

**OCCUPATIONAL RESILIENCE: AN OCCUPATIONAL THERAPY  
PRACTICE MODEL FACILITATING HIGH SCHOOL PARTICIPATION  
POST TRAUMATIC BRAIN INJURY**

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Signature

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## ABSTRACT

School participation may be disrupted post traumatic brain injury (TBI). Adolescents have to adjust to their developmental stage, multiple impairments and increased dependence resulting from the TBI. This combined with contextual factors may affect their school participation post TBI. There are no clear occupational therapy guidelines facilitating school re-entry post TBI and hence inconsistencies are noted in school transition practices. Furthermore, existing school transition programs for learners with TBI are informed by the recommendations of studies conducted in developed contexts. This study therefore sought to explore the perspectives on and experiences of adolescent high school learners' school re-entry and school participation post TBI within a developing context. It was anticipated that this would provide an improved understanding of the enablers and barriers to high school participation post TBI. The main aim of this study was to develop a practice model with a view to improve service delivery that aims to adequately prepare and support learners for high school participation post TBI.

The first phase of the study included a qualitative multi-case study. Each of the eight cases consisted of an adolescent learner, his/her primary care-giver, teacher and principal. Data collection methods included document analysis, semi-structured interviews and semi-structured observation. Analysis included an inductive process, combined with cross case synthesis. The findings indicated that personal, multi-system environmental and occupational factors served as both enablers and barriers to school re-entry and school participation post TBI. Learners reported that to overcome occupational challenges and participate in the occupation of school, required a process of adaptation (i.e. adapting for and through occupation). This process of adaptation required that learners draw upon internal resources as well as navigate and negotiate the availability and accessibility of personally and culturally relevant external resources. That is, it required a display of resilience from learners.

A theory generative design promoted by Chinn and Kramer (2015) and Walker and Avant (2015), was used to conduct the second phase of the study. This included an analysis of the concept of occupational resilience that was uncovered in the first phase of the study. The second phase of the study further included the construction of relationship statements; a description of the model as well as the evaluation and operationalization of the model, i.e. Occupational Resilience: An Occupational Therapy practice model to facilitate high school participation post TBI. The practice model highlights that occupational therapists may promote resilience to facilitate the participation in valued occupation (i.e. promote occupational resilience). Occupational resilience may be facilitated through a series of

resilience-promoting tasks that include cultivating resilience thinking, developing and employing strategies to overcome occupational challenges, engagement in occupation and fostering an enabling environment. The model further highlights that throughout the process of facilitating occupational resilience, it is necessary to create opportunities for the adolescent to display agency.

The thesis concludes with recommendations for occupational therapy practice and education. Further recommendations to the Departments of Health and Education as well as the Road Accident Fund were explicated to facilitate optimum support provision for adolescent learners with TBI.

## OPSOMMING

Skooldeelname is 'n primêre Aktiwiteit wat na 'n traumatiese breinbesering (TBB) ontwig kan word. Adollesente moet aanpas by 'n verskeidenheid van inperkings en verhoogde afhanklikheid as gevolg van die TBB. Hierdie aanpassings - gekombineer met kontekstuele faktore - kan implikasies inhou vir hul deelname aan skoolaktiwiteite na TBB. Daar is geen duidelike arbeidsterapie-riglyne wat terugkeer skooltoe fasiliteer nie en daarom word daar teenstrydighede in skooloorgangspraktyke aangetref. Daarbenewens word bestaande programme wat skooloorgang ná 'n nuutverworwe besering ondersteun deur die aanbevelings van studies uitgevoer in ontwikkelde kontekste. Hierdie studie het dus gepoog om die perspektiewe en ervarings van hoërskoolleerders se skooltoetrede en skooldeelname ná TBB binne 'n ontwikkelende konteks te ondersoek. Daar is verwag dat dit 'n beter begrip sal bied van instaatstellers en hindernisse vir hoërskoolhervatting van skooldeelname na TBB. Die hoofdoel van hierdie studie was om 'n praktykmodel te ontwikkel met die oog op die verbetering van dienste wat daarop gemik is om hoërskoolleerders voor te berei en te ondersteun om weer te kan inskakel by die skool na 'n TBB.

Die eerste fase van hierdie studie het 'n kwalitatiewe, meervoudige gevalstudie behels. Elkeen van die agt gevalle het bestaan uit 'n adollesente leerder, sy/haar primêre versorger, onderwyser en skoolhoof. Data-insameling is uitgevoer d.m.v dokument-analise, semi-gestruktureerde onderhoude en semi-gestruktureerde waarneming. Ontleding is uitgevoer d.m.v 'n induktiewe proses, gekombineer met kruisgeval sintese. Die bevindings het aangedui dat persoonlike, multi-stelsel omgewings- en beroepsfaktore gedien het as beide instaatstellers en hindernisse vir die hertoetrede en deelname aan skoolaktiwiteite na TBB. Leerders het gerapporteer dat ten einde die uitdagings van skoolaktiwiteite te kan oorkom en om deel te neem aan die waardevolle Aktiwiteit van skoolgaan, 'n proses van aanpassing vereis, word d.w.s aanpassing in en deur Aktiwiteit. Hierdie aanpassingsproses verg dat leerders interne bronne moet inspan, en dat hulle die beskikbaarheid en toeganklikheid van persoonlike en kultureel-toepaslike eksterne bronne moet beding. Dit is dus nodig dat leerders se veerkragtigheid na vore tree.

'n Teoretiese generatiewe ontwerp wat deur Chinn en Kramer (2015) en Walker en Avant (2015) voorgestel is, is gebruik om die tweede fase van die studie uit te voer. Dit is gedoen deur middel van 'n analise van die konsep van Aktiwiteitsveerkragtigheid wat in die eerste fase van die studie onthul is. Die tweede fase van die studie het verder die konstruksie van verhoudingsverklarings; 'n beskrywing van die model sowel as die evaluering en operasionalisering/werking van die model, ingesluit, naamlik Aktiwiteitsveerkragtigheid: 'n Arbeidsterapie-praktykmodel om hoërskooldeelname na 'n TBB te fasiliteer. Die model

beklemtoon dat arbeidsterapeute veerkragtigheid kan bevorder om deelname in waardevolle aktiwiteite te fasiliteer. Aktiwiteitsveerkragtigheid kan fasiliteer word deur stelselmatige veerkragtigheids-bevorderende take soos bv. die aankweek van veerkragtigheidsrelevante denke, die ontwikkeling en gebruik van strategieë om uitdagings te oorkom, deelname aan Aktiwiteite te bevorder en om 'n instaatstellende omgewing te skep. Verder beklemtoon die model dat daar gedurende hierdie fasilitering, geleenthede vir die adolessent geskep moet word om agentuur (agency) te toon.

Die studie word afgesluit met aanbevelings vir arbeidsterapie praktyk en onderrig. Verdere aanbevelings aan die Departemente van Gesondheid en Opvoeding sowel as die Padongeluksfonds word uiteengesit ten einde optimale ondersteuning aan adolessent leerders met TBB te kan verseker.

## **DEDICATION**

This thesis is dedicated to my father, my late beloved mother and grandmother. You are exceptional human beings, and were it not for your unconditional love, support, wisdom and guidance I would not be where I am today. You taught me many valuable life lessons, most notably, that through having faith in God and hard work, all things are possible!

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## OPERATIONAL DEFINITIONS OF KEY TERMINOLOGY USED IN THE STUDY

**Traumatic Brain Injury (TBI):** is described as an acquired injury to the brain (open or closed) caused by an external mechanical force, with a decreased or altered state of consciousness. TBI does not apply to brain injuries that are congenital, degenerative, or to brain injuries induced by birth trauma (Dawodu, 2013).

**School re-entry:** refers to the high school learners with TBI's re-engagement and participation in school, once they are medically stable and received rehabilitation by member/s of a team (e.g. medical doctor, nurse, physiotherapist, occupational therapist, speech therapist, social worker/ clinical/neuro psychologist).

**Continued participation in school:** in this study is defined as the continual engagement in those activities required for learning and participating in the high school environment. In this study school participation specifically refers to formal educational participation, i.e. participating in academic (e.g. math, reading), non-academic (e.g. self-care skills, recess/interval environment where the learner has lunch at school), extracurricular (e.g. sports, music) and prevocational educational activities (AOTA, 2014).

**Adolescent learner:** refers to an individual between the ages of 13 and 20 years who attends a high/secondary school (Vroman, 2015).

**High school:** refers to either the ordinary or special high/secondary school that the adolescent learner attends post TBI. Ordinary high schools refer to any school that is not a special school or an independent school. Special schools are schools that are "equipped to deliver education to learners requiring high intensive educational and other support either on a full-time or a part time basis" (DoBE, 2014, p.9).

**Occupations:** are "client-directed daily life activities viewed as central to a client's (person's, group's or population's) identity and sense of competence and have particular meaning and value to that client". Occupations include "activities of daily living (e.g. washing, dressing etc.), instrumental activities of daily living (e.g. communication management, financial management, meal preparation and clean up, etc.), rest and sleep, education/school, work, play, leisure and social participation" (AOTA, 2014, p.S4).

**Roles:** defined as positions in society, with a set of behaviours that have some socially agreed upon functions and for which there is an expected code of norms. Examples include that of learner, brother/sister, friend, etc. (Christiansen & Baum, 1997).

**Educator:** refers to a person providing professional educational services (e.g. teachers, principals, district and regional managers within the department of education). It further includes a person who provides therapy on a professional basis (e.g. occupational therapy, speech therapy, physical therapy, etc.) or provides psychological services in schools (DOE, 2000).

**Primary care-giver:** refers to a person who “assumes the primary responsibility in caring for the health and well-being of a child or adolescent”. It may include an adolescent’s biological parent, other relatives such as a grandparent or a legal guardian (Oxford Dictionary, 2014).

**Occupational Therapy:** is defined as “the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings” (AOTA, 2014, p.S1).

**Perspectives:** refers to “a particular attitude towards or way of regarding something; a point of view” (Oxford Dictionary, 2014).

**Experiences:** refers to “knowledge and skills acquired as a result of the direct participation in an activity over time”. It is also defined as the “practical contact with and observation of facts or events” (Oxford Dictionary, 2014).

**Enablers to school re-entry and participation:** those “factors (i.e. within the centre for learning, education system as a whole, the wider society or from within the learner)”, that may facilitate/enhance the learner’s ability to re-enter and participate in school following the onset of the traumatic brain injury (DoBE, 2014, p.7).

**Barriers to school re-entry and participation:** those “factors (i.e. within the centre for learning, education system as a whole, the wider society or from within the learner)”, that may hinder or negatively influence the learner’s ability to re-enter and participate in school following the onset of the traumatic brain injury (DoBE, 2014, p.7).

**Barriers to learning and development:** “Challenges in the learning process that are a result of a broad range of experiences in the classroom, at school, at home, in the community, and/or as a result of health conditions or disability. These may include:

- a) Socio-economic aspects (such as lack of access to basic services, poverty and under-development)
- b) Factors that place learners at risk, for example, physical, emotional and sexual abuse, political violence, HIV and AIDS and other chronic health conditions

- c) Attitudes
- d) Inflexible curriculum implementation at schools
- e) Language and communication
- f) Inaccessible and unsafe structural environments
- g) Inappropriate and inadequate provision of support services
- h) Lack of parental recognition and involvement
- i) Disability
- j) Lack of human resource development strategies
- k) Unavailability of accessible learning and teaching support materials and assistive technology” (DoBE, 2014, p.12).

**Preparation for school re-entry:** refers to methods and tasks that prepare the learner for performance in school.

**Model:** is used to “describe proposed or emerging conceptual systems” (Christiansen & Baum, 1997, p.41). Its purpose is to “develop theory, provide rationale for and guide practice” (Kielhofner, 1992, p.14). According to Chinn and Kramer (2015, p.159), a further description of a model includes “symbolic representations of an empiric experience in the form of words and pictorial or graphic diagrams”.

**Theory:** this refers “to the rigorous and creative structuring of ideas that are structured as concepts. These ideas represent a tentative, purposeful and systematic view of phenomena” (Chinn & Kramer, 2015, p.157).

## **CHAPTER 1**

### **THE RESEARCH PROBLEM AND CONTEXT**

#### **1.1 INTRODUCTION**

This inquiry explored perspectives on and experiences of adolescent high school learners' school re-entry and school participation post traumatic brain injury (TBI). It was anticipated that this would provide an improved understanding of the enablers and barriers to school re-entry and participation of adolescent high school learners post TBI. The main aim of this inquiry was to develop a practice model with a view to improve the efforts of service providers that seek to adequately prepare and support high school learners to re-enter and participate in school post TBI. A central focus in this inquiry was the "insider" perspective i.e. that of the main beneficiary of such services (adolescent high school learners with TBI). However, as this inquiry recognised that the learner does not function in isolation, but as part of an interdependent network (see section 2.2.4), there was therefore also a focus on the perspectives and experiences of other main stakeholders. These stakeholders included: the care-giver of each learner; the teacher that the learner identified as knowing him/her the best and the principal of the school that the learner attended. A qualitative case study design was used and the study is situated within an interpretive (constructivist) paradigm. The main methods of data collection included document analysis, semi-structured face-to-face interviews and semi-structured observation.

This chapter begins with an overview of the background and context of the study. This is followed by a statement of the problem and a discussion of the study purpose. The research questions, aims and objectives are included. The chapter further includes the research design and methodology. Details pertaining to the ethical considerations and the researcher's assumptions are provided. The chapter concludes with a brief outline of the structure of the thesis.

#### **1.2 BACKGROUND AND CONTEXT**

Worldwide traumatic brain injury (TBI) is regarded as the foremost cause of death and disability in children and young adults (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007). South Africa accounts for 89 000 of the 10 million people affected by TBI globally per year (Pretorius & Broodryk, 2013). There are peaks identified in TBI incidence throughout the life span. Mid to late adolescence is a life phase where TBI often occurs (Bauer & Fritz, 2004; Bruns & Hauser, 2003).

Adolescence is a time for tremendous growth and potential as the young person acquires new skills and undergoes many new experiences. However, this is also a time of adjustment given the physical, psycho-social and moral changes that adolescents experience (Sharp, Bye, Llewellyn & Cusick, 2006). Adolescence is described as the transition between childhood and adulthood, where the young person develops a sense of identity through ascertaining who they are and where they fit in, in life (Mealings & Douglas, 2010; Muenchberger, Kendall & Neal, 2008). School participation contributes to the development of the adolescent's sense of identity, by providing opportunities for social and emotional growth, and assists with laying the foundation for their future career decisions (Mealings & Douglas, 2010). Sustaining a TBI can interrupt an adolescent's participation in school. This may result in an identity crisis in that the adolescent not only has to deal with the expected associated adjustments of the development stage of adolescence but also has to adjust to a likely range of impairments and increased levels of dependence resulting from the TBI (Backhouse & Rodger 1999; Sharp et al., 2006). This, combined with contextual factors, may have implications for the adolescent's preparedness to re-enter school as well as their continued school participation post TBI.

South Africa seeks to address learner diversity and provide a range of support through policies such as the White Paper 6 on Special Needs Education (DoE, 2001). This policy outlines the government's intervention strategy aimed at ensuring that children who experience various barriers to learning and development have access to quality education. This reflects learners' constitutional rights to human dignity and equitable education. It specifically highlights that all children and youth - irrespective of their differences - can learn and that their participation within the culture and curriculum of educational institutions should be maximized by the uncovering and minimising of barriers to learning. It further proposes the need of structures, systems and learning methodologies within education to support the needs of all learners (DoE, 2001). However, in order for these barriers to be addressed and for learners with TBI to successfully re-enter and continue to participate in school, there is a need for an understanding of the return to school process from the adolescents with TBI's perspective.

The Western Cape Education Department (WCED), the education department of one of the nine provinces in South Africa introduced a "learning support model" which was designed to address the barriers to learning in schools in the province by providing five levels (i.e. low to high) of and various kinds of support to learners and educators (DoE, 2001, p.16). The support ranges from accommodating learners with barriers to learning in ordinary schools to accommodating them at special schools for learners with high-intensity educational support needs. The identification, assessment and provision of support that a learner needs, is now

informed by the Policy on Screening, Identification, Assessment and Support (SIAS) (DoBE, 2014). A key principle of this policy is a focus on the level and nature of support given the essential needs of the learner and their context (DoBE, 2014). Whilst current policies such as SIAS (DoBE, 2014) do provide specific guidelines for providing support when the learner is in the educational system, it fails to provide clear and practical guidelines with regards to how service providers should initially prepare and assist a learner with a newly acquired disability following an illness or injury, to re-enter school. Whilst the policy refers to the importance of inter-sectoral collaboration as essential in providing optimal support to learners, it currently lacks clear referral pathways between health and education departments following the onset of a newly acquired disability such as TBI. Furthermore, other than providing a SIAS Health and Disability form for the relevant health service provider/s to complete, there are limited explanations detailing the roles and tasks of the team members in health and education departments regarding preparing and supporting such learners in their transitions from hospital (i.e. health sector) to school (i.e. the educational sector) (DoBE, 2014).

This study seeks to explore perspectives on and experiences of adolescent high school learners' school re-entry and school participation post TBI. The interest in this topic stemmed from my fifteen years of clinical experience in the field of neurological rehabilitation where school re-integration was a priority rehabilitation goal for adolescent clients following TBI. I assisted with the facilitation of the resumption of school participation and found that this was achieved with mixed success and this resulted in questions regarding the enablers and barriers to school re-entry and participation post TBI. Currently there is a lack of clear and practical implementation guidelines in South African policy and strategic guideline documents on how service providers should initially prepare and assist a learner with a newly acquired disability to re-enter school. In addition, I also observed that amongst my colleagues there appeared to be inconsistencies in the transition practices pertaining to adolescents and their school re-entry and participation post TBI. This contributed to further question the specific components that should comprise service provision aimed at adequately preparing and supporting learners for their transition and continued participation in school post TBI and as such, informed the rationale for this research.

### **1.3 STATEMENT OF THE PROBLEM**

There is a paucity of research on TBI within the South African context, despite it being a serious global public health concern and South Africa being one of the countries with the highest rates of new cases (Pretorius & Broodryk, 2013). The bulk of this research focuses on the "medical

model of intervention” (Soeker, 2009, p.1) with the primary focus on the younger child or adult with limited attention to adolescents (Ennis, Rivara, Mangione-Smith, Konodi, Mackenzi & Jaffe, 2013; Lindsay, Hartman, Reed, Gan, Thomson & Solomon, 2015). Existing research further lacks a focus on the adolescents’ participation in their valued occupations post TBI. This may have negative consequences on the adolescents’ well-being and quality of life, given that it is the participation in valued occupations, that is essential for the “health, well-being and life satisfaction of all individuals” (AOTA, 2014, p.S3).

Furthermore, no literature could be found on the perspectives and experiences of adolescents who return to school post TBI within middle to low income contexts. Existing policies and programmes that support learners’ school transition following a newly acquired injury such as TBI are informed by the recommendations of studies that were conducted in developed contexts. These contexts differ from the South African context in terms of geographical area, culture, socio economic status, policy, legislation and hence the funding models that provide access to rehabilitative and educational related services to learners post TBI (Mealings & Douglas, 2010).

In addition to the above, current research tends to focus on the “observer” perspective, i.e. the perspectives of parents, teachers and treating clinicians of adolescents with TBI (Mealings & Douglas, 2010, p.3). Very few studies explored the “insider” perspective, i.e. the experiences and perspectives on school re-entry and participation of the adolescents themselves (Stewart-Scott & Douglas, 1998; Backhouse & Rodger 1999; Vaidya, 2002; Sharp et al., 2006; Todis & Glang, 2008; Mealings & Douglas 2010). This has implications for the manner in which support services are structured, given that there may be differences between the “observer” and “insider” perspectives regarding the priority needs and goals for adolescents post TBI (Mealings & Douglas 2010, p.2) and furthermore, raises questions around the adequacy and nature of the current provision of support services to such learners.

#### **1.4 STUDY PURPOSE**

This study sought to explore the perspectives on and the experiences of adolescent high school learners’ school re-entry and school participation post TBI. Insight into and understanding of the perspectives and experiences of adolescent learners with TBI and that of other key role players such as their primary care-givers, teachers and principals, regarding school re-entry and school participation were used to develop a practice model. This model may help funders and service providers understand the efficacy of transition back to school following a TBI and identify where



efforts in terms of service delivery are needed. Such efforts could enable service providers identify and address barriers as well as utilize the enablers to enhance the quality and access to transition services, thereby optimizing the transition process as well as the learners' successful continued participation in school.

The findings of this study could specifically aid the efforts of a newly developed task team comprising representatives from the Western Cape Education and Health Departments that is currently mandated to improve on the inter-sectoral collaboration needed to facilitate optimum school re-entry for learners following recent and chronic illness/injuries. This task team is specifically focussed on improving upon the referral pathways (between the Western Cape Education and Health departments), support provision and follow up mechanisms for such learners. This study may contribute to interventions which are further in alignment with identified needs of the main beneficiaries of services. This may foster service provision which is relevant and responsive, i.e. specifically geared towards service user needs and could thus allow for the effective and efficient allocation and use of resources (Pillay & Terlizzi, 2009).

This study further aims to contribute to a more client centred approach where the "insider" perspective will be used to help guide practice in terms of preparing and supporting learners in school participation post TBI. Providing adolescent learners the opportunity to voice their perspectives could lead to an increased sense of ownership, promote increased levels of participation and result in more positive learning outcomes (Ylvisaker et al., 2005).

## **1.5 RESEARCH QUESTIONS**

The following research questions guided the study:

- What are the perspectives on and the experiences of adolescent high school learners' school re-entry and school participation post TBI?
- What are the components of a practice model that seeks to facilitate school re-entry and school participation of adolescent high school learners post TBI?

## **1.6 RESEARCH AIM**

The study was divided into two phases. The aim of the first phase of the study was to explore and describe perspectives on and experiences of adolescent high school learners' school re-entry and school participation post TBI. It was anticipated that this would provide an improved understanding of the enablers and barriers to school re-entry and school participation of

adolescent high school learners post TBI. The aim of the second phase of the study was to develop a practice model to facilitate school re-entry and school participation of adolescent high school learners post TBI.

## **1.7 RESEARCH OBJECTIVES**

### **Objectives of Phase I**

- To explore participants' perspectives on and experiences of high school learners' school re-entry and school participation post TBI.
- To explore participants' perspectives on and experiences of the enablers to high school re-entry and school participation post TBI.
- To explore participants' perspectives on and experiences of the barriers to high school re-entry and school participation post TBI.

### **Objective of Phase II**

- To develop a practice model to facilitate school re-entry and school participation of adolescent high school learners post TBI and to develop guidelines for the operationalization of the model.

## **1.8 DESIGN AND METHODOLOGY OF THE STUDY**

Section 1.8 provides a synopsis of the design and methodology employed in this study. For further detail see Chapter 3.

The research approach was situated in the interpretivist (constructivist) paradigm. The design strategy for this inquiry included a qualitative multi-case study (i.e. collective/cross case study) (Merriam & Tisdell, 2016). In this study a case included the adolescent learner with TBI, with the learner's primary care-giver, the teacher that the learner identified as knowing him/her the best and the principal of the school that the learner attended as sub units/sub cases embedded within each case.

Following approval from the Health Research Ethics Committee (HREC) of Stellenbosch University (SU) and the relevant government departments, participants were purposely selected. The sample size was determined by saturation and included eight adolescent high-

school learners with TBI, their primary care-giver, the teacher that they identified as knowing them the best and the principal of the high school that they attended. The learners comprised 3 females and 5 males and ranged between the ages of 14 and 20 years of age (see section 3.3.1 for further detail).

To meet the objectives of Phase I of the study (see section 1.7), data were collected by means of documentation analysis, face-to-face semi-structured interviews and semi-structured observations. Data were analysed using the constant comparative method (Glaser & Strauss, 1967; Corbin & Strauss, 2007; Merriam & Tisdell, 2016). This was undertaken on a case by case basis as well as across cases.

A theory generative design promoted by Chinn and Kramer (2015) and Walker and Avant (2015) was used to achieve the second phase of the study (see Section 1.7). This included concept analysis; construction of relationship statements; a description of evolution of the model; a description of the structural framework as well as the evaluation and operationalization of the model (see section 3.6.4 for further detail).

## **1.9 CONTEXT**

The research took place in the homes and high schools (ordinary or special schools) of the adolescent learners. The research was situated in the Western Cape and specifically included the four urban districts of the Metro North, Metro South, Metro East and Metro Central, the two rural districts of the West Coast (specifically the Swartland and Saldanha Bay municipalities) and the Cape Winelands. Seven learners returned to ordinary schools following the onset of the TBI, of which 4 remained, 2 were eventually transferred to a special school (SS) and 1 ceased going to school all together. One learner re-entered an SS school linked to the children's home where she underwent rehabilitation and was then transferred to another special school.

## **1.10 ETHICAL CONSIDERATIONS**

All ethical principles pertaining to research were adhered to. The human rights of all participants were respected through ensuring that: they gave their informed consent (including assent of minors); had the right to withdraw without consequences and were reassured of their de-identification and confidentiality. This was ensured through the use of pseudonyms and the use of rigorous data management systems. In instances where negative feelings related to the experiences of TBI were evoked, the learner and parent were referred to the necessary support

systems such as the adolescents' psychologist or social worker with whom they already had a trusting relationship or to support systems readily available in the learner's area (see section 3.8. for further detail).

### **1.11 RESEARCHER ASSUMPTIONS**

I had the following assumptions and preconceived ideas about these adolescents with TBI:

i) the extent of learners' brain injuries would significantly impact on whether or not they re-entered and re-participated in school, ii) these learners experienced significant barriers to high school re-entry post TBI, iii) most of them had not been prepared adequately for school re-entry and for the year-to-year school transition post TBI, iv) most of them received little support and did not cope with the demands of school participation and v) that there were enablers that assisted some learners to successfully re-integrate into academic and other school related activities. I further assumed that all participants who were approached to participate in the study would readily agree as they saw the value of the research. This was not the case as there were teachers and principals of the ordinary schools who declined participation citing fear of backlash from the Department of Education and strained interaction with the learner and primary caregiver. I also assumed that well-resourced schools (i.e. formally known as Model C schools) would be able to better support learners in terms of their barriers to learning.

My knowledge of learners with TBI, my own professional view point as an occupational therapist and my role as a parent informed my outlook of this study's population. To assist me with maintaining a reflective stance, throughout the research process, I made use of reflective journaling (Tufford & Newman, 2012). This was done as part of field notes and memoing that facilitated sense making about the research process, in conjunction with discussions with my supervisors. Examples of reflections included my reasons for undertaking the research (see section 1.2) and my personal value system (see section 3.7.1) (Tufford & Newman, 2012).

### **1.12 BRIEF OUTLINE OF THE CHAPTERS TO FOLLOW**

#### **Chapter 2: Literature review**

This chapter includes a discussion of the changing paradigms of disability as well as the theoretical framework, including Bronfenbrenner's Bio-ecological Systems Theory and the Theory of Human Occupation. This is followed by a discussion of the literature pertaining to the epidemiology and classification of impairments of TBI. A description of the life stage of adolescence follows. The chapter further includes a discussion on inclusivity and basic

education followed by a discussion of current programmes facilitating school re-entry and school participation post TBI. The chapter concludes with a discussion of limited existing literature on the insider perspective of the factors that enable or serve as barriers to school re-entry and school participation following TBI within a developing context.

### **Chapter 3: Research Methodology**

This chapter focuses on the research process and methods used to generate the data.

### **Chapter 4: Findings**

This chapter explicates the codes, categories and themes that emerged from the analysed data.

### **Chapter 5: Discussion of the findings**

In this chapter the findings are situated and discussed within the framework of Bronfenbrenner's Bio-ecological Systems Theory as well as that of Human Occupation. This is followed by a discussion of the overall experience of high school learners' school re-entry and school participation post TBI, as a process of adaptation. The chapter ends with a summary, in which the central concept is uncovered.

### **Chapter 6: The development of a practice model to facilitate high school participation of adolescent school learners post TBI**

Chapter 6 includes a discussion of theory generation and how it was used to develop the practice model to facilitate high school participation of adolescent school learners post TBI. A discussion of the operationalization of the model is included.

### **Chapter 7: In depth description of Occupational Resilience: An Occupational Therapy practice model to facilitate high school participation post TBI**

In this chapter the practice model to facilitate high school participation of adolescent school learners post TBI will be described.

### **Chapter 8: Study strengths, contributions, limitations, recommendations and conclusion.**

This chapter provides an overview of the strengths, contributions, limitations, recommendations and conclusion of the study.

#### **1.1.3 CHAPTER SUMMARY**

Chapter 1 served to provide an overview of the background to the study, research problem that

was investigated and the purpose for the study. It further provided detail on the research questions which were posed, the aims and objectives for the two phases of the study. In addition it included a brief synopsis of the research methodology, ethical considerations and my assumptions as the researcher. The next chapter includes a review of the literature pertaining to disability, traumatic brain injury, the development stage of adolescence, inclusive education and programmes facilitating school re-entry and school participation post TBI.

## **CHAPTER 2**

### **TRAUMATIC BRAIN INJURY AND SCHOOL RE-ENTRY AND PARTICIPATION:**

#### **A LITERATURE REVIEW**

##### **2.1 INTRODUCTION**

The literature review seeks to explicate the changing paradigms of disability and hence the derivative theoretical framework for this study. Thereafter a discussion of the literature pertaining to the epidemiology and classification of impairments of TBI follows. The discussion of the sequelae of impairments post TBI seeks to illuminate the complexity of TBI as a disability that is characterised by a sudden onset and an abrupt disruption of the daily functioning and routine of the adolescent. As the study specifically focuses on adolescence, a description of this life stage is included to facilitate the reader's understanding of adolescence as a time of adjustment and the formation of self-identity. An overview of the body of knowledge on self-identity and TBI is included to reflect the impact of TBI on the ways in which individuals make sense of themselves post TBI. Given the second phase of this study aimed to develop a model to facilitate school re-entry and school participation of adolescent high school learners post TBI, the conceptualization and development of inclusive education and its operationalization within the South African context are discussed. This will be followed by a review of literature on current programmes that aim to facilitate school re-entry and participation post TBI. The chapter concludes with a discussion of limited existing literature on the factors that enable or serve as barriers to school re-entry and participation following TBI. Specific attention is directed to the limited literature that focuses on the "insider" perspective, indicating the need for this study.

##### **2.2 DISABILITY: CHANGING PARADIGMS**

Individuals with TBI are viewed as part of the group known as "people with disabilities" and it is therefore important to consider what is understood by the construct of disability. This section will include an overview of the context of disability by presenting the philosophical base and the main assumptions of the various views of disability, i.e. the "medical", "social" and the "social relational" models of disability. In addition is a brief overview of Bronfenbrenner's Bio-ecological Systems Theory and the Theory of Human Occupation, which forms the basis for the theoretical framework of this study.

### **2.2.1 The Medical Model**

The medical model stems back to the 1900s and is also known as the biomedical or the clinical model of disability. It is a model that predominantly focuses on the diagnosis and treatment/fixing of problems/deficits within the person. It views people with disabilities as being reliant on others, in need of sympathy, or requiring praise for overcoming personal difficulty (Oliver, 1989). The model has been critiqued when applied in the field of education as its approach of “diagnose-and-fix deficits” results in the assignment of labels and segregation of learners with disabilities. These learners are often placed in special school environments outside the existing “normal” mainstream/ordinary education programme to remediate and address their deficits. This promotes a premise of exclusion rather than inclusion (Swain, French & Cameron, 2003; Lloyd, 2000). Furthermore this individualistic deficit approach lacks cognisance of the role of those factors external to the learner that could pose as risks or barriers to learning (Swart & Pettipher, 2016). In terms of this model, learners in this study would most likely be referred to as “brain injured” and would automatically be referred to and educated in a special school environment. In addition these learners would receive treatment to try and get them close to “normal” as possible thereby reinforcing the segregation and institutionalization of learners who have sustained brain injuries.

### **2.2.2 The Social Model**

Criticism of the medical model of disability has led to an alternative lens of disability, i.e. the social model. This model is also known as the “socio-political paradigm” (Slee, 2006, p.141) or the “relational perspective” (Emanuelsson, Haug & Persson, 2005, p.115). The social model of disability differs from the medical model in that it highlights justice and human dignity. The model regards disability as a “social construct” as is illustrated by Mitra (2006, p.237) and Swain, et al. (2003, p.23) who refer to disability as “not the attribute of the individual; instead it is created by the social environment and requires social change”. This is further supported by Shakespeare (2006, p.34), who regards disability as being defined as a “social creation” and that it is society that affects a learner’s ability to develop and learn. The social model of disability is thought to be more aligned with inclusion as it promotes the removal of barriers for learners with disabilities and advocates that they be included in ordinary school education and become active participants (DoE, 1997). Although this model has influenced policy development for inclusive education, there are criticisms of the model. One such criticism portends that an emphasis on the social barriers of disabilities (i.e. a concern with the socio political aspects) has resulted in an insufficient focus on the experiences of the person with the disability



(Shakespeare, 2006; Swart & Greyling, 2011; Schneider, 2006). However, the social model - as is the case with the medical model - has its strengths and weaknesses. Unless there is recognition that there are individual differences in the way that barriers are experienced (based on differences in personal, cultural and locational factors) the medical and the social model use is limited (Dreyer, 2008).

In terms of this model learners with TBI would be referred to as “learners with brain injuries” and their disability would be viewed as a result of barriers in society without cognisance of their personal experiences of the disability. Examples would include noisy and overcrowded classroom environments that affect the learner’s ability to focus on the task at hand.

### **2.2.3 The Social Relational Model of Disability**

The social relational model encompasses the beliefs of the social model of disability. It is referred to as a “social relational phenomenon keeping the element of oppression and discrimination as an important distinction in contrast to disadvantage due to restriction of activity” (Reindal, 2008, p.143). It takes cognisance of the personal experiences of the person living with the decreased function as well as those social factors which impede the attainment of their goals (Reindal, 2008). The social-relational model (like the capability approach by Nussbaum and Sen (1993) fosters human dignity by advocating for a focus on that which the person is capable of doing or becoming. Similar to the social model, learners with traumatic brain injuries would also be referred to as ‘learners with brain injuries’, with the main difference being that their disability would be viewed as a result of barriers in society in combination with their personal experiences of the disability.

Given South Africa’s history of marginalization and the segregation of vulnerable groups, like people with disabilities, it would seem that the social relational model with its strong human rights focus may be an ideal lens through which to view disability given the South African Department of Education’s shift in the educational system from one of exclusion to one of inclusion of all learners including those with disabilities. Further support for this model is the fact that it proposes a holistic view of disability, i.e. that disability is a dynamic interaction between the “factors intrinsic to the individual, and extrinsic factors arising from the wider context in which he/she finds themselves” (Shakespeare, 2006, p.55). This is the basis of Bronfenbrenner’s bio-ecological systems theory (1979; 2005), which is the chosen theoretical framework for this study.

### 2.2.4 Bronfenbrenner's Bio-ecological Systems Theory

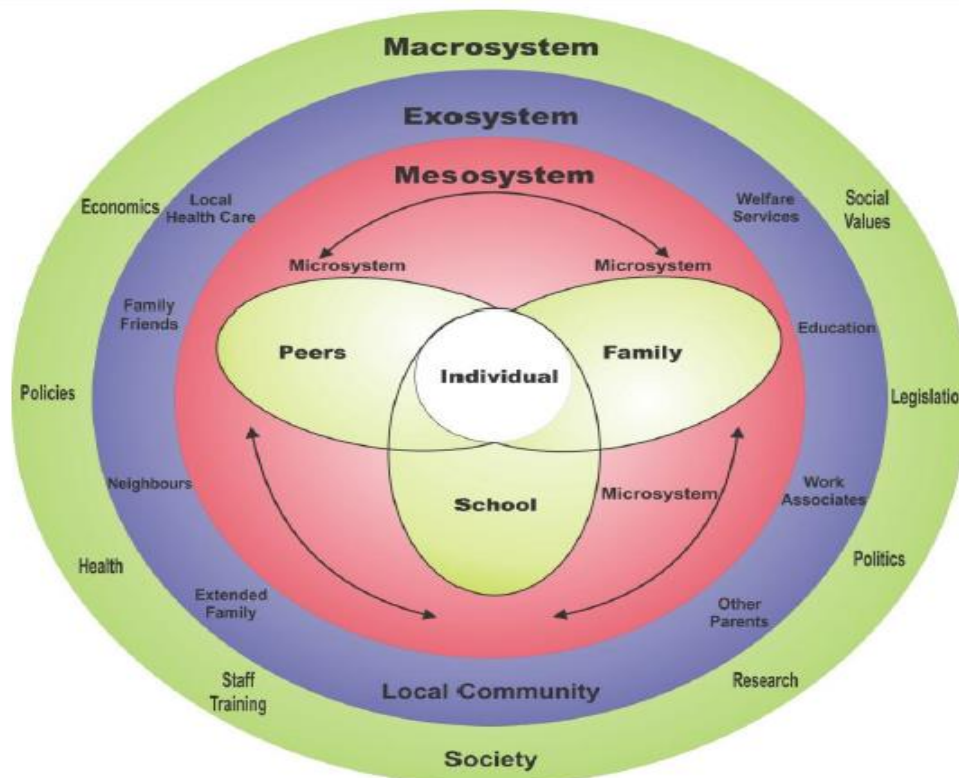
The theory was first known as the “ecological systems theory for developmental theory” as it stressed the importance of understanding the inseparable and reciprocal links between the individual and the context (Bronfenbrenner, 1979, p.276). The theory was then renamed the “bio-ecological systems theory” as in addition to taking cognisance of the dynamic relationship between the individual and the context, there was also recognition that the internal factors within the person (i.e. the “bio” aspect) are critical to the person's human development (Bronfenbrenner, 2005).

Central to Bronfenbrenner's bio-ecological perspective are four interacting dimensions (see Figure 2.1). Firstly the, proximal processes, “which are characterised as particular forms of interaction between organism and environment ...that operate over time and are posited as the primary mechanism producing human development” and secondly are the person characteristics, (i.e. dispositions, ecological resources and demand characteristics) (Bronfenbrenner & Morris, 1998, p.994). Dispositions are forces that can either a) facilitate or sustain the operation of proximal forces (e.g. characteristics such as responsiveness to efforts by others, being motivated) or b) hinder the occurrence of the proximal processes (e.g. feelings of insecurity, impulsiveness or distractibility). Ecological resources refer to the “bio-psychological assets (i.e. abilities, knowledge, skill and experiences) or liabilities (e.g. physical impairments or damage to brain function) that influence the person's capacity to engage effectively in proximal processes. Demand characteristics provoke or discourage reactions from the social environment that either facilitate or hinder psychological processes of growth (e.g. irritable or happy child or hyperactivity vs passivity)” (Swart & Pettipher, 2016, p.12). Thirdly, Bronfenbrenner identified that there are various interdependent systems of interaction within the social context:

“...activities, roles, relations in a defined setting where the learner interacts directly with others for e.g. family, peers, etc. (micro-system), the interconnections between multiple microsystems for e.g. interactions among family members and teachers, which impacts indirectly on the learner through his/her interactions within the microsystem (mesosystem), the environmental settings that an individual does not directly experience yet is still indirectly affected by for e.g. extended family networks (exo-system) and culture and society (macro-system)” (Bronfenbrenner, 2005, p.6).

Each of these systems can be seen to provide facilitators or barriers. Key role players in one system could facilitate or hinder the interaction of the individual with other systems (Berke,

2000). Time (chronosystem) - the fourth dimension - includes the changes in the person or environment over time and their influences on human development (Bronfenbrenner, 1994; 2005)



**Figure 2.1: Bronfenbrenner's bio-ecological model adapted by Bell (2013)**

I deem that a bio-ecological perspective provides a frame of reference for understanding adolescent learners' experiences of the transition of school re-entry and school participation post TBI, through considering the different systems within a learner's context as well as the different dimensions e.g. person characteristics. This perspective takes note of the fact that various enablers and barriers could be located within each of these systems. This needs further exploration as it could potentially affect the successful re-entry and continued school participation of adolescent learners post TBI. A key component of this framework is that it regards learners as partakers in their own learning and not as passive beings which are acted upon by the environment. There is a focus on the learners' perceptions of their context and this is central to understanding how learners interact with their environments and this is in alignment with the current study which seeks to explore the learner's/ "insider" perspective of school re-entry and participation post TBI. Whilst the primary focus of this study is on the learner, the framework stresses the importance of a multi perspective analysis to uncover the meaning and experiences of learners (Christenson & Sheridan, 2001). This study therefore - in addition to the

learner's perspective - seeks to also explore the perspectives of primary care-givers, teachers and principals.

According to Polatajko, Townsend and Craik (2007) occupation is viewed as the linkage between the person and the environment as it is "through engagement in occupation that the person interacts with the environment" (Ramafikeng, 2010, p.4). Whilst Bronfenbrenner focuses on the important interrelatedness of the individual and environment, his theory does not focus on occupation as a "core facet of human experience" (Wilcock, 1993, p.17). Thus the theory of Human Occupation will be used as an additional lens as it focuses on deepening the understanding of the intricacies and personal value of human occupation.

### **2.2.5 Theory of Human Occupation**

A focus on occupation in this study is of importance given that research and my own work experience has shown that post TBI, learners experience significant challenges in the re-engagement in valued occupations, particularly that of school participation (Stewart-Scott & Douglas, 1998; Backhouse & Rodger, 1999; Vaidya, 2002; Sharp et al., 2006; Todis & Glang, 2008; Mealings & Douglas, 2010).

Occupation is defined as daily activities that fill a person's time, it has purpose and meaning. Occupations may be classified as self-care/personal community living, work/productive activity or school, play/leisure, rest and spirituality (Rodger & Ziviani, 2009; AOTA, 2014). Wilcock (1998, p.249) defines occupation as the "synthesis of doing, being and becoming". Particularly in children, it is through "doing" that they learn and master skills, develop self-esteem and efficacy, and develop personal independence. In addition when "doing" with others children develop a sense of belonging and personal engagement (Rodgers & Ziviani, 2009; Wilcock, 1998). Wilcock (1998, p. 249) proposes that "doing" leads to "being", i.e. "the contemplation and enjoyment of the inner life, where the individual experiences an inner peace". "Becoming", she conceptualises as "the person whom one strives to be, as they are best fitted to be, and they hope to be" (Wilcock 1998, p.249). Healthy living is considered to be the dynamic balance between "doing" and "being" and both of these influence "whatever a person is best fitted to become" (Wilcock, 1998, p.251). Occupations hence have value, in that they facilitate a sense of purpose, routine, productivity, mastery and contribute to identity formation which contributes positively to well-being (Christiansen, 1999). The loss of valued life roles, after a major event such as a TBI brings about changes in the routine and balance of occupation (Davies Hallett, Zasler, Maurer & Cash, 1994). A natural, balanced pattern of occupations is believed to have

health benefits (Kielhofner, 1992). Health in this study is operationalised from an occupational perspective:

“the absence of illness, but not necessarily disability; a balance of physical, mental and social well-being attained through socially valued and individually meaningful occupation; enhancement of capacities and opportunity to strive for individual potential; community cohesion and opportunity; and social integration, support and justice, all within and as part of a sustainable ecology” (Wilcock, 1998, p.110).

The lack of balance, use, choice, or opportunity in occupations, can result in a variety of risk factors to health. Risk factors for occupational dysfunction (i.e. the disruption in carrying out life roles) may include: occupational imbalance, deprivation, marginalization and alienation. These are defined as:

- occupational imbalance: when “populations do not share equal privilege in the labour and benefits of economic production and where there is a lack of balance amongst a range of occupations that promote health-giving routines and social inclusion” (Townsend & Wilcock, 2004, p.82)
- occupational deprivation: "a state of prolonged preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the control of the individual. Conditions that may lead to occupational deprivation may include poor health, disability, lack of transportation, isolation, unemployment, homelessness, poverty" (Whiteford, 2003, p.222).
- occupational marginalization: “speaks to the need for humans to exert everyday choices and decision making power as we participate in occupations. Occupational marginalization may not be overt discrimination to bar certain groups, for instance, from paid occupations or recreation but operates invisibly, a major force of injustice being normative standardization of expectations about how, when, and where people ‘should’ participate” (Townsend & Wilcock, 2004, p.81).
- occupational alienation: “a lack of opportunities or resources to enable occupational meaning and enrichment. Alienation is associated with prolonged experiences of disconnectedness, isolation, emptiness, lack of a sense of identity, a limited or confined expression of spirit, or a sense of meaninglessness. Such experiences may occur whether or not people are busy or wealthy” (Townsend & Wilcock, 2004, p.80).

These risk factors for occupational dysfunction may be viewed as outcomes of occupational injustice. Occupational injustices are the result of people being denied the resources or opportunities to be engaged in occupations that are required and have personal meaning to them (Townsend & Whiteford, 2005; Wilcock & Townsend, 2000).

The above concepts are apparent in educational settings within South Africa, where a large percentage of disabled children/youth live in poverty and do not have access to quality education (Inclusive Education, 2017; Du Toit & Neves, 2007). Occupational deprivation is evident by youth with disabilities whose basic right to education is not upheld despite legislation

that is favourable towards their inclusion in educational settings (DoE, 2001). As a result, it may be argued that choice and opportunities to optimally participate in life situations, may be more limited for youth with disabilities as opposed to their non-disabled peers. The inability to participate in school and other typical childhood occupations leads to marginalization and social isolation and may impede healthy development (Rodger & Ziviani, 2009).

In South Africa, there is poverty and inequality in provision and access to basic services amongst the non-white population (e.g. education, health-care, social welfare) as a result of the past racial discriminatory and segregation practices (i.e., Apartheid) (Hardman et al., 2012). Kronenberg and Pollard (2005) highlight this form of occupational injustice as occupational 'apartheid'. It is defined as "the segregation of groups of people through their restriction of access to meaningful participation in occupation on the basis of characteristics such as colour, disability, age and gender" (Kronenberg & Pollard, 2005,p.67). Inequality is evident in the population who have brain injuries where those that have access to private health sector services, are more likely to receive rehabilitation across the continuum of recovery. These individuals are hence more likely to have favourable outcomes such as re-integration to valued occupations, including that of school (Soeker, 2009).

The above highlights the importance of participation in occupation as a means to enhancing development and well-being. This study aims to explore high school learners' participation in the occupation of school following the onset of their TBI. It is therefore necessary, as outlined in the next section of the literature review, to have an increased understanding of TBI and its impact on learners' occupational participation and well-being.

## **2.3. UNDERSTANDING TRAUMATIC BRAIN INJURY**

### **2.3.1 Epidemiological trends in traumatic brain injuries**

The annual incidence of TBI in developing countries is around 200-300 per 100 000 population (Bruns & Hauser, 2003). Unlike in developed contexts, the peaks in TBI incidence within South Africa include early childhood (0-4 years), mid to late adolescence (15 -19 years) and older adults (25-44 years) (Miller & Stander, 2010; Christ, 2007; Bruns & Hauser, 2003). More males than females are likely to sustain traumatic brain injuries. This is reflected in South African statistics that reflect an estimated male to female ratio of TBI incidence as 1.6:1 for ages 0-15 years and as high as 4:1 for the adult population (Miller & Stander, 2010; Christ, 2007; Bruns & Hauser, 2003).



In South Africa in the age group 0 to 10 years, TBIs tend to be predominantly caused by falls, pedestrian motor vehicle accidents (MVA) and being struck by/against an object. However in children aged 10-15 years being a pedestrian involved in an MVA accounted for the cause of majority TBI, followed by injury due to falls and being a passenger in an MVA (Miller & Stander, 2010; Christ, 2007; Levin, 2004). At the peak of TBI incidence in older adults, the causes of TBI are predominantly attributed to road traffic accidents and violence in young to middle aged adults (Hyder et al., 2007).

### **2.3.2 Classification and impairments of traumatic brain injury**

Traumatic brain injuries may result in altered levels of consciousness. The Glasgow Coma Scale (GCS) (a measurement of consciousness), is used to classify the severity of a brain injury as well as to predict the prognosis for recovery. The GCS includes observations of eye opening, verbal output and motor responses and is scored out of a total of 15 (Teasdale & Jennett, 1974). Lower GCS scores (minimum 3) are associated with more severe pathology, while higher scores (maximum 15) are associated with less severe pathology. Another important predictor of recovery is post-traumatic amnesia (PTA), which is the length of time from injury to when the person recalls daily events. Lower PTA is associated with a better prognosis. Brain injury is classified as mild, moderate or severe. Mild brain injury is characterised by a loss of consciousness for less than 30 minutes, a GCS score of 13-15 and PTA of 5-60 minutes. Moderate brain injury is characterised by a loss of consciousness from 30 minutes to 24 hours, a GCS score of 9-12 and PTA that lasts from 1 to 24 hours. Severe brain injury is characterized by a loss of consciousness greater than 24 hours, a GCS score of 3-8 and PTA that ranges from 1-7 days. The severity of TBI in South Africa is distributed as follows: 87.5% mild, 7.9% moderate, and 4.6% severe (Miller & Stander, 2010; Christ, 2007; Bruns, & Hauser, 2003).

The prognosis for recovery is dependent on premorbid factors that could influence recovery such as the age of the child, i.e. the younger child, who comes from a family with low socio-economic circumstances, had behavioural problems, poor scholastic performance and has less adaptive abilities pre-injury is less likely to have an optimal outcome. There are a number of post-injury factors such as the location of the brain injury and whether it was localized or diffuse. More favourable functional outcomes are associated in instances where individuals have sustained a smaller localised area of injury than those who have more global injuries such as in the instance of those with a diffuse axonal shear injury. Other post-injury factors include access to effective and regular rehabilitation, parental reactions to the brain injury as well as parental stress (Martin & Falcone, 2008; Stancin, Drotar, Taylor, Yeates, Wade & Minich, 2002).

Post TBI individuals may present with an array of impairments spanning the physical, cognitive and psychosocial domains of functioning (Middleton, 2001). These impairments may be temporary or permanent in nature and impact differently on individuals. Physical impairments may include sensory deficits, decreased motor control, with headaches and fatigue common during the early stages of recovery. Typically, the cognitive-communicative functions that are affected post TBI include that of attention, concentration, short-term memory, language, processing speed, pragmatics, sequencing and the higher-level cognitive functions including thought formation and reasoning. The psycho-social effects of TBI include changes in social, emotional and behavioural functions (Anderson & Catroppa, 2006).

The effects of TBI extend to the family. Post TBI, family functioning has been reported to be influenced in numerous ways including: higher levels of stress, decreased coping abilities, a decline in the quality of family relationships, increased psychological symptoms displayed by parents and negative changes have been observed in siblings moods (Rivara, 1994; Wade et al., 2006; 2003). This reflects the impact of TBI on both the adolescent and those who they naturally rely on for support; which brings to the fore the importance of service provision that should target both the individual with TBI and those in their immediate context.

The above description of TBI highlights the range of impairments that may affect the functioning of an adolescent physically, mentally and socially, following the onset of the TBI. This in turn, may impact on the adolescent's ability to participate in life situations. The onset of the TBI hence requires the adolescent to adjust to varied changes in abilities, skills and role fulfilment which are further complicated by the adjustments which are typical of the development stage of adolescence which will be expanded upon in the next section.

## **2.4 ADOLESCENCE**

Adolescence is typically defined as the transitional stage of development between childhood and adulthood. Vroman (2015) describes adolescence as spanning three phases, i.e. early adolescence (10-13 years), middle (14-17 years) and late adolescence (17 to 21 years). She further describes adolescence as a "time of learning, experimentation and experience" and this influences future career decisions, participation in social contexts and the overall well-being of the individual (Vroman, 2015, p.104).

Adolescence is a stage of development that is characterised by many adjustments and has an influence in determining the learner's future direction in life. This study therefore specifically focuses on learners who have sustained their TBI during adolescence. A focus on the



adolescent (as opposed to the younger child or adult) is important as current literature lacks a focus on adolescents' adjustment and their participation post TBI. This is an adjustment process that I argue is complex given that these learners' adjustment to the physical, cognitive and psychosocial changes related to the stage of adolescence is compounded by the changes in their life circumstances post TBI. As a means to illustrate the complexity of adolescence, as a transitional stage from child to adult, the information that follows includes a description of typical development within adolescence. It is important to remain cognizant of the fact that as there are variations in typical development each adolescent must be seen as an individual with his/her own strengths, needs, ambitions and context in which they function.

#### **2.4.1 Physical development**

Physically during this stage of development there are increases in physical growth, i.e. height and weight as well as body proportions that are influenced by a complex interaction of growth and sex-related hormones. The rate at which the physical growth occurs differs amongst individuals in terms of onset, intensity and duration. However adolescents who seem to reach their physical development within the norm and tend to display physical competence (e.g. in sports), tend to feel more confident as by fitting in they tend to receive validation from their peers and adults, whereas adolescents tend to be more self-conscious when their physical development is slower (Graber, Seeley, Brooks-Gunn & Lewinsohn, 2004). Adolescents require physical activity as it contributes to their overall health and wellbeing. In adolescents with TBI where physical abilities are reduced, they may be less physically active. This has implications for maintaining their functional ability, physical and emotional health as well as their ability to socialise with their peers (Vroman, 2015).

#### **2.4.2 Cognitive development**

Typically as the different parts of adolescents' brains develops so do their cognitive abilities. For example maturation of the pre-frontal lobe is linked to increases in abstract thought, processing speed and their response to inhibition (Yurgelun-Todd, 2007). Piaget (1972) referred to this maturation in cognitive functions as the formal operational stage, which is characterized by functions such as symbolic thought and hypothetical reasoning. Thinking is now more organized and the ability to reason and problem solve is more mature. It is during this stage that adolescents are able to see the link between current actions and future consequences. They also develop values (i.e. personal, social, moral and political) that are associated with becoming an adult. These values influence their decisions and their thoughts regarding their future

direction in life. The ability to self-regulate also increases, allowing adolescents to modify their behaviour according to the situation and social cues. This development in cognitive functions allows for increased independence in both thought and action (Coleman, 2011). In adolescents with TBI who have impairments within cognitive functions such as hypothetical reasoning, problem solving, understanding subtle cues and self-evaluation will hence tend to have difficulty modifying their behaviour and understanding the consequences of their actions. These adolescents may tend to function at the preceding pre-formal stage, which is the stage during late childhood where the cognitive functions are characterised by impulsive decision-making and actions.

### **2.4.3 Psychosocial development**

Sherer and Radzik (2016) describe the typical characteristics of psychosocial development in terms of the three phases of adolescence. In early adolescence, adolescents typically are self-focused (i.e. have a high concern for their personal appearance), are self-conscious and often awkward. They desire privacy, tend to distance themselves from their parents and challenge adults' rules and opinions. In early adolescence they experience changeable moods, have mostly same-sex friendships, and are susceptible to experimentation and succumbing to peer pressure. They are increasingly able to demonstrate abstract thinking and fantasize about their futures.

The middle years of adolescence are when the most intense maturation occurs. In this phase, adolescents are now more accepting of their developing bodies and engage in sexual expression. During this phase, adolescents are thought to be less concerned with the physical changes of their bodies and more concerned with their appearance and how attractive they are perceived to be. Parents are replaced by peers as the significant influence. Adolescents are more involved in formal and informal peer related activities, are more likely to conform to their peers and friends whose opinions they regard highly. Their ability to explore and reflect upon feelings of themselves and others also increases. They are also more realistic of their career goals. Risk taking behaviour and experimentation (e.g. use of drugs) may occur.

Late adolescence may be viewed as the period of consolidation, when adolescents tend to have a more established sense of self and their personal value system and are able to independently make decisions. They are also increasingly becoming more capable of completing the tasks of a young adult such as contributing to society. Relationships with parents may strengthen as adolescents now tend to seek out parental advice and help, whereas the influence of peers

seem to diminish due to increased personal values and sense of self. Typically they are now able to monitor and modify their behaviour. They start to become realistic in their career aspirations.

#### **2.4.3.1 Identity formation and well being**

Research highlights identity formation as an integral part in adolescent development (Meeus, 2011). Self-identity has two components: i) an individualistic component (Who am I?) and ii) a contextual component (Where and how do I fit into my world?). A healthy individualistic sense of identity is a stable self-concept from which the adolescent interacts with the physical and social world around them. The contextual component refers to the position from which a person understands their core values and beliefs, interests and commitments to fulfilling roles within society (i.e. daughter, friend, learner, etc.). The contextual component is influenced externally (i.e. family, peers, culture, society, historical and political events) (Marcia, 1991). Wild and Swartz (2012, p.229) highlight differences in a culture's influence on an adolescent's identity formation, particularly the development of a moral identity, i.e. "integration of self with a sense of responsibility and integrity". They state that in westernised industrialised societies individualism may be valued higher than in traditional societies where "collective orientations are more important in the adolescent's moral reasoning processes" (Wild & Swartz, 2012, p. 227).

Erickson (1968; 1980) proposed that acquiring a sense of identity was characterised by one of two states: i) identity resolution when adolescents achieve a sense of who they are and their direction in life and ii) identity confusion when adolescents experience ambivalence about themselves and the ways in which they fit into the world around them. Erikson has been critiqued for stating that the identity developmental crisis occurs in adolescence and is resolved at the end of adolescence. More recent authors hold the view that youth typically do not achieve a clear sense of identity at the end of adolescence but that it is rather solidified during the young adult years (Kroger, 2004; Harter, 2006). Erikson also implied that the formation of identity occurs in all areas simultaneously. This however, is not the case. A strong identity regarding a career choice may exist already while identity-searching in other areas such as sex roles or religious values may still be developing (Hardman et al., 2012).

Marcia (1991) expanded on Erickson's theory and proposed the identity status model, to suggest that identity development is understood by examining the extent to which an adolescent explores (i.e. actively considers, investigates, evaluates and make choices) and commits (i.e.

makes a stable investment in values, beliefs, goals and interests) to an identity across various domains in life, (i.e. occupations, religion, friendships etc.). Marcia describes four states of identity development:

- **identity diffusion:** the adolescent has not yet commenced with self-exploration of issues related to self-definition and has not made any commitment to a particular career path or ideological belief system. Prolonged identity diffusion is associated with low self-esteem, negative attitudes and a general dissatisfaction with life and others (Kroger, Martinussen & Marcia, 2010);
- **moratorium:** the adolescent has no strong commitment to a particular career or ideological belief system but is actively considering and exploring a variety of options. Adolescents in moratorium strive for autonomy and individuality. Prolonged moratorium leads to indirection in life and can cause anxiety, self-consciousness, impulsiveness and depression (Kroger, Martinussen & Marcia, 2010);
- **identity foreclosure:** an adolescent prematurely commits to an occupation and a particular set of beliefs without much exploration or deliberation of other choices and this commitment is largely based on the opinions of others (i.e. parents). Adolescents demonstrating identity foreclosure tend to assume a conventional moral stance, display less flexibility in thinking and cope better in well-structured environments. There are associations with approval-seeking behaviour, high regard for authority and avoidance of new experiences (Kroger, Martinussen & Marcia, 2010); and
- **identity achievement** (aka identify formation): the adolescent has previously gone through a period of moratorium and has emerged with a clear choice regarding occupation and commitment to ideological and religious beliefs. Identity achievement is associated with autonomy and independence in decision making (Kroger, Martinussen & Marcia, 2010; Santrock, 2012).

Other researchers have critiqued Marcia's reference to "states" in the model, implying that there is an existence of a final ideal state. This is however, not so in reality as identity formation has a pattern of continuity and is a complex ongoing process of "negotiating, adaptation and decision making" that continues to and throughout adulthood (i.e. is life-long) (Meeus, 2011, p.80). Research has pointed out the role of the breadth ("exploring various alternatives in terms of commitments before deciding on one") and depth ("indicates whether adolescents evaluate and maintain their commitments in an active manner after choosing them") of the exploration in the identity achievement (Luyckx, Goossens, Soenens, Beyers & Vansteenkiste, 2005, p.605;

Meeus, 2011, p.80). *Breadth* in the exploration of identity achievement has been negatively associated with making commitments to choices whereas *depth* has shown a positive relationship. This dual-cycle model of identity formation assumes that adolescents have a more stable sense of identity than previously thought and that adolescents should be seen as starting off with a set of commitments (although not well established) that are related to their existing ideological and personal identities. The process is one of gradually making commitments to the values, beliefs, interests and occupations that will form the basis of one's identity (Crocetti, Rubini, Luyckx & Meeus, 2008; Meeus, van de Schoot, Keijsers, Schwartz, & Branje, 2010; Meeus, 2011). Studies which explored adolescents' identity status over time have found that adolescents who display strong commitments are associated with improved adjustment (less depression, anxiety and an increased sense of well-being). They tend to display personality profiles characterised by positive traits such as openness, extroversion and they tend to have high levels of emotional stability and self-esteem whereas adolescents with low level commitments and a high level of exploration in breadth (i.e. searchers) tend to have the lowest levels of adjustment (Luyckx et al., 2005; Crocetti, et al., 2008).

In sum, the process of identity formation is thought to be influenced by factors such as: cognitive skills, personality, relationships with parents, support from peers, opportunities to explore, and an adolescent's cultural and economic context (Wild & Swartz, 2012). Adolescents who have a stable sense of identity are able to adapt and respond to personal and social demands without anxiety and have a higher sense of well-being. A relatively stable sense of self is associated with a positive self-concept, i.e. high self-esteem and efficacy in one's abilities (Meeus, 2011).

#### **2.4.3.2 Self-concept and self-esteem**

As adolescents define their identities, their self-concept (feelings and perceptions about own identity consisting of stable values, beliefs and abilities) becomes differentiated. Self-concept is multifaceted; it includes self-acceptance, which is associated with many aspects in an adolescent's life such as personal appearance, parent and peer relationships, competence in academic and non-academic school related activities and social acceptance. Social acceptance is highly valued and important to identity. Adolescents typically are self-aware and want to fit in with their peers (Rathus, 2008). Adolescents with disabilities have additional challenges in that they must constructively integrate their disabilities into a healthy self-concept so that the disability does not become their identity. Whether or not the adolescent's identity based on a disability is reinforced or shaped, it is influenced by proximal processes, i.e. the transactions between the adolescent and his/her immediate environment (i.e. parents, peers, etc.)

(Bronfenbrenner, 1979; 2005). An example is the way they choose to refer to the adolescent, i.e. using diagnostic labels/using emotive language that marginalizes or assumes that a disability is always a negative experience (e.g. the person suffering from a brain injury) or whether they choose to use language which refers to the positive qualities of the adolescent will influence how the adolescent views the primary characteristics of their identity (Vroman, 2015). Self-concept becomes more integrated and the adolescent becomes less self-absorbed with developments in cognitive functioning, moral reasoning and increased social awareness (Vroman, 2015).

A significant aspect of self-concept is self-esteem (i.e. how a person feels about him/herself, based on a self-evaluation of their values as well as negative and positive qualities). In early adolescence, self-esteem seems to decline, because of self-consciousness, a tendency to compare oneself with the ideal and an increased focus on the differences between the actual and desired self. Self-esteem is however thought to improve throughout adolescence (Rathus, 2008). Adolescents with persistent low self-esteem often have psychological difficulties (i.e. depression, anxiety, self-abuse etc.). Their desire to fit in makes them more susceptible to peer influence (Vroman, 2015). Research has shown that the self-esteem of adolescents with disabilities is affected by the same factors (i.e. self-evaluation of assets and limitations) as adolescents without disability. Factors such as being treated in an age appropriate manner, positive peer attitudes and inclusion have been found to contribute positively to an adolescent's self-esteem and sense of worth. Factors such as scholastic challenges and others' negative perceptions of disability have been found to contribute negatively (Miyahara & Pick, 2006).

As outlined above, adolescents undergo numerous changes. With these changes, they may experience an array of emotions. These could include pride on the one hand and feelings of anxiety, confusion and emotional turmoil on the other. For an adolescent to undergo a positive personal adjustment, they need to integrate these significant changes into a healthy self-concept which includes a positive body image. A positive body image is characterised by an adolescent's positive feelings, thoughts and views about his/her body and appearance (Guest & Schneider, 2003). A negative body image can be found in youth who have acquired disabilities within adolescence (e.g. TBI or chronic conditions such as Cancer). These adolescents have difficulty dealing with the limitations in functioning of their previously healthy bodies and this may impact on their ability to make a positive personal adjustment. However the support and positive feedback from significant others such as family and friends may contribute towards a more positive adjustment (Calaminus, Weinspach, Teske & Göbel, 2007).

### **2.4.3.3 Self-identity and traumatic brain injury**

The body of current knowledge on self-identity and TBI reflects a range of ways people make sense of themselves post brain injury. These include the ways in which individuals actively view themselves in terms of the changes post TBI (i.e. cognitive, physical, sensory and social), their emotions, view on life, motivation, lifestyle and uncertainty. A “loss of self” is highlighted as a key finding in existing literature on narratives of people with TBI. A “loss of self” was found to include: i) loss of knowledge of self (e.g. due to impairment in memory); ii) loss of self by comparing who they were before with who they are after the TBI; and iii) loss of self, based on other’s perceptions of who they are after the TBI (Sharp et al., 2006; Mealings & Douglas, 2010; Levack, Kayes & Fadyl, 2010; Nochi, 1998, 2000).

Studies which specifically explore learners’ perspectives of school re-entry and participation post TBI, describe the experience of loss for those with TBI as including feelings of disconnection with their pre-injury identity (Sharp et al., 2006; Mealings & Douglas, 2010; Mealings et al., 2012; 2016). How well a learner responds and adjusts to the loss and changes as a result of the TBI may be viewed as either a facilitator or barrier to their school return and participation post TBI.

For a learner to adjust to the loss and changes post TBI requires him/her to undergo “the reconstruction of self” (Levack, Kayes & Fadyl, 2010, p.986). During this process of “reconstruction of self”, persons with brain injury have highlighted that they predominantly make sense of themselves through the personal meaning linked to engaging in valued activities and occupations (Ylvisaker & Feeney, 2000). This implies that ‘doing” (i.e. practically and socially) allows persons with TBI to “reinforce who they are” and experience a sense of connectivity and competence (Gracey, et al., 2008, p.643). Despite the personal value of engaging in occupation, persons with TBI seemingly experience limited opportunities for participation in meaningful occupations, role fulfilment and social interaction (Sloan, Winkler & Callaway, 2004). This calls for interventions focused on goals that are occupation-based and seek to facilitate the engagement in occupations that are personally meaningful to the client and not focused on the interests of other stakeholders such as funders and service providers. This is further supported by Sloan (2009) who advocates for interventions that foster opportunities for individuals to participate in personal valued occupations post TBI. She suggests that this may help to develop self-identity as a foundation to improve the capacity of the individual with TBI as well as help decrease psychological distress and challenging behaviours related to the TBI.



#### 2.4.4 Resilience and youth

TBI may be regarded as an adverse event in an adolescent's life. Adversity is defined as "intense and/or persistent negative life events including: neglect, abuse, poverty, mental health challenges, addictions, disability and discrimination" (Hart, Blincow & Thomas, 2007, p 10). Adolescents who are able to positively adapt and participate in the midst of adversity exhibit resilience (Ungar, et al., 2007). Currently there is a paucity in literature which specifically explores the adaptation process of adolescents in the midst of adverse circumstances, such as the onset of a TBI (see section 2.6.2). Literature further lacks an exploration of the impact of these adolescents with TBI adaptation processes on their participation in life situations (e.g. school participation). This supports the rationale for this research study.

Historically resilience has focused on a youth's personal characteristics (e.g. motivation, temperament, intelligence, etc.) that make him/her "resistant to adversity" (Ungar, Ghazinour & Richter, 2013, p.349). This individualistic notion of resilience has been critiqued by authors who highlight the environment's role in bolstering the resilience processes of youth in the midst of adversity (Garret, 2016; Harrison, 2013; Joseph, 2013). Resilience has now been reconceptualised to include a focus on the transactional relationship between the individual and his/her wider context (i.e. processes and interactions within the multi systems of the environment) (Masten 2014; Ungar, Connelly, Liebenberg & Theron, 2017; Ungar, 2011; 2008; Ungar, et al., 2007). Ungar et al. (2008, p.225) refer to this as a socio-ecological perspective of resilience, i.e.

"In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided in culturally meaningful ways."

The crucial role of the environment has been shown in findings of studies that demonstrated that a child's ability to cope and develop under stress has a stronger association with a facilitating environment than a child's individual characteristics (DuMont, Ehrhard-Dietzel & Kirkland, 2012; Klasen et al., 2010; Panter-Brick & Eggerman, 2012). However the degree to which an environment can be seen as facilitating is dependent on the availability and accessibility of resources and the quality of the interactions between the person and those providing the resources within the person's respective contexts. Ungar et al. (2007) further state that in addition to facilitating access to resources, the promotion of resilience requires that these resources be culturally relevant and acceptable.



A recurring theme in resilience literature is that resources needed to promote resilience necessitate a combination of personal and contextual factors. This was re-iterated by the findings of a cross-cultural study across 11 different countries (including South Africa), which explicated the resources needed to promote resilience. These included:

- Access to physical resources such as food, shelter, clothing and access to health care and education;
- supportive relationships with family and those in the community, providing a sense of connectivity;
- a sense of mastery and a positive sense of identity;
- a sense of personal or collective agency;
- cultural adherence;
- experience of social justice; and
- experience of social cohesion (Ungar et al., 2017).

In addition to a consideration of personal and environmental factors, authors have called for the consideration of occupational factors in the promotion of resilience (i.e. an occupational perspective of resilience) (Wilcock & Hocking, 2014; Usaite & Cameron, 2016). Studies have shown that through engaging in meaningful occupation (e.g. leisure and vocational tasks), resilience could be promoted in youth (Hart & Heaver, 2013; Jessup, Cornell & Bundy, 2010; Grunstein & Nutbeam, 2007; DeLuca et al., 2010; Usaite & Cameron, 2016). It is my contention that the need for an occupational perspective for resilience could be based on the premise that engagement in occupation provides opportunities for the development of key facilitators of resilience that have been highlighted in resilience studies. In other words, engaging in occupation facilitates not only a positive self-identity and self-esteem when mastery is achieved but also a sense of control, social interaction and a sense of belonging. An occupational perspective of resilience resonates with Wilcock and Hocking's (2014, p.146) theory; "through doing people shape who they are and they become". I therefore support the development of resilience promoting interventions based on the premise of engaging marginalised youth in valued occupation. This in combination with the use of strategies employed to increase the availability and accessibility resources to meet youth's biopsychosocial needs, may be promising interventions that aim to promote wellbeing and resilience. However, for interventions to facilitate the availability of and accessibility to resources that the adolescent requires to nurture and sustain their well-being in adverse circumstances, demands that service providers have an understanding of the nature and extent of the adolescents with TBI's support needs. Such an understanding is best obtained from a service-user perspective and further supports this study's rationale for obtaining the insider perspective.

## **2.5 INCLUSIVITY AND BASIC EDUCATION**

Learners, including those with disabilities, experience occupational injustice when they are denied the opportunity to be engaged in the occupations that are required and are meaningful to them (Townsend & Whiteford, 2005). Such injustices may be seen in educational settings where learners with disabilities have been (and in many cases are still being) denied access to: firstly quality education and secondly to opportunities that may facilitate their successful participation in the occupation of school (Inclusive Education, 2017). South African legislation that seeks to redress this injustice and facilitate the inclusion of marginalised learners pertains to the policy on inclusive education.

### **2.5.1 The conceptualisation and implementation of inclusive education in South Africa**

Globally there are variations in the conceptualization and implementation of inclusive education. There are however broad principles which are common between contexts, i.e. social justice, educational equity and school responsiveness (Swart & Pettipher, 2016; Engelbrecht & Green, 2018).

The conceptualization and application of inclusive education in South Africa are reflected in the National Department of Education (DoE) White Paper 6: Special needs education (2001). This policy outlines that fundamentally inclusion is about practice that promotes equal participation and the development of the full capacities of learners by creating learning communities that are responsive to learners' diversity (Adams, Bell & Griffin, 2007). The vision for inclusive education is to provide all learners with access to quality education and to provide optimal opportunities for learning as well as meaningful and productive participation in society (Du Plessis, 2013). Inclusive education within the South African context can therefore be viewed using a human rights perspective. This perspective is based on the ideals of social justice for all learners, respect for diversity and equal access to a good quality education, as is reflected by Section 29 of the South African Constitution (SA, 1996).

Within the South African context, the overall framework for policy development on inclusive education has been based on international guidelines such as The Universal Declaration of Human Rights, The United Nations Convention on the Rights of the Child, the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, the African Charter on the Rights and Welfare of the Child, the Salamanca Statement and Framework for Action on Special Needs Education, the UN Convention on the Rights of People with Disabilities and the

Incheon Declaration for Education (Nel, 2018; Du Plessis, 2013). Global and societal changes have influenced general educational reform, i.e. a move from separate educational services for learners with disabilities to “a single inclusive education system” to which all learners have equal access (DoE, 2001, p.5). This coupled with the historical educational system in South Africa (i.e. inequalities in the funding and provision of educational services based on race) has resulted in a shift in policies on inclusive education from the barriers to learning solely within the human system (i.e. within the learner), to a focus on the barriers in all the interrelated systems (i.e. the school, education system and within the broader socio-economic and political context) (DoE, 2001). This shift in policy aligns with this study’s bio-ecological lens through which high school learners’ experience of school re-entry and school participation post TBI was explored and interpreted. The bio-ecological approach in this study aimed to provide a comprehensive understanding of the barriers to learning for learners with TBI. This could be used as part of efforts that aim to reform the organisation of schools, curriculum as well as teaching and learning strategies and as such, could contribute to cultivating an educational system that is responsive to a learner’s needs and is hence able to foster optimal school participation of learners post TBI. This embodies the Department of Education’s vision of enabling all learners to “actively participate in the education process to develop, extend their potential and facilitate their meaningful participation” (DoE, 2001, p.5).

Despite government’s commitment to increased participation and reduced exclusion of learners through policy, there are numerous challenges related to ensuring the successful implementation of policy that aims to ensure access to a quality education for learners with barriers to learning. It can be argued that these challenges contribute to the barriers encountered in successful school re-entry and school participation of learners with TBI. These barriers are outlined below.

### **2.5.2 Challenges facing inclusive education in South Africa**

Authors such as Donohue and Bornman (2014) are of the opinion that the progress of the implementation of inclusive education is slow. They base this on statistics that show that despite the fact that the South African policy for inclusive education was implemented more than a decade ago, not much has changed since 2001 when approximately 70% of school-aged children with disabilities were not attending school and those who did attend, were still educated separately in the special education needs system. This slow progression towards meeting the human rights and transformative agenda can be attributed to various constraints:

Donohue and Bornman (2014, p.1) refer to the lack of clarity in current policy, i.e. “ambiguity about the goals for inclusion and the means through which they can be achieved”, as a current constraint. This lack of clarity further leads to role players being uncertain of their respective roles and responsibilities, which may also impact on their levels of accountability in terms of ensuring the needed support is provided to learners (Maguvhe, 2015). Van Rooyen, Le Grange and Newmark (2002) further state that South African policies are thought to be malaligned and contradictory, thus impacting on the smooth implementation of inclusive education. Policies furthermore are often vague in terms of guidelines. For example White Paper 6 states that “curricula create the most significant barrier to learning and exclusion for many learners” (DoE, 2001, p.31), yet there are no clear guidelines with regards to how teachers are expected to adapt the curriculum to match diverse learner needs and pace of learning (Donohue & Bornman, 2014). Pather (2011) advocates for the constant reviewing of the inclusion policy to adjust implementation processes.

Maguvhe (2015) highlights that a key constraint is the perspectives of key role players regarding inclusivity. He states that transformation of these perspectives is needed prior to role players assuming the role of advocators for inclusivity. He, together with Swart and Phasha (2016, p.265) advocate for a broader view of inclusion to include all learners who are faced with barriers to learning (including those “faced with precarious life circumstances and adverse socio-economic conditions”).

