Transition from special school to post school in youth with intellectual disability: Parents' experiences.

By

EMALDA ELLMAN

(KRDEMA001)

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Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

SUPERVISOR

Ms. A. Sonday

CO-SUPERVISOR

Dr. Helen Buchanan

Date: 10 February 2015

DECLARATION

I, Emalda Rochelle Ellman hereby declare that the work on which this dissertation is built is my original work (except where acknowledgements indicate otherwise) and have used the Harvard UCT system of referencing. I declare that either the whole work or any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABSTRACT

Transitions from one life stage to the next are considered to be a normal part of every person's life. Transitions have been described as important landmarks in the educational career of youth, as successful transitions prepare them for adult life. When youth with disabilities leave school, the transition to post school does not occur naturally. Research has found that youth with intellectual disabilities and their families find the transition from school to post school to be challenging. In South Africa, Education White Paper 6 on special needs represents the country's plan for addressing shortcomings in the education system. There is still very little information available on the preparation of intellectually disabled youth for their post school future in the South African context. Consequently, parents of intellectually disabled youth face tremendous challenges when their child reaches this transition age.

This study aimed to describe parents' experience of the transition of their intellectually disabled youth from special school to post school in the West Coast. A qualitative descriptive study using in-depth interviews was conducted with five parents of youth with intellectual disability. Inductive analysis of the transcripts yielded two themes and six categories. Theme one, "It really hit us hard" had three categories: "feeling uncertain and confused", "managing without peer support" and "mixed feelings". Theme two, "Parental adjustment to post transition life" had three categories: "setting up a routine", "negotiating everyday occupations" and "accessing resources and a support system". The research found that the meanings parents attribute to their experience of transition are significantly influenced by their personal responses and coping strategies in the context they find themselves in during the transition period.

DEFINITION OF TERMS

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 (American Association on Intellectual and Developmental Disabilities, 2002).

Youth refers to every person between the ages of 15 to 35 years (African Youth Charter, 2006).

Special schools Schools equipped to deliver education to learners requiring high-intensive educational and other support either on a full-time or part-time basis (Department of Education [DOE], 2005).

Special Schools/ Resource Centres These would be special schools which are transformed to fulfil a wider function of accommodating learners who have high intensity support needs, as well as providing a range of support services to ordinary schools, full-service schools as part of the District-based Support System (Department of Education, 2005).

Full-service schools Ordinary schools which are specially equipped to address a full range of barriers to learning in an inclusive education setting. In addition to their ordinary learner population they will become accessible to most learners in an area who experience barriers to learning and provide the necessary support. In the initial implementation stages these full-service schools will be models of institutional change which reflect effective inclusive cultures, policies and practices (Department of Education, 2005).

Transition refers to "actions coordinated to prepare for or facilitate change, such as from one functional level to another, from one life stage to another, from one program to another, or from one environment to another" (American Occupational Therapy Association [AOTA], 1998).

Transition Planning refers to the section of the individualized education program (IEP) that describes the services and activities needed to prepare for both early intervention and adult life. The transition plan defines the student's long-term goals and desired outcomes following graduation (AOTA, 1998).

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ABBREVIATIONS

ADL	Activities of Daily Living
AOTA	American Occupational Therapy Association
ID	Intellectual Disability
IDEIA	Individuals with Disabilities Education Improvement Act
IEP	Individual Education Plan
ILP	Individual Learning Plan
ISP	Individual Support Plan
NGO	Non Governmental Organisation
PEO	Person Environment Occupation
RSA	Republic of South Africa
SASSA	South African Social Security Agency
USA	United States of America
WFOT	World Federation of Occupational Therapy

CHAPTER 1: Introduction

Transitions are considered a natural part of every human beings life (Stewart, 2013). People experience many forms of transition across their lifespan. These include day care, primary school, secondary school, further education and training, tertiary education, leaving home, first job, buying a home and so forth. Youth leaving mainstream high schools are usually excited about new possibilities such as further education and training, employment and other options that lead to independence (Cooney, 2002; McGill, Tennyson & Cooper, 2005; Dewson, Aston, Bates, Ritchie and Dyson, 2004). On the other hand, for youth with disabilities this transition does not occur naturally when they leave school (Hurst, 2009).

Winn and Hay (2009) and Kim and Turnbull (2004), in respective Australian and American contexts, report that for young people with intellectual disabilities (ID) and their families the transition experience from school to post school can be quite demanding. It is also usually accompanied by several challenges that include high unemployment levels, restricted participation in community activities, the common practice of continued living with parents and dependence on family (Davies & Beamish, 2009). These are key issues that arise for parents of disabled youth during the transition from school.

Occupational therapy supports transition for families and children with and without disabilities assisting children to grow and learn to be as independent as possible (American Occupational Therapy Association [AOTA], 2008). Occupational therapists have unique skills such as task and work analyses and independent living skills which prepares them to take up a vital role in the transition planning of youth with disabilities (AOTA, 2008; Miller, 2012; Mankey, 2011;

Kardos & White, 2006). However, Miller (2012:135) suggests that "school-based occupational therapists in America are currently not fulfilling their full potential as secondary transition service providers within the school system". In South Africa, occupational therapists' role with regard to transition in education has not been clearly defined.

In 2001, the South African government launched Education White Paper 6, a 20 year plan to address shortcomings, in the education system (Department of Education, 2001). The White Paper highlighted inadequate opportunities for programme-to-work linkages as a barrier to learning and development (Department of Education, 2001). Parental recognition and involvement has also been named as a cause of learning barriers among others (Department of Education, 2005). Long-term plans of the White Paper included the "development of an inclusive education and training system that will uncover and address barriers to learning, and recognise and accommodate the diverse range of learning needs" (Department of Education, 2001:45). According to this plan the role of special schools will be to provide "comprehensive education programmes that provide life-skills training and programme-to-work linkages" (Department of Education, 2001:21). The latter part of this statement alludes to the transition from school into employment. Unlike in first world countries such as the United States of America (USA) and Canada who are compelled by law to provide guidelines in order to smooth transition planning for youth with disabilities (King, Baldwin, Currie & Evans, 2005; Mankey, 2011), South Africa, an emerging first world country, does not have legislation that address the issue of transition for youth with disabilities.

Vlachos (2008) devoted her research to developing a vocational training and transition planning programme for learners with intellectual disability in the South African context. She argued that there is little information available on future vocational preparation and transition planning for the intellectually disabled child in South Africa (Vlachos, 2008). According to Vlachos (2008), it is the responsibility of every school to provide transition planning for school leavers and should ideally be the role of the life skills teacher. She however contended that teachers, at the time of doing her research, were adapting the Revised National Curriculum Statement (RNCS) to make learning materials more suitable for learners, rather than following a curriculum specifically designed for learners with intellectual disability (Vlachos, 2008). Planning for transitions from school is therefore, it seems, neglected while time is spent on adapting the curriculum.

At present, the South African Department of Education makes provision for “modifying, changing, adapting, extending, and varying teaching methodologies, teaching strategies, assessment strategies and the content of the curriculum” (Department of Basic Education, 2011:4). This approach is in line with the department’s policy on inclusion. However, even though the Department of Basic Education (2005) make reference to an individual learning plan as a viable option to address the needs of learners who continue to experience barriers to learning, transition from school to post school is not addressed. Therefore, the researcher argues that more can be done to plan for the transition of the child with intellectual disability within the South African schooling system in order to provide them with post school options.

Planning for transition assists disabled youth and their parents to prepare for an event that can otherwise be traumatising. They can gain access to information that provides a feeling of confidence in moving from one environment to the next. On the other hand, research suggests that when transition planning is neglected or deemed unimportant parents become stressed as they do not know what to expect once the child reaches transition age (Kraemer & Blacher, 2001).

Various studies (Ward, Mallett, Heslop & Simons, 2003; Kraemer & Blacher, 2001; Beresford, 2004; Smart, 2004; Bennie, 2005) report that school to post school transition are often a stressful period in the lives of parents with an intellectually disabled child. In addition, other evidence point out that parents are often only marginally involved in the transition process and planning of their child (Davies & Beamish, 2009; Bhaumik, Watson, Barrett, Raju, Burton & Forte, 2011). As children with severe disabilities frequently do not transition from primary to secondary school because they remain at the same school, parents are inexperienced when school to post school transitions occur (Hurst, 2009). Therefore it is possible that when parents are not involved or are only partially involved in their child's transition planning they may experience stress.

1.1 PROBLEM STATEMENT

In South Africa information about school to post school transition for learners with disabilities, particularly those with intellectual disability, appear to be absent in general as it is not addressed in the South African's School's Act or White Paper 6 on Inclusive Education. Furthermore, the transition of learner's with disabilities are also not attended to in supporting documents such as the guidelines for responding to learner diversity in the classroom through curriculum and assessment policy statements. It is therefore possible that in the absence of sufficient transition information, parents of a child with intellectual disability could face severe challenges. A few of the reported challenges from other countries, including the United Kingdom and Australia, are associated with difficulties in accessing services (group home, medical and other post-school services for people with intellectual disability) as well as concerns about the transition process (Bhaumik et al, 2011; Davies & Beamish, 2009). Parents have also highlighted key frustrations which include a lack of information about available options, information about the transition process and transition plan, parental involvement in decision-making and planning, support for parents and a lack of facility/school being involved with transition planning (Bhaumik et al, 2011; Gillan & Coughlan, 2010; Smart, 2004). In light of the aforementioned, a South African perspective and description of parents' experience of transition could raise awareness about parents experiences and might also provide rich information that may assist Occupational Therapists at special schools in addressing the parents' transition needs.

1.2 CONTEXT OF THE STUDY

South Africa has a land area of 1 22 813 square kilometres and an estimated population size of 50 586 756 (South African Statistics, 2012). The country is divided into nine provinces. The West Coast is situated on the western border of the Western Cape Province with its 129 462 square kilometres land area (Refer to Addendum A to view a map of the West Coast). In South Africa, the boundaries in which government agencies operate are known as district or municipal boundaries. West Coast, the area in which this research takes place, has five local municipalities: Swartland, Bergrivier, Matzikama, Cederberg and Saldanha. Historically the area is known for its agriculture and fishing and has a population of 341 544 (West Coast District Municipality, 2012). The population is predominantly coloured (71.6 %) with statistics for white and black people at 9.1% and 9% respectively (West Coast District Municipality, 2012).

The West Coast has become a popular tourist destination as it boasts rich marine life, the spectacular Cederberg mountain range, a wealth of history (fossil park) and a beautiful flower season from July through September. The local people living in the West Coast are mainly dependent on the agriculture and fishing market for employment. Saldanha Steel and Transnet are two big companies in the Saldanhabay Municipality that provides jobs for many people from the local community. Furthermore the military has its base in Saldanhabay and the airforce is based in Langebaan. This affects the dynamics of the area as it causes migration of people in and out of the West Coast area. One thus sees the disparity in the spread of rich, middle class and poor people in the West Coast.

The unemployment rate is relatively high which influences the level of crime in the area. Although crime levels are low when compared to cities such as Cape Town, the geographic area is much smaller and therefore the level of crime can be regarded as high. In the West Coast, the distance between towns is relatively far and there is no transportation system such as bus or train services. Taxis are available, but these are privately owned vehicles. The taxi fees for a one way trip to a town approximately 20km away is R40. As many cannot afford the taxi fee, people frequently walk long distances or hike between towns. Without own transport people are relatively stranded.

In the event that illness occurs, people make use of their local clinic that refers them to the district hospital. The closest tertiary hospital is in Cape Town, approximately 150km away.

Three special schools operate in the West Coast. In addition to these schools there are also two operational inclusive education teams. These teams are stationed at special schools that have been upgraded to special school resource centres and they provide services to full service schools.

During 2007 the researcher started working as an Education Therapist (Occupational Therapist) at one of the special schools in the West Coast. Soon after arriving she noticed that very little was in place for learners who left the special school at school-leaving age[1]. The learners received a school-leaving certificate at the school's

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[1] This is eighteen years in South Africa

annual diploma ceremony in November and many did not return for the remainder of the year which usually ends in early December.

During 2008, a pattern seemed to emerge: Parents of learners with intellectual disability who had completed their schooling during previous years approached the researcher for written reports confirming their child's intellectual disability and affiliation to the school in order to apply for a disability grant. Through conversing with these parents the researcher discovered that their "graduated" children were at home. Parents perceived them as being idle, some of the girls were pregnant or had children and a few of the boys had been recruited by local gangs. The parents seemed to accept the situation as if there were no other options available. This both alarmed and evoked a deep sense of responsibility within the researcher to assist future school-leavers and their parents.

1.3 RATIONALE FOR THE STUDY

Within the South African school system, learners with intellectual disabilities and those with high support needs attend special schools. In the absence of a curriculum to address these learners' educational needs, the national curriculum is currently adapted to provide educational support. However, when these learners reach school-leaving age parents are often not aware of post school options; hence the importance of planning for transition.

A deeper understanding of the parents' experience of transition for their youth with intellectual disability could impact on how transition for learners with intellectual disability is collectively planned by the school and parents. It could help to create awareness about parents' experience of transition and also enable special schools to meet the transition needs of parents.

