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**PERCEPTIONS OF INDIVIDUALS WITH
AUTISM SPECTRUM DISORDER (ASD)
AND THEIR PARENTS ABOUT THE
NEEDS AND THE ROLE OF
OCCUPATIONAL THERAPY IN THE
TRANSITION OF THESE INDIVIDUALS
INTO THE LABOUR MARKET.**

Bonang Sylvia Mhlekwa

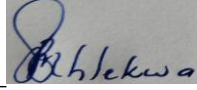
A research report submitted to the Faculty of Health Sciences,
University of the Witwatersrand, Johannesburg, in partial fulfilment of
the requirements for the degree of Master of Science in Occupational
Therapy.

Johannesburg

2021

Declaration

I, Bonang Sylvia Mhlekwa hereby declare that this research report is my own work. It is being submitted for the degree of Masters of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

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Dedication

To my participants and all the members of Pretoria Support Group as well as all the individuals with ASD, there is more that you contribute to this world than it is acknowledged.

Acknowledgments

“Give praise to the Lord, proclaim his name; make known among the nations what he has done.” Psalm 105:1(NIV). Heavenly Father, You carried me through this journey. In You I got the strength and courage to continue this journey.

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Abstract

South Africa, like other regions of the world has a high rate of autism spectrum disorder (ASD) (Bateman, 2013). Young adults with ASD disproportionately achieve lower rates of independent functioning and interpersonal success in occupation and other domains compared to similar aged peers without the disorder (Hendricks, 2010; Hume, et al., 2009, Mazurek, 2014). The transitions of these individuals in the labour market is of concern since there is a lack of services for adults with ASD and research indicates they achieve an average employment rate of 49%, even in developed countries (Howlin and Moss, 2012). The objective of this study was to explore the perceptions of individuals with ASD who have finished their formal education or training and their parents in terms of their unmet needs in relation to transitioning into the labour market. The study will also explore their perceptions about the role an occupational therapist can play in addressing these unmet needs and facilitating their transition into the labour market.

A qualitative explorative descriptive research method was used to explore perceptions of individuals with ASD and those of their parents using a phenomenological approach by exploring the lived experience transitioning to employment (Creswell. 2014:239). Semi-structured, face to face interviews were used with parents of individuals with ASD, while email interviews were used with individuals with ASD to collect data. Data was analysed using inductive thematic analysis to develop themes, categories and codes. Two broad themes were identified namely "Transitioning was really hard", and "Occupational therapists can do more". The findings emphasised the difficulties in finding and keeping a job, parents needs as well as the perception of and the suggestions for the role of occupational therapy.

Findings indicate that occupational therapists should develop vocational rehabilitation programs specifically for adolescents with ASD that can be implemented during transition process. These programs should include; case management, advocacy, skills training, and job coaching. Supported employment and advocacy in terms of employer education is also indicated as a role, occupational therapists could play.

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Operational Definitions

Autism spectrum disorder: - combines four previously separate disorders with different symptom severity levels in two core domains in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Those two domains are “1) deficits in social communications and social interaction and 2) restricted repetitive behaviours, interests and activities” (American Psychiatric Association, 2013).

In this study participants with Autism Spectrum disorder prefer being called individuals with ASD.

Labour market: refers to the place where employees and employers interrelate with each other. It is where employers compete to hire the best, and the employees strive for the best satisfying job (The Economy Times, 2020)

Self-advocacy: The implementation of methods to help oneself and their population to lead happy and productive lives (Dekker, 1999).

Transition period: The process of finishing high school and entering post-secondary education or labour market (Miller, 2012).

Underemployment: The lack of use of an employee due to a work that does not utilise the employees' skills (Nord et al., 2016).

Vocational Rehabilitation: refers to an approach by multi-professional team members which is rendered to individuals of working age with health-related impairments, limitations, or restrictions with work functioning and whose primary aim is to optimize work participation (Escorpizo et al., 2011).

Abbreviations

AOTA	American Occupational Therapy Association
ASAN	Autistic Self-Advocacy Network.
ASD	Autism Spectrum Disorder
CRPD	Convention on the Rights of Persons with Disabilities
DSM 5	Diagnostic and Statistical Manual of Mental Disorders (5)
LMIC	low middle income countries
LSEN	Learners with Special Education Needs
PWDs	people with disabilities
SAHRC	South African Human Rights Commission
VR	Vocational Rehabilitation

CHAPTER 1: INTRODUCTION

1.1 Introduction and background to the study

The rate of Autism Spectrum Disorder (ASD) in all regions of the world is increasing and it has a tremendous impact on children, their families, communities and societies (United Nations, 2015). South Africa is no exception and in the last 20 years more services for children with ASD have been provided, although these are still considered inadequate in South Africa. (Bateman, 2013).

While individuals with ASD who develop verbal comprehension and functional speech by five years of age and have an average verbal IQ tend to have better social and economic outcomes, environmental factors such as appropriate support in adulthood has been found to have the greatest impact on their outcomes and quality of life (Howlin and Moss, 2012). Most young adults with ASD however, disproportionately achieve lower rates of independent functioning and interpersonal success in occupations and other domains compared to similar aged peers without the disorder (Hendricks, 2010; Hume et al., 2009; Mazurek, 2014).

Research in developed countries found that an average of 49% of adult participants with ASD who were followed up, were in paid, sheltered, or voluntary employment positions or educational programs (Howlin and Moss, 2012). No information is available on the prevalence of ASD in South Africa and the profile of the employed persons (Statistics South Africa, 2014) does not have statistics specifically on individuals with ASD. It is indicated however, in the latest data from Statistics South Africa which is outdated, that within the population of people who were not economically active, a higher proportion were people with disabilities (10,8%) compared to those without disabilities (9,0%) (Statistics South Africa, 2014). More recently in 2019 the unemployment rate for people with disabilities was indicated at 68% (National Council of and for Persons with Disabilities (NCPD), 2019)

Previous research indicates individuals with ASD make up a proportion of these unemployed people with disabilities in South Africa, with the study by Meiring et al. (2016) indicating that transition to the worker role in adulthood is a challenging time for many of these individuals and their families. They considered transition to work for South African adolescents with ASD from the parents', teaching and training professionals' perspectives but not the perspectives of the individuals with ASD themselves. The study confirmed that in conjunction with the increased stress of what the future holds when adolescents with ASD reach adulthood, reduced support from formal education structures and appropriate resources to assist with transition to work was experienced.