Positive care-giver attitudes regarding inclusivity is important, as parents are often the main advocates to ensure their children’s right to education and the needed support are upheld. Parents therefore require education pertaining to their child’s constitutional right to a quality education as well as their right as parents to be involved in the decision-making regarding the placement of their children (Donohue & Bornman, 2014).

Successful inclusion depends on the attitudes and behaviour of principals and teachers to create a culture that is open and responsive to inclusivity (Ainscow, 2002). Educators require a positive attitude towards inclusivity. To foster this, they too require training to facilitate the efficacy and confidence needed to implement inclusive education principles as the brief training that most receive is insufficient (Chataika, McKenzie, Swart & Lyner-Cleophas, 2012; Dalton, Mckenzie & Kahonde, 2012; Walton, Nel, Muller & Lebeloane, 2014). Maguvhe (2015) specifically calls for the transformative learning of educators at all levels (i.e. national, provincial and district), which entails a change in understanding and hence personal beliefs around the philosophy of inclusive education, accompanied by changes in behaviour. In South Africa,

teachers who were historically trained, were trained to fulfil the roles of general teachers. Only those who taught in special schools completed further qualifications in special education. Most teachers therefore need to undergo both a mind shift as well as acquire the knowledge and skills to capacitate them to teach learners with diverse needs in a classroom (Ntombela, 2011). However, in addition to training, they need to receive the appropriate service support from the government for learners with barriers to learning in order to bring about a positive change in the general attitude toward inclusion (Donohue & Bornman, 2014).

The curriculum is a central component in addressing the diverse needs of learners (DoE, 2001). Du Plessis (2013, p.91) states that for a curriculum to be accessible, flexible and responsive to all learners' needs, the aspects of the curriculum under review should be comprehensive and encompass all aspects. These aspects include: "the learning environment, learning programmes, teaching practices, capacity of teachers, assessment of the learning outcomes, equipment, medium of teaching and learning, and the nature of support provided to enable the learning programme". To address teacher capacity, teachers require training and support to enable them to differentiate the curriculum. In addition, educators need to adopt the view of inclusive education as a fundamental principle of the Curriculum and Assessment Policy Statement (DoE, 2010).

As learning does not only occur in the school environment, but in the home and community, communities need to adopt a positive attitude towards inclusivity. Maguvhe (2015) proposes that within policy the role of the community should be clearly delineated allowing the community to also be held accountable for meeting their responsibility in support provision for learners with barriers to learning.

For inclusive education to be on track, inequities in the availability and access to support services between rural and urban areas needs to be addressed (DoE, 2001). There is a need for more adequate financing by the South African Department of Basic Education to the provincial education departments to allow for the implementation of the policy (Donohue & Bornman, 2014). For example the financing needed to get full-service schools fully operational. In conclusion, it can be said that policy development has been an integral focus and reflects the South African government's commitment to address diversity and provide a continuum of support to all learners. Current policy emphasises the right of all learners, including those with disabilities (such as TBI), to access and participate in school. Government has taken steps to progress towards the attainment of this vision as is evidenced through initiatives such as the development of various conceptual and operational guidelines for the implementation of

inclusive education. However legislation on its own is not sufficient, progress towards the attainment of the vision of inclusive education within South Africa will require an attitudinal change and the collective action of key role players at all levels of the education system.

## **2.6 SCHOOL RE-ENTRY AND PARTICIPATION**

### **2.6.1 School as meaningful occupation**

A fundamental element of being a child/adolescent is that of participating in school. Outside of the family, school is thought to be the primary contributor to shaping the future social, psychological and economic outcomes of the child/adolescent (Law, Petrenchik, Zivianai & King, 2009). School participation is therefore a focal part of this inquiry, given its importance and the amount of time that an adolescent devotes to this occupation.

School participation refers to “those activities needed for being a learner and participating in the learning environment” (AOTA, 2014, p.S20). School participation includes engagement in: i) academic (e.g. writing, reading and maths); ii) non-academic school related activities (e.g. break time and self-help tasks); iii) extracurricular (e.g. sports and clubs); and iv) prevocational activities. In addition to the role of learner, the adolescent fulfils many roles within the school context including that of player, class mate/peer and team mate (Hinder & Ashburner, 2010).

School provides opportunities for learners to participate in various tasks associated with the roles they fulfil within the school context. It is “through doing” in school that learners learn and master skills, learn coping strategies and adapt to limitations. School further provides opportunities for learners to experience role identity and performance competence (Hardman et al., 2012). Competence is linked to learners’ capacity to effectively interact and meet the demands of the situations or tasks within their environment. Disruption to learners’ involvement in school due to injury such as TBI, may result in them experiencing a sense of loss because of their inability to fulfil the learner role which provides opportunities for the development of competence and for their valued goals to be attained. With the experience of loss, learners may focus on their diminished abilities to meet their perceived role performance requirements as well as the expectations from society including their family, friends and teachers. Learners may respond through either adapting as a means to re-assert role competence or they may become overwhelmed by the challenge and become depressed and experience feelings of helplessness (Hardman et al., 2012).

In order for a learner to achieve success at school (in addition to engaging with the school curriculum) they are required to manage daily life and social tasks (Law et al., 2009). However, as a result of residual impairments and activity limitations following a TBI, learners may have difficulty with executing those self-help tasks needed within the school setting such as independent toileting. They may furthermore experience a decline in social interaction with their peers. This impacts on their ability to fully fulfil their role as learner and hence affects their experience of a sense of belonging to their school community (Hinder & Ashburner, 2010).

Success at school is further shaped by the range of opportunities and challenges in the school context. Experiences of success increase the likelihood of learners seeking optimal challenges whereas experiences of failure, exclusion and negative feedback result in the avoidance of challenging tasks. It is therefore important to understand the learner's specific context and its impact on learner role execution and participation in school (Case-Smith, 2015).

School participation as an occupation is integral in providing a sense of purpose and structure within learners' lives (Case-Smith, 2015). This was supported by qualitative studies that focused on the "role of school" for learners following TBI within Australia and the USA where learners highlighted the significant role school participation played in providing a sense of purpose and structure through the educational and vocational goals that they set for themselves. Learners further highlighted that socialization was a key component of their school experience and hence an essential part of their school identity. The social aspects of school were viewed as integral specifically when it allowed the learner to experience a sense of belonging, acceptance and positive recognition (Mealings et al., 2010; Sharp et al., 2006). For some learners the social experience of school may be valued over academic success (Hinder & Ashburner, 2010). This calls for service provision that - in addition to focusing on a learner's re-engagement in their academic activities post TBI - should focus on their re-engagement in non-academic/extracurricular activities. This may allow a learner the opportunity to develop his/her social skills and experience a sense of connectivity which in turn, contributes to a positive sense of self.

The above highlights the value of school as an occupation that contributes to the personal development and well-being of an adolescent. Following a TBI, school progress and participation may be disrupted for the adolescent and as such it is important to explore the learner's perspective on their experiences of school participation post TBI. This is important to understand how current support services do or do not support and uphold these learners' human right to equally participate in all life situations including school.



### **2.6.2 Adaptation and school post traumatic brain injury**

The changes in functioning as a result of TBI, may result in the disruption of fulfilling valued life roles such as that of learner. Re-integration into the valued occupation of school and the associated role of learner involves adaptation (Parsons & Stanley, 2008). The ability to adapt may be facilitated by preparing the person for the engagement in occupation (i.e. the use of adaptive methods or the acquisition of skills) as well as through the person engaging in tasks and activities that underpin their occupational roles. Occupational adaptation can therefore be viewed as an “internal process of adaptation that occurs for occupation and through occupation when occupational challenges are experienced within the context of performing occupational roles” (Schultz & Schkade, 2003, p.220).

Participation in meaningful occupations assists with the adaptation process (Schultz, 2014). In the context of adolescent learners with TBI, it may be argued that participation in occupations such as school, if regarded as personally meaningful, may serve as the impetus for an adolescent to adapt to their changed life circumstances post TBI. Currently there is a paucity of literature on youth with brain injuries’ adaptation to their learner roles. Current literature does not specifically address the developing context perspective. This warrants the need for further exploration in this area within a South African context.

Within the context of existing literature on adolescent learners with TBI, Sharp et al. (2006) proposed that the return to school process should be viewed as a continuous adjustment process that includes two critical points, i.e. a learner’s return to school and once the learner is back at school. Mealings and Douglas (2010) expanded upon this and added a third critical point, i.e. moving on from school. Sharp et al. (2006) highlight factors that should be taken into account when organizing the learner’s return to school. These factors include: education of teachers and peers, identifying accommodations and personal preparation of the adolescent learner. I argue that the before-mentioned factors may be seen as adaptive strategies employed to prepare for the learner’s re-engagement in the occupation of school. These authors further highlight factors that should be taken into consideration once the learner is back at school. These factors include: implementing and evaluating accommodations and the active involvement of parents in the adolescent’s schooling (Sharp et al., 2006). These factors could be seen as adaptive strategies used when the adolescent engages in the tasks and activities that underpin the role as learner.



As discussed in section 2.4.3.3, other authors view this “internal process of adjusting post TBI as the reconstruction of an occupational identity, as expressed and defined through occupation” (Walder & Molineux, 2017, p.226).

The majority of research that specifically explores the occupational adaptation in individuals with brain injury are focused on the adjustment of adults (Walder & Molineux, 2017). This further supports the need for research that seeks to explore youth with brain injuries’ adaptation to their valued life roles, including that of learner.

The findings of a qualitative synthesis conducted by Walder and Molineux (2017) indicate that commonly used strategies by individuals to adapt to their occupational roles post TBI included: working through negative emotions, having a positive outlook, a good social network and engaging in occupation. Furthermore, the findings reveal that individuals with injury such as TBI regain well-being through participating in occupation and the reconstruction of their identity post injury when supported by a process in which competence, motivation and confidence is developed (Walder & Molineux, 2017).

Research has shown that some individuals, using the before-mentioned strategies are able to adapt post TBI and experience a high level of community integration (including re-integrating to school). However there are also individuals who experience a low level of community integration, with reduced social and occupational participation (including participation in education/school) (Winkler, Unsworth & Sloan, 2006; Sharp et al., 2006). This highlights the notion that the school re-entry and adaptation to the role of learner post TBI may be difficult for some adolescents. It therefore warrants an increased understanding of their personal experiences of school participation post TBI as it may provide further insight into the support needs of these learners.

### **2.6.3 Enablers and barriers to school re-entry and participation post TBI**

Given the range and persistency of difficulties that learners may experience post TBI, it can be expected that there are challenges with resuming valued life roles such as that of a learner. Literature has shown that these challenges may be overcome if certain personal, contextual and occupational factors (i.e. enablers) are facilitated and others (i.e. barriers) are minimised.

Research conducted in the field of inquiry on the enablers of and barriers to school re-entry and participation post TBI, tends to focus on the “outsider” perspective (i.e. the perspectives of

experts, parents, educators and health professionals) (Mealings & Douglas 2010). This focus, coupled with present day challenges of attempting to provide support which adequately addresses the priority needs and goals of learners with TBI, has resulted in an increasing number of authors conducting qualitative research in which they include the insider perspective (Stewart-Scott & Douglas, 1998; Backhouse & Rodger, 1999; Vaidya, 2002; Sharp et al., 2006; Todis & Glang, 2008; Mealings & Douglas, 2010; Hux et al., 2010). This review however focuses on literature that included learners who sustained their injuries during adolescence and then returned to high school post TBI, as it aligns with the focus of this inquiry. One of the few studies that were conducted in this field of inquiry includes a qualitative study by Vaidya (2002), in the USA. In-depth interviews were conducted with four high school learners (16-17 years old; 3 males and 1 female), their parents and teachers. Learners stated that barriers to their school participation included that they were no longer able to work towards the same educational goals which served as motivators to achieve future career aspirations that they had prior to the onset of the TBI. For some learners it was necessary to attend special education programmes in alternate schools after the onset of TBI. Barriers further included the inability to cope with the work-load of the current grade. Learners further reported that teachers were not knowledgeable of their specific needs post TBI and hence had either too high or too low expectations of them. Learners also experienced a lack of implementation of pre-agreed upon accommodations.

Enablers to school re-entry included an organized return to school in which learners had an opportunity to visit their school and/or meet with teachers prior to their official return to school. In addition learners also valued having strong relationships with teachers, which allowed the teachers to be perceived as approachable hence allowing learners to readily ask for support. Furthermore learners felt that teachers having sufficient knowledge about TBI and their specific needs was an enabler to school participation post TBI. Learners highlighted the positive impact on their motivation and school participation when they were given a choice and some control regarding their individualized education plan. Setting achievable goals as motivators to participate in school was also regarded as an enabler to school re-entry and participation post TBI (Vaidya, 2002).

Sharp et al. (2006) conducted a longitudinal qualitative, grounded theory study in which the experiences of eight Australian adolescents (14-19 years old, 5 females and 3 males) with severe TBI and to a much larger degree that of their primary caregiving parents were explored. Factors influencing participants' return to school as reported by Sharp et al. (2006) included:

- Extended time periods off from school: this resulted in learners experiencing feelings of social isolation, dropping out of school due to pressure from educators to catch up on missed work or repeating a grade if extensive work of their current grade was missed.
- Noticeable problems including changes in mobility and physical appearance: this influenced the learners' return-to-school as they were concerned about mobilizing between classrooms as well as the negative reactions of others within the school environment.
- Hidden problems including cognitive (e.g. concentration and memory difficulties), physical (e.g. headaches and fatigue) and psychosocial problems (e.g. decreased frustration tolerance, low self-confidence and depression): this not only affected return-to-school but also affected the learners' ability to participate in the classroom.
- The response from the department of education and the school: their response played a role in the learner's decision to return to school and was also said to have an effect on the learners' scholastic performance. A positive response assisted learners and their families to feel supported and increased learners' confidence. A negative response either discouraged learners, hence affecting their performance negatively, or for some learners, it motivated them to successfully participate in school and to prove those with negative responses that they were capable.

When facilitating a learner's school re-entry it was felt that what was of paramount importance was the adequate organizing of the learner's return to school involving all the relevant stakeholders. This included education of the relevant teachers and peers regarding the learner's TBI and specific needs. Interaction between the parents, educators and the rehabilitation team to organize the needed accommodations was valued. Accommodations included assessment (e.g. extra time to complete tests), instruction (e.g. peer work tasks) and environment (e.g. preferential seating). In addition learners felt that their preparation was important and this could take the form of worksheets given to them to complete prior to returning to school or a visit to the school during which they could engage with educators and their peers (Sharp et al., 2006).

Once they had returned to school, learners felt that barriers to school participation included the teachers' inadequate response to their specific needs. This was demonstrated by their ineffective use of teaching and learning strategies. Further barriers included the lack of consistency in applying accommodations and negative reactions from peers. The degree to which learners were able to adjust to their personal losses (i.e. loss of abilities, friendships and future goals) associated with the TBI also impacted on their school participation (Sharp et al., 2006).

Mealings and Douglas (2010) conducted a qualitative phenomenological study, in which three Australian high school adolescent male learners (13-17 years old) shared their experiences of their return-to-school process following a TBI. Three central themes were identified and these included: i) "the adolescent's sense of self"; ii) "internal and external changes" and iii) "supports" (Mealings & Douglas, 2010, p.9). Findings reflected that the perception of school participation as a motivator to achieve future career goals was regarded as an enabler to school re-entry and school participation post TBI. Learners reported that an additional enabler included the experience of positive relationships that fostered a sense of connectivity and satisfaction regardless of their academic achievement. Learners further highlighted that enablers included experiences of a sense of agency through their involvement in selecting and implementing learning strategies (Mealings & Douglas, 2010).

Barriers to school re-entry and participation included difficulties within cognition, behaviour and social skills which impacted on relationships within school and hence impacted on school performance. Furthermore, barriers included the delayed onset of deficits and learners' difficulty in responding to changes post TBI. Learners further identified barriers which included their experience of a loss of achievable vocational goals that led to a cessation of school attendance (Mealings & Douglas, 2010). Mealings et al. (2016) re-analysed the data of the initial research of Mealings and Douglas (2010) to explore those factors beyond academic performance that affect educational participation. Original findings were expanded on to include additional barriers to school participation such as the invisible nature of the effect of the TBI. This resulted in teachers incorrectly attributing TBI related impairments to the developmental stage of adolescence, resulting in learners not receiving the necessary support. A further barrier was learners' lack of awareness of the changes in functioning following the onset of the TBI, which deterred them from seeking the necessary support. Learners' need for acceptance hindered their ability to disclose that they had a TBI and this too impacted on the extent of support that they received from the learner environment which in turn impacted on their school participation.

The above-mentioned studies illustrate that there are similarities in participants' perspectives regarding the enablers and barriers to school re-entry and participation post TBI. Notably, these participants identified: i) the quality of the organisation of the school return; ii) communication between team members and iii) the support from team members as factors that either enabled or hindered their school re-entry and participation post TBI.

The above studies highlight enablers and barriers to school re-entry and participation within developed contexts. These contexts are likely to be better equipped to provide learner support

in terms of human and financial resources than their developing counterparts. Within a developing context like South Africa, it could be argued that the challenges to inclusive education as outlined in section 2.5.2 are barriers to school re-entry and participation post TBI. However, given the paucity of research within the domain of school participation post TBI in developing contexts, it remains necessary to establish whether the enablers and barriers of developed and developing contexts vary. This is important as there are contextual differences in terms of geographical area, culture, socio-economic status, policy, legislation and consequently, the funding models that provide access to rehabilitative and education-related services to learners post TBI. Increased insight into the enablers and barriers to high school participation post TBI in a South African context is fundamental to providing support services which are relevant and responsive to the needs of learners within their given contexts.

#### **2.6.4 Current programmes facilitating school re-entry and participation**

Within most developed contexts, learners' transition to school following the onset of a TBI crosses the boundaries of many disciplines. Initially the focus of intervention involves a medical and rehabilitative focus and progresses to an educational framework (Mealings, et al., 2012). Historically the approach to school re-entry was regarded as a "time limited, hospital-to-school transition". However of late a more holistic approach - that encompasses cross-sector collaboration and support over time - has been advocated for (Ylvisaker et al., 2005, p.101). Within the South African context my experience as an occupational therapist has been that following the onset of the TBI, learners' interventions do involve a medical focus. However, not all learners are able to access the required rehabilitation. Learners may be discharged home without intervention from key disciplines such as therapists (occupational therapists, physiotherapists or speech therapists), educational or clinical psychologists. My experience has also been that cross-sector collaboration and the continuity of support to maximize learners' participation in school has been (and remains) limited. This however, is still an outsider perspective, but nevertheless, further highlights the need for this study which aimed at obtaining learners' perspectives regarding their experiences of services/programmes that sought to facilitate their school transition post TBI.

Internationally there are numerous programmes supporting the re-entry of learners following an injury or illness, however these tend to focus on children with chronic health conditions such as cancer (Harris, 2009; Power, DuPaul, Shapiro, & Kazak, 2003) and paediatric organ transplants (Weil, Rodgers & Rubovitz, 2006). Upon reviewing the literature, there were programmes that aimed to facilitate community participation of clients following acquired brain injury (including

TBI) (Williams, 2008; Marcantuono & Prigatanob, 2008; Sloan, Winkler & Callaway 2004). However only two of these programs will be discussed in detail as they: i) explicitly focus on children/adolescents, ii) explicate the use of intentional structured interventions affecting school re-entry and school participation for children/adolescents post TBI and iii) include evaluative outcomes. These include the Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP) (Gillet, 2004) and the “School Transition and re-Entry Program” (STEP) (Glang, Todis, Thomas, Hooda, Bedell & Cockrell, 2008).

#### **2.6.4.1 Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP)**

PABICOP is an outreach program based in Canada and is funded by the Ontario Ministry of Health and Long-term Care. It was established following consultation with community stakeholders, the Children’s Treatment Centre and the Tertiary Children’s Hospital (Fthenos & Hryniewicz, 2013). The impetus for the development of the programme included children/youth experiencing difficulties following discharge from rehabilitation settings. This was coupled with families needing support to link with schools and other community resources. PABICOP provides tailored services to children, adolescents and their families. The focus of the program is home, school and community re-integration using relevant local support for children and youth (Gillet, 2004).

The PABICOP team consists of a multi-disciplinary team including a paediatric neurologist, community out-reach co-ordinator, school liaison personnel, neuropsychologist, psychometrist, occupational therapists and speech therapists. The service delivery model is eclectic; combining a consultative clinical model (medical and therapy) and psychosocial supports with education and community outreach supports (Fthenos & Hryniewicz, 2013). Children and youth with TBI are typically referred by a paediatric neurologist (prior to discharge) for input regarding medical, psychological, and educational challenges related to the TBI (Gillett, 2004). Following a referral, the PABICOP team has a discussion about each new client. Where possible the community outreach co-ordinator and the school liaison officer meet with the family prior to the child or youth being discharged. Post-discharge contact is then made within 1-2 weeks and an appointment is made for the community outreach co-ordinator to conduct a home visit. During the home visit a report is compiled regarding the family’s level of coping, support that systems have been initiated and other issues pertaining to the family’s functioning. If counselling is required, this will be provided by the community-outreach co-ordinator and where longer term input is required the family will be put in contact with the relevant community resources. The school liaison will also use this opportunity to get an overview of the child’s or youth’s premorbid

school functioning and will seek permission to contact the learner's school and educators (Gillet, 2004).

The school liaison officer then makes an appointment for a school visit, during which a meeting is held with the principal, guidance teacher and the home-room teachers to discuss and put plans in place to address the child's specific needs. Where indicated, a school visit may also include observation of the client in the classroom. The school liaison further acts as the mediator between the families and schools and will attend meetings that are held between these parties (Gillett, 2004). The school liaison officer further plays a role in improving the teacher-learner relationship, specifically in instances where there are behavioural disturbances. Should the client need to be identified as a learner with barriers to learning to access school resources funded by the government, the school liaison officer will advocate for this to the Identification, Placement and Review Committee. It is the responsibility of the school liaison officer to oversee the process which includes the completion of the necessary documentation. The school liaison officer is also responsible for conducting professional development activities for the educators within each specific school board (Gillet, 2004).

Formal follow-ups are arranged at the closest community clinic during initial family contact. This is usually 3 months post discharge or earlier if the client needs specific medical intervention. The follow up meetings are also attended by the school liaison officer (to have an awareness of medical conditions impacting on learning) and the community outreach coordinator (to identify and refer to appropriate resources). Clients - who have traumatic brain injuries that are more severe than a concussion - are followed up until the age of eighteen. Once they turn eighteen they transition into the program that services adults (Gillett, 2004). Clinical specialists including occupational therapists, etc. may attend the meetings if they have feedback and input regarding the assessments they conducted. This allows for collaborative identification of limitations and problem solving. Prior to each clinic appointment, a questionnaire is sent to the family to complete and they are requested to bring the client's medical and school records (Gillett, 2004). During the clinic meeting all parties (client, family, service providers and school) identify future goals and strategies to put in place to help achieve these goals (Gillet, 2004).

The evaluation of this program has shown that clients and their families have fared better than those receiving standard care and this was still apparent a year later (McDougall, et al., 2006). These findings are in line with other studies which demonstrated that outcomes for children and youth with TBI are more favourable with "co-ordinated family/community focused" interventions



than standard “clinic based interventions” (Swaine, Pless, Friedman & Montes, 2000; Wade, Michaud & Brown, 2006; Braga, DaPaz & Ylvisaker, 2005).

I am of the opinion that this program appears to be a promising approach as it regards the client (i.e. adolescents’ with TBI) as the central agent. In doing so it speaks to the findings of studies where learners expressed the need to take active roles and participate in decisions regarding their interventions. When decision-making includes both the client and the family it allows service providers to effectively draw upon the client’s assets and goals when planning interventions (Racino & Williams; 1994 & Williams, 2008). The PABICOP program aims to cultivate community connections, which was evident by the collaborative approach employed by involving communities from the point of developing the program through to its implementation and evaluation. Communities (as partners) strengthen the program in that they are in touch with local resources and what is feasible in terms of service delivery. Community involvement may result in an increased sense of ownership of the program and hence allows it to be more sustainable. Further strengths of this program include role clarification of team members, with key personnel appointed to co-ordinate the hospital-to-school transition as well as guide the learner and family to navigate and access the needed support services. The program also allows for the continuity of care as once adolescents reach adulthood there are mechanisms in place for them to access services on the next level of support provision.

It is however, important to note that there have been some issues with implementation in certain counties such as Ontario, Canada. This was due to differences in resource allocation, resulting in counties lacking the necessary services or having limited services with long waiting lists. I thus pose a question, is such a program feasible and sustainable in developing contexts (like South Africa)? This is an important consideration given that developing contexts are often characterised by systemic issues such as limited human and financial resources and poor collaboration between government departments and other role players.

#### **2.6.4.2. “School Transition and re-Entry Program” (STEP)**

Glang et al. (2008) conducted the back-to-school study in the USA. This study explored the factors that enabled the identification of children with TBI for special education services in school. The findings of this study illustrated that promoting hospital to school transition was a key mechanism to promote the provision of special education services for children with TBI. Study findings served as a catalyst for the design, pilot and testing of a hospital-to-school



transition service for children with TBI and their families (i.e. STEP) (Glang et al., 2008; Ally, 2013).

Phase 1 of STEP included focus groups with parents, hospital and school staff working with children with TBI and their families and consultation with research groups in the area. The findings of Phase 1 served a basis for the development of a hospital-to-school transition service. This service was piloted. The outcomes of the pilot indicated that intervention needed to be incorporated into the existing discharge planning for children with TBI. A randomized control trial of hospital to school transition then took place with financial support from the government as well the needed support from local hospitals (space for participant recruitment and data collection), department of education (allowing full time staff to partly work as facilitators) and school boards (allowing teachers to complete surveys and interact with facilitator, family and students on individual educational plans (Ally, 2013).

STEP has 3 components (i.e. parents/families, facilitator and the hospital staff) with the child with TBI as the focal point. Participants included children between the ages of 5-18 years with a moderate to severe TBI. Seventy children were enrolled in the study. They were randomly allocated to a control or the facilitator/ STEP group. Children in the control group only received standard rehabilitation and had access to special education services where applicable. In addition to information booklets, parents of children in the experimental group were contacted by the facilitator (i.e. therapists, school psychologists, school nurses, etc.). The facilitator was trained in the aetiology of TBI and its impact on learning. The facilitator also contacted the teacher to inform him/her that the child had a TBI and conveyed parental concerns regarding their child's return to school. In addition the teacher obtained an information package and the contact information of the facilitator. Parents and teachers completed a pre-injury assessment of behaviour and academic performance. These aspects were re-evaluated at the end of the academic year, at the beginning of the new academic as well as at 12 months post TBI. Children were not asked to complete surveys/assessments. Parents were also provided access to the Brain Injury Partners Website (2010) which offers training materials for parents to become effective advocates of their child (Ally, 2013).

Authors suggested that their preliminary findings indicated that learners in the experimental group tended to be referred for specific educational services and their families displayed less stress after one year. Parents of these learners also reported that they felt more actively involved and overall experienced a greater satisfaction with the service their children received (Ally, 2013).

I am of the opinion that the development of this program is exemplary in terms of parental involvement in decisions seeking to address their children's needs. However the study did not include the perspectives of the learner. Whilst it may seek to provide support in alignment with parent and professional perspectives of the learner's needs, it lacked cognisance of the differences between the "observer" and the "insider" perspective and experience. This raises questions about such a programme's ability to rightly provide the support that is needed for the learner to successfully re-enter and participate in school. Whilst the programme addresses the development of the parents' capacity to act as advocates for their child needs, it fails to develop the advocacy of the learner (the main beneficiary of service provision). This does not resonate with the perspectives of learners on school transition practices, where it was found that they felt that in order to facilitate school re-entry and participation it was important that they be involved in the school transition process. This was highlighted by learners, as it allowed them to experience a sense of ownership (Mealings & Douglas, 2010). This is supported by Feeney and Ylvisaker (1997, p.238) who state that "opportunities for choice and control can increase the individual's level of participation ... and improve subjective ratings of the activity". The program is a good example of inter-sectoral collaboration, with clearly defined roles. However, its implementation relies on the support of a well-resourced and co-ordinated context. This again questions the feasibility of such a programme in low-resourced contexts such as South Africa, where the availability and fragmentation of services are still very much the norm.

#### **2.6.4.3 School re-entry and participation within the South African context**

Learners post TBI may experience barriers to learning. Therefore within South Africa, the school re-entry and participation of a learner following the onset of a new disability such as TBI would be guided by the policy on Screening, Identification, Assessment and Support (SIAS). Overall this policy aims at allowing children with barriers to learning, including those with disabilities, to exercise their right to basic education and access support in local schools as far as possible (DoBE, 2014).

SIAS (DoBE, 2014) is one of the incremental ways set out to operationalise the main elements of an inclusive education system as outlined in White Paper 6: Special Educational Needs-Building an Inclusive Education and Training System (DoE, 2001). SIAS further seeks to align with the United Nations Convention on the Rights of Persons with Disabilities as ratified by the South African government in 2007, specifically Article 24, which affirms "that persons with disabilities have a right to access an inclusive, quality, free, primary and secondary education

on an equal basis with other young people in the communities in which they live” (DoBE, 2014, p.12).

SIAS (DoBE, 2014) was developed over a period of 10 years and included the consultation with role players within the educational sector, organisations for and of people with disabilities - and academics. A key principle of this policy is that the organisation of support for a learner shifts from the sole focus on the category of disability to a focus on learner support. This encompasses the level and nature of support given the essential needs of the learners and their context (DoE, 2014). It should be mentioned that whilst this research does focus on a certain category of disability (i.e. TBI), it is clear that TBI is a complex condition that results in multiple difficulties. I therefore support the need for further research in the field of TBI and return-to-school processes, to allow for an increased understanding of how these sequelae of multiple difficulties affect the adolescent’s ability to re-enter and participate in school post TBI.

The policy acknowledges that parents and teachers play a central role in decision making and support processes. The responsibility for the provision of the education support includes:

- District-based support team (DBST): refers to a team at district level who provides leadership to ensure “schools are inclusive centres for learning, care and support”. Inclusive education is hence promoted through: “training; curriculum delivery; distribution of resources; infrastructure development as well as through identifying, assessing and addressing barriers to learning” (DoBE, 2014, p.7).
- Special school resource centres (SSRC): described as “special schools equipped to accommodate learners who need access to high-intensity educational support programmes and services, as well as providing a range of support services to ordinary and full-service schools” (DoE,2014, p.9).
- Full service schools (FSS): defined as “ordinary schools that are inclusive of all learners in terms of their cultures, policies and practices. They provide support to all learners irrespective of their background, culture, abilities or disabilities, their gender or race. These schools will be strengthened and orientated to address a full range of barriers to learning in an inclusive education setting to serve as flagship schools of full inclusivity” (DoE,2014, p.8).
- School-based support teams: refers to a team at a school level who co-ordinates support to the school, teachers and learners. This team is also known as an” institution-level support team” (DoBE, 2014, p.9).

The policy further seeks to clarify admission criteria to special schools in an attempt to ensure that learners are not denied access to special schools based on the severity of their disability. It

further seeks to outline how these learners' educational needs should be supported. It encourages that the policies, culture and practices in ordinary schools are welcoming to all learners (DoBE, 2014).

SIAS provides a framework that seeks to standardise the procedures to identify, assess and provide additional support to learners, thus maximizing their participation and inclusion in school (DoBE, 2014). A summary of the stages of the SIAS process as outlined in SIAS (DoBE, 2014, p. 27-28) is outlined in the table below.

**Table 2.1: Summary SIAS PROCESS, Chapter 6: The Process of Screening, Identification, Assessment and Support (SIAS) (DoBE, 2014, p.27-28)**

<p><b>STAGE 1: THE INITIAL SCREENING GUIDED BY THE LEARNER PROFILE</b></p>
<p>(1) Teachers screens all children on admission as well as in the beginning of each phase (i.e. foundation (Grades R- 3), intermediate (Grades 4-6), senior (Grades 7-9) and further education and training (FET) phase (Grade10-12)) and record their findings in the Learner Profile (LP). This information is captured in the Learner Unit Record Individual Tracking (LURITS) System.</p> <p>(2) Supplementary documentation will be used to gather applicable information, e.g. reports from parents, teacher(s) currently involved with the learner, Health and Disability Form (which is completed by the relevant health professionals specifically for learners who require additional support from the onset, such as learners with disabilities): See Appendix A.</p>
<p><b>STAGE 2: IDENTIFYING AND ADDRESSING BARRIERS TO LEARNING AND DEVELOPMENT AT SCHOOL LEVEL</b></p>
<p>(1) When a learner has been identified through the initial screening as being vulnerable or at risk (as pointed out in the Learner Profile), it is the responsibility of the teacher to assume the role of a case manager, driving and coordinating the support process.</p> <p>(2) The parent/care-giver and the learner (from the age of 12 as far as possible) must be involved throughout in the decision-making process of the SIAS. The teacher will be guided by the SIAS forms, starting with the completion of the Support Needs Assessment form 1 (SNA1) (see Appendix B). The teacher captures the following information in the SNA1 in</p>

collaboration with the parent/care-giver:

- a) The areas of concern: The teacher verifies his/her findings by discussing them with the parent/care-giver and also determines whether there has been any earlier intervention.
- b) An inventory of the strengths and needs of the learner across a broad spectrum of areas is put together.
- c) On the basis of the information gathered, an individual support plan is formulated to support the learner, and a review date is set. Such plans should be reviewed at least once a term.
- d) If the support given by the teacher proves to be ineffective, he/she will involve the School Based Support Team (SBST) by making an appointment and presenting the needs of the learner to the team for discussion.

(3) The SNA 2 form guides the SBST when a learner is referred to them.

- a) A review is done of the teacher's identification of barriers and the interventions applied.
- b) A plan of action through which the teacher/school could strengthen the support (with the help of in-house specialists and/or teachers who have a wide range of experience) is formulated.
- c) The support plan is captured and put into action. It must have a review date on which progress (or lack of progress) will be discussed. On the review date the plan is adjusted and the SBST may decide that a higher level of support is needed in which case the District Based Support Team (DBST) is asked to assist. Such plans should be reviewed at least once a term.
- d) In exceptional cases where direct referral is required to ensure the safety of a learner who is vulnerable to abuse, deviation from the standard procedure is permitted.

### **STAGE 3: IDENTIFYING AND ADDRESSING BARRIERS TO LEARNING AND DEVELOPMENT AT DISTRICT LEVEL**

1) The SNA3 form guides the DBST in their intervention strategy to:

Review the action plan of the teacher and SBST and use the *Guidelines for Support* to determine the level of support needed (\*i.e. low, moderate or high) and to *determine the decision on how support is to be provided to the learner. The DBST is guided by the following principles:*

- *The learner's right to be supported in his/her current school or the school closest to his/her home.*
- *Irrespective of the level of support required, every effort should be made to make the support available to the learner in his/her current/closest school.*
- *Consideration of accessing resources such as Outreach Programmes from Full-Service Schools (FSS) and Special School Resource Centres (SSRC).*
- *The outplacement of the learner to an alternative setting to access a specialised support should be the last resort.*

The DBST puts a further plan of action together for the learner and/or school, based on the information available. The plan will spell out a suitable support package and include:

- Planning and budgeting for additional support programmes determined in SNA 3
- Resource and support-service allocation to school and learner
- Training, counselling and mentoring of teachers and parents/legal care-givers
- Monitoring support provision.

\*See Appendix A for descriptions of low, moderate and high support

The implementation of SIAS (DoBE, 2014) was scheduled for implementation between 2015-2019 with the following objectives being met incrementally, i.e. the training of teachers on SIAS, the establishment and monitoring of SBST and DBST, the expansion of assistive devices and educational assistive device resource centres, the finalization of funding and post provisioning norms and the filling of posts for specialist professionals to provide outreach to schools (DoBE, 2014). This policy has a crucial role in facilitating support provision (at school and district levels) for learners experiencing barriers to learning in ordinary and special schools. However the Report on the Implementation of Education White Paper 6 in Inclusive Education (an overview for the period 2013-2015), has demonstrated that the Department of Basic Education has experienced challenges with meeting its said objectives and this has thus impacted on the capacity of schools, district level and provincial structures to effectively implement the policy (DoBE,2015). Examples of current shortcomings include government's inability to complete the SIAS training for the targeted number of teachers and where teachers are trained it is often limited to a once off two days of training. This appears limited given the competencies in identification, assessment and classroom based interventions teachers should have to serve as

the main case manager of the development and implementation of the learner's support plan (Inclusive Education, 2017). Other challenges include the fact that the finalization of funding and post provision (i.e. the assigning of personnel to schools and other levels within the Department of Education) has not been completed. This impacts the staffing needed to adequately implement the policy and provide the needed support to learners (DoBE, 2015).

The policy does provide specific guidelines for providing support during the "being at school" phase, i.e. the pathway to follow once the learner is back in the school system. However it fails to provide clear and practical guidelines with regards to the "organisation of the going back to school" phase, i.e. how service providers should initially prepare and assist a learner with a newly acquired disability following an illness or injury to re-enter school. It alludes to the fact that should a learner acquire a new disability and require intervention within the department of health that a team member from the department of health should complete the Health and Disability form and forward this onto the SBST/DBST. However there are no clear guidelines regarding specific time frames by when this should occur (for e.g. prior to discharge or just following discharge). Detail on additional activities (e.g., scheduling of team meetings, school visits, etc.) that should accompany the completion of this form is further lacking.

There are no clear guidelines with regards to who supports the learner during their period of recuperation at home. Nor is there detail on activities that could be done during this time to prepare the learner for school re-entry. There is no mention of who should assume the role of the case manager for the transition back to school, other than designating the teacher as the case manager of the child or youth who is already active in the school system. It is not clear who informs the teacher about the learner's condition, strengths, needs and the possibility of hidden difficulties which only become apparent over time as the scholastic demands increase on the learner.

In summary, South African guidelines could include explicit identification and explanations detailing the roles and tasks of the team members in the health and education departments regarding preparing and supporting such learners in their transitions from hospital (i.e. health sector) to school (i.e. the educational sector). To facilitate support services that are relevant and responsive to the needs of these learners as beneficiaries of these services, it is important to align the tasks that team members undertake as part of their support roles with the support needs of these learners. This further supports the need for a study within a South African context that seeks to explore the insider perspective of learners with TBI as a means to illuminate their support needs to facilitate their school participation.



## **2.7 A NEED FOR STUDIES EXPLORING THE INSIDER PERSPECTIVE OF LEARNERS WITH BRAIN INJURIES**

The literature review illustrated the knowledge gap pertaining to school transitions post TBI in the African context. It reflected that research on school re-entry and continued participation has been based on the observer perspective and their experiences have contributed to the development of school re-entry programs for adolescent learners following recent TBI. There is thus a need for further research which seeks to include the perspectives and experiences of the main beneficiary of such school transition and support services, i.e. adolescent learners with TBI. This is crucial as it is in alignment with the Department of Education's (1997, vi-vii) vision of inclusive education, as a "process that respects learners and values them as partners in teaching and learning". Furthermore it will allow for greater alignment between learners' needs and the support services that are currently provided and thereby optimizing their school participation. This "inclusion and participation is essential to human dignity and to the enjoyment and exercising of human rights" (UNESCO, 1994, p.18).

Occupational therapists are identified as one of the "duly registered health professionals specifically trained to assist learners who experience neurological barriers to learning" (DoBE, 2014, Form DBE 126, p.2). Occupational therapists are concerned with optimising participation in valued occupation (Rodger, 2010). In the context of school participation and as outlined in SIAS (DoBE, 2014, Form DBE 126, p.2), occupational therapists contribute to the team's efforts by assessing the "impact of the neurological barriers on the learner's ability to participate meaningfully and productively in the learning process". Occupational therapists are further involved in providing advice on support in and adaptations to school related tasks and the learning environment to optimize a learner's school participation. A key principle underpinning occupational therapy intervention is that of working client-centred. In the context of this study, this specifically relates to working learner-centred whereby the learner's needs and priorities remain at the fore of all interventions (Rodger, 2010). It is hence necessary for occupational therapists to have an in-depth understanding of learners with TBI's personal experiences of school participation post TBI. Despite this need, the review of the literature yielded minimal studies within occupational therapy that focused on the experience of adolescents' participation in the age appropriate occupation of school. Of these studies, few could be found that focused on clients' perspectives of their adaptation to their learner roles following the onset of TBI (see section 2.6.2). This reiterates the need for studies that seek to provide the personal perspectives of adolescents with brain injuries.



## 2.8 CHAPTER SUMMARY

In this chapter, the changing paradigms of disability were introduced to the reader, where I explicated my preference for a bio-ecological model of disability as the conceptual framework for this study. The rationale stemming from the view that both the personal characteristics and different systems within a learner's context need to be taken into consideration to allow for a holistic understanding of learners' experience of school re-entry and participation post TBI. Given that occupation may be viewed as the linkage between the person and the environment, I argued that the theory of human occupation was needed as an additional lens through which these learners' experiences could be viewed and understood.

I sought to provide the reader with insight into the multiple ways in which the functioning of the learner and his/her context is impacted by a life altering event such as the onset of a TBI. The developmental life stage of adolescence was described, highlighting the importance of this stage in terms of assisting learners to make sense of who they are and how and where they fit into the world. I introduced the role of resilience in assisting learners to achieve positive outcomes in life amidst challenges (i.e. the onset of a new disability). I further referred to promising literature that advocates for the reconceptualization of resilience from that which is solely in the person to extend to and include the role of the environment and the importance of engaging in meaningful occupation, such as school participation.

The conceptualization of inclusive education within the South African context was discussed. The importance of inclusive education in terms of ensuring that there is transformation towards a South African educational system that upholds the right of every child to obtain a quality education, despite his or her unique needs was highlighted. The literature review also revealed that despite legislative progress, the barriers to the ongoing implementation of inclusive education within South Africa remain challenging.

Barriers to success in school re-entry and participation post TBI as well as factors that support success were also reviewed. Programmes facilitating school re-entry and participation post TBI were highlighted. Whilst these were seen as promising, I discussed my concerns that some of these programmes did not fully include the learner as an equal partner. I furthermore raised questions around the feasibility and sustainability of such programmes within a developing context such as SA.

The next chapter presents the research methodology and will seek to explicate the research design. Detail will be provided on the sampling strategy, methods of data collection, data analysis and theory generation.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **3.1 INTRODUCTION AND OVERVIEW**

Chapter 3 provides an overview of the research methodology. The research was divided into two phases. Phase I consisted of a qualitative multi-case/cross case study that explored perspectives on and the experiences of adolescent high school learners' school re-entry and participation post TBI. When discussing phase I of the research, detail will be provided on the choice of research approach, the sampling strategy, data generation and data analysis methods. Phase II consisted of theory generative methodology for the purpose of developing a practice model. The description of phase II includes specific detail on the steps of theory generation (i.e. concept analysis, construction of relationship statements, model description, model evaluation, and guidelines for the operationalization of the model). The chapter concludes with a discussion of the trustworthiness of the study as well as the relevant ethical considerations.

#### **3.2 RESEARCH DESIGN: PHASE I**

The research approach for this study is situated in the interpretivist (constructivist) paradigm, which seeks to make sense of human experience from the insider perspective, using qualitative methods. This paradigm assumes that "there is no single reality and that each event is interpreted through multiple realities which are context bound", i.e. it is socially constructed (Merriam & Tisdell, 2016, p.9). Thus researchers undertaking interpretivist research do not "find knowledge, they construct it" (Merriam & Tisdell, 2016, p.9). In this study, I as a case study researcher used my experience as an occupational therapist working in the field of neurological rehabilitation, and more specifically the contextual experiences of participants to construct knowledge.

In the interpretivist (constructivist) paradigm, data are generated using personal and interactive means (i.e. qualitative methods) (Henning, Van Rensburg & Smit, 2004). The qualitative methods that were used to capture the voice of the participants in this study primarily included semi-structured interviews.

The choice of a qualitative stance for this study is based on the relationship of the study's aim (i.e. exploring the phenomenon of school re-entry and participation post TBI from the insider

perspective) with the fundamental characteristics of qualitative research. Merriam and Tisdell (2016) and other authors (Creswell, 2009; Marshall & Rossman, 2015) outline these characteristics as:

- A means of exploring and understanding the personal meaning that an individual attributes to a problem and hence tends to portray the intricacy of the situation or context: In this study, meaning was constructed by listening and interpreting the meaning of high school learners' perspectives and experiences of school re-entry and participation post TBI as described in their own words.
- Researcher as primary instrument: I as researcher collected and analysed data.
- Undertaking an inductive investigative strategy: This was done by generating data to progressing to concept building and theory generation.
- Rich description: In this study it included interviews that through the line of questioning attempted to elicit detailed responses from participants about the phenomenon of interest. This, in combination with participant and contextual descriptions and the use of quotes and excerpts, further contributed to the richness of the data. In addition, thick explanation was also provided by means of an in-depth analysis.
- An emergent and flexible study design which is responsive to changing conditions as the study progresses.

The choice of a qualitative research design is further supported by the fact that historically quantitative research has dominated TBI research, and neglected to include children's views of their lives post TBI (Asarnow, Satz, Light, Lewis, & Neumann, 1991; McKinlay, Dalrymple-Alford, Horwood & Fergusson, 2002; Boylan, Linden, & Alderdice, 2009). Using qualitative methods - which focus on the participants' personal meanings - further allows for the voices of vulnerable groups such as those with disabilities, who are often marginalised, to be heard (Brantlinger, Jimenez, Klinger, Pugach & Richardson, 2005). Given that the participants' experiences are rooted in context, this research also sought to obtain the perspectives and experiences of the learner's primary care-giver, the teacher the learner identified as knowing him/her the best and the principal of the school the learner attends (Holloway & Wheeler, 1996).

The design strategy for this inquiry includes a qualitative multi-case study (i.e. collective/cross case study). Merriam and Tisdell (2016, p.38) defines a case study as an in-depth description and analysis of a case/"object of the study" (within a specific context) around which there are boundaries. Determining the boundaries of the case is considered the defining characteristic of a case study (Merriam & Tisdell, 2016). Key features by which a case study may be defined include it being "particularistic" (i.e. focus on a specific phenomenon, situation or event), a "thick

description” of the phenomenon under study and “heuristic (it elucidates the reader’s understanding of the phenomenon of the study)” (Merriam & Tisdell, 2016, p.43). A case may include a person, a program, group, community institution or a policy (Merriam & Tisdell, 2016). In this study a case represents the adolescent learner with TBI, with the learner’s primary caregiver, the teacher the learner identified as knowing him/her the best and the principal of the school that the learner attends as sub units/sub cases embedded within each case. The case study design strategy has been selected as it allows for a focus on a particular phenomenon (i.e. school re-entry and participation in high school, following TBI), in-depth, holistic descriptions and interpretation within context using multiple sources of information (Merriam & Tisdell, 2016; Creswell, 2009). Furthermore, the qualitative case study as a design strategy is commonly used in applied fields of study such as education and health. It is also a good fit when a study aims to answer “how” and “what” questions. This design strategy is particularly useful in instances where there are unclear boundaries between the phenomenon and the context (Yin 2013; Merriam & Tisdell, 2016). A multi-case case study design strategy will be used as it is considered more robust (Yin, 2013). Given that the context is different for each case, multi-case study also allow for analysis within each context and across different contexts and furthermore allow for an understanding of the similarities and differences between cases (Baxter & Jack, 2008).

### **3.3 RESEARCH SAMPLE**

#### **3.3.1 Selection of sample**

Probability and nonprobability sampling are two types of sampling that may be employed. The former allows for the generalizing of the results from the sample to the population from which it is drawn. As “generalization (in the statistical sense) is not the goal of qualitative research”, in this study I made use of nonprobability sampling (i.e. purposive sampling). Purposive sampling is used when one aims to “discover, understand and gain insight and therefore must select participants from which the most can be learnt, i.e. information rich cases” (Merriam & Tisdell 2016, p.96).

Merriam and Tisdell (2016) state that within a qualitative case-study, two levels of sampling usually occur, i.e. selecting the case and then selecting within the case.

### 3.3.1.1 First level of sampling: Selecting the case

The first level includes selecting the case, which in this study includes an adolescent learner with a TBI (See Table 3.1 for a description of the biographic information of learners).

The following criteria were applied to select adolescent learners with TBI to participate in the study:

- Learners within middle and late adolescence as these are learners who would typically be attending high school. The age band was thus 13 to 20 years of age. (Originally, the criterion stated that the age limit would not exceed 18 years of age. This however was increased to age 20, as most learners were older than their peers in a grade. This was due to them having to repeat a grade, given the timing of the TBI in the academic year or their schooling being disrupted by prolonged periods of hospitalization and rehabilitation);
- TBI within adolescence;
- TBI that resulted in a loss of consciousness (i.e. learners with stage 3 mild, moderate and severe TBI were included). See Section 2.3.2 for the description of TBI classification;
- Learners that resided in the 4 districts as classified by the Western Cape Education Department (WCED). These included the four urban districts of the Metro North, Metro South, Metro East and Metro Central and the two rural districts of the West Coast (specifically the Swartland and Saldanha Bay municipalities) and the Cape Winelands. These districts were selected on the basis of logistics (including time and travel costs) related to the fact that at times I needed to conduct more than one interview with each participant;
- Learners who have had intervention by a medical doctor and rehabilitation by member/s of a multi-disciplinary team (e.g. physiotherapy, occupational therapy, speech therapy, social work/clinical/neuro-psychology). (Originally the criterion stated that the learner should have been assessed by a neuro-educational psychologist with the recommendation that he/she should attend school. I decided to include learners who were not formally assessed by a neuro-educational psychologist as most of the potential participants were not assessed due to a lack of access to such team members);
- Learners who have re-entered school (ordinary or special schools) for at least three months post TBI. (Originally this criterion stated that a learner should have re-entered school for more than six months post TBI. I however decided to adjust the time frame to at least three months as not to exclude those participants who had returned to school for this period before completely exiting the school system because, as expressed in their own words, “being unable to cope”. This I felt was important, as by excluding the

personal meanings of these learners could be considered a form of injustice as it further marginalised these learners with disabilities);

- Learners who have attended an ordinary secondary school prior to the onset of the TBI and not have required specialist learning support during their prior school history;
- Learners who have obtained informed consent from his/her parent/guardian and be a voluntary participant; and
- Learners from any racial group to account for cultural and ethnic diversity but who had to be able to understand questions and communicate in English, Afrikaans or isiXhosa (the three predominant languages spoken in the province).

The exclusion criteria included:

- Learners with severe cognitive and language impairments post TBI. The motivation for excluding these learners was supported by the following:
  - Learners should have adequate communication skills to describe the detail of personal experiences of the phenomenon (Terre Blanche, Durrheim & Painter, 2006),
  - There may be difficulty with establishing the extent to which limited responses are due to expressive language difficulties, or due to a lack of poor memory, a lack of insight or a lack of awareness which may impact on the reliability of qualitative accounts given by individuals with severe cognitive and language impairments (Lloyd, Datherer & Kalsy, 2006; Hubbard, Downs & Tester, 2003; Paterson & Scott-Findlay, 2002).
  - To lessen the chance of the richness of data being impacted upon as is illustrated by a qualitative study with survivors of TBI, where it was reported that as the interviews progressed, responses became shorter, more concrete and had a diminished focus (Paterson & Scott-Findlay, 2002).
  - To lessen the risk of me “imposing researcher perceptions and interpretations onto the accounts of participants given that less verbally articulate responses may be more difficult to comprehend” (Goodley, 1996).
- Learners with pre-morbid psychiatric conditions were excluded. This was to ensure that learners’ experiences and perceptions of school re-entry and participation was related to the onset of the TBI (i.e. the focus of this study) and not influenced by pre-existing psychiatric conditions.

To establish if learners had pre-morbid psychiatric conditions, it was necessary to obtain approval from the Departments of Health and Education, consent from the primary caregiver and assent from the learner. This allowed gate keepers in the health sector to

obtain information pertaining to psychiatric conditions from the adolescent learners' health records (including neuropsychological reports where available). Similarly gate keepers in the educational sector obtained such information from the adolescent learner's school records.

**Table 3.1 Biographical data of learner participants**

Participant	Age	Gender	Grade	Type of School at time of interview	Age at Onset of TBI	Severity of TBI	Language	Population	Socio Economic Status
Learner 1	17	Male	11	Ordinary	16	Mild	Afrikaans	Coloured	Low
Learner 2	19	Female	12	Ordinary	15	Severe	English	White	Middle
Learner 3	15	Male	9	SS	14	Moderate	English	Indian	Low
Learner 4	15	Male	9	Ordinary	14	Moderate	Afrikaans	Coloured	Low
Learner 5	16	Male	8	SS	15	Severe	English	Coloured	Low
Learner 6	18	Male	12	Ordinary	17	Severe	English	Coloured	Middle
Learner 7	20	Female	Left school in Grade 10	Ceased schooling	15	Severe	English	Coloured	Low
Learner 8	16	Female	10	SS	15	Severe	isiXhosa/English	IsiXhosa	Low

SS= Special School

### 3.3.1.2 Second level of sampling: Selecting within the case

The second level of sampling included selecting a sample within the case, i.e. determining who will be interviewed, what observations will be made and which documents will be reviewed within each case. This is important to allow for the system to be sufficiently bounded (Merriam & Tisdell, 2016).

#### a) Determining who will be interviewed

In this study, in addition to the adolescent learners with TBI, their primary care-giver, school principal and the teacher identified by the learner as the teacher that knew the learner best and who was involved in their school transition post TBI were selected. These individuals were selected as they were key stakeholders involved in the school transition process post TBI and could hence be regarded as information-rich participants.



The following criteria were used to select possible primary care-givers of adolescent learners with TBI to participate in the study:

Primary care-givers had to:

- Reside in the above-mentioned districts of the Western Cape;
- Be the primary person caring for the learner;
- Be able to understand questions and express themselves in English, Afrikaans or isiXhosa; and
- Be a voluntary participant.

See Table 3.2 for a description of the biographical data of primary care-givers of learners with TBI.

**Table 3.2: Biographical data of primary care-givers of learners with TBI**

Participant	Age	Relationship to Learner	Highest Level of Education	Employment Status	Marital Status	No of children	Language	Population	Socio Economic Status
Primary Care-giver 1	40-50	Mother	Grade 10	Home-executive	Married	3	Afrikaans	Coloured	Low
Primary Care-giver 2	50-60	Mother	University Degree	Employed	Divorced (single parent household)	3	English	White	Middle
Primary Care-giver 3	40-50	Mother	Grade 12	Home-executive	Married	5	English	Indian	Low
Primary Care-giver 4	50-60	Grand mother	Grade 10	Employed	Married	3	Afrikaans	Coloured	Low
Primary Care-giver 5	40-50	Mother	Grade 12	Un-employed	Married	3	English	Coloured	Low
Primary Care-giver 6	40-50	Mother	Grade 12	Self-employed	Married	3	English	Coloured	Middle
Primary Care-giver 7	40-50	Mother	Grade 10	Self-employed	Married	3	English	Coloured	Low
Primary Care-giver 8	30-40	Mother	Grade 12	Un-employed	Divorced (single parent household)	3	isiXhosa/ English	IsiXhosa	Low

The following criteria were used to select possible teachers of adolescent learners with TBI to participate in the study:

Teachers had to:

- Teach at the ordinary school that the learner returned to post TBI or teach at the special school that the learner was transferred to post TBI;
- Be the teacher who is most familiar/knows the learner the best. Each learner was requested to provide the name of the teacher they felt knows them the best and assisted them to re-participate in school;
- Be able to understand questions and express themselves in English, Afrikaans or isiXhosa; and
- Be a voluntary participant.

The following criteria were used to select possible principals of adolescent learners with TBI to participate in the study:

Principals had to:

- Be the head of the ordinary school that the learner returned to post TBI or the head at the special school that the learner was transferred to post TBI;
- Be able to understand questions and express themselves in English, Afrikaans or isiXhosa; and
- Be a voluntary participant.

See Table 3.3 for a description of the biographical data of educators (i.e. teachers and principals) of learners with TBI.

**Table 3.3: Biographical data of educators (i.e. teachers and principals) of learners with TBI**

Educators of Learners	Gender	Years of teaching experience	Type of School	Language	Population
<u>Learner 1</u> • Teacher • Principal (current) • Principal (former)	Female Male Male	20 years 25 years 30 years	Ordinary Ordinary Ordinary	Afrikaans Afrikaans Afrikaans	Coloured Coloured Coloured
<u>Learner 2</u> • Teacher • Principal	Female Female	22 years 25 years	*Ordinary *Ordinary	English English	White White
<u>Learner 3</u> • Teacher • Principal • Teacher • Principal	Female Male Female Male	12 years 18 years 10 years 20 years	*Ordinary *Ordinary SS SS	English English English Afrikaans	Coloured White White White
<u>Learner 4</u> • Teacher • Principal	Female Male	22 years 30 years	Ordinary Ordinary	Afrikaans English	Coloured Coloured
<u>Learner 5</u> • Teacher declined to participate • Principal • Teacher • Principal	- Male Male Male	- 16 years 15 years 30 years	- Ordinary SS SS	- English English English	- Coloured Coloured Coloured
<u>Learner 6</u> • Teacher • Guidance Counsellor	Female Male	6 years 18 years	*Ordinary *Ordinary	English English	White Coloured
<u>Learner 7 and Learner 8</u> Teacher and principal declined participation					

SS= Special School

\*= government schools that are administrated and largely funded by a governing body of parents and alumni.

Historically these were known as white only schools.

#### b) Determining what observations to conduct

Observations could be viewed as semi-structured and had to be recorded in field notes directly after interviews. These observations were generally descriptive and included descriptions of participants, settings (i.e., the physical setting and people in the scene and their roles), activities or behaviours of participants. Observation data that were collected had to remain cognizant of the research objectives. That is, a focus on observable data that sought to explore the enablers and barriers to school re-entry and participation post TBI (see section 3.4.2 for further detail on semi-structured observations).

#### c) Determining what documents to review:

The criteria for selecting documents that would be reviewed included:

- Documents for which consent (and assent) were obtained from participants
- Documents for which approval had been obtained from relevant health and educational authorities (with the exception of public documents).

- Personal records (e.g. learners' medical and school records) that could provide data in line with the research objectives and hence serve to supplement other data generation methods (i.e. interviews and observation) (Nieuwenhuis, 2007; Marshall & Rossman, 2015).

(See section 3.4.3 for further detail on documentation).

### **3.3.2 Description of how the sample was obtained**

- To allow for entry to a site, I made use of gatekeepers. These are key individuals who assisted with introducing me to the participants and hence assisted with accessibility to the field (Creswell, 2013). I contacted the relevant facility managers in the departments of health and education to obtain approval to access records to identify potential participants for the study (July-September 2015). Staff members (mainly occupational therapists and physiotherapists) at these facilities initially identified and approached possible participants who met the selection criteria (January 2016-September 2017). Staff members shared the objectives of the study firstly with the primary care-giver and then with the learner with TBI (i.e. a minor) and asked if they were interested in participating in the study. They were further asked for permission for their contact numbers to be given to me to make initial contact. Sites included: i) in-patient and out-patient rehabilitation centres such as the Life Rehabilitation Centre and Intercare Rehabilitation Centre, ii) Tertiary Hospitals such as Tygerberg and Groote Schuur Neurology Departments, iii) Special Schools such as Vista Nova, Jan Kriel, Eros, Astra, Paarl School and v) the Western Cape Education Department inclusive education support teams.
- I then made the initial contact with the primary care-giver of each of the learners where I obtained verbal consent for the learner to participate should they so choose, thus giving me the go-ahead to make contact with the learner to obtain assent. I simultaneously then obtained verbal consent from the primary care-giver to partake in the study. During this initial contact I obtained verbal assent from the learner to participate in the study and finalised the logistics regarding the date, time and venue of the interviews. (See Section 3.8 on ethical considerations which will explicate detail on obtaining verbal and written consent as well as assent).
- On the day of the initial interview with each learner I obtained the name of the teacher who they felt knew them best and was part of them transitioning to school post TBI. I then contacted the principal of the school and explained the objectives of the study and that I had

been given consent and assent to approach the principal and the identified teacher. Following the telephonic conversation, and as per the request of the principals, I emailed the participant information and consent sheets to the principal and the teachers. I also emailed the semi-structured interview guide to both the principal and the teacher. I was then informed via email whether they would participate and possible dates and times that would be suitable for the interviews to be conducted at the school.

### **3.3.3 Sample size**

Eight adolescent learners with TBI and each of their primary care-givers, teachers and principals were interviewed. Eight to ten data sources/sample units have shown to yield sufficient in-depth understanding of a phenomenon where more than one interview is envisaged with each participant (Seidman, 1991). Furthermore Hammel, Carpenter and Dyck (2000) propose that the quality and completeness of the information obtained should determine the sample size. The final sample size was therefore determined by data saturation from the interviews and this was indicated by the sample units yielding no new information (i.e. point of redundancy) and through collaborative discussion with my study supervisors who are knowledgeable of the research design employed in this study (Lincoln & Guba, 1985; Merriam & Tisdell, 2016).

## **3.4 DATA COLLECTION**

Interviews, observation and documentation are commonly used sources of evidence in case study research (Henning, Van Rensburg & Smit, 2004; Merriam & Tisdell, 2016). In this study, the data collection methods were multiple including face-to-face semi-structured interviews, semi-structured observation (recorded in field notes) and documentation. According to Yin (2013, p.121), “multiple data sources develop converging lines of inquiry thus through data triangulation helps to strengthen construct validity of a study.”

### **3.4.1 Interviews**

The primary method of data collection in this study was the research interview, which is the interchange between the researcher and the participant in which there is a focused dialogue on research related questions (deMarrais, 2004). Interviews are used when behaviour, feelings and people’s world view are not observable and when past events (such as school re-entry post TBI) are not repeatable (Merriam & Tisdell, 2016). The use of interviews is in line with the interpretivist (constructivist) paradigm, and is thus a good fit with this study as it seeks to

uncover the in-depth meaning and understanding of the participants' behaviour and experiences, albeit through the interpretation and construction of me as the researcher (Denzin & Lincoln, 2011).

Types of research interviews may be classified according to their level of structure, i.e. highly structured, semi-structured and unstructured. Highly structured interviews are characterised as interviews with pre-determined wording and order of questions and is usually used for obtaining information on demographic data (age, gender, etc.). The pure use of such interviews often hinders the researcher from accessing the participants' meanings and understanding of the phenomenon under study and results in the participant merely providing responses to the researcher's preconceived notions. Unstructured interviews include the use of open-ended questions and are used when the researcher does not possess sufficient knowledge of the phenomenon to ask pertinent questions and is often used as a starting point for formulating questions for subsequent interviews. Semi-structured interviews may be seen as the midpoint between the before mentioned types of interviews, as it allows for more flexibility than the highly structured interview, as the interview guide may include both more structured questions for obtaining specific data (e.g. demographic) and less structured questions (Merriam & Tisdell, 2016). The researcher is also not limited to the exact wording or ordering of questions and this allows the research to adapt within the context of the interview. For example, the researcher may adapt the vocabulary used within the interview to ensure it is within the participant's frame of reference or probe for further detail and explanation, which will in turn, improve the quality of the data obtained (Merriam & Tisdell, 2016). The chosen type of interview employed in this study was semi-structured interviews given that it allowed the researcher to obtain the specific demographic information from each of the participants, yet allowed the researcher to make adjustments during the course of the interview. A further motivation for using semi-structured interviews, is that participants' persistent cognitive and or communication difficulties post TBI could affect their ability to provide their input in response to unstructured open-ended questions (Mealings & Douglas, 2010).

It is also important to be cognizant of some of the limitations of interviews such as:

- "Individual levels of cooperativeness, articulateness and perceptiveness vary
- Flexible wording and ordering of questions may impact on the responses of participants and hence lessen the comparability of the responses
- Important and key topics may mistakably be omitted
- Biases may be introduced by the researcher's presence" (Creswell, 2009, p.51).

In order to ensure the focus of the research, an interview guide was used for each category of participants. I developed the questions of the interview guide for each category of participants (see Appendices C, D, E, F) on the basis of the sub questions of the study, my clinical experience and a review of literature on TBI school re-entry and participation (Turner, Ownsworth, Cornwell & Fleming, 2009; Merriam & Tisdell, 2016). The interview schedules focused on:

- Learners with TBI: planning the school re-entry (when, who, what), the enablers, barriers to school participation.
- Parents/primary-care-givers: planning the school re-entry (when, who, what), the enablers, barriers to school participation.
- Teachers and principals: planning the school re-entry (when, who, what), the enablers, barriers to school participation, views on inclusion in mainstream schools.

The interview guide was adjusted based on the outcomes of a pilot investigation. The pilot investigation was undertaken in June 2016 in the form of a semi-structured interview with the use of an interview guide with one adolescent with TBI, his/her parent/primary care-giver as well as the teacher and principal, who met the selection criteria. The initial purpose of the pilot was to: i) find as many as possible practical arrangements that might negatively influence the data collection process, ii) identify ambiguous or unclear questions in the interview guide and iii) obtain feedback from participants after completion of the pilot study regarding how the interview could be better structured to facilitate optimum data collection and the overall success of the research (Kim, 2011). Upon completion of the pilot, the interview guide for the learner was refined in the following ways:

- Certain questions were reworded to lessen confusion. For example, “Were you seen by a learner support teacher?” “If yes, can you explain his/her role in helping you at school?” The learner did not have an awareness of the jargon “learner support” and so was not certain what I meant by this. This question was rephrased as “There are teachers that are there to give a learner extra help when they need it, did you have such a teacher? If yes tell me about what this teacher did to help you when you came back to school?”
- Multiple questions were removed as participants tended to only answer one aspect. For example on the interviewer guide the question stated “Who helped you to prepare for going back to school and what did the person do or say?” The learner answered the first part of the question only and the two questions were hence changed to two separate questions: “Who helped you to prepare for going back to school? What did this person/s do or say to help you to prepare to go back to school?”

- Specific questions were added to allow for further exploration in subsequent interviews. For example, during a learner's interview he shared that meetings were held with members of the rehabilitation team and his parents regarding his discharge and plans for the future, including returning to school but that he was not part of this process. I hence added a question to explore if other learners had such meetings and if they were involved in the meeting and what their opinion was about this.
- Questions and probes were stated in such a way that the person could not respond with a mere 'yes' or 'no'. For example during an interview with a learner, "Would you call your school a positive place to be?" became "What does coming to school mean to you?"
- Leading questions were limited as far as possible to avoid imposing my assumption on the participant. For e.g., not asking the learner "Do you think your difficulties in school are due to the brain injury (i.e. thinking skills- memory, concentration/behaviour/physical difficulties or emotional difficulties)?" Instead I made use of an alternate line of questioning such as the "devil's advocate" (Merriam & Tisdell, 2016, p.119). For example, "Some people would say that when returning to school after a traumatic brain injury there may be some challenges. What would you tell them?"

Upon completion of the pilot, I planned to adapt my interview style in the following ways:

- I allowed the participants, specifically the learners with TBI (who have cognitive impairments) time to process and reflect what is asked of them.
- I used the line of questioning to refocus participants, when they appeared to be going on a tangent. (Memo: Pilot Study Findings, 2016)

Given that learner participants had mild to moderate cognitive impairments and some had decreased verbal abilities, a combination of guidelines put forward by Boylan et al. (2009), Lloyd et al. (2006), Paterson and Scott-Finlay (2002) and Nind (2008), were applied during the interview process. These guidelines specifically pertain to:

- the structuring of the preliminary meeting to establish rapport and negotiate the time and venue of the interview as well as to obtain a general idea of the learner's abilities so that the question style can be adapted accordingly;
- techniques used to assess if the learner had adequate insight into their injury and their resultant difficulties prior to the commencement of the interview (e.g. I used a technique as described by Hensel, Rose, Kroese and Banks-Smith (2002)) which involved asking the adolescent five questions, which focused on the purpose of the



interview, the positive and negatives of participating in the research, the number of interviews and withdrawal from the research. Where the adolescents were able to answer three of the five questions correctly this was indicative that the adolescent's level of insight was sufficient. This is however subjective and only acts as a guide and was used in combination with reviewing the learner's medical/school records to obtain his/her baseline cognitive functioning as well as by obtaining collateral from the gatekeeper that had assessed them);

- the selection and use of creative techniques applicable to the learner's circumstances and impairments (e.g. drawings, essay writing, vignettes, keeping diaries or the use of photographs);
- the importance of obtaining collateral information from family members regarding learners' patterns of fatigue and signs that they are over stimulated;
- the need for flexibility in terms of the rescheduling or continuation of interviews at another time;
- the need for the researcher to be organised; and
- guidelines on how to best structure questioning, i.e. that questions with the highest priority in terms of meeting the research objectives be asked first to avoid over tiring/over stimulating the learner, questions should be expressed in a clear, concise and positive manner, that no more than one question should be asked at a time and that silences should be tolerated to allow learners to be reflective or provide time to process the question. All of the participants were interviewed with the use of an interview guide. In an initial interview there was one learner (whom his care-giver described as very introverted) who frequently answered questions by either saying "yes" or "no", or through gesturing such as nodding his head side-to-side, up or down or shrugging his shoulders despite me trying to probe further. This particular learner in the preliminary meeting shared that he enjoyed drawing and showed me a drawing his mother had framed. I subsequently decided to use drawing to facilitate the conversation in a follow-up interview. However the learner felt that as copying (i.e. not drawing from inspiration) was what he enjoyed, he would not know what to draw. He therefore opted not to use this method of interviewing and instead opted for his mother sitting in the interview as a source of comfort.

#### **3.4.1. The Interview Process**

After obtaining telephonic consent and assent, the first interview for the learners was a preliminary meeting with them and their primary care-giver which provided an opportunity for

them to familiarise themselves with the procedures and to help establish rapport (especially in adolescents who were anxious). Written consent and assent was also obtained (see Appendices G.H, I, J, K). This interview took place at the learners' homes. Where possible I conducted a 60-90 minute interview with each of the primary care-givers on the same day as the preliminary meeting. I decided to interview the primary care-giver first, as I felt that this would provide me with a good overview of the transition process for each respective learner and would hence, where necessary, allow me to probe specific areas with the learner.

On another day, this was followed by one 60-90 minute interview or two 30-45 min interviews, dependent on the learner's levels of fatigue and concentration. These interviews were either conducted in the learner's home or in a private area at the learner's school. There were interviews in which primary care-givers were present as per the request of the learner. Teachers and principals were interviewed on the school premises. One 60-90 minute interview was conducted with each of the principals and teachers. There were certain interviews where the principal and teacher requested that their interview be conducted jointly. All interviews were conducted at a time and place that was convenient for the participants. I conducted the English and Afrikaans interviews as I am proficient in both languages. There was one isiXhosa learner but she and her care-giver opted to conduct the interview in English. There was thus no need for the isiXhosa translator to be used as was originally planned.

Post-interview debriefing occurred, thus allowing the participants to provide feedback about the research process and for me to clarify observations made during the interview (Creswell, 2009). Interviews were audiotaped (with consent from all participants) excluding the initial rapport building and the post interview debriefing (Turner et al., 2009). Field notes complemented the information obtained from the interviews and served to record my semi-structured observations. These recordings were completed directly after the interviews whilst my observations and impressions were recent enough for me to recall. The verification of the transcripts included emailing the transcribed interviews to the participants and requesting them to verify the text. Copies of the transcriptions were posted to two of the participants who did not have access to email. The verification process of the text of these two transcripts was completed telephonically. Only seven learners, seven primary care-givers, five principals and five teachers responded. They all agreed with the content of the transcriptions and no changes were suggested.

### 3.4.2 Observation

In this study observations were used as a source of data. Observation utilizes the five senses and intuition to gather information about the aspects of the context in which the research was conducted (Nieuwenhuis, 2007; Merriam & Tisdell, 2016). Observation was used as:

- it allowed me the opportunity for a first-hand account of the natural context in which the phenomenon under study occurs, thus increasing my knowledge and understanding of the context;
- it served as a way of triangulating data (i.e. together with interviews and documents) to substantiate the study findings and allowed for a holistic interpretation of the phenomenon under study (Merriam & Tisdell, 2016).
- it also allowed me to collect data about that which may not be revealed by what is specifically said during an interview as a result of the participant not wanting or feeling free to discuss a particular topic.

My stance as an observer was one of a non-participant observer. I took notes of everything that I saw, heard or felt in the interviewing context (i.e. school/home) without becoming a participant within the setting as is the case with participant-observation (Nieuwenhuis, 2007). Where I obtained permission from the principal, I mobilised around the school to obtain a general sense of whether there were any observable enablers and barriers to school participation within the school context (i.e. I focused on collecting data that were in line with the research objectives).

Examples of observations included:

- the physical setting-structure (i.e. terrain of school grounds, stairs/ramps, toilets, location of classes, technology, objectives or resources available at the school),
- people in the scene and their roles: e.g. number of learners in a class, presence of teaching assistants, etc.

Observation may be structured on a continuum from being highly structured to less structured. Highly structured interviews include pre-determining who and what will be observed and include the use of a coded sheet. I opted to make use of less structured observations (i.e. semi structured observations). My decision was influenced by the following statement:

“... where to focus or stop action cannot be determined ahead of time. The focus must be allowed to emerge and may in fact change over the course of the study” (Merriam & Tisdell, 2016, p.140).

Observations were recorded in field notes directly after the interview before I talked about it (e.g. to supervisors) to “avoid diffusing the importance of the observations” (Bogdan & Biklen, 2011, p.130). I attempted to keep field notes as descriptive as possible including descriptions of the participants, setting, activities or behaviours of the participants and they also included a component of reflection. Reflective comments included my feelings, reactions, hunches, speculations and provisional interpretations (Merriam & Tisdell, 2016).

Memos (including preliminary analysis and interpretations) were captured on ATLAS.ti 7<sup>®</sup>. An example of using a memo to record my thoughts and reflection of the pilot study conducted is provided. The screen shot below (see Fig. 3.1) shows the use of memos in this study.

The screenshot shows the ATLAS.ti Memo Manager interface. The top window title is "Memo Manager [HU: TBI Cases 14 03 2017]". Below the title bar are menu options: "Memos Edit Miscellaneous Output View". A search bar is present with the text "Search (Name)".

Name	Type	Grou...	De...	Size	Author	PDs	Families
Additional Literature to consult	Memo	0	0	124	Super	-	-
My assumptions as researcher	Memo	0	0	13...	Super	-	-
Phase II central concept: possibilities	Memo	0	0	4066	Super	-	-
Pilot Study Findings	Memo	0	0	1151	Super	-	-
Policies to consider	Memo	0	0	768	Super	-	-
Possible Study Limitations	Memo	0	0	1076	Super	-	-
Reflections on chosen conceptual framework	Memo	0	0	586	Super	-	-
Reflection on reasons to undertake research	Memo	0	0	12...	Super	-	-
Research Question	Memo	0	0	1556	Super	-	-
Theory Generation- a good match?	Memo	0	0	1655	Super	-	-

Below the table, there is an "Interview Guide" section with the following text:

**Interview Guide:**  
 \* Need to reword certain questions to lessen confusion as a result of jargon used:  
 For example, rephrase **learner support teacher** perhaps refer to **teachers that are there to give a learner extra help when they need it**.

\*Removal of multiple questions as to avoid one aspect being answered.

\*Add certain questions to allow for further exploration in subsequent interviews. For example add a question to explore if other learners had team meetings and if they were involved in the meeting and what their opinion was about this.

\*Asking questions and specifically probing in a way that the participant does not just answer yes or no. For eg., "Would you call your school a positive place to be?" perhaps ask "What does coming to school mean to you?"

\*Avoid asking leading questions to avoid imposing my assumption on the participant. For e.g., not asking the learner "Do you think your difficulties in school are due to the brain injury?".