1.4 PURPOSE OF THE STUDY

School to post school transition for youth with disabilities has been widely researched. The number of research studies with a focus on parental experience of transition has been limited. There is also a general lack of information both locally and internationally with a specific focus on parents' views concerning transition for their youth with intellectual disability. In addition, a description of the parents' experience of transition for their youth with intellectual disability has been absent from the literature as shown by an extensive search (Refer to Chapter 2). The purpose of this research was therefore to gain an in depth understanding of parents' experience of transition for their youth with intellectual disability. This research will contribute to the body of knowledge by providing a description of parents' experience of transition; an area which has to date not been addressed. In doing so, this research will contribute new knowledge from a developing country perspective.

1.5 RESEARCH QUESTION

What are parents experiences regarding the transition from special school to post school of their youth with intellectual disability?

1.6 RESEARCH AIM

To describe parents' in the West Coast's experience of the transition of their youth with intellectually disability from special school to post school.

1.7 OBJECTIVES

The objectives of the study are to:

a) Describe the parents personal responses linked to the transition of their youth with intellectual disability from special school.

b) Describe the strategies the parents used to cope with the experience of transition.

c) Identify the contextual factors that influenced the parents' experience of transition.

CHAPTER 2: Literature Review

2.1 INTRODUCTION

Intellectual disability and transition are key components of this research study. The literature review will focus on intellectual disability, the use of the term, its definition, classification and South African contextualisation and secondly on transition. The literature review will conclude by highlighting gaps in the literature to justify the focus of this research.

Key databases available on the University of Cape Town library website were utilised for the literature search. These included; but were not limited to ERIC, CINAHL, Cochrane Library, PsychINFO, PubMed, OTSeeker, Ebsco Host and Google Scholar. Various combinations of search terms related to the topic were used: “intellectual disability” AND “transition” AND “parents”; “transition” AND “disability”, “parents perceptions” AND “school to post school transition” and “intellectual disability or mental retardation”; “transition” and “special school”; “transition” AND “special school to post school”; “occupational therapy” AND “parent perspectives” and “transition”; “parent perspectives” AND “transition to post school” OR “work”; “parental views” AND “transition” AND “intellectual disability” OR “mental retardation” OR “learning disability”. In addition, reference lists were searched to detect relevant articles not located in the search. Three literature reviews pertaining to school to post school transitions were also used in this literature search.

The literature review bears testimony to the fact that transition has been the topic of numerous research studies in countries like the United States of America, Canada, Australia, England and others over the decades. Only articles that address school to post school transition for youth with intellectual disabilities and those that covered the parents, caregivers or family perspectives of transition were included in this literature review.

2.2 INTELLECTUAL DISABILITY

People with intellectual disability have endured countless acts of discrimination throughout the centuries (Hall, 2010).They have also been called by several names of which moron, imbecile and idiot are but a few (Loebenstein, 2005; Hall, 2010; Bray, 2003). In the twenty-first century, professionals are yet to reach consensus on a standardised name. In South Africa and Australia intellectual disability is used, in the United States of America mental retardation is the term employed and in the United Kingdom, learning disability is the preferred term (Loebenstein, 2005).

The most recent definition of intellectual disability states: “intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (American Association on Intellectual and Developmental Disabilities, 2002). Recently, the American Psychiatric Association (2013:1) published a document in which they announced that “intellectual disability as a DSM-5 diagnostic term replaces mental retardation”. The document also states the following:

> *Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains or areas. These domains determine how well an individual copes with everyday tasks:*
>
> - *The conceptual domain includes skills in reading, writing, math, reasoning, knowledge and memory.*

- *The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships and similar capacities.*
- *The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation and organizing school and work tasks.*

(American Psychiatric Association, 2013:1)

In addition to the aforementioned, a classification system illustrating the degree of severity of intellectual disability exists. According to this classification system, people with mild intellectual disability have an IQ range of 50 to 70 and are in many ways similar to their peers who are not disabled. Those who have moderate disabilities have an IQ range of 35 to 50. They can learn to take care of their personal needs and perform hands-on vocational tasks. People who are severely disabled have an IQ range of between 20 to 35 and are more dependent on others for basic needs and those who are profoundly disabled have an IQ range below 20 and may be largely dependent on others for their care (DSMIV, 1994; Weiten, 1998; Ellman, 2004).

The degrees of severity, the range scores and the level of function are simplified in Table 1.

Table 1: INTELLECTUAL DISABILITY –SEVERITY, IQ SCORE AND LEVEL OF FUNCTION (DSMIV, 1994; Weiten, 1998; Ellman, 2004)

DEGREES OF SEVERITY	**IQ SCORE RANGE**	**LEVEL OF FUNCTION**
Mild Intellectual Disability	50-70	Appear similar to their non disabled peers.
Moderate Intellectual Disability	35-50	Can take care of their personal needs. Perform hands-on vocational tasks.
Severe Intellectual Disability	20-35	Dependent on others for basic needs.
Profound Intellectual Disability	Below 20	Largely dependent on others for their care.

Although the naming, defining and classifying of intellectual disability may be relevant and useful among professionals, youth living with ID and their parents' battle with the consequences of the diagnosis (Bray, 2003). In a country like South Africa, where roughly one seventh of the total population have no schooling and approximately one eighth of the total population have only foundation phase schooling (South African Statistics, 2012), discrimination is still rife and people with severe intellectual disabilities living in rural areas have low life expectancy (Integrated National Disability Strategy, 1997). The White Paper on an Integrated National Disability Strategy mentions the notion that people with intellectual disability are most likely to be considered as ill and in need of constant care. They are therefore not provided with suitable opportunities to participate in society (Integrated National Disability Strategy, 1997). The latter statement, holds true to this day and as such being diagnosed with intellectual disability also impacts in a big way on social inclusion, educational possibilities and economic possibilities; adding to the vulnerability of this group. The Integrated National Disability Strategy further acknowledges that people with severe intellectual disabilities are particularly vulnerable during periods of transition from institutionalisation to community based services and families, especially those in rural areas, can seldom meet the additional financial burden of extra hospital visits and assistive devices (Integrated National Disability Strategy, 1997). The White Paper (Integrated National Disability Strategy, 1997) therefore supports the idea that parents of a child with intellectual disability face tremendous challenges at transition age.

Learners on various degrees of severity, but especially those with high support needs i.e. severe intellectual disability attend South African special schools (Daniels, 2012). As these learners are unable to cope with the demands of mainstream curriculum, teachers in special schools are currently adapting the curriculum to make it more accessible to learners with intellectual disability. The focus of special schools being on life-skills development and linking these learners with community based organisations for work opportunities. To this end, a few will be able to gain sheltered employment, while others will remain dependent on a disability grant[2]. The transition experience of these parents could potentially provide meaningful information to enhance the way in which transitions from special schools are planned.

According to the White Paper on an Integrated National Disability Strategy (1997:10) parents of a disabled child have a specific role to play in the development of that child; they are however often excluded from their families and their communities. Furthermore, their situation is worsened by professionals who take over the decision-making role by claiming they 'know better and act in the

---

[2] A disability grant is a stipend that currently amounts to R1350 that people with mental or physical disabilities that makes you unfit for work for longer than six months, can apply for.

best interest of the child' (Integrated National Disability Strategy, 1997). Mothers are said to loose self-confidence in their role as a parent (Integrated National Disability Strategy, 1997). The aforementioned is in direct contrast with the Guidelines to ensure Quality Education and Support in Special Schools and Special School Resource Centres (Department of Education, 2007:18) that claim that "special schools must ensure that they support the family of learners at the school".

When youth with intellectual disability transition from special school to post school, it is undoubtedly a period that requires a substantial amount of support. It is also a period in which all role-players need to work collaboratively in order to provide the best options for the youth with intellectual disability. Parents of the youth with intellectual disability play an important role in this process and could shed some light on the intricacies they experience during this time. By describing their experience, one could come to value the meaning attached to this important event in context.

2.3 TRANSITION

Transition is a topic that has been widely researched especially in developed countries such as Canada and the United States of America. For occupational therapists this process is of particular importance as the profession is "concerned with promoting health and well-being through occupation" (World Federation of Occupational Therapy [WFOT], 2012). The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by "working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement" (WFOT, 2012). It is also known that occupation in occupational therapy "refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do" (WFOT, 2012). Transition from school to post school is an occurrence in life that every young person attending a school will encounter should they complete their specialised or secondary education. Stewart (2013) suggest that developmental transition is part of a person's natural life course and represent a time of change and adaptation within the person and his environment. Youth with intellectual disability similarly experience transition and these adaptations within the person and environment could present some challenges. The person-environment-occupation (PEO) model (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996) is concerned with the consequences to occupational performance when there is change in either the person, environment or occupation and has been applied successfully to describe the transitions for youth with disability to adulthood (Stewart, Law, Rosenbaum & Willms, 2001). The model adopts a transactional rather than interactive approach in which the interdependence between person and environment is emphasized. A transactional approach has its unit of measurement an event and the meaning of that event to the participant (Law et al, 1996). Although parents' do not personally encounter the transition from school to post school, they also experience their child's transition from school and add meaning to that event.

Transition from school to post school is a major event in the lives of most abled young people who attend mainstream and special schools. Many transitions are experienced throughout the life span that requires adjustment and adaptations in terms of roles (Blair, 2000). However, transitioning from school to post school is an event that occurs but once in an individuals' life and as previously noted, can be characterised by certain challenges. For parents of a child with a disability, this event becomes especially significant as there are so many considerations such as the youth's living arrangements and opportunities for employment (Mcgill, Tennyson & Cooper, 2005; Cooney, 2002).

In the United States of America (USA) the Individuals with Disabilities Education Improvement Act (IDEIA) is the driving force behind policy for school-aged individuals with disabilities. During 1997 they were responsible for incorporating school to post school transition into the individual education plan (IEP) (Certo, Luecking, Murphy, Brown, Courey & Belanger, 2008). Although South Africa is making ground in terms of policy development for school-aged persons with disabilities, the country lacks policy that address transition from school to post school for learners with disabilities. As a recognised vulnerable group in society, it is of utmost importance that certain processes offers the facilitation of transition planning in special school in order to prevent exploitation of youth with disabilities. Planning for post school transition should ideally give parents of a disabled child peace of mind for the future. Once school to post school transition is enforced by law, the change in society will become evident.

New Zealand view transition for young people with intellectual disabilities as a priority starting at the age of 14 years (Bennie, 2005). This age represents the developmental stage of adolescence (Weiten, 1998) which in itself presents the child and parent with many challenges. Introducing transition at this stage could be beneficial in the sense that parent and child could form a close relationship while discussing future options. Starting on the transition plan early also means that there will be sufficient time to make adjustments if contextual factors were to influence in some way.

The abovementioned countries have clearly made provision for the transition needs of their intellectually disabled youth. In South Africa on the other hand, transition planning is still largely lacking. Vlachos

(2008), states that the South African education system has often been criticised for its weakness in preparing learners for life and the world of work. This awareness may contribute to parents' anxiety when their children reach school-leaving age. Policy writers in South Africa should learn from countries such as New Zealand where parents' inclusion as active and contributing members of the transition planning team from the beginning has been described as essential (Bennie 2005).

In a study conducted by Ward, Mallet, Heslop & Simons (2003) in England, a survey of 272 young people with learning disabilities and their parents regarding the success of transition planning legislation, reported that: 1) many had left school without transition planning, 2) when transition planning did occur, there was a mismatch between the topics the families wanted to discuss and those addressed by the professionals, 3) Few of the learners who received transition planning, had anything to do with the process and finally, parental involvement was significantly limited. On the other hand, when parents were involved, they had positive reports, stating that they valued being listened to and that their views had been heard. They also appreciated that they were able to discuss future possibilities with their sons or daughters and that they felt that they were driving the process (Ward, Mallet, Heslop & Simons, 2003). The evidence from this research clearly points to the positive involvement of parents during the transition process. It seems apparent that parents want to feel in control, not necessarily of the process, but moreover the decisions being made with regards to their child with intellectual disability. They want their opinions to be heard and taken into account. With reference to the first three points listed, it would appear as if the school to post school transition was not prioritised and was seemingly left until the last minute. As a result of this, the learners as well as the parents had negative transition experiences which could have been prevented.

An Australian survey study among 218 parents about transition planning for learners with intellectual disability found that although parents reported high levels of personal involvement, their child with intellectual disability was not included in the process (Davies & Beamish, 2009). The parents also highlighted that there was no work experience available to 59% of their children leaving special schools and in addition many of the young adults who had left school, still relied heavily on their disability pension as they earned too little. The young adults with intellectual disability were also still living at home, and those who had left home lived close to their parents (Davies & Beamish, 2009). This research study place emphasis on the fact that youth with high support needs frequently remain dependent on their parents. This fact becomes evident even from the transition process where parents reported that they were more involved in the process than their sons or daughters. It is deduced by the researcher that due to the severity of their intellectual disability, these learners were not able to contribute meaningfully to the transition process and as a result, most of the decision-making became the responsibility of the parent. The continued living at home as described by Davies and Beamish (2009) could possibly be due to a reluctance to break the attachment with the parents. With reference to the Davies and Beamish (2009) study, the youth with intellectual disability possibly feels safe being among familiar surroundings or may have no understanding of having to leave home. The transition process would therefore not make sense to this learner, therefore emphasising parental involvement once more.

Available literature on parents' experience of transition for their child with intellectual disability has mostly been geared towards service gaps. They specifically focus on factors that hinder or enable smooth transitions. In most cases large survey studies have been conducted and furthermore these studies have often been conducted in America, the United Kingdom or Australia, all of which are first world countries (Ward, Mallet, Heslop & Simons, 2003; Davies & Beamish, 2009).

