *Education for Health, 17*(3), 303-312.
- Bullock, L. M., Gable, R. A., & Mohr, J. D. (2005). Traumatic brain injury: A challenge for educators. *Preventing School Failure: Alternative Education for Children and Youth, 49*(4), 6-10.
- Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal, 52*(3), 257-260.
- Case, S. (2000). Refocusing on the parent: What are the social issues of concern for parents of disabled children? *Disability & Society, 15*(2), 271-292.

- Chan, V., Thurairajah, P., & Colantonio, A. (2013). Defining traumatic brain injury in children and youth using international classification of diseases version 10 codes: A systematic review protocol. *Systematic Reviews*, 2, 102. doi:10.1186/2046-4053-2-102
- Chisholm, J., & Bruce, B. (2001). Unintentional traumatic brain injury in children: The lived experience. *Axone (Dartmouth, N.S.)*, 23(1), 12-17.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: John Wiley & Sons, Inc.
- Clark, E. (1996). Children and adolescents with traumatic brain injury: Reintegration challenges in educational settings. *Journal of Learning Disabilities*, 29(5), 549-560.
- Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14.
- Crewe-Brown, S. J., Stipinovich, A. M., & Zsilavec, U. (2011). Communication after mild traumatic brain injury - a spouse's perspective. *The South African Journal of Communication Disorders*, 58, 48-55.
- David, R., & Kuyini, A. B. (2012). Social inclusion: Teachers as facilitators in peer acceptance of students with disabilities in regular classrooms in Tamil Nadu, India. *International Journal of Special Education*, 27(2), 157-168.
- De Vos, A., Strydom, H., Fouche, C., & Delport, C. (2005). *Research at grassroots for the social sciences and human service professions* (3rd ed.). Pretoria: Van Schaik Publishers.
- Degeneffe, C. E., & Lee, G. K. (2010). Quality of life after traumatic brain injury: Perspectives of adult siblings. *The Journal of Rehabilitation*, 76(4), 27.
- Degeneffe, C. E., & Olney, M. F. (2010). 'We are the forgotten victims': Perspectives of adult siblings of persons with traumatic brain injury. *Brain Injury*, 24(12), 1416-1427.
- Deidrick, K. K., & Farmer, J. E. (2005). School reentry following traumatic brain injury. *Preventing School Failure: Alternative Education for Children and Youth*, 49(4), 23-33.

- Department of Education. (2001). *Education White Paper 6: special needs education – building an inclusive education and training system*. Pretoria: Department of Education.
- Department of Basic Education. (2010). *Report on the 2008 and 2009 annual surveys for the ordinary school*. Pretoria: Department of Basic Education.
- Department of Basic Education. (2011). *National protocol for assessment Grades R – 12*. Pretoria: Department of Basic Education.
- Department of Basic Education. (2012). *National policy pertaining to the programme and promotion requirements of the national curriculum statement Grades R - 12*. Pretoria: Department of Basic Education.
- Department of Health. (2011). *Annual performance plan 2011/12-2013/14*. Pretoria: Department of Health.
- DePompei, R., & Blosser, J. L. (1994). The family as collaborator for effective school reintegration. In Savage & Wolcott (Eds.), *Educational dimension of acquired brain injury* (pp. 489-506).
- Donohue, D., & Bornman, J. (2014). The challenges of realising inclusive education in South Africa. *South African Journal of Education*, 34(2), 1-14.
- Draper, B., Pienaar, D., Parker, W., & Rehle, T. (2007). *Recommendations for policy in the Western Cape province for the prevention of major infectious diseases, including HIV/AIDS and tuberculosis*. Cape Town.
- Du Toit, C., Coetzee, Z., & Beeton, H. (2013). Mothers' experiences of caring for a child with severe brain injury in a disadvantaged community in the cape flats. *South African Journal of Occupational Therapy*, 43(2), 17-22.
- Duncan, M. (2009). *Human occupation in the context of chronic poverty and psychiatric disability*. Unpublished Doctoral Thesis. Stellenbosch University, South Africa.
- Dykeman, B. F. (2003). School-based interventions for treating social adjustment difficulties in children with traumatic brain injury. *Journal of Instructional Psychology*, 30(3), 225-230.

- Ehrenfors, R., Borell, L., & Hemmingsson, H. (2009). Assessments used in school-aged children with acquired brain injury - linking to the international classification of functioning, disability and health. *Disability and Rehabilitation*, *31*(17), 1392-1401. doi:10.1080/09638280802621366
- Engelbrecht, P. (2006). The implementation of inclusive education in South Africa after ten years of democracy. *European Journal of Psychology of Education*, *21*(3), 253-264. doi:10.1007/BF03173414
- Erickson, S. J., Montague, E. Q., & Gerstle, M. A. (2010). Health-related quality of life in children with moderate-to-severe traumatic brain injury. *Developmental Neurorehabilitation*, *13*(3), 175-181. doi:10.3109/17518420903479867
- Ewing-Cobbs, L., Barnes, M., Fletcher, J. M., Levin, H. S., Swank, P. R., & Song, J. (2004). Modeling of longitudinal academic achievement scores after pediatric traumatic brain injury. *Developmental Neuropsychology*, *25*(1-2), 107-133. doi:10.1207/s15326942dn2501&2\_7
- Ewing-Cobbs, L., Fletcher, J. M., Levin, H. S., Iovino, I., & Miner, M. E. (1998). Academic achievement and academic placement following traumatic brain injury in children and adolescents: A two-year longitudinal study. *Journal of Clinical & Experimental Neuropsychology*, *20*(6), 769-781.
- Farjou, G., Sinha, R., Dix, D., Shahbaz, A., Klaassen, R., & Klassen, A. (2013). Understanding the healthcare experiences of teenaged cancer patients and survivors. *Child: Care, Health and Development*, *40*(5), 723-730. doi:10.1111/cch.12109
- Farmer, J. E., Clippard, D. S., Luehr-Wiemann, Y., Wright, E., & Owings, S. (1996). Assessing children with traumatic brain injury during rehabilitation: Promoting school and community reentry. *Journal of Learning Disabilities*, *29*(5), 532-548.
- Fay, G. C., Jaffe, K. M., Polissar, N. L., Liao, S., Rivara, J. B., & Martin, K. M. (1994). Outcome of pediatric traumatic brain injury at three years: A cohort study. *Archives of Physical Medicine & Rehabilitation*, *75*(7), 733-741.
- Fleming, J., Sampson, J., Cornwell, P., Turner, B., & Griffin, J. (2012). Brain injury rehabilitation: The lived experience of inpatients and their family caregivers. *Scandinavian Journal of Occupational Therapy*, *19*(2), 184-193.

- Galvin, J., Froude, E. H., & McAleer, J. (2010). Children's participation in home, school and community life after acquired brain injury. *Australian Occupational Therapy Journal, 57*(2), 118-126.
- Gan, C., Gargaro, J., Brandys, C., Gerber, G., & Boschen, K. (2010). Family caregivers' support needs after brain injury: A synthesis of perspectives from caregivers, programs, and researchers. *NeuroRehabilitation, 27*(1), 5-18.
- Gauvin-Lepage, J., & Lefebvre, H. (2010). Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury, 24*(9), 1087-1097.
- Gfroerer, S. D., Wade, S. L., & Wu, M. (2008). Parent perceptions of school-based support for students with traumatic brain injuries. *Brain Injury, 22*(9), 649-656. doi:10.1080/02699050802227162
- Giangreco, M. F., Edelman, S. W., Luiselli, T. E., & MacFarland, S. Z. (1997). Helping or hovering? effects of instructional assistant proximity on students with disabilities. *Exceptional Children, 64*(1), 7-18.
- Glang, A., Ettel, D., Tyler, J., & Todis, B. (2012). Educational issues and school reentry for students with traumatic brain injury. In N. Zasler, D. Katz, R. Zafonte, D.B. Arciniegas, M.R. Bullock, & J.S. Kreutzer (Eds.), *Brain injury medicine: Principles and practice* (2nd ed.)
- Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with traumatic brain injury: A school-based intervention. *The Journal of Head Trauma Rehabilitation, 12*(2), 32-47.
- Glang, A., Ylvisaker, M., Stein, M., Ehhardt, L., Todis, B., & Tyler, J. (2008). Validated instructional practices: Application to students with traumatic brain injury. *Journal of Head Trauma Rehabilitation, 23*(4), 243-251. doi:10.1097/01.HTR.0000327256.46504.9f
- Graham, L. J., & Slee, R. (2006). Inclusion? *Disability Studies in Education Special Interest Group, American Educational Research Association (AERA) Annual Conference*, San Francisco. 1-25.