**Interview Style:**  
 \* Allow the participants time to process and reflect what is asked of them.

\* When they appear to be going on a tangent, use the line of questioning to refocus the participant

**Figure 3.1 Example of the use of memos in the study**

### 3.4.3 Documentation

‘Document’ is the umbrella term that encompasses, “a wide range of written, visual, digital and physical material relevant to the study at hand” (Merriam & Tisdell, 2016, p.162). Documents provide knowledge regarding the historical context, provide descriptive information and can track change or development (Glaser & Strauss, 1967). In this study, documents (i.e. medical

and school records) were used as a secondary data source to supplement other data collection methods. For example, an excerpt from a medical record was used to supplement the quote from an interview with a learner regarding her perspective of her school re-entry post TBI. The documents served to confirm the learners' baseline level of cognitive and language functioning needed to participate in the interview. This was one of the study's selection criteria. Documents were further used to provide a biographical description of each learner in accordance with the importance of contextualization for a case study (see Section 4.2).

### **3.5 DATA ANALYSIS**

The data set consisted of transcribed interviews, field notes and documents. Data analysis refers to the process of making sense of the data, i.e. answering the research question (Merriam & Tisdell, 2016). It occurs as part of a simultaneous process with data collection and includes "consolidating, reducing, and interpreting what people have said and what the researcher has seen and read – it is the process of making meaning" (Merriam & Tisdell, 2016, p.202).

Data were analysed using an inductive and comparative analytic strategy. The constant comparative method was used at two stages: i) within-case where each case is "treated as a comprehensive case and of itself" and ii) across cases resulting in a "unified description" across cases (Merriam & Tisdell, 2016, p.234). The constant comparative method includes "comparing a unit of information with the next looking for regularities within the data. These units of information seek to potentially or partly answer the research question(s) and can be as small as a word that describes the participant's feeling about the phenomenon under study or segments of text describing a certain incident" (Merriam & Tisdell, 2016, p.203). The process is one of breaking the data into units and then bringing them together into categories. In the process, the criteria for allocating data to one category or another are more clearly differentiated. Categories are thus built and refined (Glaser & Strauss, 1967; Corbin & Strauss, 2015; Merriam & Tisdell, 2016).

The steps undertaken in analysing the data will be presented as outlined in Merriam & Tisdell (2016, p.204-226).

1. Preparation of the data. This included verbatim transcription of the interview script onto a word document and thereafter checking it for errors or omissions. Field notes that were originally hand-written were typed onto a word document. Memos were created on

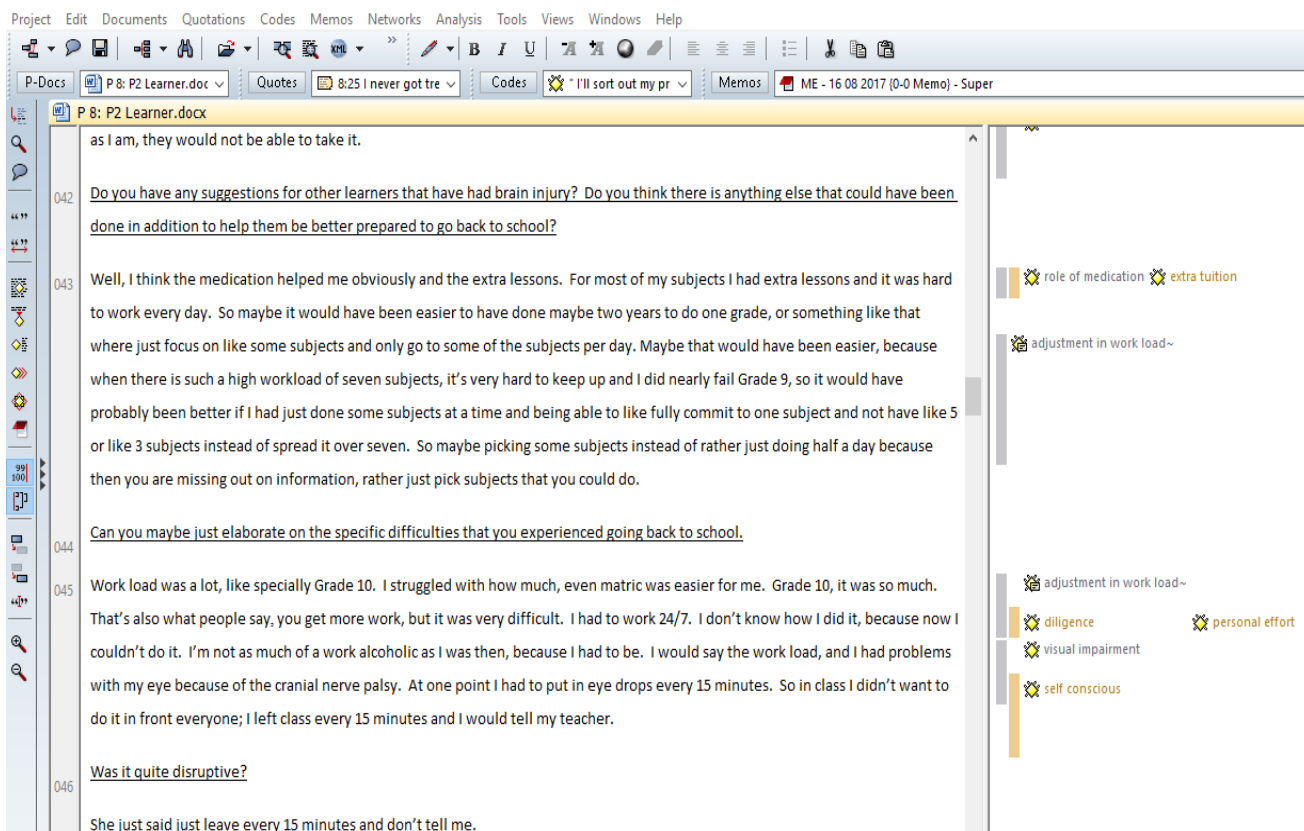
ATLAS.ti version 7, a qualitative data analysis software programme. Verbatim excerpts from personal documents such as hospital and school records (which I was not allowed to copy on site nor remove from the premises to copy) were also typed onto a word document. All data were stored on a pass word protected computer.

2. Organizing the data. Yin (2013) refers to this organization as the case study database. Data were organised and managed using ATLAS.ti version 7, where interview transcripts, field notes and relevant documents have identifying notations that allow for easy retrieval. See Fig 3.2 for a screen shot of how the data set was organised within ATLAS.ti version 7.

Id	Name	Media	Quot...	Location	Author	Families	Modified	Usable	Origin
P 1	P1 Learner.docx	Rich ...	30	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 2	P1 Mother.docx	Rich ...	54	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 3	P1 Principal (f...	Rich ...	38	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 4	P1 Principal a...	Rich ...	39	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 5	P2 Learner.docx	Rich ...	100	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 6	P2 Parent.docx	Rich ...	63	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 7	P2 Principal.d...	Rich ...	30	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 8	P2 Teacher.docx	Rich ...	38	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P 9	P3 Principal (s...	Rich ...	49	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P10	P3 Learner an...	Rich ...	69	My Library	Super		02 11 2017 13:34:07	***	C:\Users\Lee-Ann\Desktop\Trans...
P11	P3 Teacher (sp...	Rich ...	44	My Library	Super		02 11 2017 13:34:07	***	C:\Users\Lee-Ann\Desktop\Trans...
P12	P4 Grandmoth...	Rich ...	61	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P13	P4 Learner.docx	Rich ...	39	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P14	P4 Principal a...	Rich ...	56	My Library	Super		02 11 2017 13:34:07	Yes	C:\Users\Lee-Ann\Desktop\Trans...
P15	P5 Learner.docx	Rich ...	57	My Library	Super		02 11 2017 13:34:07	***	C:\Users\Lee-Ann\Desktop\Trans...

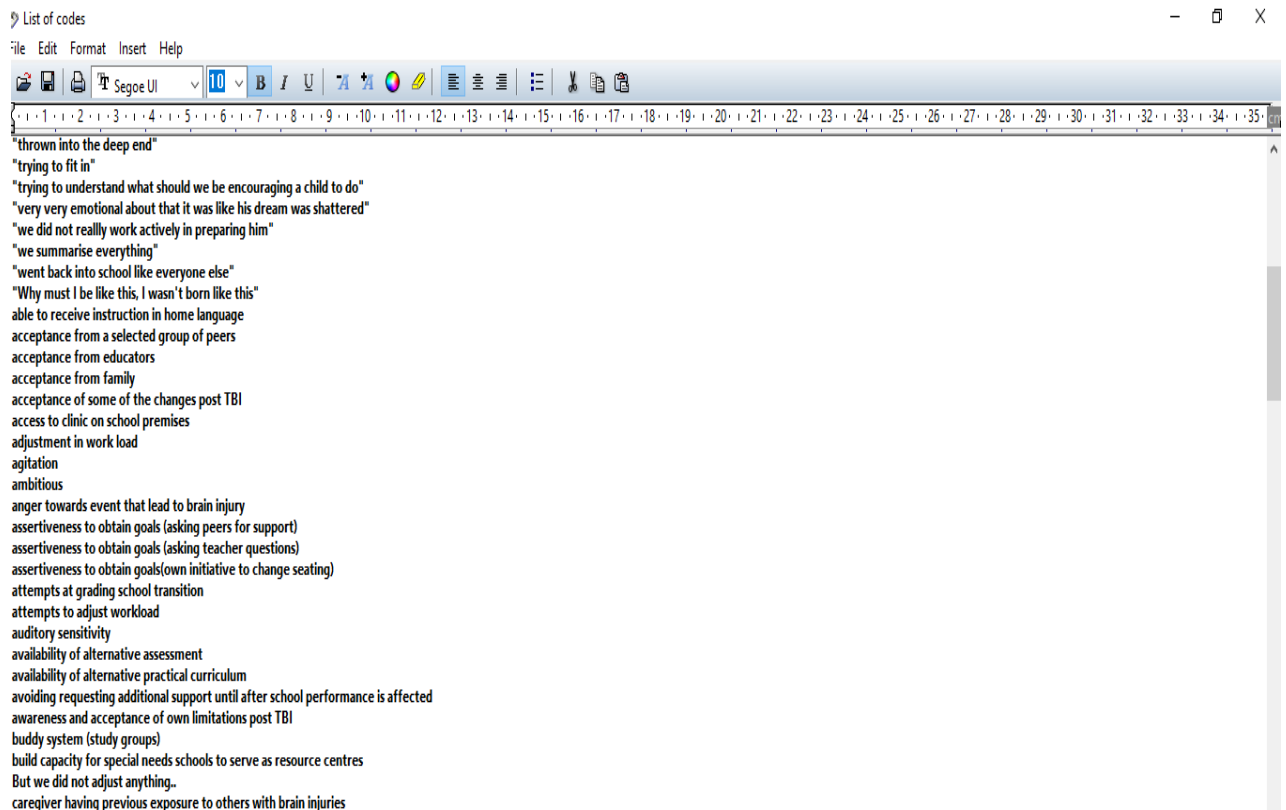
**Figure 3.2: Organisation of data set within ATLAS.ti.**

3. Read an interview transcript, field notes and document collected (e.g. Interview transcript of learner 1, field notes of interview with learner 1 and the medical/school records of learner 1).
4. Open coding – I then for example, took the interview transcript of Learner 1 in Case 1 and highlighted segments of data that were potentially relevant to answering the research question (in ATLAS. ti called quotations). Next to the segment of data (in the right margin) I then made notations (i.e. codes and comments). Codes took the form of exact words of participants (i.e. in vivo codes), my words or a concept of the literature. See example as illustrated in Fig. 3.3.



**Figure 3.3: Identifying data by means of coding**

5. Axial coding - after working through the entire transcript of Learner 1, I printed out a code list and manually checked for duplications, renamed codes, combined and deleted codes. See Fig. 3.4. for example of raw codes.



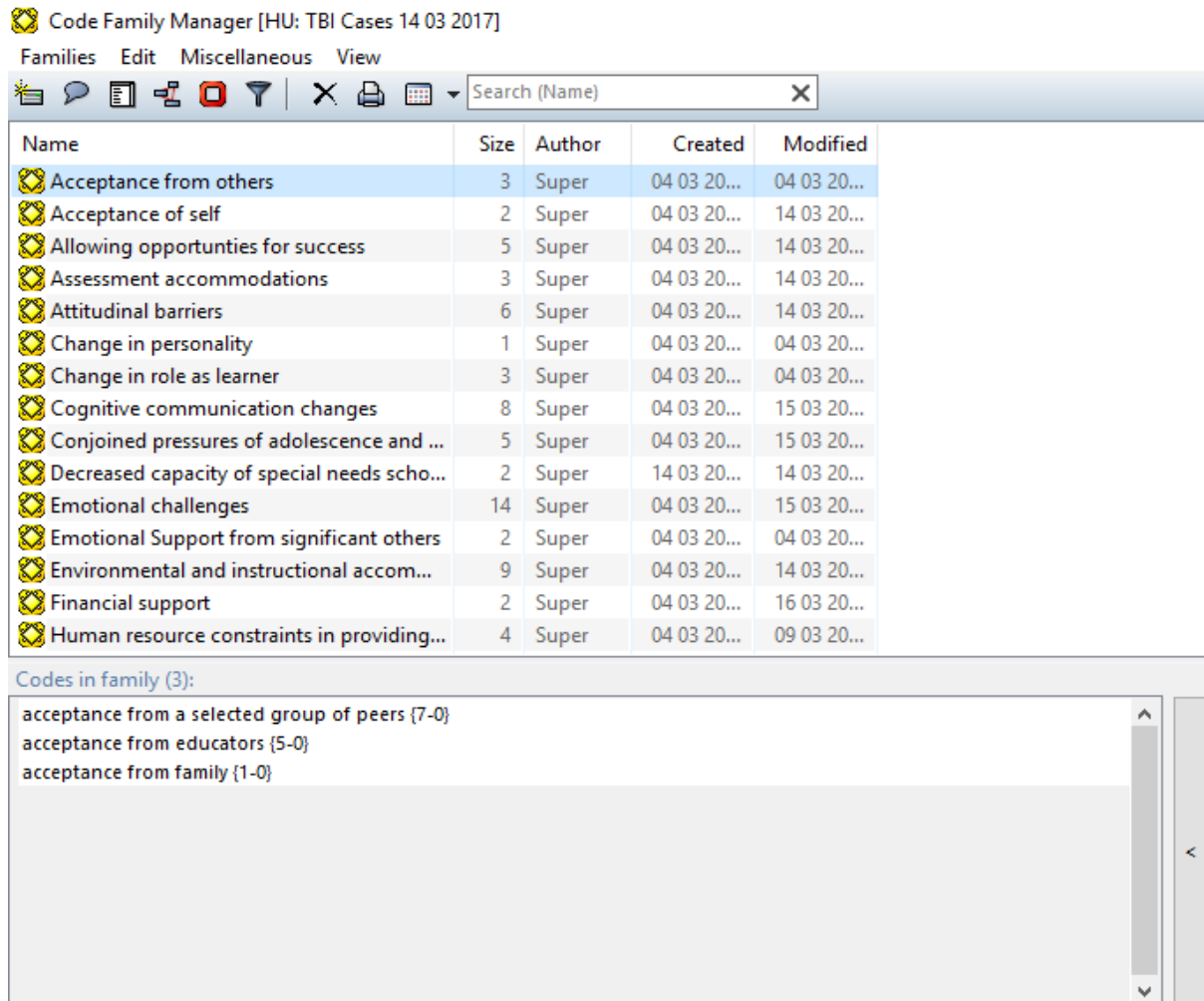
**Figure 3.4: Raw Codes**

I copied and pasted the codes onto a word document. I then grouped those codes together that appeared to link, forming categories. I also kept a separate running list of these categories.

6. I followed the same process as outlined above (3-5) with the remaining sets of data in Case 1 (i.e. interview transcripts and field notes of interviews with primary care-giver, teacher and principal) whilst keeping in mind the previous lists of categories checking whether they were also present in the subsequent sets of data.
7. I then compared the list of categories of all the data sets in Case 1.
8. I merged all the lists of categories of all data sets in Case 1 into one master list of categories. Those categories that held up across sets of data for Case 1 were retained, some categories became sub categories and others were subsumed. Categories were hence refined throughout the process of analysis. This list reflected the recurring regularities/patterns in the study that cut across all sets of data of Case 1. I entered these

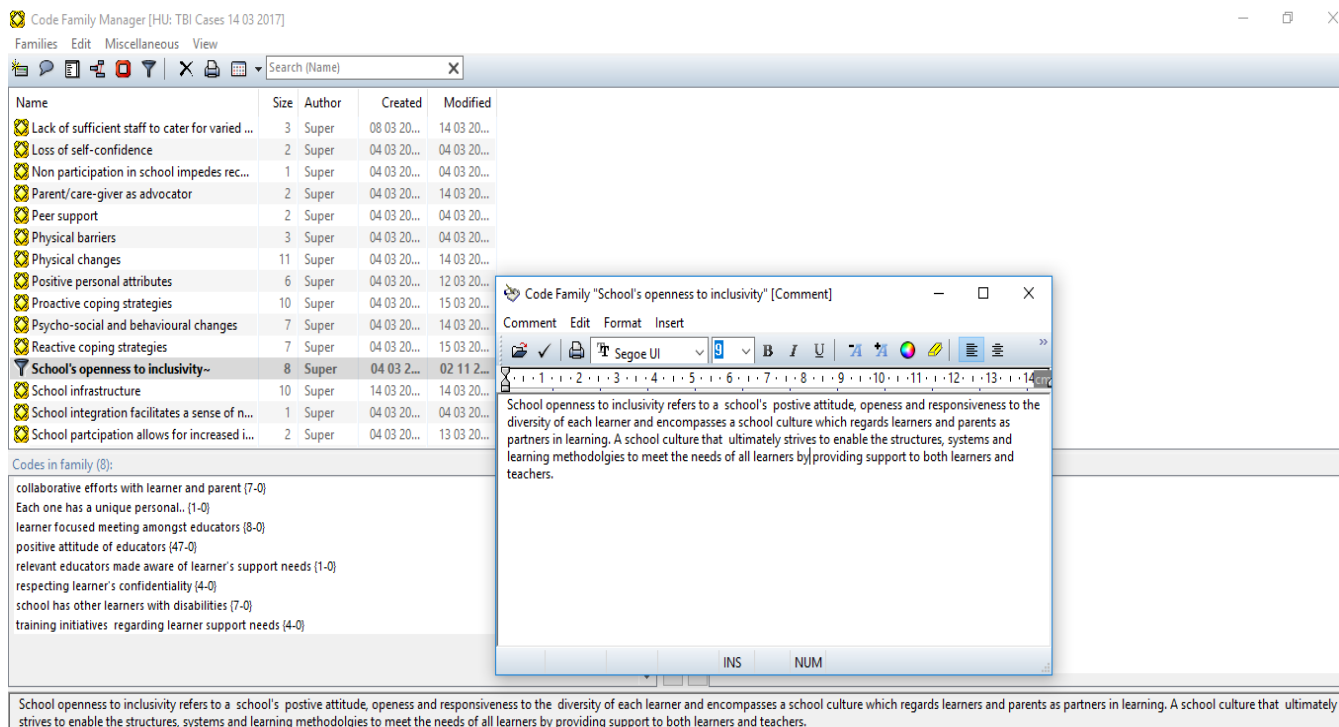


categories into ATLAS.ti 7 (which in ATLAS.ti 7 is called creating “code families”). See Fig. 3.5 for the creation of code families.



**Figure 3.5: Creation of code families**

After creating the code families (i.e. category), I re-read code comments and quotations linked to each code in a family and formulated a descriptive comment for each code family. This is illustrated in Fig. 3.6.



**Figure 3.6: Descriptive comment of code families (categories)**

9. I repeated steps 1-8 for each of the remaining cases (i.e. cases 2-8).

The process outlined above was completed for each case to allow for the case-by-case analysis.

10. The cross-case analysis was then undertaken (Yin, 2013; Merriam & Tisdell, 2016) and comprised the following:

- Each case's main categories were examined to explore the similarities and differences amongst individuals and contexts.
- Commonalities and unique features were found across cases and the data of each case were re-examined to determine shared factors that influence school re-entry and participation and propose personal/contextual features that explain variations.
- Through a process of comparing and merging salient categories, the sub categories and categories that were consistent across cases were then grouped into themes resulting in a unified description of categories and themes across cases. This is displayed in a visual format, using a table which displayed the interrelatedness between the data. (See Appendix L). This will be explicated in Chapter 4 which focuses on the findings.

### **3.6 Theory generation methodology: PHASE II**

The purpose of the second phase was to develop a practice model to prepare and support adolescents in high school participation post TBI.

Theory generation methodology was used in the second phase of the study (Van Rooyen, 2002; James, 2006; Soeker, 2009). It was chosen as a good-to-fit in attaining the said objective of this phase of the study as: i) it allows for the discovery and exploration of a phenomenon, when little is known about it in a specific context (McKenna, 1997), ii) is inductive and allows for the interrelatedness of phenomena to be clarified and described, without imposing preconceived ideas of what this interrelatedness means (Chinn & Kramer, 2015) and iii) the process of theory generation allows for the development of a defined and organised body of knowledge that can be used by a discipline (Walker & Avant, 2015). In order to develop a practice model I combined the theory generative methods promoted by Chinn and Kramer (2015), Walker and Avant (2015) and Dickoff, James and Wiedenbach (1968).

The purpose of the theory, the four levels of theory generation, reasoning strategies applied in this study and the four steps of theory generation (i.e. concept analysis, construction of relationship statements, model description and evaluation, and guidelines for the operationalization of the model) will be discussed in the next section.

#### **3.6.1 Purpose of the theory**

The general purpose of a theory “specifies the context and situations in which the theory applies can be approached by asking, why is this theory formulated?” (Chinn & Kramer 2015, p.188). The purpose of theory in this inquiry is to provide a theoretical framework and a practice model to guide occupational therapy intervention that seeks to prepare and support adolescent high school learners to re-enter and participate in school post TBI.

#### **3.6.2 Level of theory generation**

Walker and Avant (2015) refer to four levels of theory (i.e. meta theory, grand theory, middle range theory and practice theory). Although they specifically outline these levels of theory within nursing practice, applicability to occupational therapy theory is evident, as both disciplines are primarily concerned with patient/client well-being. These four levels of theory are:

- meta theory - “focuses on the philosophical and methodological questions related to the development of a theory base” (Walker & Avant, 2005, p.4). For example, a debate relating to issues such as analysing the purpose of the kind of theory needed in a discipline, or the criteria needed to evaluate theory in a discipline;
- grand theory - refers to “conceptual frameworks defining broad perspectives for practice and looking at phenomena based on these perspectives” (Walker & Avant, 2015, p.4). An example includes Newman (1986) who developed a theory on “Health as expanding consciousness”;
- middle range theory - “fills the gap between grand theories and practice” (Walker & Avant, 2015, p.4). An example includes Murrock and Higgins’ (2009) theory of music and its effects on physical activity and health; and
- practice theory- is a “practice orientated level of theory which comprises of two components, i.e. a goal and actions to meet the goal” (Walker & Avant, 2015, p.6). For example a theory such as: “Occupational self-efficacy: An occupational therapy practice model to facilitate returning to work after brain injury” (Soeker, 2009).

Middle range theory directs the “prescriptions” of practice theory (Walker & Avant 2005, p.6). McKenna (1997, p.114) mentions that “practice theories are very specific in their clinical focus, narrower in scope and more concrete in their level of abstraction than middle range”. In this study middle range and practice theory were blended. This is supported by Walker and Avant (2015, p.17) who state that “useful practice theory emerges when middle range theory is blended with practice or prescriptive theory as the hybrid efforts elevate the resulting practice theory above simple dictates or imperatives for practice”. An objective of this study was to generate a practice orientated level of theory, to improve occupational therapy practice through the development of a practice model which would serve to provide guidelines for occupational therapists to facilitate high school participation of adolescent learners post TBI.

### **3.6.3 Reasoning strategies**

There are different reasoning strategies that are crucial in the generation of theory. In this study the reasoning strategies that were used to formulate the generic statements needed for theory generation include; analysis, synthesis, derivation and inductive reasoning. These strategies enhanced the credibility of the theory generated (Walker & Avant, 2015).

- **Analysis**

Walker and Avant (2015), explain analysis as breaking down the whole into parts to allow for increased understanding. It also examines the interrelatedness of each part to one another and then to the whole. This process allows for the factors that add to the understanding of a phenomenon to be differentiated (Mouton & Marais, 1993). Analysis allows for clearly defined concepts and statements (Walker & Avant, 2015). Concept analysis refers to a “formal linguistic exercise” that determines the attributes/characteristics of concepts (i.e. determines a concept’s structure and function) (Walker & Avant, 2015, p.63). In this study, the identification of concepts occurred through conducting an analysis of the data generated about perspectives on and the experiences of adolescent high school learners’ school re-entry and school participation post TBI. These concepts were then clarified and defined as described in chapter 6.

- **Synthesis**

Synthesis combines separate parts to form the whole (Walker & Avant, 2015). According to Walker and Avant (2015, p.63) concept synthesis is based on “empirical evidence and observation”, may use qualitative, quantitative, literary or a combination of these approaches and is a way of “examining data for new insights that can add to theoretical development”. In this study concepts related to perspectives on and the experiences of adolescent high school learners’ school re-entry and participation post TBI were identified from the data. Synthesis was used to identify statements of relationships between these identified concepts.

- **Derivation**

Walker and Avant (2015) state the purpose of concept derivation is to create new perspectives of a certain phenomenon. They further purport that, “it provides a new vocabulary for an area of inquiry by relying on analogous or metaphorical relationships between two phenomena: one defined and known and one undefined and under explored” (Walker & Avant, 2015, p.75). Soeker (2009, p.51) argued that inductive reasoning is utilised in this process.

- **Inductive reasoning**

Chinn and Kramer (2015, p.216) state that theory generation is inductive as “translation is made from the empiric to theoretic given that the empiric concepts are abstractions of what can be observed or perceived in experience”. These authors further state that provided sound research procedures and processes are employed when using inductive reasoning as a strategy to refine concepts and generate theoretic relationships, the relationships may be considered credible and ready for replication in other settings (Chinn & Kramer, 2015). In this study the experiences of high school learners returning and participating in school were explored and analysed inductively. This was used as a basis from which concepts were developed. There are however, limitations with using inductive reasoning as a strategy in that it is “not possible to observe all instances of a specific event or phenomena, (and) this results in probable conclusions based on supportive evidence” (Mouton & Marais 1993, p.106).

### **3.6.4 Steps of Theory Generation**

#### **3.6.4.1 Concept analysis**

Concepts are considered the foundation of theory construction. The concept’s definition (i.e. structure) and use in theory (i.e. function) therefore necessitate clarity. “Examination of the structure and function of concepts is considered the purpose of concept analysis” (Walker & Avant, 2015, p.163). Concept analysis includes concept identification, definitions of concepts and concept evaluation.

- **Concept identification**

This includes the identification of concepts by reflecting on the themes, categories and sub categories that were generated by the data. A comprehensive understanding of the experiences of school re-entry and participation of high school learners’ post TBI was sought through synthesis. This allowed for the identification of the central concepts upon which the model is based. The central concepts of the model are ‘occupation’ and ‘resilience’. See section 6.2.1 for further explanation.

- Definition of concepts

Concepts are “mental constructions; they are attempts to order our environmental stimuli in a meaningful way. They are categories of information with defining attributes that help to decide which phenomena match the concept and which do not” (Walker & Avant, 2015, p.163). Concept analysis helps to determine these attributes. The identified concepts in this study were defined for the purpose of clarification. This was undertaken by exploring the meaning of concepts from sources that included dictionaries, existing theories and research and the use of the guidelines by Van der Steen (1993) and Wandelt and Stewart (1975) to enhance the consistency of the definitions. A list of related attributes and essential attributes to define the central concepts were then compiled. See Section 6.2.3 for further detail.

- Concept evaluation

Subsequent to the identification and defining of central concepts, “the evaluation of the maturity of the central concepts” through the criteria used by Morse, Mitchum, Hupcey and Tason (1996, p. 388-389) occurred. These criteria included:

- “Concept definitions should be well defined, consistent and cohesive”. In this study dictionaries and relevant contextual literature were consulted to meet this criterion.
- “The attributes of concepts should be clearly identifiable as to provide the determinants for the application of the concept in the context”. See Section 6.2.3 for the list of essential and related attributes of each main concept.
- “The pre-conditions and the outcomes of the concept should be described and demonstrated”. Chapter 7 provides a comprehensive description of the model.
- “The conceptual boundaries should be delineated”. In this study the boundaries were established by determining what does and what does not form part of the concept, which is indicative of the maturity of the concepts (Morse et al., 1996, p.389).

- Concept classification

The concepts were classified using a survey list by Dickoff, James and Wiedenbach (1968). The survey list allowed the main concepts to be distinguished from the related concepts. The survey list included detail on the:

- “Agent (i.e. the person who performs the activity)
- Recipient: (i.e. the person/s who receive the activity)
- Context (i.e. the environment in which the activity is performed)
- Procedures (i.e. how the activity takes place)
- Dynamics (i.e. the energy and drive source of the model)
- Terminus (i.e. the outcome of the activity)” (Dickoff, James & Wiedenbach, 1968, p. 423)

This is further expanded upon in Section 6.2.2.

#### **3.6.4.2 Construction of relationship statements**

Statements are important in generating scientific knowledge and must be formulated prior to explanations or predictions being made (Walker & Avant, 2015). Chinn and Kramer (2015, p.192) state that, “relational statements describe the linkages among and between concepts and often the relationships statements that are uncovered may be peripheral to the core of the theory”. In this study, relationship statements included descriptions of concepts relationships to one another as is outlined in Section 7.3.5.

#### **3.6.4.3 Model description and evaluation**

The following criteria set out by Chinn and Kramer (2015, p. 188-189) were used to describe the evolvment and progression of the model and the structural framework:

- “stating the purpose of this theory (explicates why the model was developed as well as the applicable context);
- the concepts of this theory;
- the concepts defined within the model (i.e. meaning of concepts);
- the nature of the relationships (i.e. statements of relationships between concepts of the model);



- the structure of the theory (i.e. whether model has a partial structure or complete form) and
- the assumptions the theory is built on (basic truth underpinning theoretical reasoning, explicate the values of the theory)". The application of these criteria is included in Section 7.3.

#### **3.6.4.4 Guidelines for the operationalization of the model:**

Chinn and Kramer (2015, p.199) re-iterate the importance of critical reflection to," i) ascertain the theory's adequacy in relation to its purpose and ii) determine how the theory may be used and further developed". I consulted with a panel of experts in the field of qualitative research to evaluate the model. Two of these experts were my research supervisors and two were experts in theory generation. The evaluation criteria as promoted by Chinn and Kramer (2015, p.199-208) were used to reflect on the model:

- "Is this model clear? This addresses the clarity and consistency of the presentation and may be both semantic and structural.
- Is this model simple? This refers to structural components and relationships within theory. The number of relational components determines if a model is simple or complex.
- Is this model general? That is, the scope of the theory, a wide scope of phenomena (generality) or a narrow scope (specificity).
- Is this model accessible? Refers to the extent that the theory is grounded in empirical phenomena.
- Is this model important? This refers to the extent to which the model leads to the achievement of goals in practice, research and education".

The application of these evaluation criteria is included in Section 7.6. In this study the guidelines for the application of the model in practice was developed through inductive reasoning and included recommendations regarding the use of the model in practice.

### **3.7 TRUSTWORTHINESS OF THE DATA**

Merriam and Tisdell (2016) state that since the assumptions and world view upon which the qualitative approach is based differs from that of quantitative research, there is support amongst authors for employing different criteria when determining whether the study has been carried

out with rigour. Conventionally (i.e. in quantitative research) these criteria would include establishing the degree of 'internal validity' (i.e. construct validity/measures what intended), 'reliability' (i.e. same approach, same result), 'generalizability' (i.e. external validity) and the 'objectivity' (i.e. negated researcher influence on data generation, analysis and reporting) (Toma, 2006). Other qualitative research authors such as Lincoln and Guba (1985), refer to these criteria as 'trustworthiness'. They propose that the trustworthiness of a researcher's findings be established through demonstrating its credibility, dependability, transferability and confirmability.

For the purpose of establishing the trustworthiness of the study I applied Lincoln and Guba's Model of Trustworthiness for Qualitative Research (1985, 2011). The model identifies the following four criteria, namely:

### **3.7.1 Credibility (also known as internal validity)**

Merriam and Tisdell (2016, p.242) state that validity (i.e. credibility) implies "truth" and the central question is, "how do research findings match reality and how congruent are the findings with reality?" Capturing an objective "truth" or "reality" is difficult but it can be enhanced through using strategies such as:

- **Triangulation**

Triangulation implies the pulling together of various forms of data in an endeavour to get nearer to the truth (Merriam & Tisdell, 2016). In this inquiry, data sources were triangulated, where data were generated from multiple participants with multiple perspectives, thereby generating data with multiple meanings. I also triangulated data collection methods, by including interviews, observations and document analysis. Triangulation allowed for a thick holistic view of the phenomenon under study.

- **Member checks**

Member checks are sometimes referred to as 'respondent validation' (Merriam & Tisdell, 2016). Member checking includes returning data and/or provisional interpretations to the participants and asking them whether it is plausible (Merriam & Tisdell, 2016) i.e. whether the data accurately described their experiences (Lincoln & Guba, 1985; Maxwell, 2013). As described in Section 3.4.1, member checking was applied by sending the transcripts to participants asking them to verify the text (i.e. data).

- Adequate engagement in data generation  
In this study data were generated to the point of saturation, i.e. a point no new information comes to light as more data are collected (Merriam & Tisdell, 2016). For a further explanation of the application of data saturation, see Section 3.3.3.
- Peer examination  
Peer examination comprised consultation with my two supervisors and two independent qualitative researchers who assessed the feasibility of the findings based on the data. I also received guidance from supervisors who are experts in research design (Merriam & Tisdell, 2016).
- Reflexivity (also known as ‘the researcher’s position’)  
Reflexivity was ensured through use of field notes (see Section 3.4.2) which helped with critical self-reflection regarding my own biography (i.e. a coloured female who comes from a poor socio-economic background, who is a mother and who has occupational therapy as a professional background). As outlined in Section 1.11 (i.e. researcher assumptions) the process of reflexivity also allowed me to be cognizant of my “assumptions, world views, biases, theoretical orientation and relationship to the study that may alter the investigation” (Merriam & Tisdell, 2016, p.249). For example in this study I had to use field notes to reflect on how I approached questions and probes pertaining to the role of parents in their child’s school re-entry and participation and ensured that I did not allow my own view of parenting - and therefore my involvement in my child’s schooling - to influence the interview or analysis process.

### **3.7.2 Transferability (also known as ‘external validity’)**

Lincoln and Guba (1985) define transferability as the degree to which the phenomenon under investigation in a specific context can be transferred to another context. In qualitative research “extrapolation (i.e. modest speculations on the likely applicability of findings to other situations under similar, but not identical conditions)” is proposed instead of generalisation (Patton, 2015, p.713). Merriam and Tisdell (2016, p.256) further purport a focus on providing in-depth descriptions of context and study findings (i.e. “rich, thick descriptions”) and that it is up to the reader to determine the fit of the study findings with their contexts (i.e. reader/user generalizability). I attempted to address the issue of transferability through providing in-depth descriptions of the context, participants and findings with evidence presented in the form of

quotes. Furthermore transferability can be enhanced through the selection of diverse participants as it reflected in Section 3.3.1, Table 2 (Merriam & Tisdell, 2016).

### **3.7.3 Dependability (also known as ‘the concept of consistency/ reliability’)**

Traditionally reliability is based on the notion of a single reality within a study which, when repeated, should yield the same results. However in qualitative research, the focus is on “explaining the world as those in the world experience it” and as there are multiple interpretations of this experience coupled with the fact that “human nature behaviour is not static”, there is no set way of repeating measures to produce replicable results (Merriam & Tisdell, 2016, p.250). Consequently, within qualitative research, there is a focus on establishing ‘dependability/consistency’ rather than ensuring ‘reliability’. Merriam and Tisdell (2016, p, 251) state that central to dependability is “whether the findings are consistent and dependable with data collected”. Therefore, rather than ensuring replicable results there is a “focus on ensuring that given the data collected the results make sense, i.e. they are consistent and dependable” (Merriam & Tisdell, 2016, p.251). Specific strategies to enhance dependability are triangulation, peer examination and investigator position (i.e. reflexivity) as outlined in section 3.7.1. I further made use of an audit trail as a strategy to enhance dependability.

Triangulation (i.e. data from multiple perspectives and data generated using multiple methods) was used to ensure that findings corresponded with the participants realities. Peer examination included discussions with professional colleagues about the preliminary findings and reflexivity included the explication of my position as a researcher and by me stating my assumptions upfront. An audit trail included dense descriptions of the theoretical, methodological (i.e. how data were generated) and analytical processes (e.g. how categories were derived). Memos were used to capture reflections, queries and decisions.

### **3.7.4 Confirmability**

Confirmability is defined as the degree to which the findings and conclusion of the study reflect the data collected (Krefting, 1991; Lincoln & Guba, 1985). It is enhanced through the use of strategies such as triangulation and the audit trail (as explained under sections 3.7.1 and 3.7.3). The guidance/consultation with supervisors who are experts in qualitative research was a means of enhancing confirmability in this study.

## **3.8 ETHICAL CONSIDERATIONS**

### **3.8.1 Respect for participants' rights and dignity**

#### **3.8.1.1 Informed consent:**

Adolescent learners are viewed as vulnerable given the power imbalance between them and the adult researcher and this vulnerability is thought to increase given their traumatic brain injuries (Boylan et al., 2009). Therefore, prior to approaching these learners, informed consent was granted by their primary care-giver (see appendix G). Assent from the adolescents themselves was then obtained (see Appendix H). As the primary care-givers were also participants in this study, informed consent was also obtained from them (see Appendix I). Included in the assent and parental consent, was permission for the gatekeepers and myself to obtain access to the learner's health and school records for the purpose of verifying details regarding their diagnosis as is needed to establish whether they met the study's inclusion and exclusion criteria. Informed consent from the teachers and principals of the adolescent learners' with TBI was only obtained once the learner and primary care-giver provided consent for the teacher and principal to provide information regarding their child's school re-entry and participation post TBI (see Appendices J & K). Complete information regarding the objectives, as well as the research ethical principles to be observed in the research process, were explained to all the participants (Cormack, 2000). It was explained to the participants that permission to take part in the study is voluntary and that withdrawal or refusal to participate would not prejudice them in any way (Brink, 1996). Voluntary participation was achieved by firstly allowing all participants to clarify any doubts related to the research project at hand and information provided to them either verbally or in writing.

Prior to signing the assent form and in the presence of a witness (i.e. their parent/trusted teacher), adolescent participants were given the necessary information and given a chance to clarify doubts related to the research project or information given (De Vos, 1998). It was important for an outside party (the primary care-giver/trusted teacher) to be present because learners with brain injury impairments are a vulnerable group and are therefore susceptible to exploitation (Boylan et al., 2009). The language used on the assent form was clearly written and understandable. As most of the adolescent participants had cognitive and language difficulties it is recommended that consent be seen as a process rather than to a once-off event. It was therefore important that I periodically check the participant's willingness to remain involved especially as consent was obtained in the pre-interview and often more than one interview was

needed (Usher & Arthur, 1998; Lloyd et al., 2006). I remained attentive of non-verbal signs that the participant was fatigued or distressed. In attempt to respect the time of the participants, I informed participants that additional interviews may be necessary should they become fatigued (Boylan et al., 2009).

### **3.8.1.2 Confidentiality and anonymity**

All data gained were considered to be privileged information: no names of persons, hospitals, schools or residential areas were mentioned in the study and I made use of pseudo names throughout. The master copies of participant names and matching pseudo names as well as the audio recordings and transcripts are kept in a locked cabinet. Information that is stored on a computer is protected by a password. In order to establish a confidential relationship with the adolescent, I was not at liberty to divulge any content of the information to their parents, without first obtaining the adolescent's consent (Thomas & O'Kane, 1998; Lewis, 2002).

### **3.8.1.3 Protection from harm**

Steps were taken to protect the participants, i.e. sending the research proposal to the Health Research Ethics Committee of Stellenbosch University (see Appendix M) and the relevant government departments to obtain clearance and permission (see Appendices N & O). The study was conducted according to the ethical guidelines and principles of the International Declaration of Helsinki (2013), South African Guidelines for Good Clinical Practice (2006) and the Medical Research Council (MRC) Ethical Guidelines for research. Measures ensuring the de-identification of participants were adopted and implemented, as this helped with the protection of the participants from harm. The participants were given the right to refuse to divulge any information perceived by them to be confidential/personal and private. This was done to protect and limit psychological harm to the participant. During the research process, emotionally traumatic experiences linked to the participants' injury/onset of the TBI may have been elicited or participants may have become distressed by probing questions. I was attentive to the participants' emotional state and was ready to provide the adolescent and parent with information about support which they could access in their area or refer them onto the adolescents' psychologist/social worker or school counsellor with whom they already have a trusting relationship (Boylan et al. 2009). None of the participants required referral. A debriefing session was provided for the participant at the end of the interview to create an opportunity for the participant to ask questions regarding any uncertainties about the interview. This was done to enhance protection of the participant from psychological harm (Creswell, 2009).

#### **3.8.1.4 Justice**

This was taken into account by being aware of my personal biases.

### **3.9 CHAPTER SUMMARY**

This chapter provided an overview of the research approach, design and the methodology. This study is situated in the interpretivist (constructivist) paradigm. The design strategy included a qualitative multi-case study (i.e. collective/cross-case study). Data generation and analysis were a simultaneous process. Data generation techniques employed in this study included interviewing, observation and document analysis. Using the constant comparative method, data were analysed inductively and comparatively in two phases, i.e. within each case and across cases. Measures to ensure trustworthiness and rigor were outlined. The applicable ethical considerations were explained. The following chapter presents the research findings.

## **CHAPTER 4**

### **FINDINGS**

#### **4.1 INTRODUCTION**

The aim of the first phase of the study was to explore and describe perspectives on and the experiences of adolescent high school learners' school re-entry and school participation post TBI. It was anticipated that this would provide an improved understanding of the enablers and barriers to school re-entry and school participation of adolescent high school learners post TBI.

This chapter includes the main findings obtained from semi-structured interviews held with eight learners with TBI and their primary care-givers, teachers and principals of the high schools they attended. This chapter will commence with an overview of the descriptive and demographic information on each learner, in accordance with the importance of contextualization for a case study. According to Wolcott (2009) there is no single correct way of reporting qualitative data. I have hence decided to provide each finding (i.e. theme with categories and sub categories) with its associated illustrative quotes from interview transcripts to portray the participants' perspectives on school re-entry and school participation post TBI. I make extensive use of quotes to allow the participants to speak for themselves. As this study seeks to provide a voice for the learners with TBI (i.e. explore the insider perspective), the learners' voice is emphasized as far as possible and where applicable is supplemented by that of their primary care-giver, teacher or principal. I then provide a cross-case synthesis of the eight cases. The chapter concludes with a summary of the main findings and includes a visual representation of how the themes relate to each other in order to portray high school learners' experience of school re-entry and school participation post TBI.

#### **4.2 DESCRIPTION OF LEARNER PARTICIPANTS**

This section seeks to elaborate on the basic biographical information of each adolescent learner provided in Section 3.3.1 (Table 3.1) to assist the reader in contextualizing the participants' responses. In order to maintain confidentiality, each participant has been de-identified through the use of pseudonyms. Each biographical description is based on what participants shared during the course of the interviews, as well as on the information I was able to obtain from the learners' medical and school records.



- Learner P1

Learner P1 aged 17, lives in a poor socio-economic area with his parents and two younger siblings in a two roomed house. He sustained a mild TBI. Medical notes revealed the following: right posterior fossa and occipital parietal extradural haematoma and small left occipital extradural haematoma with a Glasgow Coma Scale rating of 13/15. The injury was incurred after he was pushed out of a moving vehicle. At the time of the accident, he was 16 years old and attending an ordinary technical high school. He was admitted to a state tertiary hospital for a period of a week where he was treated by the hospital team which included doctors, nurses, a physiotherapist and occupational therapist. He was discharged to his home, with the recommendation from his doctor that he re-enters school after one month, without out-patient follow-up for any of the therapies he received. Upon discharge the residual impairments that he presented with included changes in attention and concentration, short-term memory, processing speed, fine motor co-ordination, temperament (i.e. decreased frustration tolerance) and personality (e.g. socially withdrawn). Learner P1 returned to his ordinary high school for full days. Prior to the onset of the TBI he was in the top third of his grade and at the time of the interview for this study he had excelled and achieved a position within the top 11 learners in his grade. He did not pursue pre-injury leisure pursuits of playing street soccer, cricket and drawing due to the changes in his functioning post TBI.

- Learner P2

Learner P2 aged 19, lives in a middle income socio-economic area with her mother and two younger siblings. She sustained a severe TBI. Medical notes revealed the following: left parietal haematoma with a Glasgow Coma Scale rating of 6/15. The injury incurred when as a pedestrian she was knocked down by a car. At the time of her accident she was 15 years old and attending a well-resourced (formally known as a Model C) school. She was admitted to a private hospital for a period of two weeks. She was then transferred to a private in-patient rehabilitation unit where she was seen by a team comprising a rehabilitation doctor, nurses, social worker, physiotherapist, occupational therapist and speech therapist for a period of 6 weeks. Upon discharge she continued with occupational therapy, physiotherapy and speech therapy on an out-patient basis which was motivated for and covered by her medical aid scheme. Whilst receiving out-patient therapy she visited her school on a few occasions as a way to re-introduce her to the environment. She resumed school at the beginning of the next school year (i.e. six months post injury). This followed a discussion regarding her school re-entry between the hospital team, mother, school principal and some of her school teachers. She was promoted to the next grade and attended school for full days. By the time she returned to school, residual difficulties that she had included changes in attention and concentration, short

term memory, processing speed, higher-level cognitive functions, personality (i.e. socially withdrawn), vision, fine motor co-ordination and dynamic standing balance. Prior to her injury she was in the top 20 students in her grade. By the time of the interview she obtained code 6 (70-79%) and a few code 5 (60-69%) for her subjects. Following the onset of her TBI she was unable to fully participate in previously enjoyed extra-curricular activities such as tennis and water polo, and she eventually quit these activities. She has applied and has been accepted to study a B Com degree at a university.

- Learner P3

Learner P3 aged 15, lives in a poor socio-economic area with his parents and three siblings in a three roomed house. He sustained a moderate TBI. Medical notes revealed the following: small left frontal extradural and skull base fracture with mild sensorineural hearing loss with a Glasgow Coma Scale rating of 12/15. The injury incurred when as a pedestrian he was knocked down by a car. He was 14 years old and at an ordinary technical high school at the time of the accident, with plans of pursuing a career as a pilot. He was admitted to a state tertiary hospital for a period of four days where he was treated by the hospital team comprising doctors, nurses, a physiotherapist and occupational therapist. He was discharged to his home with the recommendation from his doctor that after four months he resumes school in the new year, without out-patient follow-up for any of the therapies he had received. Upon discharge the residual impairments that he presented with included changes in auditory functioning, attention and concentration, short term memory, processing speed, higher-level cognitive functioning, fine motor co-ordination and dynamic standing balance. He returned to his ordinary high school where he experienced severe headaches and after a follow-up visit with his doctor he was booked off from school for a period of four months. During this time he was seen by an occupational therapist on an out-patient basis once a week and also by a psychologist for an assessment. When he returned to school for a second time he, his mother, teachers, principal and the occupational therapist felt that the school was not a good fit given his barriers to learning and the process for his transfer to a Special School (SS) commenced. He was on the waiting list for the SS for a period of six months before he was accepted. He currently lives in the hostel on the school premises and reports that he is able to participate in previously enjoyed extra-curricular activities such as soccer. Prior to his injury he was obtaining codes 5 (60-69%) and 4 (50-59%) and within his new school environment is obtaining the same grades. However he has opted for more practical subjects and has now altered his career goals in the direction of hospitality.

- Learner P4

The 15 year old P4 lives in a poor socio-economic area with his parents and three siblings in a three roomed house. He sustained a severe TBI. Medical notes revealed the following: poly-trauma, left tentorial subdural haematoma and haemorrhage in left occipital lobe with a Glasgow Coma Scale rating of 6/15. The injury incurred when he was a passenger in a vehicle that collided with another car. He was 14 years old and at an ordinary high school at the time of the accident. He was admitted to a state tertiary hospital for a period of three weeks where he was treated by the hospital team comprising doctors, nurses, a physiotherapist and an occupational therapist. He was discharged home, with the recommendation from his doctor that he attend school after two months. His grandmother, an administrative clerk, who works in the neurology ward in which he was admitted, arranged out-patient follow-up with the occupational therapist and two sessions with a psychologist who works in the ward. Upon discharge the residual impairments that he presented with were changes in attention and concentration, short-term memory, processing speed, higher-level cognitive functioning, fine motor co-ordination and dynamic standing balance. He returned to his ordinary high school for full days, whilst still receiving out-patient occupational therapy once a month. Given the extent of his fractures he is unable to resume participation in extra-curricular activities such as soccer. Prior to his injury he achieved codes 5 (60-69%) and 4 (50-59%). Following the onset of his TBI he has achieved marks ranging between codes 3 (40-49%) and 5 (60-69%).

- Learner P5

Learner P5 aged 16 lives in a poor socio economic area with his parents and two siblings in a two roomed house. He sustained a severe TBI. Medical notes revealed the following: cerebellar haemorrhage, medulla haemorrhage and associated hydrocephalus in right occipital region with a Glasgow Coma Scale rating of 5/15. The injury was incurred when he was shot in the head by a stray bullet (fired between gang members) whilst he was playing soccer with his friends. He was 15 years old and attending an ordinary high school at the time of the accident. He was admitted to a state tertiary hospital for a period of two months where he was treated by the hospital team comprising doctors, nurses, a physiotherapist and an occupational therapist. Following this he was transferred to a state in-patient rehabilitation centre for a period of two months where he was treated by a team comprising a rehabilitation doctor, nurses, social worker, occupational therapist, physiotherapist, speech therapist and psychologist. He was discharged home (with no out-patient follow up), with the recommendation from his occupational therapist that his mother make contact with his high school to discuss the plans for his return to school in the new year. Upon discharge the residual impairments that he presented with included changes in swallowing, speech, attention and concentration, short term memory,

processing speed, higher-level cognitive functioning, temperament (decreased frustration tolerance with aggression) and personality (socially withdrawn), fine motor co-ordination and dynamic standing balance. Six months post TBI, he returned to his ordinary high school where he experienced headaches, found it difficult to negotiate the stairs of the three storey building and experienced episodes of soiling himself due to inaccessible toilets. His parents asked the high school for a referral to the district educational psychologist as they and the learner felt he was not coping. The application for the transfer to the SS commenced and during that time (i.e. 6-7 months) the learner remained home with no out-patient follow up or a structured home programme to follow. At the time of the interview he was attending the SS. Prior to the TBI he was obtaining codes 4 (50-59%) and 5 (60-69%) whereas at the time of the interview there were subjects that he was failing. Prior to his injury he was a keen soccer player, but he has not participated in soccer given his decreased dynamic standing balance and the fact that soccer reminds him of the traumatic incident.

- Learner P6

Learner P6 aged 18, lives in a middle income socio-economic area with his parents and two siblings. He sustained a severe TBI. Medical records show: diffuse axonal injury with a Glasgow Coma Scale rating of 3/15. The injury incurred when he was involved in a motorbike accident. At the time of the accident he was 17 years old and at a well-resourced (formally known as a Model C) school. He was admitted to a private hospital for a period of 5 weeks. He was then transferred to a private in-patient rehabilitation unit where he was seen by a team comprising a rehabilitation doctor, nurses, social worker, physiotherapist, occupational therapist and speech therapist for a period of 8 weeks. Upon discharge he continued with occupational therapy, physiotherapy and speech therapy on an out-patient basis which was covered by a private medical aid. After two weeks, due to his difficulty with adapting to his change in level of functioning and increased dependence on family members, he was admitted to a private clinic to equip him with coping skills. After four and a half months post TBI, he returned to the ordinary high school in the last school term of the year that he sustained his injury. Following a meeting between his mother, principal and some of his teachers and based on a letter of recommendation from his occupational therapist, he re-entered school in a grade lower (i.e. Grade 11) than what he was in at the time of the injury. As part of this graded return to school he attended three subjects (Life Sciences, Physics and Accounting) which were self-chosen and the subjects in which he performed the best prior to his injury. His mother accompanied him to school for the first month to assist him mobilise between classes in the three storey building as the school stated that they would not be held liable if he injured himself. The next year he then re-entered Grade 12 for full days. By the time he returned to school, residual difficulties that he

had included changes in vision, sensation, concentration, fine motor co-ordination and dynamic standing balance. Prior to his injury he was a code 7 (80 -89%) learner and by the time of the interview he returned to this level of academic performance. Due to changes in his physical functioning post TBI, he was unable to participate in valued extra-curricular activities such as hockey and ice hockey.

- Learner P7

Learner P7 aged 20, lives in a poor socio-economic area with her parents and three siblings in a two-bedroomed house. She sustained a severe TBI in a motor vehicle accident. She was the backseat passenger in a motor vehicle driven by her aunt who died as a result of the accident. Medical notes revealed the following: right fronto-parietal haematoma and underlying depressed skull fracture with surrounding oedema and pneumocranium with a Glasgow Coma Scale rating of 7/15. She was 15 years old and attending an ordinary high school at the time of the accident. She was admitted to a state tertiary hospital for 11 days where she was mainly treated by medical practitioners and nurses and intermittently seen by other team members such as a physiotherapist, occupational therapist and speech therapist. She was discharged home with follow-up appointments for further maxillo-facial surgery but no follow up for any of the other therapies she received on an in-patient basis. She returned to her ordinary high school after one month post TBI and at that time she presented with residual difficulties which included anosmia, tinnitus, changes in behaviour (i.e. impulsive, disinhibited, aggressive, argumentative) as well as changes in her basic cognitive and higher-level cognitive functions (including decreased judgement). She returned to school for a period of three months before her mother made the decision that she should stop her schooling due to the learner's inability to cope with the demands in the school environment, repeated incidences of inappropriate behaviour reported by the school (i.e. going to school in socks, rolling up her trousers and back chatting) as well as a negative attitude from a teacher. The lawyers overseeing her Road Accident Fund (RAF) claim referred her to a clinical neuro-educational psychologist who was of the opinion that the learner should be transferred to a SS. The family opted not to pursue this route as the learner was concerned about the stigma of attending a SS and her parents felt that they did not have the means to pay the school and transport fees of this particular school. At the time of the interview the learner was not participating in school or any other pre-vocational/vocational training program, most of her time was reportedly spent at home.

- Learner P8

Learner P8 aged 16, lives in a poor socio-economic area with her mother and two siblings in a one roomed house. She sustained a severe TBI. Medical notes revealed the following: multiple

brain contusions and diffuse axonal injury with a Glasgow Coma Scale rating of 6/15. Her injury was incurred when as a pedestrian she was knocked down by a car. She was 15 years old and at an ordinary high school at the time of the accident. She was admitted to a state tertiary hospital for a period of one month where she was treated by the hospital team comprising doctors, nurses, a physiotherapist and an occupational therapist. Thereafter she was referred to a children's home for further rehabilitation. Here she attended the school linked to the children's home, where she continued with the academic tasks for her grade. Once she was able to mobilise with a walking stick she was discharged home (after six months). Following a discussion between the psychologist based at the children's home and her mother it was decided that she would be transferred to a SS. Upon entering the SS (one year and eight months post TBI) she presented with the following: residual difficulties that included changes in language (i.e. pragmatics), dynamic standing balance, fine motor co-ordination, temperament (decreased frustration tolerance) and personality (socially withdrawn). At this school she continued to receive physiotherapy and speech therapy. She also had access to a clinical psychologist. At the time of the interview the learner's mother was completing the application for her daughter to be transferred to the ordinary school that she attended prior to the TBI. The learner's academic record reflected that she obtained codes 5 (60-69%) to 7(80% or more) for her subjects and is now achieving similar results. Given her changes in functioning she has thus far been unable to return to her extracurricular activity of netball and has not resumed her leisure pursuit of sewing.

#### **4.3 PRESENTATION OF FINDINGS**

The findings of the analysis are discussed in terms of the themes, categories and sub-categories that are related to participants' perspectives and experiences of high school learners' school re-entry and school participation post TBI. To ensure brevity and to limit repetition, the themes, categories and sub categories that will be presented are those that reflect a unified description across cases.

Five themes emerged from the categories. Holding to the study's endeavour of providing a voice for the learners with TBI (i.e. explore the insider perspective), the themes were named using the words of the adolescent learners when they conveyed their experiences and perspectives of school re-entry and participation post TBI. These themes include:

- Theme One: “Kind of changed as a person”: Change in former sense of self
- Theme Two: “School means getting further to where I want to be”: The meaning and value of participating in the occupation of school.
- Theme Three: Trying “to get back into the swing of things”: Strategies used to adapt and resume participation in school.
- Theme Four: “Carrying on and pushing through”: Journey of personal growth and perseverance.
- Theme Five: “It would have helped to have support”: Support needs for re-entrance and participation in school post TBI.

#### 4.3.1 Theme one: “Kind of changed as a person”: Change in former sense of self

Theme one and categories are presented in Table 4.1.

**Table 4.1: Theme One**

Theme One	Categories:	Sub-Categories
“Kind of changed as a person”: Change in former sense of self	<ul style="list-style-type: none"> <li>• Change in functional abilities and skills</li> </ul>	<ul style="list-style-type: none"> <li>• Change in physical functions</li> <li>• Change in mental functions</li> <li>• Change in interpersonal interactions and relationships</li> </ul>
	<ul style="list-style-type: none"> <li>• Change in the role as learner</li> </ul>	<ul style="list-style-type: none"> <li>• Change in academic performance post TBI</li> <li>• Change in the level of participation in non-academic related activities</li> <li>• Change in the level of participation in extracurricular activities</li> <li>• Change in scholastic goals and future vocational goals</li> </ul>



Overall this theme reflects the participants' perspectives and experiences on the changes they experienced post TBI. These changes were experienced in functional abilities, skills and roles (specifically the role of learner) which ultimately resulted in a change in the ways learners make sense of themselves. As participants explained: *....after my accident I kind of changed as a person (P2 Learner, line 39)*

*A lot have changed. I can't use my right leg anymore, my right arm... (P5 Learner, line 62)*

*... and everything just changed due to the traumatic brain injury – short-tempered person and a very emotional person that feels like no one cares, and all of that things Miss, like that was just to be alone, that doesn't want to face the world, all of those things Miss – it really changed me (P8 Learner, line 31)*

#### **4.3.1.1 Change in functional abilities and skills**

This category is representative of the change in learners' sense of self, based on the changes in physical, mental and the social areas of functioning post TBI.

##### **4.3.1.1.1 Changes in physical functions**

This subcategory conveys descriptions of the changes in physical functions that learners experienced post TBI. These include changes in sensory function, gross and fine motor abilities and physical appearance. Additionally participants refer to other complications of TBI (e.g. headaches and incontinence) that affect the learners' functioning and school participation.

- **Changes in sensory function**

These physical changes included changes in sensory function including visual, auditory, taste and smell: As one learner, his mother and teacher stated:

*I had double vision (P6 Learner, line 113)*

*He had double vision throughout. When he left X (referring to the rehabilitation centre) he still had double vision... (P6 Mother, line 114)*

*His one side of his eye also was loopy and he had to wear a patch over his eye to make the double vision stop. So he did struggle, for example, looking at the board (P6 Teacher, line 18)*



- **Changes in gross and fine motor abilities**

Learners experienced visible changes in terms of gross motor (e.g. balance and walking) and fine motor abilities (e.g. writing). These changes impacted on their ability to fulfil tasks linked to their role of learner. At times these physical changes resulted in learners comparing themselves to their peers who had not experienced a loss in abilities and this impacted on their self-concept. This is captured by the following quotes:

*I'm a very slow writer now. I find like I can't keep up with all the notes. I did try to do like some points and I always missed out and I would like skip pages and think I would come back, but I never did. I'm a very slow writer and quite untidy. Like my friends are faster than me in writing (P2 Learner, line 51)*

*I see myself different in a way of like - what can I say – like, I'm limping; they (referring to the peers at her previous high school) can walk properly, they can walk and run. I can't do that, Miss (P8 Learner, line 132)*

- **Changes in physical appearance**

Learners shared that they experienced changes in their physical appearance post TBI. Examples include shaven heads/short hair to allow for brain surgery, permanent scars following the onset of the TBI, and the use of assistive devices (e.g. walking aids and eye patches). These changes in physical appearance impacted on the way they viewed themselves and on their perceptions of how they were viewed through the eyes of others. This is captured by a learner and her teacher:

*I had an eye patch and short hair – I must have looked crazy (P2 Learner, line 37)*

*She was terribly upset, she didn't want people to look at her and she wouldn't take off the eye patch and her hair! (P2 Teacher, line 45)*

Learner P2 further attributes her change in physical appearance post TBI, to her peers' non-acceptance. She implies that during this developmental stage, image and specifically appearance is important to facilitating adolescents to fit in and be accepted by their peers. This is reflected by her comment:

*I think definitely one thing was the way I looked. I never..., because obviously the eye patch and the short hair ..., I know it's wrong to say it's the way I looked that not a lot of people liked me, but in that age group a lot of people are very picky about who they talk to and things (P2 Learner, line 92)*

- **Other complications of TBI**

Learners mentioned other complications of TBI that impacted on their general functioning and school participation. The most common of these included frequent headaches and fatigue. Two learners alluded to incontinence as a complication post TBI.

The impact of frequent headaches was reflected by a learner and his mother:

*I used to get headaches like halfway through the day (P3 Learner, line 52)*

*So like in February they called us every Monday, every Monday he goes to school they phone us to say he's got this headache, so that went on for February. So we went back to the doctor so the doctor said we must put him off again until June (P3 Mother, line 43)*

One learner shared that she had to deal with incontinence and this made her feel like she had regressed in terms of her development which is reflected by her comparison of herself to a baby.

*I was like a baby...I was wearing a nappy because in hospital I had a catheter, but then just because I had the catheter for a long time, I couldn't control my urine and my number two, everything Miss (P8 Learner, line 15)*

#### **4.3.1.1.2 Changes in mental functions**

This subcategory conveys descriptions of the changes in mental function that learners experienced post TBI. Mental functions refer to “functions of the brain, both global functions and specific mental functions” (WHO, 2007, p.46).

- **Changes in global mental functions**

Most learners reported changes in the global mental functions, specifically consciousness, energy, temperament and personality (including a change in self-confidence). These changes

learners reported impacted on their confidence in themselves and their abilities. Learners further reported that changes in their mental functions further impacted on their participation in life situations including school and social participation.

Some learners expressed that the changes that they experienced in their functioning post TBI impacted on their self-confidence:

*So I was quite self-conscious about how I looked, how I walked, my marks weren't that good and I tried so hard. When I had like the eye patch and everything, I was not confident and I felt like no one wanted to know me because of the way I looked, which wasn't actually true. But I was set on like I look like a loser and why would anyone want to talk to me (P2 learner, line 92)*

*I wasn't really confident about going to school. I didn't know if I would be able to cope still with all of the work (P3 learner, line 4)*

An example of the impact of a change in global mental functions on school participation was illustrated by a learner and his mother when sharing how change in his endurance levels impacted on his ability to participate in a full school day upon his return to school:

*...the second week when I came, after every period my mom would come get me at the classroom, helped me to the next class – three periods a day (P6 Learner, line 64)*

*In the beginning he still had to adjust with the times – it was a little bit long for him, (P6 Mother, line 64)*

The impact of changes in global functions on social participation was reflected by the changes that learners experienced in temperament (i.e. decreased frustration tolerance) and personality (i.e. becoming more introverted) post TBI. A change in temperament is echoed by a learner:

*I was rude to my sister. She likes to make jokes; she likes to be a funny person, then I get frustrated and then I want to hit her, but my mommy said no (P5 Learner, line 66)*

This learner's mother noted that her son displayed a decreased frustration tolerance and appeared to be angered by his condition:

*And he got so frustrated and angry with the condition he's in, because he said "why must I be like this, I wasn't born like this ..." He was angry. He was so frustrated and angry ... oh jitte. We had to deal with that as parents. If he had to stand up, his mood is angry, he scolded, he's frustrated.*

*He had that – I can't explain it what kind of personality he had, but it wasn't our child. He was angry at everything (P5 Mother, lines 52-58)*

A change in personality is conveyed by a learner and echoed by the principal of the school she attended:

*I think before my accident I used to be a bit more social and like confident as well obviously. I was more social and more funny and kind of different. But, social is definitely one, like now I'm more shy and reserved (P2 Learner, line 95)*

*Her personality was very different; she was far more outgoing (P2 principal line, 52)*

- **Changes in specific mental functions**

Changes that were experienced in specific mental functions included that of attention, memory, emotion, psychomotor functions, perception, higher-level cognitive functions and mental functions of language (including reception and/or expression of spoken and written language). These changes impacted on learners' participation in school as well as on the completion of their activities of daily living and their instrumental activities of daily living.

A change in attention and concentration as well as a change in psychomotor functions (including agitation and restlessness) impacted on learners' ability to complete school related tasks as sitting down and working proved difficult. Work now required more time and demanded that some learners work in environments in which there was minimum distraction. This is captured by a learner, his mother and his teacher:

*Concentration, takes longer with my work [Konsentrasie, vat langer met my werk] (P1 Learner, line 155)*

*There must be silence around him. That's why I say to you, if he is busy with something he wants no one around him. [Daar moet stilte wees rondom hom. Dis waarom sê ek vir u as hy besig is met iets, hy soek niemand rondom hom nie] (P1 Mother, line 63)*

*He cannot focus, he cannot sit still for long, that was always his problem, fidget, stand up, and then the guy goes out, but we knew that, that pattern [Hy kan net nie fokus, hy kan nie lank stil sit nie; dit was maar altyd sy probleem, vroetel, opstaan en dan gaan die ou uit, maar ons het dit mos geken, daai patroon] (P1 Teacher, line 09)*

Most learners experienced changes in memory which resulted in them having to spend more time learning information and it impacted on their ability to independently do previous tasks such as shopping or basic meal preparation. This is reflected by two learners and their primary care-givers:

*I had to go over things a few times to remember it [Ek moes `n paar keer oor die dinge gaan om dit te onthou] (P1 Learner, line 91)*

*I can now see if he asks me for help or I send him to the shop, he comes back and asks me or he will forget something [Ek kan mos nou sien as hy vir my hulp vra of as ek vir hom winkel toe stuur, hy kom terug en hy vra vir my, of hy sal 'n dingetjie vergeet het] (P1 Mother, line 56)*

*My short term memory is, I will say it is not like it was before, but I'm trying. Last time I left the plate on at my granny's gas stove. I was baking an egg and I forgot, when I was done, I forgot to put the plate off, and my mommy's stove I left it on also (P4 Learner, line 151-157)*

*He forgets a lot. (P4 Grandmother, line 11)*

Learners expressed changes in emotion following the onset of TBI. For some it led to feelings of depression, whilst others reflected that following the onset of the TBI they experienced feelings of anger. This is reflected by two learners and their primary care-givers:

*I think I struggled a lot. The high school years of my life were very stressful, because I had to get back into all the work and all the changes at the same time, like as I was becoming an adult and everything. So I really struggled and at one point I even thought about suicide and things like that. I was so depressed (P2 Learner, line 124)*

*When we saw the psychiatrist and she had her diary, and I wasn't supposed to read the diary, but I did. She would be very negative in her diary. So every day she would go: "can't sleep, very depressed, nobody spoke to me at school, I hate my life, I hate my friends, I've got no friends" (P2 Mother, line 53)*

*I could just say maybe I have depression or something Miss or post-traumatic stress disorder or something like that Miss, because Miss I get angry so quick Miss. Really Miss, I get angry at my mother, because I just want to blame someone for everything, every wrong thing that is going on in my life, I just blame someone and then I blame my mother with that, because there is no one else. The person that is supporting me the most, I'm just pushing her away; I'm blaming her. I'm just pushing everyone that loves me away Miss (P8 Learner, line 233)*

*I'm always interested to help her with her homework, but then she just shouts at me, she just shout at me "I don't need your help, just leave me alone, I'll do my homework". I don't know Lee-Ann, when it comes to me né, I'm always there for her, for schoolwork, for everything, but I'm the one... she is always shutting me out. I'm the one she's always rude to, the one, it's like she's blaming me. So I don't mind, because I understand what happened to her (P8 Mother, line 192)*

For some learners changes in perception - specifically visual and auditory perception were evident following the onset of the TBI. This impacted on their school participation within academic and extra-curricular spheres. For one learner, visual spatial difficulties impacted on her ability to participate in her chosen extra-curricular activities and her decreased performance resulted in her becoming self-conscious. This lowered her self-confidence resulting in her quitting these activities.

*I did tennis for a bit and sometimes I did water polo. I usually end up like quitting because I was so bad like I couldn't even hit the ball when I was in tennis; it was quite bad. And water polo, that's another thing that was very embarrassing because like even in PE in high school for some reason I would always swim skew and I used to end up like going into the short end where the people couldn't swim used to go. It was quite embarrassing, like my sense of direction was all messed up (P2 Learner, line 97)*

Learners reported changes in higher-level cognitive functions, specifically organisation of thought processes and insight. These changes affected their school participation both academically and socially. One learner demonstrates that post TBI she had difficulty organizing her thought processes and this posed difficulty with academic tasks that required the formulation of paragraphs or longer essays:

*I was struggling to write something. And then write a story or write a paragraph or something on your own, then I would struggle very much. And also the thinking, of thinking what could I write about or anything; that also affected me a lot, Miss (P8 Learner, line 107)*

A learner shared that initially her general insight (i.e. both intellectual and emotional insight) was affected post TBI. This impacted on her social interaction with her peer group as she initially attributed her lack of friends to the behaviour of her peers. However, given the improvement in her insight, she now acknowledges the role of her own thought processes that could have led to her distancing herself from others: This is echoed by her and her mother:

*I almost felt that they were alienating me and that I was like not part of any group. For that year, Grade 9, I was kind of trying to fit in, trying to find a group, but never felt welcome by anyone. But it couldn't have been just my own thoughts that they didn't really want me there (P2 Learner, line 39)*

*She didn't have any friends and she didn't know how to make friends. She didn't like small talk. She didn't like social media and she felt very awkward and she was very focussed and she didn't allow people close to her. People did try and befriend her; she didn't really encourage it. She didn't know how to. She had so many challenges that she was dealing with, that she couldn't deal with other children. And yet it was a thing that she wanted the most, yet she pushed it away (P2 Parent, lines 39-40)*

As a result of the TBI, a third learner lacked insight (self-awareness) into her current level of functioning and was hence unaware of her limitations. When asked if she noticed any changes in her functioning following the onset of the TBI, she replied:

*I'm still the same (P7 Learner, line 110)*

Her lack of insight/self-awareness is confirmed by the learner's mother and by an excerpt taken from her neuro-psychological report:

*X is struggling to understand herself. She don't understand. She do things and then afterwards maybe she will think why do I do this, why didn't I go here... (P7 Mother, line 320)*

*Sequelae: lacks insight, garrulous, reactive and superficial (P7 Clinical Neuro psychology report: p. 4)*

Most learners shared that following the onset of the TBI they experienced a change in the mental functions of language (e.g. reception of spoken and written language). This included decreased processing speed and this impacted on their ability to grasp concepts that they were taught. It also impacted on their ability to process the information whilst reading. This was reflected by learners and their mothers and principals:

*I took longer to understand the work [Ek het langer gevat om die werk te verstaan] (P1 Learner, line 75)*

*If he comes to me and says, "mummy" I have just studied this, ask me quickly the questions and then I will give mummy the answers" and then I will help him in this way, but now that also made that I could see that he takes a bit long to think, because he knows the answer, but it is almost like it can't come out [As hy kom na my toe en hy sê vir my "mammie, ek het nou die geleer, vra gou net*

vir my die vrae en dan gaan ek vir mammie die antwoorde gee” en dan sal ek nou vir hom so help ja, maar nou daai het ook gemaak dat ek kon gesien het hy vat ‘n bietjie lank om te dink, because why hy ken daai antwoord maar dit is amper so dit kan nie uitkom nie] (P1 Mother, line 109)

*It look me longer to get the answer (P3 Learner, line 68)*

*Unfortunately he was a lot slower than he had been (P3 Principal, line 03)*

#### 4.3.1.1.3 Changes in interpersonal interactions and relationships

For most learners the onset of the TBI was followed by changes in interpersonal interactions. Learners hence experienced strained relationships with members of their family, who for most learners were their main support system. For some learners a change in interpersonal interactions impacted on their general social interaction, which for some led to the loss of friendships.

- **Strained relationships with family members**

Despite family members often being the learner’s closest support, learners reported strained relationships with family members, including parent-child and sibling relationships. This is reflected by learners and their mothers:

*What my mom always used to say like when I was always fighting with them (referring to her siblings), “she’s been in a car accident, she has an excuse”. They used to get so annoyed with that, because they were like this thing is carrying on for years and I need to get over it, like the accident was the past and she needs to be a normal individual (P2 Learner, line 124-126)*

*She was very difficult during those times. She was very difficult to live with and she was very critical of me. Everything I did she complained about; even the way I would make a sandwich or a cup of tea. She was critical about everything because she was unhappy. She would stand behind me and watch me buttering the bread and shout at me all the way through during it, because I’m doing it wrong (P2 Mother, line 69)*

*My brother, my baby sister, also tell me I am mad. I must be scared to tell them something outside because they’re going to tell me now right in front of the people “wait you mad”, and so (P7 Learner, line 94)*



*... I tell her brother "don't chase her away when she's standing there by you man"... but then sometimes he do get angry; he sommer sometimes pushes her in "go inside, you nag", stuff like that, you know (P7 Mother, line 323)*

- **Decreased social interaction**

Some learners reported that following the TBI, there were changes in their level of social interaction resulting in them spending more time on their own:

*Before the accident happened, I was active, playing rugby, playing soccer, so I was active, making jokes and that. But when I came back to X High I wasn't so again. I was like quiet (P5 Learner, line 126)*

*X doesn't go outside. X just sits in the house. If we move, he don't move, he stays and says 'no, I'm fine'. His father bought him a computer just to occupy him and keep him busy. The children are playing outside. What is he doing? Sitting by the TV (P5 Mother, line 189)*

*But now Miss, ...I just sit by myself, sit alone by myself, Miss (P8 learner 146)*

- **Loss of friends**

The onset of the TBI and the accompanying changes in the learners' functioning resulted in the loss of former friendships and this resulted in feelings of isolation. This is reflected by two learners and their mothers:

*My friend group that I had before, stopped being my friends and I was kind of alone (P2 Learner, line 6)*

*She lost all her friends... and she didn't know how to make friends. (P2 Mother, line 39)*

*... the friends that I had before the accident, like they rejected me after the accident, because I was limping. They said they don't want to walk with me in the streets... (P8 Learner, line 136)*

*The friends she had before, I don't know what's going on,... It's like she doesn't feel okay around them, she doesn't ... I don't know... She is assuming other people they don't care about her; they're undermining her now that she's got the condition of limping, all that stuff, ja (P8 Mother, lines 168-170)*

#### 4.3.1.2 Change in the role as learner

Following the onset of the TBI learners experienced changes in their role as learner. This was reflected in their changed academic performance as well as by their changed level of participation in non-academic (i.e. self-help) and extra-curricular activities. In addition, for some learners, the onset of the TBI and the resultant change in functioning resulted in a need for the re-consideration of their scholastic and future vocational goals.