2.4 SUMMARY

A description of parents' experiences concerning the transition from school to post school has not been initiated worldwide. As there are many changes that occur within the person, the environment as well as with regards to the occupation of the youth with ID during the school to post school transition, a description of the parents experience could produce a wealth of knowledge and/or confirm existing knowledge. An in-depth description of this transition experience is essential to address parental needs regarding transition as well as providing a voice for parents from developing countries which are seemingly absent from the literature.

CHAPTER 3: Methodology

3.1 INTRODUCTION

This chapter begins by introducing the research approach. In addition to this, the design as well as sampling is discussed. Furthermore the data collection, data capture and analysis and finally scientific rigor of the study are addressed.

3.2 RESEARCH APPROACH

A qualitative mode of inquiry was used to describe the parents' experience of transition for their intellectually disabled youth. In their definition of qualitative research, Denzin and Lincoln (2005:3) said that "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them". Qualitative research therefore suits this study as the researcher is interested in describing the meaning of an experience in context as it relates to parents of youth with intellectual disability.

3.3 RESEARCHER ASSUMPTIONS

As the parents' interviewed are those of youth who have gone through the process of transition, the researcher assumes that the participants have a basic understanding of what transition from school to post school entails.

3.4 RESEARCH DESIGN

In this study, the researcher made use of qualitative description (Sandelowski, 2000) as the research design. This research places emphasis on describing participants' experiences. According to Sandelowski (2000:336) "qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events". Researchers conducting qualitative descriptive studies are interested in both descriptive validity which is an accurate accounting of events that most people (including researchers and participants) observing the same event would agree is accurate, and interpretive validity which is an accurate accounting of the meanings participants attributed to those events that the participants would agree is accurate (Maxwell, 1992). According to Sandelowski (2000) researchers who conduct qualitative descriptive studies, rather than those who conduct grounded theory, phenomenologic, ethnographic or narrative studies, stay closer to their data and to the surface of words and events.

3.5 POPULATION AND SAMPLING

The study population comprised parents of intellectually disabled youth living in the West Coast who had experienced school to post school transition. The study was open to biological parents and those who had gone through a process of legal adoption.

According to Sandelowski (2000) practically any of the purposive sampling techniques described by Patton (1990) may be used in qualitative descriptive studies. Therefore, purposive sampling, specifically criterion sampling, was used to deliberately select individuals based on certain pre-determined criteria (Kielhofner, 2006; Creswell, 2007). The power of purposive sampling lies in selecting cases from which one can learn a great deal about issues of cardinal importance to the study ("information-rich" sources) (Patton 1989). Individuals and sites were selected because they could purposefully inform an understanding of the research problem and central phenomenon in the study (Creswell, 2007). Polkinghorne (1989) proposed that between five and twenty-five people who have experienced the event be interviewed. For the purpose of this minor-dissertation five participants were interviewed until data saturation was reached. Saturation refers to the repetition of discovered information and confirmation of previously collected data (Morse, 1994).

3.6 SELECTION CRITERIA

Parents (biological or adoptive) of an intellectually disabled child currently residing in the West Coast were selected as study participants provided their child:

- had attended a special school for learners with intellectual disability,
- was between 18 and 35 years of age and
- had experienced transition from school to post school.

Parent also had to have sufficient verbal communication skills in either English or Afrikaans to be able to describe their experiences.

3.7 PARTICIPANT RECRUITMENT

Participants were recruited through an organisation for people with disabilities in the West Coast. The organisation offers services to people with intellectual disabilities and high support needs as well as people with other types of disabilities. The researcher made telephonic contact with the managers of four organisations and explained the research to them. Only one manager responded positively and was willing to recruit participants. A meeting was arranged and copies of the interview questions (Addendum C), information letter/ informed consent form (Addendum D) as well as the selection criteria were shared with the manager in person.

3.8 GAINING/ NEGOTIATING ACCESS

The study received ethical clearance from the Faculty of Health Sciences Human Research Ethics Committee [FHS HREC] of the University of Cape Town (Addendum E). HREC reference number 625/2012. The researcher made telephonic contact with the managers of four organisations for people with disabilities in the West Coast and explained the research to them once approval had been received. They were also asked to recruit participants according to the selection criteria. A meeting was arranged with the manager who was interested in assisting with the research and copies of the interview questions, information letter/ informed consent form as well as the selection criteria were handed to her. Table 2 gives an overview of the parents who met the selection criteria and participated in this study:

Table 2 STUDY PARTICIPANTS

PSEUDONYMS	AGE	MARITAL STATUS	CHILD'S DISABILITY
Mary	65	Married	Severe Intellectual Disability Down Syndrome
James	58	Married	Severe Intellectual Disability Cerebral Palsy
Richard	67	Married	Severe Intellectual Disability Down Syndrome
Anne	60	Married	Severe Intellectual Disability
Lisa	47	Married	Severe Intellectual Disability

3.9 DATA COLLECTION

For qualitative descriptive studies, it is recommended that minimally to moderately structured open-ended individual and/or focus group interviews are conducted (Sandelowski, 2000). In this study, data was collected through individual in-depth interviews that participants could express themselves more freely. Each participant was interviewed twice. The second interview was done in order to elicit details of the participants' experience (Seidman, 2006). The in-depth interviews allowed each participant more time to share their thoughts, feelings and opinions. (Refer to Addendum B for interview questions). Seidman (2006:15) noted that for in-depth interviews, interviewers primarily make use of open-ended questions as “their major task is to build upon and explore their participants’ response to questions … The goal is to have the participant reconstruct his or her experience within the topic under study.” Interviews lasted approximately 45-60 minutes each. Four participants were interviewed at their homes and one participant was interviewed at the non-governmental organisation. Participants were able to speak freely and without interruption. The interviews were conducted in both English and Afrikaans. Afrikaans interviews were translated by an independent researcher who holds a Masters Degree from a South African University and studied English and Afrikaans as an undergraduate.

3.10 DATA CAPTURE AND ANALYSIS

Data were audio recorded using a Dictaphone and transcribed verbatim by the researcher. Inductive reasoning was used along with a content analysis approach. According to Zhang and Wildemuth (2000) and Mayring (2000) this is an approach by which themes and categories emerge from the data or material. Elo and Kyngäs (2008) assert that this type of analysis requires open coding. According to Mayring (2000:4) the most important aspect of inductive content analysis is to form a criterion of definition that stems from the theoretical background and research question and determines which aspects of the data are considered. In this study, the focus was on personal responses of parents’ experiences and coping strategies that parents employed which influenced their transition experience. Content analysis steps as illustrated by Mayring (2000:4) were adhered to. Figure 1 shows the steps of the model by Mayring (2000).

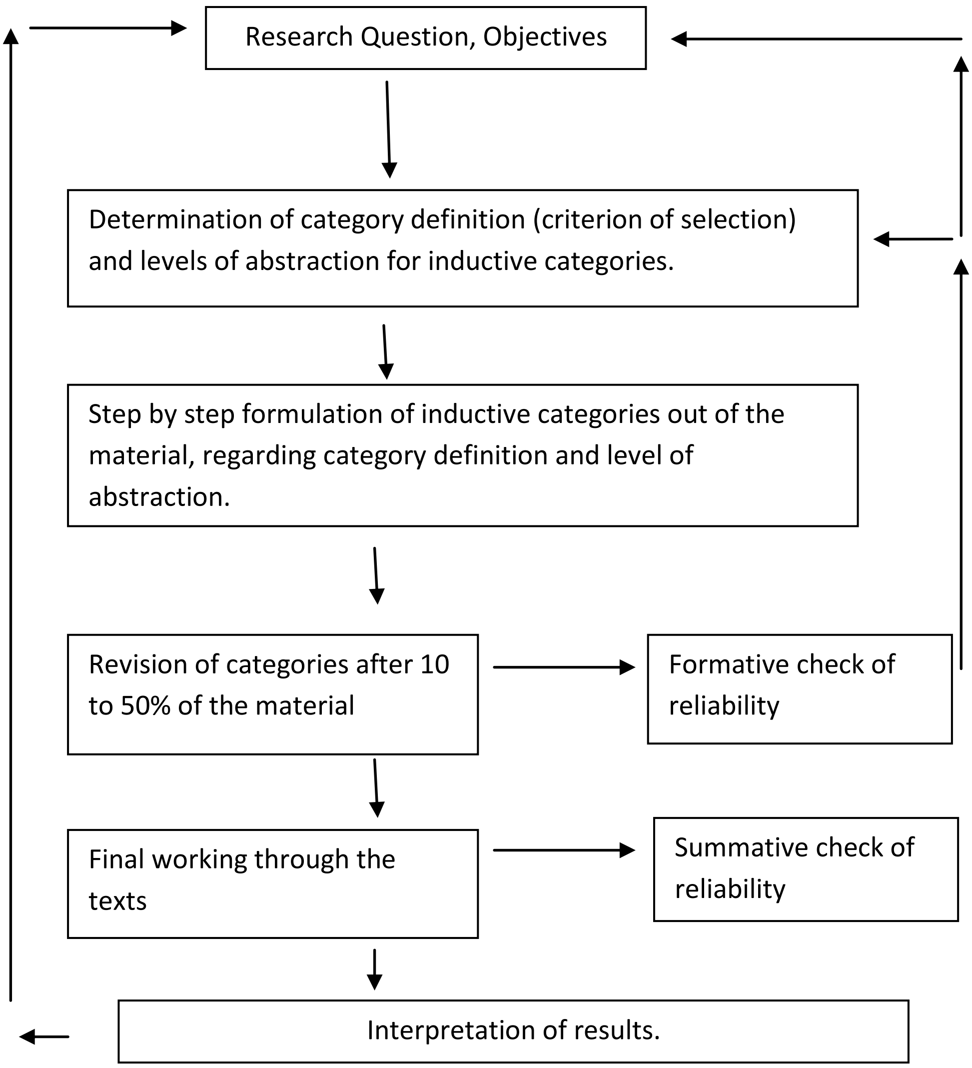


Figure 1: Content analysis steps (Mayring, 2000)

Following the criterion, the researcher worked through the data codes and provisional categories were identified. In collaboration with her supervisors, feedback was obtained and the categories revised until the final themes and categories emerged.

3.11 SCIENTIFIC RIGOR FOR THE STUDY

3.11.1 Trustworthiness

Guba (1981) proposed four criteria to ensure trustworthiness in a qualitative research study. The validation strategies of credibility, transferability, dependability and confirmability were applied in this study. The selected measures as suggested by Shenton (2004) to ensure the abovementioned criteria were met were applied as explained in the next section.

3.11.2 Credibility

Credibility is an evaluation of whether or not the research findings are a valid representation of the original data from the participants (Lincoln & Guba, 1985). According to Merriam (1998) credibility refers to the congruency of the research findings with reality. Krefting (1991) suggests that credibility necessitates sufficient submerging in the research setting in order that recurring patterns may be identified and verified. She (Krefting, 1991) proposes that sufficient time is spent with the research participants to identify recurring patterns as a means to ensure credibility.

In this study credibility was achieved in the following ways:

3.11.2.1 Early familiarity with the culture of participating organisations

The researcher consulted with the manager of the participating NGO in order to confirm that candidates who met the selection criteria were available to be interviewed. The consultation also served as a means of building a relationship of trust between the researcher and the organisation.

3.11.2.2 Sampling

Although purposive sampling was used to recruit participants for this study, the researcher had no foreknowledge of who the participants would be. They were selected by the manager of the participating NGO who recruited people strictly according to the selection criteria.

3.11.2.3 Triangulation

3.11.2.3.1 Range of informants – The selection criteria was very specific in terms of its participants, but allowed room for both fathers and mothers, biological or adoptive, to participate in the study. As a result parents with varying viewpoints and experiences were interviewed. A wide range of people were therefore able to contribute to the description of their experience of school to post school transition for youth with intellectual disability.

3.11.2.3.2 Peer scrutiny of the research project – Scrutiny of the project by two experienced supervisors occurred for the length of the project. Their feedback was taken into account and adhered to.

3.11.2.3.3 Member checks – The findings were taken back to the participants to read and verify as a true reflection of what they had experienced. At this stage, participants were also able to add to the information they had shared and were also given the opportunity to rectify any information in that they viewed as not bringing across the meaning they intended.

3.11.2.3.4 Tactics to help ensure honesty in participants

Shenton (2004:66) suggested that only participants who are genuinely willing to take part and who are prepared to offer information freely should be allowed during the data collection stage. To ensure this, participants were able to refuse participation in the study at any stage. They were also reminded of this right at the onset of the interviews.

3.11.3 Transferability

Transferability is concerned with the extent to which the findings of one study can be applied to other settings (Merriam, 1998). According to Krefting (1991) it is important to enhance strategies to ensure transferability in the event the researcher plans to generalise research findings. Lincoln and Guba (1985) proposed that it is crucial to provide dense background information about the participants as well as context and setting. In this study, the researcher has contextualised the study by providing sufficient information about the West Coast and its demographics (Refer to Chapter 1). She has also included information regarding gender, marital status, age and youth’s disability for each of the study participants.