- Greeff, P., & Grobler, A. (2008). Bullying during the intermediate school phase: A South African study. *Childhood, 15*(1), 127-144.
- Griffin, J. M., Friedemann-Sánchez, G., Hall, C., Phelan, S., & van Ryn, M. (2009). Families of patients with polytrauma: Understanding the evidence and charting a new research agenda. *J Rehabil Res Dev, 46*(6), 879-892.
- Harn, W. E., Bradshaw, M. L., & Ogletree, B. T. (1999). The speech-language pathologist in the schools changing roles. *Intervention in School and Clinic, 34*(3), 163-169.
- Harris, D., & Stuart, A. (2006). Adolescents' experience of a parental traumatic brain injury: Research. *Health SA Gesondheid, 11*(4), 46-56.
- Hartley, L. (1995). *Cognitive-communicative abilities following brain injury: A functional approach*. San Diego, CA: Singular Publishing Group, Inc.
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Mychalkiw, W. (2004). Return to school after brain injury. *Arch Dis Child, 89*, 136-142.
- Hawley, C.A. (2012). Self-esteem in children following traumatic brain injury: An exploratory study. *NeuroRehabilitation, 30*(3), 173-181.
- Hawley, C. A. (2004). Behaviour and school performance after brain injury. *Brain Injury, 18*(7), 645-659.
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2002). Children's brain injury: A postal follow-up of 525 children from one health region in the UK. *Brain Injury, 16*(11), 969-985.
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury, 17*(1), 1-23.
- Hennink, M. M., Bailey, A., & Hutter, I. (2011). *Qualitative research methods*. London ; Thousand Oaks, Calif.: Sage.
- Hines, M., Balandin, S., & Togher, L. (2014). The stories of older parents of adult sons and daughters with autism: A balancing act. *Journal of Applied Research in Intellectual Disabilities, 27*(2), 163-173.

- Hux, K., Bush, E., Zickefoose, S., Holmberg, M., Henderson, A., & Simanek, G. (2010). Exploring the study skills and accommodations used by college student survivors of traumatic brain injury. *Brain Injury, 24*(1), 13-26.
- Hux, K., & Hacksley, C. (1996). Mild traumatic brain injury: Facilitating school success. *Intervention in School and Clinic, 31*(3), 158-165.
- Hyatt, K., Davis, L. L., & Barroso, J. (2014). Chasing the care: Soldiers experience following combat-related mild traumatic brain injury. *Military Medicine, 179*(8), 849-855.
- Ilie, G., Mann, R. E., Boak, A., Adlaf, E. M., Hamilton, H., Asbridge, M., . . . Cusimano, M. D. (2014). Suicidality, bullying and other conduct and mental health correlates of traumatic brain injury in adolescents. *PLoS ONE, 9*(4)  
doi:10.1371/journal.pone.0094936
- Kao, H. S., & Stuijbergen, A. K. (2004). Love and load - the lived experience of the mother-child relationship among young adult traumatic brain-injured survivors. *The Journal of Neuroscience Nursing, 36*(2), 73-81.
- Kathard, H. (2003). *Life histories of people who stutter: On becoming someone*. Unpublished Doctoral Thesis, University of Durban-Westville, KwaZulu-Natal, South Africa
- Kathard, H. (2009). Personal truth making: A cautious celebration. In R. Dhunpath, & M. Samuel (Eds.), *Life history research: Epistemology, methodology and representation* (pp. 19-38). Sense Publishers.
- Kathard, H., & Pillay, M. (2013). Promoting change through political consciousness: A south african speech-language pathology response to the world report on disability. *International Journal of Speech-Language Pathology, 15*(1), 84-89.
- Kelly, S. E. (2010). Qualitative interviewing techniques and styles. In I. Bourgeault, R. Dingwall & R. G. De Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 307-326). Thousand Oaks, California: SAGE Publications, Inc.

- Kinsella, G. J., Prior, M., Sawyer, M., Ong, B., Murtagh, D., Eisenmajer, R., . . . Klug, G. (1997). Predictors and indicators of academic outcome in children 2 years following traumatic brain injury. *Journal of the International Neuropsychological Society*, 3(06), 608-616.
- Kirk, S., Fallon, D., Fraser, C., Robinson, G., & Vassallo, G. (2014). Supporting parents following childhood traumatic brain injury: A qualitative study to examine information and emotional support needs across key care transitions. *Child: Care, Health and Development*. doi: 10.1111/cch.12173
- Kortessluoma, R., Hentinen, M., & Nokkonen, M. (2003). Conducting a qualitative child interview: Methodological considerations. *Journal of Advanced Nursing*, 42(5), 434-441.
- Krol, M., Sixma, H., Meerdink, J., Wiersma, H., & Rademakers, J. (2014). Exploring young patients' perspectives on rehabilitation care: Methods and challenges of organizing focus groups for children and adolescents. *Child: Care, Health and Development*, 40(4), 507-514.
- Lash, M., & Scarpino, C. (1993). School reintegration for children with traumatic brain injuries: Conflicts between medical and educational systems. *NeuroRehabilitation*, 3(3), 13-25.
- Lebby, P. C., & Asbell, S. J. (2007). *The source for traumatic brain injury: Children and adolescents*. East Moline, Illinois: LinguiSystems Inc.
- Lefebvre, H., Pelchat, D., Swaine, B., Gelinias, I., & Levert, M. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, 19(8), 585-597.
- Lefebvre, H., Cloutier, G., & Josee Levert, M. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, 22(7-8), 535-543.
- Leith, K. H., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with TBI and their families: The South Carolina experience. *Brain Injury*, 18(12), 1191-1208. doi:10.1080/02699050410001719943

- Levin, K. (2004). Paediatric traumatic brain injury in South Africa: Some thoughts and considerations. *Disability & Rehabilitation*, 26(5), 306-314.
- Lewis, A. (2011). The importance of silence when hearing the views of children and young people with speech, language and communication needs. In S. Roulstone, & S. McLeod (Eds.), *Listening to children and young people with speech, language and communication needs* (pp. 55-62). Albury, Guildford: J&R Press Ltd.
- Lewis, A. (2002). Accessing, through research interviews, the views of children with difficulties in learning. *Support for Learning*, 17(3), 111-116.
- Leyser, Y., & Kirk, R. (2004). Evaluating inclusion: An examination of parent views and factors influencing their perspectives. *International Journal of Disability, Development and Education*, 51(3), 271-285.
- Liamputtong, P. (2009). *Qualitative research methods* (3rd ed.). South Melbourne, Vic; New York: Oxford University Press.
- Liang, H., Flisher, A. J., & Lombard, C. J. (2007). Bullying, violence, and risk behavior in south african school students. *Child Abuse & Neglect*, 31(2), 161-171.
- Liddle, J., Fleming, J., McKenna, K., Turpin, M., Whitelaw, P., & Allen, S. (2012). Adjustment to loss of the driving role following traumatic brain injury: A qualitative exploration with key stakeholders. *Australian Occupational Therapy Journal*, 59(1), 79-88.
- Limond, J., Dorris, L., & McMillan, T. M. (2009). Quality of life in children with acquired brain injury: Parent perspectives 1-5 years after injury. *Brain Injury*, 23(7-8), 617-622.
- Marsh, N. V., Kersel, D. A., Havill, J. H., & Sleigh, J. W. (2002). Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 24(4), 434-447.
- Mashiya, N. (2014). How inclusive is South African inclusive education? A case study of three foundation phase classes. *Anthropologist*, 17(2), 599-605.
- McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2010). My speech problem, your listening problem, and my frustration: The experience of living with

childhood speech impairment. *Language, Speech and Hearing Services in Schools*, 41, 379-392.

- McKinlay, A., McLellan, T., & Daffue, C. (2012). The invisible brain injury: The importance of identifying deficits following brain injury in children with intellectual disability. *NeuroRehabilitation*, 30(3), 183-187.
- McLeod, S. (2011). Listening to children and young people with speech, language and communication needs : Who, why and how? In S. Roulstone, & S. McLeod (Eds.), *Listening to children and young people with speech, language and communication needs* (pp. 23-40). Albury, Guildford: J&R Press Ltd.
- McLeod, S., McCormack, J., McAllister, L., Harrison, L. J., & Holliday, E. (2011). Listening to 4- to 5- year old children with speech impairment using drawings, interviews and questionnaires. In S. Roulstone, & S. McLeod (Eds.), *Listening to children and young people with speech, language and communication needs* (pp. 180-186). Albury, Guildford: J&R Press Ltd.
- Mealings, M., Douglas, J., & Olver, J. (2012). Considering the student perspective in returning to school after TBI: A literature review. *Brain Injury*, 26(10), 1165-1176.
- Mealings, M., & Douglas, J. (2010). 'School's a big part of your life...': Adolescent perspectives of their school participation following traumatic brain injury. *Brain Impairment*, 11(1), 1-16. doi:10.1375/brim.11.1.1
- Meltz, A., Herman, C., & Pillay, V. (2014). Inclusive education: A case of beliefs competing for implementation. *South African Journal of Education*, 34(3), 01-08.
- Minnes, P., Graffi, S., Nolte, M. L., Carlson, P., & Harrick, L. (2000). Coping and stress in Canadian family caregivers of persons with traumatic brain injuries. *Brain Injury*, 14(8), 737-748.
- Mokhosi, M., & Grieve, K. (2004). African families' perceptions of traumatic brain injury. *South African Journal of Psychology*, 34(2), 301-317.
- Morris, P. G., Prior, L., Deb, S., Lewis, G., Mayle, W., Burrow, C. E., & Bryant, E. (2005). Patients' views on outcome following head injury: A qualitative study. *BMC Family Practice*, 6(30), 6. doi:10.1186/1471-2296-6-30