##### 4.3.1.2.1 Change in academic performance post TBI

Learners experienced a change in academic performance post TBI, and for some these changes were extreme where learners went from being top achievers in their grade to barely passing some of their subjects. This is reflected by a learner and confirmed by her mother and teacher:

*But, a lot of my subjects I think I was failing...I used to be quite academic (P2 Learner, lines 6 & 127)*

*It made her feel terrible because she was use to..., she would work hard and she would do well. Now she would work hard and she couldn't even pass (P2 Mother, line 51)*

*But she definitely wasn't in the class she would have been, if it wasn't for the accident (P2 Teacher, line 16)*

Another learner and his mother shared the change in academic performance post TBI and how this change in scholastic abilities brought to the fore the change in the learner pre and post TBI.

*I still continued working. I just couldn't cope that fast as I had before (P3 Learner, line 38)*

*From Grade 3, X wanted to be a pilot, so I made an effort to get him to school when he said mommy I want to do this, get me a school. There were two schools, like one in X and X because he needed aviation and maths. That is the reason he went into that school and it is difficult to get into X. You must have a high IQ and he had a high IQ. Due to the accident, it changed (P3 Mother, line 129)*

#### 4.3.1.2.2 Change in level of participation in non-academic related activities

One learner shared that residual impairments, like his decreased mobility (i.e. walking ability) impacted on his ability to attend to his toileting (i.e. self-help skills) within the inaccessible school setting:

*The toilet was far away and I was walking very slowly at that time (P5 Learner, line 110)*

The learner's mother confirms the impact of the TBI on the learner's inability to independently attend to his toileting needs. She further shares how this had a negative impact on her son emotionally.

*So I could see on his face, his expression. He told me once "I was wetting myself because I couldn't go fast enough to the toilet; it's frustrating me". I said no stop. Now we stop. (P5 Mother, line 49)*

Through the learner sharing his frustration, he and his parents ultimately came to view his decreased level of participation in self-help skills within the school setting as one of the major barriers to him participating and remaining within his ordinary high school.

A second learner communicates that his inability to complete his self-help skills after being discharged from the rehabilitation setting, led to him having to be dependent on others. This increased dependency led to him feeling like he was a burden:

*I didn't like it, because I needed everything to be done. ... I had to shower with a chair in the shower. I needed them to come and help me do so many things. You come out and you realise I can do nothing and then you also start to feel like you're a burden (P6 Learner, lines 125 & 149)*

This learner's mother echoes how having to be dependent on others once he was discharged from the rehabilitation setting, affected her son emotionally and this ultimately led to him having to attend an in-patient clinic for 3 weeks:

*...he couldn't manage and then we had to get him help (P6 Mother, line 126)*

#### 4.3.1.2.3 Change in level of participation in extra-curricular activities

For most learners, extra-curricular activities had meaning and served as a way for them to display competency. However following the onset of the TBI, their participation in these extra-curricular activities was limited. This is reflected by a learner and his mother:

*I was good at soccer; now I can't play soccer (P5 Learner, line 64)*

*He don't go out and play. I always say to him here's boys in the street that play ball. His biggest thing was the ball. He don't do that anymore, because he can't (P5 Mother, line 236)*

Another learner shared how he missed participating in ice hockey, a sport in which he excelled. He shared that he had to change his role from player to that of a spectator. His inability to actively participate affected him emotionally:

*I used to play ice hockey – and Monday night I went to watch ice hockey, and it really made .... I played Western Province and would have gone probably for SA trials last year and I couldn't go...so I went to go watch Monday night and just to see them playing on the ice and how they move and just the sound of a slap shot and check into the boards, it just made me miss it. You know I haven't been on the ice since I've had my accident so I don't even know if I can still skate. I still have my skates, but I haven't put them on, so that's something I really miss and then yesterday morning, I think because of Monday night, yesterday morning I broke down a little bit (P6 Learner, line 207)*

The learner's teacher confirms the value he placed on engaging in sporting activities such as hockey.

*Hockey was his passion; he loved it, and ice hockey. Ice hockey was his number one and then field hockey was his second and unfortunately he's going to take a while before he can ever play that again. And it's not about him physically not being able to, it's about him getting injured because he's much slower than he's ever been before (P6 Teacher, line 44)*

#### 4.3.1.2.4 Change in scholastic goals and future vocational goals

The onset of the TBI, for some learners meant that they had to pursue alternate scholastic and ultimately future vocational goals. For some, this seemed possible, but it required the selection of careers that were more closely aligned with their current abilities and skills. For others,

changing their scholastic and vocational goals proved more difficult, leaving them with a sense of uncertainty of their futures.

Given the changes in functioning that a learner had experienced post TBI, he had to accept that it would be better for him to change his vocational goal. This included a change in his career aspirations from becoming a pilot to a career that which he felt passionate about yet matched his abilities:

*But in my situation I felt that it's best if I choose something that I'm passionate about also still and that I could get good at for my career choice now (P3 Learner, line 136)*

This learner's mother shares the emotional difficulty that her son had experienced when he realised that he would not be able to pursue his initial vocational goal of becoming a pilot. She also states that as a parent she was faced with the emotional difficulty that her dreams for her child's future would never realise:

*So in the beginning X was very, very emotional about that. It was like his dream was shattered... and then eventually we went to the neuro psychologist and she wrote in her report that X will always have a low income and that actually shattered me (P3 Mother, line 130)*

Another learner shares his realization that following the onset of the TBI he too had to make a change in his career path:

*I wanted to become a scientist, and now I see science is not for me (P5 Learner, line 40)*

This learner further states that after he realised he needed a change in his vocational goals, he is uncertain of his future vocational plans:

*I don't know what I want to be (P5 Learner, line 140)*

Similarly his mother also shares that following the onset of the TBI, they as parents are uncertain about their child's future direction in life.

*He's a teenager; whereto from there now? Where to with his life from there? ...But he is now 16. We think ahead. When he is 18, what is there for him to replace, because now my husband says what are we going to do; where do we put him? He is not a child that can go to a normal Technicon (P5 Mother, lines 190-191)*

The uncertainty about the learner's future direction in life resonates with his teacher:

*What happens to X when he matriculates, I don't know (P5 Teacher, line 73)*

A learner shares that as a result of changes in her functioning post TBI she had to transfer to a SS. This change in learner environment she now viewed as a major stumbling block to her achieving her vocational goal as the SS, unlike her previous ordinary high school environment, does not provide the required subjects. This causes her much frustration and although she stated that she enjoyed school in general, she had a negative attitude towards her current learner environment:

*Miss, I love school in general, but in this school Miss I don't like going to this school... Miss, sorry to say this, but I hate every day, every minute of being in this school, Miss, because I feel like this school is going to stand in my way of achieving my dreams that I have for my life, of becoming a chartered accountant. Then I'll have to, even now I was thinking of what career would I have in doing these subjects? (P8 learner, lines 184-194)*

#### **4.3.2 Theme two: "School means getting further to where I want to be": The meaning and value of participating in the occupation of school.**

Theme two and categories are presented in Table 4.2:

**Table 4.2: Theme Two**

<b>Theme Two</b>	<b>Categories</b>	<b>Sub Categories</b>
<p>"School means getting further to where I want to be": The meaning and value of participating in the occupation of school.</p>	<ul style="list-style-type: none"> <li>• School as valued occupation</li> </ul>	<ul style="list-style-type: none"> <li>• School re-entry and participation facilitates a sense of normality post TBI</li> <li>• School re-entry and participation serves as a motivator to progress post TBI</li> <li>• School participation facilitates social engagement</li> <li>• School participation helps to re-build confidence post TBI</li> </ul>

	<ul style="list-style-type: none"> <li>• Non participation in school impedes recovery post TBI</li> </ul>	<ul style="list-style-type: none"> <li>• Non participation in school is perceived as debilitating</li> <li>• Non participation in school reduces cognitive stimulation</li> </ul>
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Overall this theme reflects learners' perspectives and experiences with regard to the role of school in their journey of recovery and adaptation post TBI. It includes views of how non-participation in school impacted on their recovery post TBI as well as how school serves as a vehicle for learners to progress post TBI. This is captured by the words of a learner who when asked what school means to him, stated:

*School means getting further to where I want to be (P3 Learner, line 167)*

#### **4.3.2.1 School as valued occupation**

This category is representative of the value that learners attributed to school re-entry and participation post TBI. The value of school is reflected by learners' experiences of it as a constructive occupation that motivates and facilitates a sense of normality following a range of changes that learners experienced post TBI. It further aids in assisting learners to regain a degree of independence and facilitates the re-building of self-confidence. School allows opportunities for social engagement and for some learners allowed them to experience a sense of belonging.

##### **4.3.2.1.1 School re-entry and participation facilitates a sense of normality post TBI**

This sub-category conveys descriptions of learners' perspectives and experiences that re-entering and participating in school allowed them a sense of normality, i.e. to be treated as they were prior to the TBI and the same as their peers. This is reflected by a learner who expressed that upon returning to school, he was keen for things (including where he sat in the classroom) to remain as they were prior to his TBI:

*I told them I'm still going to sit where I used to sit (P4 Learner, line 59)*

This learner's grandmother and principal highlighted that he was treated like every other learner in the school so as not to single him out from his peers:

*If they feel that he talks too much, then they would treat him ... they treat him normal as the other children ... like "X, shut-up, doen jou werk (do your work)" (P4 Grandmother, line 173)*

*What we can say is when receiving him there was more empathy towards him but to a degree that we did not try and make him feel different to other learners here, to integrate into the normal run of our school. (P4 Principal, line 3)*

Another learner and her mother similarly shared that she too was treated like other learners in her school:

*She (referring to a teacher) did kind of treat me like a normal student and like said I was wrong when I was wrong and kind of got annoyed with me if I didn't do my homework or something like that; which was good I guess (P2 Learner, line 31)*

*It's a big school and life goes on, and they very much wanted her to just fit in and be one of the normal kids, you know, which I think is quite positive. They tried not to single her out (P2 Mother, line, 46)*

A learner shared that after prolonged periods of hospitalization; school helped her feel like her life was getting back to normal:

*I think that (referring to school) is where you start to feel like your life is going back to normal (P8 Learner, line 311)*

#### **4.3.2.1.2 School re-entry and participation serves as a motivator to progress post TBI**

Learners stated that their need to re-enter school and participate served as motivator to make progress post TBI. These learners saw success in school as a way to attain their life goals, despite the onset of the TBI. An additional motivator for some learners was that school provided them opportunities to be productive and to use and display their practical skills (i.e. school participation is constructive).

The view of school as a motivator is captured by the words of learners, in response to being asked "what does going to school mean to you?"

*I was keen to go back to school because I know I want to study and I'm going to study, so I needed to go back to school (P6 Learner, line 163)*



*I think it was really, like I wanted to succeed and I wanted to pass, I wasn't going to let what happened to me, stop me (P2 Learner, line 87)*

*I don't want to be a no one; I want to be someone (P4 Learner, line 83)*

*School will take you further in life. If you don't have education, you are going to stand on the streets and beg for money (P5 learner, 226)*

Some learners shared that they viewed school as that which allows them to experience positivity, productivity and that it encompasses an element of practicality, i.e. it was constructive. This served as further motivation for them to participate in school and progress post TBI. This is conveyed by a learner and his teacher:

*Actually yes I feel happy to be at school, because the subject choices that they have, is not a wide range, but it's more specific of what I want now, which is hospitality (P3 Learner, 117)*

*I must mention that he is one of my top academic learners and he also excels quite well in the practical part of it (P3 Teacher, line 5)*

Another learner who attended an ordinary technical school shares that he enjoys school, specifically the practical aspect of working with his hands:

*I enjoy school...The practical side of school, working with your hands. [Ek geniet skool. Die praktiesheid van die skool, om met jou hande te werk] (P1 learner, lines 144 and 151)*

#### **4.3.2.1.3 School participation facilitates social engagement**

Learners shared that school facilitated a sense of social engagement, and for some this allowed them to experience a sense of belonging.

The opportunity that school participation allows for social engagement is reflected by a learner and confirmed by his teacher:

*And then here at my new school, I live in the hostel and I go in the week days and us friends there usually go out and play touch rugby and soccer (P3 Learner, line 159)*

*Him also being in the hostel, you know, opens up a whole new social game, if I can put it in that way. And I think he is well-liked by his peers (P3 Teacher, line 16)*

For one learner who transitioned from an ordinary school to a SS, he experienced a sense of belonging as in the new learner environment he had a sense of connectedness to his peers who similarly experience barriers to learning. This is reflected in the words of the learner and his teacher at the SS:

*The friends, most of them they went through the same stuff as I did (P5 Learner, line 178)*

*He sits in a class and he discovers you also have the same problem I have in terms of mathematics; I also didn't catch that answer immediately. So he finds it more comfortable maybe because there's other learners' also experiencing the same disability, the same problems he is experiencing, cognitive and physical as well. So that kind of makes him comfortable like 'there are people like me out there' (P5 Teacher, line 26)*

After leaving his ordinary high school he attended pre TBI, a learner moves to a SS where he now has to reside in the school's hostel. He expresses the sense of connectedness he experiences with friends he has made in the hostel; he now considers them close to brothers:

*And then here at my new school, I live in the hostel ... Living in a hostel it feels like my brothers, or so (P3 Learner, lines 159-161)*

#### **4.3.2.1.4 School participation helps to re-build confidence post TBI**

Learners' incremental successes that they experienced in both their physical and mental recovery as well as in school participation served as confidence boosters. Returning to school and being able to participate to the same extent as their peers helped to build confidence. School participation further helped to re-build confidence in instances where learners were given opportunities to increase their independence. For some learners, independence was reflected by their active involvement in decisions regarding their re-entry to school post TBI.

A learner and his teacher shared how through school participation, his confidence was boosted. This was facilitated by positive feedback on his functional recovery as well as on his academic success from others in the school environment:

*They (his teachers) also noticed the progress now as well, like they can say "oh I see you are walking much better now this week" or "last week Friday I saw you walking a lot more with the stick, now you're walking fine"; so they are also giving me an update of my recovery because it's harder for me to see it because I'm with myself 24/7 (P6 Learner, line 89)*

*At the end of term one when he got an A aggregate in this term one, when he walked up onto the stage, he was walking with his little crutch I call it, and the school literally like exploded – they like clapped and oooh (P6 teacher, line 100)*

A learner shares that when she returned to school and saw that she was able to do what her peers are doing this helped to re-build confidence and allowed her to participate in school:

*I think when you go back to school and communicate with the other children and see that the other children are doing what you are doing, you are able to do what the other children can do, then you're able to focus to do your schoolwork and everything (P8 Learner, line 311)*

Some learners were actively involved in the planning of their school transition post TBI. This increased their degree of independence and allowed them to experience a sense of agency. This contributed to re-building their self-confidence. One learner shared that his school re-entry was a graded process in which he first participated in three subjects. He took the final decision regarding which three subjects he would attend and participate in upon his return to school. This is reflected by his words and confirmed by his teacher:

*I chose to go back to Life Sciences, Physics and Accounting (P6, Learner, line 100)*

*So he went to Physics, Accounting and Life Science, because those are the three subjects he chose, so those are his subjects that he wants to go into (P6 Teacher, line 16)*

Another learner stated that he took the decision regarding how he would catch up on work he missed once he re-entered school, which was to ask his peers for assistance:

*I myself, took my friends books home to catch up on work [Ek het self my vriende se boeke huise toe gebring om op te vang met die werk] (P1 Learner, line 42)*

This learner's mother confirmed that within school, he was allowed to work as independently as possible:

*The teacher left him alone, because why the teacher said to me, he as the teacher wanted him to do things by himself. The teacher did not want to place that pressure on him. He must self- how do you call it- he must adjust by himself [Die meneer het vir hom gelos because why toe sê die meneer vir my die meneer wou gehat het hy moet self dinge doen. Die meneer wil nie daai pressure op hom gesit het nie. Hy moet self – hoe noem mens dit – hy moet self weer aanpas] (P1 Mother, line 22)*

#### 4.3.2.2 Non participation in school impedes recovery post TBI

This category is representative of the participants' perspectives and experiences of how non participation in school impeded learners' recovery. For some learners' non participation in school was perceived as debilitating and for others impacted on the cognitive stimulation needed to promote their recovery.

##### 4.3.2.2.1 Non participation in school is perceived as debilitating

Some learners viewed non participation in school as debilitating, i.e. they felt incapacitated and they were hence unable to progress. A learner alluded to feeling incapacitated by her lack of active involvement in the decision regarding the cessation of her participation in school.

A learner shared that her non-participation in school affected the way she viewed herself and it felt that she was unable to move forward and continue with her education:

*...after staying in hospital for a long time not getting any schoolwork, being told that you have TBI, you think that oh I'm crazy, my life just has stopped, I can't go back to school (P8 Learner, line 311)*

Another learner alluded to her non-participation in school, resulting in her feeling incapacitated. This she attributed to her mother's decision for her to leave school, despite her desire to continue her participation in school. When asked how she felt about non participation in school, she responded:

*Sad, and I still dress me for school (P7 Learner, line 172)*

When asked why she felt this way, she responded:

*Because I still wanted to go to school (P7 Learner 174)*

For this learner non participation in school further denied her the opportunity to prove to others that she is on her road to recovery:

*I would like to go to school to prove everybody that I'm good (P7 Learner line166)*

#### 4.3.2.2.2 Non-participation in school reduces cognitive stimulation

A learner, who could not cope with the pace and the structural inaccessibility of an ordinary high school, spent a period of six months at home whilst awaiting placement at a SS. During this time he and his mother report that he was passive and lacked structured cognitive stimulation. He described himself as being bored during this time and when asked what he did for the six months whilst his was awaiting placement he replied:

*Sit on the couch and watch TV...I didn't focus on the concentration stuff when I was home (P5 Learner, lines 146 &154)*

His mother confirmed her son's passivity and she voiced her concern about the lack of cognitive stimulation given her son's changes in mental functions post TBI:

*Now X is sitting six months being a couch potato, and it wasn't good for us, because now X is looking around here. He came out of hospital... Everything is done; what now? We're sitting with a child's that his brain needs to be active, it needs to function all the time, it needs to work, it needs to run as in school, educated and whatever. Now he is sitting and he is losing out for six months (P5 Mother, line 187)*

#### 4.3.3 Theme three: Trying 'to get back into the swing of things': Strategies used to adapt and resume participation in school

Theme three and categories are presented in Table 4.3:

**Table 4.3: Theme Three**

Theme Three	Categories	Sub Categories
Trying "to get back into the swing of things": Strategies used to adapt and resume participation in school	<ul style="list-style-type: none"> <li>Enhancing day-to-day functioning</li> </ul>	<ul style="list-style-type: none"> <li>Re-learning old function</li> <li>Learning new function</li> </ul>
	<ul style="list-style-type: none"> <li>Personal Coping Strategies</li> </ul>	<ul style="list-style-type: none"> <li>Taking active steps</li> <li>Seeking advice from others</li> <li>Preventative steps</li> <li>Avoidance strategies</li> </ul>

	<ul style="list-style-type: none"> <li>• Learning Support Strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Peer Support</li> <li>• Environmental and instructional accommodations</li> <li>• Assessment accommodations</li> </ul>
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Overall this theme reflects learners' perspectives and experiences of the adaptive strategies used to resume participation in school. Strategies used to adapt were interpreted to include the re-learning of old function, learning new function, personal coping and learner support strategies.

The essence of this theme is captured by the words of a learner who stated:

*Every day I had to really spend a lot of time getting back into the cycle and getting back into work (referring to school work) ...just to get back into the swing of things, like into normal life (P2 Learner, lines 6- 13)*

#### **4.3.3.1 Enhancing day-to-day functioning**

This category is representative of the day-to-day improvement in functioning learners with TBI experienced as they gradually started to resume participation in their valued occupations. This included the re-learning of functional abilities and skills that was affected by the onset of the TBI. It also encompasses learning new functions to compensate for lost function and to assist with the adaptation process.

##### **4.3.3.1.1 Re-learning old function**

This sub-category is representative of the everyday function (e.g. walking, hand function, self-help skills, etc.) that learners re-learnt on an in-patient and outpatient basis to facilitate re-participation within valued occupations. This is reflected by a learner and his mother:

*I went to X Rehabilitation Centre to learn to walk (P5 Learner, line 16)*

*... at the beginning they (referring to therapists) came there and they worked on him, they said, "we are working towards him to get better and to walk out of here and to go back into school (P5 Mother, line 19)*

Another learner shared that she needed to re-learn to write in order for her to complete school related activities. Writing was hence something she practiced everyday:

*Well learning to write again. I had to be able to write, and every day I had to write (P2 Learner, line 11)*

In order to improve his mental functions, a learner and his grandmother stated that he had to complete exercises and worksheets recommended by the occupational therapist:

*She (referring to the occupational therapist) was giving me like things to remember. She would say stuff, she would say things to me and then give me something to do and when I'm done, then she ask me (P4 Learner, line 95)*

*Memory games and work sheets and things like that she would do. We would sit there and then he would ... the last time I was in the session with him she played a game where you must give 5 boys names with A and 5 girl names with B; and lots of other stuff (P4 Grandmother, line 48)*

#### **4.3.3.1.2 Learning new function**

To enable participation in occupation it was necessary for some learners to learn new functions to compensate for the loss of function resultant of the TBI (e.g. dominance re-training). For others the change in their level of functioning required that they learn new functional skills, such as coping skills, to assist with their adaptation process and hence facilitate their re-participation in valued occupation.

One learner mentioned that after a lack of return of voluntary movement in his dominant upper limb he had to undergo dominance re-training:

*I was first right handed, but now left handed (P5 Learner, 20)*

Another learner and his mother shared that upon returning home from in-patient rehabilitation the realization of the major changes he had undergone in functioning post TBI came to the fore. He was no longer in an accessible environment and was dependent on his family. This caused him much emotional distress and he now needed to be admitted to a clinic where he could learn coping skills. This was confirmed by his mother:

*We had to book him into a clinic where he could learn coping skills in order to adjust and to say it's ok to be like it, to fit in, you see. So he went away for two weeks, three weeks...he needs to*

*cope and the skills that he learnt was to fit in with others and it will obviously be ok to fit in with others, and you know that type of thing. So he did that process as well. And after that obviously it was better because he needed to learn and know that it's cool, it's ok to be so, it will get better and things like that (P6 Mother lines 126-128)*

Learner P6 shared an overview of what it was like at the clinic:

*They do group therapy and they do one-on-one sessions as well. ... like you'll have like a life skills group and then break and then another life skills group, then break for lunch and then they (referring to the occupational therapists) have crafts and then you're free for the rest of the day. But anytime throughout the day your psychologist or psychiatrist can come and see you (P6 Learner, line 59)*

When asked what the experience at the clinic equipped him with, he responded:

*Just things to keep calm and like it's ok to like need help sometimes because after a while I'm going to be fine again and I'm going to be able to do it (P6 learner, line 161)*

#### **4.3.3.2 Personal coping strategies**

This category is representative of the personal coping strategies which influenced learners' capacity to re-participate in school. These include learners demonstrating their assertiveness by taking active steps to assist with their resumption of and participation in school activities post TBI. Other coping strategies included using avoidant strategies (e.g. humour, denial) and seeking advice from others. Some learners put preventative measures in place to lessen the chance of changes in functioning negatively impacting on their participation.

##### **4.3.3.2.1 Taking active steps (assertiveness to obtain own goals)**

In order to re-participate in valued occupations such as school, learners shared that it was necessary for them to take action and not be passive recipients in their school transition process. This is reflected by one learner's initiative to change his seating in light of his decreased hearing post TBI:

*I had to move to the front myself, because I couldn't hear properly after the accident (P3 Learner, line 56)*



Another learner and her teacher shared that given her changes in cognitive functioning, i.e. decreased attention and slow processing speed, she took it upon herself to ask questions to optimize her understanding and hence her ability to participate in school related tasks:

*I always ask questions and things; I try to do that (P2 Learner, line 58)*

*She wanted to do well and she used to research her Shakespeare and ask me questions (P2 Teacher, line 77)*

In an attempt to attain her goals for improving her academic performance, a learner expressed that she took steps to pursue a tutor that she felt was best suited to her learning needs:

*I went to a lot of extra lessons, and a lot of searching for the right tutor. I had a lot of maths tutors and they were all horrible and I finally found one that was quite good (P2 Learner, line 105)*

#### **4.3.3.2 Seeking advice from others**

Given the sudden onset of the TBI and the accompanying changes in functioning some learners spoke to others who were in similar situations to obtain advice on how to cope and adapt:

*When I was at X (referring to rehab centre) I was next to an old man, Mr X (Uncle X). He helped me a lot. He is a very holy man and he also taught me a lot of life lessons, be patient with yourself, look at what you can do, thank God for what you have. Don't like moan at God for what you don't have, but thank Him for the blessings that you do have (P6 Learner, line 171)*

Another learner (given her improvement in mobility and mental function and the need to pursue subjects which the SS she attended did not offer) took the initiative of asking one of her teachers for advice regarding how she could be transferred back to the ordinary high school she had attended prior to the TBI:

*I've spoken to one teacher and then the one teacher she was really proud of me, because she told me that I'm determined about my life. And then she said that I must go ask a transfer from the psychologist (P8 Learner, line 188)*

#### 4.3.3.2.3 Preventative steps

Learners stated that in light of residual impairments such as decreased memory, they put steps in place to prevent it from impacting on their ability to complete tasks. One learner shared that he makes use of external memory strategies such as making lists, which he referred to when necessary:

*When my mommy send me to the shop and I have a lot of stuff to buy, then she don't write it down. She's just telling me and then I will forget and I will tell her write it down for me. So I try to remember. I'll keep the paper and I see if I can remember and if I can't, then I check (P4 Learner, line 158)*

Another learner stated that given her slow writing speed due to decreased fine motor control, she would obtain and print the slides prior to the lesson. This she did in an attempt to prevent her from falling behind on copying the information during the lesson:

*I would print out the slides and then I write on the slides because to write everything, I just can't (P2 Learner, line 51)*

A learner stated that, in order to avoid anger outbursts directed at her family (as a result of her frustration with the changes in functioning post TBI) she resorted to writing down her feelings instead:

*I have a book where I write down how I feel. Every time I'm angry I just take a book and I write down how I feel (P8 Learner, line 237)*

#### 4.3.3.2.4 Avoidance strategies

Learners stated that they have resorted to using avoidant strategies such as humour and denial as a way of deterring their focus from the changes in functioning and the occupational challenges that they were faced with post TBI.

A learner's response reflected her use of denial as a coping strategy when she was asked if she had regular visits with the social worker who her school employs to provide psychological support to their learners:

*I did see her sometimes but I tried to just carry on with my life and pretend that nothing really happened, but obviously it did (P2 Learner, line 35)*

Other learners used humour as a coping strategy:

*...spend time with your friends, talk like nonsense and like just learn the work. I make school fun; I mean why have a boring day when you can have a fun one? (P6 learner, line 165)*

### **4.3.3.3 Learning support strategies**

This category is representative of the learning support strategies, i.e. peer support, environmental, instructional and assessment accommodations which influenced learners' capacity to re-participate in school.

#### **4.3.3.3.1 Peer support**

Most learners relied on their peers to support their re-participation in school. Peer support included the use of peers' class notes and buddy systems for studying. Some learners relied on their peers to assist in areas (e.g. hearing of instructions) where there were difficulties as a result of a change in functioning post TBI.

The majority of learners used their peers' class notes in an attempt to stay on par with academic demands. This is reflected by a learner and his grandmother:

*I took someone else's book; my friend's book in class so I can catch up with work (P4 Learner, line 71)*

*The teacher would allocate somebody's book that was on par and give it to X- everyday a book. Every day he had to take a book and then catch up and over weekends she would give him 3 or 4 books because he had more time now to catch up (P4 Grandmother, line 85)*

For some learners buddy systems were used to support their own learning as well as a means to motivate them to keep up with their academic load. This is reflected by a learner and his teacher:

*We always worked in a group [Ons het altyd saam in 'n groep gewerk] (P1 Learner, line 66)*

*That is an outstanding class yes. That is the top class that he is in and it's where the motivation comes from, For Grade 9 and 10 they were all together- the Afrikaans group- but they are top learners. His peers that he is friends with, they are all top learners and I think he can just say and then they will talk about a section of work and then he will hear [Dit is 'n uitstekende klas, ja. Dit is die top klas waarin hy is en dit is waar die motivering vandaan kom. Van Graad 9 en 10 was hulle almal saam – die Afrikaans groeie – maar hulle is top leerders. Sy maats met wie hy bevriend is, is top leerders en ek dink hy kan net sê en dan sal hulle nou praat oor die werkstuk en dan sal hy net hoor] (P1 Teacher, line 38)*

#### **4.3.3.3.2 Environmental and instructional accommodations**

As a result of their changes in functioning post TBI, some learner environments provided accommodations to facilitate the learners' capacity to re-participate in school. These accommodations included extra classes, a graded return to school, preferential seating and a reduction in the learner-teacher ratio.

A learner reflects that in order to facilitate her capacity to re-participate in school she received extra classes:

*I got a lot of support and stuff, a lot of people tried to help, a lot of extra lessons at first like every day I had an extra lesson (P2 Learner, line 06)*

Some learner environments further attempted to grade learners' transition to school as is reflected by a learner and her principal:

*Well, before I did go because my history teacher use to drive me, I think I went about three times, drive me to school, sometimes pick me up, take me in history ... I don't know maybe it was to reintroduce me to school again... So that could have been just grading me, getting me ready for the following year (P2 Learner, lines 23-27)*

*She came in sort of a lesson and we chose lessons where she felt confident and where she loved the teacher and ... and so for a couple of times she came in just to try and get used to being in class and for us to assess how she has managed in class before she actually came back (P2 Principal, line 18)*

Another learner, his mother and teacher shared that his return to school was graded in that although he was in Grade 12 at the time of the accident, he returned to Grade 11 during the last

term of that school year. He then participated in three subjects as a way to grade his return to school:

*I went for 3 subjects, but the first week I went to the matrices. They (referring to those at school) gave us a lot of leeway... but then the second week when I came... three periods a day (P6 Learner, line 64)*

*She (referring to the occupational therapist) wrote a motivation letter asking if they can assist with at least three subjects so that X, we need to find out how X's improvement will be and to make him school-ready for the following year; so they did that, ja. So they have accommodated that (P6 Mother, line 62)*

*The process was last year when he, after his accident, about 3-4 months afterwards, he returned back to Grade 11. So he didn't go to Grade 12 which he was in when he had the accident. He came back to Grade 11 in term 4 for the last 4-5 weeks of school, and then in those 4-5 weeks he had three days in a week at the school and it was only about 4-5 hours because his body couldn't handle the whole walking up and down the stairs with the schoolbag and everything (P6 Teacher, line 3)*

Learners shared that they were given preferential seating to accommodate for the changes in functioning post TBI:

*At first they did want me to sit in the front. I think for maths I remember I was sitting in the front (P2 Learner, line 64)*

Learner environments such as SS, further attempted to accommodate learners' learning support needs by reducing the learner-teacher ratio as was expressed by these learners and their primary care-giver or teacher:

*The teacher can give more attention to you and here's not a lot of children in this school (P5 Learner, line 176)*

*And the classes, it's less children – 12 or 15 children is in a classroom and they can focus more (P5 Mother, line 263)*

*There was less children in the class ... Say if you have a problem, you don't have to wait that long and maybe forget about what you were thinking. You can still keep it in your head and ask the ma'am... (P3 Learner, line 105-107)*

*Like I said, he does benefit on the one-on-one that we can do; we're fortunate having the opportunity to that in the classes (P3 Teacher, line 15)*

#### **4.3.3.3 Assessment accommodations**

Given changes in functioning, learners were accommodated in terms of assessment practices. These accommodations included: extra time for tests and exams, the use of scribes, simplification of tests questions and the use of open book tests.

Most learners received extra time for tests and exams given their barriers to learning including changes in mental and fine-motor function:

*Extra time, ja. I used to get 10 minutes an hour extra which has changed to 15 minutes an hour, which I'm very thankful for because I need it (P2 Learner, line 70)*

*Yes, she got extra time. That was the one thing they did do, they gave her extra time (P2 Mother, line 35). She does write slower, you know, but the extra time helped (P2 Mother, line 44)*

*Also things like extra time would have been given so that she had the time to actually just battle with what she could manage (P2 Principal, line 27)*

The use of a scribe helped Learner P8 to complete tests and exams:

*A scribe; at first I needed a scribe Miss, because of my wrist it would be painful. It gets tired very quickly. When I write a lot of work, then it starts to be painful and it gets tired, then I have to rest my hand (P8 Learner, line 301)*

Within Special Schools (SSs), teachers explicitly mentioned that learners included in this study were accommodated in terms of assessment through the simplification of test questions, the use of open book tests as well as teachers reading through the questions with the learners:

*My exam question paper, I simplify the exam paper so that it would be like one word, or three words or one sentenced answers (P5 Teacher, line 13)*

*Normally we do small open books tests or things like that... Like I said we do the slideshow and then immediately after that we hand out the worksheet, so it is testing previous knowledge and using the newly acquired knowledge immediately in the worksheets ... I tend to read the*

*questions for the learners and I say “come guys, read with me, take your pencil” (P3 Teacher, line 33 & 52)*

#### 4.3.4 Theme four: “Carrying on and pushing through“: Journey of personal growth and perseverance

Theme four and categories are presented in Table 4.4:

**Table 4.4: Theme Four**

<b>Theme Four</b>	<b>Categories</b>	<b>Sub Categories</b>
“Carrying on and pushing through“: Journey of personal growth and perseverance	<ul style="list-style-type: none"> <li>• Positive personal attributes driving recovery and adaptation</li> </ul>	<ul style="list-style-type: none"> <li>• Positive attitude towards changed life situation</li> <li>• Willingness to apply personal effort to achieve goals</li> <li>• Intrinsic motivation and determination</li> </ul>
	<ul style="list-style-type: none"> <li>• The role of faith</li> </ul>	<ul style="list-style-type: none"> <li>• Faith of the learner</li> <li>• Faith of the family</li> <li>• Faith of the broader community</li> </ul>
	<ul style="list-style-type: none"> <li>• Finding acceptance of changes in life circumstances post TBI</li> </ul>	<ul style="list-style-type: none"> <li>• Acceptance of self</li> <li>• Acceptance from others</li> </ul>
	<ul style="list-style-type: none"> <li>• External supports increasing learners’ capacity to positively adapt</li> </ul>	<ul style="list-style-type: none"> <li>• Primary care-giver as advocator</li> <li>• Emotional support from significant others</li> <li>• Interdisciplinary therapeutic intervention and support</li> <li>• Financial support</li> <li>• School’s commitment to inclusion</li> </ul>

Overall this theme reflects learners' perspectives and experiences on that which helped on their journey of personal growth and assisted them to persevere to full participation in valued occupations such as school.

#### **4.3.4.1 Positive personal attributes driving recovery and adaptation**

This category reflects the learners' perspectives on the personal attributes that ultimately allow them to believe that they are able to overcome barriers and positively adapt. These personal attributes include having a positive attitude towards changed life circumstances, willingness to put in personal effort, being intrinsically motivated and determined.

##### **4.3.4.1.1 Positive attitude towards changed life circumstances**

Learners felt that having a positive attitude assisted them to adapt to their condition. A positive attitude was reflected by learners' attempts to seek the positives in their current situation following the onset of the TBI. For some learners this included reflecting on the fact that, similar to others they have met on their road to recovery, the TBI could have affected their functioning to a greater extent.

Seeking the positive in their current life situation allowed them to adapt to their condition:

*... you make most decisions in your life and you can choose the way you feel about something. So instead of looking at what I couldn't do, I rather looked at what I couldn't do since I woke up and what I can do now. So count your blessings and not your burdens (P6 Learner, line 171)*

The same learner also shared that a positive that he experienced from his situation – one that has helped him to adapt - is his changed outlook on life, lifestyle choices and view of the world. Another positive for this learner is that he realises that he could be much “worse off” if he compares himself to others he has come across during his rehabilitation (e.g. someone with a spinal cord injury):

*...Changed the way I see everything, ... I'll go out and be adventurous and do whatever with my friends, but I'll think more carefully about my decisions that I make. I'll make sure that ok, this is the situation, if I do this, these are the possible outcomes, if I do this, these are the possible outcomes and weigh it up and the pro's and con's and make my decision like that. It changed the way I viewed the world. I never knew that people who had brain injuries or people who are disabled with a leg or arm or whatever, I never knew that they needed so much help and how*



*difficult life is for them and I salute all people who have accepted their situations like that. I mean a quadriplegic can never do anything for himself ever again... (P6 Learner, 206)*

This learner's changed outlook and lifestyle choices that he experienced post TBI was echoed by his teacher:

*Before his accident, did stuff that a 17-year-old boy shouldn't do – illegal stuff – smoking ganja and stuff like that, but often, not just once off; often. And unfortunately because I'm younger than the rest of the teachers, I picked it up and after his accident he had changed completely. He was like 'I got another chance, I got another opportunity, so what I want to do now is I want to try my best'. So, yes I'm sure now and then he'll do whatever he does on weekends, but it's nothing compared like it was last year at the beginning of the year when he was in the accident. He literally seems like he's become more positive and more hardworking and wants to accomplish something; not it's going to fall in my lap because I'm clever, which he always used to be like (P6 Teacher, line 50)*

#### **4.3.4.1.2 Willingness to apply personal effort to achieve goals**

Learners shared that in order to re-participate in school it took tremendous personal effort on their part. This included both physical and cognitive effort. This is reflected by a learner, her mother and teacher:

*It was quite crazy how much work had to go into going back to school... I had to work 24/7 (P2 Learner, line 45)*

*She used to wake up early, she woke up at 5 in the morning, she would go to bed at 1 in the morning, she would be at school, she would do extra lessons and everything, she just would work herself to the bone (P2 Mother, line 50)*

*By matric in her class she did more than the others, because they were kind of loafers, some of them, and she was not a loafer. She wanted it. She wanted to do well (P2 Teacher, line 77)*

#### **4.3.4.1.3 Intrinsic motivation and determination**

Participants shared that learners' intrinsic motivation and determination assisted with their recovery and adaptation post TBI. Learners experienced the value of goal setting as a means to drive their process of recovery. Determination was highlighted as a personal attribute to overcome occupational barriers, persevere and make a positive adaptation.

A learner, his mother and teacher reflect that this learner sets goals for himself. This serves as his motivation to overcome occupational barriers and accomplish in life.

*You must keep to your dreams. If you want to be this thing, say to yourself 'yes, I want to be this; I want to stick with it' (P3 Learner, line 136)*

*He exactly knows, of all my kids now, what he wants to be, where he wants to go (P3 Mother, line 129)*

*I know that X is also someone that sets goals for himself and he works towards that, which is great, because it shows you that he thinks about life. He thinks about choices. He thinks about the future and it directs him (P3 Teacher, line 18)*

Another learner shares that by setting small goals for himself to do previous tasks and through achieving small successes, his sense of self belief increased. This in turn motivates him to eventually overcome occupational barriers (i.e. his inability to walk):

*Like I would walk between the parallel bars, so I could count how many steps I took and every day it goes better by like one, two – but all of that one's and two's add up... So that's the only way that you can improve, is to do what you couldn't do before (P6 Learner, line 171 & 214)*

When asked what has helped them to adapt and re-participate in school, many learners alluded to their determination.

A learner reflects that it is his determination to overcome occupational barriers that has allowed him to make a positive adaptation:

*I don't give up hope [Ek gee nie moed op nie] (P1 Learner, 140)*

His mother echoes her son's determination in both personal and academic spheres of his life and she mentions that whilst others may underestimate his abilities post TBI, he is determined to prove them wrong:

*He is more firm. He keeps by his, it's not that he is going to show I am scared of you. He may be scared, but he won't show it, but he will show them that I won't give you your way. This is how he has become. With his school work too. For him it was I can do this...For him it is also like, I will show I can do this, I am not that person that you say I am [Hy is meer standvastig. Hy hou by sy, is nie dat hy gaan nou wys ek is nie bang vir julle nie. Hy is miskien bang, maar hy gaan nou vir hulle wys nou*

maar ek gaan nie julle sin vir julle gee nie. Nou so het hy kom raak. Met sy skoolwerk ook. Vir hom was dit hy kan dit doen. Nou vir hom is dit amper so, ek gaan julle wys ek kan dit doen; ek is nie daai persoon wat julle sê ek is nie] (*P1 Mother, line 66-68*).

This learner's determination is resonated by his principal and teacher:

*I have seen that the learner is a go-getter (P1 Principal, line 16)*

*He carried on his own, and the fact that he is one of the top 11 (referring to top 11 learners in his grade), is wonderful to me [Hy het self aangegaan en dat hy in die top 11 is, is vir my wonderlik] (P1 Teacher, line 36)*

The role of determination in learners' ability to positively adapt to occupational barriers was reflected by two other learners and their mothers:

*I'm definitely determined and ambitious which definitely helped (P2 learner, line 86)*

*The overlying thing was how well she did and how determined she was ... She is one of the most driven people I know (P2 Mother, lines 18& 62)*

*Never give up (P5 Learner, line 146)*

*Wow, they are so amazed of what this child .... They said you know it doesn't come from them; it comes from himself and you as parents because why you had put a lot in and that child was a fighter. He was a fighter, you know...we tried to help and tried to talk to him and said to him 'you just have to fight, fight, fight; and that is what we did. Fight, fight, fight; all the way through, he fight (P5 mother line 143)*

#### 4.3.4.3 The role of faith

This category includes the faith of the learner, family and the broader community that served as a source of hope and support and facilitated an adaptation by learners. This was reflected by a learner, his mother and teacher:

*Like there was a time in X (referring to the rehabilitation unit) when I used to wake up in the morning and pray to God that I opened my eyes, that I have the ability to open my eyes, to drink a glass of cool drink – at a time, I told you, I couldn't lift up a cup. When I could drink a cool drink with my hand, I thanked God for that... I mean a lot of people prayed. I mean we had Priests over the world praying. (P6 Learner, lines 171-181)*

*All we had to do was trust in God and pray like we've never prayed before, you understand (P6 Mother, line 120).*

*I think he is very much involved in church and I think the family is that way inclined and I think that's probably part of the driving force behind it (P6 Guidance Teacher, line 95)*

When a learner was asked what he would tell other youth who have had a TBI, he responded by affirming that there is a higher power who has helped him along his journey to recovery:

*I will tell them there is a God (P5 Learner, line 195)*

His mother affirms that as a family their faith is what gives them hope as by having faith anything is possible:

*We have the Lord on our side, anything is possible (P5 Mother, line 163)*

The faith of the broader community also played a role in providing learners and their families with hope and helped them feel supported during the learners' recovery. This was reflected by a learner's mother and the principal of her high school:

*People at school were praying for her (P2 Mother, line 20)*

*They all knew and they knew through the church as well. I think her church was good to her (P2 Teacher, line 59)*

#### **4.3.4.3 Finding acceptance of changes in life circumstances post TBI**

This category is indicative of self-acceptance (and acceptance from others) of the changes in learners' functioning post TBI. It highlights the role of finding acceptance of changed life circumstances; in facilitating learners' ability to positively adapt.

##### **4.3.4.3.1 Acceptance of self**

The reflection on their life circumstances and the acceptance of their limitations facilitated learners' ability to adapt. A learner expressed that she had constantly been comparing herself to her peers in terms of the amount of effort and the resultant academic performance. She

however had to accept that because of her current barriers to learning she needed to invest more physical and cognitive effort than her peers:

*I tried so hard, like someone who didn't try as hard, got better than me, which was like horrible for me but it happened even till matric, even now it happens. But, I've got to accept that (P2 Learner, line 92)*

A learner shared that for him acceptance of his condition and his limitations post TBI is an ongoing process. His approach was to work through his feelings and accept changes in functioning and roles when he encountered situations that bring changes in functioning to the fore:

*So I mean there's things that you think you have accepted it first, but there's going to come a situation that you haven't encountered before and you're going to go through that and you might not have accepted that part of your, like of how far you have recovered or what you've been through. So, ja I think I've accepted it; it's difficult, but you can do it (P6 Learner, line 208)*

In contrast another learner stated that she has not accepted her “post-injury self”. For this learner it appears that she is fixated on her “pre-injury self”:

*I just want my normal life back, Miss; that is what it feels like now I'm different from the other children, so now my life changed. Now I just want my normal life back! (P8 Learner, 217)*

Based on Learner P8's comments and that of her mother, this lack of self-acceptance appears to have impacted on her ability to adapt:

*I'm still adjusting to the situation even though the year, I have been here almost for a whole year Miss, but I still haven't adjusted really to the environment of this school (referring to the SS) (P8 Learner, line 196).*

*Because X was undermining the school. She said the school is for slow learners and that the school is for disabled and she is not disabled...Ja, she was not accepting to be in that school (P8 mother, line 118-120)*

A second learner reflected that she had not accepted her “post injury self”. This is reflected by the manner in which the learner throughout the interview made several attempts to preserve her pre-injury self-image. Throughout the interview she made references to the fact that she is not “mad” or “dumb”:

*I can't shout, then I'm mad. Normal, people that wasn't in an accident can shout, then they're not mad. If I shout, I was in an accident, I'm going to be mad; so are they? (P7 Learner, line 106) I'm not dumb (P7 Learner, line 193)*

In addition, her lack of insight into her changed abilities and skills post TBI, also impacted on her ability to acknowledge and hence come to terms and accept her current limitations post TBI:

*I'm still the same (P7 Learner, line 110)*

#### **4.3.4.3.2 Acceptance from others**

Learners reflect that understanding and acceptance of their change in functioning (i.e. abilities, skills and role execution) from those in their learner context, assisted them to adapt upon their return to school.

One learner mentioned how acceptance by and support from her learner environment helped her to adapt to the school demands and environment post TBI:

*But, it was a good environment, especially an all-girls school, so it was a lot more understanding even though I did have some bad things. If I think I was in X or a co-ed school it would have been so much worse I'm happy I was in all-girls for that, it helped me to get back. I could look the way I looked and I wasn't judged for how I looked by most people. I was judged by a few, but most people understood what I went through. It was good to be with girls and like even the teachers was supportive (P2 Learner, line 84)*

This acceptance of the learner in her context was also reiterated by her school principal:

*There was a huge amount she knew she wasn't who she was and that caused her to put great pressure on herself and also a fair amount of depression that went with the territory and that what we talked about more as teachers, how to cope with that, how to allow her space to be who she was, to not put pressure on (P2 Principal, line 24)*

Another learner alluded to the fact that he was better equipped to adapt to the academic demands of his new school as his teachers had an understanding and acceptance of the barriers to learning he experiences as a result of the TBI:

*At my new school the teachers understand you better there; they understand that you need to work at a certain pace (P3 learner, line 107)*

This learner's principal similarly highlighted that within this learner context there is an acceptance of the learner's barriers to learning, leading to more effort being focussing on the learner's strengths:

*So we are acutely aware of the disability of the learner or the learning hindrances or challenges there are, we say, ok good, come we work with what we have and from there come we see and you build confidence. [So we are acutely aware of the disability of the learner or the learning hindrances or challenges there are, sê ons ok maar goed, kom ons werk met dit wat ons het en vandaar af kom ons kyk en 'you build confidence'] (P3 Principal, line 69)*

#### **4.3.4.4 External support increasing learners' capacity to positively adapt**

This category reflects the role of external support from significant others (notably family), interdisciplinary teams, funders and the school in terms of increasing the learner's capacity to positively adapt.

##### **4.3.4.4.1 Primary care-giver as advocator**

All of the learners highlighted the role that their primary care-givers played in supporting and advocating for their return to school:

*I had support and I love how like my mom and like they (referring to rest of family) always try like make sure I go to extra lessons, even if they are really expensive (P2 Learner, line 82)*

*There were a lot of discussions with her mom as to what she should do when she came back (P2 Principal, Line 5) In terms of with us mom was sort of the primary driver (Principal, P2, Line 55)*

*My parents contacted the school (P5 Learner, line 82)*

*We did make the contact with the school. My husband and me went there and speak to the principal (P5 Mother, line 33)*

*... And you know the amazing part of his father, he never stopped. He never stopped at anything. He went to the highest of the highest of the highest of all to get our child to what he is today, and that he saw, that his parents are fighting for him; just not leave it there; we fight for him (P5 Mother, line 157)*

*The parents are playing more than their role on his side (P5 Teacher, line 32)*

The active role of care-givers' continued involvement in the return-to-school process is further highlighted by a teacher:

*Parent evenings X mother also speaks to the teachers, naturally about his special needs and so on [Oueraande soos daai wat X se ma ook saam met die onderwysers praat, natuurlik oor sy spesiale benodighede, en so aan] P1 Teacher, line 51)*

#### 4.3.4.4.2 Emotional support from significant others

Learners highlighted that the emotional support that they received from their family and friends helped them along their journey of recovery and adaptation. In many cases family and friends served as a source of extrinsic motivation to help learners to persevere.

- Family

The support of the learner's family was felt to be an important source of support:

*My family played the supporting role. It's a role that they like never gave up on me (P3 Learner, line 144).*

His mother confirms that during her son's recovery she and the rest of their family unit served as source of support for their son during his recovery:

*But it was just us man, just us; his brothers and my husband. We are very close. Me and my kids; they're like the world to me and I like to be there for them (P3 Mother, line 142)*

When another learner was asked what helps him cope at school, he answered:

*Mostly my mommy and my daddy...I speak to my mommy when I am down (P5 Learner, line 192 & 216)*

The role of the family is reiterated by the learner's mother in terms of his recovery and process of adaptation:

*We had to work and we had to talk and we had to deal with every situation with him. And we had to take him through that process because it wasn't easy...Wow! The support of his family, that boosted X life (P5 Mother, line 67 & 156)*



- Friends

For some learners, friends served as a source of support during their adaptation. This is reflected by one learner who when asked, “given how well you are doing at school, what at school would you say helps you”, he replied:

*My friends and within myself is what helps [My vriende en van myself af is wat my help] (P1 Learner, line 126)*

The role of his friends in his adaptation was confirmed by his principal and teacher:

*And I think that the class that he is in, is a very supportive class [En ek dink die klas wat hy in is, is ook 'n baie ondersteunende klas] (P1 Principal, line 37)*

*It is the top class that he is in and that is where his motivation comes from... His friends that he has, are top learners [Dit is die top klas waarin hy is en dit is waar die motivering vandaan kom.... Sy maats met wie hy bevriend is, is top leerders] (P1 Teacher, line 38)*

The support from friends, even through the use of social media for one learner was a means of motivation and support:

*And when my accident happened also a lot of people posted on my wall, like I have pages to read on my Facebook wall about it... I felt it like encouraging. Like I felt almost if people believe I can do it ,I should belief, I should try harder or like I don't want to fail because I also want to succeed but also everyone else also wants me to succeed, so I'm not alone (P2 Learner, lines 80-82)*

#### **4.3.4.4.3. Interdisciplinary therapeutic intervention and support**

During their road to recovery most learners' paths crossed that of a variety of disciplines within both the health and education sector. Some of these team members served as a support to both the learner and their family.

This is reflected by a learner, who when asked how he eventually got into the new school (i.e. SS) he answered:

*A lady (referring to the educational psychologist) helped my mom and my dad. She was also there in X (referring to the area in which his ordinary school is) (P5 Learner, line 156)*

The role of the educational psychologist in assisting the learner's parents to obtain placement in a school which was a better fit for his needs is re-iterated by the learner's mother:

*She (educational psychologist) helped us a lot. In that 6 months she fight for that child to get into X (SS) because there's a period of time before people go into that ... And she fight; she went to the Education Department there at Western Cape. She sit with them, the Board. It was backwards, forwards (P5 Learner, line 121)*

Another learner and her mother commented on the supportive role that her team at the in-patient rehabilitation centre played during her recovery:

*Definitely was through the therapy, I don't think I would make it out without that. They taught me everything again and I had to learn everything again (P2 Learner, line 9)*

*They (referring to the therapists) had a very positive attitude and they took her and they started to work with her in all different areas – speech, occupational therapy, physiotherapy and routine (P2 Mother, line 7). They were very open towards me. I was there every day, all day and they showed me things and what to do with her. So they would have their sessions and then I would carry on for the rest of the day doing little exercises with her, and they often use to thank me for that and they would let me come in on the exercises with them; so they never excluded me, they always were happy that I was there and they always said that my input was valuable, so I felt like part of the team really, which was great (P2 Mother, line 73)*

When another learner was asked what he would say helped him to get back to the school, he answered:

*Everybody in the hospital (P4 learner, line 117)*

The role of the hospital team as supporters during her grandson's recovery was reinforced by his grandmother:

*What the occupational therapist hammered on his head; you will get better, don't give up, even though it is going to take you a little bit longer. Some will take one year, you will take two years, but it's gonna get there (P4 Grandmother, line 130)*

#### 4.3.4.4.4 Financial support

Two learners and their families received financial support following the onset of the TBI. One learner received a payment from the Road Accident Fund (RAF) and the other is a recipient of a disability child grant.

One learner shared the role medication played in assisting with improving her mental function and her mother states that her daughter was only able to access the services of the psychiatrist and the prescribed medication as a result of a payment she received from the RAF. Her mother further highlights that the financial support from the RAF also allowed them to have a permanent roof over their head. It also allowed her daughter to have funds to pursue her education on a tertiary level:

*Well, I think the medication helped me (P2 Learner, line 43)*

*I took her to this special psychiatrist and she put her onto a lot of medication. I didn't have the finance before that to see anyone ... no it was in Grade 11 because we got some money from the Road Accident Fund. So she put her onto Ritalin, and she put her onto mood stabilisers, anti-depressants (P2 Mother, line 52)*

*So she got a pay out from the Road Accident Fund which enabled us to buy this house and to have some money for her university (P2 Mother, line 83)*

A learner's mother refers to the disability child grant that she receives towards providing the basic needs of her son. Whilst it helps she does share that it is difficult to stretch this amount to cover his needs as a growing teenager:

*R350, I think is the school a month and R255 or something is the bus. So it is R560, almost R600 a month – we can't, we really can't. He is getting a R1005; he needs a lot of stuff. He's still growing; he's a teenager (P5 Mother, line 199)*

#### 4.3.4.4.5 School's commitment to inclusion

The schools' commitment to inclusion is reflected by schools' active role in preparing learners for their school re-entry as well as by the positive attitude of educators. It is further reflected by schools' responsiveness to learners' support needs post TBI and the school's commitment to ensuring that these learners' are treated equitably. Schools which had adequate infrastructure also assisted learners' with their ability to adapt post TBI.

- School's active involvement in preparing the learners for their return to school

For a few learners a school's commitment to inclusion was demonstrated by their involvement in the planning for the learner's return to school. Participants reflected that the schools' involvement included timely communication and planning with relevant team members within the health department as well as with the parents of the learners. This was confirmed by a learner, her mother and principal:

*I think it was a few months before school started, they went, with all the therapists, they went to go see the Head Master and my tutor teacher and they discussed it. And they knew that I didn't want to go back to Grade 8, because it would be like kind of embarrassing, you know, I wouldn't be with my friends. I would be so old, because I already failed, not failed, but I was already behind a year, so I didn't want to (P2 Learner, line 15)*

*Yes, we had a meeting towards the end of the year with the team – the occupational therapist, speech therapist and I'm not sure about the physiotherapist (can't remember). They met with the principal and guidance teacher and we discussed what we should do – whether we should put her back into Grade 8 because she was in the middle of Grade 8 and she had been getting awards and doing well, or just keep her with her friends and put her into Grade 9 (P2 Mother, line 13)*

*There was a lot of conversations with mom and me and teachers about the integration, how long she would be at school every day – all of those kinds of things – so a lot of discussion pre her coming back (P2 Principal, line 7)*

- Positive attitude of educators

A schools' commitment to inclusion is reflected by the positive attitude of its educators, specifically teachers. Teachers were a source of encouragement. Teachers were understanding of learners' changes in functioning post TBI and allowed them to adapt at their own pace:

*They (referring to the teachers) encouraged me [Hulle het my aangemoedig] (P1 learner, line 28)*

This learner's mother highlighted the positive attitude of his teacher in terms of allowing her son the time he needed to adjust given the changes in his physical appearance post TBI:

*He did not want to remove that cap off his head – that’s what the teacher said. But the teacher just left him because he knew what his problem is, he was mostly shy about the mark he had on his head [Hy wil nie daai keppie van sy kop afgehaal het nie – daai het die meneer gesê. Maar die meneer het vir hom net so gelos, because why die meneer het mos nou geweet wat is sy probleem, hy was meestal skaam oor die merk wat hy gehet op sy kop] (P1 mother, line 18)*

- School responsiveness to learner support needs

A school’s commitment to inclusion is demonstrated by learners who reflect that teachers within their learner context were responsive to their support needs in light of their barriers to learning (e.g. changes in mental function). This is reflected by the responses of learners, when they were asked what assisted them to cope at school:

*lot of teachers tried to help me and everything and they were like always trying to make me pass and help me to understand things (P2 Learner, line 37)*

*The teacher can give more attention to you (P5 Learner, line 176)*

The teachers of learners also mentioned their commitment to inclusion by sharing how they as teachers attempted to be responsive to the learner’s support needs:

*If it is a large slideshow, I won’t do it in one day because I know my kids will never be able to cope with that; we’ll break it up...We summarise everything and that makes it easier – smaller chunk at a time (P3 Teacher, line 47 & 55)*

*But now you see I’m forced to work slower through the work, so I don’t get x amount of work done, but as long as I know what I’ve taught them, they know. I try and I take the little stuff out. Obviously the curriculum doesn’t accommodate learners like X so I take things out and I try to accommodate the curriculum for the learners (P5 Teacher, line 85)*

- School’s responsiveness to learner diversity and educational equity

Learners, teachers and principals were of the opinion that the creation of schools that are responsive to learner diversity and provide equal educational were important:

*I never got treated like I was stupid or anything like that. A lot of teachers understood when I couldn’t do things or when I didn’t like understand, or I did things a bit oddly (P2 Learner, line 31)*

*We wanted her to integrate back in her social environment and I think all the way through Grade 9 – because she came back for Grade 9 – we actually just let things ride. If she was going to get through, she was going to get through and if she didn't, we would take those decisions when it got to that point. But more a case of allowing her to believe in herself again, which was a very slow process for her (P2 Principal, line 29)*

*Our principal, said to the staff basically whatever marks X gets between now and matric, X is here to say ... You know, a school like this, our head mistress is a psychologist and she just... a lot of schools would have kind of quietly suggested another school. This school never did. They stuck with her (P2 Teacher, line 8 & 20)*

A learner shares that her experiencing inclusion as opposed to exclusion is what helped her to adapt:

*Also including us when there's something, then we will also be able to participate in that thing; not excluding us, saying that 'oh, these children have TBI, so they can't take part in this thing. Allowing us to also take part, involving us in many things, also can help a person really much, can help us get, let me say it helped me a lot where people treat me the way they treat the other children, when they treat me the same way (P8 Learner, line 314)*

- School Infrastructure

School infrastructure includes access to services such as a clinic, psychological support (i.e. psychologists/social workers) and therapeutic services from allied health professionals (i.e., occupational therapists, physiotherapists, speech therapists). Infrastructure further includes school environments that are structurally accessible.

Learners stated that the school infrastructure assisted them to adapt to their learner role post TBI:

*They offer a psychologist. If you have a headache or something, there is a clinic there and they can give you medication (P3 learner, line 103)*

*Here's no stairs here. Like when you walk up, there is not stairs here. And the school is just suitable...And here's OT's and speech therapists here and physio's. At my old school, there is nothing there, there is just school work (P5 learner, lines 175 -179)*

- Seeing learners and primary care-givers as partners in learning

Collaboration with a learner and his/her primary care-givers reflects a school's culture of viewing learners and primary care-givers as partners in learning. These collaborative efforts were

evident during the stage of initially planning a learner's return to school as well during the structuring and revising of the learner's support package throughout their school career. This was expressed by a learner who demonstrated he was given the opportunity to provide input regarding the subjects he would do as part of his graded return to school:

*I chose to go back to ... (P6 learner, line 100)*

This learner's guidance teacher reflected that the school regards his parents as partners in learning who give input regarding their son's needs and the resultant support:

*And in terms of a school, in my capacity what we did now also because of his mom's request for concessions, so I've applied to the Education Department for extra time, so that he has less stress with regard to completing the papers on time – so I've done that last term (P6 Guidance Teacher, line 4)*

#### **4.3.5 Theme Five: “It would have helped to have support”: Support needs for re-entrance and participation in school post TBI**

Theme Five and categories are presented in Table 4.5:

**Table 4.5 Theme Five**

<b>Theme Five</b>	<b>Categories</b>	<b>Sub Categories</b>
“It would have helped to have support”: Support needs for re-entrance and participation in school post TBI.	<ul style="list-style-type: none"> <li>• Effective communication channels as part of the planning for school re-entry</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of communication between other team members, learners and their primary care-givers impacting on learners' preparedness for school re-entry.</li> <li>• Lack of intersectoral communication between the Departments of Health and Education regarding learners' abilities and needs</li> </ul>
	<ul style="list-style-type: none"> <li>• Adequate resources within the Department of Education to provide the required learner support in ordinary schools</li> </ul>	<ul style="list-style-type: none"> <li>• Human resource constraints in providing specialised learner support</li> <li>• Inadequate training of educators in ordinary schools on relevant policy and learning support</li> <li>• Lack of implementation of reasonable and effective learner accommodations</li> </ul>

		in ordinary schools
	<ul style="list-style-type: none"> <li>• Accessibility and safety within ordinary schools</li> </ul>	<ul style="list-style-type: none"> <li>• Physical barriers</li> <li>• Attitudinal barriers</li> <li>• Lack of safety within and around ordinary schools</li> </ul>
	<ul style="list-style-type: none"> <li>• Psychological support to both the learner and family</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of psychological support to the learner</li> <li>• Lack of psychological support to the family</li> </ul>
	<ul style="list-style-type: none"> <li>• Timorous financial assistance from Government</li> </ul>	<ul style="list-style-type: none"> <li>• Financial constraints that hampers learner access to support</li> <li>• Financial implications on household for out of pocket expenditure to support the learner's needs</li> </ul>

Overall this theme reflects learners, their primary care-givers' and educators' perspectives on the gaps in current service provision that supports high school re-entry and participation post TBI. These gaps essentially reflect the support needs of learners as well as those who provide the learners with support (i.e. care-givers and educators). Participants highlighted the need for effective communication channels as part of the planning for the learner's school re-entry as well as the need for psychological support for both learners and their families. A need for adequate resourcing within the Department of Education to provide the required learner support in ordinary schools as well as timely governmental financial support to the learner was highlighted. Accessibility and safety within and around ordinary high schools were indicated as current gaps in service provision that aims to support the school re-entry and school participation of learners post TBI.

Theme Five is reflected by a learner who when asked what could be done in addition or differently to assist with her school re-entry and participation post TBI she stated:

*Maybe it would have helped to have support ... (P2 Learner, line 101)*

#### **4.3.5.1 Effective communication channels as part of the planning for school re-entry**

This sub-category reflects the need for effective communication as a key element of the planning phase for learners' school re-entry post TBI. This communication encompasses communication at two levels. Firstly, communication between other team members, learners



and their primary care-givers. This communication, amongst other aspects, should include information on referral pathways and school options that would best suit learners' support needs post TBI. Secondly, inter-departmental communication between the Departments of Health and Education regarding learners' abilities and needs to facilitate appropriate planning and structuring of the learner's support package, is required.

#### **4.3.5.1.1 Lack of communication between other team members, learners and their primary care-givers impacting on learners' preparedness for school re-entry.**

Most of the learners felt that there was no communication nor a formal process of preparing them for their return to school post TBI. Learners hence felt that they were not sufficiently prepared for the school re-entry post TBI. This resonated with the views of their primary care-givers and the principals of the schools they attended. When asked how the learner was prepared to re-enter school post TBI, participants' responses were as follows:

*No they (referring to team members at the hospital) did not prepare me [Nee hulle het nie my voorberei nie] (P1 Learner, line 10)*

*The day that they discharged him, was a public holiday, and then the Dr just said how long he had to stay at home and when the school re-opens, because it's now March month, almost Easter, they said after Easter when the schools re-open he can go back to school. That's all they said [Die dag wat hulle vir hom ontslaan het, was op 'n vakansiedag gewees, maar toe het die dr net gesê nou vir hoe lank moet hy nou by die huis wees en as die skole nou weer oopgaan, want dis mos nou March maand, amper paasfees mos nou gewees, toe sê hulle nou na Paasfees, wanneer die skole oopgaan, kan hy terug skooltoe gaan. Daai's al wat hulle gesê het] (P1 Mother, line 8)*

*No, I just went back to school (P4 Learner, line 29)*

*We just took him back to the school (P4 Grandmother, line 21)*

*Look, we from outside, we did not really work actively in preparing him; we've accepted him, but the preparation was done off our school, so I can't really speak about the preparation (P4 Principal, line 134)*

*No I didn't think I was ready to go back to school and my mommy and my daddy also didn't think so (P5 Learner, line 104)*

*No team involved from the Department. Nobody actually recommended us anything (P5 Mother, line 109)*

*Look there wasn't really a process... There's no real policy that school has. I'm not aware of any of the ... if there's a policy that the Department has with regards to dealing with kids that have being shot or trauma, all kinds of things. So we kind of just do our own thing. We try and approach I suppose any kind of trauma with children in a very caring way (P5 Principal, lines 4-5)*

Another learner shared that she was not emotionally prepared for the transition from an ordinary high school to a SS:

*Emotionally, no Miss, because I had that in my mind that this year I was going back to my normal school, but then the psychologist and the occupational therapist told me that I can't go there... I think Miss, something they could have done, I think they should have sat with me and told me the reasons why, not just I hear that X you're going to X School; that was a surprise Miss; it really was a surprise... (P8 Learner, line 266 & 280)*

A lack of communication regarding school options and referral pathways from members of the interdisciplinary team was also expressed as a current gap in service provision:

*I felt that they could have first-hand off, refer us and told us about 'listen guys, there is a disability school'. As we know yes there is, but which one, where do we go, how do you go? From that side they needed to tell us 'listen if you're not happy and satisfied in that school, there is this and that', and we will see for him .... We had to do our own routes and get our child, for six months, we fought to get him into that school; I think that is unacceptable. From their side they could have come in and say if you do not feel happy, come back to us and we will put him immediately in a school (P5 Mother, line 184-185)*

#### **4.3.5.1.2 Lack of inter-sectoral communication between the Departments of Health and Education regarding learners' abilities and needs**

The lack of communication regarding one of the learner's current abilities and needs were not communicated clearly when she was discharged from the rehabilitation unit and this led to her teachers' initially having unrealistic expectations of her:

*Also for me when I went back, because I used to be quite academic, they put me in an academic class where everyone ... it was the highest class with the smartest people in it, which maybe wasn't the best idea initially (P2 Learner, line 127)*

Participants expressed a need for increased inter-sectoral communication specifically around the learner's condition to allow for an increased understanding of the learner's needs:

*The people at the hospital should tell the school more about brain injury [Die mense by die hospitaal kan die skool meer vertel van breinbesering] (P1 Learner, line 120)*

*And on the one hand, it is something good if the doctor or whoever could have informed the school that they could have maybe helped him more in the school [En aan die eenkant is dit ook iets goed as 'n dokter of whatever miskien nou vir die skool kan ingelig het dat hulle miskien vir hom beter kan gehelp het in die skool in] (P1 Mother, line 53)*

*I personally would have loved the Department first of all to come into the picture. Maybe first we need to go to that particular department, be it Health, be it Social Development. I don't know the processes, however, I would have thought them to come to me, to give me a breakdown, or even to call the school to make an appointment to come, and then I would have wanted to know, because my job description of principal is to see overall and not to specialise in a particular..., it's all those learners. He's one learner out of 1300. How do you now give him specialised attention? We don't have that. So I would have expected that from the Health Fraternity or the Social Services; in this is how you handle it when there is a lapse of concentration, when he acts out (Principal P1, line 18)*

#### **4.3.5.2 Adequate resources within the Department of Education to provide the required learner support in ordinary schools**

This category includes the current constraints in the resourcing from the Department of Education that impact on the capacity of an ordinary school to provide learners with the necessary support. These constraints include human resource constraints in providing learner support; inadequate training of educators in ordinary schools on relevant policy and learning support and a lack of implementation of reasonable and effective learner accommodations in ordinary schools.

##### **4.3.5.2.1 Human resource constraints in providing learner support**

This sub-category specifically reflects participants' perspectives on the human resource constraints that impact on the delivery of learner support where needed. These constraints include a lack of specialists at Departmental level, a lack of sufficient staff to cater for varied learner needs within the school setting, a lack of SSs and the decreased capacity of existing SSs to serve as resource centres.

- Human resource constraints in providing specialised learner support at Departmental level

Some educators shared their perspectives on the human resource constraints (i.e. limited specialists such as psychologists, social workers and other allied health professionals) at departmental level which impacts on the Department of Education's capacity to provide the needed support to the school. This in turn impacts on the school's capacity to provide support to the learner:

*I come from a public school in X (referring to name of area) you see. We don't have a psychologist. We are not privy to have, you have one psychologist or two or three social workers who are stationed at the Department, you know. And when you speak to them they tell you about the hundreds of cases they have – it's rape cases – it is much worse than what we have. So when our turn comes, Miss, no, it's not working out at the moment (P1 Principal, line 34)*

*Our social worker, as sir says works in 35 different schools, so it takes very long [Onse social worker, soos meneer gesê het, werk in 35 verskillende skole. Dit neem verskriklik lank] (P1 teacher line 75)*

*Look, when a learner is in an LSEN school (referring to SS), their exams would be different. The volume of work, the pressure on the child is going to be totally different. They can reduce the number of assignments. The curriculum can be adjusted. So in that way they can assist the child. The child will have more individual attention. The child will be exposed to specialist people like speech therapists, occupational therapists. We have those people within the education sector, but unfortunately being a mainstream school, we have to apply and there might be one psychologist for 20 schools. So 20 schools would translate to something like 20000 learners. So it becomes one in that 20000; we're losing it (P4 Principal, line 50)*

A principal of a well-resourced ordinary school mentioned that given the human constraints at the departmental level, as a school, they prefer to assist learners internally without referring the learners to specialists at the Department of Education:

*You know there are District Support Teams but they kind of have to work with 35000 children, or whatever, and you know we are a well-resourced school where people pay school fees, we do have social workers, we've got an academic person who will deal with extra time and those kind of things and it's better to do it in-house, because then at least we're governing what's going on and whoever it is, can see the social workers once or twice a week, or whatever it is. Some of them will see them every day for 5 minutes to touch base or whatever. Some will spend a lesson down there when things get too much. But when you*

*deal with the Department, you might get somebody coming in today and another one in 5 weeks' time and that doesn't actually help. So we have tended to keep that kind of thing in-house (P2 Principal, line 36)*

- Lack of sufficient staff to cater for varied needs of large volume of learners in classes

Educators shared their perspectives on the challenge of supporting varied needs of learners in a class, given that schools are insufficiently staffed:

*I think also sometimes the schools are not equipped. We have so many learners and if you look at, I mean there is more than one child in a class that have issues, different issues. This now being a mental, you know psychiatric problem; I don't know if you can say it like that. And then you have other children with learning, with hyperactivity; you know there is more than one aspect. So how do you deal with all these children in one class? (P4 Teacher, line 100)*

*... I think what is at times difficult, is we have something like 19 different types of diagnoses to handle. So even although we're a school that caters for a specific type, there is still varieties within that, you know; autism, physical disabilities, partially hearing disabilities, and so on. And that makes it, I think, a little challenging for us, it's not the child's fault, it's the system fault in way, because a lot of these barriers to learning, come we call it that, work against each other. So you have a child with, a type of learner is X and another learner with Y, we are geared to help both, but purely the presence of these two learners in the same class, is not conducive for that particular combination... [ek dink wat vir ons soms moeilik is, is ons het iets soos omtrent 19 verskillende tipe diagnoses wat ons hanteer. So even although we're a school that caters for a specific type, there is still varieties within that, you know; autism, physical disabilities, partially hearing disabilities, and so on. En dit maak dit, dink ek, bietjie 'challenging' vir ons; it's not the child's fault, it is the system's fault in a way, want baie van hierdie leerhindernisse, kom ons noem dit nou dit, werk teen mekaar. So jy het 'n kind met 'n, tipe leerder is X en 'n ander leerder met Y; ons is 'gegear' om albei te help, maar die blote teenwoordigheid dat die twee leerders nou in dieselfde klassie is, 'is not conducive for that particular combination] (P3 Principal, line 26)*

- Lack of Special Schools (SSs)

A lack of special schools is reflected by the mothers of two learners who felt that when the ordinary school was found not to be the best fit for their children, it took some time before their children were able to be transferred to a SS:

*Like I've said that's a long waiting list, so I don't think they could have done anything. We just had to maar wait (P3 Mother, line 123)*

*She (referring to the educational psychologist) said you wait for a year or two to go into that school (referring to SS)... , because the list is long (P5 Mother, line 111)*

A few educators expressed their concern about the lack of Special Schools, given that (in their view) ordinary schools currently do not have the capacity to support these learners' needs:

*I think fundamentally the whole idea of having these learners integrated into mainstream, must be reviewed. These children need specialist facilities; now we're going to lose them (P4 Principal, line 60)*

*I feel they must open two or more Special needs schools, because they closed, right? [Ek voel hulle moet nog, seker twee of wat meer 'Special Needs' skole maar open; hulle het mos toegemaak, né?] (P1 Teacher, line 112)*

- Decreased capacity of Special Schools (SSs) to serve as resource centres

The principals of the SSs expressed the importance for SSs to be capacitated to serve as resource centres:

*I think some of the main challenges still remaining are to empower special schools which are running well to be more of a resource centre, because according to the policies they all should be resource centres with inclusive education teams that move out and share their expertise... We are a resource centre but we don't have IE-team on our staff establishment, so whatever outreaches we do, we do it with the staff that we have, and currently all schools experienced the strain from the Education Department Budget constraints (P3 Principal, line 79-81)*

#### **4.3.5.2.2 Inadequate training of teachers in ordinary schools on relevant policy and learning support**

Learners, primary care-givers, teachers and principals shared the sentiment that teachers require training to enable them to understand the learners' needs and hence provide the learners with the appropriate support:

*They (referring to teachers) did not understand [Hulle het nie verstaan nie] (P1 Learner, line 158)*

*These are teachers who go from mainstream, who go from varsity; education is their core function, so we didn't have speciality. Look there's nothing wrong with the school-based support team, but we are teachers, right, and we are not the qualified people in those fields in the supporting. So our role basically is to gather information and then pass it on, you see. It is expected that teachers must gather information and do something about it, which is not always ... I think there is certain things that you can do something about and other things that you need to pass on, you know (P1 Principal, line 18 and 56)*

*The teachers didn't really understand what was wrong (P3 Learner, line 60)*

*I would say the teachers didn't really understand, because they knew he was in an accident so they just let him be. So whenever he got a headache after a time they couldn't send him home anymore, so they said "just sleep it off like in the class, just sleep it off". For me it wasn't something like he really had to do, you understand. I mean he couldn't take crowds, so for me it wasn't really up to standard (P3 Mother, line 62)*

*The teachers don't feel empowered [Die onderwysers voel nie bemagtig nie]. They want to, but they don't know how to and that is absolutely true and that's just because hulle is nie getrain nie [they are not trained] Hulle is nie goed genoeg opgelei vir dit nie [They are not sufficiently trained for it]. You know we expect schools to become inclusive and to become full-service schools, and it must just happen, but we forget that those teachers haven't been trained (P3 Principal, line 35)*

Teachers and principals felt that their difficulty to assess and identify the barriers to learning impacted on their ability to provide learners with the needed support:

*It's going to be difficult because you don't know what are you looking for. They need to actually brief us on what must we look for in this child. You know, as we say, we're not equipped to deal with those things so that child will get lost in the system and to the child's detriment (P4 Teacher, line 134)*

*The rate that we are travelling now, our classes are growing and we don't have enough teachers. So we are expecting those that we do have, to perform specialist skills; they don't have it ... We try and put things in place but we could do more harm than assisting the learner (P4 Principal, lines 109 & 135)*



*I'm sure I'm doing more harm, because I'm not focusing on the gap, because I don't know what the gap is, you know (P1 principal, line 104)*

*It's difficult to assess. You sit and think and pray and say "God give me the strength, guidance and wisdom" and then we go ahead [Dis moeilik om te bepaal. Jy sit maar en dink en bid maar en sê "Here gee my krag en leiding, wysheid" en dan gaan ons maar voort] (P1 Teacher, line 109)*

*.. kids range from physical to intellectual to mental to all capabilities and if they don't train the teachers to be able to deal with those problems in the beginning when they study and when they prac (practical) teaching, then there's no way there will ever be inclusive education, because someone that has an OCD or someone that can't or swops letters, I don't know how to deal with that ... (P6 Teacher, line 112)*

#### **4.3.5.2.3 Lack of implementation of reasonable and effective learner accommodations in ordinary schools**

A learner and her mother shared how a lack of accommodation (i.e. not adjusting her workload), impacted on her ability to keep up with scholastic demands given the barriers to learning she experienced post TBI:

*There is such a high workload of seven subjects, it's very hard to keep up and I did nearly fail Grade 9, so it would have probably been better if I had just done some subjects at a time and being able to like fully commit to one subject and not have like five or like three subjects instead of spread it over seven (P2 Learner, line 43)*

*She was very down. It was just that the workload was overwhelming (P2 Mother, line 50)*

One teacher mentioned that he is unable to offer accommodations in the form of audio-visual instruction and assessment as a result of the school's lack of resources to obtain the needed audio-visual equipment. He also mentioned that although the learner had difficulty writing and should have been accommodated with the use of a scribe, the school was unable to offer this service free of charge to learners:

*I only have one Khanya room (referring to the audio-visual/computer room), you know in that regard. I don't get an opportunity to take my learners to the Khanya room. That's why I say we are technologically challenged. We don't have those things. Getting scribes costs money. If X's parents could afford it, yes, they could get him a scribe (P5 Teacher, line 46-50)*



Two principals of ordinary schools stated that no accommodations were implemented, despite their learners requiring accommodations in light of their barriers to learning post TBI:

*We couldn't apply particular things, because we weren't taught it (P1 Principal, line 18)*

*But we did not adjust anything for him in particular (P4 Principal, line 3)*

A mother felt that despite the ordinary high school trying to accommodate her son, after a while the school indicated their difficulty with trying to accommodate the learner's needs. This eventually contributed to the decision for him to be placed in a SS:

*But to give one child out of a whole class, just to adjust this for him, it's a problem. It caused a problem and they can't just keep up with it (P5 mother line, 83)*

#### **4.3.5.3 Accessibility and safety within ordinary schools**

Participants highlighted that inaccessibility and a lack of safety were viewed as barriers to school participation within ordinary high schools. Physical barriers (e.g. stairs, inaccessible toilets) and attitudinal barriers (e.g. negative attitudes of teachers and peers as well as stigma) were mentioned. A lack of safety also served as a barrier to learners entering and exiting the school premises, and impacted on the school's ability to provide learner support outside of school hours.