3.11.4 Dependability

Dependability refers to the quality of the research process. According to Krefting (1991:221) “the exact methods of data gathering, analysis, and interpretation in qualitative research must be described”. In this study, initial interviews were conducted with each of the participants. These interviews were audio recorded and transcribed verbatim and taken back to the participants for member checking. After this process early submersion in the data began and initial data analysis was started. Two experienced supervisors oversaw the process. Following these events, a second round of interviews was conducted. These interviews were also audio recorded and transcribed verbatim in addition to member checks being done. Once data analysis was done, members checked to ensure the findings represent their transition experience. The whole process was overseen by two experienced supervisors.

3.11.5 Confirmability

According to Krefting (1991:221) a number of strategies are useful in the establishment of confirmability. One of the strategies she identified is triangulation. In this study, initial and follow-up interviews were transcribed verbatim. These were member-checked. Once the data was analysed member checking was done again to ensure that the findings accurately depict participants’ experience. The research process was consistently overseen by two experienced supervisors.

3.12 ETHICAL CONSIDERATIONS

The study received ethical approval from the Faculty of Health Sciences Human Research Ethics Committee, HREC reference number 625/2012 (Appendix E). The study adheres to the Declaration of Helsinki (World Medical Association Seoul version, 2008).

3.12.1 Autonomy

The right of the participants to exercise autonomy was respected. This was done through informed consent and confidentiality. Written informed consent (Appendix D) was obtained from the participants before data collection.

3.12.2 Beneficence

There were no direct benefits to parents' who participate in the study. The information gained through this research study may however be used to impact in the lives of future learners with intellectual disabilities and their parents. This was explained to the participants before data collection and they were fully aware that they could refuse to continue with the study at any stage.

3.12.3 Confidentiality

All participants were informed of their rights to confidentiality. The researcher kept all voice recordings and transcribed data confidential. Recordings were coded by using a pseudonym so that only the researcher knew which mp3 belonged to which participant. They were also saved under password protection on a memory stick and locked away. All transcriptions were kept safe in a lockable cupboard to which only the researcher had access.

3.12.4 Justice

The researcher ensured that participants were treated fairly by explaining the confidentiality clause and all other possible questions. Participants were purely selected based on the research requirements and not because of vulnerability. The researcher ensured that the research was not more intrusive than it needed to be. Participants were allowed to stop with their interview when they felt they had shared enough. The researcher also undertook to stop probing when the participants wished to stop.

3.13 SUMMARY

In this chapter the methodology of this study was described. Five participants who conformed to the selection criteria were recruited for this study via an organisation for people with disabilities. The participants were interviewed twice and audio recordings were transcribed verbatim and analysed. Chapter 4 will describe the outcome of the data analysis in terms of the themes and categories that emerged.

CHAPTER 4: Findings

4.1 INTRODUCTION

This chapter will describe the findings of the research study as it pertains to the parents' perspective of transition for their youth with intellectual disability. The inductive analysis of the data yielded two themes, each having three categories. Table 3 gives an overview of the themes and categories, which are discussed in depth in the next sections.

Table 3: Overview of the findings

THEMES	CATEGORIES
"It really hit us hard"	▪ Feeling uncertain and confused ▪ Managing without peer support ▪ Mixed feelings
Parental adjustment to post transition life.	▪ Setting up a routine ▪ Negotiating everyday occupations ▪ Accessing resources and a support system

4.2 THEME 1: "IT REALLY HIT US HARD"

The first theme captures the parents' feelings at the onset of their youth's transition. It describes the emotional side of the parents' transition experience as they came to terms with the realities they faced.

4.2.1 Feeling uncertain and confused

The initial feelings of the parents were described as a time when things were unfamiliar and unnatural. It was a time when parents' felt uncertain and unaccustomed as they did not know what was expected of them or what was happening. Their recollection is of a period in which they were in doubt about the future and lacked guidance. This uncertainty and confusion meant that for at least a short while, life came to a standstill. Not making progress or being able to move forward in terms of the youth's transition created a set-back and meant that these parents were not able to make timely decisions for their own and their youth with intellectual disability's future. James said:

> *"You are without counsel because you don't know what's going to happen next. My wife and I had to plan, you always had to plan that there's someone at home or that she had to move with us which was difficult because you can't leave her on her own. That also limited us in a way. Like when you want to go out or if you get an invitation because you have somebody."*

Much of the uncertainty came about as a result of poor communication. The parents assert that the special school did not communicate with them about their youth's transition from school. An exchange in this regard, whether verbal or written did not happen. Anne responded in the following way:

> *"There was a big unsureness as to whether we should place the child in [NGO name] or keep him at home as the school did not inform us as to what [NGO name] is and what it is like there and who is going to work and care for our children. The school did not help us in this regard."*

A few of the participants recall the school communicating that when their youth turns eighteen, they have to leave school. Although the parents in this study seemed to have a deep gratitude, appreciation and a sense of trust in the educators and staff of the special school, they were disappointed that details regarding the transition from special school were not communicated to them. One parent said:

> "*The school did not communicate with us about [NGO name] or that the child is completing his school year and we were really not properly prepared for this transition and it really hit us hard once the child actually completed their schooling and had to go to a new environment which we did not know or understand and it was foreign to the child as well.*"

In general parents felt that they were not suitably prepared for the transition. This lack of information caused them to feel uncertain and confused. When the school did arrange for post-school placement, parents lacked information about the placement their child was going to. As the child was transitioning from familiarity (the special school) to the unknown (NGO placement, other organisation or home) parents felt that they did not know much about what to expect. They were in the dark about the placement.

Information that parents deemed important such as the size of the group their child had to go to, the qualifications of the staff at the new placement, the functional level of the youth at the placement as well as concerns about safety were not communicated to them. One parent described her feelings regarding her son's transition from special school saying it was uncertain as well as traumatising. The NGO her child was referred to formed part a bigger NGO in the West Coast. Soon after her son's transition, the NGO name changed. As the name change was not explained to her, she was unsure about the placement her son was referred to. She did not know anything about their functioning and was concerned for her son who could not express his needs verbally. She explained:

> "*it was very uncertain and traumatic…because uh we didn't really know much about uh back then it was [name of NGO] but now it is [name of NGO]. Um about what happens here, how many children, the safety of the children, if the staff is trained to look after your child*

> *because it was something strange. Um, um It wasn't school like [child's name] was used to with a uniform, routine, he didn't know the people here..."*

They were therefore uncertain about what the immediate future had in store and felt disappointed as they expected to be informed about post school options.

Being stripped of knowledge about their child's transition from school was a common occurrence among all the parents in the study. One father in particular often worked the night shift and his wife was also in a profession that required her to work shifts. As their child had multiple disabilities, they felt dependent on guidance from the school their child attended to assist them in providing in her transition needs. As he played an active role on the school governing body, he expected the school would provide him with some information that would assist him and his wife to find a placement for their daughter. Of particular interest were post school placements such as NGO's, where the daughter could be placed if both parents had to work the same shift. Not knowing what was going to happen next caused an uncertainty about the future that made the transition period challenging. An added obstacle to the participants' situation was that there were very few options in terms of post school placement for people with disabilities in the West Coast. As parents knew their options were limited they felt a huge weight on their shoulders and an enormous uncertainty about impending events. In addition they felt they were not adequately prepared and this unpreparedness caused them to make life changing decisions. Lisa explained:

> *"I was not ready yet, not ready to leave my job. I felt I still wanted to work but did not have a choice. I, I, I…always felt she is my problem and I could not expect or ask other people to look, to take care of her because it's my problem."*

4.2.2 Managing without peer support

Parents vividly described the transition of their son or daughter from special school as a time when they had to cope on their own. They felt it was their burden to carry and could not involve other people. The parents' struggled to reach out to other people and subsequently ended up alone. Often they felt they did not want to intrude on people or be a nuisance to them. Most parents embraced their situation of being alone, handled circumstances as they arose and carried on with their lives. However, for all of the participants the transition of their youth with intellectual disability from special school proved to be a challenging experience. Much of the experience is characterised by the absence of significant people to assist or support the parent during this stage of their lives. One mother's frustration is captured in the following quote:

> *"it hurts, you feel hurt, knowing you have family and they don't care. Even the people from church, they are with you in church but no one supports you or offers their help."*

The hurt described by this participant, was similarly experienced by others who felt the emotional stress of absent family. Some deliberated on the situation while others opted to endure what they felt was their lot, saying the youth was their problem, though all sadly agreed that they hardly ever encountered some assistance from people outside their nuclear family. Participants' talked about the disparity in families, saying that the youth with a disability was often treated different to the other youth in the extended family. Some of the participants' proposed that the reason that family or friends never extended a helping hand was because they were not used to the ID youth. Mary said the following:

> *"I just accepted that he was our problem over and out. Many times if a person does not know such a person or you're not used to them you have the attitude, I don't want you close to me, like*

> *that, we don't understand you so what, fine. You won't even understand, that type of thing. But that didn't, I just accepted everything. This is my child and I have to deal with him. So we didn't have support from anywhere...I never received any support from family or friends, or help or so on. Nobody ever came forward, say my husband and I want to go somewhere, say we'll take him for the day so you can go out. No, never."*

In essence the youth's transition from special school brought about a sense of loneliness for most of the parents for whom valued support from family and friends were not felt. A participant explained:

> *"If you have a disabled person…child or adult then you don't have friends. I don't know if you've noticed. As soon as you have such a person then there's not friends for you. I don't know what the problem is. Then you have to…sometimes you long for people to come to you."*

This sentiment was shared by other participants as well. They similarly expressed the lack of support and friendship from people in general but more specifically locals. Even though they were in need of friendship and wanted to engage with people, they were scared of reaching out and connecting with people. Some of the parents expressed the notion that they thought it worked the other way around that people could see they needed support and therefore the onus would be on them to reach out.

All the participants in this study seemed to embrace the loneliness and coped on their own. They hardly reached out to people to ask for help and very rarely people reached out to them. Even though there was a general longing to engage with other people, they never initiated or created an opportunity to engage with other people. And so they later felt like they hardly had a chance to enjoy life and it was slipping pass them.

Another parent summed up the total experience in the following way:

> *"this is a lonely road, a very alone road"*

4.2.3 Mixed feelings

This category describes a range of feelings parents experienced while going through the transition of their youth with intellectual disability from special school. In some instances the experiences were positive while in most situations, experiences were particularly negative. Their mixed feelings were mainly influenced by context, particularly relating to their physical and social environments.

At certain intervals after the youth transitioned from school, parents were happy, even content, felt pleased and experienced joy. During this time they described their experiences as positive. It was a novel experience for the youth to be at home after so many years of schooling and parents enjoyed having the youth at home. Parents also found themselves in a space where they were not stressed or anxious about the future. Some could continue with home management tasks such as cleaning, cooking and shopping knowing that the youth is safe at home. After a while volunteers from a NGO came to recruit young people for their organisation and this was also viewed as positive by parents. One parent shed some light on the subject:

> *"Okay, we were happy when there was an alternative to [child's name] sitting at home."*

Parents were grateful that they had the option of a placement available to them. Having an alternative to their youth being at home made all the difference for these parents. As the West Coast is relatively rural the parents were aware of available resources as well as the lack thereof. The majority of the participants had previous experience of sending their child away from home (to Cape Town) in order to access education while the child was still very young. One parent for example told the story of his first encounter with transition (from home to school). He reflected on the events as they occurred on that day, when his son was still very young and had to be left behind in Cape Town at a school for the intellectually disabled, and seemed to relive the emotional turmoil and pain he experienced. Therefore parents' were grateful to have options (no matter how limited) available to them in the West Coast. It contributed to a much more positive experience of the youth's transition as parents were much keener to have their youth with intellectual disability with them at home. In the words of one father:

> *"It was much easier because he was closer. He came home every night. It was much easier for me. I am happy. He is happy. It was positive." (Richard)*

On the other hand, there were also negative experiences which seemed to outweigh the positive. Parents frequently disclosed feeling stressed, worried, uneasy and troubled. These were brought about by fears of the youth's safety. Parents were worried about leaving the youth at a placement they did not have any information about and they also did not know the people who worked there. Some parents were anxious because they had work responsibilities that required attention and they could not find suitable people to look after their youth with multiple disabilities.

Feeling confined or restricted and with no expectation of anything positive happening in the near future was also experienced by some of the participants who had to stay at home in order to take care of their youth. These feelings were as a result of circumstances in which the parents lacked transition information that could assist them in making arrangements or planning ahead for their youth with intellectual disability's transition from special school. Many of them were left feeling extremely discouraged even indicating that they were exhausted and felt defeated despite attempts to change the view of their situation in which they felt duty-bound to stay at home in order to take care of their youth with intellectual disability.

Some parents viewed the transition of their child from special school as the end of a road saying that life came to a standstill. Sadly, this experience came about because there were no NGO's where parents could place their youth at the time the youth finished school. Youth were compelled to stay at home and parents, especially mothers, often had to make the decision to stay home with them. In certain instances the transition was therefore labelled as being painful and crude.

One mother said,

> *"At that time you couldn't go anywhere when she was at home. So you couldn't at all; you can't leave her here and then you walk out. So actually I'm just a recluse. Till now…we actually did it for her." [Lisa]*

This mother felt tired all the time. She felt that she never had a break where she could just sit back and relax as she had to do everything by herself. Having her child at home was also a constant reminder that there were completely no alternatives for the child after school and this realisation made her feel frustrated.

Her circumstances dictated that the best choice would be to leave her work. Evidently she had to cope with her own feelings about leaving her job at a time when she felt she still wanted to work as well as coming to terms with her young adult child being at home. As a career woman it was hard for this mother to make the shift from working to staying at home. She was accustomed to being independent and buying what she needed. When she left her work, she became dependent on her husband's salary. Her financial status therefore changed immediately and this was a major change she had to get used to.