- Naicker, S. (2006). From policy to practice: A South African perspective on implementing inclusive education policy. *International Journal of Whole Schooling*, 3(1).
- Nicholl, J., & LaFrance, W. C. (2009). Neuropsychiatric sequelae of traumatic brain injury. *Seminars in Neurology*, 29(3) 247-255.
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine*, 46(7), 869-878.
- Norman, R., Matzopoulos, R., Groenewald, P., & Bradshaw, D. (2007). The high burden of injuries in South Africa. *Bulletin of the World Health Organization*, 85(9), 695-702.
- Ntombela, S. (2011). The progress of inclusive education in South Africa: Teachers' experiences in a selected district, KwaZulu-Natal. *Improving Schools*, 14(1), 5-14.
- Ollerenshaw, J. A., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry*, 8, 329-347.  
doi:10.1177/10778004008003008
- Oosthuizen, D. (2007). *Families of children with traumatic brain injuries: Stressors and needs in the South African context*. Unpublished Honours in Psychology, University of Cape Town, South Africa.
- Paterson, B., & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injuries. *Qualitative Health Research*, 12, 399-409.  
doi:10.1177/104973202129119973
- Penn, C., Watermeyer, J., & Schie, K. (2009). Auditory disorders in a South African paediatric TBI population: Some preliminary data. *International Journal of Audiology*, 48(3), 135-143.
- Peters, S.J. (2004, November). *Inclusive education: An EFA strategy for all children*. World Bank. Retrieved from  
[http://siteresources.worldbank.org/EDUCATION/Resources/278200-1099079877269/547664-1099079993288/InclusiveEdu\\_efa\\_strategy\\_for\\_children.pdf](http://siteresources.worldbank.org/EDUCATION/Resources/278200-1099079877269/547664-1099079993288/InclusiveEdu_efa_strategy_for_children.pdf)

- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology, 52*(2), 137-145. doi:10.1037/0022-0167.52.2.137
- Prigatano, G. P., & Gray, J. A. (2007). Parental concerns and distress after paediatric traumatic brain injury: A qualitative study. *Brain Injury, 21*(7), 721-729.
- Prigatano, G. P., & Gupta, S. (2006). Friends after traumatic brain injury in children. *The Journal of Head Trauma Rehabilitation, 21*(6), 505-513. doi:00001199-200611000-00005 [pii]
- Prinsloo, E. (2006). Working towards inclusive education in South African classrooms. *South African Journal of Education, 21*(4), 344-348.
- Rabiee, P., Sloper, P., & Beresford, B. (2005). Doing research with children and young people who do not use speech for communication. *Children and Society, 19*(5), 385-396.
- Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2), 139-150.
- Rillotta, F., & Nettelbeck, T. (2007). Effects of an awareness program on attitudes of students without an intellectual disability towards persons with an intellectual disability. *Journal of Intellectual and Developmental Disability, 32*(1), 19-27.
- Rodstet, M. (2008). Adolescents with traumatic brain injury and their school situation: A qualitative study. *Scandinavian Journal of Disability Research, 10*(2), 90-103. doi:10.1080/15017410801927807
- Roscigno, C. I., Fleig, D. K., & Knafl, K. A. (2014). Parent management of the school reintegration needs of children and youth following moderate or severe traumatic brain injury. *Disability & Rehabilitation, (0)*, 1-11.
- Roscigno, C. I., & Swanson, K. M. (2011). Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research, 21*(10), 1413-1426. doi:10.1177/1049732311410988

- Roscigno, C. I., Swanson, K. M., Vavilala, M. S., & Solchany, J. (2011). Children's longing for everydayness: Life following traumatic brain injury in the USA. *Brain Injury, 25*(9), 882-894. doi:10.3109/02699052.2011.581638
- Roundhill, S. J., Williams, W. H., & Hughes, J. (2007). The experience of loss following traumatic brain injury: Applying a bereavement model to the process of adjustment. *Qualitative Research in Psychology, 4*(3), 241-257.
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing the art of hearing data* (2nd ed.). Thousand Oaks, California: Sage Publications Inc.
- Samuel, M. (2009). Risking ambiguity: Exploring voice in research. In R. Dhunpath, & M. Samuel (Eds.), *Life history research: Epistemology, methodology and representation* (pp. 85-92). Sense Publishers.
- Savage, R. C. (1997). Integrating rehabilitation and education services for school-age children with brain injuries. *The Journal of Head Trauma Rehabilitation, 12*(2), 11-20.
- Savage, R. C., Pearson, S., McDonald, H., Potoczny-Gray, A., & Marchese, N. (2001). After hospital: Working with schools and families to support the long term needs of children with brain injuries. *NeuroRehabilitation, 16*(1), 49-58.
- Savage, R. C., DePompei, R., Tyler, J., & Lash, M. (2005). Paediatric traumatic brain injury: A review of pertinent issues. *Pediatric Rehabilitation, 8*(2), 92-103.
- Schutz, L. E., Rivers, K. O., McNamara, E., Schutz, J. A., & Lobato, E. J. (2010). Traumatic brain injury in K-12 students: Where have all the children gone?. *International Journal of Special Education, 25*(2), 55-71.
- Seedat, M., Van Niekerk, A., Jewkes, R., Suffla, S., & Ratele, K. (2009). Violence and injuries in South Africa: Prioritising an agenda for prevention. *The Lancet, 374*(9694), 1011-1022.
- Semple, P. L., Bass, D. H., & Peter, J. C. (1998). Severe head injury in children-a preventable but forgotten epidemic. *South African Medical Journal-Cape Town-Medical Association of South Africa-, 88*, 440-443.

- Sharp, N. L., Bye, R. A., Llewellyn, G. M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability and Rehabilitation, 28*(12), 767-778. doi:10.1080/09638280500386668
- Singh, I., & Keenan, S. (2010). The challenges and opportunities of qualitative health research with children. In I. L. Bourgeault, R. Dingwall & R. G. De Vries (Eds.), *The SAGE handbook of qualitative methods in health research* (pp. 696-713). Thousand Oaks, California: SAGE Publications Inc.
- Smit, M. J. (2006). *A Qualitative Exploration of Experiences of Others and Accounts of Self in the Narratives of Persons Who have Experienced Traumatic Brain Injury*. Published Masters Thesis, University of Pretoria, South Africa.
- Soeker, M. S. (2011). Occupational adaptation: A return to work perspective of persons with mild to moderate brain injury in South Africa. *Journal of Occupational Science, 18*(1), 81-91.
- Sohlberg, M. M., McLaughlin, K. A., Todis, B., Larsen, J., & Glang, A. (2001). What does it take to collaborate with families affected by brain injury? A preliminary model. *The Journal of Head Trauma Rehabilitation, 16*(5), 498-511.
- Stevens, M. M., Lord, B. A., Proctor, M., Nagy, S., & O'Riordan, E. (2010). Research with vulnerable families caring for children with life-limiting conditions. *Qualitative Health Research, 20*, 496. doi:10.1177/1049732309356097
- Swart, E., & Oswald, M. (2008). How teachers navigate their learning in developing inclusive learning communities. *Education as Change, 12*(2), 91-108.
- Tate, R. L., & Perdices, M. (2008). Applying the international classification system of functioning, disability and health (ICF) to clinical practice and research in acquired brain impairment. *Brain Impairment, 9*(3), 282-292. doi:10.1375/brim.9.3.282
- Taylor, H. G., Swartwout, M., Yeates, K. O., Walz, N. C., Stancin, T., & Wade, S. L. (2008). Traumatic brain injury in young children: Post-acute effects on cognitive and school readiness skills. *J Int Neuropsychol Soc, 14*(5), 734-745. doi:10.1017/S1355617708081150
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in

children: Behavior and achievement. *Neuropsychology*, 16(1), 15-27.  
doi:10.1037/0894-4105.16.1.15

Turner, B., Fleming, J., Ownsworth, T., & Cornwell, P. (2011). Perceptions of recovery during the early transition phase from hospital to home following acquired brain injury: A journey of discovery. *Neuropsychological Rehabilitation*, 21(1), 64-91.

United Nations. (2006). *Convention on the Rights of Persons with Disability (CRPD)*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>

UNICEF. (1989). *The United Nations Convention on the Rights of the Child (UNCRC)*. Retrieved from [http://www.unicef.org/crc/files/Rights\\_overview.pdf](http://www.unicef.org/crc/files/Rights_overview.pdf)

Van Tol, E., Gorter, J. W., DeMatteo, C., & Meester-Delver, A. (2011). Participation outcomes for children with acquired brain injury: A narrative review. *Brain Injury*, 25(13-14), 1279-1287.