##### **4.3.5.3.1 Physical barriers**

Learners mentioned that within ordinary schools there are physical barriers which impact on their ability to mobilise independently and safely in and around the school:

*It was difficult. There was a lot of stairs and I had a crutch that time. It was difficult... Yes most of my classes were upstairs. The toilet was far away (P5 Learner, lines 84-86)*

*I go to a three-story school, so there are stairs everywhere, and I have classes on all three levels ... I had a friend there (P6 Learner, lines 81-83)*

*.. physical barriers that are at X (referring to the high school where she teaches); so not having ramps, not having any staircases where kids can go up that are disabled, definitely that (P6 Teacher, line 105)*

#### 4.3.5.3.2 Attitudinal barriers

Attitudinal barriers impacted on the ability of some schools to fully commit to inclusion. Two principals expressed that at schools they are often so focused on completing the curriculum and learner throughput that there is often not sufficient time for individual time to be spent with learners who have specific barriers to learning:

*Mainstream is geared towards positive pass, you need to pass, you need to stand out, the school need to stand out, because if a school doesn't reach that 60% pass, they are being termed as a terrible school and immediately the following year, all the Departmental people are there. So principals are under the pressure to perform; they cannot sit still with that learner...It's very difficult in the mainstream because everyone is geared to caps, there are pressure on learners; the principals wants his pound of flesh from every educator, is the syllabus done? (P1 Principal, lines 3 & 30)*

*At times they deal better with the problem at the primary school, than we do at the high school, because at the high school we are so curriculum driven. We are outcomes driven. We are given a target and you need to meet that target; so many learners must pass. So the attention, the true educational attention was lost in this whole system of trying to get to the targets that are set (P4 Principal, line 30)*

The negative attitude of teachers and principals may also be viewed as a barrier to inclusion. This was confirmed by a learner who shared that his teachers did not assist him upon his return to school.

*No the teachers did not help [Nee die onderwysers het nie gehelp nie] (P1 Learner, line 56)*

This learner's mother felt unhappy with regards to the initial attitude of her son's high school principal. At first, the principal would not re-accept her son given his concerns that her son would not be able to cope and may place the welfare of others in jeopardy given that some of the classes are practical and involve the use of machinery and chemicals:

*For me, he didn't have ... almost like the confidence that my child could achieve something. My child was very heart sore when the principal introduced me to what they are working with. The principal came with that business that they work with mechanical stuff and that works all with the brain and if he now maybe... so he gave an example now my child must perhaps throw something into something and then he throws in too little or too much or whatever, and then it explodes and then it places other children in danger. But then I felt so heart sore, because why, give a child a chance in life [Hy het nie vir my, dis amper soos hy het nie daai*

vertroue gehad dat my kind kan iets bereik nie. My kind was baie hartseer gewees toe die hoof vir my nou voorstel van waarmee hulle werk. Die hoof kom met daai besigheide dat hulle werk met mechanical goete en dit werk alles met die brein en as hy nou iets miskien, toe maak hy 'n voorbeeld, soos nou moet my kind miskien nou daai ietsie ingooi en dan gooi hy miskien te veel of te min of te veel of whatever, en dan explode dit en dan sit hy ander kinders in gevaar. Maar toe voel ek so seer, because why, jy gee 'n kind mos 'n kans in die lewe] (P1 mother, line 143)

A learner experienced negative reactions from those in her learner environment. She specifically shared the negative reaction of peers upon her return to school. That is, she had a mental illness:

*The other children 'she's mad'... Still here, today still, if they look at me they don't even know me, they did never meet me. Now she's mad, then they just look at me with that intention, they don't even meet me or anything, talk to me ... just no, she's mad, so (P7 Learner, line 81)*

This learner's mother shared the negative attitude of a teacher towards her daughter and she felt that this attitude contributed to her decision of removing her daughter from school. The learner then confirms the incident but said that she only remembered it as a result of her mother raising this in the interview:

*He told her that yes 'ja, you're mad, I'm going to send you to Lentegeur Hospital' – in front of a lot of children. She never came back and told me that, but somebody else came back and told me ja this sir said in front of, I don't know if it was assembly or whatever? (P7 Mother, line 229)*

*Now that my mommy is talking, ja, but I didn't remember it out of my own. I forgot about it (P7 Learner, line 236)*

The negative attitude of peers is also shared by other learners as a difficulty to their initial adjustment following their re-entry to school post TBI:

*I was teased a lot... once I walked passed by like a girl in my grade and she said that I ran into a car – like she told her friends and they laughed at me while I was standing there with an eye patch. But I didn't run into a car (P2 learner, line 39)*

A principal reflects that the negative attitude of some teachers regarding learners who require support as “being extra work” may also be a barrier to the re-entry of these learners into ordinary schools:

*... even our teachers view learners differently. Our opinion is formed before we start working with that child. Nou dis nou weer las, dus nou vir klomp werk vir my [This is now a nuisance, this is now a lot of work for me]... (P4 principal, line 122)*

A learner shares that the stigma in her community regarding a SS, it what contributes to her difficulty with adapting to this learner environment:

*Also coming to school in the bus; I hate the word that says 'Special School for Special Children with Special Needs'... people will think that I was born like this, but they won't accept I had an accident...Also another thing that the children and the people in my community, they put me under pressure in terms of you go to a school for physically disabled children, you go to a school for disabled children and then they like "so you, you're also disabled". They make me feel bad for going to this school; they make me feel really bad, Miss (P8 Learner, lines 201-206)*

A principal was of the opinion that the stigma associated with brain injury may impact on the learner obtaining the needed support as it may result in the care-giver and the learner not making a full disclosure to the school regarding the extent of the changes in functioning post TBI, and that this may pose some barriers to learning:

*Sometimes they also have their reasons. You know at the high school, the name calling and things like that; the stigma that's attached (P4 Principal, line 106)*

Another principal felt that the stigma associated with a SS may impact on the care-giver and learner's decision for the learner to be transferred to a SS, even though the SS may be a better fit in terms of the level and the extent of the support the learner needs:

*A lot of the time a child gets a place in a special school, by our school for example and then the parent will turn around because of stigma and say "no, but Jannie passed maths again he got his 31% so let's keep him rather longer here, we are no longer going to place him at the special school, because he has started to cope again ... baie keer kry 'n kind 'n plek in 'n spesiale skool, by ons skool for example, en dan sal die ouer byvoorbeeld omdraai, because of stigma, en sê "nee maar, Jannie het nou weer sy wiskunde deurgekom", he's got his 31%, so let's keep him rather longer here; ons gaan hom nie nou in die spesiale skool sit nie, want hy het nou weer gecope". So there is sometimes even a reluctance that because of the perception of special schools and so on and so forth (P3 Principal, line 78)*

#### 4.3.5.3.3 Lack of safety within and around schools

A lack of safety in the area in which the school is situated may impact on the learner's school participation. This is specifically the case in instances where as a result of a lack of safety, schools are not able to provide extra-curricular activities or extra classes after school, out of fear for the learners' safety:

*When we go home we used to go to the train station. It wasn't that safe, so we would all go as a group to the train station and climb on the train and each one gets dropped off like that (P3 Learner, line 158)*

*I stay in this area myself, but there are days that I fear for my children that go to school [ek bly nou in die gebied, maar daar is partykeers wat ek self bang is vir my kinders wat skooltoe] (P1 Mother, line 81).*

*But what you also need to take into account is the sub-cultures that exist outside of the school. Our communities are very territorial; so you belong to X (name of area) and that one belongs to X (name of area). So, during the school day it is fine, we cross those boundaries, but after school you come out of an area that's controlled by the 'Americans', and you move into an area that is controlled by the "Dollarbrands" then it becomes an issue...so these are all things that impact on schools after hours. We would so much want them to be integrated into sports, but we've got problems with presenting all these things (P4 Principal, line 71)*

#### 4.3.5.4 Psychological support to both the learner and family

Participants reflect that after a life altering experience such as a TBI the learner requires psychological support. This is needed to assist learners' acceptance of their change in functioning post TBI and to facilitate a positive adaptation. However as the TBI also impacts on the family, participants also reinforced a need for psychological support to extend to the immediate family of the learner with the TBI.

##### 4.3.5.4.1 Lack of psychological support to the learner

A learner, his mother and teacher highlight the need for psychological support for the learner to prepare and support the learner for the changes in functioning that may come to the fore upon discharge from the hospital/rehabilitation setting:

*They should speak more about ...Because it's a lot to accept going home and needing help, so like speak to the patients before they go home and tell them 'look here, when you go back home, things are going to be different and you're going to need a lot more help than what you needed previously' – so, just try to get them to accept that before they leave the rehab unit (P6 Learner, 190-192)*

*I advised X, the therapist at X (referring to the rehabilitation centre) I told her that the adjustment for X at home wasn't so great and that we got him help, so they should look into that. So she said she will make a note of that. It is important for them (referring to the health team) to realise or to know that going home is not going to be easy because they overlooked the going-home part. So she said she will then try and work on that part (P6 Mother, lines 189-191)*

*I think the only other extra thing you could have done, was mentally or emotionally, could have been the one, because I know he did get depressed at a certain time. That was after he was at X (referring to the rehabilitation centre) and they sent him home. From that time until he came back to school he was on another level depressed. He was sad, he was upset, he was cross with the world (P6 Teacher, line 52-56)*

#### **4.3.5.4.2 Lack of psychological support to the family**

The need for psychological support for the family is something that should be offered as part of standard service provision. In both instances below, mothers had to seek and pay for the psychological support which impacted on their already very limited budget:

*I think when one person in a family has an accident, it affects the whole family. So I think we all needed counselling, which I couldn't really afford. So I think that was something that we missed as a family because we were all battling (P2 Mother, line 88)*

*As a family we had zero support, as a family. Ja, she is the baby and she (referring to the learner's younger sister) saw what happened (referring to her son being shot in the head) The oldest one he didn't see it, but they were traumatised; we all were traumatised with it, but there was no one that came to us. We had to do our own thing. We had to go and pay people to assist us as family, because it made an impact on our lives as well. We as parents, you know, what happened at the end, it affected my husband's work. It affected me when I went to work and he had to deal with me. It causes conflict as well. We had a lot of conflict, because now I'm working, I'm moody. He had to go out of work, fetch me and then go to the hospital every day. Now this and that, and the children, we neglected them. Because now we work, we went to hospital, we work; there was nothing for them (P5 Mother, line 170-176)*

A learner's mother experienced anguish regarding the lack of psychological support for her as the main support for her daughter following the onset of the TBI. When asked if she received psychological support she responded:

*Nothing, nothing from nobody. I'm actually clueless. I'm not clueless when it comes to raising a child; I've got four kids, but I'm clueless when it comes to her, I don't know how to handle her, really (P7 Mother, line 148)*

#### **4.3.5.4.3 Timeous financial assistance from Government**

Primary care-givers mentioned the socio-economic implications of the untimely financial assistance from government (i.e. RAF or Disability Child Grant) to assist with the coverage of their children's' learner support needs. In most cases they were the primary financier for most of the service provision that learners required post TBI (either out-of-pocket or through the payment of medical aid coverage). Care-givers hence re-iterated the financial constraints that served as a challenge for them to provide their child with the needed support. In instances where they had no choice but to pay out of pocket for their child's support needs they highlighted the financial implications this had on the rest of the household.

Most learners were entitled to claims from the RAF, but most are still awaiting settlement of these claims to assist with the payment for the support that is required:

*Finance is a big part of it. When you come out of that, if the Road Accident Fund actually ever does pay you out, you have to wait 5 years, but in the first 5 years, it is when you need it most. That's your optimum time for brain injury recovery and that's when you need the therapy, when you need the support, when you need the training, it's at that point. After the 5 years it's almost ... you missed the boat (P2 Mother, line 88)*

#### **4.3.5.5.1 Financial constraints that hampers learners' access to support**

The lack of timeous compensation from the RAF places financial constraints on the family and this often impacted on learners' ability to access the needed support.

*You know that year she actually wasn't seeing anyone. We did see a psychiatrist in Grade 10. I took her to this special psychiatrist and she put her onto a lot of medication. I didn't have the finance before that to see anyone (P2 Mother, line 53)*

*This child needed much, much more serious tutoring and I was just so sad that nobody could come up with the money (P2 Teacher, line 04)*

*He came out of hospital, he gets every day physio, every day therapy; we can't go every day to X, (referring to state hospital) we don't have that money (P5 Learner, line 187)*

*Getting scribes costs money. If X parents could afford it, yes, they could get him a scribe, but we struggle as a school just to make ends meet at the end of the month, just to pay our .... I'm on the Governing Body, so I know these things. Our account is in the minus, so we don't have resources like that (P5 Teacher, line 50)*

#### **4.3.5.5.2 Financial implications on household for out-of-pocket expenditure to support the learner's needs**

The lack of timeous compensation from the RAF has financial implications on the household's budget. One mother stated that because her son was awaiting placement at a SS for more than six months, she had to quit her job to watch over him during the day as she could not afford to pay someone else to do so:

*I had to leave my job again and assist him because now he is at home and you know it didn't go well (P5 Learner, line 101)*

In another case, the mother had to personally pay for her son to access the services of a behavioural optometrist because unlike in other countries, this is not a part of standard rehabilitation care:

*We then saw X. His a behavioural optometrist in X (referring to the name of area). So he assisted also by obviously first thing was to bring Tyler's vision back – his eyesight...you know; it is all private, mostly private, because he then sells these lights... (P6 Mother, line 114-116)*

#### **4.4 CROSS CASE SYNTHESIS**

The cross case synthesis as described by Yin (2013) and Merriam and Tisdell (2016) includes an examination of the similarities and differences found across cases. This is important to determine the shared factors that influence school re-entry and school participation of adolescent high school learners post TBI and to propose personal/contextual features that explain variations. Table 4.6 depicts the similarities and differences across cases.





4.1.2	Willingness to apply personal effort to achieve goals	*	*	*	*	*	*	X	*
4.1.3	Intrinsic motivation and determination	*	*	*	*	*	*	X	*
4.2	The role of faith	*	*	X	*	*	*	X	*
4.3	Finding acceptance of changes in life circumstances								
4.3.1	Acceptance of self	*	*	*	*	*	*	*	*
4.3.2	Acceptance from others	*	*	*	*	*	*	*	*
4.4	External supports increasing learners' capacity to positively adapt								
4.4.1	Primary care-giver as advocator	*	*	*	*	*	*	*	*
4.4.2	Emotional support from significant others	*	*	*	*	*	*	*	*
4.4.3	Interdisciplinary therapeutic intervention and support	X	*	*	*	*	*	X	*
4.4.4	Financial support	X	*	X	X	*	*	X	X
4.4.5	School's commitment to inclusion	*	*	*	*	*	*	X	*
<b>Theme 5: "It would have helped to have support": Support needs for re-entrance and participation in school post TBI</b>									
5.1	Effective communication channels as part of the planning for school re-entry								
5.1.1	Lack of communication between other team members, learner and their primary care-givers impacting on the learner's preparedness for school re-entry.	*	*	*	X	*	X	*	*
5.1.2	Lack of inter-sectoral communication between the Departments' of Health and Education regarding learners' abilities and needs.	*	*	*	*	*	*	*	*
5.2	Adequate resources within the Department of Education to provide the required learner support in ordinary schools								
5.2.1	Human resource constraints in providing specialised learner support at Departmental level	*	*	*	*	*	*	*	*
5.2.2	Inadequate training of teachers in ordinary schools on relevant policy and learner support needs	*	*	*	*	*	*	*	*
5.2.3	Lack of implementation of reasonable and effective learner accommodations in ordinary schools	*	*	*	*	*	*	*	*
5.3	Accessibility and safety within ordinary schools								
5.3.1	Physical barriers	X	*	*	*	*	*	*	*
5.3.2	Attitudinal barriers	*	*	*	*	*	X	*	*
5.3.3	Safety within and around ordinary schools	*	X	*	*	*	X	*	*
5.4	Psychological support to both the learner and family	*	*	*	X	*	*	*	*

5.5 Timeous financial assistance from Government	X	*	*	X	*	*	*	*
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Key: \* = sub-category reflected in case

X= sub-category not reflected in case

Participants in this study shared many similarities in terms of their experiences of school re-entry and participation post TBI. Notably all learners experienced changes in their abilities, skills and role as a learner following the onset of the TBI.

Further similarities included learners' overall regard of school as a valued occupation. For most learners participation in school enabled the rebuilding of confidence. This however differed for learner P7 who ceased attending school. For this learner, school did not allow her the opportunity to gain an increased sense of independence due to her lack of involvement in the decision to terminate her schooling, despite her desire to continue attending school as a means to prove her recovery to others. This impacted on her sense of self-belief.

All learners regarded school as a means to bring about a sense of normality following the life altering experience of the TBI. School further served as source of motivation to drive their recovery. School allowed for social engagement for all learners. However for three learners school participation did not facilitate a sense of belonging. Two (P2 & P7) of these learners felt that their peers/educators displayed negative attitudes when they returned to school and that this attitude affected their ability to fit in and feel part of the school community. The third learner (P8) felt that the SS school she had been transferred to was no longer a good fit, given the recovery she had made. She hence felt out-of-place in this school environment.

Similarities regarding the impact of non-participation in school on recovery were reflected in three cases (P5, P7 & P8). Learners ascribed the impact of non-participation in school to aspects of their mental recovery, i.e. their cognitive abilities as well as on the way they viewed themselves.

Learners expressed that re-participation in school necessitated the use of adaptive strategies such as i.e. learning new skills, re-learning old skills, coping strategies and learner support strategies. All cases reflected the role of the learners' positive attributes towards their changed life circumstances (referring to at least one) in assisting with the adaptation process post TBI. The role of acceptance as a facilitator along learners' journeys of personal growth and recovery was evident in all cases (even in the two cases P7 and P8, that reflected the lack of acceptance (of self and by others) negatively impacted on their adaptation). In addition, external support was highlighted as a facilitator to increasing learners' capacity to make a positive adaptation.

The role of the primary care giver as the main advocator for the learners' return to school was highlighted by all participants.

Interestingly, the only case which did not give some indication of the school's commitment to inclusion was case P7: the learner ceased going to school altogether. The learner and her mother alluded to the lack of the school's commitment as a reason for her not attending school. However it should be noted that this is also a case in which the principal and teacher/s declined to participate in this study.

All cases reflected the lack of communication between the departments of health and education and its subsequent impact on understanding learners' barriers to learning and their support needs. Most learners expressed that, due to ineffective communication channels between themselves, care-givers and other team members, they did not feel that they were sufficiently prepared to re-enter school. There were however, two cases in which learners did feel prepared. The first case (P4) included a learner who has a grandmother who works in a neurological unit at a tertiary hospital and had the necessary networks to ensure that her grandson received the applicable in and out-patient services. As a result of her exposure to patients with TBI in her work setting, she also had a background regarding the changes in functioning post TBI and the probable needs of the learner. The second case (P6) in which the learner felt prepared was in an instance where - as a result of having private medical coverage - he could access in-patient rehabilitation, as well as access a private clinic where he was taught coping skills prior to his return to school. This was also the learner where his return to school was a graded process, following communication between his mother, his therapist based in the health sector and his teachers and principal. The graded return to school allowed his return to three subjects in the previous grade (where he had already displayed competency) as a way to ease him into school and rebuild his confidence prior to him being exposed to new subjects of the next grade.

The need for further training regarding inclusion and learning support came to the fore in all cases as being critical to capacitate teachers to provide the needed support. Training was also thought to be essential to bring about changes in attitude. It was evident in all cases that despite having barriers to learning, learners felt that they were not fully accommodated within the ordinary school environments. Despite most experiencing physical changes in balance and walking, all ordinary schools (including the well-resourced ordinary schools in the study) were structurally inaccessible. Physical barriers did not come to the fore in case 1 as this was one of

the only learners who was fully independent in terms of his mobility at the time of re-entering school post TBI.

Interestingly the 6 cases (P1, P3, P4, P5, P7, P8) in which learners attended schools in low socio economic areas, the impact of the lack of safety on a school's ability to cater to the learner's needs on both academic (e.g. extra classes) and extra-curricular levels were reflected. The need for psychological support was highlighted in all cases except in case P4 (in which the learner had access to psychological support services through his grandmother's work contacts).

The case which appears to deviate most from the others, is case P7. This is the only learner who after re-entering her school for a period of 3 months, ceased attending school all together. This learner and her mother reflect that, unlike other learners in this study, she did not experience a sense of adaptation through her re-participation in school, in light of her negative experiences at school. In relation to these negative experiences, both her and her mother specifically mentioned the lack of understanding of her barriers to learning and the lack of support within the learner environment (both these were part of the sub-category: school's commitment to inclusion). What was further evident, is this learner's lack of positive coping strategies which also influenced her personal attributes and hence her acceptance of her condition. The lack of coping strategies could be linked to her decreased insight, as according to Shotton, Simpson and Smith (2007, p.866) some individuals with TBI may "experience some reduction in their ability to identify and utilise coping strategies due to neuropsychological issues, e.g. PTA, confusion or a general lack of insight into their condition". This learner did not receive any therapeutic intervention in an attempt to improve her general insight into her condition.

The above cross-case synthesis shows that there are many similarities in the experiences of the learners' high school re-entry and participation post TBI. Differences that were reflected, amongst others, appear to be linked to differences in the acceptance of changed life circumstances post TBI; access to financial and human support as well as the readiness and the level of commitment of the learner environment to inclusion.

#### **4.5 CHAPTER SUMMARY**

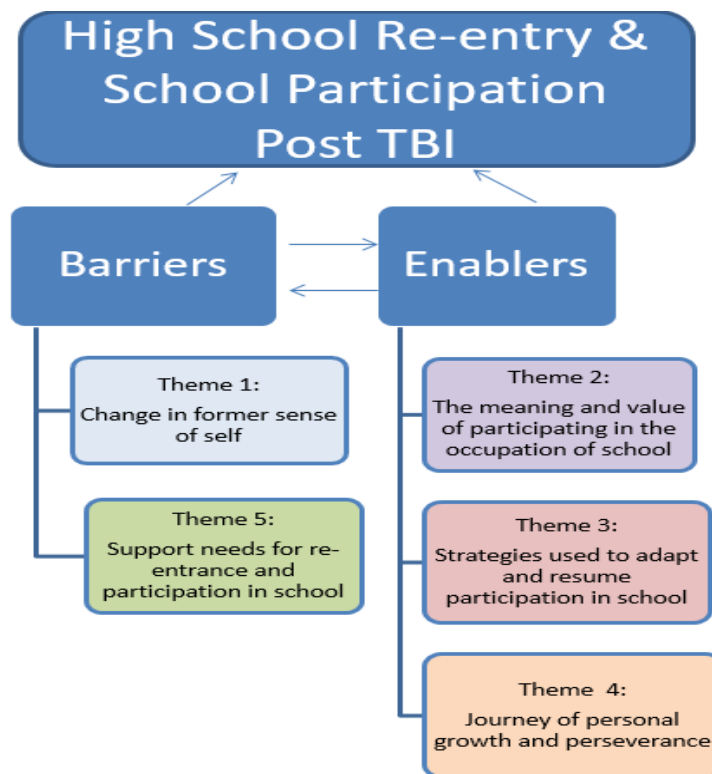
This chapter commenced with a biographical description of each learner in accordance with the importance of contextualisation in a case study.

The chapter proceeded to provide an overview of the five themes that emerged from the data pertaining to participants' perspectives on and experiences of adolescent high school learners' school re-entry and school participation post TBI. Theme one ("Kind of changed as a person": Change in former sense of self) displayed the changes in roles, skills and abilities that reflected the learners' change in former sense of self post TBI. Theme two ("School means getting further to where I want to be": The meaning and value of participating in the occupation of school) highlighted the value of school in boosting learners' confidence and motivation as well as facilitating a sense of normality and social engagement. Learners reflect that non-participation in school impeded their recovery process post TBI and resulted in feelings of incapacitation and negatively impacted on their cognitive recovery. Theme three (Trying "to get back into the swing of things: Strategies used to adapt and resume participation in school) represented the strategies used by learners as part of the school transition process post TBI. These strategies included those used to enhance day-day function, personal coping strategies as well as learner support strategies. Theme four (Carrying on and pushing through": Journey of personal growth and perseverance) reflected the role of personal attributes, faith, acceptance (of self and from others) as well as external supports in increasing learners' capacity to make a positive adaptation post TBI. Theme five ("It would have helped to have support": Support needs for re-entrance and participation in school post TBI), included those factors that are perceived gaps in current service provision that seeks to support the school re-entry and school participation of adolescent high school learners post TBI. These perceived gaps included a lack of effective communication channels as part of planning the school re-entry, a lack of adequate resourcing within the Department of Education, a lack of safety and accessibility within and around schools, a lack of psychological support to the learner and family and a lack of timely financial assistance from government.

A cross case synthesis was provided as a means to depict the similarities and differences across cases. Variations in the cases were found to be attributed to differences in personal and contextual characteristics.

The manner in which the five themes are related to each other is depicted in Figure 4.1 and may be described as follows: theme one representing the learners' change in former sense of self post TBI and theme five representing the gaps in current support services (i.e. support needs for re-entrance and participation in school) may be viewed as the barriers to high school re-entry and participation post TBI.

Theme two representing the value of engaging in meaningful occupation as a facilitator to learners' recovery and adaptation post TBI, theme three representing the strategies used by learners to adapt and resume participation in school and theme four representing the factors which help learners on their journey of personal growth and perseverance may be viewed as the enablers/facilitators to high school re-entry and participation post TBI.



**Figure 4.1: The enablers and barriers to high school re-entry and participation post TBI**

The overall experience of high school learners' re-entry and participation in school post TBI may be explained in terms of changes they experienced post TBI as well as the adaptation process that they underwent to resume and continue to participate in school post TBI (see Figure 4.2). The process of adaptation as is reflected by the participants in this study may be explained in terms of "occupational adaptation" as proposed by Schultz and Schkade (2003): "adaptation for and through occupation". Adaptation for occupation is reflected by theme three (*trying "to get back into the swing of things": strategies used to adapt and resume participation in school*). Whilst adaptation through occupation is reflected by theme two (*"school means getting further to where I want to be": the meaning and value of participating in the occupation of school*) and theme four (*"carrying on and pushing through": journey of personal growth and perseverance*). Theme five (*"It would have helped to have support": support needs for re-entrance and*

*participation in school* may be viewed as those factors which could impact on the adaptation process positively (if present) or negatively (if absent).

Learners in this study allude to adaptation as an ongoing process:

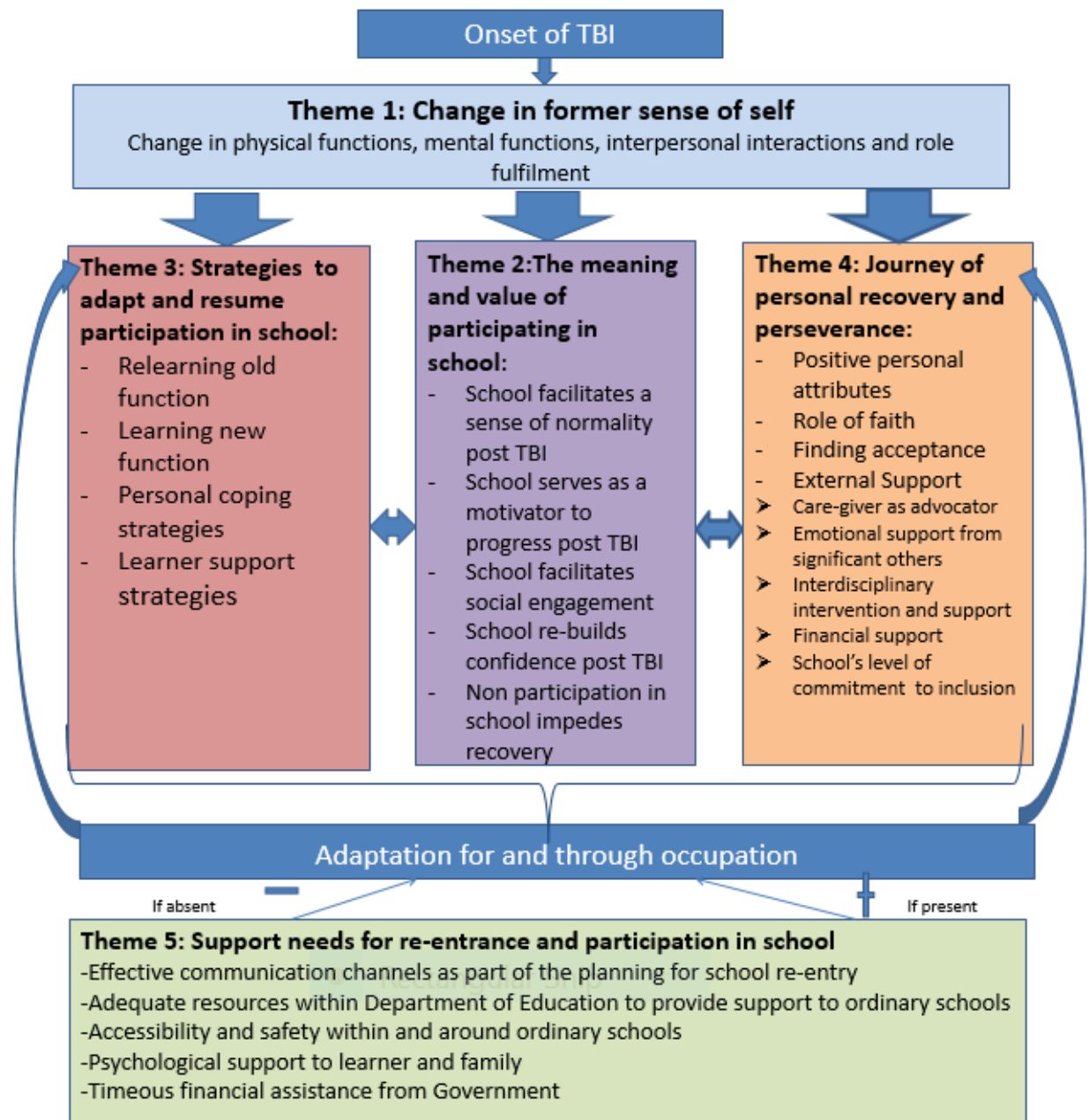
*It has been, and it's still a long journey, Miss. The journey is not finished yet (P8 Learner, line 258)*

*You know it's a long journey; it's very long (P6 Learner, line 171)*

The adaptation process is also not a linear process as was illustrated by a learner's comment that for him his adaptation process may be seen as a "back and forth" process. He found that as he encountered new occupational challenges along his journey of recovery, it brought changes in his functioning to the fore. This required him to re-accept and adapt to changes in his life circumstances:

*..there's going to come a situation that you haven't encountered before and you're going to go through that and you might not have accepted that part of your, like of how far you have recovered or what you've been through...(P6 Learner, line 208)*





**Figure 4.2: The experience of high school re-entry and participation post TBI**

The next chapter will include a discussion of the main findings of this study.

## CHAPTER FIVE DISCUSSION

### 5.1 INTRODUCTION

Chapter 5 includes a discussion of the findings that have emerged from the data. In order to augment an understanding of high school re-entry and school participation post TBI the discussion will be framed using Bronfenbrenner's Bio-ecological Systems Theory and Theory of Human Occupation as outlined in Sections 2.2.4 and 2.2.5. As the discussion will be set out in line with the objectives of the first phase of the study it is important to revisit the aim and the objectives:

The aim of the first phase of the study was to explore and describe perspectives on and the experiences of adolescent high school learners' school re-entry and school participation post TBI. It was anticipated that this would provide an improved understanding of the enablers and barriers to school re-entry and school participation of adolescent high school learners post TBI.

Objectives of Phase One that emanated from the main research question were as follows:

- To explore participants' perspectives on and experiences of high school learners' school re-entry and school participation post TBI.
- To explore the participants' perspectives on and experiences of the enablers to high school re-entry and school participation post TBI.
- To explore the participants' perspectives on and experiences of the barriers to high school re-entry and school participation post TBI.

This chapter begins with a discussion of the enablers and barriers to high school re-entry and school participation given person characteristics, the context (which includes micro, meso, exo, macro systems that interact with the chronosystem) and person-context interactions as is framed within the bio-ecological systems model. A discussion of the meaning of participating in occupation, such as school, is discussed from the perspective of learners with TBI. This chapter then proceeds with a discussion of the overall experience of high school learners' school re-entry and participation post TBI, as a process of adaptation which was introduced in Sections 2.6.2 and 4.5. The chapter ends with a summary, in which the central concept is uncovered.

## 5.2 THE ENABLERS AND BARRIERS TO HIGH SCHOOL RE-ENTRY AND PARTICIPATION POST TBI

### 5.2.1 Person Characteristics

Person characteristics refer to those factors within the person (i.e. dispositions, ecological resources such as bio-psychological assets and liabilities as well as demand characteristics that are critical to human development (Bronfenbrenner & Morris, 1998). See section 2.2.4 for further elaboration.

#### 5.2.1.1 Enablers to school re-entry and participation post TBI

When youth are able to make positive adaptations in the midst of adverse situations (i.e. the onset of a new disability such as a TBI), it allows them to re-participate in valued occupations such as school (Parsons & Stanley, 2008). Literature has shown that there are numerous mechanisms at a person level (i.e. protective factors) that may have a significant influence on youth's ability to make positive adaptations in response to adversity. These include personal attributes such as: having a positive disposition about life circumstances and the future, being goal-directed, resourceful, socially competent, possessing problem-solving skills and displaying a sense of agency (Boyden & Mann, 2005; Van Breda & Theron, 2018).

In this study, theme four: *“carrying on and pushing through”*: *journey of personal growth and perseverance*, participants highlighted that certain *personal attributes* assisted learners to adapt to their changes in functioning as well as the demands of the occupation and the occupational environment. These included a positive attitude towards changed life circumstances, the willingness to put in personal effort to achieve goals, intrinsic motivation and determination. These findings were similarly found amongst students who re-entered secondary and post-secondary educational settings post TBI (Hux et al., 2010; Todis & Glang, 2008; Stewart-Scott & Douglas, 1998).

In this study learners reflected their positive attitudes by sharing that they reframed their perceptions and used the TBI recovery experience as a means to seek out the positives in their situations i.e. being grateful for improvements they experienced in general functioning. For some learners, adopting a positive attitude included perceiving themselves as 'well-off' (i.e. more functional and independent) in comparison to others they encountered during the course of their rehabilitation (i.e. “downward comparisons”). According to Shotton, Simpson and Smith

(2007, p.867), similar findings emerged amongst participants in their phenomenological study and they report that these “downward comparisons” appeared to serve as self-esteem boosters for participants with brain injury. High self-esteem was found to facilitate “positive or better-than-expected outcomes” in adolescents in the midst of adversity (Van Breda & Theron, 2018, p.3).

Some learners stated that resuming their valued role of learner required cognitive and physical effort. Setting goals for themselves and achieving incremental success served as a means to motivate them and helped instil a sense of self-belief that they were able to overcome occupational barriers. Walder and Molineux (2017) confirm that following the onset of the TBI, individuals found motivation and displayed their perseverance and determination by setting and working towards goals of increasing independence and re-participating in valued occupations.

Similar to the findings of a study by Williams and Murray (2013, p.42), learners with brain injury in this study found that the adaptation process was facilitated by learners’ “willingness to overcome problems and try new things”. Learners used strategies to adapt to occupational challenges. These included re-learning old functions, learning new functions, employing personal coping strategies and making use of learner support strategies. This was reflected in theme three: *“Trying to get back into the swing of things”: Strategies used to adapt and resume participation in school.*

Following the onset of the TBI, learners followed the advice from therapists regarding the re-learning of functions that they performed prior to the TBI and where this was not fully possible, learning compensatory methods. The latter relate to strategies that learners initially used to adapt to the changes in functioning post TBI. Shotton, Simpson and Smith (2007, p.862) are of the view that these strategies may be indicative of individuals with TBI’s internal drive to “keep going” and further, of their determination. According to Klinger (2005, p.13) through learning and developing new ways of doing things caused learners with TBI to develop “a sense of satisfaction at being able to engage in valued occupations” (i.e. occupational competence). Increased occupational competency is linked to increased self-confidence and motivation (Walder & Molineux, 2017). Furthermore, these strategies that learners used for learning and developing new ways of doing may reflect their resourcefulness. Learners’ resourcefulness is thought to enhance their coping and therefore their ability to adapt in response to adverse situations (Boyden & Mann 2005).

Personal coping strategies in this study relate to the cognitive and behavioural actions that learners put in place in response to adverse circumstances (Connor-Smith, Compas,

Wadsworth, Thomsen & Saltzman, 2000). These include effortful responses of both engagement (i.e. active) and disengagement (i.e. avoidant) coping strategies. The former are aimed at “bringing about a change in the adverse circumstances or the associated thoughts and emotions” and the latter are aimed at “orientating oneself away from the adverse circumstances, associated thoughts and emotions” (Connor-Smith et al., 2000, p.977). In this study, learners felt that the use of engagement coping strategies such as taking active steps, taking preventive steps and seeking advice from others, helped them to make a positive adaptation and facilitated their resumption of school activities. This is supported by research that has shown that an engagement coping strategy is linked to adolescents’ increased well-being, and increased social and academic competence. Engagement coping is further considered as a promotor of positive adaptations in response to adverse circumstances. That is, engagement coping promotes resilience (Clarke, 2006).

Learners demonstrated a sense of agency by taking active steps, taking preventative steps as well as through seeking advice from others to obtain the applicable support. This further reflected the learners’ motivation and determination. The active steps that learners undertook are indicative of their assertiveness to achieve their goals. It included initiatives such as exercising preferential seating, asking questions to clarify learning material and exploring options to ensure a good tutor-learner fit. Preventative steps (e.g. making lists, pre-printing slides) were taken to prevent residual impairments post TBI (e.g. changes in memory and fine motor ability) from impacting on the learners’ ability to execute tasks linked with the various life roles they fulfil. Some learners took the initiative of seeking advice from others. For example, one learner (who as a way of asserting her occupational choice) sought advice with regards to her transfer from the SS to the ordinary school she previously attended. This allowed her to pursue a subject choice in line with her future vocational goals. It further illustrated her determination and drive. Learners reflected that by demonstrating a sense of agency they were able to adapt and re-participate in valued occupations such as school following the onset of the TBI. This finding is supported by Boyden and Mann (2005) who found that where adolescents were more actively taking control of their lives, they were more likely to make positive adaptations in response to stressful situations. The findings of a systematic review on South African child and youth resilience studies by Van Breda and Theron (2018) echoes that adolescents in the midst of adverse situations reported agency as a key resilience enabler.

The above findings regarding personal characteristics resonate with Walder and Molineux’s (2017) findings that the process of adjustment following major disease or injury, amongst other

factors, involves becoming motivated through having a positive outlook, being goal-orientated and determined.

In order for learners to adapt to occupational and occupational environmental demands participants refer to the need for self-acceptance. In this study reflection on their life circumstances and the acceptance of limitations facilitated the learners' ability to reframe their self-identity and adapt. This is reflected in theme four: *"Carrying on and pushing through": Journey of personal growth and perseverance* and is supported by Klinger (2005, p.13), whose study highlighted that it was "necessary for persons with TBI to adapt and accept the new identity (i.e. "post injury self") before an individual is able to successfully integrate to occupational adaptation". In this study some learners felt that self-acceptance - and therefore adaptation - is an ongoing process due to new occupational challenges that may bring the change in functioning and the change in their ability to fulfil their roles following the onset of the TBI to the fore. This results in the learner having to re-adapt. This is consistent with previous research where participants expressed that they were "continually adjusting to their injury or changes in their perceptions as they began to realize their limitations" (Shotton, Simpson & Smith, 2007, p.867).

Faith assisted most learners with their adaptation and recovery as it served as a source of hope and support. Having faith in a higher power also instilled confidence as these learners found security knowing that there is a God who will provide for their needs. This is supported by authors who have found that spirituality may serve as a protective factor and hence facilitate adolescents to make positive adaptations in response to adverse events; that spirituality strengthens youth's resilience (Boyden & Mann, 2005; Van Breda & Theron, 2018). The role of faith or spirituality did not feature prominently in other studies which explored a similar research focus, such as that by Mealings and Douglas (2010) and Sharp et al., (2006). This difference could be attributed to the differences in the role of faith/religion within varying contexts.

#### **5.2.1.2 Barriers to school re-entry and participation post TBI**

Within this study, learners refer to the changes in their abilities and skills following the onset of the TBI (reflected in theme one: *"kind of changed as a person": change in former sense of self*). These changes include the sequelae of impairments characteristically associated with a TBI, such as changes in physical, mental and social functions and the resultant change in the learners' sense of former self. This is congruent with the findings in studies by Mealings and Douglas (2010), Levack et al. (2010); Gracey et al. (2008) and Sharp et al. (2006) which report

that post TBI, learners experience changes in how they view themselves. If learners tend to view themselves in a negative light, this lessens their confidence and motivation and consequently, impact negatively on their adaptation and participation in school.

Physical changes include visible changes in fine and gross motor abilities and physical appearance. In addition, invisible changes such as sensory dysfunction and headaches which are not as observable to others, also occur. This is supported in literature where learners in former studies allude to the “noticeable problems” and the “hidden problems” (Sharp et al., 2006, p.770).

For some learners in this study, changes in physical abilities and skills resulted in them comparing themselves to their “able-bodied” peers (i.e. “upward comparison”) and this impacted on the way they viewed themselves. According to Shotton et al. (2007, p.867) “upward comparisons” are associated with low self-esteem and this reflects how changes in physical abilities and skills post TBI may in turn alter a learner’s self-concept and hence lower his/her sense of self belief. Changes in physical abilities and skills initially result in decreased levels of competence in that learners become dependent on others for the execution of their non-academic related activities (i.e. self-help skills). This decreased level of competence lowered the learners’ self-confidence as in order to enhance confidence and motivation, individuals should recognise themselves as being competent (Walder & Molineux, 2017).

Changes in physical appearance often resulted in learners becoming more self-consciousness and this further lowered their self-belief, as their appearance impacted on the way they viewed themselves and their perceptions of how they were viewed by others. This is congruent with the psycho-social development of adolescence, specifically middle adolescence (i.e.14-17 years) where adolescents are thought to be overly concerned with their physical appearance and how attractive they are perceived to be (Sherer & Radzik, 2016). The occurrence of headaches was a frequently reported secondary complication and this is supported in the literature (Ylvisaker et al., 2005; Hawley, Ward, Magnay & Long, 2004; Hopper et al., 2004).

Changes in mental function included changes in global and specific mental functions as explained in section 4.3.1.1.2. Notably, all learners had experienced changes in mental functions. For learners who had experienced changes in temperament and personality, this impacted on their sense of identity as they reported social changes i.e. some learners reported experiencing a change from being highly sociable to more quiet and reserved. There were also frequent reports of emotional changes (especially decreases in frustration tolerance) which



impacted on learners' interpersonal interactions and relationships. The finding of a link between changes in mental function and changes in social function is confirmed in previous studies (Glang et al., 2004; Stewart-Scott & Douglas, 1998; Ylvisaker et al., 2001).

In addition to frustration, the most commonly reported changes in emotion included depression, blame and anger. In other studies, "initial emotional turmoil and loss of control over emotions" were reported by participants and until such time that participants gained competence in establishing emotional stability they were unable to adapt (Walder & Molineux, 2017, p.235). For one learner her depression resulted in her contemplating suicide. This depression could be attributed to the learner's initial difficulty with adapting to occupational challenges and this could partly be due to her difficulties with her acceptance of the underlying changes in her functioning.

Changes in mental function such as attention and concentration, memory, psychomotor function, higher-level cognition function and processing speed affected the learners' community participation, including school participation. The learners reported that school related tasks now required more cognitive effort than before. For some learners these changes in mental function resulted in a negative change in their academic performance which led to a loss in self-belief as they compared their academic performance and standing pre and post TBI (Nochi, 1998, 2000). For these learners the decreased level of competence that they experienced in academic tasks, further decreased their self-confidence and affected their sense of self belief.

For some learners changes in mental function (e.g. change in perception) affected their ability to participate in those extra-curricular activities associated with their learner role. The change in mental abilities and function resulted in decreased levels of competence which in turn, lowered their levels of self-confidence and resulted in the learners quitting previously enjoyed activities. This finding is supported by Walder and Molineux (2017) who state that a lack of competence affects self-confidence which in turn, may impact on an individual's motivation to participate in valued occupations.

One participant's lack of general insight post TBI affected her ability to identify and utilise positive personal coping strategies and consequently, her ability to cope. She also did not display self-acceptance, which for other learners in this study, was a key component of making a positive adaptation post TBI. She subsequently did not make a positive adaptation and her schooling was terminated. This finding is congruent with a perspective on stress and coping, which states that an individual's difficulty in coping with a negative life event may result in a negative attitude toward themselves (i.e. poorer self-acceptance) or lower their confidence in



mastering their environment. This in turn impacts on their ability to make a positive adaptation and impacts on their well-being (Bryden, Field & Francis, 2015).

## **5.2.2 The context**

There are multiple levels of the environment (also known as contexts, ecological levels or environmental systems), that are interrelated and influence a person's development. These include the microsystem, the mesosystem, the exosystem and the macrosystem. These all interact with the chronosystem (time dimension) (Bronfenbrenner, 1979).

### **5.2.2.1 Microsystem**

The microsystem includes the "patterns of activities, roles and interpersonal relations experienced between individuals and the systems in which they actively participate" (Swart & Pettipher, 2016, p.14; Bronfenbrenner, 1994, p.1645). It is in the immediate environment where the person-environment interaction (i.e. proximal processes) takes place.

For this study, findings at this level revealed four microsystems in which the learner with TBI is involved, i.e. the learner's: family, peers, school (including educators such as teachers, principals and therapists within the school context) and the health team (including doctors, nurses and therapists such as occupational therapists, physiotherapists, speech therapists, psychologists, social workers, etc.).

#### **5.2.2.1.1 Enablers for high school re-entry and participation post TBI**

Learners highlighted that their *family* - from whom they received ongoing support and acceptance - enabled them to re-enter and adapt to the demands of their occupation and the occupational environment. This is congruent with the findings of Mealings and Douglas (2010) in which one of the major relationships highlighted as important in school transition and participation post TBI is that between the learner and the family. Shotton et al. (2007) state that in their study, participants with brain injury reported that support from families was invaluable in assisting them to cope and served as encouragement for them to achieve more. Unlike in the other studies which explored high school re-entry and participation post TBI, in this study learners explicitly highlighted that it was their mothers who often served as their main support, advocating for them to re-enter school and to receive the necessary learning support. In one case the grandmother was highlighted as a central support. Within the South African context,

grandparents have a role in terms of providing emotional, financial and practical support and they hence often play an important role in the lives of adolescents (Wild & Swartz, 2012). In stressful situations it has been shown that positive involvement of grandparents has the potential to benefit the overall well-being (including academic well-being) of adolescents (Attar-Schwartz, Tan, Buchanan, Flouri & Griggs, 2009; Yorgason, Padilla-Walker & Jackson, 2011).

For some learners, social engagement with their *peers* served as a motivator for them to return and to continue their participation in school-related activities. The support and acceptance from their peers contributed to their positive adaptation upon return to school. Peers assisted learners through providing them with their class notes which helped them catch up on lost work or to remain on par with academic demands. Studying in small groups with their peers (i.e. buddy systems) supported the learners in terms of their learning but also served as a motivator for them to keep up to date with their peers and hence keep up with the academic load. These findings are in alignment with other studies (Mealings & Douglas, 2010; Sharp et al., 2006). The supportive role of the learners' peer group in their adaptation process is also congruent with the developmental stage of adolescence (specifically middle adolescence) where the peer group plays a significant role in their development (Sherer & Radzik, 2016).

For two of the three learners who transferred to a SS where they were interacting with a new peer group with whom they had shared experiences - fostered a sense of belonging. According to Walder and Molineux (2017), this sense of belonging brought about as a result of interactions with a new peer group fosters confidence and motivation and hence contributes to a positive adaptation. Boyden and Mann (2005) also stated that positive peer relationships contribute to adolescents making positive adaptations in response to adversity. Interacting with their peers allows adolescents a platform where they are able to develop a sense of competency, develop relationships, empathise and experience a sense of belonging, which are important for building their self-esteem and resilience.

A *school's role* in assisting a learner to make a positive adaptation following the onset of a life altering incident has been well documented (see section 2.4.4 "resilience and youth"). In this study, learners also commented on the effect of their school's commitment to inclusion by assisting them with their school re-entry and continued school participation (reflected in theme 4: *"carrying on and pushing through": journey of personal recovery and perseverance*). In this study the school's commitment to inclusion is reflected by the positive attitude of the teachers. Learners' reported that it is the positive attitude of some of their teachers that helped them feel accepted as part of the school community and hence assisted with their positive adaptation.

Teachers who seemed to have an openness to work with the learner following his/her changes in functioning post TBI and an openness to adapt their teaching practices, helped these learners adapt to the demands of school. Similarly, in a study by Mealings and Douglas (2010, p.8), it was found that upon returning to school after the TBI, positive teacher-learner relationships were associated with positive school experiences and even in cases where learners' academic outcomes were not met, they still experienced school as "being okay".

A school's commitment to inclusion is further demonstrated by the culture within a school. In this study the school culture that learners felt assisted with their adaptation was one where a school was responsive to learner diversity and equity. In this study many of the ordinary schools respected these learners' right to return to their school and receive an education alongside their peers despite their changes in functioning post TBI. A school's responsiveness to learner diversity and equity is further reflected by learners sharing that some teachers adapted their teaching and learning methods (including the implementation of applicable instructional, environmental and assessment accommodations) to meet the needs of the learners. This contributed to some learners feeling empowered (as in the example of the learner who stated that his teacher accepted and understood his needs, and that he felt empowered by this to raise his hand in class and ask questions regarding areas he experienced difficulty in).

Learners who alluded to making a positive adaptation, are cases in which they were acknowledged as partners in learning (i.e. given choice and input regarding the structuring of their learning support). This allowed learners to display a sense of personal agency which helps to build self-confidence and helps learners to positively adapt amidst adversity (i.e. display resilience). According to Ungar et al. (2017) resilience is developed when adolescents are in school environments in which they are provided with opportunities where they are able to make their voices heard.

Schools which adopted a strengths based approach, where they focused on utilizing a learner's assets and accommodating the areas in which they experience barriers to learning, were also seen as enablers to school re-entry and participation. This also facilitated the positive adaptation of the learner. According to Mealings et al. (2016) focusing on the learners' strengths rather than their weaknesses helps to build their self-esteem and allows them to feel accepted.

Learners referred to the supportive role that *members of the health team* played following the onset of the TBI. These team members played a crucial role in motivating and supporting these learners whilst assisting them to re-learn old and learn new functions initially on an in-patient

basis and then later on an out-patient basis further down the line of their recovery. The role of the health team is also re-iterated by Bush et al. (2011, p.245), where study findings indicated that positive outcomes for learners with TBI, amongst other factors, depend “on the tenacity of professionals working to help individuals develop, modify and apply compensatory techniques effectively.” A study by Gagnon, Swaine, Champagne and Lefebvre (2008), which included the perspectives of adolescents regarding service needs post TBI, highlighted that they valued the professional rehabilitative interventions provided. This was specifically mentioned when these adolescents spoke about their needs relating to support upon returning to school.

The above findings highlight the role of supportive relationships in enhancing the capacity of adolescents to overcome occupational challenges in the midst of adversity. This is supported by Van Breda and Theron (2018) who stated that friends, primary care-givers and teachers were the most prominent sources of support that fostered a sense of belonging and value amongst adolescents. This support facilitated the adolescent to experience positive adaptation in the midst of adversity.

#### **5.2.2.1.2 Barriers to high school re-entry and participation post TBI**

Learners reported changes in interpersonal interactions and relationships post TBI. For some learners it was often the relationships with those who would naturally support them that were most affected (i.e. learner-parent, learner-sibling relationships). This is congruent with literature which reports that common difficulties post TBI include deteriorated family relationships (Mealings, & Douglas 2010; McMahon, Noll, Michaud, & Johnson, 2001; Rivara, 1994; Wade et al., 2006; Wade et al., 2003). These relationships are crucial, as without family support learners are less likely to experience a sense of belonging and emotional support which are essential in building confidence and providing the motivation needed to facilitate a positive adaptation (Ungar et al., 2017).

Some learners experienced decreased social interactions with peers following the onset of the TBI. For some this resulted in the loss of friends. The impact on the social facet of the school experience has been reported by participants in studies by Sharp et al. (2006) as well as Mealings and Douglas (2010). In this study, learners who did not experience positive relationships with their peers reported feeling isolated. This resulted in a change in their former sense of self, specifically in cases where learners reported that they were very sociable prior to the onset of the TBI. These learners did not experience a sense of belonging within their school community. These factors could result in learners experiencing school as negative and hence

affect their confidence and motivation to continue to participate in school and could negatively impact on their adaptation.

Within some cases there appeared to be a decreased level of the school's commitment to inclusion which was reflected by the negative attitudes of some teachers. The principals of the ordinary schools that these learners attended concurred that a barrier to school re-entry and participation is the negative attitude of some teachers who tend to formulate an opinion that the learner will be a nuisance and an "add on" to their already high workload. In a qualitative synthesis undertaken on clinician and educator experiences of facilitating learners' transition back to school following acquired brain injury, teachers did not make reference to added workload as contributing to their reluctance to except and support these learners within their classrooms (Hartman, Duncanson, Farahat & Lindsay, 2015). This could be attributed to the fact that in the developed contexts within which these studies were conducted, learners would have access to services such as teacher/integration aides. Services such as these assist and support teachers which in turn, increases the teacher's capacity to support the learner's needs. Teachers in these studies specifically reported that teacher aides provided them with much needed support in the classroom as they "allowed the teacher and student to focus their time and energy on the teaching and learning rather than on addressing the physical, environmental, social and or behavioural issues for which the student also requires attention" (Hartman et al., 2015, p.1395).

Participants in this study also attributed the negative attitudes of teachers to the teacher's lack of understanding of the learner's needs and required support. The perceived lack of understanding and training regarding the learner's condition and support needs were supported in other studies (Ball & Howe, 2013; Mohr & Bullock, 2005; Vaidya, 2002). The lack of understanding, coupled with the stigma of individuals with TBI as being less capable and or crazy amongst teachers affected one learner's negative feeling about her educational participation, and consequently contributed to her leaving school. Participant learners in a study by Vaidya (2002) also reported that their teachers' lack of understanding of the effects of acquired brain injuries (including TBI), resulted in their needs not being adequately accommodated and as such, resulted in five of the seven participants wanting to cease school attendance (Vaidya, 2002).

A school's decreased level of commitment to inclusion was also reflected by the lack of adaptation of teaching and learning methods to suit the needs of the learners. This was reflected by the lack of implementation of reasonable accommodations in terms of instruction

(e.g. graded return to school, adjustments in terms of work load, etc.), the environment (e.g. preferential seating, ramps, grab rails, etc.) and assessment (e.g. extra time, use of scribes, etc.) (Friend & Bursuck, 2015). For some learners this resulted in them experiencing school as stressful, given the extra effort they needed to invest in school related activities. Consequently, their performance at school deteriorated, leading to a decreased feeling of competence, confidence and motivation, which are essential elements for a positive adaptation following major injury (Walder & Molineux, 2017).

Most of the learners reported that they were insufficiently prepared for their return to school following being discharged from the hospital or the rehabilitation unit they were in which resulted in a perceived lack of competence, confidence and decreased participation in school. Generally this finding was not explicitly mentioned in other studies, as within the developed context learners were involved in “personal preparation” (Sharp et al., 2006, p.772). “Personal preparation” was specifically aimed at preparing the adolescent for their return to school whilst still recovering at home, and included completing homework assignments, social preparation which included intermittent visits from peers and educators or a school visit prior to the learner returning to school.

Some participants referred to the lack of psychological support for learners specifically when the learner is discharged home. It is upon discharge when the learner is often dependent on others in the household and when the changes in functioning post TBI are most apparent. This is a very different scenario from when learners were in health-care environments which were structurally accessible and where they were amongst others who were dependent on health care providers for daily support (i.e. where dependency was the norm). Learners hence had difficulty adapting upon their return home. The key message that emerged from the study by Mealings et al. (2016) was that when preparing and supporting these learners for their return to school, the focus must be broader than purely academic outcomes. The need for psychological support from the relevant health professionals is also important given that learners have to deal with the “emotional conflict of having to replace their pre-injury self with a post injury concept that is both meaningful and satisfying” (Tipton-Burton, McLaughlin & Englander, 2005, p.851).

### **5.2.2.2 Mesosystem**

The mesosystem includes the interconnections between two or more microsystems (Bronfenbrenner & Morris, 1998).

#### **5.2.2.2.1 Enablers to high school re-entry and participation post TBI**

Notably where parents acted as intermediaries between the health and the educational teams, some schools were kept abreast of the learner's progress by parents requesting reports from the health teams and submitting this to the school or through parents relaying information from the health team regarding their child's condition, strengths and needs. As a result, teachers had an increased understanding of a learner's needs which assisted them in offering learning support. For some learners, learning support in the form of instructional, environmental and assessment accommodations (when implemented correctly) increased their self-confidence and facilitated their school participation. Parents in an ethnographic study in the USA, similarly acted as intermediaries between the two teams and reported more positive outcomes in terms of their child's adaptation and academic progress as teachers more readily implemented the applicable accommodations (Crylen, 2015). However, the parents highlighted that this strategy was only effective when it included the relaying of information to the teachers who were directly involved in the teaching of their children.

Hartman et al. (2015) caution against parents/family being the only source of information to the school team with regards to the learner's condition, needs, progress and potential for recovery as they do not always accurately or completely divulge information pertaining to the learner. These authors report that there were instances in studies where parents over-reported the extent of the severity of the child's residual impairments out of fear that the school would not deem the nature and extent of the learner's needs severe enough to warrant learning support. Some parents tend to do the opposite and under-report due to embarrassment of their child's abilities. However it should be noted that where parents felt that the school was open to communicating with them, they would more readily divulge pertinent information regarding their child's condition, needs and prognosis.

#### **5.2.2.2.2 Barriers to high school re-entry and participation post TBI**

As learners were minors at the onset of the TBI, primary care-givers were involved in organizing their children's return to school. Some care-givers hence reported that during the organisation of their child's return to school, information regarding the process of facilitating their child's return to school was lacking from members from both the health and education teams. An example of the detrimental effect of this lack of communication is illustrated in a case where the timing of a learner's school re-entry was delayed whilst his parents were blindly looking for school options that best fit his current needs. This resulted in the learner sitting at home for a



period of over six months without attending out-patient therapy or following a home-programme and this impacted on his recovery. Mothers in an ethnographic study in the USA, echoed their frustration about the lack of communication from other team members, with more than 75% of these parents expressing that details and recommendations on how to facilitate their child's return to school were lacking (Crylen, 2015).

Learners, parents and educators (i.e. teachers and principals) in this study felt that the communication regarding the learner's condition, strengths and needs from the department of health to the school was inadequate. As a consequence, teachers were ill-prepared for the return of the learner in that they were unsure of what to expect and how to support the learner given their barriers to learning post TBI. In some cases this resulted in a mismatch between a learner's current abilities and the teacher's expectations. Learners reported that expectations that were too high meant that they were not able to deliver and this in turn affected their sense of competence and confidence and negatively impacted on their school participation. For others the lack of inter-sectoral communication meant that they did not receive the needed learning support and this impacted on their school participation as outlined in section 4.3.5.1.2. The need for a formal link between health and educational teams were similarly shared by participants in other studies where learners reported that the lack of communication from the health team meant that teachers were unable to implement the applicable accommodations needed to optimize the learners' school participation (Gagnon et al., 2008; Crylen, 2015).

Within this study one learner explicitly mentioned the need for the members of the health team to formally address her peers at her ordinary school during the course of an assembly. For this learner, this action would facilitate a better understanding of her condition and needs. She felt that this could have lessened the stigma she perceived amongst her peers regarding individuals with brain injury. She reported that this perceived stigma resulted in her being fearful and therefore presented another barrier against her transition from the SS to the ordinary high school to pursue the subject choice she needed to attain her future career goals. Although this was only explicitly highlighted by one learner, it is worthwhile to mention as literature has shown that learners with TBI experience repeated questioning by peers, unwanted special treatment or teasing (Sharp et al., 2006, p. 776). Literature has further shown that the education of peers assists with awareness and understanding of TBI, which results in more positive peer reactions upon the learner's return to school which could assist the learner in feeling supported. Feeling supported helps learners to feel that they better "fit in" or belong and increases their feelings of acceptance, which in turn could help to build self-confidence and motivation and hence assist their overall adaptation (Sharp et al., 2006; Abbot & Wilkinson, 1992). The main support of the



learner, i.e. the primary care-givers, indicated that the family unit did not receive adequate psychological support from members of the health team. Findings in literature support this contention, as it has been found that emotional support was the greatest unmet need for the learner and his or her family (Davies, Gfroerer, Wade & Wu, 2008). Primary care-givers in this study stressed that the TBI impacted on the family unit as a whole and not solely on the individual learner. Literature also reports that post common TBI-related difficulties include: a decline in a family's interpersonal relations and coping resources; increased stress and the burden experienced by family members as well as increased psychological symptoms exhibited by parents and siblings (Mealings & Douglas 2010; McMahon et al., 2001; Rivara, 1994; Wade et al., 2003; Wade et al., 2006). Inadequately supporting the learner's family can serve as a barrier for the learner's school participation as the learner relies on the family for support. Furthermore Boyden and Mann (2005) argues that adults within the family often model and reinforce the motivation, problem-solving and coping skills that learners require to facilitate more positive adaptations in response to adverse situations. The chances of such mentoring however, decreases when the adults within the family do not have the necessary coping resources. The lack of psychological support to a family, including the lack of strengthening of the family's coping resources, may therefore impact on the support that the learner needs to adapt; it impacts on a learner's school re-entry and school participation post TBI. A learner who feels supported by his or her family is able to feel more confident and motivated, and if other environmental supports are in place, is more readily able to make a positive adaptation and achieve more favourable outcomes in terms of school participation.

### **5.2.2.3 Exosystem**

The exosystem refers to "one or more environments in which the developing learner is not involved directly as an active participant but which may influence or be influenced by what happens in settings and relationships that directly influence the learner" (Swart & Pettipher, 2016, p.15).

#### **5.2.2.3.1 Enablers to high school re-entry and participation post TBI**

For some learners, the social networks that they had access to as a result of family members served as enablers to them for their return to and participation in school. For one learner, he was privy to support services on an in and out-patient basis through his grandmother's work contact. He reported that the support he received made him feel more prepared to re-enter school.

A further source of support for some learners, was the contribution from members of their church community who continuously held them in prayer. Learners felt that this support instilled some hope and served as means to motivate them to “keep going” and work towards their recovery. It was also through a church member that one learner was put in touch with a behavioural optometrist who assisted him with his double vision, which was an area that greatly impacted on his ability to participate in school (i.e. see and copy from the board as well as mobilise the school grounds safely and independently). Crylen (2015) reports that parents of learners with TBI referred to the role of the community as a familiar and constant source of support. The community provided support throughout the learner’s recovery and whilst the parents were exploring the resources that would support their child’s school re-entry and school participation post TBI.

#### **5.2.2.3.2 Barriers to high school re-entry and participation post TBI**

Within the Western Cape Education Department (WCED), the context in which this study is situated, teachers specifically highlighted that they do not have access to the specialist services of team members comprising the DBST. As a consequence, the learners were therefore not being referred for the necessary psychological support. Psychological support is important as school re-entry and participation is likely to occur during a time when the learner is undergoing a period of adaptation and re-construction of self, following changes in functioning and in their former of sense of self (Mealings et al., 2016).

For one well-resourced ordinary school in particular, the lack of adequate access to specialist services from the DBST meant that the school tended to deal with the learner and her ongoing needs internally via the SBST. This raises questions about how the WCED is able to fulfil its responsibility (as outlined in DoBE, 2014) to monitor the individual support plan that has been put in place for such learners to ensure that it is applicable to learners’ needs, implemented correctly and adapted when applicable. The need for the monitoring of the implementation of accommodations for learners with TBI was highlighted in the study by Sharp et al. (2006) where findings reflected that some schools were not implementing the accommodations that they had promised. Furthermore, in schools where there were accommodations for learners these were implemented within varying degrees across classrooms, with learners or parents often having to remind teachers to implement the accommodations.

In this study, learners, parents and educators (i.e. teachers and principals) felt that teachers were ill-informed about the learner’s support needs and did not have the skills to put the

necessary support in place. Teachers and principals attribute this lack of knowledge and skills to the lack of undergraduate training and inadequate professional development training opportunities for teachers on inclusive education and learning support by the WCED. Teachers and principals hence expressed that they did not feel capacitated to assess learners' barriers to learning nor were they able to put the necessary learner support in place. This serves as a barrier for learners post TBI as according to Davies Gfroerer et al. (2008), delaying service provision for the learner may exacerbate barriers to learning as well as result in the misidentification of the condition (e.g. severe behavioural problem rather than TBI).

Decreased capacity of SSs within the WCED to serve as resource centres, may be viewed as a barrier to school participation post TBI. The decreased capacity of SSs to serve as resource centres is contrary to the expectations of DoBE (2014) that resource centres should ideally be providing out-reach specialist services to ordinary schools for learners who experience barriers to learning. However, due to human resource constraints within SSs, this is not operational and learners (specifically those with moderate learning support needs) are not adequately being supported which could in turn, impact on their school participation.

For some parents and educators in this study, the incapacity of the WCED to provide more SSs could be viewed as a barrier for learners for whom an ordinary school is currently not a good fit given the level and extent of the learning support required. These learners currently have to wait for placement given the long waiting lists for existing SSs in the province. This may have a detrimental impact on the learner as discussed in Section 4.3.5.2.1. However it could be argued that if ordinary schools were capacitated with a better infrastructure and adequately trained staff who displays openness to inclusion and if there were more full service high schools, most learners could be supported within these learner contexts. This would lessen the demand for highly specialist services at SSs.

Community safety (including safe places to walk, learn and play) have been linked to an increase in an adolescent's capacity to make a positive adaptation in the midst of adversity (Van Breda & Theron, 2018). In this study the lack of community safety in which learners attended school and lived served as a barrier to school participation. For many of the schools in unsafe areas it was not possible for them to offer after-school learner support or extra-curricular activities out of fear for the safety of the learners and the educators. Primary care-givers in this study mentioned that they were fearful for their children's safety as they travelled to and from school. The safety of learners was not mentioned in other studies as a barrier to school re-entry and participation post TBI. It should however be noted that the Western Cape Province has a

reputation for being one of the most violent provinces in the country. The WCED has thus implemented initiatives such as the “walking bus initiative” (before school - where members of the community volunteer to walk with learners to and from school), “safe schools programme” (during school - including putting safety measures in place such as access control, security systems, emergency procedures and youth development) and after school programmes for non-fee schools which includes access to safe sport opportunities, academic support, arts/culture and life skills (Western Cape Government, 2017). From the interviews conducted in this study it appeared that these programmes are not fully operational in the areas that the learners lived in or attended school.

#### **5.2.2.4 Macrosystem**

The macrosystem refers to “dominant social and economic structures and the attitudes, beliefs, values and ideologies inherent in the systems of a particular society” (Swart & Pettipher, 2016, p.15).

##### **5.2.2.4.1 Enablers to high school re-entry and participation**

South African policies as highlighted in sections 2.5 and 2.6.4.3, specifically White Paper 6: Special Needs Education - Building on Inclusive Education and Training System (DoE, 2001) and SIAS (DoBE, 2014), may be viewed as enablers to school re-entry and participation as these policies specifically advocate for the basic right to a quality education for all learners to be upheld. These policies serve to promote the inclusion of all learners within the educational system, including learners with TBI.

##### **5.2.2.4.2 Barriers to high school re-entry and participation**

The poor implementation of key South African policies largely due to inadequate resourcing may be viewed as a barrier to school re-entry and participation. National budget constraints have impacted on the National Department of Basic Education’s capacity to meet its objectives in terms of fully operationalizing key policies such as SIAS (DoBE, 2014). Examples include the lack of training of the targeted number of educators and not meeting targets in terms of the provision of human resources. For further elaboration see section 2.5.2: Challenges facing inclusive education in South Africa. This impacts a learner’s school re-entry and participation post TBI given the interrelatedness of the various systems within the learner’s environment.

For learners in this study who were unable to access education due to long waiting lists at SSSs or the school environment's inability to provide adequate learning support, this may be viewed as a form of injustice. The non-participation in school for these two learners (i.e. P5 and P3) led to them being marginalized and socially isolated which impacted on their general well-being (Rodger & Ziviani, 2009).

The stigma attached to individuals with TBI as being less capable prevails within societies. In this study learners refer to the negative reactions of those in their environment, which reflects society's need for people's personal belief system and hence their behaviour to evolve to viewing learners with TBI as individuals who are capable specifically in environments where their diversity is embraced and where they are supported in the manner that is applicable to their needs.

Primary care-givers highlighted that learners are often not able to access the support services that they require due to financial constraints and this negatively impacts on the learners' school participation. This may be viewed as learners experiencing a form of occupational deprivation (Whiteford, 2003). Primary care-givers further stated that in an attempt to provide the learner with the needed support often placed a further financial burden on the household's budget. Primary care-givers hence voiced the need for the more efficient processing of third party claims such as that administered by the Road Accident Fund (RAF) (which averages 5 years for the settlement of a claim) and government support such as disability child grants. This is important, as it is specifically during the initial 2 years where there is a window for recovery to be facilitated by therapeutic intervention (Fleminger & Ponsford, 2005). A similar finding was found amongst individuals with TBI in a South African study where participants reported that they were frustrated and felt disempowered by the administration process of the RAF (Soeker, 2009).

Inequities in terms of access to support provision were apparent in this study. Those who had the financial means to afford private medical aid coverage were more readily able to access in-patient rehabilitation and other support services such as in-patient clinics where they could receive input on coping strategies and adapt to their changes in functioning. Inequities in terms of access to support post TBI was also evident in the difference between those individuals who sustained a TBI as a result of a road accident and would hence be eligible for compensation via the RAF (providing for future support needs) and those who sustained TBI due to other causes such as gunshot wounds. For those who experienced less access to support, one could argue they are occupationally deprived as the circumstances mentioned above impacted on these learners' ability to engage in meaningful occupations such as school (Whiteford, 2003).

### 5.2.2.5 Chronosystem

The chronosystem includes “the dimension of time and how it relates specifically to the interactions between systems and their influences on individual development” (Swart & Pettipher, 2016, p.16).

Within this study the remnants of the apartheid system still impact on learners today as was reflected by the differences in availability of on-site resources (i.e. human and technical) to learners in former Model C (historically white advantaged schools) vs ordinary government funded high schools.

The findings of this study also revealed that although inclusive education had been implemented and policies such as the White Paper 6: Special Needs Education - Building on Inclusive Education and Training System (DoE, 2001) and SIAS (DoBE, 2014) provide guidance on inclusive education provisioning in South Africa, schools have not been prepared for the changes needed in the education system over time. This is evidenced by study participants' reports of:

- structural barriers within schools
- teachers reporting a lack of technical equipment needed to provide alternative instruction and assessment
- teachers reporting inadequate training on inclusive education and the relevant policy
- learners' being inadequately supported by structures within the school and the district.

The bio-ecological systems model was used to frame the enablers and barriers to high school re-entry and participation post TBI. It was demonstrated that post TBI, both internal and external resources (at multiple levels) are instrumental to facilitate the adaptation process and the re-participation in valued occupations such as school.

## 5.3 THE VALUE OF OCCUPATION

Literature (as outlined in section 2.6.1) has shown that the engagement in occupation such as school has benefits in terms of helping individuals to give meaning to their lives, adapt to occupational challenges and facilitate an overall sense of well-being.

Learners all alluded to school as a meaningful occupation and this was reflected in numerous ways. Learners expressed that school re-entry and participation facilitated a sense of normality

post TBI. Mealings and Douglas (2010) report that within their study learners similarly viewed school as a part of their everyday lives thus making it a natural phase in their life participation following the TBI. In this study participants highlighted that it was important for learners not to be singled out but rather that they felt part of the school community. The sense of belonging and acceptance boosted their self-confidence and motivation and hence assisted with a positive adaptation.

Many learners regarded school as a motivator as it allowed them an opportunity to display competence, a sense of who they are and to work towards them achieving their future goals. This is confirmed in a study by Mealings and Douglas (2010), where learners saw school as a place where students develop a sense of identity and their career path.