All these different events contributed to an ambivalent experience of transition in which parents' feelings about the transition was mostly mixed.

The first theme is captured in the three categories namely *feeling uncertain and confused, managing without peer support and mixed feelings.* This theme describes the emotions parents experienced at the onset of their youth's transition from special school. In addition, the parents' feelings as they coped with their youth's transition are also described. Through the parents' descriptions, one also becomes aware of the influence the context in which they live; have on participants' feelings during their youth's transition from school.

4.3 THEME 2: PARENTAL ADJUSTMENT TO POST TRANSITION LIFE.

Theme two captures the participants' experience as they grapple with changes in their personal lives after their youth's transition from special school.

4.3.1 Setting up a routine

Once the youth completed special school, parents found that they had to work out a structured system or else the day seemed to pass by too slowly. The change in the youth's program after completing special school seemed to have a direct effect on the parent's routine. For some parents it meant that they had more time to themselves and they were able to relax. This was mainly because the early morning stress of getting up and preparing the youth for school no longer applied. On the other hand, other parents found that their child's transition from special school placed certain limitations on their personal routines. One participant explains before and after transition routine in the following way:

> *"When she was in school I woke up in the mornings and bathed her and gave her food and packed her things and then she, then the bus came to fetch her and she stayed there until about two o'clock, half past one the school came out and then they brought her home. So I had a nice stretch in that time to look at the house but when she finished*

> *school [short pause] then it wasn’t nice for me because then in the mornings she was at home. Say she got up eight o’clock, then I had to take care of her, wash, that time she could get out of bed easily then I had to help her out of bed because my husband was working at the time. Then I take her out of bed and then I give her food, and then she watches TV but then when I get busy-then I get busy with my work [short pause] the house work but then she calls all the time. Mommy do this; change the channel; mommy I want that-where I wasn’t bothered other times. See?”*

Having her child at home created a barrier to this mother’s normal morning routine. She was not accustomed to having anyone at home while she tackled her daily household chores. Therefore, this break from the norm took some getting used to and a new routine formed in the days that followed.

After the transition from special school, parents seemed to connect with their children during the time the youth spent at home. They got to know them better and were able to determine what interested and provided joy for them. Playing with the toys or writing in the books they had at home no longer created pleasure, instead they became uninteresting. In an attempt to salvage the situation (before parents had the option of NGO available to them), some parents attempted to arrange play dates with other youth with intellectual disability, who lived in the vicinity. Although it created the opportunity for the young people to socialise, it seemed to impact negatively on the parent’s routine. The parent would often be interrupted while engaging in household tasks to explain what the friend said when the youth did not understand one another. As both youth with intellectual disability had poor speech, they struggled to understand one another when engaging in conversation. The parent would then be called to clarify what was said and act as interpreter.

For some parents, the youth's transition from school opened doors for them in terms of establishing new routines. Some parents' reached out to the NGO's their children stayed with during the day. They volunteered their services, assisting with the daily running of the NGO, and in this way became involved in their community. Through assisting at the NGO, parents were also able to keep an eye on their youth. A participant said,

> *"Lately I've volunteered at [name of NGO] as a parent, I'm there every day…I speak with the other children there and this also contributed to him fitting in more easily."*

For this parent, it meant a great deal that her son was now fitting in easier. As he could not speak, she was always concerned about his well –being as he could not tell her if he was being bullied or if he got hurt. She enjoyed volunteering at the NGO as it provided her with peace of mind she needed because she was able to observe her youth's interactions during the day.

A parent also indicated that she was able to relax more since her child's transition from special school, saying she was on her own time. Instead of preparing the youth for school in the morning and waiting on the school bus, she was now able to manage her time more effectively and do her chores without the constant worry of running late. This meant that since her youth's transition from special school she was able to manage her time to her advantage.

Other parents indicated that there was no significant change in their routine. While the youth attended school, they were picked up by the school bus in the mornings. Now that they no longer went to school, they seemed to have exchanged one means of transport for another as the NGO's transport would pick up their son or daughter in the mornings. This allowed them to continue in more or less the same manner as when the youth went to school. However, once these initial changes to an existing routine were dealt with, parents were able to form a new routine which helped them to become more relaxed.

4.3.2 Negotiating everyday occupations

For many parents, making practical arrangements was a key element during the transition of their son or daughter from special school. For some this meant waking up very early in order to wash, groom and prepare breakfast for the youth with intellectual disability. One mother explained that when their daughter required assistance at night, she would get up and allow her husband to sleep especially if he had to work the following day.

Parents frequently had to talk with their spouse and others about daily schedules. What makes this different to the norm is that an eighteen year old or older youth without an intellectual disability is able to take up certain roles and responsibilities. They are allowed to e.g. carry a house key to let themselves into their home, prepare their own meals etc. whereas youth with intellectual disability, especially those with high support needs are often not independent enough to take on these roles and responsibilities. Therefore parents were required to balance work and social obligations in order to live a more stable life in which the needs of their youth with intellectual disability were met. Often this meant working shifts that would not clash with the youth's pick-up and drop-off times or looking for jobs that were half-day. In one father's words:

> *"My wife and I had to plan, you always had to plan that there's someone at home or that she had to move with us"*

Reliable family was an invaluable benefit for these parents. They often had to arrange amongst themselves and immediate family if they were in need of assistance or if they wanted to attend social events. One participant said that she could always call on her son and his wife to come over if she needed to go somewhere and they would not disappoint her.

In households where both parents were working, negotiating shifts became important to the general function of the home. As both parents were responsible for taking care of the youth with intellectual disability parents had to be careful to avoid burnout therefore taking turns to work also assisted in providing relief for parents. A participant said,

> *"there was a time when she worked day shift and I worked night shift so we could relief one another"*

Other parents were not in the fortunate position to negotiate shifts like the parents where there was a single breadwinner. In situations where both parents were working, holidays became particularly challenging when there was no-one to take care of or supervise the youth. These circumstances required of them to make the necessary arrangements with their employer as they were compelled to take the youth with them to work. A good relationship with the employer was advantageous in these conditions. One parent explained that she worked as a housekeeper for a substantial number of years. Fortunately, her employer uniquely understood her situation as he also had a son with the same condition as hers. He managed the situation favourably and allowed her to bring her son with her to work during holidays and on days when there was no-one to take care of him. Other parents did not have the same experience and so leaving a job they loved seemed to be the only other option.

The participants in this study also explained the effort ordinary occupations and activities of daily living took. They frequently had to do their research and be thoroughly informed about a specific area before attempting to go somewhere. Often, when considering outings, parents found that they had to obtain information about the place they wanted to go to in order to make the necessary planning arrangements. This method was particularly relevant especially when the youth was a wheelchair user. Parents were then compelled to find out whether the area was wheelchair friendly. The situation often proved to be challenging and frequently parents had to rely on people to stand in when they urgently had to go somewhere.

4.3.3 Accessing resources and a support system

During the transition from special school to post school, many of the participants accessed supports to help sustain and enhance their quality of life during this demanding time. Parents' made use of resources that they were previously oblivious to. These resources which include things like their faith in a higher power, their families, personal skills and abilities, community organisations and knowing influential people in the community became a means to deal more effectively with the transition of their son or daughter with intellectual disability from special school.

Parents felt frustrated as there were absolutely no options for their children after they finished school. There were occasions when parents felt weak and turned to their faith. They felt that they did not want to burden other people with their problems and opted to pray instead. When they were lonely, their spirituality seemed to sustain them as they did not feel comfortable to communicate with other people but instead felt that speaking with their God was the only option. A parent explains,

> *"…you can just ask the Lord to help you because who can help you through that loneliness"*

Some parents also became involved with NGO's for various reasons. They were concerned about their son or daughter's safety so they opted to volunteer their time at the NGO to keep an eye on the youth. Some parents noticed that the NGO's were short staffed and felt they could lend a hand and then there were also parents that volunteered their services in order to secure a place for their child at the NGO.

One participant felt somewhat relieved to discover that her cousin was running the NGO her son was going to. Although it did not make the decision to send him there easier, it provided her with the peace of mind she needed to make the decision to send him instead of keeping him at home. This mother felt contained knowing her son was taken care of by someone she knew and trusted.

Another parent volunteered services to the NGO as it assisted him in securing a place for his daughter. As he is very active in the community he has valuable people skills and knowledge of the community. He is therefore able to assist the NGO in their needs and they mutually assist him by taking care of his daughter. Using their skills and people knowledge strategically therefore assisted parents to deal with the transition of their son or daughter in a more positive light.

For other parents, the transition of their son or daughter from special school was more challenging. James said:

> *"Unfortunately there were no facilities and no preparation with regards to transition from school to the world of work in the West Coast. We were on the lookout for placement of our daughter at private institutions, but we could not afford it. So there was nowhere she could be placed and it was a difficult time for us, because either myself or my wife had to be at home with her, because she needed a fulltime caregiver and she was used to my wife or me".*

A participant explained how his wife had to leave her job in order to take care of their youth after she completed her schooling. He mentioned that leaving her job impacted on the family's family status in a big way as it meant they would lose one salary. During this time, he says that the only support they received came from South African Social Security Agency (SASSA). This sentiment was shared by other participants who claimed the “SASSA money” was all the support they received.

Family, especially parents own children and grandchildren provided a relieving role in times when urgent matters had to be done. This almost invisible resource was also constantly available to parents during the transition period.

The second theme provides a description of the parents’ experience as they come to terms with changes in their personal lives after the youth’s transition from special school. The categories, *setting up a routine, negotiating everyday occupations and accessing resources and a support system*, encompass the participants’ experiences of transition. These experiences are also influenced by the context in which the participants’ find themselves in.

4.4 SUMMARY

Chapter 4 describes the parents’ experience of their youth with intellectual disability’s transition from special school. The findings indicate that there appears to be a significant interaction between parents’ personal responses and coping strategies in the context they find themselves in during the transition period. Chapter 5 will discuss the findings in more detail.

CHAPTER 5: Discussion

5.1 INTRODUCTION

This study aimed to describe how parents experience the transition from special school to post school of their youth with intellectual disability. The research objectives were to (a) describe the parents' personal responses linked to the transition of their youth with intellectual disability from special school (b) describe the strategies the parents used to cope with the experience of transition and (c) identify the contextual factors that influenced the parents' experience of transition.

The findings suggest that the meanings parents' attribute to their experience of transition are largely influenced by the interaction between their personal responses and the coping strategies they employ. In addition, the contexts in which the parents experience the transition impact on their personal responses and coping strategies. The interactions between the context, personal responses and coping strategies were particularly visible and will be discussed further with regard to the parents' preparation for transition, stress and risk of burnout as well as managing occupations. Figure 2 depicts the interplay between the two constructs, personal responses and coping strategies, and their interaction with the context.

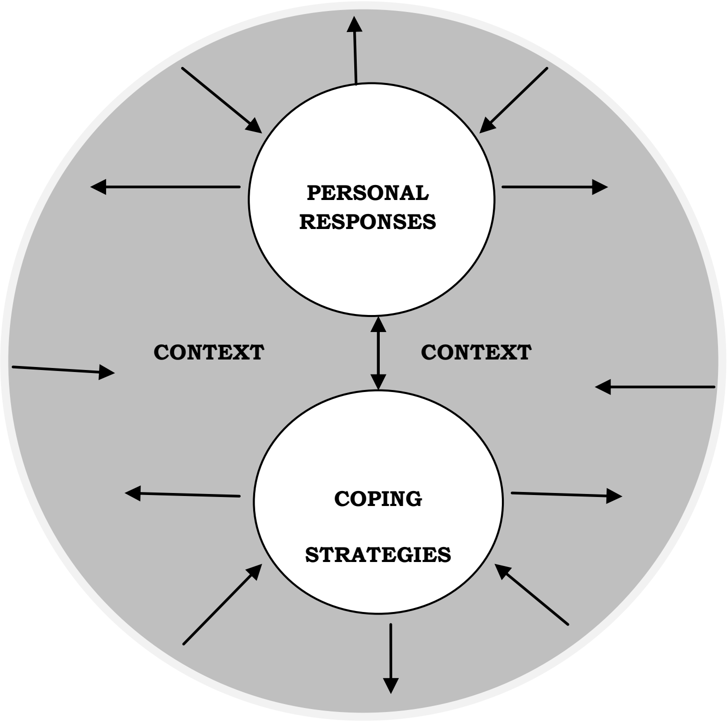


Figure 2: Diagrammatic presentation of findings

The diagram shows the co-existence of the parents' personal responses, their coping strategies and the influence of the context. The context, consisting of temporal (chronological and developmental age, life cycle and disability status) and environmental (physical, social and cultural) aspects (Dunn, Brown, McClain & Westman, 1994)is portrayed as the area (grey in the diagram) in which personal responses and coping strategies are embedded. From the diagram it is noted that personal responses and coping strategies impact on one another, in addition the context also impacts on both the personal responses and coping strategies. The diagram attempts to capture the parents' experience of their youth's transition within the particular context of the West Coast, South Africa. Research into context has shown that contexts are very influential on occupational performance (Dunn et al., 1994; Green, 2002). Von Zweck (2004) added that if we understand our environmental contexts, we can build on our foundation for the future. In this study, the youth with intellectual disability's transition originated in the environmental context of the

West Coast. As explained in Chapter 1, the West Coast is located approximated 150km from the nearest resourceful town, which is Cape Town. Small towns in the West Coast are widespread and there is no established transport system. This means that parents of a child with intellectual disability would mainly be dependent on resources that their own town could offer. In terms of the transition from special school this would mean that parents had to send their youth with intellectual disability to a town with more resources or settle with the limited options available to them in their own town. In this way the environmental context, in which the transition occurred for the youth with intellectual disability elicited a personal response from the parents either emotional or psychological, which prompted them to apply coping strategies to address or alleviate the impact of the transition. The environmental context could also drive parents' to employ coping strategies. In Chapter 4, the example is mentioned of one mother who left her job in order to take care of her daughter. Due to the limited options presented by her environment, the mother saw it fit to offer up her employment in order to provide her daughter with the comfort, care and support she needed. As the coping strategies parents employ are either successful or not, they consequently elicit a personal response. The mother from the aforementioned example elicited a personal response in the sense that she became stressed and later felt like a recluse. Two examples to clarify this point follow:

1) The personal responses have a direct impact on the coping strategies e.g. parents were poorly informed by the school (context) about the transition process so when the youth transitioned from school parents responded by feeling unsure, anxious, stressed and feeling without counsel (personal response). They then coped by arranging that one person stay at home all the time so that there would be constant supervision available for the youth with intellectual disability (coping strategy).