Walton, E. (2011). Getting inclusion right in South Africa. *Intervention in School and Clinic*, 46(4), 240-245.

Walton, E., Nel, N., Hugo, A., & Muller, H. (2009). The extent and practice of inclusion in independent schools in South Africa. *South African Journal of Education*, 29(1), 105-126.

Watson, D., Abbott, D., & Townsley, R. (2007). Listen to me, too! lessons from involving children with complex healthcare needs in research about multi-agency services. *Child: Care, Health and Development*, 33(1), 90-95.

West, S., Dunford, C., Mayston, M. J., & Forsyth, R. (2013). The school function assessment: Identifying levels of participation and demonstrating progress for pupils with acquired brain injury in a residential rehabilitation setting. *Child: Care, Health and Development*, 40(5), 689-697. doi:10.1111/cch.12089

World Health Organization. (2001). *International Classification of Functioning, Disability and Health short version*. Geneva: WHO Library Cataloguing-in Publication Data, (p. 190).

World Health Organisation. (2007). *ICF-CY: International Classification of Functioning, Disability and Health: Children and Youth Version*. Geneva: author.

- World Health Organisation. (2011). *World Report on Disability summary*. Geneva: World Health Organisation.
- Wingate, I. A. (2006). *Children without disabilities' attitudes toward and involvement in the recreation of their siblings with disabilities*. Published Masters Thesis. Available from ProQuest. (1428341).
- Wongvatunyu, S., & Porter, E. J. (2005). Mothers' experience of helping young adults with traumatic brain injury. *Journal of Nursing Scholarship, 37*(1), 48-56.
- Yeates, K. O., & Taylor, H. G. (2006). Behaviour problems in school and their educational correlates among children with traumatic brain injury. *Exceptionality: A Special Education Journal, 14*(3), 141-154. doi:10.1207/s15327035ex1403\_3
- Ylvisaker, M., Feeney, T., & Mullins, K. (1995). School reentry following mild traumatic brain injury: A proposed hospital-to-school protocol. *The Journal of Head Trauma Rehabilitation, 10*(6), 42-49.
- Ylvisaker, M., Adelson, P. D., Braga, L. W., Burnett, S. M., Glang, A., Feeney, T., . . . Todis, B. (2005). Rehabilitation and ongoing support after pediatric TBI - twenty years of progress. *Journal of Head Trauma Rehabilitation, 20*(1), 95-109.
- Ylvisaker, M., Todis, B., Glang, A., Urbanczyk, B., Franklin, C., DePompei, R., . . . Tyler, J. S. (2001). Educating students with TBI: Themes and recommendations. *The Journal of Head Trauma Rehabilitation, 16*(1), 76-93.
- Yssel, N., Engelbrecht, P., Oswald, M. M., Eloff, I., & Swart, E. (2007). Views of inclusion A comparative study of parents' perceptions in South Africa and the United States. *Remedial and Special Education, 28*(6), 356-365.

## APPENDIX 1: UCT HUMAN RESEARCH ETHICS COMMITTEE APPROVAL



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E52-24 Old Main Building  
Grootes Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6938 • Facsimile [021] 406 6411  
Email: [hrec@uct.ac.za](mailto:hrec@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

14 September 2012

**HREC REF: 480/2012**

**Ms A De Villiers**  
C/o Prof H Kathard  
Speech & Therapy  
Health & Rehab  
F Floor  
OMB

Dear Ms De Villiers

**PROJECT TITLE: Stories of being back at school following traumatic brain injury (TBI): the experiences of children, their parents and educators**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until 30 September 2013.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/research/humanethics/forms](http://www.health.uct.ac.za/research/humanethics/forms))

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the HREC reference no in all your correspondence.**

Yours sincerely



**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN ETHICS**

## APPENDIX 2: GROOTE SCHUUR HOSPITAL ETHICS BOARD APPROVAL



Western Cape  
Government

Health



**GROOTE SCHUUR HOSPITAL**

Enquiries: Dr Bhavna Patel

E-mail : [Bhavna.Patel@westerncape.gov.za](mailto:Bhavna.Patel@westerncape.gov.za)

Ms Amy de Villiers  
C/o Professor H. Kathard  
Department of Health & Rehabilitation Sciences  
F45 – Old Main Building

E-mail: [Amy.DeVilliers@westerncape.gov.za](mailto:Amy.DeVilliers@westerncape.gov.za) & [Harsha.Kathard@uct.ac.za](mailto:Harsha.Kathard@uct.ac.za)

Dear Ms de Villiers

**RESEARCH: Stories of School Reintegration Following Traumatic Brain Injury: The Experiences of Children, Their Primary Caregivers and Educators in the Western Cape**

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

- a) Your research may not interfere with normal patient care
- b) Hospital staff may not be asked to assist with the research.
- c) No hospital consumables and stationary may be used.
- d) **No patient folders may be removed from the premises or be inaccessible. Please contact Mr Noel Weeder on ext. 4058 or 4066 in this regard.**
- e) Please introduce yourself to the person in charge of an area before commencing.
- f) Confidentiality must be maintained at all times.

I would like to wish you every success with the project.

Yours sincerely

**DR BHAVNA PATEL**  
**SENIOR MANAGER: MEDICAL SERVICES**

Date: 5<sup>th</sup> October 2012

G46 Management Suite, Old Main Building,  
Observatory 7925

Private Bag X,  
Observatory, 7935

## APPENDIX 3A: CHILD INFORMATION LETTER AND ASSENT (ENGLISH)



**Department of Health and  
Rehabilitation Sciences  
Faculty of Health Sciences**  
Divisions of Communications Sciences and  
Disorders, Nursing and Midwifery,  
Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur  
Hospital,  
Observatory 7925  
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406  
6323  
Internet: [www.uct.ac.za](http://www.uct.ac.za)

My name is Amy de Villiers. I work in a hospital and help children who have been in accidents. I want to learn more about what it is like for children to go back to school after an accident. This is why I want to talk to you. I have also asked your mom/dad and one of your teachers to tell me about what it was like for them. It will help other children like you when they go back to school.

It is up to you if you want to talk to me about this or not. If you'd like to talk to me, I need you to give me your permission. I also need your permission to talk to one of your teachers.

If you want to do this, we will meet two or three times. Each visit will be about an hour long. You will tell me what it was like for you to go back to school after your accident and I will listen to you. There will be no right or wrong answers. You are the expert! Later I will meet with you again to check that I understood your story properly. If I made mistakes, I will ask you to help me fix them.

People will not find out what you have told me because I will keep your name a secret. I will not tell your family or teachers.

I will bring something to eat and drink to the meetings. It will not cost you or your mom/dad anything to take part in this.

If you are worried about anything or have any questions, you can ask me. Your mom/dad have my telephone number too.

I will come and ask you if you would like to take part in this project after you have had some time to think about it.

You can tick your choice below:

I agree to take part in this study.

I do not agree to take part in this study.

## APPENDIX 3B: PARENT INFORMATION LETTER AND CONSENT (ENGLISH)

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**Department of Health and  
Rehabilitation Sciences  
Faculty of Health Sciences**  
Divisions of Communications Sciences and  
Disorders, Nursing and Midwifery,  
Occupational Therapy, Physiotherapy

F45 Old Main Building, Groote Schuur  
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6323  
Internet: [www.uct.ac.za](http://www.uct.ac.za)

---

My name is Amy de Villiers. I am doing my Masters degree at the University of Cape Town. This letter is to tell you about my study and how I would like you to be part of it.

The name of the study is **“Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape.”** I am studying what it is like for children who have had a brain injury to return to school. I also want to find out what it is like for their parents and teachers. That is why I have asked you to be part of the study. The information from this study is important because it will be used to show therapists and teachers how to help other children and parents with similar problems in future.

It is completely your choice whether you want to take part or not. You will not be paid to take part. If you choose to be part of the study you will be required to give your consent. This means that you understand what is required of you and that you give your permission for the information you provide to be used in the study. Even if you agree, you may later leave the study at any time if you don't want to carry on. You do not need to tell me why. There is no penalty for leaving the study. With your permission, I will also ask your child and one of his/her teachers to take part.

If you agree to take part in this study, you will be interviewed on at least two separate occasions by yourself. I will ask you tell me your story about when your child went back to school after his/her accident. Each interview will last between 1 -2 hours. At a later stage, I will get in touch with you again, so that you can check that I have understood you correctly. This meeting will also be about 1 hour. You can choose the place and time that suits you best for these meetings.

There is no cost to take part in this study. I will assist you with transport costs to the meeting place, if that is needed. I will provide something small to eat and drink at the interviews. There are no risks to being part of this study. However, it might be upsetting for you to talk about

your experience. I will listen to you and help you if I can. Otherwise I will refer you to a social worker, if you prefer.

Some people find it helpful to tell others about their experiences.