Parents do have access to support and advice in schools and hospital therapy departments which address the needs of children with ASD. Services for adolescents and young adults with ASD however, are lacking even though research shows that only about 20% of these individuals are able to live independently as adults. Most adults with ASD stayed with their parents or were institutionalised (Howlin and Moss, 2012). These individuals are frequently underserved in terms of VR services and have fewer resources designed to meet their needs, including transition to employment (Lake, Perry and Lunskey, 2014). The experiences of individuals with ASD who have completed their formal education or training and are transitioning into the labour market have not been well explored in South Africa.

As long ago as 2006, there were calls for professionals to look at individuals with ASD's own perspectives. Thus, Renty and Roeyers (2006), suggest that those offering professional support should assess the met and unmet needs of individuals with ASD from their viewpoint and their parents. Current research reports gaps in understanding the challenges that prevent individuals with ASD from gaining and maintaining employment. Occupational therapy services could play a role in employment outcomes (Harmuth et al., 2018). However, occupational therapists have very little information on which to base decisions regarding intervention and services for this population in the South African employment context. This has resulted in a lack of services offered to adolescent and adult individuals with ASD.

1.2 Statement of the problem

The researcher is a member of a Pretoria Autism support group which consists of individuals with ASD and their parents, but she does not render any occupational therapy services or play any occupational therapy related role within the group. Rather, as an ordinary member she has an opportunity to observe the proceedings and to learn about the group members' needs. According to the parents many adolescent and adult individuals with ASD are not getting as much support from multi professional team members as they did while they were younger and completing their formal education or training. They feel that these individuals are somehow "dumped" once they finish their education and remain under the care of their parents who have to provide for these individuals financially.

Some of these parents feel that their children have vocational skills which can be utilized in the labour market. They feel that their children's abilities are not being recognized and that support in terms of transition into the labour market is not being addressed. The individuals with ASD and their parents in the Pretoria Autism support group have expressed an interest in knowing how the researcher as an occupational therapist could contribute in addressing their children's concerns and needs in relation to their expectations in terms of transition into the labour market. Thus, there is a need to investigate their specific perceptions and experiences to allow occupational therapists to hear what the needs of the population actually are in order to plan services and support.

1.3 Purpose of the study

Jean-Paul Bovee, a self-advocate with ASD, stated, "Behaviour is not static, nor is how autism is in our lives static" (Bovee, 2000: p 250). Acknowledging this frame of thought, this research has been developed in consultation with the Pretoria Autism support group to explore how occupational therapists can facilitate the transition of individuals with ASD into the labour market and to identify gaps in their interventions.

The purpose of this study is to explore the perceptions of individuals with ASD who have finished their formal education or training, and their parents in terms of their unmet needs in relation to transitioning into the labour market. The study will explore these needs from

the viewpoint of the individuals with ASD and their parents and will also explore their perceptions about the role an occupational therapist can play in addressing these unmet needs and facilitating their transition into the labour market.

1.4 Research question

What are the perceptions of individuals with ASD who have finished their formal education or training and their parents about their unmet needs in terms of transitioning into the labour market and the role an occupational therapist can play in addressing these unmet needs?

1.5 Aim of the research

To explore perceptions of individuals with ASD who have finished their formal education or training and that of their parents about their unmet needs in terms of transitioning into the labour market and the role that the occupational therapist can play in addressing these unmet needs.

1.6 Research objectives

1. To explore perceptions of adult individuals with ASD who have finished their formal education or training about their unmet needs in terms of transitioning into the labour market
2. To explore perceptions of parents of adult individuals with ASD who have finished their formal education or training about the unmet needs of their children in terms of transitioning into the labour market
3. To explore the perceptions of adult individuals with ASD who have finished their formal education or training about the role that the occupational therapists can play in facilitating the unmet needs of individuals with ASD in transitioning into the labour market
4. To explore the perceptions of the parents of adult individuals with ASD who have finished their formal education or training about the role that the occupational therapists can play in facilitating the unmet needs of individuals with ASD in transitioning into the labour market

1.7 Justification for the study

The significance of the study is that: it has the potential to raise awareness amongst occupational therapists regarding their role in understanding the unmet needs of and facilitating individuals with ASD in their transition into the labour market. The study can be used as a baseline in developing different projects that will assist individuals with ASD in their transition into the labour market. The benefit of seeking out individual perceptions from this population will provide these adults with the opportunity to share their individual life experiences and their individual needs which should be addressed. One of the benefits of the study is to present participants with an opportunity to have their voices heard and reinforce the idea that their interests are worth pursuing.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This literature review focuses first on the context of work regarding people with disabilities. ASD as a condition is then reviewed with transition from school to the labour market considered with particular reference to individuals with ASD. The challenges encountered by individuals with ASD in transitioning to work and the possible role of occupational therapy in transition are included. Again, the importance of hearing about this process from individuals with ASD is incorporated, since one of the goals of the study is to present participants with an opportunity to have their voices heard and reinforce an idea that their interests are worth pursuing (Galler, 2013). The individuals with ASD and their parents are the very people who have the lived experience.

Literature was sourced from ERIC, EBSCO Host, Direct Science, PubMed, EPUB, PMC, Springer, Wiley databases, CrossRef and Google Scholar

2.2 Contextual background: the employment context

"South Africa belongs to all who live in it; we are united in our diversity...."(Constitution of the Republic of South Africa, 1996). This powerful statement, together with Chapter 2 of the Constitution - the South African Bill of Rights, enshrines the goal of a free, fair, diverse society that functions without discrimination for any reason (Constitution of the Republic of South Africa, 1996). Fair opportunity for employment as well as the freedom to choose the form of employment form part of this lofty goal. In theory, therefore, all South Africans have equal opportunity for employment without discrimination in terms of race, sex, age or disability. The reality however does not quite live up to this goal (Maja et al., 2011). Some of the reasons for these problems are that current laws are poorly enforced. Affirmative action seems to be a critical factor in increasing the impact of employment-related legislation for PWD and should involve social associates (employers' and workers' representatives) and PWDs in the process of designing law and policy (International Labour Organization, 2003).

Worldwide, employment for PWDs is a complex issue and influenced by many factors and systems that are interrelated (Lindstrom, Hirano and Thomas, 2018). While progress has been made in recent years with regards to the development of policies and laws to support employment of PWDs, the success of these policies is questionable. Globally there has not been a significant improvement in the employment status of PWDs (World Report on Disability, 2011). PWDs are still more likely to be unemployed or underemployed than their able-bodied counterparts (Buys, 2015).