2) The coping strategies have a direct impact on personal responses e.g. parents were poorly informed by the school (context) and opted to take care of their youth themselves (coping strategy), but then ended up feeling frustrated, anxious and stressed (personal response) when the youth felt bored at home.

These interactions between the context, personal responses and coping strategies impact on the parents' health, well being and occupational performance. Due to the limitations in their context, parents were unable to engage in occupations that they deemed important and that brought enjoyment to them. Instead they sacrificed their own active engagement in meaningful occupations and later felt that their own life came to a standstill.

The following sections discuss the impact of the interaction of the context, personal responses and coping strategies in terms of the parents' preparation for transition, stress and risk of burnout and their management of important occupations.

5.2 PREPARATION FOR TRANSITION

Similar to other transition studies (Gillan & Coughlan, 2010; Raghavan et. al., 2013; Bhaumik et al., 2012; Chamber et. al., 2004, Ward et. al., 2003), the parents in this study also report that they were not well prepared for the transition from special school and generally lacked information about post school options. This general lack of information refers to basic communication of the changes that would take place with regard to the ID youth's transition from school. As mentioned in Chapter 1, transition from school for youth with ID does not occur naturally (Hurst, 2009). For this reason, it necessitates that parents be informed about post school options such as the availability of placement facilities once the ID youth leaves school. Ellman (2004) asserts that learners with ID have a diverse range of needs, unique to the individual. It has been noted that for some individuals with special needs the acquisition of personal skills may assume greater importance at a particular life stage (Ellman, 2004). Therefore, unlike their mainstream counterparts, parents of youth with intellectual disability have to consider support needs unique to their child. Youth with intellectual disability require much more intensive support that could include planning for basic activities of daily living (ADL) such as dressing, washing, toileting, medication routines, community mobility, emergency responses and socialisation amongst others. Parents have to ensure they are properly cared for and safe, while at the same time providing them with enabling opportunities. The parents of youth with intellectual disability should therefore and want to be, thoroughly informed as primary caregivers of a vulnerable group. If parents of youth with intellectual disability lack information about their child's transition from school, it could potentially place their already vulnerable child at further risk. Special schools that do not provide parents' of youth with intellectual disability with essential transition information are not playing their role in furthering the Department of Education's vision of working collaboratively with parents. Prior to 1996, learners who experienced barriers to learning were accommodated in special schools. These special schools were designated according to categories of disability and learners experiencing barriers to learning who were not in special schools were unable to access education (Department of Education, 2005). However in 2001, White Paper 6 was launched in which we are reminded of our constitutional right that 'everyone has the right to basic education' (Department of Education, 2001:11). White Paper 6 is also the reason that the curriculum was adapted and during the process of changing the curriculum, barriers to learning and development as well as the causes thereof were identified. Lack of parental recognition and involvement was highlighted as one such barrier (Department of Education, 2005). Therefore special schools who continue to follow the status quo with regard to not involving parents could, in the researcher's opinion, be viewed as perpetuating this already identified cause. The results of this study are testament to the fact that a lack parent involvement remains a challenge to deal with. Special schools will have to do their bit in reaching out to parents when it comes to communicating transition information. This could ensure that parents are informed about the transition early and reduce the negative effects as mentioned in Chapter 4.

In this study, parents were also dissatisfied that they were not involved in the transition process, an occurrence that has been noted frequently in the literature (Gillan & Coughlan, 2010; Raghavan et al, 2013; Bhaumik et al, 2012; Chamber et al, 2004, Ward et al, 2003). Johnson (2003) proposes four steps in the basic transition process: planning, preparation, linkage and exit. Parents or family are viewed as integral to this process. Bennie (2005) also view parents as integral to the team and suggest that they should be active contributing members of the team from the beginning. He suggests that this can be problematic if planning is left to the last year or two of schooling. In this study, planning for transitions was seemingly not viewed as a priority as the parents in this study indicated that the transition from school was extremely difficult. They complained that the special school did not communicate with them about the youth's transition from school which made the transition difficult for them. On the one hand, one would expect special schools to take initiative in planning for the transition of their learners with intellectual disability while on the other hand one cannot really blame special schools for not planning for transitions as there are no South African policies or guidelines that mandate them to do so or that guide them in how to do it. Education White Paper 6 on special needs merely alludes to transition in stating "…special schools will also include the provision of comprehensive education programmes that provides lifeskills training and programme-to-work linkages" (Department of Education, 2001). This refers to the learners while parental involvement is not mentioned. Therefore, special schools do not have a guideline to follow when it comes to transition planning.

It is evident from this study that parents of youth with intellectual disabilities want information about post school options. However, the literature suggests that parents or caregivers are frequently out of the loop when their youth reach transition age. Bhaumik et al (2012), Raghavan et al (2013), Chambers, Hughes & Carter (2004) report that there is a general lack of information for carers and youth about post school options. As previously mentioned, special schools in South Africa are not mandated by law to plan for the transition of youth with intellectual disability leaving school. It can therefore be argued that principals and staff at these special schools may be uncertain or even unaware of the idea of planning for transitions. Government should therefore set clear guidelines to education departments about how, when and who should be involved with transition planning for school leavers in South African schools. Parents' in this study suffered in terms of their psychological well- being as they felt confused, anxious, unsure and even without counsel about the future as they were poorly prepared and had no information about the transition of their youth with intellectual disability. The fact that parents were poorly prepared and lacked information also contributed negatively on their occupational performance and choice in terms of the occupations they engaged in. It also impacted negatively on their health. Gillan & Coughlan (2010) report similar findings and it is further noted that even in situations where the transition was planned well, parents still wanted information about the transition process (Ward, et al, 2003). The parents in this study reported stress as a result of the uncertainty originating from "not knowing". They also felt tired and frustrated and even helpless as they lacked information to make arrangements for their son or daughter with intellectual disability. These negative feelings could be avoided if the youth had a transition plan and parents were involved in the planning process. In fact Raghavan, Pawson and Small (2013), state that parents should be involved in planning their child's transition from school. It was found that decision-making about transition planning in addition to family involvement with the child and service providers are key factors in transition success (Blacher, 2001). In the present study, these factors were missing and consequently accounted for a transition experience marked by several challenges (stress, anxiety, uncertainty, etc.) Crawford (2012) points out that irrespective of whether youth with disabilities plan to go directly from school to work or attempt studies, they should have a transition plan, whether formal or informal, that address practical strategies in order to achieve successful outcomes pertaining to maintenance of the youth's health and wellness and more long-term goal of moving from the parents home to more independent living. It has also been reported that parents who look after a child with intellectual disability experience more physical health problems than parents who do not (Gallagher & Whiteley, 2013). Showing how important it is to plan for transitions from school. However, transition planning is seemingly an area that requires some development within the South African context. This is an area that should be mandated within the South African schooling context, especially since the lack of parental recognition and involvement has been identified by the Department of Education (2005) as a cause of barriers to learning. In South Africa, it is not clear who is responsible for the transition planning of learners but it is said to be mainly the job of the guidance teacher (Vlachos, 2008). However, occupational therapists in special schools are uniquely skilled to deal with transition planning and are in a position to meet with parents without putting pressure on the curriculum. In other parts of the world, occupational therapists are viewed as key members of the transition team as they have skills in supporting a learner's function and performance in ADLs as well as support engagement in occupation (AOTA, 2002). The researcher is of the view that the transition team should ideally consist of the occupational therapist, the parents, youth with intellectual disability, educator and other professionals such as speech and language therapist who are involved with the youth’s educational processes. Occupational therapists are also knowledgeable with regard to “technology, task and work analysis, behaviour and psychosocial needs, sensory processing and independent living skills” (AOTA, 2008:2). These skills make them vitally important in dealing with transition in youth as well as parents. Furthermore, transition is also mentioned as one of the standards of practice for South African occupational therapists (HPCSA, 2004). Occupational therapists are required to prescribe a transition plan that is “based on the client’s identified needs” (HPCSA, 2004). They should also manage the transition process in collaboration with the relevant team which includes the family and community resources (HPCSA, 2004). Transition thus seems like a process that all occupational therapists should be implementing and be aware of. However, irrespective if they are aware of their role in terms of transition, occupational therapists are ideally suited to lead the transition processes in special schools.

5.3 STRESS AND BURNOUT

These study findings are unique from a South African perspective and in addition build on the results of similar studies in other contexts. An Irish study for example, reported that all the parents described negative transition experiences with specific reference to uncertainty and lack of options regarding services (Gillan & Coughlan, 2010). In this study parents’ experienced stress, anxiety, frustration and uncertainty that stemmed from a lack of options in terms of services that are central themes in other studies as well (Gillan & Coughlan, 2010; Davies & Beamish, 2009; Cooney, 2002; Beresford, 2004; Kraemer & Blacher, 2001; Rapanaro, Bartu & Lee, 2008). The reported stress, anxiety and worry as well as frustrations were mainly, though not exclusively experienced by mothers in this study who were primarily responsible for the caregiving of the youth after he/ she transitioned from school. As the transition from school was not well planned these parents were caught off guard when their youth left school and opted to take care of their youth themselves as there were no other options available or explored prior to the youth's transition from school. In the West Coast, options are severely limited in terms of resources for people with disabilities. The distance between towns also impact hugely on parents' access or lack of access to resources. The transport system is almost nonexistent which means that parents are cut off from accessing available resources and support if they do not have their own transport or are unable to afford the transport (minibus taxi) costs. Strain is then placed on the family's finances which in many cases are already limited as parents in this study reported relief at receiving some money in the form of a disability grant from SASSA.

Mothers of children with intellectual disability are especially prone to suffer from stress and fatigue and if not managed well, could suffer from burnout (Bilgin & Gozum, 2009). It has also been reported that parents who take care of a child with intellectual disability report more psychological stress and have more physical health problems (Gallagher and Whiteley, 2013). Stress and fatigue of parents should and can be avoided by providing parents with relevant information even before they reach transition age. A concerted effort should be made to introduce a transition plan early which defines the learners' long-term goals once they leave school. In other contexts, the transition plan forms part of the individual education plan (IEP), better known as an individual learning plan (ILP) in the South African context. The ILP is a document in which the specific learning needs of an individual with special needs are captured (DOE, 2005). Presently it should consist of "an individual learning program, a work schedule or work plan and the specific adapted lesson plans" (DOE, 2005:20).

Although this document provides valuable information about the youth's educational support needs while at school, it does not provide a collaborative future plan for once the youth leaves school. Bennie (2005) reported that it may be problematic to leave transition planning for the last year or two as there are many issues and anxieties that may be required to work through and options that need to be explored. The experience of parents' in the present study is testament to what happens when transition planning is left to the last minute. The West Coast, which comprises five local municipalities as mentioned in Chapter 1, has limited options available in terms of post-school options. Parents therefore often explore options in Cape Town, approximately 150km away, which is the nearest town with sufficient resources for persons with intellectual disability. However, exploring options in another town often has financial implications, as parents in this study also experienced. Parents seem to expect that the special school would make arrangement for their youth in terms of the youth's transition needs. Therefore parents' experienced a sense of hopelessness, anxiety, fear and experienced stress when they learnt that no plans were made for their youth once they left school and options in the West Coast have been severely limited for the past five years and were non-existent ten years ago when there were no nongovernmental organisations who catered for youth with intellectual disability once they left school. Parents' had to hastily make arrangements for their youth with intellectual disability which caused stress and a risk of burnout.

5.4 MANAGING OCCUPATIONS

This study found that parents struggled to manage occupations at the time their youth transitioned from school. Occupations in occupational therapy “refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (WFOT, 2012). The parents in this study found it particularly challenging to continue with paid work or continue working the same shifts, doing home management tasks and socialising. The implication was that once they stopped engaging in occupations that were meaningful to them, parents’ had negative experiences of transition and became stressed and anxious.