For some learners school was seen as constructive, i.e. it allowed for productive use of time and encompassed an element of practicality which allowed them to demonstrate their practical skills. Through mastering these practical skills they were able to experience a sense of competence at a time when they are often confronted by their diminished abilities as a result of the TBI. Experiencing competence strengthened their sense of self belief. Mandich et al. (2001) state that mastering activities linked to the roles a child fulfils, leads to a positive self-identity. Interestingly the view of school being constructive, particularly resonated with the perspectives of male learners. Research has shown gender differences in coping with TBI, where amongst other factors, males coped by making productive use of their time and through adopting a realistic view of their limitations (Shotton et al., 2007).

School participation facilitating social engagement was important for learners who had experienced changes in interpersonal interactions and relationships as it allowed learners to feel a sense of connection with those in their school environment and helped to re-build their school identity. This finding is congruent with study findings of Mealings and Douglas (2010) and Sharp et al. (2006), where learners expressed that the socialization within school was important as it allowed them to experience a sense of belonging, acceptance and positive recognition.

School facilitated a sense of belonging, specifically amongst learners who felt that they had shared experiences with their peers. In the cases P3 and P5 in this study, learners were transferred from ordinary high schools to SSs where their peers had similar conditions. A sense of connectedness with their new peer group, contributed to feelings of acceptance which according to Walder and Molineux (2017), is fundamental to re-building self-identity.



In Western societies adolescence is a time during which the individual starts to develop independence (Wild & Swartz, 2012). However, following the onset of the TBI and the subsequent changes in function, many learners lost their level of independence. School participation helped increase independence in that learners were able to take some ownership of decisions pertaining to their school re-entry e.g. which subjects they would opt for first when their return to school was a graded process. For other learners the fact that their learner environment allowed them to work independently allowed them to experience a sense of independence in school after a recovery process which included a period of dependency on health-care personnel or family members. Walder and Molineux (2017) state that the adaptation process following major injury or illness is often marked by individuals taking on personal responsibility and moving towards being autonomous.

The findings of this study highlight that where learners were able to master skills and experience competence through participating in occupations and experience understanding and acceptance from those in their occupational environment, they were able to re-build confidence. According to Walder and Molineux (2017), this is critical for positive adaptation.

Awaiting placement in SSs affected learners' participation in school. Learners' basic right to access a quality education was infringed. These learners hence experienced occupational marginalization (Townsend & Wilcock, 2004). For the learner who remained at home for a period of six months, non-participation in school meant that he was not receiving the stimulation (i.e. outpatient-therapy/following a home programme) to assist his recovery nor was he receiving the applicable learning support. This learner hence experienced occupational deprivation (Whiteford, 2003). The second learner who - whilst awaiting placement at the SS school - continued to attend the ordinary school despite it not being a good fit given the level and extent of the barriers to learning he experienced. Remaining in the occupationally unjust environment meant that this learner did not experience a sense of occupational meaning or enrichment and he therefore experienced occupational alienation (Townsend & Wilcock, 2004).

After three months of attending school post TBI, a third learner ceased attending school and remained home as a result of the learning environment not being a good fit given attitudinal barriers and the lack of support to meet her barriers to learning. She also experienced occupational deprivation and occupational alienation as non-participation in school resulted in her feeling isolated (i.e. disconnected from her peers) and she experienced that without school, she had no purpose nor structure to her days.



#### 5.4 ADAPTATION AND SCHOOL POST TBI

Given the diverse nature of a brain injury and individual differences there are no set rules regarding the best ways to cope and adapt. Walder and Molineux (2017, p.235) describe an individual's adaptation post TBI as a journey, during which there is movement "from a state of denial, escapism and difficulty adjusting to occupational challenges and their underlying causes, through to a state of adjustment and acceptance of the changed reality". In this study learners' shared that their adaptation was a process which included self-acceptance of their changes in functioning post TBI (i.e. physical, cognitive and social), changes in their life roles as well as changes in their environment. Within this study there were learners along varied points of the continuum of adaptation, some who had not reached a state of self-acceptance and therefore had difficulty adapting and others who had made a positive adaptation.

Learners further reflected that adaptation is a difficult and ongoing process which includes a process of re-building self-identity and drawing on both internal and external resources. These internal resources were identified as personal positive attributes and coping strategies. External resources were reflected by the external support (including understanding and acceptance of the learner post TBI) received from significant others (notably immediate family), peers, interdisciplinary team members, the community and their school's level of commitment to inclusion.

The re-building of their self-identity was facilitated through the engagement in occupations such as school that allowed for a sense of purpose and meaning. The value of engagement in occupation in terms of facilitating the adaptation process is captured by the words of a learner:

*I think when you go back to school and communicate with the other children and see that the other children are doing what you are doing, you are able to do what the other children can do, that you're able to focus to do your schoolwork and everything. I think it (referring to school) is also a way to help us go through what we are going through, the trauma thing that we're going through. I think it can also help a person. (P8 Learner, line 311)*

This finding is supported by Gracey et al. (2006) who state that when individuals with TBI engage in occupations they experience a sense of belonging and feel as though they are capable. It reinforces who they are and allows them to experience a sense of connectedness.

Walder and Molineux (2017, p.238) contend that the adaptation process involves the individual "finding motivation and becoming confident". In this study learners who have made positive adaptation reflect that they were intrinsically motivated but also extrinsically motivated by their

support network. These learners further stated that through engagement in occupation and having the opportunity to master skills, they were able to re-build self-confidence. They also reflect that their self-confidence was further bolstered by the confidence that they had within their support networks from which they received understanding and acceptance.

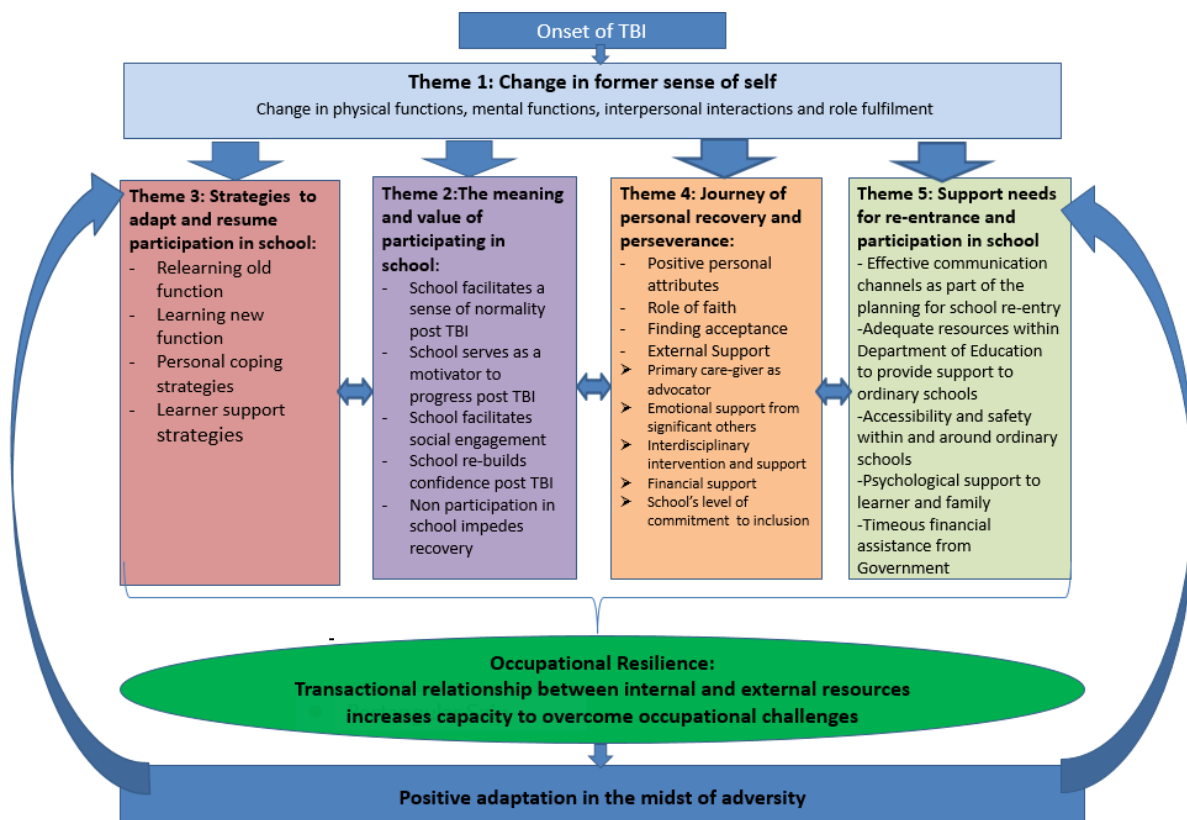
## 5.5 CHAPTER SUMMARY

Chapter 5 sought to discuss the personal, contextual and occupational factors that serve as enablers or barriers to high school re-entry and school participation post TBI. In doing so, it became apparent that following the onset of the TBI learners experienced a change in their former sense of self. Furthermore, it was reflected that their levels of competence, confidence and motivation were negatively affected.

Learners expressed that their overall experience of high school re-entry and participation post TBI may be viewed as a process of adaptation. The process of their adaptation was facilitated by internal resources (i.e. personal factors) and external resources (i.e. enabling environments) (as is reflected in theme 3: *adaptive strategies used to resume and participate in school* and theme 4: *journey of personal growth and perseverance*). Learners felt that this process of adaptation is an ongoing and difficult journey. However, in terms of Ungar's (2008; 2011; 2012) concepts of "navigation" and "negotiation", findings reveal that when a learner is able to draw upon internal resources and is able to "navigate" and "negotiate" the support resources within his/her environment, their capacity to make a positive adaptation was increased. According to a socio-ecological perspective, this capacity is referred to as *resilience* (Masten 2014; Ungar et al., 2017; Ungar, 2011, 2008; Ungar et al., 2007). Learners further reflect that the process of adaptation was facilitated through participation in the valued occupation of school.

The findings of this study thus highlight two concepts: Firstly, the concept "occupation" as in line with Schultz and Schkade's (2003) definition of occupational adaptation, it was through preparing themselves for the re-participation in occupation that learners started to make adaptations (i.e. re-learning old functions, learning new functions and employing personal coping strategies: theme 3: *adaptive strategies used to resume and participate in school*). However it is also clear that through participating in occupations (e.g. school comprising academic, non-academic and extracurricular activities), learners were able to adapt (i.e. theme 2: *the meaning and value of participating in the occupation of school*).

The second concept is “resilience” (as conceptualised in section 2.4.4). In this study it was reflected that through the transactional relationship between internal and external resources it is possible to increase the individual’s capacity to make a positive adaptation amidst adversity (i.e. following onset of a life altering injury such as TBI). The central concept that is therefore proposed to assist learners with making a positive adaptation to allow for the meaningful participation in their valued occupations is that of “occupational resilience” (see figure 5.1). This will be further elaborated upon in Chapter 6 where the central concept will be used in theory generation to meet the second objective of the study namely to develop a practice model to facilitate high school re-entry and school participation post TBI.



**Figure 5.1: Illustration of the central concept of occupational resilience**

## **CHAPTER 6**

### **THE DEVELOPMENT OF A PRACTICE MODEL TO FACILITATE HIGH SCHOOL PARTICIPATION OF ADOLESCENT LEARNERS POST TBI**

#### **6.1 INTRODUCTION**

The main concepts of occupation and resilience were developed from the empirical findings of this study. These main concepts served as the basis for the development of the practice model. Chapter 6 includes the discussion of the concept analysis, which was the first step in the development of the practice model.

#### **6.2 CONCEPT ANALYSIS**

Concept analysis included identifying, classifying and defining the main concepts of the practice model to facilitate high school participation of adolescent learners post TBI. The main concepts were identified upon reflection of the unified descriptions of themes, categories and sub categories across all cases. This allowed for a global picture of participants' experiences of high school re-entry and participation post TBI and facilitated the identification of the main concepts that informed the development of the practice model.

##### **6.2.1 Identification of the main concepts of the model**

As outlined in Section 5.4, the findings of this study revealed that following the onset of the TBI, adolescents experienced changes in physical, mental and social functions as well as changes in their role as learner. These changes resulted in an altered former sense of self. Furthermore, it was evident that the learners' levels of competence, confidence and motivation were negatively affected due to their changes in functioning and their inability to fulfil valued life roles.

Most of the adolescents reflect that post TBI they were not adequately prepared for the resumption of valued life roles, such as that of learner. They further felt that to resume these roles required a process of adaptation. The process of adaptation was ongoing and difficult; it required that learners increase their belief in their personal capability and rebuild their self-identity by: reflecting on their life circumstances, trying to accept their limitations and adjusting their future life goals based on who they are post TBI. In this study, adaptation therefore required introspection and self-acceptance. Adaptation further required the learner to be willing

to take active steps (i.e. make use of cognitive and behavioural coping strategies) and attempt “doing” in other ways (i.e. learn new function and employ learner support strategies).

Learners reflected that the role of an enabling environment was critical to the adaptation process. External support was important in terms of helping learners to experience a sense of belonging and acceptance. The sense of belonging and acceptance contributed to the adolescents’ ability to re-build their confidence and motivation to “keep going” and engage in meaningful occupations such as school.

It was thus evident that for learners in this study the process of adaptation was facilitated by learners drawing upon internal (i.e. personal) and external (i.e. environmental) resources (as is reflected in theme 3: *strategies to adapt and resume participation in school*). The findings of this study show that some learners were able to make a positive adaptation when they were able to “navigate and “negotiate” support resources with the facilitation of their environment. This according to a socio-ecological perspective, is referred to as resilience (Masten, 2014; Ungar et al., 2017; Ungar, 2011, 2008; Ungar, et al., 2007). Resilience has hence been identified as the main concept of the model describing adaptation.

In addition, learners felt that the process of adaptation was facilitated through participation in the valued occupation of school. It was through preparing themselves for the re-participation in occupation that learners started to make adaptations; a perception that formed part of the categories *re-learning old functions, learning new functions and employing personal coping strategies* (theme 3: *strategies to adapt and resume participation in school*). However it is also clear that through participating in occupations (e.g. school comprising academic, non-academic and extra-curricular activities) that learners were able to experience purpose and structure, display competence, re-establish a sense of belonging and increase levels of independence. Ultimately, this participation assisted them in re-building their confidence and motivation which facilitated a positive adaptation and the re-building of their self-identity (i.e. theme 2: the *value and meaning of participating in school*). Occupation is hence identified as the second main concept.

The central concept that was therefore proposed to assist learners with making a positive adaptation to allow for the meaningful participation in their valued occupations was that of “occupational resilience”. The analysis revealed that the occupational therapist could facilitate these learners’ school re-entry and participation by developing or strengthening their resilience through building their internal (i.e. personal) resources through their engagement in occupation

as well as by fostering an enabling environment (further expanded upon in section 7.2.). The model will therefore focus on “occupational resilience” as a mechanism to facilitate adolescents’ high school re-entry and participation post TBI.

### 6.2.2 Classification of the concepts of the model

Occupational resilience has been identified as the central concept in this study. A model facilitating high school participation post TBI is based on this central concept. The classification of the concepts of this model will now be explicated in terms of the agent, recipient, context, dynamics, procedure and terminus (Dickoff, James & Wiedenbachs, 1968, p.422):

- **Agent:** In this model the agent refers to the occupational therapist that plays a role in the school re-entry and school participation of the adolescent with the TBI. The occupational therapist may be situated within a health-care setting (i.e. hospital or rehabilitation unit) or educational setting (i.e. occupational therapist employed by the department of education).
- **Recipients:** The primary recipient is the adolescent with TBI, who is currently in mid to late adolescence (i.e. of high school attending age, i.e. 14-21 years old), who is functioning on Level VIII of the Ranchos Los Amigos Cognitive Scale (purposeful and appropriate). This model does not serve to exclude adolescents on lower levels of the scale; instead it seeks to be relevant and responsive to the findings of this study, where learners have shared that in order to make a positive adaptation it required introspection and acceptance of their changes and limitations in functioning post TBI. The model was therefore developed for adolescent learners who are orientated, able to learn and carry over skills, have the ability to increase their insight into both their strengths and limitations and who are able to develop their problem solving and planning abilities (Case-Smith & O’Brien, 2015). Other recipients include key role players involved in the learners’ re-participation in the occupation of school such as their family, teachers, principals, peers/friends and those in the community (i.e. other health or educational team members as well community organisations).
- **Context:** The development of the model of high school participation post TBI occurred within the context of relevant policy, the health care-setting i.e. hospital or rehabilitation unit, as well as the adolescent learner with TBI’s high school and home contexts.
- **Dynamics:** The dynamics that serve as energy and drive source for this model include the need or desire of adolescent learners with TBI to re-participate in valued occupations, such

as school. These learners experience a change in the ways that they make sense of themselves given changes in their abilities, skills and role fulfilment post TBI. This in turn impacts on their belief in their personal capacity to cope and positively adapt to their changed life circumstances post TBI. Learners' abilities to adapt to occupational challenges are also dependent on the level and extent of the environmental support that they receive.

- **Procedure:** The occupational therapist serves as a facilitator during the process of strengthening or developing the resilience of the adolescent learner with TBI. This is facilitated through cultivating the learners' belief in their personal capacity to adapt to occupational challenges in the midst of adversity and participate in occupation. In addition, through the engagement in tasks and activities that underpin occupation, the occupational therapist facilitates opportunities for the adolescent to experience mastery, competence, confidence, motivation and a sense of personal agency which further bolsters the adolescent's internal resources. The occupational therapist further fosters an enabling environment that supports the learner's participation in school. The process includes the learner and his/her family, relevant role players in the school (i.e. teacher/s, principal and peers) and community contexts (i.e. other members of the interdisciplinary team, or community organisations) who could serve as sources of external support.
- **Terminus:** Through a process of strengthening the resilience of the adolescent learner with TBI, they will experience an increase in their capacity to adapt to occupational challenges and participate in meaningful occupations such as school.

### 6.2.3 Definitions of the concepts of the model

Section 6.2.3 provides an overview of the concept definitions of the model, a model case, descriptions of main concepts of the model and the final definition of the central concept of the model.

The central concept of Occupational Resilience, was defined according to: i) dictionary definitions of the concepts in the main concept, ii) contextual subject specific definitions and iii) conceptual definition (Chinn & Kramer, 2015, p.168-171).

- **Dictionary definitions of the concept of occupation**  
Occupation is defined by the Oxford Dictionary (2014) as "a job or profession, a way of spending time; the period, **action** or state to **occupy** or the **action** of entering and taking

control". The Collins dictionary (2018) defines occupation as a "person's regular work or profession; job or principal **activity**; any activity on which time is spent by a person; that which chiefly **engages** one's time; or something that you spend time doing, either for **pleasure** or because it **needs to be done**".

The words '**occupy**', '**action**', '**taking control**', '**activity**', '**engages**', '**pleasure**' will be further explored to allow for increased clarity on the concept of occupation. See Table 6.1.

**Table 6.1: The concept Occupation**

<b>CONCEPT</b>	<b>DEFINITION THE OXFORD DICTIONARY (2014)</b>	<b>DEFINITION THE COLLINS DICTIONARY (2018)</b>
<b>To occupy</b>	"to <b>fill or take up time</b> ; <b>be situated in</b> or at a <b>position in a system</b> or hierarchy; <b>to hold</b> ; to <b>keep busy and active</b> or to <b>take control</b> "	"to hold possession; to hold (a position or office); to take up or <b>fill up time or space</b> or to employ, be <b>busy</b> , or <b>engage oneself</b> , one's attention or mind"
<b>Action</b>	"fact or <b>process of doing something</b> , typically to <b>achieve an aim</b> , the way in which something <b>has an effect or influence</b> or an <b>exciting or notable activity</b> "	" <b>doing something for a particular purpose</b> ; all the <b>important and exciting things that are happening in a situation</b> ; <b>behaviour which is voluntary and explicable in terms of the agent's reasons</b> , as contrasted with that which is coerced or determined causally or <b>to put into effect</b> "
<b>Control</b>	"the <b>power to influence</b> or <b>directs behaviour</b> or the <b>course of events</b> ; <b>personally directs the activities</b> or to <b>maintain influence</b> or authority over"	"having the <b>power to take all the important decisions</b> or <b>ability to use effectively</b> "
<b>Activity</b>	"the condition in which <b>things are happening or being done</b> ; busy or <b>energetic action or movement</b> or a <b>thing that a person or group does</b> or has done"	"the quality or <b>state of being active</b> ; <b>action</b> ; <b>energetic action</b> ; liveliness; alertness; normal <b>function of the body or mind</b> ; an <b>active force</b> , any <b>specific action</b> or <b>pursuit</b> , or the thing been <b>done in order to achieve</b>



		aims”
<b>Engage</b>	“ <b>occupying</b> or <b>attracting interest</b> or attention; <b>participate</b> or <b>become involved</b> in or <b>establish a meaningful contact or connection</b> ”	“to draw into; <b>involve</b> and <b>feel connected</b> ; <b>to attract and hold</b> (the attention, etc.); to employ or <b>keep busy</b> ”
<b>Pleasure</b>	“feeling of <b>happiness, satisfaction and enjoyment</b> or an event or <b>activity from which one derives enjoyment</b> ”	“a feeling of happiness, satisfaction, or enjoyment from it or <b>one's wish, will, or choice</b> ”.

- **Contextual subject specific definition of occupation**

In the field of Occupational therapy, ‘occupation’ as outlined in Section 2.6.1 is defined as the **daily activities** performed by individuals for **self-maintenance**, to **take care of others**, to be **productive** and for **enjoyment**. It “**enables skills development** and is **driven by the intrinsic need for mastery, competence** and **self-identity**”. It further allows for a **sense of accomplishment, purpose** and allows for the means to **organize time and space**. The **meaning and purpose of an occupation is determined by an individual’s values and culture**. Occupation includes the **engagement in activities** which **support role fulfilment within the individual’s environment** (Case-Smith, 2015, p.28). Occupation is also defined as that which “**supports health and participation in life**”. It may also be regarded as a “**means to reach therapeutic goals**” (Pendelton & Schultz-Krohn, 2012, p.12). Occupation may also be regarded as **a means or an end** in occupational therapy interventions. Occupation **as a means** includes the use of “**preparatory, purposeful or goal directed activities** with a focus on **remediation or restoration**”. Examples include **exercise** and **therapeutic occupation** (AOTA, 2014, p.S33). Occupation **as an end** includes the use of “**occupation based activities** and focuses on **health promotion, compensation, adaptation** and **prevention**”. Examples include **use of assistive devices, teaching compensatory strategies** and **physical or social modifications**” (AOTA, 2014, p.S33).

- **Dictionary definitions of the concept of resilience**

According to The Oxford dictionary (2014) ‘resilience’ is “the **capacity to recover quickly from difficulties; toughness** or a substance or object’s **ability to spring back into shape**”. The Collins dictionary (2018) defines resilience as the “ecosystem’s **ability to return to its original state after being disturbed**; the **ability to bounce or spring back into shape**; position or the

**ability to recover strength**, spirits, good humour quickly; **buoyancy**". Both the Oxford and Collins dictionaries state synonyms for resilience namely **flexibility, adaptability, strength, character**.

The words 'capacity', 'recover', 'toughness', 'ability', 'bounce back', 'strength', 'buoyancy', 'flexibility', 'adaptability' and 'character' will be further explored to allow for increased clarity on the concept of resilience. See Table 6.2.

**Table 6.2: The concept Resilience**

CONCEPT	DEFINITION THE OXFORD DICTIONARY (2014)	DEFINITION THE COLLINS DICTIONARY (2018)
<b>Capacity</b>	"the <b>ability to do or understand</b> something or a <b>specified role</b> or position"	the " <b>ability to do</b> , power or strength as well as referring to a <b>function, role or position</b> "
<b>Recover</b>	"the <b>return to a normal state of health</b> , mind or <b>strength</b> ; to <b>find</b> or regain possession; <b>regain control of oneself</b> , physical or mental state; <b>make up for a loss</b> and to <b>extract for use</b> "	"the return of; to regain after illness, a setback or shock; to <b>compensate for</b> ; make up for; to <b>get back to a state of control, balance</b> , composure, to <b>catch or save oneself</b> from a stumble or feeling"
<b>Toughness</b>	"the state of being <b>strong</b> enough to <b>withstand adverse conditions</b> ; the <b>ability to deal with hardship</b> or to <b>cope in difficult situations</b> "	"being strong and <b>determined</b> and displaying <b>tolerance for difficulty</b> or suffering; having a great <b>capacity for endurance</b> or being strong or resilient"
<b>Ability</b>	"the possession of the <b>means or skills to do</b> something or the <b>talent, skill or proficiency</b> in a particular area"	"the <b>possession of qualities required to do</b> something; necessary <b>skill, competence</b> or power"
<b>Bounce back</b>	" <b>recovering well after a setback or problem</b> "	"the <b>recovery following a setback</b> ; to <b>recover one's health, confidence</b> or good spirits easily after a setback or it is to very quickly <b>return to your previous level of success, enthusiasm or activity</b> "
<b>Strength</b>	"the <b>emotional or mental qualities necessary in dealing</b>	"the physical or mental energy that you have, which gives you the <b>ability to</b>

	<b>with difficult or distressing situations;</b> a good or <b>beneficial quality or attribute</b> of a person or thing or a person or thing perceived as a <b>source of mental or emotional support</b> ”	<b>perform</b> various actions; refers to the <b>confidence</b> or <b>courage</b> someone has in a difficult situation; the qualities and <b>abilities</b> which makes a person successful or the <b>capacity for producing a reaction or effect</b> ”
<b>Buoyancy</b>	“a cheerful and <b>optimistic attitude or disposition</b> or a <b>high level of activity</b> or to <b>keep afloat</b> ”	“a person’s ability to remain cheerful, even in sad or unpleasant situations or the quick <b>ability to recover after setbacks</b> ”
<b>Flexibility</b>	“the ability to be easily <b>modified</b> or the <b>willingness to change</b> or <b>compromise</b> ”	“the <b>ability to change</b> easily and <b>adapt to different circumstances</b> as they occur; <b>adjustable to change</b> or <b>capable of modification</b> ”
<b>Adaptability</b>	the “ability to <b>adjust to new conditions</b> or the capacity to be <b>modified for a new use of purpose</b> ”	“a <b>change in ideas or behaviour</b> in order to <b>deal with new situations</b> , different conditions or a new environment; <b>change to make suitable for a new purpose or situation</b> ; <b>adjust to new or changed circumstances</b> ”
<b>Character</b>	“ <b>strength and originality</b> in a person’s nature or the <b>mental and moral qualities distinctive to an individual</b> ”	“ <b>the ability to deal effectively with difficult situations</b> or statement about the qualities or behaviour of a person”

- **Contextual subject specific definition of resilience**

In the field of psychology, Luthar, Cicchetti and Becker (2000, p.543) define resilience as “a **multidimensional, dynamic process** encompassing **positive adaptation within the context of significant adversity**”. Two crucial conditions must be met to be resilient: “**exposure to significant threat or severe adversity** and the **achievement of positive adaptation**”. Resilience is not an individual trait but a “**product of the environment**” as well as a **result of the child-environment interaction**. They suggest **good quality relationships** underpin resilience and **strengthen intrinsic skills such as self-efficacy, competence and confidence** (Luthar & Brown, 2007).

Theron (2006, p.199) suggests that within the context of educational psychology, resilience is defined as “capable functioning amidst adversity and is linked to a triad of protective

factors". This triad includes "**personal protective factors**, i.e. **inherent strengths** which **empower** individuals to **cope with adversity** such as **autonomy, self-help skills and aptitude**); **familial protective factors** (i.e. family factors including amongst others **sound family structure** and a **supportive family network**) and **extra-familial protective factors** (i.e. **environmental factors** such as **bonds with pro-social adults, positive peer relationships** and **effective schools**)" (Theron, 2006, p.199). Personal protective factors that have been identified include: "a moderately **positive self-concept, positive attitude, positive future orientation, assertiveness** (i.e. **autonomous functioning, independent-mindedness** and the **ability to fight for deserved personal rights in a socially appropriate manner**), **enthusiasm, drive** (i.e. **creative problem-solving ability, associated with tension to achieve goals**), **good interpersonal relationships, empathy, internal locus of control** (i.e. **sense of authorship or choice over one's destiny**)" (Theron, 2004, p.319). Van Rensburg, Theron and Rothman (2018, p.73) purport that resilience is "**scaffolded by resilience-enabling supports**" and that **relationship-building** is a key mechanism of resilience.

In the field of child psychiatry, Rutter (2006, p.8) writes: 'the notion of resilience focuses attention on **coping mechanisms, mental sets**, and the operation of **personal agency**. In other words, it requires a move from a focus on external risks to a focus on **how these external risks are dealt with by the individual**". Resilience, according to Rutter, is concerned most with the **dynamic processes that engage multiple risk and protective factors** leading to **positive developmental outcomes** over the longer term. **Protective factors** he describes in terms of **mental features/operations** (i.e. **planning, self-control, self-reflection, sense of agency, belief in personal capability (self-efficacy), self-confidence** and **self-determination**) and **positive social relationships**. Rutter's 2013 definition of resilience states that resilience is when "some individuals have a relatively **good outcome despite having experienced serious stresses or adversities** – their outcome being better than that of other individuals who suffered the same experiences" (Rutter, 2013, p.474). He further proposes that resilience "is not related to individual psychological traits or superior functioning, but rather it is an ordinary **adaptation given the right resources**". The importance of resources within the environment "is reinforced by the finding of **turning points** in individuals' lives, i.e. a discontinuity with the past that removes disadvantageous past options and provides new **options for constructive change**". These turning points may be generated through the introduction of **appropriate psychosocial resources** that may facilitate positive changes (Rutter, 2013).

Within the field of psychology Person and Hall (2007, p.1) define resilience as the “**ability to cope effectively with life challenges**”. The ability to cope with challenges is influenced by **flexible thinking patterns** (i.e. **resilient thinking**), that a “situation may be **viewed as a challenge that can be overcome** if **options are explored** and **one keeps trying**”. Resilience hence reflects a person who “views a situation with **realistic optimism**” (Person & Hall, 2007, p.1; Reivich & Shatté, 2002).

In the field of social work, Ungar (2008, p.25) states that “in the context of **exposure to significant adversity**, resilience is both the **capacity of individuals to navigate** their way to the **psychological, social, cultural, and physical resources** that **sustain their well-being**, and their **capacity individually and collectively to negotiate** for these resources to be provided and experienced in **culturally meaningful ways**. **Navigations to resources are shaped by negotiations between individuals or groups (families and communities)** and those who **act as gatekeepers to the resources** that **nurture well-being**”. Ungar (2012, p.13) further states that “it is a **child’s interactions with multiple reciprocating systems, and the quality of those systems** that account for most of children’s **developmental success** under negative stress”. Ungar et al. (2007, p.287) identified seven environmental aspects associated with “**doing well under stress** across cultures: **relationships; a powerful identity; power and control; social justice; access to material resources; a sense of cohesion; belonging and spirituality; and cultural adherence**”. Ungar (2012, p.13) proposes resilience can be assessed as “the **quality of the interaction between the child and the child’s environment**, and the **competence of each side of the individual-environment equation** to provide what is necessary to **sustain well-being**”. An “**adequately resourced environment, i.e. an enabling environment** increases the likelihood that **intrinsic factors** such as **motivation** and **temperament** contribute to **positive developmental outcomes**” (Ungar, 2012, p.14). Resilience requires **co-contributions to resilience prompting interactions between adolescents and “their social ecologies (i.e. the relational and organisational systems in which the adolescent is nested)”** (Ungar 2015, p.37). Ungar states that resilience is **supported by “social-ecological stakeholders (such as parents, service providers, or policy makers)”** through the **availability and accessibility of “relevant resilience-enabling resources (e.g., good schools, mentorship opportunities)”**. “Adolescents contribute to resilience when they **petition adults to provide resources that are unavailable at that point in time and that are likely to support positive developmental outcomes**” (Ungar, 2011, p.2). There is usually a **diverse use of resources** which is dependent on “**perceived availability of relational and contextual**

**resources** and the **meaning attached to resources** (i.e. if resources are **relevant (e.g. to socio-demographic factors such as developmental stage or gender), respectful of personal values, culture and religious beliefs**)” (Ungar, 2013, p.348).

Neves (2012, p.301) views resilience as “shaped by the **interplay between individual and societal factors** and is shaped by **cultural learning, socialization and adaptation** during **times of social stress and transition**”.

Wong (2012, p.585) from a perspective of positive psychology, defines resilience as “the **ability to overcome and transcend adversity**”. In his ABCDE model, a **meaning-centered pathway** of resilience, he outlines two possible outcomes after a tragic or traumatic event, i.e. “become bitter and experience depression/post-traumatic stress disorder or experience post traumatic growth”. He outlines the pathway of resilience as: “**accept the reality, believe in possibilities, commit to achievable goals (action principle), discover new resources or solutions, evaluate and enjoy the progress**”.

Masten (2014, p.6), in the field of clinical psychology and child development, defines resilience as “the **capacity** of a dynamic system **to adapt successfully** to disturbances that threaten system function, viability, or development”. Masten, Cutuli, Herbers and Reed (2009, p.118) suggest two criteria as an indication of resilience, i.e. “a measure of **positive adaptation or development** and the past or current **presence of conditions that threaten to disrupt positive adaptation**”. They define “positive adaptation or development as meeting developmental tasks and fundamental human adaptation systems”. Developmental tasks are the “**expectations of a given society or culture in a historical context** for the behaviour of children in different age periods and situations”. Essential “**human adaptation** systems include **attachment relationships and parenting, pleasure-in-mastery motivational systems, self-regulatory** systems for emotion, arousal and behaviour, **families, formal education systems, cultural belief systems, religion and spirituality**” (Masten et al., 2009, p.126). Masten et al. (2009, p.119) identify “**protective factors at the individual, family and community level** that operate in resilience”.

Hart, Heaver, Brunberg, Sandberg, Macpherson, Coombe and Kourkoutas (2014, p.399) in the domains of child, family and community health and education, define resilience as “**positive development despite adversity**” and that the “locus and nature of resilience is a **dynamic transaction between the individual/environment**”. They report that enhanced resilience is linked with increased **confidence, coping** and **self-esteem**.

In the field of paediatric occupational therapy, using a developmental frame of reference, resilience is defined as a “child’s **internal characteristics to thrive and develop despite high-risk factors** in the environment” (Case-Smith, 2015, p.75). A resilient child is thought to have **protective factors** that facilitate the development of **positive interpersonal relationships** and **general competence** in the midst of negative experiences or social environments that hinder their development (Case-Smith, 2015). Both **child factors** and **family protective factors** are thought to facilitate positive outcomes for a child (Vanderbilt-Adriance & Shaw, 2008). Examples of child protective factors include “**intelligence, prosocial behaviour, ability to regulate emotions and social competence**” (Case-Smith & O'Brien, 2015, p.75). Resilient children are thought to be “**reflective**, demonstrate an **internal locus of control** and use **flexible coping strategies** in overcoming adversity” (Jaffe & Cosper, 2015, p.146). Family protective factors could include: “**material resources, love, nurturance, sense of safety and quality of parent-child relationships**” (Vanderbilt-Adriance & Shaw, 2008, p.38). Law, Petrenchik, Ziviani & King (2009, p.75) define resilience as a “**process of positive adaptation in a context of adversity**”. They further purport that resilience (including individual, family and environmental such as schools), “fosters a child’s **sense of being able to overcome obstacles**”.

Health promoting models of intervention state that resilience is enhanced by building **competence, personal resources and connectivity**. Resilience is linked to **positive identity formation**, perceptions of **competency** and where a child has **access to good social networks** (Rodgers & Zivanni, 2009).

- **Attributes of the concepts**

Walker and Avant (2015) propose that once the concepts have been verified, the essential and related attributes should be identified. They further purport that the definition of concepts remains tentative as with time the understanding of the concept will change.

Attributes of the concepts of “occupational resilience” will be presented by means of the following tables:

Table 6.3: Attributes of the concept Occupation

Table.6.4: Essential and related attributes of the concept Occupation

Table 6.5: Attributes of the concept Resilience



Table 6.6: Essential and related attributes of the concept Resilience

Table 6.7: Essential and related attributes of the concept Occupational Resilience

**Table 6.3 Attributes of the concept Occupation**

<b>List of attributes of the concept Occupation</b>	
<p><b>To occupy</b> way of spending time keep busy and active be situated to hold a position to organize time, space</p> <p><b>Activity</b> energetic action active force function of the body and mind thing that person or group does</p> <p><b>Engage oneself</b> attracting interest participate become involved feel connected establish meaningful contact supports health and participation in life</p> <p><b>Pleasurable</b> enjoyment happiness satisfaction</p> <p><b>Action of taking control</b> personally directs the activities power to influence or directs behaviour or the course of events power to take all the important decisions ability to use effectively maintain influence</p>	<p><b>Meaning</b> important and exciting things that are happening in a situation notable activity determined by personal values and culture one's wish, will or choice</p> <p><b>Purpose</b> done in order to achieve aim behaviour which is voluntary and explicable in terms of the agent's reasons to put into effect specific action needs to be done enables skill development productive</p> <p><b>Driven by intrinsic need for mastery, competence and self-identity</b> sense of accomplishment</p> <p><b>Support role fulfilment within the environment</b> self-maintenance to take care of others</p> <p><b>Occupation as means</b> preparatory, purposeful or goal directed activities remediation or restoration exercise therapeutic occupation</p> <p><b>Occupation as ends</b> occupation based activities health promotion compensation and compensatory strategies adaptation, use of assistive devices, physical or social modifications prevention</p>



**Table 6.4: Essential and related attributes of the concept Occupation**

<b>Essential Attributes</b>	<b>Related Attributes</b>
<b>To Occupy</b>	<p>way of spending time  keep busy and active  be situated  to hold a position  to organize time, space</p>
<b>Meaning and Purpose</b>	<p>one's, wish, will or choice  determined by personal values and culture  driven by intrinsic need for mastery, competence and self-identity  sense of accomplishment  pleasurable  important and exciting things that are happening in a situation  notable activity  done in order to achieve aim  productive  behaviour which is voluntary and explicable in terms of the agent's reasons  to put into effect  specific action  ability to use effectively</p>
<b>Engagement</b>	<p>attracting interest  participate  become involved  feel connected  establish meaningful contact  occupation as means  occupation as ends  support role fulfilment within the environment  self-maintenance  taking care of others  action of taking control  supports health and participation in life</p>

**Table 6.5: Attributes of the concept Resilience**

<p><b>Capacity</b>  means or skills to do  ability to understand  possession of qualities required to do  competence  fulfil a role</p> <p><b>Recover</b>  return to a normal state of health  regain control of oneself  make up for a loss</p>	<p><b>Multidimensional dynamic process</b>  child's interactions with multiple reciprocating systems,  and the quality of those systems  engage multiple risk and protective factors  interplay between individual and societal factors and is  shaped by cultural learning, socialization and adaptation  co-contributions between adolescents and "their social  ecologies (relational and organisational systems)  competence of each side of the individual -environment  equation  inherent strengths empower coping with adverse</p>
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<p>extract for use regain after illness, a setback or shock; to compensate for to get back to a state of balance to catch or save oneself</p> <p><b>Bounce back</b> recovering well after a setback or problem recover one's health, recover one's confidence return to previous level of success, return to previous enthusiasm return to previous activity spring back into shape</p> <p><b>Toughness</b> withstand adverse conditions ability to deal with hardship cope in difficult situations determined tolerance for difficulty capacity for endurance</p> <p><b>Strength</b> emotional or mental qualities necessary in dealing with difficult or distressing situations; source of mental or emotional support presence of physical or mental energy ability to perform confidence courage capacity for producing a reaction or effect.</p> <p><b>Buoyancy</b> optimistic attitude or disposition high level of activity keep afloat ability to recover quickly after setbacks</p> <p><b>Flexibility</b> capable of modification compromise willingness to change ability to change to adapt to different circumstances adjustable to change</p> <p><b>Adaptability</b> adjust to new conditions modified for a new use of purpose. change in ideas or behaviour change to make suitable for a new purpose or situation adjust to new or changed circumstances</p> <p><b>Character</b> strength</p>	<p>circumstances productive of environment good quality relationships strengthens resilience skills meaning centred pathway</p> <p><b>Process of positive adaptation within context of significant adversity</b> adaptation given the right resources adapt successfully capacity to cope effectively with life challenges capacity to recover from difficulties enhance experience of well-being sense of being able to overcome obstacles ability to overcome and transcend adversity</p> <p><b>Protective factors</b> Individual protective factors/mental features or operations/personal resources: personal agency: sense of authorship, choice over own destiny self –regulation: goal setting, planning, performance, self-reflection creative problem solving navigate to psychological, social, cultural and physical resources that sustain well-being discovery new resources or solutions accept the reality flexible thinking patterns (resilient thinking): view that challenge can be overcome positive attitude positive future orientation self-efficacy/belief in personal capability ability to regulate emotions positive identity internal locus of control self confidence self-esteem motivation enthusiasm drive self-determination (autonomy, competence and relatedness) pleasure-in-mastery self-help skills assertiveness: negotiate for resources to be provided In culturally relevant ways/ petition adults to provide support resources that are unavailable at that point in time aptitude social competence general competence empathy coping mechanisms flexible coping strategies intelligence</p> <p>Family protective factors: material resources love, nurturance,</p>
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<p>originality ability to deal effectively with difficult situations</p>	<p>sense of safety quality of parent-child relationships sound family structure supportive family network</p> <p>Community protective factors/extra-familial protective factors/Environmental /Support factors: effective school community bonds with pro-social adults, positive peer relationships</p> <p><b>Enabling environment</b> adequate resourcing of the multi-tiered systems availability and accessibility of “relevant resilience-enabling resources meaningfulness of resources (relevant, respectful of personal values, culture and religious beliefs access to good social networks supported by “social-ecological stakeholders (such as parents, service providers, or policy makers) relationship building turning points – options for constructive change appropriate psychosocial resources access to material resources social justice sense of cohesion belonging connectivity cultural adherence religion and spirituality collective efficacy</p>
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**Table 6.6: Essential and related attributes of the concept Resilience**

List of essential and related attributes of the concept Resilience	
Essential Attributes	Related Attributes
<p><b>Personal resources to cope amidst adversity</b></p>	<p>personal agency: sense of authorship, choice over own destiny self-regulation: goal setting ,planning, performance, self-reflection creative problem solving/discover new resources or solutions navigate to psychological, social, cultural and physical resources that sustain well-being accept the reality flexible thinking patterns (resilient thinking): view that challenge can be overcome positive attitude positive future orientation self-efficacy/belief in personal capability ability to regulate emotions positive identity internal locus of control self confidence self-esteem motivation enthusiasm</p>

	<p>drive  self-determination (autonomy, competence and relatedness)  self-help skills  assertiveness: negotiate for resources to be provided in culturally relevant way  empathy  coping mechanisms  flexible coping strategies  intelligence  means or skills to do  possession of qualities required to do  inherent strengths empower coping with adverse circumstances</p>
<b>Enabling environment</b>	<p>family protective factors  community or environmental factors  adequate resourcing of the multi-tiered systems  availability and accessibility of "relevant resilience-enabling resources  meaningfulness of resources (relevant, respectful of personal values, culture and religious beliefs)  access to good social networks supported by "social-ecological stakeholders (parents, service providers, or policy makers)  relationship building  turning points – options for constructive change  appropriate psychosocial resources  access to material resources  social justice  cultural adherence  capable of modification  willingness to change  adaptable</p>
<b>Connectivity</b>	<p>interaction between the adolescent and the environment  co-contributions between adolescents and their social ecologies (relational and organisational systems)  positive interpersonal relationships  sense of cohesion  sense of belonging  religion and spirituality</p>
<b>Process of positive adaptation in the context of significant adversity</b>	<p>adaptation given the right resources  to compensate for  change in ideas or behaviour  adjust to new or changed circumstances  to get back to a state of balance  recover one's confidence  return to previous enthusiasm  return to previous activity  capacity to cope with life challenges  enhance experience of well-being  sense of being able to overcome obstacles</p>

### 6.2.3.1 Model case

The model case (as outlined in section 3.6.4.1) will be presented as a representation of the central concept of "occupational resilience" as to the best of my present understanding (Chin & Kramer, 2015, p.168). The case reflects the narrative of a participant in this study.

Thomas is 18 years old and a Grade 12 learner. He sustained a severe TBI when he was involved in a motorbike accident. He shares his experience as follows:

*I was on my way home from school when a car hit my motor bike. I was at X hospital, I was in a coma and I couldn't wake up, couldn't speak, couldn't eat, couldn't talk, couldn't walk or use my arms or anything. I was in this hospital for five-six weeks. From there I went to a rehabilitation unit for 8 weeks.*

*When I arrived at the rehabilitation unit I could not sit for more than three minutes without support and I had to re-learn almost everything (**restoring performance skills and performance patterns**). By the time I got to the rehabilitation unit I thought I had accepted my injury because since I woke up that was what I was used to; everything was there and being done for me in the hospital. Then when I got at rehab and then that first night they had a chocolate and orange cake there and a cup of coffee, and so my dad took out his phone to record me. Previously I had to just drink through a straw. Now I tried to bring the cup to my mouth for the first time again using both hands because I could not take it into my right hand. When I tilted the cup, the coffee spilled all over me and then I realized how bad it was, then I just cried.*

*At the rehab I had a team, including the occupational therapist who worked on things like getting me to re-learn old functions, such as doing the everyday things for myself, improve my thinking and physically do things like write. The speech therapist worked on the tone of my voice and we did language therapy which included problem solving and a lot of quick thinking exercises. I also saw a physiotherapist who worked on my strength, balance and improving my ability to walk and there was a social worker I could speak to from time to time (**enabling environment: access to physical and psychosocial resources; restoring performance skills and performance patterns**).*

*In the rehab we had team meetings where we discussed my goals (**enabling environment: create opportunities for agency; guided person-centred occupational goal setting**). We also discussed the plan of action (**collaborative action plan**) for me to reach them. This took place in the first week of my arrival and then two weeks before I was discharged we re-looked at my goals and my progress (**open channels of communication: monitoring progress**). We all attended the meeting; I was there, my dad and my mom together with the doctor and the therapists that I saw. We discussed my return to school because I was keen to go back to school (**enabling environment: create opportunities for agency, recognises right to***

**inclusively participate in desired occupations; client-centered occupational goal setting)** because I know I want to study Chartered Accounting and I'm going to study (**personal resource: motivation and determination**), so I needed to go back to school (**engagement in occupation: choice, meaning, purpose**). I also missed spending time with my friends and doing things like talking nonsense (**engagement in occupation: feeling connected, pleasure**). In the meeting the occupational therapist said she would help me and my parents explore which school environment would fit me the best (**guided navigation of environmental resources**).

Once I was discharged from the rehab unit I continued to see the occupational therapist, speech therapist and the physiotherapist on an out-patient basis to help me to be more functional (**restoring and establishing performance skills and performance patterns**). But when I came home I was really struggling to adapt. I mean everyone did everything for me in the hospital. Like if I needed coffee, I ring a bell, I ask the nurse for a cup of coffee, ok cool, there's a cup of coffee there on the table. Here at home when I needed to come to make my cup of coffee and take it to my room to go and drink, I couldn't do it. I felt I couldn't fit in. I didn't like it, because I needed everything to be done. I needed my family to come and help me do so many things and I felt like a burden. My parents, the therapists and I then felt that I needed help so they looked around and found a centre where I could learn coping skills (**guided navigation of environmental resources**) in order to adapt and to say it's ok to be like that, to fit in. At this centre we did **life skills (strategies to overcome occupational challenges)** and **craft groups (engagement in occupation: occupation as a means)** run by the occupational therapist and at any time throughout the day your psychologist would come and see you to provide psychological support (**enabling environment; availability and access to psychosocial resources**). Learning these skills taught me things to keep calm and like it's ok to like need help sometimes, so for the time being I'm just going to take the help and accept it (**personal resource: self-reflection**). After the injury I was withdrawn a bit but obviously with the skills that I had to apply, it's ok to be out there, you know, I've started being sociable again (**reflection on occupational performance and usefulness of strategies**).

Whilst I was attending out-patient therapy and attending the centre to improve on my coping skills, my occupational therapist contacted my school to discuss my return to school (**enabling environment: building relationships, open lines of communication between role players**). She spoke to the guidance teacher and my grade head and they wanted me to come back to school even though they knew how badly I was hurt after the accident (**enabling environment: recognises right to inclusively participate in desired occupations**). The occupational

*therapist recommended to the school that I gradually return to school (**adaptive strategy**) in the last school term of the year that I had my injury and that I return to 3 subjects in Grade 11 (**enabling environment: willing to negotiate availability and access to resources**). Although I had just started Grade 12 when my accident happened, I, my parents and the occupational therapist felt it was best if I return to school in Grade 11 as I had already passed and done well in Grade 11 and so I felt confident that I would be able to manage the content of the work (**personal resource: belief in personal capability, self-confidence**). Except I requested (**personal resource: personal agency (autonomy)**) that I be allowed to attend the last week of school with the Grade 12's, my peer group. I wanted to be part of the Valedictory and the matric farewell as I should have been there if it was not for the accident (**enabling occupation: feeling connected, provides developmentally appropriate tasks and activities**). The school gave us a lot of leeway, they accommodated my requests (**enabling environment: adaptable and willing to change**). I was even allowed to choose which three subjects I would attend, I chose Life Sciences, Physics and Accounting (**enabling environment: create opportunities for agency**).*

*Before I went back to school, the occupational therapist had a meeting with my mother and gave her a typed report with recommendations on what and how things could be done for me to go back to school (**enabling environment: role players capacitated to provide support**). My mother then met with the principal and the guidance teacher to discuss the practical aspects of me attending school especially as I still needed help to walk and my school is a three storey building (**enabling environment: open lines of communication between role players, building relationships**). The school mentioned that they were fearful I would fall when walking with my walking stick, the principal offered that for classes that were not on the ground floor that my work be brought to a ground floor class (**enabling environment: willingness to adapt, availability and access to physical resources**). Due to this my mother went with me to school for three weeks where she would help me to walk between the three classrooms (**personal coping strategy: preventative steps; enabling environment: access to good social network, responsive to individual's needs**). As I became more confident walking around the school premises (**engagement in occupation: creating opportunities for competency and increased sense of abilities**) and as a teacher or my peers would carry my bag from class to class, especially when I had to walk up and down the stairs (**enabling environment; good social network**), my mother no longer needed to come with me to school. I did however still go to out-patient occupational therapy to work on my hand function and to get me to think faster. I still went to see the physiotherapist for my balance and to improve my walking but we stopped*



*the speech therapy (restoring performance skills and performance patterns; enabling environment: availability and access to physical and psychosocial resources).*

*My parents are really a pillar of support. They really supported me to do the things I really wanted to do (enabling environment: access to good social network). I had just turned 18 and I was really looking forward to vote so I asked them to try and organise things on my behalf (personal coping strategy: seeking help from others; navigation of environmental resources), they went as far as contacting the ISC to come to the hospital to register me to vote (enabling environment: provides developmentally appropriate occupations). The day I voted, although I needed assistance to walk to the voting station and I could not really write properly I still scribbled my name (personal resource: motivation and determination). This meant so much to me it allowed me to do what was part of everyday life (engagement in occupation: meaning; sense of satisfaction).*

*I am progressing, getting stronger, doing things better, stronger all the time, so at the beginning of this year I went back to matric that first week and I stayed the whole day (engagement in occupation: creating opportunities for competency and increased sense of abilities; capacity to adapt to occupational challenges in the midst of adversity: return to previous activity). It was a normal week for me at school. In the beginning I still had to adjust with the times, it was a little bit long but you know I am a pusher and I went for it and coped (personal resources: motivation and determination, competence). Being back at school I could see I can still think in a school sense, hold the knowledge with me and know what is going on and understand (engagement in occupation: purpose, creating opportunities for competency and increased sense of abilities). I have come to a stage where I have changed the way I see everything, really how I see myself. I think more carefully about my decisions that I make. I'll make sure that ok, this is the situation, if I do this, these are the possible outcomes, if I do this, these are the possible outcomes and weigh it up and the pro's and con's and make a decision like that (personal resource: self-reflection and introspection, problem-solving).*

*Yes currently I go to a three-storey school, so there are stairs everywhere, and I have classes on all three levels but I don't worry I can handle it myself (personal resource: belief in personal capability). I use the rail going up (adaptive strategy), but now when I go to school now I can even walk up the stairs with my bag. When I walk with my stick in my hand, like it's just there with me and then I can just walk up the stairs like normal, now it's gotten much better (engagement in occupation: creating opportunities for competency and increased sense of abilities). Look, there are some challenges like now in a physical sense basically just writing*



*and double vision. But my vision is improving because a lady from our church told my mom about a behavioural optometrist and seeing him has helped (enabling environment: access to good social network). My school is helping me with the slow writing, they applied to the Department of Education for an extra 15 minutes for me to write my tests and exams (enabling environment: guided navigation of environmental resources; adaptive strategy). Another challenge is like being with this group of students, it's not my group that I was with for 12 years, so it is different and I didn't really know them like I knew my classmates previously, so I didn't really like that at the beginning and it was something I had to get used to, but eventually I got used to it now (capacity to adapt to occupational challenges: adjust to new or changed circumstances), made new friends (engagement in occupation: feeling connected) and I'm making the best of it (personal resource; positive attitude). I now make school fun. I mean why have a boring day when you can have a fun one? So I make the school the best it can be and make me the best of school (personal resource: positive attitude; personal coping strategy: humour).*

*What also helps me to cope are my peers (enabling environment: good social network). Like when I got an A aggregate in this term one, and I walked up onto the stage, the school literally like exploded they like clapped and oooh, so definitely my peers (enabling environment: positive feedback, encouragement). My friends also help (enabling environment: good social network), with my slow writing they would also give me extra notes and stuff like that (adaptive strategy). My teachers are also very helpful, they are always there for me if I need anything (enabling environment: good social network). Like now when I walk down the passages like the teachers would just say 'hi, how you're doing, how's the day going, are you fine?' They also noticed the progress now as well, like they can say 'oh I see you are walking much better now this week' or 'last week Friday I saw you walking a lot more with the stick, now you're walking fine'; so they are also giving me an update of my recovery because it's hardest for me to see it because I'm with myself 24/7 (enabling environment, positive feedback, encouragement).*

*You know it's a long journey, it's very long but my family and the people at our church really support me a lot (enabling environment: good social network, feeling connected) and we pray and trust in God to get me through (personal resource: faith/relatedness). I try and stay positive I look at the opportunity of the situation, you can choose the way you feel about something (personal resource, positive attitude, internal locus of control). So instead of looking at what I can't do, I rather looked at what I couldn't do since I woke up and what I can do now (personal resource: positive attitude). So count your blessings and not your burdens*

**(personal resource: positive attitude).** *I told you, I couldn't lift up a cup. When I could drink a cool drink with my hand, I thanked God for that* **(personal resource: faith/relatedness).** *I set goals and monitor my progress, like in the beginning I could like count how many steps I could take* **(personal resource: self-regulation (goal setting)).** *Like I would walk between the parallel bars, so I could count how many steps I took and every day it goes better by like one, two – but all of that one's and two's add up. So it takes a while; you don't have to sit back, eventually you'll get there.*

*You know I think I have accepted my situation but then I have also learnt, I mean there's things that you think you have accepted, but there's going to come a situation that you haven't encountered before and you're going to go through that and accept that part of your life. It's difficult, but one can do it* **(personal resource: accept the reality).** *What I can say is that I have learnt that the only way I will improve in my functioning and reach my goal is to challenge myself to try and do things that I couldn't do the day before* **(personal resource: flexible thinking- reappraisal of occupational limitation as an occupational challenge that can be overcome).** *I am a pusher* **(personal resource; motivation and determination)** *and I even went for a driving assessment, because I got my license in February and in March the accident happened. Now I am driving short distances on my own* **(engagement in occupation: creating opportunities for competency and increased sense of abilities).** *You can't hold me back, you know. I'm still living a normal life as far as I possibly can* **(capacity to adapt to occupational challenges in the midst of adversity, positive adaptation, accomplishment, control over life, empowerment).**

**Table 6.7: A list of essential attributes of the concept of Occupational Resilience**

<b>Occupational Resilience</b>	
<b>Essential Attributes</b>	<b>Related Attributes</b>
<b>Belief in personal capability</b> <i>(cultivation of resilience thinking)</i>	<ul style="list-style-type: none"> <li>• Reflection and Introspection of self as an occupational being</li> <li>• Guided person-centred occupational goal setting</li> <li>• Guided navigation of occupation-supporting resilience resources:               <ul style="list-style-type: none"> <li>○ personal resources                   <ul style="list-style-type: none"> <li>▪ to be strengthened</li> <li>▪ to be developed</li> </ul> </li> <li>○ environmental resources:                   <ul style="list-style-type: none"> <li>▪ multi-level</li> <li>▪ available,</li> <li>▪ accessible</li> <li>▪ personally meaningful/useful</li> <li>▪ culturally acceptable</li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• Collaborative action plan</li> <li>• Re-appraisal of occupational limitation as an occupational challenge that can be overcome given adequate resourcing</li> <li>• Increased acceptance of changed life circumstances</li> </ul>
<p><b>Strategies to adapt to occupational challenges:</b> <i>(occupation-supporting resilience strategies)</i></p>	<ul style="list-style-type: none"> <li>• Means or skills to increase resources to overcome occupational challenges in desired tasks and activities underpinning occupational role <ul style="list-style-type: none"> <li>○ Restoring and establishing performance skills and performance patterns</li> <li>○ Personal coping strategies (cognitive and behavioural strategies)</li> <li>○ Adaptive strategies (adapt task and/environment)</li> </ul> </li> <li>• Present within person or environment or needs to be developed</li> <li>• Combination of strategies deemed personally meaningful</li> <li>• Combination of strategies influenced by what is available and accessible in the environment</li> <li>• Strategies must be flexible given changes in occupational needs of person and changes in occupational environment</li> </ul>
<p><b>Engagement in occupation</b></p>	<ul style="list-style-type: none"> <li>• Engagement in occupation based activities and tasks <ul style="list-style-type: none"> <li>○ one's choice</li> <li>○ meaningful</li> <li>○ purposeful</li> <li>○ culturally relevant</li> <li>○ feeling connected</li> <li>○ pleasurable</li> </ul> </li> <li>• Good fit between person assets - demands of tasks underpinning occupation role and the occupational environment</li> <li>• Creating opportunities for competency and increased sense of abilities</li> <li>• Reflection on occupational performance and usefulness of strategies</li> </ul>
<p><b>Enabling environment</b></p>	<ul style="list-style-type: none"> <li>• Recognises right to inclusively participate in desired occupations</li> <li>• Creates opportunities for agency</li> <li>• Creates opportunities to develop skills and for mastery</li> <li>• Provides developmentally appropriate tasks and activities</li> <li>• Respectful of person's values, culture and religious beliefs</li> <li>• Responsive to person's needs (provides relevant resourcing)</li> <li>• Adaptable and willing to change</li> <li>• Availability and access to physical resources</li> <li>• Availability and access to psychosocial resources/good social network: <ul style="list-style-type: none"> <li>- psychological support/ encouragement /positive feedback</li> <li>- facilitate sense of connectivity (understanding,</li> </ul> </li> </ul>

	<p>acceptance and belonging)</p> <ul style="list-style-type: none"> <li>• Willing to negotiate the availability and accessibility of physical and psychosocial resources to support adaptation to occupational challenges</li> <li>• Relationship building between key role players from multi systems/ Open channels of communication between role players</li> <li>• Clearly defined roles of role players within multiple systems</li> <li>• Role players capacitated to provide support</li> </ul>
<b>Capacity to adapt to occupational challenges in the midst of adversity</b>	<ul style="list-style-type: none"> <li>• Process of positive adaptation within context of significant adversity</li> <li>• Adjust to new or changed circumstances</li> <li>• Return to previous activity</li> <li>• Accomplishment</li> <li>• Sense of satisfaction</li> <li>• Control over life</li> <li>• Empowerment</li> <li>• Positive developmental outcome</li> </ul>

### 6.2.3.2 Description of the essential concepts of the model

- **Belief in personal capability (*the cultivation of resilience thinking*)**

The occupational therapist facilitates a process of reflectiveness whereby the adolescent explores him or herself as an occupational being. The occupational therapist guides the adolescent to set occupational goals, navigate the occupation-supporting resilience resources and jointly develop an action plan that will support the fulfilment of valued occupational roles such as that of learner. Through this process, the adolescent increases belief in his/her personal capability, which results in the adolescent's appraisal of occupational limitations post TBI as occupational challenges which can be overcome given adequate resourcing. This process forms the basis for increased acceptance of changed life circumstances.

- **Strategies to adapt to occupational challenges (*occupation-supporting resilience strategies*)**

'Strategies' refers to the means or skills (within the person or environment) to increase the resources that assist adolescents to overcome occupational challenges in the execution of tasks and activities that underpin their valued occupations (e.g. school). These include a combination of strategies such as restoring or establishing performance skills and performance patterns (i.e. re-learning old functional skills and learning new functional skills embedded within productive habits and routines); personal coping strategies (i.e. engagement coping skills such as taking active steps, seeking advice from others, preventative steps) and adaptive strategies

(i.e. adapting task and/or environment). Strategies may be existing or developed. The combination of strategies should be flexible, environmentally available and accessible and deemed personally meaningful by the adolescent.

- **Engagement in occupation**

‘Engagement in occupation’ comprises the performance of tasks and activities underpinning occupation (i.e. occupation based tasks and activities). Occupation-based tasks and activities are self-chosen, meaningful, purposeful and culturally relevant to the adolescent. The selected occupation based tasks and activities should be a good fit between the adolescent, demands of the tasks underpinning the occupation and the occupational environment. Engagement in occupation builds the personal (e.g. competency, self-confidence, motivation, self-efficacy etc.) and environmental resources (e.g. relational and contextual resources) that promote resilience and facilitates the fulfilment of an occupational role; it ultimately leads to the “participation in desired life situations” (e.g. school participation) (AOTA, 2014, p.S4).

- **Enabling environment**

An ‘enabling environment’ refers to the occupational therapist fostering an environment that recognizes the adolescent’s right to inclusively participate in their desired occupations and is characterised by positive adolescent-environment interactions and is respectful of the adolescent’s personal values, culture and religious beliefs. It further displays understanding, acceptance of and responsiveness to the adolescent’s needs and enables him/her to experience a sense of connectivity. An enabling environment is adaptable and willing to change. It provides opportunities to engage in developmentally appropriate occupations and for the individual to experience a sense of mastery. An enabling environment creates opportunities for agency, and is willing to negotiate the availability and accessibility of the physical and psychosocial resources that are required to support the adolescent in adapting to occupational challenges and re-engage in valued occupations. It includes relationship building between key role players from multi-systems, whose roles are defined and who are capacitated to provide support. The active involvement of all key role players is co-ordinated with open channels of communication.

- **Capacity to adapt to occupational challenges in the midst of adversity**

The 'capacity to adapt' refers to the outcome of an adolescent that displays occupational resilience. It reflects an adolescent who has made a positive adaptation to occupational challenges in the midst of adversity and is able to re-participate in valued occupations such as school. The adolescent's re-participation in valued occupation results in him/her experiencing a sense of accomplishment, empowerment and control within his/her life.

### 6.2.3.3 Definition of the central concept of the model

The process of occupational resilience is facilitated by the occupational therapist who cultivates resilience thinking. Resilience thinking fosters the adolescent's belief in personal capability to adapt to occupational challenges in the midst of adversity given the right resources, and forms the basis of acceptance of their changed life circumstances post TBI. The belief in personal capability is fostered by the occupational therapist facilitating reflectiveness whereby the adolescent explores himself/herself as an occupational being. The adolescent is guided to set occupational goals and to navigate occupation-supporting resilience resources. These include personal resources (strengthened or developed through the engagement in occupation) and the environmental resources within an enabling environment. Learners' ability to adapt to occupational challenges is enhanced through the use of occupation-supporting resilience strategies, which include restoring and establishing performance skills and performance patterns, the use of personal coping strategies and adaptive strategies. The process ultimately enhances adolescents' capacity to adapt to occupational challenges in the midst of adversity, participate in valued occupations and experience a sense of accomplishment, empowerment and control within their lives.

**Table 6.8: A description of the process of facilitation of Occupational Resilience**

<b>AGENT</b>	<b>RECIPIENT</b>
Occupational Therapist	Adolescent learner with TBI. Family, teachers, peers, principal and community context (i.e. other members of the interdisciplinary team, or community organisations)

**PROCEDURE**

The process of facilitating occupational resilience as a means to facilitate the re-entry and participation in school post TBI includes the following important aspects:

- **Belief in personal capability (*cultivation of resilience thinking*)**

The occupational therapist facilitates a process of reflectiveness whereby the adolescent explores his or herself as an occupational being. The occupational therapist guides the adolescent to set occupational goals, navigate the occupation-supporting resilience resources and jointly develop an action plan that will support the fulfilment of valued occupational roles such as that of learner. Through this process the adolescent increases belief in his/her personal capability. This results in the adolescent's appraisal of occupational limitations post TBI as occupational challenges which can be overcome given adequate resourcing. This process forms the basis for increased acceptance of changed life circumstances.

- **Strategies to adapt to occupational challenges (*occupation-supporting resilience strategies*)**

Strategies refer to the means or skills (within the person or environment) to increase the resources that assist adolescents to overcome occupational challenges in the execution of tasks and activities that underpin their valued occupations (e.g. school). These include a combination of strategies such as restoring or establishing performance skills and performance patterns (i.e. re-learning old functional skills and learning new functional skills embedded within productive habits and routines); personal coping strategies (i.e. engagement coping skills such as taking active steps, seeking advice from others, preventative steps) and adaptive strategies (i.e. adapting task and/or environment). Strategies may be existing or developed. The combination of strategies should be flexible, environmentally available and accessible and deemed personally meaningful by the adolescent.

- **Engagement in occupation**

Engagement in occupation includes the performance of tasks and activities underpinning occupation (i.e. occupation based tasks and activities). Occupation based tasks and activities are self-chosen, meaningful, purposeful and culturally relevant to the adolescent. The selected occupation based tasks and activities should be a good-fit between the adolescent, demands of the tasks underpinning the occupation and the occupational environment. Engagement in occupation builds the personal (e.g. competency, self-confidence, motivation, self-efficacy etc.) and environmental resources (e.g. relational and contextual resources) that promote resilience and facilitate the fulfilment of an occupational role. It ultimately leads to the "participation in desired life situations" (e.g. school participation) (AOTA, 2014, p.S4).



- **Enabling environment**

An enabling environment refers to the occupational therapist fostering an environment that recognizes the adolescent's right to inclusively participate in their desired occupations. It is characterised by positive adolescent-environment interactions and is respectful of the adolescent's personal values, culture and religious beliefs. It further displays understanding, acceptance of and responsiveness to the adolescent's needs and enables him/her to experience a sense of connectivity. An enabling environment is adaptable and willing to change. It provides opportunities to engage in developmentally appropriate occupations and for the individual to experience a sense of mastery. An enabling environment creates opportunities for agency, and is willing to negotiate the availability and accessibility of the physical and psychosocial resources that are necessitated to support the adolescent to adapt to occupational challenges and re-engage in valued occupations. It includes relationship building between key role players from multi systems, whose roles are defined and who are capacitated to provide support. The active involvement of all key role players is co-ordinated with open channels of communication.

**DYNAMICS**

The dynamics that serve as energy and drive source for this model include: Adolescent learners with TBI need or desire to re-participate in valued occupations, such as school. These learners experience a change in the ways that they make sense of themselves given changes in their abilities, skills and role fulfilment post TBI. This in turn impacts on their belief in their personal capacity to cope and positively adapt to their changed life circumstances post TBI. Learners' abilities to adapt to occupational challenges are also dependent on the level and extent of the environmental support that they receive.

**CONTEXT**

The development of the model of school participation occurs within the context of applicable policy, the health care-setting (i.e. hospital or rehabilitation unit) as well as the adolescent learner with TBI's high school and home contexts.

**TERMINUS**

The process ultimately enhances the learner's capacity to adapt to occupational challenges in the midst of adversity, participate in valued occupations and experience a sense accomplishment, empowerment and control within their lives.



### 6.3 CHAPTER SUMMARY

Chapter 6 discussed the concept analysis - the first step in the development of a model to facilitate high school participation of adolescent learners post TBI. Two main concepts were identified and analysed, i.e. occupation and resilience. These concepts were combined to formulate the central concept of “occupational resilience” which is proposed as a mechanism to facilitate adolescents’ high school re-entry and school participation post TBI. The concepts were verified via dictionary definitions, contextual subject literature and by means of a model case. Lists of essential and related attributes were developed for each of the main concepts and the central concept.

The classification of the concepts of the model was explicated. The ‘agent’ refers to the occupational therapist and the ‘recipients’ includes the adolescent with TBI (primary recipient) and other key role players such as family, teachers, principals, peers/friends and those in the community (i.e. other health or educational team members as well community organisations). The ‘context’ includes health care settings (hospital or rehabilitation unit) as well as the adolescent’s high school and home contexts. The dynamics of the model was explicated as: adolescents needing or desiring to participate in occupation, their changes in functioning post TBI impacting on their belief in personal capability, ability to adapt and their acceptance of their changed life circumstances post TBI. Adolescents’ abilities to adapt are also dependent on the level and extent of the environmental support that they receive. The procedure detailed the role of the occupational therapist in facilitating an increase in the adolescent’s belief in personal capability through facilitating the adolescent’s exploration of self as an occupational being, occupational goal setting and the navigation of occupation-supporting resilience resources. Other key elements that promote resilience included: occupation-supporting resilience strategies, engagement in occupation and an enabling environment. These elements serve as means to support adolescents with TBI to adapt to occupational challenges in the midst of adversity and support their participation in valued occupation such as school. Such elements may allow adolescents with TBI to experience a sense of accomplishment, empowerment and control within their lives.

The next chapter includes the model’s overview, description of the structure, process and guidelines for operationalization. The chapter concludes with an evaluation of the model.

## **CHAPTER 7**

### **OCCUPATIONAL RESILIENCE: AN OCCUPATIONAL THERAPY PRACTICE MODEL TO FACILITATE HIGH SCHOOL PARTICIPATION POST TBI**

#### **7.1 INTRODUCTION**

Chapter 7 seeks to provide an overview and a description of the structure of the model by explicating the purpose, assumptions, context, theoretical concept definitions and the relationship statements of the model. This is followed by a description of the model's process and the guidelines for operationalization. The chapter concludes with an evaluation of the model.

#### **7.2 OVERVIEW OF THE MODEL**

A general overview of the model will be provided in this section. Specific detail on the process and the operationalization of the model are explicated in sections 7.4 and 7.5.

The findings of this study reveal that following the onset of the TBI, adolescents experience a disruption of participation in valued occupations such as school. Adolescents' re-participation in occupations included a process of adaptation. During this process of adaptation adolescents drew upon personal and environmental resources to increase their capacity to overcome occupational challenges and participate in occupations in the midst of adversity (i.e. displayed resilience). The adaptation process informed the conceptualization of Occupational Resilience as a model for facilitating high school participation post TBI.

Within the model it is envisioned that the occupational therapist is the facilitator of the process of promoting occupational resilience. Throughout the process the occupational therapist creates opportunities for agency for the adolescent. The occupational therapist remains cognizant of the adolescent's needs, wants, preferences, personal values, beliefs and cultural norms. The occupational therapist also fosters collaborative efforts between key multi-system role players within an adolescent's environment including his/her family, teachers, principals, peers and other community role players including members of the interdisciplinary team and community organisations.

The facilitation of occupational resilience includes a range of resilience promoting tasks. These tasks may overlap or unfold in succession:

- Cultivating resilience thinking (i.e. enhancing belief in personal capability): A process of reflectiveness where the occupational therapist facilitates the adolescent to: explore him/herself as an occupational being, set occupational goals, navigate occupation-supporting resilience resources, jointly develop an action-plan and re-appraise occupational limitations as occupational challenges that can be overcome given the availability and accessibility of environmental resources. The adolescent determines the meaningfulness/usefulness of environmental resources. The process of reflection is thought to serve as a basis for acceptance of changed life circumstances post TBI and is congruent with a key finding of this study in which adolescents with TBI suggested that in order to adapt to occupational challenges and re-participate in occupation, self-reflection and self-acceptance are required.
- Developing or strengthening strategies to adapt to occupational challenges (i.e. occupation-supporting resilience strategies): Strategies that enable the adolescent to adapt to occupational challenges and execute the tasks and activities that underpin their valued occupations (e.g. school). These include restoring or establishing performance skills and performance patterns (i.e. re-learning old functional skills and learning new functional skills embedded within productive habits and routines); personal coping strategies (i.e. engagement coping skills such as taking active steps, seeking advice from others and taking preventative steps) and adaptive strategies (i.e. adapting task and/or environment). The strategies are identified as part of the action plan which is collaboratively developed by team members. A combination of these strategies are employed during the performance of tasks and activities underpinning occupation, evaluated after performance and are continuously refined overtime to meet the adolescent's changing needs.
- Engagement in occupation (i.e. creating opportunities for competency and an increased sense of abilities): The performance of occupational-based tasks and activities that are self-chosen, meaningful, purposeful and culturally relevant to the adolescent. Engagement in occupational based tasks and activities facilitates the building of adolescents' personal (e.g. competency, self-confidence, motivation, self-efficacy etc.) and environmental resources (e.g. relational resources) that promote resilience and facilitate the engagement in occupation. Ultimately if engagement in occupation occurs in ways which are of personal satisfaction and adheres to adolescents' cultural norms, it leads to the "participation in desired life situations" (e.g. school participation) (AOTA, 2014, p.S4). To facilitate participation in school the occupational therapist may use existing occupations which seek to maintain the adolescent's existing interests and positive relationships. Alternatively the

occupational therapist may introduce the adolescent to new occupations to broaden their interests and social network, creating further opportunities for the adolescent to develop their personal and relational resources which they could draw upon to facilitate their adaptation and re-participation in the occupation of school.

- **Fostering an enabling environment:** This refers to the occupational therapist fostering an enabling environment (directly and indirectly) through fulfilling various roles including that of: facilitator, supporter, coach, consultant and advocator. The occupational therapist cultivates a nurturing, trusting and respectful environment. There is a focus on the adolescent's strengths with attempts to cultivate a strong belief in self. This is facilitated by creating opportunities for the adolescent to experience mastery, competence and a sense of his/her abilities through the engagement in occupation. The occupational therapist advocates for the adolescent's right to inclusively participate in desired occupations through a) creating opportunities for the adolescent to experience agency and b) negotiating the availability and accessibility of environmental resources that are meaningful to the adolescent. The exchange of knowledge and skills and the provision of emotional support may be used as mechanisms to empower the adolescent to self-advocate. This mechanism may also be used to coach the family to advocate for the adolescent to have access to the support services needed to facilitate his/her participation in valued occupations. In addition to the family, the occupational therapist (in collaboration with other members of the health and education teams) builds the resources of the adolescent's other informal supports such as his/her peers/friends and members of community organisations to which he/she is affiliated. The occupational therapist facilitates open communication between team members. As the aim is to facilitate school participation, the occupational therapist specifically consults with the adolescent's teachers who together with the family, are a critical source of ongoing support throughout the adolescent's schooling.

The outcome of this model, i.e. occupational resilience, is displayed by an adolescent's capacity to adapt to occupational challenges in the midst of adversity, participate in valued occupations and experience a sense of accomplishment, empowerment and control within their lives.

### 7.3 DESCRIPTION OF THE MODEL BY MEANS OF THE FOLLOWING:

#### 7.3.1 Purpose of the model

Chinn and Kramer (2015:188) state that *the purpose* of the model speaks to the reasons for the model being generated.