In South Africa, policy development has focussed on integrating PWDs within the regular employment context. The South African White Paper on an Integrated National Disability Strategy (1997), visualizes "A society for all...encompassing human diversity and the development of all human potential" (Office of the Deputy President, 1997: p22). This view of disability encourages PWDs to contribute using their skills, competences, and capacities to both national and international development. However, Statistics South Africa indicated that only a small number of PWDs occupy labour market positions (Statistics South Africa, 2014). Nel, van der Westhuyzen and Uys, (2007) indicated that, even though the Equity Act and its Code of Good Practice have been promulgated, these acts and codes appear to have made little difference to the percentage of PWDs who are employed. Again, professionals' experience of the current status indicated that there was no consensus between what was written (the law) and what was practiced. This finding is supported by studies in countries with different levels of income including middle income countries (MIC) like South Africa, which indicates that PWDs are still more likely to be unemployed or work in lower income situations (Nel et al., 2007).

Unemployment or underemployment of PWDs could be due to systematic barriers in the workplace and possibly lower education levels (Lindstrom, Hirano and Thomas, 2018). This is supported by the finding that labour market participation is related to the degree of disability. It was indicated that within a small number of PWDs who are employed, people with sight disability are more likely to be employed than individuals with other severe types of disability in South Africa (Statistics South Africa, 2014). According to the Integrated National Disability Strategy, contributing factors including discrimination and lack of implementation of the supportive South African labour law contributes to high

levels of unemployment amongst PWDs particularly in open labour markets (Office of the Deputy President, 1997). The high unemployment rate in South Africa also affects numerous people without disabilities. The unemployment rate was reported to be 29,1% of the adult population in the last quarter of 2019 (Smit, 2019). Therefore, there is high competition in low-income jobs, which can lead to reduced employment opportunities for PWDs.

One group of people affected by disability which results in difficulty in transitioning into and finding employment are those with ASD (Lindsay, Hartman and Fellin, 2016) in South Africa. Research indicates disappointing employment outcomes for this group globally (Meiring et al., 2016). In order to understand the challenges individuals with ASD experience in the workplace, we must first explore what ASD is and how it may affect general functioning.

2.3 What is Autism Spectrum disorder?

It is vital in reviewing the challenges that come with finding employment and the transition of individuals with ASD into employment, to understand the ASD diagnosis.

ASD as described in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5), combines four previously separate disorders with different symptom severity levels into two core domains (American Psychiatric Association, 2013). Those two domains are 1) persistent deficits in social communication and social interaction across multiple contexts, and 2) restricted repetitive behaviours interests and activities. At the moment, ASD comprises, according to DSM-5, autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (American Psychiatric Association, 2013). ASD is a lifelong developmental disorder which can cause challenges for individuals throughout their lives (National Autistic Association, 2020). Individuals with ASD are faced with the challenges of developing personal relationships and participating in social interactions. Increased levels of anxiety, stress, and depression in people with the ASD is worsened by fear of change and can result in social isolation and self-injurious behaviour (Hillier et al., 2011).

While change can be daunting for anyone, individuals with ASD have a particular need for routine, predictability and sameness (Sevin, Rieske and Matson, 2015). Thus, they sometimes present with recurring identical kinds of behavioural patterns resulting in inappropriate “melt down” behaviour when overwhelmed. Those signs and features of ASD contribute to the individual’s ability to successfully or unsuccessfully transition between development levels, particularly to adulthood where they are supposed to take responsibility for themselves. This includes transitioning into the worker role. This transition from scholar to worker marks an important milestone in the transition from child to adult (Hendricks, 2010). Hence, this transition period of the individuals with ASD into the labour market is considered.

2.4 The Transition Period

The process of finishing high school and entering post-secondary education or labour market is a transition period (Miller, 2012) and it encompasses tasks matched to prepare for or facilitate change. Individuals move from the functional level and life stage of adolescence to adulthood (American Occupational Therapy Association, 2000). As transition periods are generally periods of higher stress for anybody, this transition will first be reviewed in the neurotypical population, then for PWDs, and finally for individuals with ASD in order to identify whether or not there are unique challenges facing individuals with ASD.

2.4.1 Transition from adolescence to adulthood

Developmental transition is a part of the life stages that people go through as they grow older. It involves adjusting to life stage changes and one's environment (Hendricks, 2010). The transition from adolescence to adulthood is a thrilling time for many individuals, but it can be a trying period at the same time. Transition from school to adult life, as used here, refers to a change in a role from acting primarily as a student to assuming new adult tasks in the society (Hendricks and Wehman, 2009; Halpern, 1994). Late adolescence to adulthood is a crucial stage of an individual's development because individuals start to make choices and decisions that will impact the rest of their lives. The transition from adolescence to adulthood is associated with numerous challenges. During youth, young

people are expected to advance from school, complete vocational training or university, and get their first employment and, also, find their first home, be in a romantic relationship and start a family (Tophoven, Reims, and Tisch, 2019). The procedure of supporting this transition encompasses the partaking and organisation of school programs, adult agency services, and natural supports in the society (Halpern, 1994).

As adults, people need to adapt and be included in employment, participate in post-secondary education, retain a home, get involved in the community, and undergo satisfying personal and social relationships (Hendricks and Wehman, 2009). However, there are significant changes and challenges in development during adolescence stage as young people acquire and amalgamate most of the essential life skills for transitioning into adulthood successfully. Eccles and Gootman (2002), reported that some of the biggest challenges identified in late adolescence are: the ability to control challenging developmental roles, and knowing their abilities and weaknesses to deal with these roles. Additionally, significance and determination in the societal roles attained have to be understood and able to weigh and make sound decisions about life changes and cope with them. For adolescents to manage all these challenges, they have to possess psychosocial, physical, and cognitive skills. Social support is of great importance, as well as the sound developmental context that will allow enough exploration and interaction with these challenges (Eccles and Gootman, 2002).

Although the transition from adolescence into adulthood is always a challenge for any child, the educational curriculum in South Africa has never had a successful plan to support this transition (Buys, 2015). Even though finishing high school symbolises, a remarkable watershed for all individuals generally, many leave with no clear idea of how they will transition to the next phase of their lives and how to start to fulfil their adult obligations, including how to find employment (Miller, 2012). This may be particularly true for PWDs, which means they need transition services to function within the same level as their counterparts (Meiring et al., 2016).