As noted in Chapter 4 of this study, transition planning did not occur for the parents of youth with intellectual disability in this study. Therefore, parents had to hastily make arrangements for their youth once they transitioned from school. These arrangements impacted on their personal lives and caused changes to take place which were stressful for parents. In some instances, parents had to leave their work in order to take care of their youth with intellectual disability. A mother in this study mentioned that she was not ready to leave her job yet but felt obligated to do so because there was no-one to take care of her child. Davies and Beamish (2009) also report the example of a mother who resigned from her paid job in order to be at home with her child. Mothers found managing their occupations particularly challenging as they had the added responsibility of taking care of the youth with intellectual disability. In the instance where both parents were working, they arranged to work different shifts and even slept at different times in order to make sure their household was functional. This arrangement had its own negative implications as it placed strain on the marital relationship as parents could not spend quality time with one another. Parents’, specifically mothers who were primarily responsible for the caregiving of their youth while they were at home post transition, struggled with home management tasks as they were interrupted by the youth at inconvenient times. Even going to the store to buy groceries became a calculated task. Parents arranged amongst themselves that one of them had to be at home at all times so there would be supervision for the youth at home. This arrangement became problematic when parents wanted to spend some quality time alone or socialise with other people. McDougall, Buchanan and Peterson (2014) also concur that when carers place more emphasis on their caring occupation they leave little opportunity to engage in other meaningful occupations. Parents are then at risk of stress and burnout as the participants of this study experienced. Situations such as these, where parents feel devoid of options and unable to manage occupations which are important to them, can be avoided if parents are fully informed and part of the transition process. The researcher agrees with the likes of Bennie (2005), Crawford (2012) and AOTA (2008) who suggest that transition planning should begin early, possibly at the age of twelve years and that parents should be involved and receive written feedback regarding the transition plan. In addition, parents should also receive ongoing support during the transition process. This is a gap within the South African schooling system that should be addressed with immediate effect.

5.5 SUMMARY

The interaction between parents' personal responses and coping strategies embedded within their specific contexts are similarly observed in all the participants' transition experiences. The findings in this study are unique from a South African perspective as it is the first South African study to investigate transition from special school from the parents' perspective. This study concurs with discoveries of other researchers, specifically those in developed countries. It is different to other studies as it found that the context can have a determining role in how transition from school is collectively experienced. The research found that the meanings parents attribute to their experience of transition are significantly influenced by their personal responses and coping strategies in the context they find themselves in during the transition period. The research also shows that there is a gap for occupational therapists in South African special schools to render a transition service that could possibly alleviate the stress experienced by parents during the transition period. In addition, transition planning would be more organised or structured and accountability assumed by a specific department or person. The goal would ultimately be to have well prepared parents and youth with intellectual disability transitioning from South African special schools.

CHAPTER 6: Conclusion and recommendations

6.1 CONCLUSION

The purpose of this research study was to gain an in depth understanding of parents' experience of transition for their youth with intellectual disability. The research aimed to describe parents' in the West Coasts' experience of the transition of their intellectually disabled youth from special school to post school. A qualitative mode of inquiry was utilized and the overall research design was qualitative description.

Five parents, of youth with intellectual disability who have experienced transition from school to post school, participated in the study. They were interviewed twice and the transcripts of these interviews were analyzed. Inductive analysis yielded two themes: "It really hit us hard" and "Parental adjustment to post transition life" as well as six categories which were: feeling uncertain and confused, managing without peer support, mixed feelings and setting up a routine, negotiating everyday occupations and accessing resources and a support system.

The first theme brings to the fore the parents' experience of doubt, their inability to make decisions in the absence of information to do so and the range of feelings they experienced. The second theme captured the parents' experience as they dealt with changes in their personal lives arising due to their youth's transition from special school. The theme describes parents' attempting to normalize their lives through the creation of routines and their struggle in terms of everyday occupations and limited resources.

Findings suggest that the meanings parents ascribe to their experience of transition are mainly as a result of the interaction between their personal responses and coping strategies. Furthermore, the context in which the transition takes place can be quite influential and impact on parents' personal responses and coping strategies. These were particularly visible in terms of the parents' preparation for transition, parents' stress and risk of burnout and their management of occupations.

This study shows the extent of parents' needs at the point of transition and thereafter. It also makes inference to the idea that occupational therapists have a leading role to play in the management of transition services in particularly South African special schools. South African school based occupational therapists have the skills in task and work analysis as well as independent living skills in order to impact in a crucial way on the transition needs as of intellectually disabled youth and their parents, as highlighted in this study.

6.2 LIMITATIONS

Limitations in this study pertain to sampling. Four NGO's in the West Coast were approached to participate in the study, however only one NGO responded positively. Purposive sampling of participants at the one organisation occurred. This means that parents' perspectives of one particular area in the West Coast are described within this research. The research findings cannot therefore be generalised to the broader population, however one can learn a great deal about the influences, personal responses and coping strategies in the context parents find themselves in have on the meanings parents attribute to their experience of their intellectually disabled youth's transition from special school.

6.3 RECOMMENDATIONS

The following recommendations are made to encourage a smooth transition period for parents of learners with intellectual disability.

6.3.1 Recommendations for policy

- Develop national policies that address transition services

The Department of Education recognises the need for an inclusive education system and also makes provision for learners with special needs/ barriers to learning to access the curriculum. The individual learning plan is the document that currently addresses the school's plan to help the learner with special needs access the curriculum. As gathered from this research, the needs for learners with special needs are so diverse; they also require a future plan for once they finish school. A guideline that address early transition with elements such as planning, preparation and exit, in which the parents of learners with disabilities are key collaborators, could assist special and other schools to become more experienced with matters of transition from school. The researcher will disseminate the findings of this present study to the Head of Specialised Education in the Western Cape by providing him with a report of the study findings. The researcher will also do a presentation of the study and invite occupational therapists in the West Coast including the district based occupational therapist and the head of therapy in the Western Cape Education Department.

6.3.2 Recommendations for practice

- Define occupational therapists' role with regard to transition services

The role of occupational therapists' with regard to transition services in South African special schools need to be clearly defined in order to enhance service delivery in that particular area. The Health Professions Council of South Africa's (HPCSA) Professional Board of Occupational Therapy and Medical Orthotics / Prosthetics refer to transition services as a direct intervention under its standards of practice. The researcher aims to create awareness of occupational therapists role with regard to transition services by reporting this study's findings to the Occupational Therapy Association of South Africa (OTASA) as their school based occupational therapy group could influence the way in which transition services is viewed nationally. The researcher will also disseminate the findings at key congresses and through publications.

6.3.3 Recommendations for education

- Collaboration among key role players in special schools such as occupational therapists, educators, circuit based education officials and parents.

Key role players should work collaboratively and have clearly defined roles in order to create a smooth transition process. In South Africa information pertaining to transition is quite limited, however, each of the professional and parents involved in the process for a particular individual with intellectual disability have information. What is absent is the collaboration. Special schools should ideally take it upon themselves to develop transition information brochures for distribution to interested parties and especially parents of learners who are approaching transition. These brochures could contain information that prepares the learner and family for changes in roles and routines. To this end, the researcher will create awareness of the present situation by doing a presentation of the present research study at the special school where she is employed, the Western Cape Forum for Intellectual Disability, as well as at the circuit school based support team meeting which has representatives of all the schools in the circuit. The researcher will also initiate workshops or meetings with parents of youth with intellectual disability at various stages in order to address relevant transition information. She will also publish her research in a peer reviewed journal.

6.3.4 Recommendations for research

- Continued research

Future studies should address transition of learners from special schools from other more resourced areas in South Africa as well. As the context in this area impacted so intensely on parents' views of transition, a more resourced area could yield a different result. Studies should also look into South African occupational therapists' involvement in transition services in special schools. An intervention to address transition issues with parents and learners could also be developed and tested in order to address specific elements of the transition from school. In addition studies that explore the youth's experience of transition could add intellectually disabled youth's voice to the literature.

References

American Association on Intellectual and Developmental Disabilities. Ad Hoc Committee on Terminology and Classification. 2002. *Mental Retardation: Definition, Classification, and Systems of supports, 10th ed.* Washington D.C: American Association on Intellectual and Developmental Disabilities.

American Psychiatric Association. 2013. *DSM-5 Intellectual Disability Fact Sheet.* American Psychiatric Publishing.

African Youth Charter. 2006. Adopted by the seventh ordinary session of the assembly, held in Banjul, The Gambia on 2nd July 2006.

American Occupational Therapy Association (AOTA). 1998. Standards of practice for occupational therapy. *American Journal of Occupational Therapy.* 52:866.

AOTA. 2008. FAQ: Occupational Therapy's Role in Transition Services and Planning. Bethesda: AOTA.

Bennie, G. 2005. *Effective transition from school to employment for young people with intellectual disabilities in New Zealand.* (Country Report for 25th Asia-Pacific International Seminar on Special Education National Institute of Special Education, Japan). Palmerston North: New Zealand.

Beresford, B. 2004. On the road to nowhere? Young disabled people and transition. *Child: Care, Health & Development.* 30(6):581-587.

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T. & Forte, J. 2011. Transition for teenagers with intellectual disability: Carer's Perspectives. *Journal of Policy and Practice in Intellectual Disabilities.* 8(1):53-61.

Bilgin, S. & Gozum, S. 2009. Reducing burnout in mothers with an intellectually disabled child: an education programme. *Journal of Advanced Nursing.* 65(12):2552-2561.

Blacher, J. 2001. Transition to adulthood: mental retardation, families and culture. *American Journal of Mental Retardation.* 106:173-188.

Blair, S.E.E. 2000. The centrality of occupations during life transitions. *British Journal of Occupational Therapy.* 63 (5):231-237.

Bray, A. 2003. Definitions of intellectual disability. Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability. National Advisory Committee on Health and Disability. Wellington.

Certo, N., Luecking, R.G., Murphy, S., Brown, L., Courey, S. & Belanger, D. 2008. Seamless transition and long-term support for individuals with severe intellectual disabilities. *Research and Practice for Persons with Severe Disabilities.* 33(3):85-89.

Chambers, C.R., Hughes, C. & Carter, E.W. 2004. Parent and Sibling Perspectives on the Transition to Adulthood. *Education and Training in Developmental Disabilities.* 39(2):79-94.

Conaboy, K.S., Davis, N.M., Myers, C., Nochajski, S., Sage, J., Schefkind, S. & Schoonover, J. 2008. *Transitions for Children and Youth. How Occupational Therapy Can Help.* Bethesda: American Occupational Therapy Association (AOTA).

Cooney, B.F. 2002. Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation.* 40: 425-435.

Crawford, C. 2012. *Youth with disabilities in transition from school to work or post-secondary education and training: A review of the* *literature in the United States and United Kingdom.* The Institute for research and development on inclusion and society (IRIS).

Creswell, J.W. 2007. *Qualitative inquiry and research design: Choosing among five approaches* 2nd ed. United States of America: Sage Publications.

Daniels, B. 2012. Strengthening specialised education support in the WCED [Provincial Principal's Forum]. Cape Town. February 10

Davies, M.D. & Beamish, W. 2009. Transitions from school for young adults with intellectual disability: Parental perspectives on "life as an adjustment. *Journal of Intellectual & Developmental Disability*. 34(3):248-257.

Department of Education. 2001. *Education White Paper 6. Building an Inclusive Education and Training System,* Department of Education, Pretoria: Government Printers.

Department of Education. 2011. *Guidelines for responding to learner diversity in the classroom through curriculum and assessment policy statements.* Pretoria: Department of Basic Education.

Department of Education. 2005. *Curriculum Adaptation Guidelines of the Revised Nasional Curriculum Statement.* Pretoria: Department of Education.

Department of Education. 2005. *Guidelines for Inclusive Learning Programs.* Pretoria: Department of Education.

Department of Education. 2007. *Guidelines to ensure quality education and support in special schools and special school resource centres.* Pretoria: Department of Education.

Denzin, N.K. & Lincoln, Y.S. 2005. *The SAGE handbook of qualitative research.* United States of America: Sage Publications.

Dewson, S.J., Aston, P., Bates, H., Ritchie & Dyson, A. 2004. *Post-16 transitions: A longitudinal study of young people with special* *educational needs: Wave two,* Nottingham, UK: Department of Education and Skills.

Diagnostic and statistical manual 4th ed (DSMIV). 1994. American Psychiatric Association.

Dunn, W., Brown, C., McClain, L. & Westman, K. 1994. The ecology of human performance: A contextual perspective on human occupation.

Ellman, B. 2004. The experience of teachers in including learners with intellectual disabilities. Masters in Special Education Thesis. Stellenbosch University.

Elo, S. & Kyngäs, H. 2008. The qualitative content analysis process. *Journal of Advanced Nursing.* 62(1):107-115.

Gallagher, S. & Whiteley, J. 2013. The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of health psychology.* 18(9):1220-1231.

Gillan, D. & Coughlan, B. 2010. Transition from special education into postschool services for young adults with intellectual disability: Irish Parents' Experience. *Journal of Policy and Practice in Intellectual Disability.* 3:196-203.

Green, M.C. 2002. Promoting occupational therapy; how we see ourselves/Promouvoir l'ergothérapie, notre facon de nous percevoir. *Occupational Therapy Now/ Actualités ergothérapiques.* 4(4): 32-33.

Guba, E.G. 1981. Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational communication and technology journal.* 29:75-92.

Hall, S. A. 2010. The social Inclusion of Young Adults with Intellectual Disabilities: A phenomenology of their experiences. Doctor of Philosophy Theses. University of Nabraska at Lincoln.