Everything you tell me will be kept confidential – only I will know what you have told me. To do this, I will not use your real name in any of the study and will keep information locked away. The recording of the interview will be protected by a password. No one will be able to link the information to you. I will use your real name in reporting if you wish me to.

I will answer any questions that you have in person or via telephone. I can be contacted on (021) 404 6458/6466.

I will be supervised by Harsha Kathard, an associate professor at the University of Cape Town. If you have any questions for her you can contact her on (021) 406 6593.

This research has been approved by the Faculty of Health Sciences Human Research Ethics Committee (FHS HREC) of the University of Cape Town and its reference number is HREC REF 480/2012

Professor Marc Blockman is Chairperson of the FHS HREC and he can be contacted on (021) 406 6492 if you would like more information on the approval of this research.

If you agree to participate in this study please fill in the form:

I agree to participate in the research study “Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape.”

I understand what is required of me and that I have the right to leave the study at any stage. I have had the study explained to me and I have read or been read the previous information page. I understand that my name will not be used in any reporting of the research unless I choose to have it included. I have had the chance to ask questions and my questions have been answered. I understand that I will not receive anything for participating in the study.

I consent to my child’s participation in this study if he/she wishes to. I also give the researcher permission to contact one of my child’s educators to participate in this study.

Name in Print: \_\_\_\_\_

Signed: \_\_\_\_\_

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

## APPENDIX 3C: EDUCATOR INFORMATION LETTER AND CONSENT (ENGLISH)

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Department of Health and  
Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communications Sciences and  
Disorders, Nursing and Midwifery,  
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6323

Internet: [www.uct.ac.za](http://www.uct.ac.za)

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My name is Amy de Villiers. I am doing my Masters degree at the University of Cape Town. This letter is to tell you about my study and how I would like you to be part of it.

The name of the study is **“Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape.”** I am studying what it is like for children who have had a brain injury to return to school. I also want to find out what it is like for their parents and teachers. That is why I have asked you to be part of the study. One of the children you teach as well as his/her parent, will also be asked to take part. The information from this study is important because it will be used to advise therapists and teachers on how to better assist other children, parents and teachers in future.

Participation is completely voluntary. You will not be paid to take part. If you choose to be part of the study you will be required to give your consent. This means that you understand what is required of you and that you give your permission for the information you provide to be used in the study. Even if you agree, you may later leave the study at any time if you don't want to carry on. You do not need to tell me why. There is no penalty for leaving the study.

If you agree to take part in this study, you will be interviewed on at least two separate occasions by yourself. I will ask you tell me your story about having a child with a brain injury in your class. Each interview will last between 1 -2 hours. At a later stage, I will get in touch with you again, so that you can check that I have understood you correctly. This meeting will also be about 1 hour. You can choose the place and time that suits you best for these meetings.

There is no cost to take part in this study. I will assist you with transport costs to the meeting place, if that is needed. I will provide something small to eat and drink at the interviews. There are no risks to being part of this study.

Some people find it helpful to tell others about their experiences.

Everything you tell me will be kept confidential – only I will know what you have told me. To do this, I will use a false name for you and will keep information locked away. Interview recordings will be password protected. No one will be able to link the information to you. I will use your real name in reporting if you wish.

I will answer any questions you have in person or via telephone. I can be contacted on (021) 404 6458/6466.

I will be supervised by Harsha Kathard, an associate professor at the University of Cape Town. If you have any questions for her you can contact her on (021) 406 6593.

This research has been approved by the Faculty of Health Sciences Human Research Ethics Committee (FHS HREC) of the University of Cape Town and its reference number is HREC REF 480/2012.

Professor Marc Blockman is the Chairperson of the FHS HREC and he can be contacted on (021) 406 6492 if you would like more information on the approval of this research.

If you agree to participate in this study please fill in the form:

I agree to participate in the research study “Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape.”

I understand what is required of me and that I have the right to leave the study at any stage. I have had the study explained to me and I have read or been read the previous information page. I understand that my name will not be used in any reporting of the research unless I choose to have it included. I have had the chance to ask questions and my questions have been answered. I understand that I will not receive anything for participating in the study.

Name in Print: \_\_\_\_\_

Signed: \_\_\_\_\_

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

## APPENDIX 3D: CHILD INFORMATION LETTER AND ASSENT (ISIXHOSA)

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**Department of Health and  
Rehabilitation Sciences**

**Faculty of Health Sciences**

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Igama lam ngu Amy de Villiers. Ndisebenza esibhedlele yaye ndinceda abantwana ebebe chaphazeleke ezingozini. Ndifuna ukufunda ngokuthe chatha ngokuba ingaba kunjani ukuba ngaba bantwana ukuphindela esikolweni emva kwengozi. Yilonto ebangela ukuba ndifune ukuthetha nawe. Ndimcelile naye umama/ utata wakho nomnye wotitshala ukuba andixelele bekunjani kubo. Izakunceda abanye abantwana abafana nawe xa bebuyela esikolweni.

Ixhomeke kuwe ukuba uyafuna ukuthetha ngalento okanye hayi. Ukuba ungathanda ukuthetha nam, ndifuna undinike imvume. Ndifuna undinike nemvume yokuthetha nomnye wotitshala bakho.

Ukuba uyafuna ukwenza lento, sizakudiban izihlandlo ezibini okanye ezithathu. Utyelelo ngalunye luzakuthatha iyure. Uzakundixelela ukuba ibinjani kuwe into yokubuyela esikolweni emva kwengozi yakho yaye ndizakumamela kuwe. Akukho mpendulo iyiyo nengeyiyo. Nguwe ungqondo-ngqondo. Emva kwethuba ndizakuhlangana nawe kwakhona ukuqwalasela ukuba ndikuve kakuhle. Ukuba ndenze impazamo, ndizakucela wena undincedise ukuyilungisa

Abantu abazokuyazi into ondixelele yona kuba ndizakuligcina liyimfihlo igama lakho. Andizokuba xelela abantu bakokwenu okanye ootitshala.

Ndiza kuza nento yokutya nokusela xa ndisiza kwiintlanganiso. Awuzokuhlawula wena, umama okanye utata wakho ngokuthatha inxaxheba kulento.

Ukuba ukhathazekile nangantoni na okanye unemibuzo, ungandibuza. Umama okanye utata wakho unayo inombolo yam.

Ndiza kuza ndizokucela ukuba uyafuna ukuthatha inxaxheba kule nkqubo emva kokuba ufumene ithuba lokucinga ngayo.

Ungazikhethela uphawu ngezantsi:

\_\_\_\_\_ Ndiyavuma ukuthatha inxaxheba kwesi sifundo.

\_\_\_\_\_ Andivumi ukuthatha inxaxheba kwesi sifundo.

## APPENDIX 3E: PARENT INFORMATION LETTER AND CONSENT (ISIXHOSA)

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Igama lam ndingu Amy Devilliers. Ndenza izifundo zam ezikwi qondo eliphezulu eDyunivesiti yase Ntshona Koloni (UCT). Le ncwadi izakuxelela ngezifundo zam nangendlela endifuna ukuba ube yinxalenye yayo.

Igama lesi sifundo yi **"Amabali esikolo sokubuyisela ingqondo kwisimo sayo alandela ukuxhwaleka kwengqondo yingozi : amava abantwana, abanakekeli bokuqala kunye nootitshala eNtshona Koloni."** Ndifunda ukuyazi ukuba kunjani ukuba ngaba ngabantwana ebebe nomonzakalo wengqondo ukubuyela eskolweni. Ndifuna nokufumanisa ukuba kunjani ukuba ngabazali notitshala babo. Yilonto ebangela ukuba ndikucele ukuba ube yinxalenye yesi sifundo. Omnye wabantwana obafundisayo ngokunjalo nomzali wakhe, naye uzakucelwa abe yinxalenye. Ulwazi lwesi sifundo lubalulekile kuba luzakutyenziswa ukucebisa abeluleki ngqondo nootitshala ukuba bangabanceda njani ngokuphuhlileyo abanye abantwana, abazali notitshala kwixesha elizayo

Uthatha inxaxheba ngokuziqgatsa okupheleleyo okusimahla. Awuzokuhlululwa ngokuthatha inxaxheba. Ukuba ukhetha ukuba yinxalenye yesi sifundo kuza kufuneka ukuba unike imvume. Lonto ithetha ukuthi uyayiqonda into efunwa kuwe yaye unike imvume ngolwazi olunikayo oluzakusetyenziswa kwesi sifundo. Nokuba uyavuma, ungasiyeka nanini isifundo ukuba awusafuni ukuqhubeka. Akukho mfuneko yokundixelela ukuba kutheni. Akukho sohlwayo ngokuyeka esi sifundo.