2.4.2 Transition of individuals with disabilities

The transition from adolescence to adulthood poses a big developmental achievement which may be threatened or fail in adolescents with disabilities (Fegert et al., 2016). This is related to people with long-lived physical, mental, intellectual, or sensory impairments. These impairments, combined with other limitations, inhibit them from engaging in societal activities including employment either partially or entirely, on the same level as the other members of the society (Convention on the Rights of Persons with Disabilities, 2016).

The opportunities for PWDs entering into employment are limited (South African Human Rights Commission, 2017). Factors which impact these opportunities are not only the scarcity of rehabilitation services to provide transition services but with the denial of opportunities for children with disabilities to participate in early primary and secondary education, life skills, and vocational training (Parnes et al., 2009). Lack of preparation for transition into adulthood and work in educational institutions for youth with disabilities contribute to their deficiency of life skills, giving employers validation for discernment against PWDs in the work place (Roggero et al., 2006). Apart from lack of preparation, there is lack of knowledge and awareness of disabilities, attitudes of employers and colleagues, discrimination, physical infrastructure of environment, rental cost, PWDs' productivity, and laws and regulations guiding PWDs' employment (Maja et al., 2011). These result in young PWDs having higher unemployment rates, settling for menial jobs, or earning wages below their equivalents without disabilities (Groce, 2004).

Young PWDs are frequently hired last, the first to be retrenched or fired and have less chances for growth. Even when they have good education, young individuals with disabilities take longer to get a job, have decreased job security (Engelbrecht, Shaw, and Van Niekerk, 2017) and have less chance of progression than their counterparts without disabilities with comparable education levels (Groce, 2004). These difficulties are exacerbated, with youth with disabilities spending more time unemployed or seeking employment than individuals without disabilities. Research emphasises the fact that PWDs are more likely to be side-lined when it comes to getting equal opportunities than

their counter parts in the job markets and contradicts the idea of equal opportunity for all in the labour market (Lindsay, Hartman and Fellin, 2016).

Transition from high school for adolescents in at risk groups, such as adolescents with disabilities, presents with added complicated challenges since they also have to deal with limitations imposed by their disability (Tophoven, Reims, and Tisch, 2019). Among the many disabilities mentioned, for individuals with ASD, the transition is impacted as indicated by Nicholas et al. (2018), by a vast gap between job preparation/support and becoming employed.

2.4.3 Transition of individuals with Autism Spectrum disorder

There is limited research on the transition of individuals with ASD into the labour market within the South African context, hence the development of this specific study. There have been a number of studies done in other countries concerning transition of individuals with ASD into the labour market. Some of this literature may be applicable to the South African context.

Hendricks and Wehman (2009), in a review of studies done in the United States of America stated that transition from childhood to adulthood can be a very challenging period, even more difficult if an individual has an identified disability. Young individuals with ASD are among those who experience some challenges during the transition period. Both Roux et al. (2015) and Jacob et al. (2015), indicated that the rate of employment for individuals with ASD was between 50%-75% in the developed countries. This was lower than that for individuals with intellectual disability without ASD and closely aligned to all other populations with special needs. The report by Roux et al. (2015), included individuals with ASD from different cultures, levels of socio economic status and education levels. They reported in the postsecondary employment experiences among young adults with ASD, that adults with ASD from higher-income households, had better conversational or functional skills, or those who had attended postsecondary schools had more positive employment prospects. Wei et al, in a later study in 2018 found that the rates of adults with ASD having ever been employed ranged from 25% to 63.2%. As Shattuck et al. (2012), indicated that these individuals are faced with lack of support from

formal education systems and lack of other resources important for a successful transition into adulthood. All these studies were conducted outside South Africa however it is possible that there may be the same issues in South Africa.

The accessed literature indicated that transition to employment for individuals with ASD is impacted by many integrated challenges which are to be reviewed below.

2.5 Challenges regarding the transition of the individual with Autism Spectrum disorder

The literature suggested that decreased employment rates of individuals with ASD observed globally are possibly due to individual and environmental factors (Soeker, 2020). At the personal level, poor social communication and interpersonal skills were usually reported as challenges to getting and keeping employment (Brownlow, 2010; Gal, Ben Meir, and Katz, 2013). At the environmental level, it was postulated that the real obstacles to getting jobs for individuals with ASD lie not in the socially atypical mannerisms and behaviour of ASD but instead in society's labelling of the peculiarities related to ASD as "deficits" rather than of good qualities in the workplace (Lorenz et al., 2016).

2.5.1 Personal challenges

According to literature, individuals with ASD are often affected by cognitive difficulties, communication impairments, and social problems (Hendricks and Wehman, 2009; Hendricks, 2010; Galler, 2013). These issues present them with difficulties in work, education, relationships and living arrangements (Galler, 2013). According to Meiring, et al. (2016), the behavioural aspects of individuals with ASD, such as difficulty and lack of motivation to engage in conversations with other people, lack of ability to understand, and control emotions, which may lead to inappropriate presentation of themselves, have a negative impact on their employability. They present with a lack of social skills which include a variety of deficits that are vital for fruitful interconnections. These may involve unsuitable hygiene and grooming abilities, struggling to adhere to social guidelines, lack of awareness regarding how their behaviour affects others, insisting on working by

themselves, and misbehaving with individuals of the opposite sex (Koning and Magill-Evans, 2001). All these aspects can affect relationships with the employer and fellow employees of the individuals with ASD, and make it difficult for others to associate with them in the workplace. Briel and Getzel (2014), indicated that these social and communication problems were identified as hindrances to getting and keeping a job, predominantly associated to partaking in interactions with co-workers and superiors. Wehman et al. (2014) stated that in the process of assisting the individuals with ASD to transition into the labour market, they need training in social skills as well as job seeking skills.

Again, showing aggravated symptoms of ASD at work was depicted as a problem. Mostly atypical and disruptive symptoms such as restrictive and repetitive behaviours (Giarelli, Ruttenberg, and Segal, 2013), self-harm (Hendricks, 2010), and abnormal sensitivity to sensory stimuli resulting in “melt down” (Harmuth et al., 2018) were reported to be those affecting workplace behaviour among individuals with ASD. The behaviour of these individuals can also be noticed in obsessive devotion to routine (Gal et al., 2013) or conservative attitudes regarding life changes (Hurlbut and Chalmers, 2004) which come as obstacles when they get to the labour market.