This model is geared towards occupational therapists and other members of the interdisciplinary team that support clients to attain their goals of participating in valued occupations in the midst of adversity. The model seeks to provide an understanding of the key components that should underpin interventions that serve to enhance the occupation-supporting resilience resources and strategies that promote adaptation to occupational challenges and the participation in valued occupations.

#### 7.3.2 Assumptions of the model

Chinn and Kramer (2015, p.198) define assumptions as the “accepted truth that underlie theoretic reasoning and may be based on philosophic values or factual assertions (i.e. perceptual experience)”. This model’s assumptions have partly been influenced by the theories underpinning the conceptual framework of this study, i.e. Theory of Human Occupation (Christiansen, 1999, Kielhofner, 2002; Whiteford, 2003, Townsend & Wilcock, 2004; Polatajko, Townsend & Craik, 2007), and Bronfenbrenner’s Bio-ecological Systems Theory (Bronfenbrenner, 2005). The assumptions are further influenced by the comprehensive task-based model of adaptation to chronic illness (CTBMA) (Samson & Siam, 2008, 2011) as well as Ungar’s social-ecological model of resilience (2013).

The assumptions of this model are:

- Individuals possess a desire to engage in occupation. Occupation serves as a drive for mastery, confidence and self-identity.
- Engagement in occupation may be disrupted due to occupational challenges following adverse situations in which individuals experience changes in their abilities, skills and role fulfilment.

- Re-engagement in meaningful occupation is facilitated by a process of adaptation that enables opportunities for agency.
- Engagement in occupation enables individuals to build their personal/internal resources by reshaping their abilities, skills and identities which enables adaptation.
- Engagement in occupation may assist with the expansion of good social networks and hence strengthen the individual's access and use of environmental resources which enable adaptation.
- Engagement in occupation occurs as a result of personal factors and multi-system environmental influences.
- When individuals are faced with occupational challenges they draw upon personal and environmental resources to adapt which support their engagement in occupation.
- The adaptation process in the midst of occupational challenges and adversity is highly individual and is influenced by the individual's; a) appraisal of his/her occupational challenges, b) environment and c) the coping strategies he/she employs:
  - a) When individuals appraise their occupational challenges with realistic optimism, after taking stock of their personal and environmental resources, they have an increased belief in their personal capability which facilitates the adaptation process.
  - b) Creating enabling environments require the empowerment of individuals or communities to explore and negotiate adequate resourcing from multi-level systems to meet their occupational needs.
  - c) The coping strategies used to adapt to occupational challenges will vary over the life span, given various life transitions of the individual as well as changes in their occupational needs, occupational demands and the occupational environment.
- When individuals engage in occupations in ways that are of personal satisfaction and adhere to cultural norms they are able to participate in life situations, experience health and well-being.

### 7.3.3 The context of the model

The context of Occupational Resilience: an occupational therapy practice model to facilitate high school participation post TBI, could include the health care-setting (i.e. hospital or rehabilitation unit) as well the home and high school contexts of adolescents with TBI.

The occupational therapist's initial contact with the client may take place in an inpatient rehabilitation/hospital setting where he/she supports the client to work towards their goal of participating in valued occupations such as school. Alternatively the occupational therapist may support the clients' attainment of their goal to participate in meaningful occupation on an out-patient basis whilst they are either in their home context recovering prior to their return to school or in their school context following their school re-entry.

The occupational therapist works in collaboration with other key role players involved in the adolescent's school participation post TBI. These role players are found within different systems within the adolescent's environment and may include his/her parents/primary care-givers, teachers, principal, peers, other members of the interdisciplinary team and community organisations.

The model may be applied across varied cultures and religious backgrounds as it is recommended that occupational therapists employ cultural adherence as a principle underpinning interventions. This is necessitated by the varied ways in which cultural contexts regulate and influence an individual's engagement in occupation (Rodger & Ziviani, 2009). As outlined in Section 6.2.2, this model is specifically geared for adolescents with TBI who are functioning on Level VIII of the Ranchos Los Amigos Cognitive Scale (i.e. purposeful and appropriate).

### 7.3.4 Theoretical definitions of the model

The theoretical definitions of the model as outlined in Section 3.6.4.3 are derived from the definition of the central concept of the model. The central concept of Occupational Resilience is defined as follows:

The process of occupational resilience is facilitated by the occupational therapist who cultivates **resilience thinking**. Resilience thinking fosters the adolescent's **belief in personal capability** to **adapt** to **occupational challenges** in the midst of **adversity** given the **right resources**, and

forms the basis of **acceptance** of their changed life circumstances post TBI. The belief in personal capability is fostered by the occupational therapist facilitating **reflectiveness** whereby the adolescent explores himself/herself as an **occupational being**. The adolescent is guided to set **occupational goals** and to **navigate occupation-supporting resilience resources**. These include **personal resources** (strengthened or developed through the **engagement in occupation**) and the **environmental resources** within an **enabling environment**. Learners' ability to adapt to occupational challenges is enhanced through the use of **occupation-supporting resilience strategies**, which include **restoring and establishing performance skills and performance patterns**, the use of **personal coping strategies** and **adaptive strategies**. The process ultimately enhances adolescents' capacity to adapt to occupational challenges in the midst of adversity, **participate in valued occupations** and experience a sense of **accomplishment, empowerment** and **control** within their lives.

**Resilience thinking:** Refers to the adolescent's cognitive re-appraisal of occupational limitations, due to changes in functioning post TBI, as occupational challenges that are adaptable given the right resources.

**Belief in their personal capability:** Refers to the adolescent's increased confidence and vision for the future to attain his/her goals of participating in valued occupations. It is influenced by occupational goal-setting, the guided navigation of occupation-supporting resilience resources and the joint development of an action plan. This increases the adolescent's belief in his/her capacity to adapt to occupational challenges and re-engage in valued occupations given the right resources.

**Adapt:** To cope or adjust to occupational challenges and re-engage in occupation in the midst of adversity.

**Adversity:** Refers to a major life stressor that disrupts the adolescent's participation in occupation and impacts on his/her ability to fulfil valued life roles. A major life stressor in the context of this study is the onset of a newly acquired disability, i.e. the TBI.

**Right resources:** These refer to the resources that the adolescent deems as personally meaningful, useful and culturally relevant.

**Occupational challenges:** Refers to circumstances within the adolescent or his/her environment that serve as barriers to the execution of tasks and activities that underpin



engagement in occupation. These may however be overcome given the availability and accessibility of the right resources.

**Acceptance:** Refers to an adolescent's acknowledgement of the changes in his/her functioning (i.e. skills, abilities and role fulfilment), following the reflection of his/her life circumstances post TBI. This is not a static state. The adolescent may experience a shift in the level of acceptance depending on the experiences along his/her journey of recovery and personal growth post TBI.

**Reflectiveness:** The adolescent reflects on the self as an occupational being. During this process the occupational therapist explores the adolescent's occupational history, context and goals. The adolescent is facilitated to reflect on the impact of the TBI on his/her occupational performance and wellbeing. Perceptions of the adolescent's occupational strengths and limitations are explored. Further reflection includes the adolescents' perspectives and priorities regarding his/her role fulfilment (e.g. the learner role).

**Occupational being:** In the context of this study it refers to the adolescent and his/her valued life roles that were fulfilled prior to the TBI and which are desired to be fulfilled in the future. It includes the tasks and activities that underpin occupations, the adolescent's activity preference and patterns of engagement. It includes the context in which these occupations are undertaken.

**Occupational goals:** These reflect the adolescent's preferences and prioritisation of the occupation-based tasks and activities that they want or are expected to do to fulfil their valued life roles post TBI.

**Navigate occupation-supporting resilience resources:** In the context of this study it refers to the exploration and identification of personal and environmental resources that adolescents may draw upon to overcome occupational challenges and support their engagement in valued occupations such as school. Personal resources include existing resources that could be strengthened or those that could be developed through the engagement in occupation and employing occupation-supporting resilience strategies. Environmental resources include those that are currently available and accessible to the adolescent or could include those that are currently unavailable but that the adolescent and his/her family (with guidance) could negotiate access to. The adolescent should deem these resources as meaningful or useful. Resources should be culturally relevant and may be influenced by temporal factors (e.g. the development or socio-historical factors which may influence the availability and accessibility of environmental resources) (Ungar, 2015).

**Personal resources:** In the context of this study, ‘personal resources’ refers to the capacities within the adolescents that support their engagement in occupations. These capacities include attributes and skills within the physical and psychosocial (including spiritual) components of the adolescent’s functioning. Examples include: a positive disposition about life circumstances and the future, goal directedness, resourcefulness, possessing problem solving skills, social competence, self-confidence, motivation, belief in personal capability (i.e. self-efficacy), displaying a sense of agency and having faith (Boyden & Mann, 2005).

**Engagement in occupation:** The performance of tasks and activities underpinning occupation (i.e. occupation based tasks and activities). Occupation based tasks and activities are self-chosen, meaningful, purposeful and culturally relevant to the adolescent. The selected occupation-based tasks and activities should be a good fit between the adolescent, demands of the tasks underpinning the occupation and the occupational environment. Engagement in occupation builds the personal (e.g. competency, self-confidence, motivation, self-efficacy etc.) and environmental resources (e.g. relational resources) that promote resilience and facilitate the fulfilment of an occupational role. It ultimately leads to the “participation in desired life situations” (e.g. school participation) (AOTA, 2014, p.S4).

**Environmental resources:** In this study the concept ‘environmental resources’ refers to the physical (e.g. food, shelter, etc.), emotional, psychological and political (e.g. relevant policy, advocacy groups for inclusive education, etc.) resources available and accessible to adolescents to support their engagement in occupation. Emotional and psychological resources may include support from formal (e.g. professionals working as part of a health or educational team) and informal resources (e.g. adolescent’s family, friends and community) that provide the resources necessary to improve and maintain the well-being of the adolescent (Ungar, 2015).

**Enabling environment:** An ‘enabling environment’ is an environment that recognizes adolescents’ right to inclusively participate in their desired occupations. It is characterised by positive adolescent-environment interactions and is respectful of the adolescent’s personal values, culture and religious beliefs. It further displays understanding, acceptance of and responsiveness to the adolescent’s needs and enables the individual to experience a sense of connectivity. An enabling environment is adaptable and willing to change. It provides opportunities to engage in developmentally appropriate occupations and for the individual to experience a sense of mastery. An enabling environment creates opportunities for agency, and is willing to negotiate the availability and accessibility of the physical and psychosocial resources that are required to facilitate adolescents’ adaptation to occupational challenges and

re-engagement in valued occupations. It includes relationship building between key role players from multi-systems, whose roles are defined and who are capacitated to provide support. The active involvement of all key role players is co-ordinated through open channels of communication.

**Restore or establish performance skills and performance patterns:** In the context of this study this concept implies the re-learning of functional skills that were affected by the onset of the TBI (e.g. motor skills, processing skills and social interaction skills) as well as learning new functional skills (e.g. dominance retraining, assertiveness training). These functional skills are linked and used in combination as the adolescent engages in occupation. Functional skills need to be “embedded within a set of productive performance patterns (i.e. habits, routines, rituals) that supports engagement in occupation and adheres to the adolescents’ cultural norms” (AOTA, 2014, p.S8).

**Personal coping strategies:** Operationally these refer to specific cognitive-behavioural strategies that are used to support the engagement in occupation. They include engagement coping skills such as taking active steps, where the adolescent reflects his/her assertiveness to achieve his/her goals. It further includes seeking advice from others as well as taking preventative steps (i.e. preventing changes in functioning post TBI from affecting the adolescent’s ability to execute tasks and activities underpinning occupation).

**Adaptive strategies:** Strategies that involve modifications to task demands and/or the environment in which the task is executed. Adopting these strategies ultimately complement adolescents’ occupational strengths and support their engagement in occupation. Examples of adaptive strategies - in relation to school participation - include learner support strategies such as peer support, environmental and instructional accommodations as well as assessment accommodations.

**Participation:** In the context of this study, may be viewed as the outcome experienced by the adolescent once he/she is able to engage in occupations in ways that are satisfying on a personal level and is in line with his/her cultural expectations (AOTA,2014).

**Valued occupations:** The adolescent deems an occupation as ‘valued’ when it has “purpose, meaning, and perceived utility” (AOTA, 2014, p.S6).

**Accomplishment:** This refers to the adolescent experiencing pleasure-in-mastery as a result of adapting to occupational challenges and participating in valued occupations. Accomplishment results in experiences of competency that further enable the adolescent's belief in personal capability.

**Empowerment;** Through the process of occupational resilience the adolescent experiences an increased sense of confidence which adds to his or her feeling of control over his/her personal situation and the exercising of his/her right to inclusive participation in desired occupations.

**Control:** Refers to the adolescent experiencing a sense of personal agency, as a result of their active involvement in directing decision-making and problem solving regarding actions facilitating his/her participation in valued occupation.

### 7.3 Relationship statements of the model

Chinn and Kramer (2015, p.193) refer to relationship statements as the "linkages among and between concepts". These relationships may take the form of description, explanation and prediction. The relationship statements of this model are as follows:

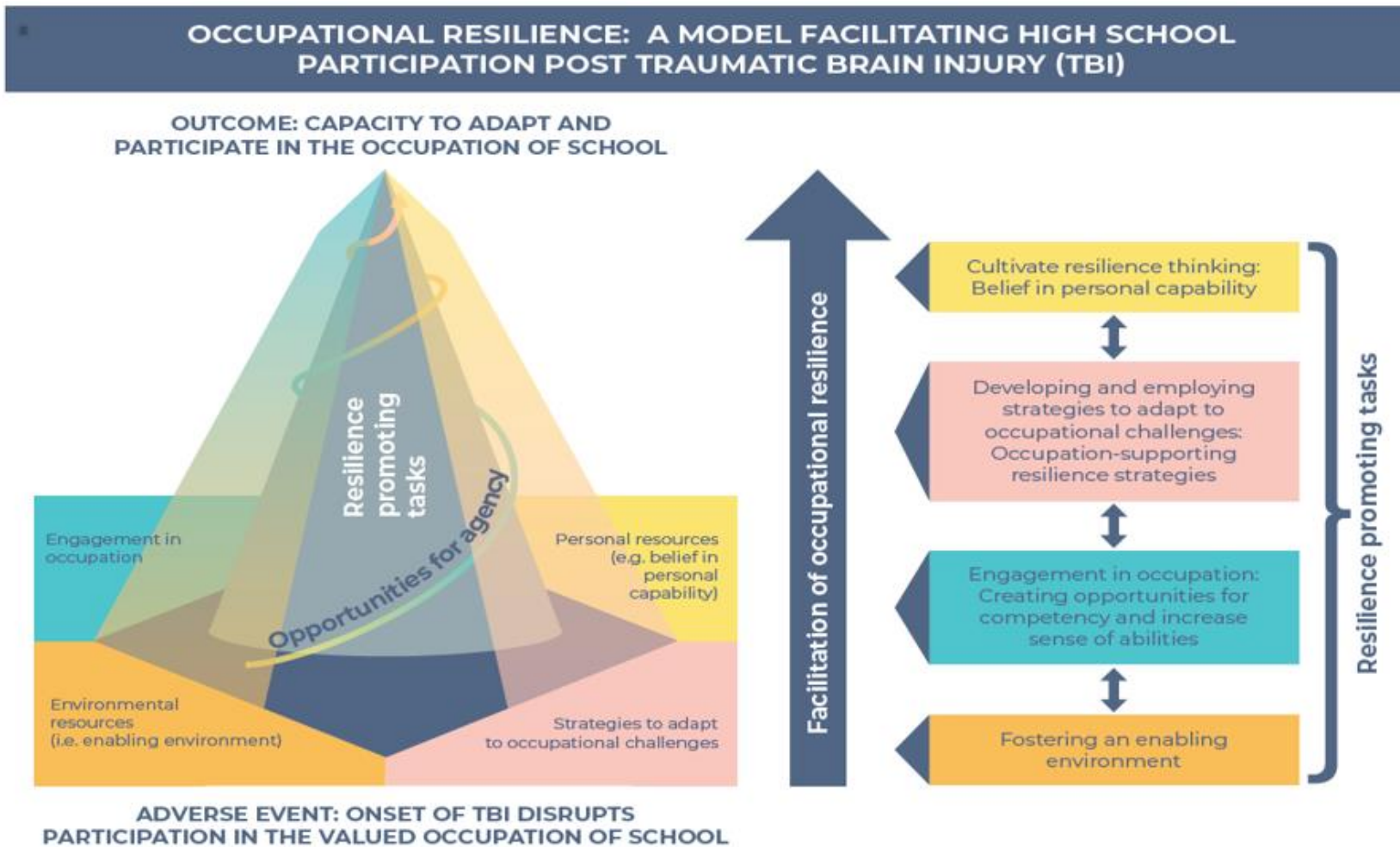
- Developing an individual's belief in personal capability helps strengthens his/her capacity to navigate and negotiate the resources needed to adapt to occupational challenges and engage in occupation.
- Environmental resources that are accessible, available, culturally acceptable and deemed useful by an individual enable an environment that supports the adaptation to occupational challenges and the engagement in occupation.
- Identifying and employing strategies build the occupation-supporting resilience resources (i.e. personal and environmental) that enable an individual to adapt to occupational challenges and execute the tasks and activities that underpin their occupations.
- The engagement in occupation that is personally meaningful, purposeful and culturally relevant will promote resilience resources that assist an individual to adapt to occupational challenges and fulfil his/her valued occupational roles.

#### **7.4 PROCESS OF THE MODEL**

Section 7.4 seeks to provide a description of the process of the model. Detail on the methods that may be used to achieve the tasks outlined in the process of the model is expanded upon in section 7.5: Guidelines for the operationalization of Occupational Resilience: An occupational therapy practice model to facilitate high school participation post TBI.

The structure of the model is a task-based model that was adapted from Samson and Siam's (2008; 2011) comprehensive task-model: adaptation to chronic illness. The model (based on the empirical findings of this study) provides a description of the process of occupational resilience and is aimed at adolescents with TBI who: a) currently are in-patients in a health-care setting (i.e. hospital or rehabilitation setting), b) have been discharged from a health-care setting and are currently out-patients whilst they undergo further recovery before re-entering school or c) have resumed school post TBI. The model is cognisant of individual and subjective differences in the process of adaptation to occupational challenges in the midst of adversity (i.e. resilience). The model is hence not a linear stage-based model but is based on the premise that occupational resilience is promoted by a non-linear series of tasks. A resilience-promoting task may be defined as an undertaking to adapt to an occupational challenge in the midst of adversity. These tasks are interrelated, some tasks are undertaken in succession and others simultaneously.

The model (as illustrated in Figure 7.1) depicts a pyramid, with each of the four triangular sides representing the core aspects that are interrelated and of equal importance in promoting resilience (i.e. personal resources, engagement in occupation, environmental resources and strategies to adapt to occupational challenges). These core aspects form part of the resilience-promoting tasks that ultimately support participation in occupation. Central to the promotion of occupational resilience is the resilience promoting tasks. The spiral around the resilience-promoting tasks represents the opportunities for agency that should be provided for the adolescent throughout the process of facilitating occupational resilience.



**Figure 7.1: Occupational Resilience: A model facilitating high school participation post TBI**

The resilience-promoting tasks are outlined below:

- **Cultivate resilience thinking: Foster belief in personal capability**

Zimmerman and Cleary (2006, p.51), conceptualises the belief in personal capability (i.e. self-efficacy) as a “forethought process due its proactive impact on performance”. That is, their study findings have reflected that an adolescent who has a belief in his/her personal capability to perform a task, becomes more engaged in a task and sustains his/her persistence and effort even in the midst of obstacles. This is in line with other authors who have identified a belief in personal capability as a resilience prompting resource (i.e. personal protective factor) (Masten & Tellegen, 2012; Ungar, 2011). The belief in personal capability is linked to the adolescent’s individual thinking style and may affect the way that challenging or adverse situations are perceived, reacted and responded to (Kruger & Prinsloo, 2008). Cultivating the adolescent’s belief in personal capability can lead to appropriate problem-solving strategies that may enable the adaptation to occupational challenges and the engagement in valued occupation. (Kordich-Hall & Pearson, 2003). Similar to many other problem solving interventions (Zimmerman, 2002; Polatajko et al, 2001; Wade, Michaud & Brown, 2006 and D’Zurilla & Nezu, 2007), an occupational therapist may cultivate an adolescent’s belief in personal capability through a process of reflectiveness which includes the following:

a) Situating the client:

‘Situating the client’ allows the occupational therapist an increased understanding of who the adolescent is as an occupational being as well as their occupational engagement. Information is gathered on the adolescent’s:

- *Occupational history* regarding his/her significant life roles (i.e. both within and beyond the school context) as well as the tasks and activities that underpin these roles. This facilitates the occupational therapist’s understanding of the adolescent’s activity preferences, patterns of engagement and motivation to engage in the role-related tasks and activities (Pollock, Missiuna & Rodger, 2010). This will be used to guide the selection of tasks and activities that the occupational therapist may use as part of the intervention as well as influence the goals that adolescents set to achieve the outcome of re-participating in meaningful occupations such as school.
- *Occupational environment* (physical, social cultural): Understanding the adolescent’s occupational environment is vital, given that it is often a primary source for finding solutions



for the occupational challenges that are impeding the adolescent's engagement in occupation (Graham & Rodger, 2010). Furthermore, it is the opportunities and challenges in the environment that influence the range of occupations that the adolescent engages in (Hinder & Ashburner, 2010). Increased understanding of the occupational environment could be used in the occupational therapist's attempts to facilitate an enabling environment as well as when the occupational therapist guides the adolescent to explore appropriate and meaningful environmental occupation-supporting resilience resources and strategies.

'Situating the client' is done using a combination of sources and methods, including interviewing the adolescent, reviewing his/her health and school records, the use of standardised tools and interviews with other members of the interdisciplinary team who works towards the adolescent's educational goals (including family, teachers, principals and other members of the educational and health teams). Collateral information is obtained from team members regarding their perspectives of the adolescent's history, concerns and priorities. Further understanding of the environment could be obtained through the occupational therapist conducting a visit to the context in which the adolescent engages in occupation, i.e. conduct a school visit. Where possible the occupational therapist could also observe the adolescent engaging in occupation, e.g. observe the adolescent engaging in school compromising of the academic, non-academic and extracurricular school related tasks and activities.

b) Guided occupational goal setting

In order to facilitate the adolescent's readiness to engage in setting goals and explore the occupation-supporting resilience resources, the occupational therapist provides emotional support as the adolescent may need to express emotions (e.g. frustration, anger) regarding the impact of the TBI on their life situation. The provision of emotional support forms the basis for a trusting therapeutic relationship (Graham & Rodger, 2010).

Goal setting should be done in collaboration with all team members to ensure that it is line with the overall educational goals of the adolescent. The process of setting goals should however, be client-centred, so that the goals reflect the adolescent's priorities. Allowing the adolescent to experience an increased sense of ownership of goals increases his/her motivation and commitment to goals (Pollock, Missiuna & Rodger, 2010). Furthermore, studies have also revealed that there are differences between the goals of adolescents and parents and teachers regarding school participation post TBI and authors hence highlight the importance of advocating for the personal



choice and self-determination of the adolescent to be emphasised (Stewart-Scott & Douglas, 1998; Backhouse & Rodger 1999; Vaidya, 2002; Sharp et al., 2006; Todis & Glang, 2008; Mealings & Douglas, 2010). This is supported by Hemmingson and Penman (2010, p.47) who state that:

“It is a risk that children and young people with disabilities may feel dependent, insignificant and powerless when adults define their problems and outline the methods for addressing their issues. Involving children and young people with disabilities in the decision making process in matters that influence their everyday lives, prepares them for active participation in society. With their input their needs can be more accurately identified and potential solutions to identified issues impacting on their inclusiveness can be identified and discussed.”

To guide the process of goal setting, the occupational therapist obtains the learner’s perceptions of their occupational strengths and limitations and its influence on their engagement in tasks and activities underpinning the occupation. This allows the occupational therapist to explore an adolescent’s perception of competence and fosters an increase in the adolescent’s self-awareness regarding their performance (Cohn & Coster, 2015). The occupational therapist facilitates the adolescent to identify tasks and activities that he/she wants and are expected to do as part of their occupations but where engagement is limited due to a mismatch between their skills and abilities, activity demands and the occupational environment. This forms the basis for occupational goal setting.

c) Guided navigation of occupation-supporting resilience resources

As highlighted in Section 6.2.3, there are identifiable resources within an individual and his/her environment which increase an adolescent’s capacity to adapt to occupational challenges in the midst of adversity and to engage in occupation (i.e. occupation-supporting resilience resources). The occupational therapist guides the adolescent to explore and identify personal strengths and environmental resources to generate possible solutions for current occupational limitations. The adolescent decides on which of the accessible and available environmental resources they regard as being potentially useful as well as meaningful given their personal and cultural values.

d) Collaborative development of the occupation-supporting action plan

A plan of action is formulated, where the adolescent’s needs and preferences remain the focal point. It includes strategies to adapt to occupational challenges and hence support the engagement in desired occupation. The formulation of the action plan is done in collaboration with the adolescent’s

primary care-givers and other members of the interdisciplinary team including his/her teacher/s and other members of the health and educational teams. A collaborative approach is essential given that team members each have expertise and input with regards to which strategies are practical and implementable within the adolescent's context and increases the likelihood of the action plans being implemented (Graham & Rodger, 2010).

e) Re-appraisal of occupational limitations as occupational challenges that can be overcome given the right resources

An adolescent's belief in personal capability is influenced by his/her engagement in self-reflection, goal-setting and strategic planning (Zimmerman & Cleary, 2006; Mandich, Polatajko, Missiuna & Miller, 2001). The guidance the occupational therapist offers in terms of reflecting on the impact of his/her strengths and limitations on occupational performance, exploring and identifying personal and environmental resources, setting occupational goals and developing a plan of action, contributes to the adolescent's appraisal of occupational limitations as occupational challenges which can be overcome given the right resources. The appraisal fosters the adolescent's perception of an increased belief in his/her personal capability and mobilizes the adolescent to make adaptations to occupational challenges (Samson & Siam's, 2011). This process forms the basis for increased acceptance of changed life circumstances.

• **Developing and employing strategies to adapt to occupational challenges: occupation-supporting resilience strategies**

Zimmerman and Cleary (2006) state that prior to engaging in desired activity, the appropriate strategies that will serve as the tools individuals employ to improve upon performance and enable competence, should be identified. These strategies may also be used to enable adolescents to adapt to occupational challenges and support their engagement in occupation. Taking the occupational tasks or activities that the adolescent has identified as part of his/her goal setting, the occupational therapist performs a task analysis to identify knowledge and cognitive-behavioural strategies (specific to performance) needed to enable the adolescent's competence in a desired occupation. The occupational therapist also determines the strategies needed to adapt the task and the occupational environment to enhance the adolescent's current abilities and skills to engage in occupation. The occupational therapist - together with other team members - guides the adolescent to identify the combination of strategies that he/she deems useful to adapt to occupational challenges and support his/her engagement in occupation. The combination of strategies is

individualised and will depend on the adolescent's needs and preference. It is further influenced by what is accessible and available within the adolescent's environment. These strategies may already be present within the person and/or environment or needs to be developed. The strategies that need to be developed may be facilitated by different team members depending on their expertise, rapport with the adolescent and the team member's availability. Strategies may overlap. Possible strategies include:

- Restoring and establishing performance skills and performance patterns. The adolescents in this study stated that re-learning old functions and learning new functions supported their re-participation in school. Examples include the occupational therapist engaging the adolescents in tasks and activities that could be structured to improve on their ability to mentally attend to the task at hand. It could also include the adolescent acquiring knowledge and skills with regards to specific life skills such as assertiveness training.
- Personal coping strategies (i.e. engagement cognitive and behavioural coping skills). Strategies include taking active steps, preventative steps and seeking advice from others. An example would be where adolescents utilise strategies such as asking a teacher for assistance when they encountered challenges within academic-related work tasks and activities.
- Adaptive strategies: adapting task and environment. Examples could include the use of learner support strategies such as instructional, environmental and assessment accommodations. For further detail on specific teaching and learning strategies that could be employed within the classroom, See section 7.5: Developing and employing strategies to adapt to occupational challenges: occupation-supporting resilience strategies. An example of adapting the environment could also include the occupational therapist's role of facilitating an enabling environment through which teachers and the family are educated on the adolescent's strengths and support needs that could facilitate realistic expectations and support which is relevant and responsive (Hinder & Ashburner, 2010).

Strategies to overcome occupational challenges will be employed during engagement in tasks and activities underpinning occupation. The employment of a strategy needs to be flexible and refined given changes in the occupational needs of the adolescent (for example as he/she matures), and as environmental expectations expand (Hinder & Ashburner, 2010).

- **Engaging in occupation: creating opportunities for competency and an increase sense of abilities**

Engagement in occupation-based tasks and activities that enable experiencing mastery and a sense of connectivity facilitates the building of adolescents' personal (e.g. competency, self-confidence, motivation, self-efficacy etc.) and environmental resources (e.g. relational resources) that promote resilience and facilitate their engagement in occupation (Bryson-Campbell, Shaw, O'Brien & Holmes, 2016; Gracey et al., 2008; Klinger, 2005). The occupational therapist can facilitate the engagement in occupation(s) that have been determined in the goal-setting phase. Although the outcome is to facilitate school participation, the occupation-based tasks and activities that the adolescent will engage in could be related to academic, self-care, extra-curricular/leisure or social domains of the adolescent's daily life and should ideally meet as many of the following criteria:

- be the adolescent's choice
- be meaningful
- be purposeful
- be cultural relevant
- foster connectivity
- be pleasurable
- have good fit between the i) adolescent's strengths; ii) demands of the occupation based tasks and activities and iii) the occupational environment. This would have been determined following the guided navigation of the adolescent's personal and environmental resources as well as the task analysis.
- create opportunities for the adolescent to experience competency and an increased sense of abilities (i.e. build personal resources) (Ziviani & Muhlenhaupt, 2006; Heah, Case, McGuire & Law, 2007).

To facilitate participation in school the occupational therapist may facilitate the engagement in existing occupations which seek to maintain the adolescent's existing interests and positive relationships. Alternatively, the occupational therapist may introduce the adolescent to new occupations to broaden his/her interests and social network. This creates further opportunities for the adolescent to develop personal and relational resources which could be drawn upon to facilitate his/her adaptation and re-participation in the occupation of school (Hart, Blincow & Thomas, 2012).

Variations of engaging in occupation will be illustrated by two examples. One example is based on a participant's actual experience of high school re-entry and school participation post TBI. The other example is based on my clinical reasoning that was informed by literature and the insights I was able to obtain from the findings of this study, regarding the value and role of occupation in facilitating a positive adaptation post TBI.

Example 1: Sally, 16 years old, sustained a moderate TBI, 12 months ago and has resumed attending her former ordinary school for the last six months. She has been referred to occupational therapy as although she is able to complete her academic tasks successfully (when she does attend school), her main challenges are that she has not been motivated to attend school regularly and is generally socially withdrawn when at school. Her mother confirms that at home she is also socially withdrawn and often seems angry and frustrated and this has put strain on their mother-daughter relationship. Sally enjoys sketching and sewing and has been doing it for 3 years since her mother (a seamstress at a local NGO) taught her. However since the onset of the TBI, Sally reports that she has not re-engaged in any of her previously enjoyed leisure pursuits. As part of occupational goal-setting, Sally has identified sewing as an interest. She feels that this is an occupation that she will be able to do following the formulation of a plan that outlined strategies that could be employed to support her engagement in the desired occupation of sewing. Examples of strategies include improving her hand function skills (restoring performance skills), asking her mother for assistance with aspects that are challenging (i.e. personal coping strategies: seeking help from others) as well as adapting the task (e.g. using a needle threader). Using Sally's mother's knowledge of sewing, the occupational therapist discusses ideas with her regarding how she could support her daughter (i.e. physically and emotionally through encouragement and positive feedback) as well as how to structure the sewing activity at home to allow Sally a sense of mastery. The occupational therapist uses the personally meaningful occupation of sewing to allow Sally the opportunity to experience competency and an increased sense of abilities. Sally's home room teacher indicates that she and a group of learners meet twice week to make items for the craft table for the school's annual fund-raising event which is scheduled to take place in eight months' time. She suggests that this may be an ideal opportunity for Sally to join and use her creative skills. Sally joins the group and manages to sew a washing peg bag which she was able to sell at the fund raiser. This provides further opportunities for Sally to increase her competency, confidence, and motivation. Being part of this craft group also allows her to experience a sense of connectivity. In this instance the occupational therapist uses an existing interest of the adolescent (i.e. sewing), to create opportunities for her to experience pleasure-in-mastery and positive feedback from significant others in her environment as a means to build her sense of self. This increased sense of capability allows her to explore new activities within her school environment that serves as a means for her to further develop her

competence as well provide an avenue for her to experience a sense of connectivity. This ultimately fosters her re-participation in school.

Example 2: Charles is 14 years old and sustained a severe TBI. He was discharged from the rehabilitation unit and followed up on an out-patient basis. Charles identified re-entering and participating in school related activities as his goal. Just prior to his discharge, his guidance and home room teachers attended a team meeting where - after a discussion of his strengths and needs - Charles felt that whilst at home he wanted to gradually re-engage in academic related activities. The team agreed that while at home, he would be sent three school work tasks to complete per week. In order to facilitate his engagement in academic-related school activities he was given a pencil grip to improve upon his ability to complete the written tasks. In addition, Charles and the occupational therapist brainstormed how his week could be structured to allow him the time to complete his school work, whilst allowing him time to fit in his out-patient therapies, personal management, church activities and allow him time to rest. Further brainstorming included strategies around how to structure tasks and the environment to compensate for his decreased concentration and decreased short term memory. Prior to Charles returning to school, the occupational therapist guided him to identify occupation-supporting resilience strategies that he could use (e.g. asking to be moved to the front of the class to try and limit the distraction) as well as environmental resources (e.g. getting his best friend to carry his back pack whilst he negotiated the stairs). After three months, Charles returned to school for half a day for the first two weeks. After each week Charles and the team evaluated his performance and the use of his strategies. By the end of the first two weeks he felt he was coping and he resumed school for full days. Throughout the year and when transitioning to the next grade, Charles continued to monitor his performance in school and refined his strategies with assistance from his teachers and his primary care-givers (i.e. social network). This case illustrates the graded engagement in occupation that allowed Charles to engage in academic tasks of incremental challenge, allowing him to achieve success. This hence increased his ability to achieve mastery and experience competence. This facilitated an increase in his belief in personal capability, confidence and motivation to re-participate in the occupation of school.

- **Fostering an enabling environment**

Fostering an environment that enables school participation post TBI requires input at multiple levels of the environment during critical phases of school participation, i.e. “organizing the school return”, “being back at school” (including the grade to grade transition) as well as “preparing to move on from school” (Sharp et al., 2006, p. 770; Mealings & Douglas, 2010, p.11). It requires that the

occupational therapist fulfil various roles (i.e. facilitator, coach, supporter, consultant and advocator) through the provision of direct services or indirect support to other members of the team (notably the adolescent's family and teachers) (Bruce, Newcombe & Chapman, 2012). An enabling environment supports the adolescent's school participation post TBI through:

- Advocacy
  - The occupational therapist and other team members seek to cultivate opportunities for the adolescent to display agency through advocating the adolescents' right to exercise their personal choice and be actively involved in goal setting, planning and decision making. This is supported by research evidence that has shown a link between positive developmental/participatory outcomes and youth being afforded opportunities to exercise their agency in the negotiation of resources they require to meet their support needs (Liebenberg & Ungar, 2012; van Breda & Theron, 2018).
  - The occupational therapist empowers a) the adolescent's informal support base (i.e. family) to advocate and b) the adolescent to self-advocate for the right to inclusive participation in desired occupation to be upheld through negotiating for the availability and access to meaningful and culturally relevant resources. The need to build self-advocacy is supported by Mealings et al. (2016, p.10), as it positively influences the adolescent's "self-esteem and self-reliance and enhances their opportunities to seek appropriate support".
- Focusing on the adolescent's strengths and cultivating a strong belief in self
  - The team creates opportunities for the adolescent to develop skills and experience mastery, on which he/she is given positive feedback and encouragement. The occupational therapist creates opportunities for mastery by engaging the adolescent in occupations that are in line with his/her interests and talents, are developmentally appropriate and match his/her strengths and abilities. This is supported by Hart, Blincow and Thomas (2012) who purport that confidence and resilience can be built by following a strengths focused approach that cultivates the adolescents' interests and talents, get them to reflect on their achievements and use this as a way of helping them to cope and adapt in the midst of adversity.



- Fostering a nurturing environment

A nurturing environment in the context of this study refers to an environment that strives to be responsive to the bio-psycho-social needs of the adolescent and this may be facilitated through:

- The cultivation of a milieu of respect for the adolescent and his/her personal and cultural values.
- Emotional support being made available and accessible to the adolescent to facilitate his/her well-being. Emotional support promotes positive interactions between the adolescent and significant others in their environment. It is important as the impact of the TBI on the adolescent's emotional functions may affect their interpersonal interactions and relationships, specifically with those whom they rely on for support (Walder & Molineux, 2017; Glang et al., 2004; Stewart-Scott & Douglas, 1998; Ylvisaker et al., 2001).
- An exchange of knowledge with relevant role players (specifically family, teachers, peers, community organisations) regarding the adolescents' strengths may lessen the stigma of TBI, by reframing their views of adolescents with TBI as capable individuals who have potential. Increased acceptance by others may contribute to the adolescent experiencing a sense of connectivity (Mealings et al., 2016).
- Facilitating the access to the physical resources that support the adolescent's engagement in occupation. Numerous study findings demonstrate youth who demonstrate more resilience are those who have access to physical resources (Ungar, et al., 2017; Ungar, 2008; Nettles, Mucherah & Jones, 2000). Examples of these physical resources include necessities such as access to food (via a school feeding scheme), access to safe and accessible transport to commute to and from school, a structurally accessible school environment based on universal design principles or safe and accessible sports facilities.
- A nurturing environment should also strive to be the best match to the level and extent of the adolescent's learning support needs. The adolescent's preference should also be factored in assessing the best fit for the adolescent as the findings of this study have revealed that where adolescents did not feel that the school was a match in terms of supporting their career aspirations, they did not experience a sense of belonging and this impacted on their participation in school.



- Building the resources of informal supports
  - Informal supports are sources of psycho-social support that are "lay, spontaneous, often based in reciprocal obligation" (Gilligan, 2008, p.39). It includes family, friends, fellow members of faith-based, recreational or community organisations. Formal supports (e.g. professionals) tend to have more short term relationships with adolescents given high caseloads and limited funding. Building the resources of informal supports, notably that of family, has been found to promote resilience, specifically as they tend to play an active and ongoing part of the adolescent's life and are therefore potential long-term consistent sources of support (Gilligan, 2008). The family's resources may be built through:
    - Providing the adolescent's family with emotional support to build their coping resources which will enable them to provide support to the adolescent (Graham & Rodger, 2010).
    - The exchange of knowledge and skills with families regarding: the impact of the TBI on the adolescent's functioning, his/her needs and strengths, enables realistic expectations of the adolescent and allows the adolescent to feel he/she is understood and accepted.
    - Coaching the family on specific strategies that can be employed to support the adolescent's participation in occupation (Graham & Rodger, 2010). For example, the family could be educated to employ adaptive strategies where they are taught to a) modify the task (e.g. simplifying tasks by changing the steps of the activity) and b) modify the environment by minimizing or changing environmental factors such as noise, level of activity, etc. that may impact on the adolescent's performance. In keeping with a client/learner-centred approach, the strategies that will be employed need to be developed in collaboration with the adolescent.
  - Friends are an important source of emotional support for youth during times of stress. Maintaining trusting relationships may allow the adolescent to experience a sense of belonging (Ungar et al., 2017). Positive adolescent-peer interactions could also be fostered through providing opportunities for social preparation. This includes the adolescent receiving intermittent visits from peers whilst recovering at home, or when accompanied by another team member, the adolescent visits the school prior to their resumption of school (Sharp, 2006).

- Hart, Blincow and Thomas (2012, p.22) reiterate the importance of 'keeping good relationships going as they assist youth to experience "stability and constancy in their lives and this will in turn help them feel more resilient". Families and schools are not always stable and constant sources of support for the adolescent; it is therefore important for positive relationships with community organisations that existed prior to the onset of the TBI (i.e. faith based, recreational, etc.) to be maintained. These positive relationships may be maintained through the exchange of knowledge and skills with regards to strategies that could be employed to support the adolescent's engagement.
- Mealings and Douglas (2010) also suggest that those supporting the adolescent should be made aware of their helping styles. They should strive to foster the adolescent's sense of agency, e.g. through engaging the adolescent in decision-making rather than making decisions or assumptions on what they need or want.
- **Relationship building and open channels of communication between role players**

This entails:

- The provision of information to the family on the details and recommendations on how to facilitate the adolescent's school re-entry (Schilling & Getch, 2012; Gagnon, et al., 2008).
- Timely communication between team members of the health and education teams where the health team relays information regarding the impact of the TBI on the adolescent's ability to fulfil his/her valued life roles and occupations, his/her strengths and needs. This is necessary to allow members of the educational team to have realistic expectations of the adolescent, which would in turn allow for more relevant and responsive learner support (Schilling & Getch, 2012; Davies Gfroerer et al., 2008; Gagnon et al. 2008).
- Open channels of communication, characterised by a collaborative approach where action plans are co-produced and where team members' roles are clearly defined (Rathbone, 2017).
- Relationship building between the occupational therapist and the teacher is strongly encouraged (specifically a teacher who actively teaches the adolescent), as teacher-learner relationships have shown to influence adolescents' engagement and performance in

school. Teachers through the quality of the relationships that they build with youth are able to bolster the resilience resources of adolescents (Liebenberg, Theron, Saders, Munford, van Rensburg, Rothman & Ungar, 2016).

- Collaboration with the teachers and other relevant school personnel on professional development initiatives that seek to build on teachers' knowledge and skills on specific adaptive strategies, facilitates efficacy and confidence and fosters positive attitudes amongst teachers (Chataika et al., 2012; Engelbrecht & Hay, 2018). When teachers display positive attitudes, (e.g. display openness to work with the adolescent following their changes in functioning and to adapt their teaching practices), positive teacher-adolescent interactions are fostered (Mealings & Douglas, 2010).
- Regular communication to facilitate monitoring of the adolescent's progress would be beneficial to ensure that the support given is adapted accordingly. Hence the need to facilitate the continuity of flexible support given changes in occupational demands, needs and life trajectories of the adolescent (Liebenberg & Ungar, 2012). This is important given that with an increase in occupational demands (i.e. scholastic demands), the impact of the TBI on the adolescent's functioning may become more pronounced. In contrast, the adolescent's functioning may improve as he/she recovers. This may result in the need for support to be withdrawn where applicable, thus allowing the adolescent to experience an increased sense of independence which could further build his/her self-esteem, confidence and motivation.

## **7.5 GUIDELINES FOR THE OPERATIONALIZATION OF OCCUPATIONAL RESILIENCE: AN OCCUPATIONAL THERAPY PRACTICE MODEL TO FACILITATE HIGH SCHOOL PARTICIPATION POST TBI**

This section provides detail on the methods which may be employed to undertake the resilience-promoting tasks that are central to the facilitation of occupational resilience. Each resilience promoting task will be stated as an objective, followed by the relevant guidelines to achieve the stated objective.

- **To cultivate resilience thinking (increase belief in personal capability):**
  - The adolescent should have a level of abstract reasoning to self-assess and determine personal goals (Pollock, Missiuna & Rodger, 2010).
  - The therapist uses a client-centred approach: the adolescent's priorities are the focal point.
  - The therapist uses a strengths-based and problem-solving approach.
  - An interdisciplinary team approach is used, of which the adolescent and his/her family (i.e. primary care-givers/parents) are key role players. Other key team players include teachers, other members of the educational and health teams.
  - Despite a focus on school participation, in order to explore the adolescent as an occupational being, the therapist needs to explore the adolescent's life roles within and beyond the school context.
  - Exploration of the adolescent's school (including the school's culture, routines and philosophy), home and community contexts is vital to understand the impact of the environment on the adolescents' ability to execute their roles and participate in valued occupations (Hinder & Ashburner, 2010).
  - To obtain information on the adolescent's occupational history the following assessment tools may be used: the Adolescent Role Assessment (ARA) (Black, 1976), Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) and the School Outcome Measure (SOM) (McEwen et al., 2003). These assessment tools were reviewed as part of 27 tools that sought to facilitate occupation-centred assessment of children. They were found to be applicable to adolescents and have reasonable validity and reliability (Brown & Chien, 2010).
  - For adolescents who have resumed school, information on the adolescents' perception of the impact of the school context on the learners' engagement in school can be obtained via tools such as the School Setting Interview SSI (Hemmingson & Penman 2010).
  - For adolescents who have not as yet resumed school, the occupational therapist could, using the adolescent's prior knowledge and experience of the school context, explore potential barriers

and enablers (i.e. environmental resources) within the school context. The occupational therapist could be guided by Hanft and Shepherd (2008) who propose a focus on:

- Physical accessibility (i.e. bathroom, classroom, playground, sports facilities, etc.)
  - Social interactions (i.e. adolescent-teacher, adolescent-peer, etc.)
  - Cultural environment (i.e. classroom structure, openness to diversity, etc.)
  - Sensory stimulus (i.e. auditory, visual input, etc.)
  - Virtual environment (i.e. access and use of digital technologies)
  - Temporal aspects (i.e. schedule of school routine and breaks, school calendar and transitions (e.g. transition from one grade to the next or the transition from one school context to the next)).
- 
- Information gathered from the adolescent should be supplemented with that obtained from other key team members to allow the occupational therapist to have a comprehensive picture of the adolescent's roles, routines and habits as well as the occupational environment.
  - In order to facilitate the adolescent's readiness to engage in setting goals and explore the occupation-supporting resilience resources, emotional support through "active listening, empathising, guiding and encouraging" are needed (Graham & Rodger, 2010).
  - To determine the adolescent's goals include the use of tools that are reliable and have cross-cultural validity such as the Canadian Occupational Performance Measure (COPM) (Law et al., 2005).
  - Goals should be stated in a manner that reflects what the adolescent is working towards rather than in a manner that reflects what he or she cannot or should not do.
  - The occupation-supporting resilience resources need to be adequately explored before direct decisions about action plans are concluded.
  - Action plans require collaborative involvement of all key role players in the interdisciplinary team to ensure it is a good fit with the adolescent's goals and is educationally relevant (i.e. support teaching and learning process). This increases the chances of implementation (Hinder & Ashburner, 2010).

- **To develop and employ strategies to adapt to occupational challenges: occupation-supporting resilience strategies:**
  - Strategies need to address the full experience of the adolescent's school experience encompassing academic, non-academic (i.e. self-help skills) and extra-curricular aspects (Ziviani & Muhlenhaupt, 2006).
  - Strategies need to support the attainment of collaboratively set occupational goals.
  - A collaborative approach is essential given that team members each have expertise and input with regards to which strategies are practical and implementable within the adolescent's context.
  - The team should collaboratively identify strategies which are a good fit with the adolescent's strengths (Dunbar, 2007).
  - Strategies need to be deemed meaningful or useful by the adolescent. This could be informed by the use of tools such as the School Setting interview (Hemmingson & Penman, 2010) where in relation to 16 related school tasks (including academic, non-academic and extra-curricular), the adolescents are able to identify what currently helps them to manage and what could be adjusted to enable their participation in school.
  - A combination of strategies should be used, with a predominant focus on using existing or developing personal coping strategies (i.e. engagement in cognitive and behavioural coping skills) and adaptive strategies (i.e. adapting task and environment). Remediation (i.e. restoring components of function) should not be a sole focus as remediation on its own does not readily translate to improvements in function and participation in school (Denton, Cope & Moser, 2006).
  - Strategies for application within the school context could be guided by the Guidelines for Inclusive Teaching and Learning (DoE, 2010), specifically sections 5: "inclusive strategies for learning, teaching and assessment" and 7.1.3: "common disabilities, learning difficulties and chronic medical conditions in children: traumatic brain injury".
  - To optimise the implementation of strategies within the school context and for reinforcement in other contexts within which the adolescent engages in occupation, all team members need to be capacitated in terms of its application. That is, knowledge and skills of strategies should be

enhanced through opportunities for education and training and accompanied materials (Wehrmann, Chiu, Reid & Sinclair, 2006).

- The use of strategies need to be evaluated following the engagement in occupation and should be re-defined to adapt given the fluidity of the adolescent's needs, roles and contexts (Hinder & Ashburner, 2010).
- **To engage in occupation:**
  - Engagement in school includes the full school experience, including academic, self-care, extra-curricular/leisure and social (i.e. including interpersonal interactions and relationships) aspects (Ziviani & Muhlenhaupt, 2006).
  - The therapist should create opportunities for the adolescent to experience competence and an increased sense of abilities (i.e. opportunity to build personal resources) (Heah, Case, McGuire & Law, 2007).
  - Through the engagement in self-chosen occupation, the adolescent's sense of agency should be fostered (Gilligan, 2008).
  - The therapist should guide the adolescent to navigate environmental resources that will help sustain his/her engagement in desired occupation.
  - The occupational therapist facilitates the learner to reflect on his/her performance and the usefulness of the strategies on completion of the task (Zimmerman & Cleary, 2006).
- **To foster an enabling environment:**
  - The therapist fosters opportunities for the adolescent to experience agency by working in a client-centred manner and continuously allowing the adolescent to give input to determine what is personally meaningful to them. Adolescents should further actively partake in planning their school re-entry as well as be involved in the development and monitoring of action plans to support their participation in school.

- The therapist develops the adolescent's self-advocacy skills through education on his/her right to a quality education as well as the range of support that should be made available and accessible. Education is done using the adolescents' frame of reference and in combination with skills development such as developing the adolescent's assertiveness and communication skills. Such skills are necessary to increase the adolescent's capacity to seek and ask for the learner support he/she requires.
- The therapist provides emotional support through active listening, being empathetic and providing encouragement. Families may need to be referred to other team members such as psychologists or social workers to receive further psycho-social support.
- A nurturing environment should also strive to be the best match to the adolescent's level and extent of his/her learner support needs. This can be determined by using tools such as the SIAS Health and Disability Form (DoBE, 2014).
- Information exchanges with parents and teachers should be facilitated in a manner that seeks to acknowledge and expand on their existing knowledge.
- Information exchanges should highlight the strengths and potential of the adolescent to cultivate positive attitudes towards who the adolescent is post TBI.
- The adolescent's right to confidentiality needs to be respected. Thus prior to a team member briefing the adolescent's peers on his/her condition, consent from the primary care-giver and assent from the adolescent should be obtained.
- The promotion of positive interactions between the adolescent and those in his/her environment is influenced by the preparation of both parties. For example if the adolescent is to visit the school prior to his/her return, he/she should be prepared regarding: the purpose of the visit, who are they likely to interact with during the visit as well as the duration of the visit. The adolescent should also be prepared to answer questions regarding his/her injury, change in abilities and recovery (Crylen, 2015). The school visit should be pre-arranged for a specific class and time. The teacher should be informed of the purpose of the visit as well as be given input that could be relayed to peers regarding the adolescent's condition and general tips as not to overwhelm the adolescent.



- Information to the family on the details and recommendations on how to facilitate the adolescent's return to school can be informed by recommendations such as those by Schilling and Getch (2012, p.58): "Getting my bearings, returning to school. Issues facing adolescents with traumatic brain injury - suggested steps for school entry for students with traumatic brain injury".
- The SIAS Support Needs Assessment form, including the individual support plan (DoBE, 2014) in combination with the Guidelines for Inclusive Teaching and Learning (DoE, 2010) policy may be used to guide the planning of the provision of support needs for the adolescent once he/she has returned to school. These tools that are provided as part of SIAS (DoBE, 2014) may also be used as a means to guide the more consistent team members in the adolescent's schooling (i.e. school based support team, teacher and parents) with regards to monitoring and refining the continuity of support that the adolescent is likely to require throughout his/her school career.
- Early communication between team members of the department of health and education should preferably be done prior to the adolescent returning to school.
- When building relationships with relevant school personnel to collaborate in the planning of support provision, it is advised to include a teacher who actively teaches the adolescent and is hence able to use his/her knowledge and experience of working with the adolescent to inform input on strategies. The teacher should ideally also be the teacher who in line with the SIAS policy (DoBE, 2014) will be responsible for the implementation and monitoring of the individual support plan. However as this teacher may change as the learner progresses from grade to grade it is recommended that a more constant educator also be involved (e.g. guidance teacher or member of the school based support team).
- The access to physical resources could be facilitated through:
  - o conducting a school visit and making recommendations regarding the structural accessibility of toilets, classroom, paths for mobility in and around the school as well as facilities for extra-curricular activities.
  - o Investigating options available at school or within the adolescent's environment to facilitate access to a safe and reliable means of transport to and from school.

- Education of the parents on their child's right to a quality, equitable education and what this entitles them to. Empower parents to advocate for:
  - their child's access to food via the school feeding scheme
  - technical equipment to provide alternative instruction and assessment (parental advocacy with support from teachers)
  - the implementation of initiatives from the WCED to implement initiatives such as the safe schools programme that includes access to safe sport opportunities, academic support, arts/ culture and life skills (parental advocacy with support from School Governing Body (SCB) and community organisations)
- Referring the family and adolescent to a relevant team member, i.e. social worker that could facilitate access to government financial support such as the Disability Child Grant.
- To facilitate the continuity of flexible support, the monitoring of support, could include re-using the COPM (Law et al., 2005). By specifically using the performance and satisfaction scales, progress can be monitored over time and used after intervention to evaluate change.

## **7.6 EVALUATION OF THE MODEL**

The criteria by Chinn and Kramer (2015, p.199-208) as outlined in Section 3.6.4.3, guided the evaluation of the model. The criteria include evaluating the: clarity, simplicity, generality, empirical applicability, consequences, meaning and logical adequacy, operational adequacy and pragmatic adequacy of the model. The evaluation of the model was facilitated through discussions with four experts in the field of qualitative research of which three are occupational therapists and one is from an educational psychology background.

### **7.6.1 Clarity**

To allow for understanding of the model the central concept of the model was defined (see section 7.3.4). The central concept served as a basis for the description of the model structure and process. Clarity was further enhanced through explicating the relationship statements that reflect the connections between the main concepts.

### **7.6.2 Simplicity**

I attempted to develop a model that was simple and applicable. The number of relational components within the theory was limited to that which was essential to serve the purpose of the model. The purpose of the model was substantiated by the central concept and its essential and related attributes (see Section 6.2.3.1; Table 6.7).

### **7.6.3 Generality**

The model seeks to assist occupational therapists and other health or educational personnel involved in supporting the participation of adolescents with TBI in valued occupations such as school. The model is operational within formal and informal learning contexts including healthcare, home, school and relevant community settings. The model is suitable for adolescents with TBI, who are functioning at level VIII of the Ranchos Los Amigos Cognitive Scale. It is however envisioned that this model may be operational for adolescents who have had their school participation disrupted by chronic illness or injury such as other acquired brain injuries or spinal cord injuries.

### **7.6.4 Empirical applicability**

Empirical applicability was enhanced through clarifying the model's purpose and description which was outlined in Sections 7.3.1 and 7.4. It was further enhanced through explicating the concept definitions (see Section 7.3.4) as well as the relationship statements (see Section 7.3.5).

### **7.6.5 Consequences of the model**

The contribution of this model is that it provides guidelines for the use of the construct occupational resilience as a means to facilitate adolescents' high school re-entry and school participation post TBI. Following the model's application within practice, its evaluation and refinement, it is envisioned that this model could result in enhancing the health and well-being of adolescents through facilitating and sustaining their participation in valued occupations such as school. Sustaining adolescents' participation in school is a means towards achieving their future career goals and upholds their right "to participate as equal members of society" (DoE, 1997, p.44). Sustained school participation may also assist with increasing the throughput rate of learners with disabilities, who successfully transition from secondary to post-secondary education.

### **7.6.6 Meaning and logical adequacy**

The Theory of Human Occupation (Christiansen, 1999; Kielhofner 2002; Whiteford, 2003; Townsend & Wilcock, 2004; Polatajko, Townsend & Craik, 2007), Bronfenbrenner's Bio-ecological Systems Theory (Bronfenbrenner, 2005), Samson and Siam's theory on adaptation to chronic illness (2008, 2011) as well as Ungar's social-ecological model of resilience (2013) serve as the bases for the meaning and logical adequacy of this model.

### **7.6.7 Operational adequacy**

Operational adequacy has been promoted through operationally defining the theoretical concepts of the model (see section 7.3.4).

### **7.6.8 Pragmatic adequacy**

Occupational Resilience is a practice-orientated model that through the promotion of resilience, seeks to capacitate adolescents to adapt to occupational challenges in the midst of adversity. The aim is to facilitate their participation in valued occupations such as school.

## **7.7 CHAPTER SUMMARY**

Chapter 7 included a discussion of Occupational Resilience as a model to facilitate high school re-entry and school participation of adolescents post TBI. The core concepts and the process of the model were explicated. Chapter 8 will include a discussion of the strengths, contributions, limitations, recommendations and the conclusion of the study.

## **CHAPTER 8**

### **STUDY STRENGTHS, CONTRIBUTIONS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION**

Chapter 8 provides an overview of the strengths, contributions, limitations, recommendations and conclusions of the study.

#### **8.1 STRENGTHS AND CONTRIBUTIONS OF THE STUDY**

The strengths and contributions of this study include the following:

- The study represents the first inquiry seeking to explore the experiences of adolescents' high school re-entry and participation following the onset of a TBI within a South African context.
- Given the lack of focus on the insider perspective, this study specifically provides a voice for adolescents with TBI. It enables a service user perspective of service provision that aims to support their participation in valued occupations. This could tailor services that are relevant and responsive to clients' needs.
- The study made use of a case-study design, which included the perspectives of other key stakeholders within the school transition process, including parents and educators (i.e. teachers and principals). The case-study design allowed for a broader understanding of experiences of high school re-entry and participation post TBI. Linked to the case-study design was a qualitative database including data from semi-structured interviews, semi-structured observations and a documentation review (see section 3.4). The database provided a trace of the rich and descriptive data that were generated and analysed.
- The study used a bio-ecological perspective to illuminate the role of the multiple systems in the environment in enabling or hindering the adolescent's school re-entry and participation post TBI.
- This study provides an occupational perspective of resilience. Findings highlight the role of engaging in occupation in the promotion of resilience.
- This study provides for an improved understanding of the role of occupation in facilitating the health and well-being of adolescents with TBI.
- The findings of the study add to the body of knowledge on adaptation and return to occupation following the onset of TBI in adolescents.

## 8.2 LIMITATIONS OF THE STUDY

- The scope of this study was to conceptualise a theoretical model. Hence the model is to be applied in practice and evaluated.
- The study population did not include adolescents with severe language and cognitive difficulties and this may be viewed as taking an ablest stance. It should be noted however, that this was after much consideration as outlined in the exclusion criteria in Section 3.3.1.
- The sample size of eight cases is small, but it should be reiterated that the purpose of qualitative research is to gain an increased understanding rather than to generalize results.
- Joint interviews with principals and teachers may have resulted in either party not feeling free to speak, especially in the case of the teachers, as there is a power imbalance, where the principal is a teacher's line manager and hence oversees his/her overall performance management (Merriam & Tisdell, 2016).
- There was no inclusion of direct observation (e.g. learner–teacher interaction in class or learner–peer interaction in class or learner participation in non-academic school related activities). Such observation could have aided in an increased understanding of how these adolescents experience school participation post TBI.
- The participants recruited for this study did not allow for variation in the sample in terms of geographical setting (i.e. rural vs urban) or much variation in terms of culture. Including adolescents who come from rural areas may have allowed for an increased insight into the role that the context, specifically in terms of access and availability of support services, plays in their experience of school re-entry and participation. Adolescents with diverse cultural backgrounds may have also provided an increased understanding of the influence of culture on school re-entry and participation following a newly acquired disability such as TBI. An increase in the cultural diversity of the participants may assist to elucidate the role of cultural resources in the promotion of resilience (van Breda & Theron, 2018). It should however be noted that in South Africa, there is no central database with information regarding learners' barriers to learning or categories of disability. This impacted on the recruitment of participants and variation in terms of the sample.
- Literature has shown that there are differences in the coping styles between males and females. In this study there were more male than female participants. This is however in line with the incidence of TBI which is more prevalent amongst males than females in this age group (Miller & Stander, 2010; Christ, 2007; Bruns, & Hauser, 2003).
- The onset of the TBI and hence the adolescent's resumption of school may have occurred more than a year prior to the interview with the adolescent. This, combined with short term memory

impairments as a result of the TBI, may have introduced recall bias into the study. However I tried to limit this bias by making use of informant triangulation (by including key stakeholders involved in the school transition process, who could hence confirm or dispute specific details regarding the onset of the TBI, its functional impact and the adolescent's school transition).

Specifically during the data analysis, one could argue that by including the perspectives of these stakeholders, it could have clouded the perspectives of the adolescents. That is, findings may be portrayed as the adolescents' perspective (i.e. insider perspective) when they were instead exclusively the perspectives of other stakeholders (i.e. outsider perspectives). I did however try and limit this by ensuring that categories and hence themes were consistent across all adolescents' cases and that these were substantiated by evidence of adolescents' perspectives in the form of quotes. I also endeavoured to explicate those categories which were exclusively the perspectives of other role players such as parents and educators. For example the "human constraints to provide specialist support at a departmental level", was a category that reflected the perspective of parents and educators as adolescents may not have had insight into what services are available at a departmental level. Such categories I felt were important to include as it provided a more holistic picture of current service provision and specifically highlights the current gaps.

- This was not a longitudinal study and therefore the study did not explore how the adolescents' support needs evolved and if their support plans were adjusted accordingly. This is of specific importance for the learners in this study who had more recently sustained their TBI. These learners' support needs may change given that further recovery may be possible or the full extent of their cognitive difficulties associated with a TBI are yet to surface until such time that the scholastic demands on the learner increase.

### **8.3. RECOMMENDATIONS**

Recommendations are outlined in terms of enhancing occupational therapy practice, education and research. Recommendations for important role players such as the Departments of Basic Education and Health as well as the Road Accident Fund (RAF) will be outlined.

#### **8.3.1 Recommendations for occupational therapy practice**

- The Occupational Resilience model could be used by occupational therapists within both the public and private sectors of health and education. Occupational therapists may use the

model once the adolescent reaches level VIII of the Ranchos Los Amigos Cognitive Scale and is able to partake in the process of reflectiveness.

- The Occupational Resilience model should be used in combination with other modalities of treatment that are used as part of occupational therapy intervention for clients with upper motor neuron lesions.
- Occupational therapists should strive to work family-centered. This includes involving the adolescent and his/her family in the planning and decision-making with regards to the adolescent's school re-entry post TBI.
- Adolescents and their families should be educated on the adolescent's right to inclusively participate in valued occupations such as school. Information regarding what this right entails as well as the range of support that the adolescent is entitled to, should be clearly communicated as a basis for developing his/her advocacy skills.
- Occupational therapists should seek to use a strengths-based approach and should advocate that team members foster the attitude of viewing the adolescent with TBI as capable and having potential.
- The adolescent's participation should seek to encompass both the roles that are important to the adolescent within and beyond the school context.
- The planning of the school return should encompass the adolescent's full school experience. Planning should hence seek to address: organizing the adolescent's return to school, supporting the adolescent once back at school as well as assisting with support to facilitate longer term plans such as the progression between each grade and planning to move on from high school.
- School preparation should commence early, include making contact with schools and where possible, include a school visit.
- Planning the return to school should seek to include personal preparation of the adolescent as well as preparing those in their learning contexts including home, school and relevant contexts within the community.
- Personal preparation of the learner should include developing their self-advocacy skills to allow them to explore and where possible, negotiate access to the needed support. It should further seek to develop the adolescent's problem-solving and self-regulation skills to allow them to seek ways of overcoming occupational challenges and adapt. Creating opportunities for adolescents to develop their social skills is of importance as the findings of this and other research have shown that changes in social function post TBI place strain on the adolescent's interpersonal interactions and relationships which impact on their sense of connectivity.



- Occupational therapists should seek to build the resources of the informal supports of the adolescent (i.e. family, friends and community members) to allow for long-term and consistent sources of support.
- Occupational therapists should build relationships and facilitate open channels of communication with key supports such as teachers. The education of teachers regarding the impact of the TBI on the adolescent's functioning including academic and social aspects should be relayed in a manner that acknowledges the teacher's existing knowledge and skills.
- Strategies that are mutually agreed upon by the team should be personally meaningful for the adolescent, be effectively implemented within the home and school routines and adapted regularly.
- Both adolescents and their families should be provided with emotional support and should be referred to the necessary team members to ensure that this support extends beyond the interim of in-patient care. Emotional support should be available on an ongoing basis given the adolescent's various life transitions, changes in occupational needs and changes in environmental expectations.
- Occupational therapists as part of their role in facilitating school participation post TBI, needs to ensure that as part of their advocacy role, they facilitate increased access to the basic amenities (such as food, clothing, shelter, safety, transport, finance, etc.). This is of importance given that literature has shown that the availability and access to basic amenities promote the resilience of youth in adverse situations.

### **8.3.2 Recommendations for occupational therapy education**

- The curriculum should reinforce that although an occupational therapist may work within a school context and work towards the educational outcomes of a learner, it is important to have a holistic understanding of the adolescent as a person whose life roles extend beyond that of learner. Interventions should therefore be holistic and strive to facilitate optimal participation in life situations in and outside of the school context.
- The curriculum should develop the attributes of occupational therapy students that will enable them to be competent in the key roles needed to support school participation post TBI (Bowden, Hart, King, Trigwell & Watts, 2000). These roles include:

- Professional

Develop occupational therapy students' knowledge and skills in using evidence based assessment tools which are able to provide the adolescent's perspective on:

- factors impacting on school participation
- his/her performance and satisfaction
- what has worked and
- what could be done in addition to support his/her participation in school?

Examples of such tools include the COPM (Law et al., 2005) and the School Setting interview (Hemmingson & Penman, 2010).

- Collaborator

Develop students' role as a team member. To work towards school participation requires a collaborative approach between all team members. The occupational therapist may have to refer the adolescent to other team members for a specific type of support and this requires that they are knowledgeable about the roles of other key professionals. Occupational therapy students further need to cultivate an attitude whereby they regard the adolescent and his/her family as key team members who should be the focal point of goal-setting, planning and evaluation.

- Communicator

Occupational therapy students' communication skills should be developed as facilitating school participation requires building of relationships with team members in other sectors. It requires consultation with formal and informal supports of the adolescent which includes teaching and being able to communicate the impact of the TBI, the adolescents' needs and strengths as well as make recommendations on strategies that can be employed. The curriculum should highlight the principle of cultural adherence in terms of the ways in which information is gathered and relayed.

- Advocator

In order for occupational therapy students to advocate for adolescents' rights to

inclusively participate in occupation, empower adolescents to become self-advocators and their families to become advocates, occupational therapy students need to be educated about the relevant inclusive education policies and legislation (including SIAS (DoE, 2014) and the Guidelines for Inclusive Teaching and Learning (DoE,2010)). The curriculum could cultivate an attitude of creating opportunities for clients to experience agency throughout the process of occupational therapy interventions.

Findings from this study suggest that financial and human constraints in government departments often meant that adolescents were not able to access the support services from the full complement of professionals. Given that these constraints may continue in the future, it calls for training institutions to explore the development of curricula that would allow future therapists to work as part of a transdisciplinary team. A transdisciplinary team is defined as a collaborative team approach in which team members share roles and this may lead to the crossing of discipline boundaries (Columbia Centre for Teaching). For an occupational therapist, working as part of a transdisciplinary team may include training other team members who are more consistently involved in supporting the adolescent to provide and adapt the support needed to meet the adolescent's needs. Alternatively the occupational therapist (within the framework of the scope of practice for occupational therapists) may need to learn to fulfil the support roles of other team members.

### **8.3.3 Recommendations for occupational therapy research**

- The Occupational Resilience model should now be applied in practice and evaluated. The model should be evaluated in terms of its efficacy through:
  - Occupational therapists reporting on
    - Positives of the model
    - Areas for further refinement of the model
  - Experimental pre-post-test study: where the adolescents' resilience is measured before and after intervention with the model, using measures such as the 28-item version of the Child and Youth Resilience Measure (CYRM-28) (Liebenberg, Ungar, & Van de Vijver, 2012) or the CYRM-24, a version of the CYRM that was validated among South African adolescents' (Govender, Cowden, Oppong Asante, George & Reardon, 2017). In addition adolescents' performance and satisfaction in participating in occupation

could also be evaluated pre and post intervention using measures such as the COPM (Law et al., 2005).

- The current study could be expanded to include the perspectives of participants within rural contexts as well as in other parts of South Africa. This is needed to explore if there are rural-urban differences in the enablers and barriers to school re-entry and participation as well as the strategies used to overcome occupational challenges. This would also allow the findings to be more generalizable to South Africa.
- A longitudinal study could be conducted, where the participants in this study are followed up to explore their support needs to prepare for their post high school transition.

#### **8.3.4. Recommendations for the Department of Health**

- Planning towards participation in life situations should commence as soon as the adolescent is medically stable. For example, if whilst in hospital the adolescent identifies school participation as a goal the team could include school related tasks and activities as part of in-patient intervention. This could serve as means to prepare the adolescent for his/her return to school in a graded manner. It may further serve as a source of motivation to enable the adolescent to remain committed to his/her goals as well as serve as a means to create opportunities for the adolescent to experience competence and an increased sense of his/her abilities which may result in building a positive sense of self.
- Establish clear referral pathways to the Department of Basic Education to ensure that adolescents and their families are followed up and obtain ongoing support. It would be useful to have a standard operating procedure where in instances of children or youth, a designated person from the health team should serve as a liaison with the department of education/the school. It is also important to ensure follow-up or referral of the adolescent and his/her family to the relevant community services for emotional support. This is crucial as findings from this study indicate that once adolescents were discharged from in-patient health-care settings they struggled to adapt and their families were uncertain of how to support them.
- Facilitate open lines of communication with the adolescent and involve him/her in planning that will contribute to the attainment of his/her goal of re-entering and participating in school post TBI. Open communication with the adolescent's family and relevant members of the

educational team (notably teachers) with regards to the impact of the adolescent's health condition on their overall functioning as well as their strengths and needs should be undertaken. See Appendix P for suggestion for planning school re-entry post TBI.

### **8.3.5. Recommendations for the Department of Basic Education**

- Teachers should be capacitated to increase their competency to provide learner support that is relevant and responsive. This is facilitated through the provision of education on the relevant policy on inclusive education. Training should focus on developing teachers' knowledge and skills on the implementation of SIAS (DoBE, 2014). Teachers should receive training on specific assessment tools that could be utilised to identify barriers to learning and specific learning support strategies that may be employed. This capacity building should begin at an undergraduate level and should extend to professional development opportunities for qualified teachers.
- Posts within the District Based Support Teams should be created and filled to give schools the support they need in order to support learners with barriers to learning. These posts should seek to include occupational therapists which would be in alignment with the Salamanca Statement that cites occupational therapists, amongst others, as key personnel in supporting learners' educational needs (UNESCO, 1999; DoBE, 2018).
- The DoBE should give careful consideration to their proposed plan of reducing the number of full-time professional and specialist support staff based at existing SSs (DoBE, 2018). This is important given that the principals at SSs in this study stated that currently they do not have the capacity to provide optimal specialist support services to their learners. This currently means that SSs do not have the capacity to fulfil the role as a resource centre for ordinary or full-service schools. One could hence argue that SSs will be less likely do so in the future if their full time staff are further reduced and the staff at the SS (in addition to their current roles) are expected to provide support services to residential care centres of the Departments of Health and Social Development who cater for learners with severe to profound intellectual disability.
- The SBST should consider the inclusion of an occupational therapist in meetings in which the learner with a TBI/new disability is discussed. The occupational therapist could make a meaningful contribution in terms of providing advice on support and adaptations to school

related tasks and the learning environment to optimize a learner's school participation. This would however require that the allocation of one occupational therapist per 100 schools be reviewed (DoBE, 2018, p.28).

- Funding should also be directed at assisting schools to provide learner support in terms of teaching aides, scribes and technical equipment needed to reasonably accommodate the learners' barriers to learning. This is needed to lessen the financial burden on the adolescents with TBIs' families, as currently parents /primary care-givers often have to fund additional support.
- Funding should be sought and directed at improving the structural accessibility of school buildings and sports facilities following the principles of Universal Design. This is specifically needed to facilitate the optimal participation of learners with marked challenges in their mobility due to changes in physical and sensory functions post TBI.
- Guidelines that seek to support school participation following disruption due to the onset of new disabilities or chronic illness need to be more specific. This is needed as currently they are vague and do not offer much guidance in terms of active steps that could be taken to support learners. For example the Guidelines for Inclusive Teaching and Learning (DoE, 2010, p.79) for learners with traumatic brain injury vaguely states, "Careful planning for school re-entry is essential". See Appendix P for suggestion for planning school re-entry post TBI.
- Quality assurance mechanisms as outlined in SIAS (2014) need to be implemented to ensure that the individual support plans are developed in collaboration with the learners and their primary care-givers. These mechanisms should also be implemented as planned and adjusted according to the learner's changing needs. The monitoring should include following up with the beneficiaries of support services such as learners and their primary care-givers to obtain their feedback on the quality of support as well as to obtain feedback on how support provision may be improved upon.
- The Department of Basic Education should seek to collaborate with other government departments to ensure that the package of support that is offered is comprehensive (as envisioned in the White Paper 6). Examples include:

- Liaising with the Department of Transport to explore and negotiate the provision of safe and accessible transport for learners to and from school.
  - Liaising with the Department of Social Services to explore and negotiate the provision of emotional support as well as access to financial support from government such as the Disability Child Grant. This would aid the family to support youth whose care needs may have increased due to the onset of the TBI.
  - Liaising with the Department of Police to assist with the implementation of the safe schools programme as schools in six of the eight cases in this study were unable to offer extracurricular or extra tuition after school hours due to safety concerns.
  - Liaising with the Department of Arts and Culture to provide funding and put schools in contact with individuals who would be able to assist learners to expand upon their interests and develop their talents.
- More emphasis should be placed on assisting adolescents to plan for the future, as for most the onset of the TBI meant a change in their vocational plans. Adolescents and their families need support to put measures in place for the adolescents to identify and plan for the attainment of their vocational goals.
  - At a school level, the school should draw upon community resources to assist with supporting the learner. For example communities could advocate for access to safe and accessible recreational/sports facilities.

### **8.3.6 Recommendations for the Road Accident Fund (RAF)**

- This study's finding regarding the delayed administration of RAF claims, correlates with that of other studies that similarly focused on the support needs of individuals with TBI to enable their participation in life situations. An example of such a study was conducted by Soeker (2009), who recommends that the RAF should appoint case managers (i.e. nurses or occupational therapists) to manage the RAF claim. This recommendation would be of value to improve upon the monitoring and continuity of support service provision for adolescents with TBI. A finding of this study revealed that adolescents were often seen and assessed by health professionals, over a very short space of time, to gather information to support their claim and help establish the compensation amount. Whilst these professionals provided reports with recommendations they were not implemented and there was no follow up with the family and adolescent to ensure that

they were able to access the recommended support. The appointment of a case manager would thus be of benefit to ensure that the needed avenues of support are explored.

#### **8.4 CONCLUSION**

The current study used a multi-case study design, to explore the experiences of high school re-entry and participation post TBI. The study aimed to gain an increased understanding of the enablers and barriers to high school participation post TBI. Enablers included the engagement in the valued occupation of school, the use of strategies, personal attributes and external supports which increased the adolescents' capacity to adapt. The main barriers included changes in abilities, skills and role fulfilment post TBI; a lack of open communication between team members; human and financial constraints; a lack of preparation of the adolescent and their context; inaccessibility (structural, attitudinal and lack of safety) as well as a lack of psychological support to both the adolescent and his/her family.