Ukuba uyavuma ukuthatha inxaxheba kwesi sifundo, uzakwenziwa udliwano ndlebe izihlandlo ezibini ezahlukeneyo ngoku nokwakho. Ndizakucela ukuba undixelele ibali lakho ukuba kunjani ukuba nomntwana ofumene ingozi yengqondo egumbini lakho lokufundisa. Udliwano-ndlebe ngalunye luzakuthatha iyure enye ukuya kwezimbini. Emva kwethuba, ndizakunxulumana nawe kwakhona, ukuze uqwalasele ukuba ndikuve kakukhle. Le ntlanganiso nayo izakuthatha iyure. Ungazikhethela indawo nexesha lentlanganiso ezilungele wena ngokupheleleyo.

Akukho ntlawulo ngokuthatha inxaxheba kwesi sifundo. Ndizakuxhasa ngendleko zokukhwela ukuya kwindawo yentlanganiso, ukuba kuyimfuneko. Ndiza kukhupha intwana etyiwayo neselwayo kudliwano ndlebe. Akukho mingcipheko ukuba yinxalenye yesi sifundo.

Abanye abantu balufumana kuluncedo olukhulu ukuxelela abanye abantu ngamava wabo.

Yonke into ondixelela yona iza kuba yimfihlo-ndim kuphela ozakuyazi into ondixelele yona. Ukwenza oko andizokulisebenzisa igama lakho eliyinyani nakwesiphina isifundo yaye ndizakuligcina olu lwazi lukhuselekile. Ushicilelo lodliwano ndlebe luzakukhuselwa ngamanani ayimfihlo. Akukho mntu ozakunxulumanisa olu lwazi kunye nawe. Ndiyakusebenzisa igama lakho eliyinyani ukwenza ingxelo ukuba unqwenela kube njalo.

Ndizakuyiphendula imibuzo yakho onayo ngomnxeba. Unganditsalela umnxeba kule nombolo (021) 404 6458/ 6466.

Ndizakube ndiphantsi kweliso lika Harsha Kathard, ungqondo-ngqondo owayamene neDyunivesiti yeNtshona Koloni. Ukuba unayo nayiphina imibuzo yakhe ungaqhamshelana naye ku (021) 406 6593.

Olu phando luphunyezwe yiKomiti yesebe lezempilo yenzululwazi ngophando lomntu olu lulo nolungelulo lwe Dyunivesiti yeNtshona Koloni yaye inombolo ongabhekisa kuyo yile HREC REF 480/2012.

Ungqondo-ngqondo uMarc Blockman ngusihlalo wale komiti yaye ungaqhamshelana naye kule nombolo (021) 406 6492 ukuba ungathanda ukufumana ulwazi oluthe vetshe ngophunyezwa koluphando.

Ukuba uyavuma uthatha inxaxheba kwesi sifundo nceda ugcwalise olu xwebhu:

Ndiyavuma ukuthatha inxaxheba kolu phando sifu ndo "Amabali esikolo sokubuyisela ingqondo kwisimo sayo alandela ukuxhwaleka kwengqondo yingozi: amava abantwana, abanakekeli bokuqala babo kunye nootishala eNtshona Koloni.

Ndiyakuqonda endikubuziweyo yaye ndine lungelo lokuyeka kwesi sifundo nakweliphi inqanaba. Esi sifundo ndisicaciselwe yaye ndilifundile ulwazi olu kwiphepha eligqithileyo. Ndiyayiqonda ukuba igama lam alizokusetyenziswa ukwenza nayiphina ingxelo yoluphando ngaphandle kokuba ndiyafuna ukuba yinxalenye. Bendinalo ithuba lokubuza imibuzo yaye imibuzo yam iphenduliwe. Ndiyayiqonda ukuba akukho nto ndizakuyifumana ngokuthatha inxaxheba kwesi sifundo.

Imvume yomntwana wam yokuthatha inxaxheba ukuba unqwenela njalo. Yaye ndinike umphandi imvume yokunxulumana nomnye wotitshala ukuthatha inxaxheba kwesi sifundo.

Bhala Igama: \_\_\_\_\_

Tyikitya: \_\_\_\_\_

Umhla: \_\_\_\_\_

## APPENDIX 3F: EDUCATOR INFORMATION LETTER AND CONSENT (ISIXHOSA)

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Igama lam ndingu Amy Devilliers. Ndenza izifundo zam ezikwi qondo eliphezulu eDyunivesiti yase Ntshona Koloni (UCT). Le ncwadi izakuxelela ngezifundo zam nangendlela endifuna ukuba ube yinxalenye yayo.

Igama lesi sifundo yi **"Amabali esikolo sokubuyisela ingqondo kwisimo sayo alandela ukuxhwaleka kwengqondo yingozi : amava abantwana, abanakekeli bokuqala kunye nootitshala eNtshona Koloni."** Ndifunda ukuyazi ukuba kunjani ukuba ngaba bantwana ebebe nomonzakalo wengqondo ukubuyela eskolweni. Ndifuna nokufumanisa ukuba kunjani ukuba ngabazali notitshala babo. Yilonto ebangela ukuba ndikucele ukuba ube yinxalenye yesi sifundo. Ulwazi olusuka kwezi zifundo lubalulekile kuba luzakusetyenziswa ukubonisa abaluleki bengqondo, otitshala ukuba bangancedisana njani nabanye abantwana kunye nabazali abanengxaki efana nale kwixesha elizayo.

Kukuzikhethela kwakho ngokupheleleyo ukuba ufuna ukuthatha inxaxheba okanye hayi. Awuzokuhlalulelwa ngokuthatha inxaxheba. Ukuba ukhetha ukuthatha inxaxheba kwesi sifundo uzakucelwa ukuba unike imvume. Lonto ithetha ukuthi uyayiqonda into efunwayo kuwe yaye unika imvume ngolwazi olunikayo ukuba lusetyenziswe kwesi sifundo. Nokuba uyavuma, ungangahamba nangaliphi ixesha ukuba awusafuni ukuqhubekeka. Akukho mfuneko yokundixelela ukuba kutheni. Akukho sohlwayo sokushiya isifundo. Ngemvume yakho, ndizakusele ndicela nomntwan wakho nomnye utitshala wakhe ukuba athathe inxaxheba.

Ukuba uyavuma ukuthatha inxaxheba kwesi sifundo, uzakwenziwa udliwano ndlebe izihlandlo ezibini ezahlukeneyo ngoku nokwakho. Ndizakucela ukuba undixelele ibali lakho ngexesha umntwana wakho abuyele esikolweni emva kwengozi. Udliwano-ndlebe ngalunye luzakuthatha iyure enye ukuya kwezimbini. Emva kwethuba, ndizakunxulumana nawe kwakhona, ukuze uqwalasele ukuba ndikuve kakukhle. Le ntlanganiso nayo izakuthatha iyure. Ungazikhethela indawo nexesha lentlanganiso ezilungele wena ngokupheleleyo.

Akukho ntlawulo ngokuthatha inxaxheba kwesi sifundo. Ndizakuxhasa ngendleko zokukhwela ukuya kwindawo yentlanganiso, ukuba kuyimfuneko. Ndiza kukhupha intwana etyiwayo neselwayo kudliwano ndlebe. Akukho mingcipheko ukuba yinxalenye yesi sifundo. Nakanjani kungakuhlupha ukuthetha ngamava akho. Ndizakukumamela yaye ndincele ukuba ndiyakwazi. Kungenjalo ndizakuthumela kunontlalontle ukuba ukhetha oko.

Abanye abantu balufumana kuluncedo kakhulu into yokuxelela abanye abantu ngamava wabo.

Yonke into ondixelela yona iza kuba yimfihlo-ndim kuphela ozakuyazi into ondixelele yona. Ukwenza oko andizokulisebenzisa igama lakho eliyinyani nakwesiphina isifundo yaye ndizakuligcina olu lwazi lukhuselekile. Ushicilelo lodliwano ndlebe luzakukhuselwa ngamanani ayimfihlo. Akukho mntu ozakunxulumanisa olu lwazi kunye nawe. Ndiyalikusebenzisa igama lakho eliyinyani ukwenza ingxelo ukuba unqwenela kube njalo.

Ndizakuyiphendula imibuzo yakho onayo ngomnxeba. Unganditsalela umnxeba kule nombolo (021) 404 6458/ 6466.

Ndizakube ndiphantsi kweliso lika Harsha Kathard, ungqondo-ngqondo owayamene neDyunivesiti yeNtshona Koloni. Ukuba unayo nayiphina imibuzo yakhe ungaqhamshelana naye ku (021) 406 6593.

Olu phando luphunyezwe yiKomiti yesebe lezempilo yenzululwazi ngophando lomntu olu lulo nolungelulo lwe Dyunivesiti yeNtshona Koloni yaye inombolo ongabhekisa kuyo yile HREC REF 480/2012

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Ukuba uyavuma uthatha inxaxheba kwesi sifundo nceda ugcwalise olu xwebhu:

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Imvume yomntwana wam yokuthatha inxaxheba ukuba unqwenela njalo. Yaye ndinike umphandi imvume yokunxulumana nomnye wotishala ukuthatha inxaxheba kwesi sifundo.