Another reported issue is, decreased executive functioning skills (Hendricks, 2010) which causes individuals with ASD to struggle with processing abstract information that leads to communication misunderstandings and lack of problem solving skills. The executive function skills such as memory, self-control, attention, decision making, problem solving, time management, ability to initiate and complete a task (Diamond, 2013) are all needed for improved performance in the work environment. The understanding of concepts by individuals with ASD can be concrete and factual and they struggle to understand fiction work. They also fail to understand the need for flexibility and consider other people's needs (Hendricks, 2010). Lastly, mental health concerns and other diagnoses of mental health conditions such as depression, anxiety (Hill et al., 2013), behaviour management and stress (Scott et al., 2019), generated barriers to employment and retention of jobs for individuals with ASD.

Challenges such as difficulty to interact, which is associated with the diagnosis of ASD, account for the most significant vocational impact (Hiller et al., 2007), which is further exacerbated by environmental problems. It is therefore necessary to shift focus from the personal problems of individuals to the non-accommodating environment that doesn't allow for diversity.

2.5.2 Environmental challenges

Individuals with ASD and their families are reported to encounter more challenges when the individuals leave the adolescence stage and have to deal with the transition out of the structured formal support of the schooling context, into adult life. According to Howlin (2004), individuals with ASD and their families do not only experience increased stress and uncertainty of what they have to do to transition to employment, but they are also faced with insufficient support from formal education systems and lack of other resources essential for a successful transition into adulthood. Soeker (2020), reported that society stigmatizes individual with ASD due to their functional limitations and ignore their abilities. Haertl et al. (2013), investigated the perspectives of individuals living with ASD and gained insight into the experiences of the actual individuals diagnosed with ASD. In this study individuals with ASD suggested that their challenges were due to insufficient education and suitable training for the labour market and service suppliers rather than from core issues related to ASD. The study was conducted to explore the lived experience of individuals with ASD and its psychosocial effects on relationships, socialization and occupational participation. This, therefore, suggests that the gap in transition into adulthood for adolescents with ASD requires support in areas of education, social interaction, communication, interpersonal skills (Soeker, 2020), vocational possibilities, and community integration (Meiring et al., 2016).

In South Africa, PWDs are exposed to many kinds of discrimination in countless social setups, for instance; accessibility to health care facilities, education as well as employment (South African Human Rights Commission, 2017). South African Human Rights Commission (SAHRC), reported that, there has been delayed improvement made by the South African Government regarding issues related to disability and the execution of the Convention on the Rights of Persons with Disabilities (Convention on the Rights of

Persons with Disabilities, 2016). The insufficiency of resources and commitment of the different institutions including training facilities and labour markets, to adequately accommodate PWDs is one of the challenges. This hampers PWDs (individuals with ASD included) from successfully transitioning into employment and education systems.

Some literature indicates that the social environment, mostly the system of empathetic and accepting individuals close to the adult with ASD, was a strong facilitator to employment, this includes customized workplace accommodations (Soeker, 2020), support from co-workers (Hudson, 2004), support staff (Friedman, Warfield and Parish, 2013), family (Cimera et al., 2012), and associates (Brownlow, 2010). Nel, van der Westhuyzen and Uys (2007), however, emphasized that South African individuals with ASD are faced with several environmental challenges, that include lack of services and lack of societal support. These two issues will be reviewed in more detail below.

2.5.1.1 Lack of access to services

Domican (2013) indicates that autistic children grow into autistic adults, and that, early intervention allows for better outcomes, as the individuals come to accept the condition and, therefore, plan for it. However, early intervention alone is not enough. It is necessary to continue supporting individuals with ASD throughout their life span. Scott Michael Robertson, an autistic self-advocate in Pennsylvania and vice president of the Autistic Self-Advocacy Network (ASAN), emphasized that media focuses on matters concerning children with ASD and tends to ignore adolescents and adults with ASD (Robertson, 2009). Hendricks (2010), concurred as he stated that paediatric health care centres focus more on the child's all-inclusive health necessities, and that of adults with ASD are considered less. There is less emphasis on recognizing and upholding their medical and other needs and on teaching health and support services on how to facilitate the smooth transition of the individuals with ASD into the labour market (Haertl et al. 2013).

According to Van Pelt (2008), there are considerable differences between services available to children with ASD and those available to adults with ASD. There are fewer services (e.g. medical facility services) at the disposal of the adult with ASD than the children with ASD. Engelbrecht, Shaw and Van Niekerk (2017), reported a shortage of

programs, such as VRs, in place for assisting PWDs to get into the open labour market in South Africa. The Constitution of South Africa (1996), indicated that some laws could assist people with disabilities to access employment which addressed accessibility and reasonable accommodation but it is up to the individual organization to make an effort in applying the regulation. However, that does not help because the professionals' experience of the current status indicated a lack of consensus between what was written (the law) and what was practiced (Nel, van der Westhuyzen and Uys, 2007).

Literature is therefore, suggestive that there is a limited or non-existence of services for adolescents with ASD that can assist in smoothing their transition into the labour market. There are laws in SA that encourage the employment of PWDs including individuals with ASD. The problem with the enactment of this law is that it is up to members of the society and the employers taking responsibility to support individuals with ASD. And they are not necessarily bound to do so. Individuals with ASD, therefore, still lack support from the community (Meiring et al., 2016).

2.5.1.2 Lack of societal support

Bandura (1989), stated that for individuals with ASD to be independent regarding their developmental course, they would need a lot of social support and resources. The degree of the societal system support determines "people's opportunities to influence the course of their lives" (Bandura, 1989: p4). Successful employment of individuals with ASD is dependent on employers and co-workers who make an environment user friendly for them (Hudson, 2004; Friedman, Warfield and Parish, 2013; Soeker, 2020). People who oversee, intermingle, or work together with individuals with ASD must be patient, flexible, and tolerant for these individuals to keep their employment (Hendricks, 2010). Hendricks (2010), continued to say that, work environment's adaptations, changes to communication processes, and providence of support concerning social interaction are necessary for successful job retention of individuals with ASD.