Halpern, A.S. 1994. The transition of youth with disabilities to adult life: A position statement of the Division on Career Development in Transition, The Council for Exceptional Children. *Career Development for Exceptional Individuals.* 17(2):115-124.

Hughes & Carter. 2004.

Hurst, J. 2009. The challenges of maintaining occupation at times of transition. In *Occupational Therapy for people with learning disabilities. A practical guide.* Goodman, J., Hurst, J. & Locke, C. Toronto: Elseriver. 149-160.

Health Professions Council of South Africa. 2002. Standards of Practice for Occupational Therapists. Professional Board for Occupational Therapy, Medical Orthotics and Prosthetics and Arts Therapy.

Integrated National Disability Strategy. 1997. *White Paper. Integrated National Disability Strategy.* Western Cape: Rustica Press (Pty) Ltd.

Johnson, J.R. 2003. *Parent and family guide to transition education and planning. What parents and families need to know about transition education and planning for youth with disabilities: An insider's perspective.* http://www-rohan.sdsu.edu/~jrjohnso/SFTEP1/SFTEP1.htm [2012, February 6]

Kardos, M.R. & White, B.P. 2006. Education options for secondary transition planning. *American Journal of Occupational Therapy.* 60(3):333-339.

Kielhofner, G. 2006. *Research in occupational therapy-Methods of inquiry for enhancing practice,* F.A. Davis Company: Philadelphia.

Kim, K. & Turnbull, A. 2004. Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and practice for persons with severe disabilities.* 29(1):53-57.

King, G.A., Baldwin, P.J., Currie, M. & Evans, J. 2005. Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care.* 34(3):195-216.

Kraemer, B. & Blacher, J. 2001. Transition for young adults with severe mental retardation: school preparation, parent expectations, and family involvement. *Mental Retardation.* 39(6:)423-435.

Krefting, L. 1991. Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy.* 45(3):214-222.

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P. & Letts, L. 1996. The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy.* 63(1):9-23.

Lincoln, Y.S. & Guba, E.G. 1985. *Naturalistic inquiry.* Beverley Hills, CA: Sage.

Loebenstein, H. 2005. Support for learners with intellectual disabilities in the transition to secondary schools. PhD. Thesis. Stellenbosch University.

Mankey, T. A. 2011. Occupational Therapists' beliefs and involvement with secondary transition planning. *Physical and Occupational Therapy in Paediatrics.* 1-14.

Mayring, P. 2000. Qualitative content analysis. *Forum: Qualitative Research.* 1(2): 2-10.

Maxwell, J. A. 1992. Understanding and validity in qualitative research. *Harvard educational review.* 62(3): 279-300.

McGill, P., Tennyson, A. & Cooper, V. 2005. Parents whose children with learning disabilities and challenging behavior attend 52-week residential schools: Their perceptions of services received and expectations of the future. *British Journal of Social Work.* 35:1-20.

Merriam, S.B. 1998. *Qualitative research and case study applications in education.* San Francisco, CA: Jossey Bass.

Miller, E.K. 2012. Occupational Therapists' intevention approaches in secondary transition services for students with disabilities. Master of Science Theses. Eastern Kentucky University.

Morse, J.M. 1994. Critical issues in qualitative research methods. London: Sage Publications.

Moustakas, C. 1994. *Phenomenological research method.* Thousand Oaks CA: Sage.

Patton, M.Q. 1990. *Qualitative evaluation and research methods.* 2nd ed. Newbuty Park, CA: Sage Publications.

Patton, M.Q. 1989. *Utilisation-focussed evaluation.* 3rd ed. Newbury Park, CA: Sage Publications.

Polkinghorne, D.E. 1989. Phenomenological research methods. In R. S. Valle and S. Halling (Eds.), *Existential- phenomenological perspectives in psychology.* New York: Plenum.

Raghavan, R., Pawson, N. & Small, N. 2013. Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research.* 57(10):936-946.

Rapanaro, C., Bartu, A. & Lee, A.H. 2008. Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of applied research in intellectual disabilities.* 21: 34-47.

Sandelowski, M. 2000. Whatever happened to qualitative description? *Research in Nursing and Health.* 23:334-340.

Seidman, I. 2006. *Interviewing as qualitative research: A guide for researchers in education and the social sciences.* Teachers College Press: New York.

Shenton, A.K. 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information.* 22:63-75.

Smart, M. 2004. Transition planning and the needs of young people and their carers: the alumni project. *British Journal of Special Education.* 31(3):128-137.

South African Statistics. 2012. Pretoria: Statistics South Africa.

Stewart, D. 2013. Transition to adulthood for youth with disabilities. Evidence to support Occupational Therapy Practice. *In Transitions to adulthood for youth with disabilities through an occupational therapy lens.* Slack Incorporated.

Stewart, D., Law, M., Rosenbaum, P. & Willms, D. 2001. A qualitative study of the transition to adulthood for youth with disabilities. *Physical and Occupational Therapy in Paediatrics.* 21(4):3-22.

United Nations. 2006. *Final Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.* United Nations.

Vlachos, C. J. 2008. Developing and managing a vocational training and transition planning program for intellectually disabled learners, PhD. thesis, University of South Africa.

Von Zeck, C. Understanding our context for occupational therapy practice: a key to strategies for future success. *Canadian Journal of Occupational Therapy.* 71:133-137.

Ward, L, Mallett, R, Heslop, P & Simons, K. 2003. Transition planning: how well does it work for young people with learning disabilities and their families? *British Journal of Special Education.* 30(3):132-137.

Weiten, W. 1998. *Themes and variations, fourth edition.* Brooks/ Cole Publishing Company: Pacific Grove.

West Coast District Municipality Integrated Development Plan 2012-2016. 2012. Available: http://westcoastdm.co.za/documents/idp-documents/ [2014, Novemeber 2]

Whetstone, M. & Browning, P. 2002. Transition: A frame of reference. *AFCEC Online Journal.* Special Issue, October, 1-9.

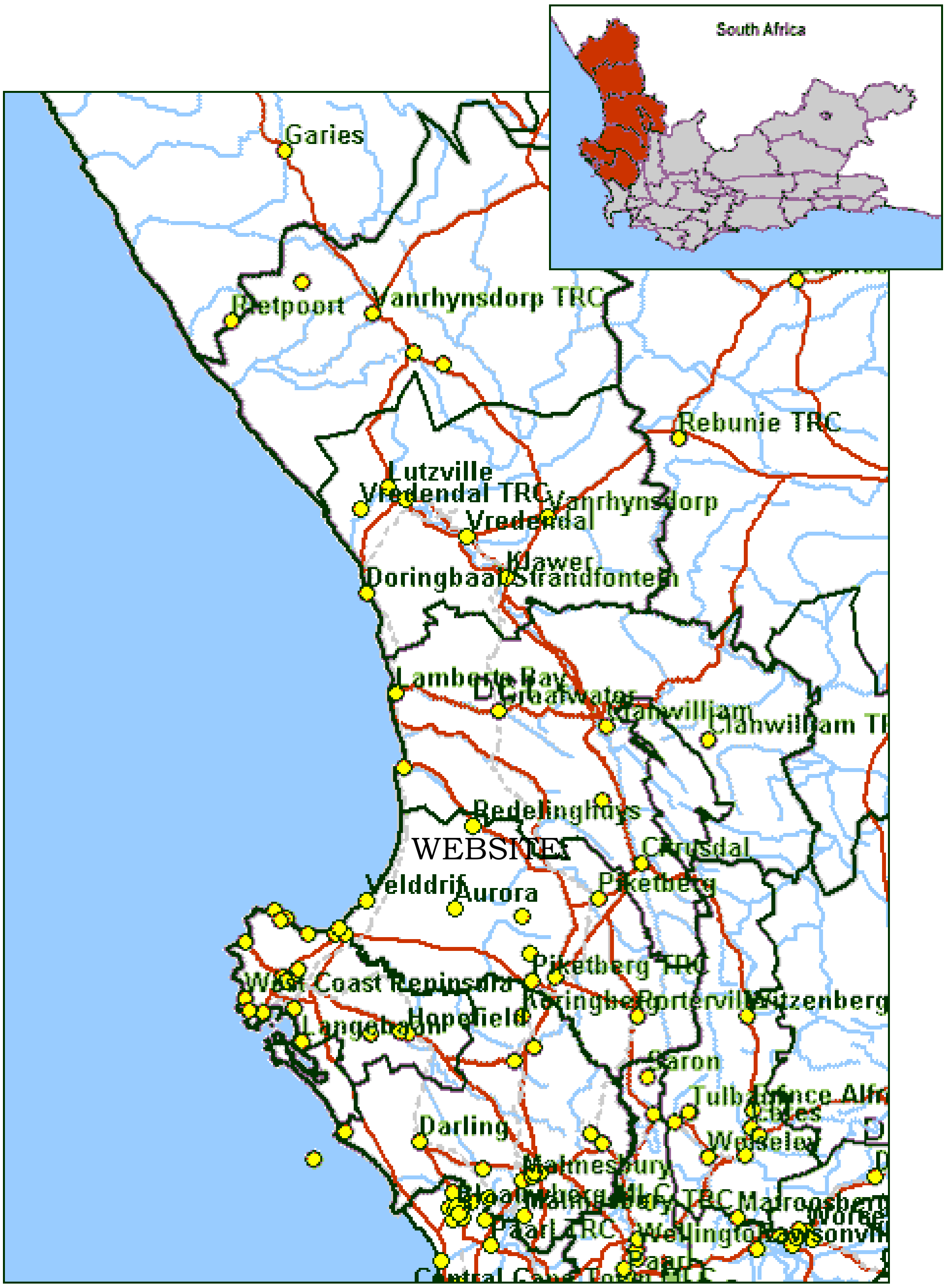
Winn, S. & Hay, I. 2009. Transition from school for youths with a disability: issues and challenges. *Disability and Society.* vol. 24(1):103-115.

World Federation of Occupation Therapy [WFOT]. 2012. Definition of Occupational Therapy. http://www.wfot.org/AboutUs/AboutOccupationalTherapy/DefinitionofOccupationalTherapy.aspx [2014, January 8]

Zhang, Y. & Wildemuth, B.M. 2000. Qualitative Analysis of Content. https://www.ischool.utexas.edu/~yanz/Content_analyis.pdf [2014, March 15]

APPENDIX A

MAP OF THE WEST COAST



www.westcoastdm.co.za/

APPENDIX B

INTERVIEW QUESTIONS

Questions	Probes
Tell me about your experience with the transition of your child.	How did it make you feel? Elaborate
What contexts or situations have influenced or affected your experiences of transition for your child?	School? Community? Where? When? What? How? Elaborate.

APPENDIX C

INFORMATION LETTER

UNIVERSITY OF CAPE TOWN

Parents' experience of transition in youth with intellectual disability

Information Letter

Dear participant

My name is Emalda Ellman. I am an Occupational Therapist and currently enrolled at the University of Cape Town. I have a special interest in transition for youth with intellectual disability and have therefore decided to conduct my research towards a Master of Science degree in Occupational Therapy in this field.

The title of my research project is Transition from special school to post school in youth with intellectual disability: Parents' experiences. The purpose of this study being to gain insight into parents' experience of transition for youth with intellectual disability. Transition refers to the change from one life stage to another or from one program to another, or from one environment to another. As your child with intellectual disability has gone through the transition from school to post school in the West Coast, you meet the selection criteria for this study.

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to decide not to participate. If you decide to participate, you may withdraw at any time without this affecting your relationship with the researcher or the University of Cape Town.

You will be interviewed (in-depth) at most two times. These interviews will be recorded and will last approximately 90 minutes each. The researcher will also keep field notes of observations. Only the researcher will be involved with the study; however she will be guided by a supervisor and co-supervisor. Participants' identities will be kept strictly confidential if they wish to remain anonymous.

Do not hesitate to ask any questions about the study either before participating or during the time that you are participating. I would be happy to share the findings with you after the research is complete. You may contact me telephonically should you wish to enquire about the findings and an arrangement can be made for us to meet in this regard. Please be advised however, that your name will not be associated with the research findings in any way. Your identity will only be known to the researcher who will make use of pseudonyms when writing up the final thesis.

There are no known risks and/or discomforts associated with this study. However arrangements can be made with the local Nongovernmental Organisations (NGO's) if further service needs arise. The expected benefits associated with your participation are that the information about your experience of transition for your youth with intellectual disability could assist in addressing parents' needs that currently have children with intellectual disability in special schools. You may also find it therapeutic to talk about your transition experiences and lastly you have an opportunity to participate in a qualitative research study.

Please be advised that there will be no payment involved for your participation in this study. The researcher will meet with you at a place and time that is suitable for you.

Please sign your consent with full knowledge of the nature and purpose of the procedures. A copy of this consent form will be given to you to keep.

…………………………… …………………………

Signature of participant Date

Emalda R. Ellman (Researcher)

Contact Number: 0722 908 583

APPENDIX D

UNIVERSITY OF CAPE TOWN

Parents' experience of transition in youth with intellectual disability

Informed Consent Form

I, ……………………………………have read (or had read to me by………………………………)
(Name and Surname) (Name and Surname)

the information letter. I understand what is required of me and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I know that I can withdraw at any time if I wish to do so and will have no bad consequences for me.

Signed:

…………………………………………….	……………………………………………………….
Participant	Date and Place
……………………………………………	……………………………………………………….
Researcher	Date and Place
…………………………………………..	……………………………………………………….
Witness (if necessary)	Date and Place