Bhala Igama: \_\_\_\_\_

Tyikitya: \_\_\_\_\_

Umhla: \_\_\_\_\_

#### **APPENDIX 4: FIELD NOTE EXCERPTS**

Parent A (Mrs Mohamed), Interview 1, 20 November 2012, 11:30 – 12:30

She spoke a lot. Only stopped once to take a few sips of tea. It wasn't at all about school reintegration. It was family issues, it was fights between siblings, it was gangsterism and it was TBI/behaviour issues in general and as she experienced them at home. My feeling during the interview was it was a lot about the child and very little about her – though I managed to get her to state some things from *her* point of view, how it affected *her*, how *she* felt, a few times.

A couple of times I really wanted to bring her back to “school reintegration” and didn't know how to – there was little to grab hold of. And much of what she said was of great interest to me. I was worried that it was the therapist in me listening and not the researcher, but I was aware of this *while* listening and tried to avoid it but at the same time though I really didn't want to direct the interview/conversation (more of a monologue! Is that ideal?) I looked at the prompting questions/areas in the topic guide and felt like she was covering most areas, though it was TBI in general and NOT school reintegration.

She gestured quite a bit and acted things out that he did, e.g. facial expressions or how he hugs her. She was definitely more at ease as the interview went on, bit withdrawn during the bio info. She kept looking at the photo of Mohamed (the child) that she'd given me. I thought she was distracted by the Dictaphone. I was distracted a bit by it – checked 2x to see it was still recording! So worried I lose info somehow!

I left with a sense of the load she's bearing. But not with much clarity on what her experience if school reintegration has been like. How am I going to get that info from her? Not info, story!

She became tearful at one point in interview near the end when speaking of how she cries it out at times still at home. She didn't yawn or look/get distracted or fidgety. She was on a roll. She kept talking, even when I was making the motions of pack up/finish.

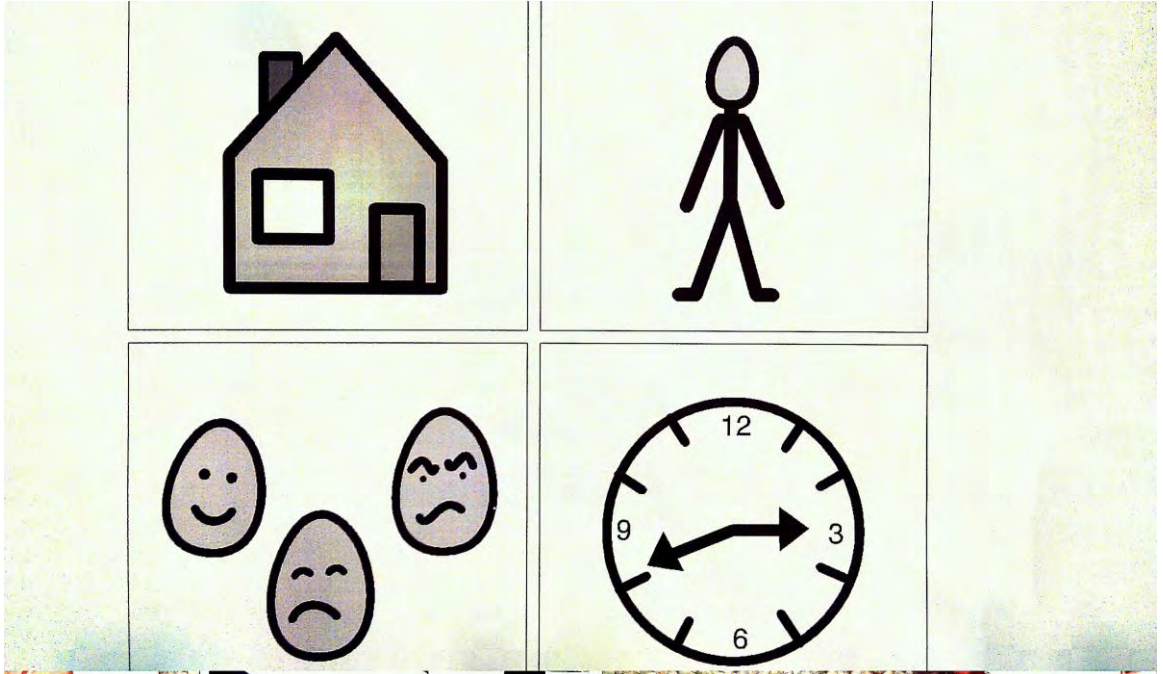
Child B (Simpfiwe), Interview 2, 12 October 2013, 10:30 – 11:45

Simpfiwe tired easily. We took a break at about 30 minutes and had something to eat and drink. It was much more relaxed and talkative this time round, not emotional. I also felt more like an interviewer doing business, not someone managing chaos as in the first time round with him. We continue after that but he was definitely flagging and apparently at one point (this she told me after) said, under his breath “Nditiniwe” (I am tired). It was exciting to see him get into the interview, leaning forward and using his

hands while talking. I repeated questions or scenes from the previous interview to ensure truth of what had been said. I think it might've bothered him slightly to go over "old info" as he said "Like I told last time..."

The use of the pictures as prompts seemed to have a little benefit but not huge. I would've hoped it would prompt a lot more variety of response but he seemed to view the picture as referring to only one person or thing said or place or feeling, not a range. ?TBI limited generativity?

**APPENDIX 5: PICTURE CUES FOR CHILD INTERVIEWS SHOWING PLACE, PERSON, FEELINGS AND TIME**



(Pictures from Boardmaker, a registered Mayer-Johnson product)

## **APPENDIX 6A: CHILD INTERVIEW TOPIC GUIDE**

**Tell me about what it was like for you to go back to school after your accident. / Tell me about your first day back at school after your accident./ Where would you like to start telling me about what it was like going back to school after the accident?**

**Facilitators/barriers** (easier/ more difficult)

People: friends; teachers; family

Activities: subjects; sports; interval; homework

Facilities: classroom; hallway; playground

Feelings/ attitudes

### **Change**

Before accident

Differences

Specific TBI challenges

One day

**What would you like to tell your friends/family/teachers about children like you who go back to school after an accident?**

## **APPENDIX 6B: PARENT INTERVIEW TOPIC GUIDE**

**Where would you like to begin about what it was like to send your child back to school after his/her accident? Tell me about what it was like for you to ...**

**Facilitators/barriers** (easier/more difficult)

People

Places

Other

**Change**

Before injury

Currently

Expectations – re return to school; re future now?

**What would you like other parents and teachers to know about having a child with brain injury? (specifically re return to school). What would you like to tell them?**

**What would you say to other parents whose children have had a brain injury and are returning to school?**

## **APPENDIX 6C: EDUCATOR INTERVIEW TOPIC GUIDE**

**Where would you like to start telling about having this child at school? / Tell me about what it is like having this child at school.**

### **Barriers/facilitators**

Prior experience – LD, schooling in general

### **Change**

- Initially, currently, expectations

## **APPENDIX 7: PARTICIPANT INFORMATION FORMS**

### **Child A / B**

DoB

CA at interview

Languages

Gender

Ethnicity

Religion

Current grade; any repeated (pre/post injury?)

School name and area

TBI date

Medical info – initial GCS, CT Brain results, additional injuries, ICU stay;

transfer to rehab date, length of rehab stay, Rx received from?, diagnoses,  
additional investigations?, discharge home date;

follow-up therapy attendance, current medication

Date of return to school

Seen by Educational Psychologist?

Number of children in class

Class and school language medium

Distance to school from home; accessed how?

**Parent A / B**

Age

Languages

Gender

Ethnicity

Religion

Educational level

Area

Marital status

Other children, ages

Employment

Number of people in house

Amenities in house –w/l, electricity, number of rooms

**Educator A / B**

Age

Languages

Gender

Ethnicity

Religion

Years experience as educator

Years at this school

Years with this grade

Length of time known to learner

Subjects taught to learner

Other roles within school

Number of children in class

Received/aware of TBI discharge report? Read discharge report?

?Aware of diagnosis of TBI – if so, how?

## APPENDIX 8: INTERPRETER INFORMATION LETTER AND CONSENT

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My name is Amy de Villiers. I am doing my Masters degree at the University of Cape Town. This letter is to tell you about my study and how I would like you to be part of it.

The name of the study is, **“Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape.”** I am studying what it is like for children who have had a brain injury to return to school. I also want to find out what it is like for their parents and teachers. The information from this study is important because it will be used to show therapists and teachers how to help other children and parents with similar problems in future.

I will be interviewing the participants and they will tell me their stories. Some of them may have isiXhosa as their first language. It is important for the research that they are able to communicate in their first language. I would like you to assist me as an interpreter.

This would involve translating what I say into isiXhosa and what they say into English during the interviews. You would need to observe what happens during the interview carefully, as I would also need you to discuss your impressions and thoughts about the interview with me afterwards. If a participant becomes upset while speaking and you want to comfort them, it is important that you first check with the researcher, as this could influence the results of the study. There will be at least two interviews per participant which will last between 1 and 2 hours each. At a later stage, we would need to go back to the participants once more to check that I have understood their story correctly. This will take about an hour.