Therefore, there must be support systems on individual and environmental aspects to assist individuals with ASD to combat their unmet challenges during the transition to the labour market. Domican (2013) reported that the adult ASD population is not accepted

and welcomed as the child population while Van Pelt (2008), stated that adults with ASD are often treated as outcasts just because the members of the society are not well informed about ASD. This is supported by Nicholas et al. (2018), in their study which stated that when a prospective employer or supervisor learned about the individual's diagnosis of ASD, they subsequently tended to not be hired. Ohl et al. (2017), disagreed with this since they indicated that disability disclosure actually contributed to successful employment status of PWDs in the United States of America.

Understanding how these aspects influence individuals with ASD during their transition into the labour market can be gained by exploring the lived experience of individuals with ASD.

2.6 The lived experience of individuals with Autism Spectrum disorder in relation to employment

In South Africa, the majority of research into ASD has not focused on the individuals themselves (Galler, 2013). In a study conducted by Magan (2018), individuals with ASD stated that they are the ones living with ASD therefore, their opinions must be appreciated and taken into consideration. The individuals said that neurotypical members of the society must include them in research concerning ASD and they do not want to be the spectators of their own lives (Magan, 2018). Research data should be collected from those with first-hand experience. According to Browning et al. (2009), there was little literature regarding the views and perceptions of the individuals with ASD themselves in general. Except for studies by Magan (2018) and Soeker (2020), no study in the South African context could be found in which the individuals with ASD provided data, which means there is a great need to have more studies in which the individuals with ASD have a say about themselves. As a result, it is essential to hear what the individuals with ASD, and their parents say about transitioning into the labour market. Hence the saying "Nothing About Us Without Us" (Charlton, 1998).

Hattenstone (2018), London Representative on UK Youth Voice addresses how letting other people speak for individuals with ASD negatively affects them "..... one has learned that if we do not speak up for ourselves, few people will. Moreover, when they

do, they tend to pigeonhole us – so we all lack empathy, or we are super smart at math, or we spend our life counting cars. In other words, we are reduced to autistic clichés." Hattenstone (2018: p1). Galler (2013), stated therefore that hearing the perceptions of individuals with ASD provided the most critical information for successful future activities. The voices of individuals with ASD must be heard to support appropriate post-secondary transition planning. Failure to gather information from the individuals with ASD has led to missing data in the available literature. And that, could be one of the causes of the limited accommodation of these individuals in the workplace. Taking into consideration what the individuals with ASD have to say could contribute to the provision of precise information, which has been somewhat neglected in information of those who presented the individuals with ASD (Galler, 2013; Soeker, 2020).

Researchers have been encouraged to conduct more studies to explore the experiences of individuals with ASD (Browning, Osborne and Reed, 2009). According to Haertl et al. (2013), individuals with ASD expressed a desire for their voices to be heard and to contribute in recommending for their evaluation and intervention. Moustakas (1994: p71), added that "we must not lose sight of the fact that a person is present in perception, someone who perceives what is given, enters into an encounter with it, a person who may be awakened to a memory."

Thus, it is essential to appreciate the perspectives of the people within the situation and their families. Considering the concerns expressed by individuals with ASD might assist in accessing resources that will minimize some of the challenges they may encounter post-school (Browning et al., 2009).

Individuals with ASD have also indicated that they have decided to become self-advocates for ASD (Magan, 2018). The benefit of seeking out individual perceptions from the individuals with ASD will allow these individuals to share their life experiences to address individual needs based on first-hand experience regarding the life of a person living with ASD. Galler (2013) added that due to multiple challenges, individuals with ASD have become strong and independent in their abilities. A contribution to assisting young individuals with ASD to stop being preoccupied with their anxiety, distressing about how neurotypical members of the society will judge them, about not being accepted and being

concerned that they sound strange when they talk. It should minimize the habit of silencing themselves with their self-consciousness (Hattenstone, 2018).

Furthermore, participating in research is a motivational aspect for individuals with ASD as they feel compelled to teach and empower the society about ASD (Lynas, 2014). Wehman et al. (2016), added that as much as the individuals with ASD reported a need to be trained in different life skills, they also indicated that the training explicit to ASD would intensify the appreciation and support of co-workers and overseers of individuals with ASD. Individuals with ASD also struggle with issues related to sensory processing, which present as sensory overload, which leads to them having meltdowns (Magan, 2018) within different environmental setups. Therefore, if their employers know about ASD and what might be expected when individuals with ASD are confronted with specific situations, it will be easier to work with individuals with ASD.

The individuals with ASD expressed the need for added support, which they indicated is useful in finding and keeping a job and yet there was a lack of support in the labour market for difficulties associated with their ASD (Baldwin, Costley and Warren, 2014). Furthermore, individuals with ASD who had jobs for at least a year or more report that personalised services, backing from a trainer, focus on social cognition and vocational services (Brooke et al. 2018) were essential to fruitful work experiences. Primarily this is so when began in the high school academic years and continued through pre-vocational and vocational training for their survival in a job environment (Muller et al., 2003).

The lived experiences of individuals with ASD, are suggestive of the type of support needed to gaining and maintaining employment and occupational therapists have a role to play during the transition into the labour market. Because neurotypical society excludes and fails to understand and know about ASD, having occupational therapists support them will assist them in developing ASD services in different areas (Miller-Kuhaneck and Watling, 2010). Literature does not say much about the occupational therapy practitioner's service delivery towards the population of discussion. This poses a need to have a study that will look at the individuals with ASD as an occupational therapy professional.

2.7 The role of the occupational therapist for individuals with Autism Spectrum disorder during the transition phase

According to (Haertl et al., 2013; Soeker, 2020) individuals with ASD may present with psychosocial and cognitive difficulties such as socialization, communication, sensory processing, and restricted patterns of behaviour which may have a negative impact on participation in activity. Those negative impacts on occupational participation are vital areas in occupational therapy. In accordance with the Occupational Therapy Practice Framework (American Occupational Therapy Association 3rd edition, 2014), occupational therapists emphasize client-centred approach with an aim to improve occupational participation. As Wilcock (1999: pg. 4), reported; “Occupational therapists help make doing possible”.

No research could be found during the literature search for this project which was specific to the South African population. Therefore, no specific guidelines could be found regarding how to prepare and support individuals with ASD for the transition from high school or post-secondary education to the labour market. However, the roles of occupational therapists with respect to VR services to support youth and young adults with disabilities to obtain professional preparation and to access the labour market (Tophoven, Reims and Tisch, 2019) are reviewed. VR in occupational therapy aims to improve employment prospects after a phase of incapacity to work and for people with disabilities.