A model was developed on the central concept of occupational resilience. The central concept was based on the findings that revealed in order for adolescents to re-participate in school, following the disruption brought about by the TBI, required them to display resilience. This was displayed by adolescents drawing upon both personal and environmental resources to undergo a process of adaptation. Occupational therapists may hence promote resilience to facilitate the participation in occupation (i.e. promote occupational resilience). Occupational resilience is facilitated through a series of resilience-promoting tasks that include cultivating resilience thinking, developing and employing strategies to overcome occupational challenges, engagement in occupation and fostering an enabling environment. Throughout the process of facilitating occupational resilience it is necessary to create opportunities for the adolescent to display agency. The approach to intervention should be: client-centred, strength-based and a collaborative team approach in which the adolescent and their primary care-givers are pivotal team members. Interventions specifically aimed at supporting the attainment of the goal of school re-entry and participation post TBI should encompass all the critical phases of school participation (i.e. "organizing the school return" to "moving on from school"). School participation should focus on the academic and non-academic school related activities as both are of equal importance in terms of providing adolescents' with opportunities to display their competence, have an increased sense of the abilities and experience a sense of connectivity. These are key elements in promoting resilience.



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**C. DIAGNOSTIC CRITERIA**

<b>Notes for the health-care professional/practitioner completing the form</b>		
<p>* Learners who have been screened through the health system, their parents, the School-based Support Team (SBST) or the District-based Support Team (DBST), and suspected of having a disability and/or health condition, need to be referred for further assessment by a healthcare professional.</p> <p>The purpose of such an assessment is to obtain information on the impact of the disability and/or medical condition on the learner's ability to participate meaningfully and productively in the learning process.</p> <p>Recommendations should be made on the medical/health interventions and support required by the learner.</p> <p>In accordance with the <b>definition</b> of the Convention on the Rights of Persons with Disabilities (CRPD), persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.</p> <p><b>“Moderate to severe limitation”</b>, in the context of disability, means a significant restriction on a person's ability to function or/perform one or more basic daily activities after maximum correction, except where indicated. Maximum correction in this context means appropriate therapy, medication, educational and personal support and use of devices.</p> <p>The diagnostic criteria seek to assess the functional impact of the impairment on a learner's ability to perform daily activities and participate in learning.</p> <p>Please complete the section(s) that apply to your patient/ client and fall(s) within your scope of practice.</p>	<b>Disability/ Medical Condition</b>	<b>Duly registered health professional specially trained to deal with condition</b>
	<b>Vision (including eye conditions, visual processing)</b>	Professional trained in the assessment of vision function in children using specialised assessment tests which include at least LogMAR charts, contrast sensitivity charts and near-vision charts (e.g. an optometrist primary health-care nurse practitioner)
	<b>Hearing (including ear conditions, auditory processing)</b>	Professional trained to perform or conduct a battery of diagnostic audiometry tests (i.e. Audiologist) or auditory processing (speech-language therapist OR audiologist)
	<b>Physical</b>	Physiotherapist or occupational therapist, medical practitioner and relevant specialists
	<b>Communication</b>	Speech-language therapist, audiologist
	<b>Intellectual</b>	Clinical psychologist, educational psychologist, counselling psychologist, psychiatrist, paediatrician
	<b>Mental Health</b>	Psychiatrist, clinical psychologist, educational psychologist, counselling psychologist, medical practitioner, paediatrician, occupational therapist.
	<b>Chronic health condition</b>	Medical practitioner, professional nurse, paediatrician, physiotherapist.
	<b>Neuro-Developmental disorder</b>	Physiotherapist or occupational therapist, medical practitioner, educational psychologist and relevant specialists
<b>PLEASE COMPLETE THE PARENTAL CONSENT FORM AT SECTIONS F AND G</b>		



**Chronic Health Condition**

Condition diagnosed by Health Professional\*: \_\_\_\_\_

The condition of the learner impacts on his functioning in school in the following areas:

Tick when Applicable	Area of functional limitation	Recommendations of support that could be provided to School
<input type="checkbox"/>	School attendance	
<input type="checkbox"/>	Administration of medication and access to medical supplies	
<input type="checkbox"/>	Learning and concentration	
<input type="checkbox"/>	Endurance	
<input type="checkbox"/>	Interpersonal relationships	
<input type="checkbox"/>	Personal care	
<input type="checkbox"/>	Obesity or malnutrition	
<input type="checkbox"/>	Pain	

**Notes:**

A chronic condition refers to a condition that continues or persists and will require management over an extended period of time and can include:

- Non-communicable diseases (diabetes, hypertension, asthma)
- Persistent communicable diseases (HIV & TB)
- Long-term mental disorders
- Persistent physical impairment (stroke)

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Mobility**

Condition Diagnosed\*: \_\_\_\_\_

A learner is regarded as a learner with a physical/mobility impairment if he/she experiences activity limitations and participation restrictions in at least two of the domains of gross mobility, fine mobility, self-care and communication, e.g. the learner:

Tick when Applicable	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	Is unable to walk, e.g., wheelchair user	
<input type="checkbox"/>	Is only able to walk with the use of assistive devices, e.g., callipers, crutches, walking frames and other such devices	
<input type="checkbox"/>	Is able to walk without the use of assistive devices but with a degree of difficulty, e.g., learners with cerebral palsy	
<input type="checkbox"/>	Is functionally limited in the use of their upper limbs	
<input type="checkbox"/>	Has a fine mobility restriction	
<input type="checkbox"/>	Has a communication restriction	
<input type="checkbox"/>	Needs assistance with personal care	

**Notes:**

- Areas in which support can be provided are provision of assistive technology, accessible environment, educational or physical support by peers, teacher, personal assistant or therapist, etc.
- How frequently must support of the above nature be available?

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Other Mental Disorders**

Condition Diagnosed by Health Professional\*: \_\_\_\_\_

With the exclusion of intellectual disability, a learner is regarded to be a learner with a mental disability if he or she has been diagnosed, in terms of accepted diagnostic criteria (*Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (*DSM-5*),

2013 or the *International Statistical Classification of Diseases and Related Health Problems*, 10th revision of the WHO (ICD10)) by a mental health-care practitioner authorised to make such diagnosis:

Tick when applicable	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	A mental impairment that disrupts daily functioning	
<input type="checkbox"/>	An impairment that moderately or severely interferes with or limits the performance of major life activities, such as learning, thinking, communicating	
<input type="checkbox"/>	Impairment that interferes with sleeping	
<input type="checkbox"/>	Impairment that interferes with socialisation	
<input type="checkbox"/>	An impairment that limits cooperation	
<input type="checkbox"/>	Effect of medication limits participation	
<input type="checkbox"/>	Conditions that require access to medication	
<input type="checkbox"/>	Impairment which results in serious behaviour Challenges	

**Notes:**

- Moderate impairment means a Global Assessment Functioning Score (GAF-Score) between 31 and 60
- Severe impairment means GAF-Score of 30 and below.
- Support recommended: educational, social or psychological support by peers, teacher, social worker, psychologist or counsellor, etc.
- Sensitisation of teachers and peers required to support and accommodate learner.

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Developmental Functioning/Learning Disability/Intellectual Disability**

Condition Diagnosed\*: \_\_\_\_\_

In terms of the Diagnostic and Statistical Manual of mental Disorders Fifth Edition (DSM-V) Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains. The following criteria must be met:

*-Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from experience, confirmed by both clinical assessment and individualised, standardised intelligence testing;*

*-Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal in dependence and social responsibility. Without on-going support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation and independent living, across multiple environments, such as home, school, work and community;*

*-Onset of intellectual and adaptive deficits during the developmental period.*

Tick when applicable	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience	
<input type="checkbox"/>	Self-care	
<input type="checkbox"/>	Social/interpersonal skills	
<input type="checkbox"/>	Self-direction impacting on independence at school	
<input type="checkbox"/>	Functional cognitive skills	
<input type="checkbox"/>	Concentration, leisure, health and safety	

**Notes:**

- An IQ test is not a recommendation but could be administered to determine the actual academic ability of the learner for support planning purposes, provided that the test being used has been standardised in his/her home language
- Support recommended: remedial interventions, assistive technology, adapted learning and teaching support materials, educational or physical support by peers, teacher, personal assistant or therapist, etc.
- Specify current severity: Mild, moderate, severe or profound.

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Vision**

Condition Diagnosed\*: \_\_\_\_\_

The minimum requirement for a learner to be classified as a visually impaired learner is as follows:

Tick	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	Visual acuity in the better eye with best possible correction, less than 6/12 (0.3). <3/60 Snellen in the better eye, after maximum correction, constitutes blind 6/60 to 3/60 Snellen in the better eye = severe visual loss (partially sighted learner, sometimes considered blind, depending on complicating specific eye conditions)	
<input type="checkbox"/>	Visual Field 10 degrees or less around central fixation. 6/6 – 6/18 = normal vision 6/18 to 6/60 Snellen = moderate visual loss (partially-sighted learner);	

**Notes:**

- “6/18” means that what a person with normal vision can read at 18 metres, the person being tested can only read at 6 metres.
- “Best possible correction” refers to the position after a person’s vision has been corrected by means of spectacles, contact lenses or intraocular (implanted) lenses.
- Support recommended: assistive technology, adapted LTSM, orientation and mobility or Braille instruction, educational or physical support by peers, teacher, assistant, ophthalmic nurse, therapist, etc.

When did your patient meet the above criteria for the first time?	YY/MM/DD
---	----------

**Communication**

Condition Diagnosed\*: \_\_\_\_\_

A learner is regarded as having a moderate to severe communication disability if he or she has any one or a combination of the following, which even with appropriate therapy, medication and devices, substantially limits (that is, more than inconvenient or bothersome) one or more major life activities below age-appropriate:

Tick when applicable	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	Inability to make him/herself understood to familiar communication partners using speech in a quiet setting	
<input type="checkbox"/>	Inability to make him/herself understood, to familiar and or non-familiar communication partners and to meet communication needs as appropriate for his/her age by using speech, in less than 30 intelligible words	
<input type="checkbox"/>	Problems in understanding meaningful language by familiar communication partners that lead to substantial difficulty in communicating	
<input type="checkbox"/>	Relying on augmentative or alternative communication (AAC), including unaided (Sign language or other manual signs)	
<input type="checkbox"/>	Aided means of communication (ranging from communication boards to speech-generating devices)	

**Notes**

Support recommended: assistive technology, educational support by peers, teacher, interpreter or therapist, etc.

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Hearing**

Condition Diagnosed\*: \_\_\_\_\_

Hearing disability is defined as the functional limitations resulting from a hearing impairment. Hearing impairment is a sensory impairment that will influence verbal communication between speaker and listener.

Tick when Applicable	Area of functional limitation Degree of hearing loss (PTA)	Recommendations of support that could be provided at school
<input type="checkbox"/>	-10 to +15 dB HL (hearing level): Normal Hearing	
<input type="checkbox"/>	16 to 25 dB HL: Minimal loss	
<input type="checkbox"/>	26 to 40 dB HL: Mild loss	
<input type="checkbox"/>	41 to 55 dB HL: Moderate loss	
<input type="checkbox"/>	56 to 70 dB HL: Moderately severe loss	
<input type="checkbox"/>	71 to 90 dB HL: Severe loss	
<input type="checkbox"/>	91 dB HL and more: Profound loss	
<input type="checkbox"/>	Chronic otitis media	

**Notes:**

- Hearing impairment is an abnormal or reduced function in hearing resulting from several causes.
- A child is a person between the ages of 0 to 18 years.
- Amplification devices include hearing aids, bone conductors, implantable devices and assistive listening devices.
- Pure Tone Average (PTA): average of hearing sensitivity thresholds (in decibel hearing level) to pure tone signals at 500 Hz, 1000 Hz and 2000 Hz of each ear.
- Bilateral hearing loss is a hearing sensitivity loss in both ears.
- Unilateral hearing loss is a hearing sensitivity loss in one ear only.

When did your patient meet the above criteria for the first time?

YY/MM/DD

**Neurodevelopmental and Neurological Disorders**

Condition Diagnosed by Health Professional\*: \_\_\_\_\_

Can include disorders such as epilepsy, cerebral palsy, traumatic brain injury, attention deficit disorder, dyslexia, foetal alcohol syndrome and autism.

Tick when Applicable	Area of functional limitation	Recommendations of support that could be provided at school
<input type="checkbox"/>	Communication (ability to effectively communicate using speech/language)	
<input type="checkbox"/>	Self-care (ability to effectively perform activities of daily living. e.g. feeding, dressing, washing, etc.)	
<input type="checkbox"/>	Social/interpersonal skills (ability to interact appropriately with peers and adults)	
<input type="checkbox"/>	Mobility (ability to ambulate or use assistive devices to move)	
<input type="checkbox"/>	Functional cognitive skills (ability to pay attention, concentrate, learn, etc.)	
<input type="checkbox"/>	Vocational/Scholastic (ability to execute academic tasks)	
<input type="checkbox"/>	Leisure/Play/Sports (ability to actively participate in leisure tasks)	
<input type="checkbox"/>	Sensory (seeing, hearing and related functions)	

**Notes:**

With the exclusion of intellectual disability, a learner is regarded as being a learner with a neurological or neurodevelopmental disorder if he or she has been diagnosed, in terms of accepted diagnostic criteria, by a medical practitioner authorised to make such diagnosis:

When did your patient meet the above criteria for the first time?

YY/MM/DD

**D. RECOMMENDATIONS BY HEALTH-CARE PROFESSIONAL**

Summary of conditions diagnosed:

Specific interventions required by the learner (Tick when applicable):

<input type="checkbox"/>	Medication/ medical Examination	<input type="checkbox"/>	Assistive devices and consumables	<input type="checkbox"/>	Psycho-social support and counselling
<input type="checkbox"/>	Physiotherapy	<input type="checkbox"/>	Occupational therapy	<input type="checkbox"/>	Family/care-giver support and counselling
<input type="checkbox"/>	Speech language therapy and/or audiology	<input type="checkbox"/>	Psychotherapy	<input type="checkbox"/>	Other



<b>FURTHER REFERRAL NEEDED:</b>		Yes		No	
Describe/Explain					
<b>EFFECT OF MEDICAL CONDITION OR DISABILITY ON PATIENT'S ABILITY TO LEARN IN A SCHOOL</b> (Tick when applicable):					
<b>None/minimal</b>		<b>Moderate</b>		<b>High</b>	
<input type="checkbox"/>	<i>Learner ought to cope in an unmodified school environment with recommended assistive devices</i>	<input type="checkbox"/>	<i>Will be able to cope in a slightly modified school environment and may need assistive devices</i>	<input type="checkbox"/>	<i>Will only be able to cope in a modified school environment (modified toilets/ ramps/ground- level classrooms, etc.)</i>
<input type="checkbox"/>	<i>Learner needs a low level of support in school environment</i>	<input type="checkbox"/>	<i>Needs occasional therapy/ treatment/support</i>	<input type="checkbox"/>	<i>Needs frequent, high level of treatment/therapy/support by a medical professional</i>
Explain your choice					

**E. DECLARATION BY HEALTH-CARE PROFESSIONAL**

**PLEASE ATTACH DETAILED REPORTS WHERE APPLICABLE**

Signature: Date: 20 ... / ... / .....

Initials and surname (print): .....Tel no.: .....

**F. HEALTH-CARE PROFESSIONAL WHO COMPILED THE REPORT**

**PLEASE ATTACH DETAILED REPORTS WHERE APPLICABLE**

Signature: .....Date: 20 ... / ... / .....

Initials and surname (print): .....Tel no.: .....

**PARENT/LEGAL CARE-GIVER'S PERMISSION TO SHARE INFORMATION**

I hereby give permission to dispose this report, which was discussed with me, to the school or other relevant professionals for the benefit of my child.

Signature of parent/legal care-giver: .....

Date: 20 ... / ... / .....

Print name: ..... Tel. no. ....

**Appendix B: Support Needs Assessment form 1 (SNA1), Form, SIAS, 2014.**



**basic education**  
 Department:  
 Basic Education  
**REPUBLIC OF SOUTH AFRICA**

**SUPPORT NEEDS ASSESSMENT FORM**

**(SNA)**

**SNA 1 & 2: SCHOOL LEVEL**

Surname and names of learner	DOB: 20.... / ..... / ..... (yy/mm/dd)
	ID No. ....
	LURITS/CEMIS No. ....
Name of school:	EMIS No.: .....

**CONFIDENTIAL**

This is a confidential document that must be kept in the Learner Profile

**SUPPORT NEEDS ASSESSMENT (SNA 1 & 2)**

**(School-Level Intervention)**

*Both SNA 1 and 2 must be completed at school level*

*A Learner Profile, SNA 1 and SNA 2 will be required when support is requested from the District-based Support Team (DBST).*

**SNA 1: ASSESSMENT AND INTERVENTION BY TEACHER**

*To be completed by the class teacher and/or subject teachers if the learner is taught by more than one teacher.*

-To be completed if the Learner Profile or Screening Report or teacher observation or parent interview shows that a learner has additional support needs.

- Captures information that will be needed when support is requested from the School-based Support Team (SBST) by the teacher concerned.

**1. AREAS OF CONCERN**

Describe your concern about the learner.

--

When did you become aware of this? \_\_\_\_\_ How did you become aware of this – own observation or was it reported?

--

How is this observation currently affecting the learner's learning and development? Describe.

--

Complete the following table with regard to the learner's scholastic profile (information extracted from Learner Profile)

<b>YEAR</b>							
<b>GRADE</b>							
<b>RESULT (Pass/more time/ progressed)</b>							
<b>NUMBER OF SCHOOLS ATTENDED</b>							

Has any disability been diagnosed by a healthcare professional?

(as captured in *the Medical and Health Assessment Form [Annexure D]*)

If Yes, complete the following and attach reports.

Health-care Professional	Date of assessment	Summary of results

## 2. STRENGTHS AND NEEDS OF THE LEARNER

Indicate the strengths and needs of the learner by completing the sections below.

### 2.1 Communication:

The learner's ability to understand what other people are saying as well as to express him/herself in a way that other people understand – receptive and expressive language

Strengths	Needs/At risk factors	Support needed

### 2.2 Learning:

The learner's ability to participate satisfactorily on grade level regarding subject content and assessment

Strengths	Needs/At risk factors	Support needed

### 2.3 Behaviour and social competence:

The learner's ability to interact and work with other learners, as well as follow classroom routines

Strengths	Needs/At risk factors	Support needed

**2.4 Health, wellness and personal care:**

The learner's physical appearance (looking healthy, clean, well-fed), emotional well-being and health status (consult School Health Screening Report/Road to Health Card)

Strengths	Needs/At risk factors	Support needed

**2.5 Classroom and school:**

Factors within the classroom and school environment (policies, ethos, attitudes, skills, resources, safety, etc.) that are impacting on the learner's effective participation in the learning process and programmes offered at the school

Strengths	Needs/At risk factors	Support needed

**2.6 Family, home and community situation:**

Factors that may be impacting on the learner's ability to achieve satisfactorily at school (e.g. family structure, family stability, biological parents, siblings, other significant adults, orphan, child-headed household, number of schools attended, homeless, in foster care, refugee, immigrant, substance abuse, domestic violence, divorce, neglect, disabled/ill parents, poverty-stricken home background)

Strengths	Needs/At risk factors	Support needed

**3. TEACHER INTERVENTIONS/SUPPORT****3.1 Curriculum Intervention:**

*What curriculum interventions have you as teacher implemented to address your concerns?*

*3.1.1 Comment on/explain how the **curriculum content has been differentiated**, e.g. taking into account that every learner should have access to the grade level teaching and assessment best suited to his/her needs. Have the learner's needs been met by a differentiated curriculum? Have the learner's abilities determined what is expected of him/her without discrimination? Etc.*

Successes	Challenges

*3.1.2 Comment on how **teaching methods** have been adapted/differentiated, e.g. how classroom management has been changed to accommodate learners working at different levels of knowledge; how activities have been modified to ensure*

that they are meaningful; how a range of graded materials has been used (how material has been modified to allow for a learner's disability, for instance); how the presentation has been modified (e.g. by using pictures/pictures with descriptions/explanations, etc.)

Successes	Challenges

3.1.3 Comment on how the **assessment** has been modified, e.g. by organising the learner's tasks, using different methods of assessment, without compromising the curriculum standards.

Successes	Challenges

**3.2 What interventions have you as a teacher implemented in the learning environment (classroom/school) to address your observations and concerns about the learner?**

Comment, for example, on how the following have been modified: classroom management (e.g. culture/class rules/attitudes/ awareness of disabilities); playground management, e.g. buddy system.

Successes	Challenges

**3.3 Comment on how the physical environment has been modified/adapted**

E.g. the seating arrangement of the learner has been changed to limit distractions, use of flexible grouping(s) to accommodate learner, the environment has been made wheelchair-friendly.

Successes	Challenges

**3.4 Any additional comments that you want to make about the barrier(s) to learning experienced by the learner, the support/interventions provided and continuing challenges that are experienced.**

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**3.5** What additional support/intervention do you as a teacher require from the School-based Support Team (skills, resources, knowledge about curriculum differentiation (both in teaching and assessing)?

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**3.6** Schedule/Log of consultation(s) with: Parent/Legal Guardian/Care-giver/Learner himself or herself.

Date	Purpose	Outcome

**3.7** Views expressed by Parent/Legal Guardian/Care-giver/Learner during the consultation(s):

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Role player	Initials and surname of person (print)	Signature	Date
Teacher/ Manager			20... / ... / ...
Parent/Legal Care-giver			20... / ... / ...
Learner (if applicable)			20... / ... / ...

**SNA 2: ASSESSMENT AND INTERVENTION BY SCHOOL-BASED SUPPORT TEAM (SBST)**

*To be completed by the SBST in consultation with the teacher*

*To be completed when requesting support from the DBST by the school*

<b>1.</b>	<b>REVIEW</b>	SBST reviews the information provided by the teacher: Section 1, supporting documents, verbal reporting.		
<b>1.1</b>	<b>Does the SBST agree with the teacher's identification of the learner's barrier(s) to learning, strengths and needs/challenges? If not, provide comments:</b>			
<b>YES</b>	<input type="checkbox"/>	<b>NO</b>	<input type="checkbox"/>	Comments:

<b>1.2 Does the SBST agree with the teacher’s support to deal with the barrier(s) to learning? If not, provide comments or suggest alternative support:</b>			
YES		NO	Comments:

**2. SUMMARY OF IDENTIFIED BARRIERS TO LEARNING AND SUPPORT THAT WAS/ IS/WILL BE PROVIDED BY SBST**


**3. INDIVIDUAL SUPPORT PLAN (COMPLETED BY CLASS TEACHER AND SBST)**

List the area(s) in which the support needs to be provided: Communication; Learning; Behaviour and social competence; Health, Wellness and personal care; Classroom and school; Family, home and community; Teacher development/ training, etc. (See SNA1)

Area(s) in which support is needed	Target to be achieved	Strategy of intervention <i>(If the learner needs concessions, or is an immigrant who needs exemptions, use Annexure B If a medical condition must be investigated by a medical or other specialist, use Annexure D)</i>	Responsible person	Time frame	Review date (to assess achievement of the target)	Comment on progress made in achieving target(s)
<i>E.g. Behaviour</i>	Stop	<i>Assign a mentor teacher to support learner                      Raise awareness during assembly                      Review school conduct policy                      Call in parent/legal care-givers</i>	Principal	<i>Within 1 week</i>	<i>15 April 20..</i>	

## Appendix C: Interview Guide: Learner with TBI

### Personal Information

The following personal information will be recorded:

- Name and surname of learner
- Date of interview
- Gender
- Age
- Geographical location of where learner lives
- Type of TBI
- Date of onset of TBI
- Level of Cognitive Impairment (i.e. mild or moderate)
- Physical Impairments
- Duration at School following TBI
- Type of School (i.e. ordinary high school, special high school)
- School Setting (i.e. rural, urban, peri urban)
- Grade

### Interview Guide

- A preliminary interview/ meeting with the adolescent learner will be conducted prior to the research interview.
- The research interview:
  - Will commence with a short summary of what the interview is about
  - I will reinforce to the adolescent that there are no right or wrong answers so that she/he does not feel pressurised to give the correct answer.
  - The interview may be conducted over two or more 30-45 min sessions dependent on the learner's levels of fatigue or if he/she becomes over- stimulated.

The below mentioned are examples of the sort of questions that may be asked. It also includes examples of possible probes that could be used during the interview. I am aware that this is a semi structured interview and that I should therefore allow for flexibility, but given that these learners may have problems with cognition such as concentration, memory, topic maintenance etc. it is recommended that interviewers make use of interview guides (Boylan et al, (2009:268), Lloyd et al (2006:1397) and Paterson and Scott-Finlay (2002:405).

- Tell me about how you first felt about going back to school after your brain injury?
- Tell me when did the planning for your return to school first start?  
Probes: Were you first prepared in hospital or only once you were discharged home?  
Who first spoke to you about going back to school?
- Was there a meeting to talk about you going back to school?  
Probe: Who was present?  
Were you at the meeting?  
What do you think, should you or should you not be at the meeting?  
Why do you say so?
- Tell me about how you were prepared for your return to school?  
Probes: Who helped you to prepare for going back to school?  
What did this person/s do or say to help you to prepare to go back to school?  
How would you say you were prepared for your return to school?
- Do you think you were prepared enough for your return to school?  
Probe: Can you explain further?
- Do you think that the people at school (i.e. teachers, peers, principal, other team members) were prepared for your return to school?  
Probe: What were the attitudes of your peers towards you when you returned to school?  
What were the attitudes of the teachers/staff towards you when you returned to school?  
What was the attitude of the principal towards you when you returned to school?  
Do you know if your teachers/ other staff and your peers received education about your brain injury and the support you will need?
- What do you think could have been done differently or extra to help you be better prepared for when you returned to school?
- Tell me about when you first came back to school after your injury, how did that go?  
Probes: Was it easy or difficult?



What was different from when you were at school before your injury?

Probes: For e.g. the classroom, the work, the people (friends, teachers etc.)

- What did the school put in place to help you cope at school?

Probes: Were there any changes in the class/physical school environment?

Were there changes in how your school work was presented?

Were you helped by a class mate or a teaching assistant?

There are teachers that are there to give a learner extra help when they need it, did you have such a teacher? If yes tell me about what this teacher did to help you when you came back to school?"

Was there any special equipment you could make use of?

When you found you were having difficulty was there a counsellor/someone in the school to whom you could speak?

- Some people would say that when returning to school after a traumatic brain injury there may be some challenges. What would you tell them?"

Probes: What are the things that make going back to school easier after your brain injury?

What are some of the difficulties you had/still have after going back to school after your brain injury?

Do you have difficulties with reading, maths or writing etc.?

- Do you have difficulty with talking – like answering questions or asking for help?
- Do you have difficulty with moving about indoors or outdoors at school?
- Do you have difficulty with attending to your personal needs (i.e. feeding, toileting, etc.)?
- Do you have difficulty with socialising with your peers in and outside the classroom?
- Why do you think you had/have these difficulties?

- Who helps you with your school work at home?

- What do you think could be done differently or extra to help you do well at school?

Probe: What would you change about how things are done now?

- What does going to school mean for you?

- Thank you very much, you have been very helpful through giving lots of information!

- Is there anything else you want to tell me?

- Just a reminder that I may visit you again to ensure that I understood you correctly or if I need more information to increase my understanding of your experience of returning and taking part in school after your brain injury.

## Appendix D: Interview Guide: Primary care-giver

### Personal Information

The following personal information will be recorded:

- Name and surname of Parent
- Date of interview
- Gender of Parent
- Age of Parent
- Relationship Status (i.e. single, married, divorced)
- Highest Level of Education
- Economic Status (low, middle, high)
- Geographical location of where parent lives
- Age of child
- Gender of child
- Type of TBI child sustained
- Date of onset of child's TBI
- Level of Cognitive Impairment of child (i.e. mild or moderate)
- Physical Impairments of child
- Duration of child at school following TBI
- Type of School child attends (i.e. ordinary high school, special high school)
- School Setting of child (i.e. rural, urban, peri urban)
- Grade of child

### Interview Guide

Whilst I stated that the interview may be conducted over a period of 60 minutes. I have factored into my planning that this may need to be broken down into two shorter sessions or be longer than the anticipated 60 min session dependant on the parents' levels of fatigue and the amount of information they want to share.

- Interview will commence with:
  - Personal introduction
  - Explanation of the aim of the research
  - Explanation of ethical issues
  - Opportunity for questions

The below mentioned are examples of the possible questions that could be asked during the interview:

- Tell me about the process of preparing your child's return to school after his/her brain injury?
- What was most helpful in preparing your child with his or her return to school?
- What was least helpful in preparing your child with his or her return to school?
- What do you think could have been done differently or in addition to help your child be better prepared for the initial return to school following the brain injury?
- Tell me about when your child first went back to school after the injury, how did it go?
- What helps your child to cope at school?
- What are some of the difficulties your child still experiences at school after their brain injury?
- Why do you think your child has/had these difficulties?
- What do you think could be done differently or in addition to help your child achieve success at school?
- What role do you play in your child's schooling?
- What are some of the difficulties you are faced with when trying to provide your child with the support that he/she needs to do well in school?
- What support do you receive from the external community?
- What are the teachers' attitudes towards you?
- Do you feel that you can easily and freely approach the principal and teachers if you have requests or questions? How often do you approach them?
- How are you kept in informed about your child's performance at school?
- Thank you very much for helping me! Is there anything else you want to tell me?
- Just a reminder that I may visit you again to ensure that I understood you correctly or if I need more information to increase my understanding of your child's experience of returning and taking part in school after their brain injury.

## Appendix E: Interview Guide: Teacher

### Personal Information

The following personal information will be obtained:

- Name and surname of Teacher
- Date of Interview
- Gender of Teacher
- Highest Level of Education
- Years of Teaching experience a) Ordinary b) Special Needs
- School Setting (i.e. rural, urban, peri urban)
- Age of learner
- Gender of learner
- Geographical location of where learner lives
- Type of TBI of learner
- Onset of TBI of learner
- Level of Cognitive Impairment of learner
- Physical Impairments of learner
- Duration of learner at School following TBI
- Grade of learner

### Interview Guide

Whilst I stated that the interview may be conducted over a period of 60 minutes. I have factored into my planning that this may need to be broken down into two shorter sessions or be longer than the anticipated 60 min session dependant on the teachers' levels of fatigue and the amount of information they want to share.

- Interview will commence with:
  - Personal introduction
  - Explanation of the aim of the research
  - Explanation of ethical issues
  - Opportunity for questions

The below mentioned are examples of the possible questions that could be asked during the interview:

- Tell me about the process of preparing your learner for his/her return to school after the brain injury?
- What do you think was most helpful in preparing your learner for his/her return to school after the brain injury?
- What do you think was least helpful in preparing your learner for his/her return to school after the brain injury?
- What do you think could have been done differently or in addition to help your learner be better prepared for the initial return to school following the brain injury?
- Tell me about when your learner first came back to school after his/her injury, how did it go?
- What helps your learner to cope at school?
- What are some of the difficulties your learner experienced at school after the brain injury?
- Why do you think your learner had/have these difficulties?
- What are some of the difficulties or challenges you are faced with in supporting your learner with a brain injury?
- What support do you receive whilst teaching your learner with brain injury?
- What is the role of the parents in the learner's schooling?
- What is the role of the community in the learner's schooling?
- How is the learner's performance monitored at school and how often?
- How are the parent and the learner informed about their progress?
- How is your learner prepared for the year to year transition of going from one grade to the next?
- What do you think could be done differently or in addition to help your learner achieve success at school?
- Thank you very much for helping me! Is there anything else you want to tell me?
- Just a reminder that I may visit you again to ensure that I understood you correctly or if I need more information to increase my understanding of your learner's experience of returning and taking part in school after their brain injury.

## Appendix F: Interview Guide: Principal

### Personal Information

- Name and surname of the Principal
- Date of Interview
- Gender of Principal
- Highest Level of Education
- Years of Teaching experience a)Ordinary b)Special School
- Type of School
- School Setting (i.e. rural, urban, peri urban)
- Age of learner
- Gender of learner
- Geographical location of where learner lives
- Type of TBI of learner
- Onset of TBI of learner
- Level of Cognitive Impairment of learner
- Physical Impairments of learner
- Duration of learner at School following TBI
- Grade of learner

### Interview

Whilst I stated that the interview may be conducted over a period of 60 minutes. I have factored into my planning that this may need to be broken down into two shorter sessions or be longer than the anticipated 60 min session dependant on the principals' levels of fatigue and the amount of information they want to share.

- Interview will commence with:
  - Personal introduction
  - Explanation of the aim of the research

The below mentioned are examples of the possible questions that could be asked during the interview:

- Tell me about the process of preparing your learner for his/her initial return to school after the brain injury?
- What do you think was most helpful in preparing your learner for his/her return to school after the brain injury?
- What do you think was least helpful in preparing your learner for his/her return to school after the brain injury?
- What do you think could have been done differently or in addition to help your learner be better prepared for the initial return to school following the brain injury?
- Does the school have a vision and a mission statement that promotes inclusion? What does it specifically state?
- Tell me about when your learner first came back to school after the injury, how did it go?
- What type of support did and does your learner still receive at school?
- What are some of the difficulties your learner experienced at school after the brain injury?
- Why do you think your learner had/have these difficulties?
- What support has the Department of Education provided?
- What is the role of the parents in the learner's schooling?
- How is the learner's performance monitored at school and how often?
- How are the parent and the learner informed about their progress?
- What role does the external community (parents, businesses, organisations, universities) play in the inclusion of the learners?
- What can you recommend in order to improve the process of inclusion of learners with brain injuries?
- Thank you very much for helping me! Is there anything else you want to tell me?
- Just a reminder that I may visit you again to ensure that I understood you correctly or if I need more information to increase my understanding of your learner's experience of returning and taking part in school after the brain injury.

**Appendix G: Parent information sheet****PARENT INFORMATION LEAFLET****TITLE OF THE RESEARCH PROJECT:**

**A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape.**

**REFERENCE NUMBER: S15/03/055**

**PRINCIPAL INVESTIGATOR: Lee-Ann Juliana Jacobs-Nzuzi Khuabi (nee: Jacobs)**

**ADDRESS:**

**Division of Occupational Therapy  
Second Floor Teaching Block  
Faculty of Medicine and Health Sciences  
Franzie Van Zyl Drive  
Parow  
7500**

**CONTACT NUMBER: XXX (office) XXX (cell)**

Dear Parent/ Primary care-giver

My name is Lee-Ann Juliana Jacobs-Nzuzi Khuabi and I am a registered PhD student in Occupational Therapy at Stellenbosch University. I would like to invite your child to participate in a research project that aims to understand the experiences of adolescent high school learners regarding those factors that help or challenge their ability to return and participate in school after traumatic brain injury (TBI).

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your child's participation is **entirely voluntary** and he/she free to decline to participate. If your child says no, this will not affect them negatively in any way whatsoever. They are also free to withdraw from the study at any point, even if they do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki 2013.

After brain injury there are many changes that learners need to adjust to, which includes returning to school. Most of the research that has been done has focused on the experiences and opinions of others (i.e. parents, teachers and health professions) on how learners should be prepared and supported for their return to school after brain injury. This research is being done as there is a need to give the learners a chance to speak about their own experiences of returning to school after brain injury. In this research I am specifically interested in how your child has been prepared for this process and the support that he/she has received and continues to receive upon their return to school. The views of your child will help to improve on the services that prepare and support learners with brain injury to return and participate in school.

Your child will be one of ten high school learners invited to participate in this study within the Western Cape. Before your child participates in this study I will have to review their health (e.g. neuropsychological report) or school records to obtain information about their brain injury and their level of functioning following this injury. I will also require your permission to interview the teacher who knows the child the best and the principal of the high school your child attends. Should your child and you agree, your child will take part in two or three interviews of 30-45 minutes each depending on their levels of concentration and fatigue. Your child may be contacted for another interview if I need to double check that I have understood everything in the way your child wanted to express their opinions and experiences. The interviews will be conducted in English, Afrikaans or isiXhosa. If your child prefers to speak in isiXhosa a translator will be present in the interview. I will meet your child at a place and time of his/her choice. Your child will get money to cover the cost of his/her travelling expenses should he/she choose to meet at a venue other than their home or school. They will also receive a snack at the end of each interview. Your child's responses will be audio recorded and their responses will be recorded word for word. The data (audio files) will be kept in a locked cabinet to which only I will have access. All information that is stored on a computer will be protected by a password. Your child's identity will be protected by assigning them a code name. Only I, the translator, my supervisors and the person that types what your child's says from the tape recorder may see their responses. If your child's responses are used in the write up of a research report or articles on brain injury, their code name and not their real name will be used.

Your child will not experience any physical harm as a result of taking part in this study. However they may find that talking about their experiences may upset them and in such cases it will be arranged for them to speak to a trusted person (psychologist /social worker) who can assist them to work through these feelings.

As a result of them sharing their experiences and opinions, it is possible that the services that prepare and support learners to return to school after brain injury can be improved. This will help other learners who have brain injuries better adjust to their return to school after brain injury and help increase their chances of being successful in school.

If there are any queries please feel free to contact me (primary investigator: Lee-Ann Juliana Jacobs-Nzuzi Khuabi: XXX), my supervisors (Prof E Swart: XXX or Dr MS Soeker: XXX) or the Health Research Ethics Committee at Stellenbosch University (021 9389156).

**If you are willing to for your child to participate in this study please sign the attached Declaration of Consent and hand it to me.**

Yours sincerely

Lee-Ann Juliana Jacobs-Nzuzi Khuabi (Principal Investigator)

### **Declaration by parent**

By signing below, I ..... agree to allow my child to take part in a research study entitled "A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape".

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that my child taking part in this study is **voluntary** and I have not been pressurised to allow him/her to take part.
- My child may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished, if the researcher feels it is in my child's best interests.

Signed at (*place*) ..... On (*date*) ..... 2015.

..... Signature of parent

**Appendix H: Assent form****PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM****TITLE OF THE RESEARCH PROJECT:**

**A model to assist high school learners to return and participate in school after traumatic brain injury in the Western Cape.**

**REFERENCE NUMBER: S15/03/055**

**PRINCIPAL INVESTIGATOR: Lee-Ann Juliana Jacobs-Nzuzi Khuabi (nee: Jacobs)**

**ADDRESS:**

**Division of Occupational Therapy  
 Second Floor Teaching Block  
 Faculty of Medicine and Health Sciences  
 Franzie van Zyl Drive  
 Parow  
 7500**

**CONTACT NUMBER: XXX (office) XXX (cell)**

**What is RESEARCH?**

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find better ways of helping people.

**What is this research project all about?**

- After brain injury there are many changes that learners need to adjust to, which includes going back to school.
- Most of the research that has been done has focused on the experiences and opinions of others (i.e. parents, teachers and health professions) on how learners should be prepared and supported for their return to school after brain injury.
- This research is being done as there is a need to give the learners a chance to speak about their own experiences of going back to school after brain injury. In this research I am very interested in how you



were prepared for this process and the support that you received and continue to receive upon your return to school.

- Your views and that of your parent/main care-giver, the teacher you feel knows you the best and your school principal will help to improve on the services that prepare and support learners with brain injury to go back and participate in school.

#### **Why have I been invited to take part in this research project?**

- You are one of ten high school learners in the Western Cape, who has been invited to take part in this study as you have a brain injury and your experiences and opinions of how you have been prepared and supported in school is important in improving on the services that aim to prepare and support other learners with brain injuries return to school.

#### **Who is doing the research?**

- My name is Lee-Ann Juliana Jacobs- Nzuzi Khuabi and I am an occupational therapist and a lecturer at Stellenbosch University. I am doing this research because of my past work with learners with brain injury where I realised that I needed to hear from learners if they felt that what we were doing was sufficient and what they needed to adjust to going back to school and be successful in school after brain injury.
- This research I will also use as part of furthering my studies to obtain a PhD degree.

#### **What will happen to me in this study?**

- Before you take part in this study you will agree that I may review your health (e.g. neuropsychological report) or school records to obtain information about your brain injury and level of functioning following this injury. You will give your permission for me to interview your parent/main care giver, the teacher who knows you the best and the principal of the high school you attend.
- In this study you will take part in two or three interviews of 30-45 min each depending on your concentration and your levels of tiredness.
- The interviews will be conducted in English, Afrikaans or isiXhosa. If you prefer to speak in isiXhosa a translator will be present in the interview.
- We will meet at a place and time of your choice. You will get money to cover the cost of your travelling expenses should you choose to meet at a venue other than your home or school. You will receive a snack at the end of each interview.
- What you say will be recorded on a digital voice recorder. The tapes will be kept in a locked cabinet to which only I will have access. All information that is stored on a computer will be protected by a password. Your name will not be used instead you will be given a code name to protect your identity.
- You may be contacted for another interview if I need to double check that I have understood everything in the way you wanted to express your opinions and experiences.

**Can anything bad happen to me?**

- No physical harm will be experienced as a result of you taking part in this study. However you may find that talking about your experiences may upset you. In such cases you are please to tell me or your parents and it will be arranged that you speak to a trusted person (psychologist/social worker) who can assist you to work through these feelings.

**Can anything good happen from this study?**

- As a result of you sharing your experiences and opinions, it is possible that the services that prepare and support learners to return to school after brain injury can be improved. This will help other high school learners who have brain injuries better adjust to their return to school after brain injury and help increase their chances of being successful in school.

**Will anyone know I am in the study?**

- Your name and identity will be kept private. Only I, the translator, my supervisors and the person that types what you say from the audio recorder may see your responses. If what you say is used in the write up of a research report or articles on brain injury, your real name will not be used.

**Who can I talk to about the study?**

- If you have any questions or problems because of taking part in this study you may tell your parent, teacher or contact me: Lee-Ann Jacobs-Nzuzi Khuabi XXX (cell) or XXX (office).

**What if I do not want to do this?**

- You are free to refuse to take part in this study even if your parents have agreed to take part.
- You can stop being in the study at any time without getting in trouble.

Do you understand this research study and are you willing to take part in it?

 YES

 NO

Have I as the researcher answered all your questions?

 YES

 NO

Do you understand that you can pull out of the study at any time?

YES

NO

---

Signature of Child

---

Date

**Appendix I: Parent consent form****PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM****TITLE OF THE RESEARCH PROJECT:**

**A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape.**

**REFERENCE NUMBER: S15/03/055**

**PRINCIPAL INVESTIGATOR: Lee-Ann Juliana Jacobs-Nzuzi Khuabi (nee: Jacobs)**

**ADDRESS:**

**Division of Occupational Therapy  
Second Floor Teaching Block  
Faculty of Medicine and Health Sciences  
Franzje Van Zyl Drive  
Parow  
7500**

**CONTACT NUMBER: XXX (office) XXX (cell)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

- This research will be conducted to understand the experiences of adolescent high school learners with traumatic brain injury (TBI), their parents, the teachers who know them best and principals regarding those factors that help or challenge adolescent learners to return and participate in school after TBI. This could help funders and service providers understand the back to school process after a TBI and identify

where efforts in terms of service delivery is needed. The findings of this study will be used to develop a practice model to prepare and support these learners in school participation.

- The study will be conducted in the Western Cape at a location and time that is convenient for you.
- The interviews will be conducted in English, Afrikaans or isiXhosa. If you prefer to speak in isiXhosa a translator will be present in the interview.
- Interviews will be audio recorded and data will be recorded word for word. The data (audio files) will be stored in a locked cabinet. All data gained is will be handled with utmost care and respect. To ensure confidentiality no names of persons, hospitals, schools or residential areas will be mentioned in the study and I will assign a code name to each participant. The master copy of participant names and matching code names will be kept in a separate storage place. All information that is stored on a computer will be protected by a password. The code names will be used when discussing the data collected. I will be making field notes at the end of each interview.

#### **Why have you been invited to participate?**

- You together with ten other parents/main care-givers of a teenager with TBI have been invited to participate in this study. You are chosen as you are one of the persons who know your child best and are therefore able to provide valuable information about your child's process of returning and participating in school following TBI.

#### **What will your responsibilities be?**

- You will be expected to participate in a 60 minute interview in which you will be asked questions about your child's return to school process and their participation in school following the TBI. I will meet you at a place and time of your choice. You will get money to cover the cost of your travelling expenses should you choose to meet at a venue other than your home.
- After the interview you may be contacted to clarify any of your responses or observations that I may have made during the interview.

#### **Will you benefit from taking part in this research?**

- You will not benefit directly However through your involvement in this study, the preparatory and support services for learners with TBI may be improved on which may facilitate a successful school re-integration and continued school participation post TBI.

#### **Are there in risks involved in your taking part in this research?**

- There are no risks to you partaking in this research. Measures will be taken to ensure your responses remain confidential. The study does not require the conduction of procedures that could cause physical harm. You have the right to refuse share any information you perceive as confidential/personal and private.

**Who will have access to your records and research data?**

- All information collected will be treated as confidential and protected. The findings that will be publicised for the purposes of a research report or articles on brain injury, will keep your identity confidential. Only I, the translator, my supervisors and the person that types what you say from the tape recorder may see your responses.

**Will you be paid to take part in this study and are there any costs involved?**

- No you will not be paid to take part in the study. There will be no costs involved for you, other than your travel costs should you chose not to be interviewed at your home. You will be refunded for the costs of the transport.

If there are any queries please feel free to contact me (primary investigator: Lee-Ann Juliana Jacobs-Nzuzi Khuabi: XXX my supervisors (Prof E Swart: XXX or Dr MS Soeker: XXX) or the Health Research Ethics Committee at Stellenbosch University (021 9389156).

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled “A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests.

Signed at (*place*) ..... on (*date*) ..... 2015.

.....  
**Signature of participant**

.....  
**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2015.

.....

.....

**Signature of investigator**

**Signature of witness**

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....

.....

**Signature of interpreter**

**Signature of witness**

**Appendix J: Teacher consent form****PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM****TITLE OF THE RESEARCH PROJECT:**

**A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape.**

**REFERENCE NUMBER: S15/03/055**

**PRINCIPAL INVESTIGATOR: Lee-Ann Juliana Jacobs- Nzuzi Khuabi (nee: Jacobs)**

**ADDRESS:**

**Division of Occupational Therapy  
Second Floor Teaching Block  
Faculty of Medicine and Health Sciences  
Franzie Van Zyl Drive  
Parow  
7500  
CONT**

**CT NUMBER: XXX (office) XXX (cell)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

- This research will be conducted to gain insight and understanding into the perceptions and experiences of adolescent high school learners with traumatic brain injury (TBI), their parents/primary care-givers, the



teachers who know them best and the principal regarding the enablers and barriers to school re-entry and school participation post TBI. This will potentially help funders and service providers understand the efficacy of transition back to school following a TBI and identify where efforts in terms of service delivery is needed. The findings of this study will be used to develop a practice model to prepare and support these learners in school participation.

- The study will be conducted in the Western Cape at the learner's school and at a time that you deem convenient. The interviews will be conducted in English, Afrikaans or isiXhosa. If you prefer to speak in isiXhosa a translator will be present in the interview.
- It is anticipated that 10 other teachers of learners with TBI will be interviewed.
- Interviews will be audio recorded and data will be recorded verbatim. The data (audio files) will be stored in a locked cabinet. All data gained is considered to be privileged information and therefore will be handled with utmost care and respect. To ensure confidentiality no names of persons, hospitals, schools or residential areas will be mentioned in the study and the researcher will assign a code name to each participant. The master copy of participant names and matching code names will be kept in a separate storage place. All information that is stored on a computer will be protected by a password. The code names will be used when discussing that data collected. I will be making field notes at the end of each interview.

#### **Why have you been invited to participate?**

- You have been invited to participate in this study as you are one of the persons who know the learner best within the school context and are therefore able to provide valuable insights into the learner's process of returning and participating in school following TBI.

#### **What will your responsibilities be?**

- You will be expected to participate in a 60 minute interview in which you will be asked questions about the learner's return to school process and their participation in school following the TBI. After the interview you may be contacted to clarify any of your responses or observations that I may have made during the interview.

#### **Will you benefit from taking part in this research?**

- You will not benefit from this study directly. However through your involvement in this study, the preparatory and support services for learners with TBI may be improved on which may facilitate a successful school re-integration and continued school participation post TBI.

#### **Are there in risks involved in your taking part in this research?**

- There are no risks to you partaking in this research. Measures will be taken to ensure your responses remain confidential. The study does not require the conduction of invasive procedures that could cause physical harm. You have the right to refuse to divulge any information you perceive as confidential/personal and private.

**Who will have access to your records and research data?**

- All information collected will be treated as confidential and protected. The findings that will be publicised for the purposes of a thesis or other research outputs, your identity will remain anonymous. Only I, the translator, my supervisors and the person that does the transcription may see your responses.

**Will you be paid to take part in this study and are there any costs involved?**

- No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

If there are any queries please feel free to contact me (primary investigator: Lee-Ann Juliana Jacobs-Nzuzi Khuabi: XXX), my supervisors (Prof E Swart: XXX or Dr MS Soeker: XXX) or the Health Research Ethics Committee at Stellenbosch University (021 9389156).

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled, “A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if researcher feels it is in my best interests.

Signed at (*place*) ..... on (*date*) ..... 2015.

.....

**Signature of participant**

.....

**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ..... 2015.

.....

**Signature of investigator**

.....

**Signature of witness**

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....

**Signature of interpreter**

.....

**Signature of witness**

**Appendix K: Principal consent form****PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM****TITLE OF THE RESEARCH PROJECT:**

**A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape.**

**REFERENCE NUMBER: S15/03/055**

**PRINCIPAL INVESTIGATOR: Lee-Ann Juliana Jacobs-Nzuzi Khuabi (nee: Jacobs)**

**ADDRESS:**

**Division of Occupational Therapy  
Second Floor Teaching Block  
Faculty of Medicine and Health Sciences  
Franzie Van Zyl Drive  
Parow  
7500**

**CONTACT NUMBER: 021 XXX (office) XXX (cell)**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this research study all about?**

- This research will be conducted to gain insight and understanding into the perceptions and experiences of adolescent high school learners with traumatic brain injury (TBI), their parents/primary care-givers, the teachers who knows them best and the principal regarding the enablers and barriers to school re-entry

and school participation post TBI. This will potentially help funders and service providers understand the efficacy of transition back to school following a TBI and identify where efforts in terms of service delivery is needed. The findings of this study will be used to develop a practice model to prepare and support these learners in school participation.

- The study will be conducted in the Western Cape at the learner's school and at a time that you deem convenient. The interviews will be conducted in English, Afrikaans or isiXhosa. If you prefer to speak in isiXhosa a translator will be present in the interview.
- It is anticipated that 10 other principals of learners with TBI will be interviewed.
- Interviews will be audio recorded and data will be recorded verbatim. The data (audio files) will be stored in a locked cabinet. All data gained is considered to be privileged information and therefore will be handled with utmost care and respect. To ensure confidentiality no names of persons, hospitals, schools or residential areas will be mentioned in the study and the researcher will assign a code name to each participant. The master copy of participant names and matching code names will be kept in a separate storage place. All information that is stored on a computer will be protected by a password. The code names will be used when discussing that data collected. I will be making field notes at the end of each interview.

#### **Why have you been invited to participate?**

- You have been invited to participate in this study as you are one of the key persons involved in a learner's re-integration to school post TBI. You are therefore able to provide valuable insights into the learner's process of returning and participating in school post TBI.

#### **What will your responsibilities be?**

- You will be expected to participate in a 60 minute interview in which you will be asked questions about the learner's return to school process and their participation in school following the TBI. After the interview you may be contacted to clarify any of your responses or observations that I may have made during the interview.

#### **Will you benefit from taking part in this research?**

- You will not benefit from this study directly. However through your involvement in this study, the preparatory and support services for learners with TBI may be improved on which may facilitate a successful school re-integration and continued school participation post TBI.

#### **Are there in risks involved in your taking part in this research?**

- There are no risks to you partaking in this research. Measures will be taken to ensure your responses remain confidential. The study does not require the conduction of invasive procedures that could cause physical harm. You have the right to refuse to divulge any information you perceive a confidential/personal and private.

**Who will have access to your records and research data?**

- All information collected will be treated as confidential and protected. Findings that will be publicised for the purposes of a thesis or other research outputs, your identity will remain anonymous. Only I, the translator, my supervisors and the person that does the transcription may see your responses.

**Will you be paid to take part in this study and are there any costs involved?**

- No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

If there are any queries please feel free to contact me (primary investigator: Lee-Ann Juliana Jacobs-Nzuzi Khuabi: XXX), my supervisors (Prof E Swart: XXX or Dr MS Soeker: XXX) or the Health Research Ethics Committee at Stellenbosch University (021 9389156).

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled “A model for the facilitation of school re-entry and continued participation of adolescent high school learners following traumatic brain injury in the Western Cape”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests.

Signed at (*place*) ..... on (*date*) ..... 2015.

.....

**Signature of participant**

.....

**Signature of witness**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ..... 2015.

.....

**Signature of investigator**

.....

**Signature of witness**

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....

.....

**Appendix L: Table displaying the interrelatedness between the data**

Codes	Sub-categories)	Categories	Theme
<p>“no confidence” self-conscious } Change in self- confidence</p> <p>Change in personality</p> <p>Change in energy</p> <p>Changes in behaviour</p> <p>Decreased frustration tolerance } Change in temperament “I get angry so quick”</p> <p>“negative thinking” Suicidal thinking “I was so depressed” “ very very emotional about that, like his dream was shattered” } Change in emotion</p> <p>Memory impairment Concentration impairment Perceptual impairments Decreased processing speed Agitation Difficulty multi-tasking Receptive language difficulties Impairment in organisation of thought processes Speech impairment Decreased insight } Cognitive, language &amp; communication changes</p> <p>Change in physical appearance</p> <p>Visual impairment Hearing impairment /Auditory Sensitivity } Change in sensory function Change in sense of taste</p> <p>Fine motor Inco-ordination Decreased motor control } Change in gross and fine motor abilities Gait/walking impairment</p> <p>Headaches Swallowing difficulties } Other complications post TBI Dizziness Incontinence</p> <p>Decreased social interaction, Loss of friends Strained relationships with parents Strained relationships with siblings } strained relationships with family members</p>	<p>Changes in Mental functions Comment: Change in global and specific mental functions)</p> <p>Change in physical functions</p> <p>Change in interpersonal interactions and relationships</p>	<p>Changes in functional abilities and skills (comment: changes in mental, physical &amp; interpersonal interactions and relationships)</p>	<p><b>Theme 1:</b> “kind of changed as a person”: <b>change in former sense of self</b> <u>Description:</u> Reflects participants’ views on the changes learners experience in abilities, skills and roles post TBI.</p>



<p>"I was failing...I used to be quite academic" "couldn't cope as before"</p> <p>Inability to complete self-help skills independently</p> <p>"don't go out and play" change in role from player to spectator</p> <p>Uncertainty about the future "it was like his dream was shattered"</p>	<p>} Change in academic performance post TBI</p> <p>Change in level of participation in non-academic related activities</p> <p>} Change in level of participation in extra-curricular activities</p> <p>} Change in scholastic and future career goals</p>	<p>} Change in role as learner</p>	<p><b>Theme 1:</b>  <b>"kind of changed as a person":</b>  <b>change in former sense of self</b>  <u>Description:</u> Reflects participants' views on the changes learners experience in abilities, skills and roles post TBI (cont.).</p>
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Code	Sub Category	Category	Theme
<p>“integrate into the normal run of school”                      “treat me like a normal student”                      “fit in and be one of the normal kids”</p> <p>School motivates,                      School allows for positive experience                      School as productive                      School allows learner to display practical skills</p> <p>“I ve got new friends “                      there are people like me”                      “I am not the only one</p> <p>School provides opportunity to display mastery                      School allows for increased sense of independence</p> <p>“My life has stopped..I cant go back to school”                      Lack of involvement in decision to cease school</p> <p>Lack of cognitive stimulation                      “sitting and losing out”</p>	<p>School re-entry and participation facilitates a sense of normality post TBI</p> <p>School participation serves as a motivator to progress post TBI</p> <p>School participation facilitates social engagement</p> <p>School participation helps to re-build confidence post TBI</p> <p>Non participation in school is perceived as debilitating</p> <p>Non participation n school reduces cognitive stimulation</p>	<p>School as valued occupation</p> <p>Non participation in school impedes recovery post TBI</p>	<p><b>Theme 2:</b>                      “School gets me further to where I want to be”  <u>Description:</u> Reflects participants’ views on the meaning and value of participating in the occupation of school.</p>

Code	Sub Category	Category	Theme
Cognitive stimulation Gait re training	Remediation of residual impairments post TBI	Enhancing day-day function	<p><b>Theme 3:</b>                      “Trying to get back into the swing of things”  <u>Description:</u> Reflects participants’ views on the strategies used to adapt and resume participation in school</p>
Writing retraining Speech therapy Improving hand function			
Dominance re-training Learning coping skills			
Asking questions of teachers Own initiative to change seating Own initiative to ask peers for support “speaks out, knows what he wants” Pursued ssearch for tutor who best meet needs	Learning new function		
Obtaining advice from others who can relate to changed life circumstances Ask advice regarding school and futuire vocational goals	Taking active steps		
external coping strategy _writing things down Printting and reading class material before lesson Rehearsing work Write down feelings instead of venting at family	Seeking advice from others		
Denial Hunour Avoiding requesting additional support until after school performance is affected “I ‘ll sort out my own problem you don’t need to intefere” Social withdrawal Projection Non disclosure of extent of brain injury	Preventative steps		
Using peer class notes Buddy system: study groups- ask peers for explanations	Avoidance strategies		
extra classes attempts to adjust work load Preferential seating Attempts at grading school transition Use of technology “I tend to read the question to the learner” “we summarise everything” Regular breaks Short periods	Peer Support		
Extra time for tests and exams Availiability of alternative assessment Simplification of exam papers	Environmental and instructional accommodations		
	Assessment accomoddatins	Personal Copying strategies	
		Learning Support Strategies	

Code	Sub Category	Category	Theme
"count your blessings and not your burdens" "I am actually lucky in that regard" Personal effort Physical and cognitive effort "I had to work 24" Self-determination Sets goals for self "I don't give up" Ambitious	Seeking the positive in current life situation Positive attitude towards changed life circumstances Willingness to put in personal effort to achieve goals Intrinsic motivation and determination	Positive personal attributes driving recovery and adaptation	<p><b>Theme 4: "Carrying on and pushing through"</b>                      Description: Reflects participants' views on that which help learners on their journey of personal growth and helps them to persevere in being fully integrated to school post TBI</p>
Faith of learner Faith of family Faith of broader community	Faith of the learner Faith of the family Faith of the broader community	The role of faith	
Awareness and acceptance of own limitations post TBI; Acceptance of some of the changes post TBI	Acceptance of self	Finding acceptance of changed life circumstances post TBI	
Acceptance from family Acceptance from educators Acceptance from selective group of peers	Acceptance from others		
"mom was sort of the primary driver" "my parents contacted the school"	Support from primary care-giver drives school re-entry Primary care-giver as main advocator		
Emotional support from extended family Emotional support from friends	Emotional support from significant others		
In-patient interdisciplinary therapeutic intervention Out-patient therapy Home programme School visit Made to feel part of the team "providing re-assurance"	Interdisciplinary therapeutic Intervention and support support from therapists	External support increasing learners capacity to positively adapt	
Financial support from the Road Accident Fund; Financial support from Disability child grant	Financial Support		

<p>School's active involvement in preparing the learners for their return to school</p> <p>Seeing learners and primary care-givers as partners in learning</p> <p>Positive attitude of educators</p> <p>Working at the learner's pace</p> <p>Focusing on areas of strength</p> <p>Availability of alternative practical curriculum</p> <p>Flexibility in school setting</p> <p>"I never got treated like I was stupid"</p> <p>"treat me the way they treat other children"</p> <p>Trained specialists available at the school</p> <p>Access to clinic on school premises</p> <p>Structurally accessible</p>	<p>School's commitment to inclusion</p>	<p>External support increasing learners capacity to positively adapt (cont.)</p>	<p><b>Theme 4: "Carrying on and pushing through"</b></p> <p>Description: Reflects participants' views on that which help learners on their journey of personal growth and helps them to persevere in being fully integrated to school post TBI (cont.)</p>
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<p>“they just said he needs to go back”                  “Thrown into the deep end”                  “they did not prepare me”                  “we just took him back to school”,                  “we did not work actively in preparing him”                  “No I don’t think I was ready...”                  Lack of communication regarding school options and referral pathways</p>	<p>Lack of communication between other team members, learners and their primary care-givers impacting on learners’ preparedness for school re-entry.</p>	<p>Effective communication channels as part of the planning for school re-entry</p>	
<p>“nobody actively recommended anything”                  Educators’ unrealistic expectations of learners’ abilities.                  “Trying to understand what should we be encouraging a child to do”                  Need for communication between departments’ of health and education, Caregiver role as intermediary between departments of health and education</p>	<p>Lack of intersectoral communication between the Departments’ of Health and Education regarding learners’ abilities and needs.</p>		
<p>“keeping things in house”                  Lack of specialist assessment                  Lack of additional ways to monitor progress level                  Constraints in number of specialists available at departmental level</p>	<p>Human resource constraints in providing specialised learner support at Departmental level</p>		
<p>Too many students too few teachers;                  Varied needs of learners in one class                  More individual time needed</p>	<p>Lack of sufficient staff to cater for varied needs of large volume of learners in classes</p> <p>Human resource constraints in providing learner support</p>		
<p>Lack of Special Schools (SSs)                  Build capacity of special needs school to serve as resource centres                  Constraints in number of specialists available at special schools</p>	<p>decreased capacity of SS to serve as resource centres</p>	<p>Adequate resources within the Department of Education to provide the required learner support in ordinary schools</p>	
<p>Educators insufficiently knowledgeable on learning support needs.                  Principals insufficiently knowledgeable of relevant policies,                  Need for capacity development of staff                  “we couldn’t apply particular things because weren’t taught it”</p>	<p>Inadequate training of teachers in ordinary schools on relevant policy and learning support</p>		
<p>Need for Teaching assistants                  Need for scribes                  “learners complain about not enough time”                  No adjustment of work load                  no extra classes                  No graded process of returning to school,                  no preferential seating,                  but we did not adjust anything for him in particular”</p>	<p>Lack of implementation of reasonable and effective learner accommodations in ordinary schools</p>		<p><b>Theme 5: “It would have helped to have support”</b>                  Description: Reflects participants’ views on their support needs for re-entrance and participation in school post TBI.</p>

<p>“they didn’t move my classes downstairs”                  Lack of technological resourctces to provide support to learners                  Stairs as structural barrier                  inaccessible toilets                  large number of learners in one area</p> <p>“throughput is the goal”                  “is the syllabus done?” } Negative attitude of educators                  Negative attitude of peers                  Stigma of special needs school                  Stigma of brain injury /Non-disclosure of extent of brain injury</p> <p>Social circumstances_safety</p> <p>Lack of psychological support to the learner                  Lack of psychological support to the family</p> <p>Medication costs                  Out-patient therapy costs                  Costs foir extra lessons                  School fees and travel costs for learner to attend special school</p> <p>“I had to leave my job”                  Paying privately to access services</p>	<p>Physical barriers</p> <p>Attitudinal barriers</p> <p>Lack of safety within and around schools</p> <p>Lack of psychological support to the learner                  Lack of psychological support to the family</p> <p>Financial constraints that hampers learners’ access to support</p> <p>Financial implications on household for out-of-pocket                  expenditure to support the learner’s needs</p>	<p>Accessibility and Safety within                  ordinary schools</p> <p>Psychological support to both the                  learner and family</p> <p>Timeous financial assistance from                  Government</p>	<p><b>Theme 5: “It would have helped to have support”</b>                  Description: Reflects participants’ views on their support needs for re-entrance and participation in school post TBI (cont.)</p>
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## Appendix M: HREC approval letter



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### Approval Notice New Application

20-May-2015  
Jacobs, Lee-Ann LJ

**Ethics Reference #: S15/03/055**

**A model for the facilitation of school re-entry and continued participation of adolescent high school learners following Title: traumatic brain injury in the Western Cape.**

Dear Miss Lee-Ann Jacobs,

The **New Application** received on **23-Mar-2015**, was reviewed by Health Research Ethics Committee 1 via Committee Review procedures on **06-May-2015** and has been approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **06-May-2015 -06-May-2016**

**Present Committee Members:**

Weber, Franklin CFS  
Unger, Marianne M  
Barsdorf, Nicola N  
Botha, Paul JP  
Decloedt, Eric EH  
Rohland, Elvira EL  
Hoek, Kim KGP  
Werely, Cedric CJ  
Hendricks, Melany ML  
Ferris, William WF  
Welzel, Tyson T  
Abulfathi, Ahmed AA  
Mukinda, Fidele FK

Please remember to use your **protocol number (S15/03/055)** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

**After Ethical Review:**

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239



The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States

Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western

Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further assistance, please contact the HREC office at 0219399657.

### **Included Documents:**

Declaration M Soeker

CV L Jacobs

CV E Swart

CV M Soeker

Consent and assent forms

Protocol Synopsis

Email re Phd approval for ethics evaluation

Checklist

Application form

Approval letter Dept of Education

Approval letter Dept of Health

Declaration E Swart

Protocol

Declaration L Jacobs

Sincerely,

Franklin Weber

HREC Coordinator

Health Research Ethics Committee 1

## **Investigator Responsibilities**

### **Protection of Human Research Participants**

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2. Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.

4. Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur**. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.

5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.

6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HRECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures [www.sun025.sun.ac.za/portal/page/portal/Health\\_Sciences/English/Centres%20and%20Institutions/Research\\_Development\\_Support/Ethics/Application\\_package](http://www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package) All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

7. Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC

8. Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.

9. Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.

10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.

11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

**Appendix N: Approval from Western Cape Health Department**

STRATEGY & HEALTH SUPPORT  
 Health.Research@westerncape.gov.za tel: +27 21 483 6857: fax: +27 21 483 9895 5th Floor, Norton  
 Rose House,, 8 Riebeek Street, Cape Town, 8001  
[www.capegateway.gov.za](http://www.capegateway.gov.za))

REFERENCE: WC 2015RP30 276  
 ENQUIRIES: Ms Charlene Roderick

Stellenbosch University

Private Bag XI  
 Matieland

7602

For attention: MRS Lee-Ann Jacobs-Nzuzi Khuabi

Re: A MODEL FOR THE FACILITATION OF SCHOOL RE-ENTRY AND CONTINUED PARTICIPATION OF

ADOLESCENT HIGH SCHOOL LEARNERS FOLLOWING TRAUMATIC BRAIN INJURY IN THE WESTERN CAPE.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:


Mitchells Plain Hospital	H Human	Contact No. • 021 370 3742
False Bay Hospital	W Waddington	Contact No. • 021 782 1121
Swellendam	J du Toit	Contact No. • 021 467 2121
Otto du Plessis	J du Toit	Contact No. • 021 46 72121
Paarl Hospital	B Kruger	Contact No. • 021 860 2501
Khayelitsha Hospital	A Kharwa	Contact No. • 021 360 4227
Eerste River Hospital	A Anthony	Contact No. • 021 902 8019

Kindly ensure that the following are adhered to:

- 1 . Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([Health.Research@westerncape.gov.za](mailto:Health.Research@westerncape.gov.za))
3. The reference number above should be quoted in all future correspondence.

Yours

sincerely

  
A. HAWK D  
M. KRIDGE  
HEALTH IMPACT ASSESSMENT  
24/6/2015

DR A

HAWK D

DIRECTOR: HEA

DATE:

Cc K GRAMMER

DIRECTOR: SOUTHERN/ WESTERN

P OLCKERS

DIRECTOR: KLIPFONTEIN/ MITCHELLS  
PLAIN

G PEREZ

ACTING DIRECTOR: KHAYELITSHA/  
EASTERN

## Appendix O: Approval from Western Cape Education Department



[Audrey.wyngaard@westerncape.gov.za](mailto:Audrey.wyngaard@westerncape.gov.za)

tel: +27 021 467 9272

Fax: 0865902282

Private Bag x9114, Cape Town, 8000

wced.wcape.gov.za

**REFERENCE:** 20150527-48599

**ENQUIRIES:** Dr A T Wyngaard

Mrs Lee-Ann Jacobs-Nzuzi Khuabi



Dear Mrs Lee-Ann Jacobs-Nzuzi Khuabi

### **RESEARCH PROPOSAL: A MODEL FOR THE FACILITATION OF SCHOOL RE-ENTRY AND CONTINUED SCHOOL PARTICIPATION OF ADOLESCENT HIGH SCHOOL LEARNERS FOLLOWING TRAUMATIC BRAIN INJURY (TBI) IN THE WESTERN CAPE**

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **08 April 2016 till 30 September 2016**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

**The Director: Research Services  
Western Cape Education Department  
Private Bag X9114  
CAPE TOWN  
8000**

We wish you success in your research.

Kind regards.

Signed: Dr Audrey T Wyngaard

**Directorate: Research**

**DATE: 06 April 2016**

**Appendix P: Planning school re-entry post TBI**

<b>Planning school re-entry post TBI</b>	
	<ul style="list-style-type: none"> <li>• This may be used to supplement the Guidelines for Inclusive Teaching and Learning (DoE, 2010), Section 7.1.3 and SIAS (2014).</li> <li>• Planning the school re-turn should actively involve learners and their primary care-givers.</li> <li>• The planning phase should ideally incorporate the following tasks:</li> </ul>
<b>TASK 1: Initiate cross sector communication</b>	
Who?	<ul style="list-style-type: none"> <li>• Team member from the Health team (e.g. occupational therapist) makes contact with a member of the School Team (e.g. the co-ordinator of the SBST).</li> </ul>
When?	<ul style="list-style-type: none"> <li>• Communication is initiated once consent from the primary care-giver and assent from the learner has been obtained.</li> <li>• Communication should be initiated timeously after the learner is medically stable.</li> <li>• A further indicator for the initiation of communication is, the learner identifying school participation as a priority goal during the goal setting phase for therapeutic intervention.</li> </ul>
What?	<ul style="list-style-type: none"> <li>• Communication to assist with the identification of members of the school team who are likely to be involved in the planning of the learner's school re-entry.</li> <li>• The logistics for the school re-entry planning meeting is arranged.</li> </ul>
<b>TASK 2: Conduct a school re-entry planning team meeting</b>	
Who?	<ul style="list-style-type: none"> <li>• The meeting should include all team members: the learner, family, members of the health team and school team (specifically the co-ordinator of the SBST and a teacher that actively teaches the learner).</li> </ul>
When?	<ul style="list-style-type: none"> <li>• Prior to the learner being discharged from the hospital or rehabilitation setting.</li> </ul>
What?	<ul style="list-style-type: none"> <li>• The meeting includes a discussion of the basic aetiology of TBI and the impact it has on the learner's functioning. Members of the health team should inform those of the school team of the learner's potential for recovery as well as that barriers to learning may become more pronounced as the scholastic demands on the learner increases.</li> <li>• The learner's strengths and support needs should be highlighted by the members of the health team.</li> <li>• All team members should discuss the preliminary plan of action regarding the learner's return to school. The discussion should include: <ul style="list-style-type: none"> <li>- The best fit of school environment given the level and extent of the learner's support needs.</li> <li>- The process of the school re-turn (graded or complete return). A graded return is recommended. A decision regarding the timing of the school return should be discussed.</li> <li>- The need for a school visit to assess the school environment.</li> <li>- Possible strategies that could be put in place to support the learners' school participation.</li> <li>- Strategies may include: <ul style="list-style-type: none"> <li>○ Restoring and establishing performance skills and performance patterns</li> <li>○ Personal coping strategies (i.e. cognitive behavioural strategies)</li> <li>○ Adaptive strategies (i.e. adaptations to the task and environment)</li> </ul> </li> </ul> </li> <li>• The plan of action should be guided by the Support Needs Assessment form 1 (SNA1) and the Health and Disability form as outlined in SIAS. The Guidelines for Inclusive Teaching and Learning should also be referred to (DoE, 2010).</li> <li>• Team members' roles in the learner's school re-entry process should be clarified.</li> </ul>

**TASK 3: Personal preparation of the learner**

## Who?

- A team member from the Health team would facilitate this process.
- The team member from the Health team should be actively involved in the school transition process and have a good therapeutic relationship with the learner.
- The learner's primary care-giver, head of the SBST, applicable teachers and peers will be involved in this process.

## When?

- Prior to the learner returning to school.

## What?

- To prepare the adolescent for the learner role Incorporate school related activities as part of therapeutic interventions in hospital or rehabilitation setting.
- Social preparation: with assent and consent from the learner and family facilitate brief visits with a few of the learners' friends/peers (in hospital or once discharged) to provide the learner opportunities for social re-engagement prior to the learners' return to school.
- Coach the learner how to answer questions regarding the TBI.
- Coach the learner how, what and when to disclose information about TBI.
- Psychological support for the learner to work through anxiety of returning to school given the changes in functioning, levels of dependence and for some drastic changes in appearance.
- Graded return to school: including a brief visit to the learner's homeroom class, attendance of school for a few hours/learner attending specific subjects, building up to a full day.
- Learners should have input with regards to the subjects they would like to complete as part of their graded return to school. Subject choice should however match the learner's strengths to allow him/her the opportunity to achieve mastery and re-build confidence.

**TASK 4: Preparation of the learning context**

## Who?

- A team member from the Health team would facilitate this process.
- The team member from the Health team should be actively involved in the school transition process and have a good therapeutic relationship with the learner.
- The learner's primary care-giver, head of the SBST, applicable teachers and peers will be involved in this process.

## When?

- Prior to the learner returning to school.

## What?

- Conduction of a school visit to assess and make recommendations on applicable accommodations in terms of:
  - Physical accessibility (i.e. bathroom, classroom, playground, sports facilities, etc.)
  - Social interactions (i.e. adolescent-teacher, adolescent-peer etc.)
  - Cultural environment (i.e. classroom structure, standards of behaviour, flexibility and tolerance of diversity)
  - Sensory environment (i.e. noise levels, visual clutter and crowding)
  - Virtual environment (i.e. access and use of digital technologies)
  - Temporal aspects (i.e. schedule of school routine and breaks, school calendar)
- Coaching of primary care- givers regarding:
  - Their rights as parents as equal partners in their child's education
  - Their role in the child's school re-entry process (i.e. source of regular communication with the learner's school and fulfilling a role as advocator).
  - Availability and access to resources to support their child's needs as outlined in the applicable South African Legislation on Inclusive Education.
- Knowledge exchange with all the teachers actively teaching the learner, regarding:
  - Basic aetiology of TBI, impact of TBI on learners' functioning, potential for recovery and that the learners' level and extent of barriers to learning may change should the scholastic demands increase. The information is disclosed following consent and assent from primary care-giver and learner is obtained.
  - The learners' strengths and needs
  - Possible strategies that could be put in place to support the learners' support needs
  - Contact numbers of other health team members that may be contacted if additional

information is required.

- Education of the learner's peers regarding:
  - TBI (basic information is relayed, only if parent and learner consents to this)
  - How they may support the learner with TBI.

**Once the learner has returned to school the support process continues as outlined in SIAS (2014).**

- An important consideration once the learner has returned to school is the need for regular monitoring and adaptation of the learner's individual support plan. The monitoring should ideally be done at various points of the school re-turn:
  - End of the first week
  - End of the first month
  - Mid-year
  - Grade to Grade transition
  - Other educational transitioning, e.g. from high school to post high school setting or transitioning from SS to ordinary school or vice versa.
- Learners should also be given ongoing psychological support to help the learner to monitor and adapt coping strategies as well as for the learners to address emotional challenges they experienced once being back at school.

Source: Adapted from Schilling and Getch, 2012; Hanft and Shepherd, 2008 and based on this study's empirical findings.