Assisting me in this study would be voluntary. You will be paid \_\_\_\_\_ as a thank you gift for your help. I will drive you to and from the interviews.

There is no risk to taking part in this study.

You will gain further experience as an interpreter and specifically translating in research. You will learn about the experiences of people who live with a brain injury.

It is important to understand that whatever is said and done in the interview is confidential and is not to be shared with anyone other than the researcher.

I will answer any questions that you have in person or via telephone. I can be contacted on (021) 404 6458/6466.

I will be supervised by Harsha Kathard, an associate professor at the University of Cape Town. If you have any questions for her you can contact her on (021) 406 6593.

This research has been approved by the Faculty of Health Sciences Human Research Ethics Committee (FHS HREC) of the University of Cape Town and its reference number is 480/2012. Professor Marc Blockman is Chairperson of the FHS HREC and he can be contacted on (021) 406 6492 if you would like more information on the approval of this research.

If you agree to assist me in this study as an interpreter please fill in the form:

I agree to assist as an interpreter in the research study "Stories of school reintegration following traumatic brain injury (TBI): the experiences of children, their primary caregivers and educators in the Western Cape."

I understand what is required of me. I have had the study explained to me and I have read the previous information page. I have had the chance to ask questions and any questions have been answered. I understand that all interview and research information is to remain confidential.

Name in Print: \_\_\_\_\_

Signed: \_\_\_\_\_

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

**APPENDIX 9: EXCERPT FROM TRANSLATED INTERVIEW TRANSCRIPTION SHOWING DIFFERENCE BETWEEN WORD-FOR-WORD TRANSLATION AND INTERPRETATION DURING THE INTERVIEW**

**PARENT B (Mrs Dyasi):** (23:12.7) And then kengoku into eyenzekayo ndamxelela ndazisola ukuba bendimxelela ntoni.

*So what happened is that I told him, then I regretted having told him.*

Wavela wakhala wakhala ndimxelele ngoDecember xa kuzovulwa izokolo ndathi ndoda uyayazi mos wena awungomntana ofana nabanye abantwana and then noba ufailile bazakuyi understander abanye abantwana ba why because wena ubulimele wathi andicingi mna mama bendibhale kakuhle. Kaloku wena awuyazi into yobana imeko yakho injani na but ndicela u-understander mntanam.

*He just cried continuously when I told him in December when the schools had closed. I said to him, "Young man, you know you are not like the other children and then even if you fail the other children will understand, because you were injured." Then he said, "I won't Mama, I wrote well". Then I said, "Well, you don't know what your situation is like. Please understand my child."*

Bathe baza kuproomter ngoJune ndiqonda nam andiyazi ndithetha nton ndithi at least uzoba ne6 months then bazakusa kwi next grade.

*They said they would promote him in June. I'm not really sure, at least he will have 6 months then they will send him to the next grade.*

Wayemkela kengoku ngolohlobo.

*So he accepted it that way.*

Then ngo January waya esikolweni but ngo January ngelixesha eya esikolweni babizwayo kengoku uba uba mabangene kwigrades abapasileyo nalapho zange ayamkele wayelila sendtsho laveki yokuvulwa kwesikolo yonke wayengeko right until wayi understander kengoku wayamkela sendtsho uthe ufika uJune waye seyamkelile uyiphidile igrade and nasesikolweni bambiza bamhlalisa phantsi bamcacisela uba Someleze awu failanga kuba udom siyayazi ubuqhuba njani before i-accident then lento yenzeke after the accident so wena ulimele entloko so kwezinye izinto ubamba uyeka that is why ufailer.

*Then in January he went to school, when they called the ones that had passed and were moving on to the next grade he could not accept it, he cried the whole time. I mean, that whole week when schools had opened he wasn't ok, until he understood then he accepted it. I mean, by the time June came he had already accepted that he*

*had to repeat the grade and the school called him in and sat him down and explained to him that, "Someleze, you haven't failed because you are stupid. We know how you were performing before your accident. So this happened after the accident. So you had a head injury, so you are not able to grasp everything that's why you failed".*

Sometimes andixelele utishala wakhe athi bendithetha naye ngoku Someleze ndimnika umsebenzi ngoku awu understander ngoku aphume abheke ebreakin xa ebuya ebreakin ndiphinde ndimbuza lanto akasayazi.

*Sometimes his teachers tell me that, "I give Someleze some work now and he understands it, but when he goes out for break and comes back he will have forgotten it".*

So ke ungumntana onjalo ke nasendlini unjalo, endlini funeka ubangaba uyamthuma uyiphindaphinde into uba Someleze into ethile ubane umkhumbuza and angatsha because akanayo langqondo yentobana andimelanga ndiyithathe lento because ishushu so funeka umgadile awunamthuma kwindawo ezi dangerous funeka uzazi indawo omawumthume kuzo because kwayena senditsho aka cope-y right kwizinto ezininti

*So, then he's that kind of person. Even at home he's like that. When you send him for something at home, you have to repeat it over and over, because Someleze needs to be reminded all the time. He could even hurt himself and burns because he can't reason that he mastn't touch something because it is hot. So, he needs to be watched over, you can't send him to places that are dangerous. You need to know where the best places to send him are, because he doesn't cope well with a lot of things.*

**Interpreter:** (26:39.6) {unclear} she kept the results till at the end of the year 2011 when she was trying to explain to him that he won't be able to proceed with the rest of his peers. So she says she did that and in doing that he was very emotional and he cried, he wasn't able to understand why because his impression is that he wrote well and he performed the way that he usually does but then, so she explained the situation as well and then in January when you know, now he is going into school, he {unclear} but even then he hadn't fully accepted his situation. So they had to explain at school as well, listen it's not because you're dumb or because you know you're stupid or anything like that, it's because you were in an accident and we understand that and we understand that you performed well before this accident and we're going to take things slowly. So in June, so now the whole situation was that they would wait until June and see how his progress was and see whether he would be able to {unclear}. So now by the time June came he had come to terms with the situation and you know he was

coping much better. Then she also mentioned that she spoke to the teacher and the teacher would say that, when he explained something to him, he will understand it now but then he would go to break and come back and he has forgotten everything that has been explained to him and even at home the same thing, when he has to do chores or he as to be sent somewhere, you need to repeat it and you need to remind him all the time and be patient with him as well, you need to be conscious of where you're sending him because you know he's not aware of the dangers, he might even {unclear} if you're not careful as to where you're sending him to.

## APPENDIX 10: EXAMPLES OF CREATIVE WRITING TECHNIQUES USED IN STORIES

- Repetition

From Mr Magoda's story:

I was glad she spoke with me as **I hadn't gotten information** from, Mrs Luthu, his Grade 5 class teacher. At least, I would've liked a proper report as to what happened with the car accident and with his learning after. Mrs Luthu just told me he was in an accident. **No other information.** She didn't give me copies of the hospital reports. She said she didn't have them; she forwarded his school profile to someone. And his parents said they had sent everything to the lawyers (Road Accident Fund). That really was very unfortunate, **not having all that information about him.**

- Present tense

From Simphiwe's story:

When I get in the door of the class the other kids stand up and clap! But those kids they just sit there and watch me. And then they just say "tsk!" and shake their hand. They don't really want to do the welcome back. My friends in the class bought the cake for me and they put it out; the other kids they just leave then when we have the cake, they just go out of the class to the bathroom.

- Use of exclamation and italics for emphasis

From Simphiwe's story:

I *wanted* to go back to school after the accident. I couldn't wait!

It was better than I expected! On my first day back, my class threw me a welcome back party. This was really nice!

- Rhetorical questions

From Mrs Dyasi's story:

I was worried how would he cope at home? You have to cross the road to go to the toilet. He needed help with everything. How will we cope with him? It is going to be a big struggle. And what about going to school?

## APPENDIX 11: EXAMPLE OF MEMBER CHECKING INFORMATION LETTER

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Dear

### **Re: Checking your story**

Here is the first copy of your story after our interviews. I wrote what I understood you had told me *your experience* of \_\_\_\_\_ return to school after his accident was. I will need to meet with you again to make sure that what I have written in the story is the truth of *your experience* as you see it. It is your story and it must say what you meant it to say.

I will phone you to arrange a meeting at a time and place that suits you.

Before the meeting:

1. Please will you read the story carefully.
2. Please make notes on this copy about **anything you would like me to change** (for example, things I should take out; things I should add; things I should emphasize; things I should mention less), **any comments** you have, and **any questions** you want to ask.

At the meeting we will then check the story together, discuss your notes and comments and make the changes you feel are necessary so that the story will be true to what you meant in the interviews.

Please note that I have changed the names in the story.

Please also ignore the numbers in brackets (for example, (45:35) ).

I look forward to meeting with you and thank you for your very valuable input this far.

Kind regards,

Amy de Villiers (Researcher)