The broad application of VR in various types of employment models within developing and emerging countries include transitional employment, supported employment and job coaching, reasonable accommodation, successful case-replication within a community-based rehabilitation model, and work co-operatives. An employment model has been presented by occupational therapists for the South Africa context but requires further development to be applied across an inter-sectoral domain of practice and for all sectors of the economy (Coetzee et.al, 2011).

Occupational therapists are not always fully utilized as part of teams which support learners transitioning out of high school, particularly from schools for learners with special education needs (LSEN). It is unfortunate because occupational therapists have expertise in helping students engage in self-determination and building goals based on their strengths and preferences (Clark, 2019). The American Occupational Therapy Association has identified 'Transition Services' as one of the eight standards of practice for occupational therapy (American Occupational Therapy Association, 2000), emphasizing the provision of supports in significant life areas of occupation. "Occupational therapists have exceptional skills and intervention approaches to improve these areas for students with disabilities while in high school. However, there is limited theory and research to support the role of the occupational therapist in intervention approaches associated with transition services for secondary students with disabilities" (Miller, 2012).

According to American Occupational Therapy Association (AOTA), occupational therapists practicing in VR field perform work assessments in relation to capacities of a worker, the work place and task performance, and deliver services regarding these parts (American Occupational Therapy Association, 2017). This includes linking the person's functional capabilities to those mandatory to the job in relation to the person's motor, physical, psychological, and cognitive body functions. "Besides, occupational therapists have the observational skills, training, and expertise to perform complex task analysis and assessment of the environmental factors affecting work performance" (American Occupational Therapy Association, 2012: p 2). This capability to evaluate tasks is among the most exceptional attributes to prosperous transition planning, because activity analysis assists in determining the performance requirements of preferred activities and the needed supports (American Occupational Therapy Association, 2017).

Occupational therapy services can focus on transition planning, to facilitate prospects for vocational training and work skills with long goals of occupation and enriched life quality (Miller, 2012). The occupational therapists can facilitate learners to create their future selves that will continue outside the secondary education environment (Keptner and McCarthy, 2020) by engaging them in occupation and skill development programs within

the work environment. Occupational therapy practitioners again facilitate effective transition results for high school learners to adulthood by assisting them in developing and sustaining positive work habits and study skills. Learning strategies for community living, acquiring self-determination, and self-advocacy skills can also be included as well as developing and maintaining supportive relationships with others (Orentlicher et al., 2017). Wilcock (1999: p195), emphasized that the occupational therapy profession should not only limit its focus to neurological, physical, or mental disorders rather expand it to individuals who have challenges concerning the diseases of “occupational deprivation, occupational alienation, and occupational imbalance”. Occupational therapists are considered helpful in super scribing skills that go beyond what is needed to succeed in school to success in finding and keeping a job after graduation (van Biljon et al., 2016).

This has suggested the literature extends to assisting with advocacy which is also a traditional role in occupational therapy (Sachs and Linn, 1997; Smith, 2005) and some literature suggests that advocacy can be in the form of occupational therapists' actions for the transition of individuals to employment, such as providing education to society and employers (Dhillon et al., 2010). Guidance to employers by the occupational therapist on how to optimally work with employees with the diagnosis of ASD was recommended (Nicholas et al., 2018).

It is suggestive that occupational therapists may play a key role in enhancing service delivery to elevate employment outcomes for individuals with ASD (Harmuth et al., 2018). Within the South African context, the VR services seem to be restricted and disjointed, preventing the development of the comprehensible service which is essential for increasing employment prospects for PWDs (Coetzee et al., 2011). There is therefore a need for occupational therapists to position themselves where they can be of assistance during transition.

2.9 Summary

Transition occurs throughout the life span, and it is a process that both individuals with and without disability encounter. There are challenges in each transition phase including transitioning from adolescence to adulthood and into employment. Hearing and taking

into consideration the voices of those affected by the diagnosis of ASD is necessary, as it will assist in developing ASD Community co-operative programs.

There is a need for improved interventions to help them develop skills to learn about different life skills, even though resources are currently inadequate, especially in employment. As skilled and trained members in vocational services, occupational therapy professionals must consider how to best assist individuals with ASD to make the transition into paid employment and keep their jobs once they have them.

For a smooth transition for individuals with ASD, it is necessary to undertake measures to combat discrimination so that they can find and retain jobs. Accommodations may need to be implemented for individuals with ASD. These include standards for their integration in an ordinary working environment, taking into account their skills and possibilities and vocational training at the highest level that is geared to the employability of individuals with ASD.

CHAPTER 3: METHODOLOGY

3.1. Introduction

This chapter will discuss the methodology followed in exploring the perceptions of individuals with ASD and their parents regarding their unmet needs during transition into the labour market and how they expect the occupational therapist to help them. The chapter will also focus on the research design relevant for this study, the tools used to gather data as well as measures used in ensuring validity and reliability of data. Lastly, the data analysis will be described as well as the ethical considerations that were employed.

3.2 Type of Study and General Design

The objectives of the study were best addressed by using qualitative research. This research approach provides a meaningful way of describing and understanding the human experiences (Streubert and Carpenter, 2011). This study was approached from the perspective of a qualitative explorative, descriptive design with phenomenological characteristics to explore the meaning people ascribe to their own experience (Creswell, 2014). In this case this was the perceptions of individuals with ASD and those of their parents on their unmet needs in transitioning into the labour market and how occupational therapists can assist with this process.

Explorative designs are employed when little or no scientific knowledge is known about a group, process, activity or situation. Marshall and Rossman (2011), assert that such research has potential to generate new hypotheses. This is found relevant for this study as the perceptions of individuals with ASD and their parents regarding their unmet needs during transition into the labour market have not been explored in South Africa. Burns and Grove (2009), indicate that descriptive designs are aimed at providing an accurate portrayal of a particular event, for the purpose of finding a meaning, discovering what exists and the frequency of occurrence of such a phenomenon. It was considered appropriate for this research as the questions focused on exploring the perceptions of

individuals with ASD and their parents in Tshwane during their transition in the labour market, and that is poorly understood phenomenon (Kim, Sefcik, and Bradway, 2017).

The descriptive approach was used to explore the lived experience of the participants, through giving them time and opportunity to describe the issue being explored from their perspective (Creswell, 2014). This approach attempts to understand people's perceptions, perspectives and understanding of a particular situation (de Vos et al., 2005). The outcomes of this study could be used to assist employers, parents, therapists and young adults with ASD in development of appropriate transition programs with proper plans in hope of a successful work placements (Galler, 2013).

3.3 Population and Context

3.3.1 Context/site

The research was conducted in the City of Tshwane and this is the metropolitan that forms the local government of the northern Gauteng Province, South Africa. The Metropolitan area is centred in the city of Pretoria with the surrounding towns and localities included in the local government.

The participants resided in Pretoria and were members of the Pretoria Autism Support Group which was run by the parents of the individuals with ASD. The support group was initiated by one of the parents who saw a need for the parents and individuals with ASD to support each other. It consists of different age groups; children who are as young as five years old to adults as old as 75 years old. The purpose of the group was to discuss daily life challenges that are encountered by the families affected by the diagnosis of ASD. The challenges ranged from different issues such as education, use of medication, ways to support one's children in a non-accommodative environment. The support group meets on the last Saturday of every month at a restaurant and meetings are in the form of a social gathering. Participants meet and chat and there is no formal agenda for their meetings. The only requirement for joining the group was, "there must be an individual with ASD in the family". The membership was open as the members came and left. However, the participants of this study were the regular attendants who have been with the group for a number of years.

The researcher joined the group because she had been looking for a support group for her clients and heard about this specific support group. She then asked for a permission from the group leader, to attend the group meetings so that she could experience the support offered before recommending the group to her clients. After experiencing the activities and discussions at the group, the researcher was supposed to leave but the members invited her to stay. She was not invited as a therapist but as a family member to this support group even though she does not have a family member with ASD.

It must be noted that the individuals with ASD who participated in this study refer to themselves as autistic individuals. They will however be addressed as individuals with ASD for the purposes of this study as per ethics requirement.

3.3.2 Sampling

Purposive sampling was used to select participants who are more knowledgeable about the problem to be studied (Bless et al, 2013). The individuals with ASD who had completed their formal (school) training and their parents who could provide rich information relevant to the subject to be studied and who met the inclusion criteria were included in the study. This sample consisted of the individuals who consented to be interviewed and who could communicate verbally or via technology (such as email) and were currently employed or looking for a job. Some of the parents included in the sample were those of the individuals with autism who were interviewed for this research (Meho, 2006). Other parents were also included if their child was currently employed (as they know about work habits, and the issues surrounding the workplace), **OR** was employed at some stage of their life **OR** was still looking for a job.

3.3.3 Sample size

Literature indicates that the scope of study and the quality of data should be considered when deciding on a sample size in qualitative research (Curtis et al., 2000). In this study the participants were chosen with the aim that their response will serve purpose related to the research question (Collingridge and Gantt, 2008). Therefore, a sample size of between five and fifteen participants was considered for data saturation to be achieved (Morse, 1995). The researcher planned to interview eight individuals with ASD and eight

parents of individuals with ASD. Ten individuals with ASD and 10 parents of individuals with ASD were approached during the support group's meetings and invited to participate in the study. Eight parents of the individuals with ASD responded and agreed to participate while eight individuals with ASD responded. Three individuals with ASD who had given consent never responded to the email interviews despite a number of follow ups so five individuals with ASD were interviewed.

3.4 Research Instruments

The method used to collect data consisted of both a demographic questionnaire and in-depth face-to-face and email interviews.

3.4.1 Piloting of interview guide

The interview guide was piloted by the both the researcher's colleague and supervisor in order to check flow, timing and usefulness of questions. The interviews were practiced with both colleague and supervisor in separate instances, using the same interview questions that were to be used with the participants. They were then asked to comment on whether they understood the content of the questions or if they felt they questions needed to be changed. In both cases they felt the interview questions could be used unchanged. Not enough participants were available to pilot the interview guide with individuals with ASD or their parents.

3.4.2 Demographic Questionnaire

A demographic questionnaire (Appendix A) was used to collect information regarding the participants' age, home language, gender and work experience. This was done to better understand the background characteristics of the participants, and to determine whether they met the criteria of the participants needed for this study.

3.4.3 In depth Interview

Two types of in-depth interviews were used, namely email interviews with individuals with ASD and face-to-face interviews with parents. An interview schedule with three questions and probes was developed by the researcher

3.4.3.1 Email interviews

e-Mail interviews (Meho, 2006) were used for individuals with ASD (Appendix B). This is an emerging design that allows for individuals with ASD to be direct participants in research. The email interviews have been used in research successfully (Beck, 2005; McCoyd and Kerson, 2006; Stacey and Vincent, 2011; Hawkins, 2018). The use of email, removes the social anxiety experienced by individuals with ASD that is associated with face-to-face communication (McCoyd and Kerson, 2006). The individuals with ASD find it easier to respond using technology because of their limited social skills/barriers and open-ended e-mail interviews are thought to provide them with enough time to process the information and provide adequate response (Magan, 2018). Again, email interviews permit the researcher to reflect on responses and amend questioning as desired. These types of interviews save both time and money in transcription and travelling costs (Hawkins, 2018). However, email interviews can be more time consuming than oral interviews as the participants have to create the written responses (Fritz and Vandermause, 2017; Gibson, 2014). Another disadvantage of the email interview is the possibility for short, brief answers and potential erosion as participants may stop the exchange. Furthermore, the written responses of email interviews do not portray social cues that contribute to a full understanding of the participant's experience and the researcher does not have an opportunity to observe and interpret visual cues, tone, hesitation, or silence (Fritz and Vandermause, 2017).

3.4.3.2 Face to face interviews

The in-depth interviews were conducted face to face with parents (Appendix C), the audio recorder was used to record gathered information and field notes were made on information that could not be audio recorded e.g. bodily expressions. The in-depth interviews were used because Polit and Beck, (2012), indicate that these types of interviews are suitable when there is limited information about the subject of interest, further, they permit the participants to fully express themselves without being directed

by a set of prepared questions. This was the best choice for interviews with parents as it was believed that the interviewed participants' perspectives would be better voiced than they would be in email interviews and the participants could ask for clarity of questions immediately (Oltmann, 2016).

3.5 Research Procedure

Once ethical clearance was obtained from the Human Research Ethics Committee at the University of the Witwatersrand (Appendix D) and permission letter from the manager of the support group (Appendix E), recruitment of the participants for the study was initiated. The researcher presented the proposed study to Pretoria Autism Support group members at one of the meetings. It was explained how the study will be conducted and they were told that they would receive a detailed information if they were interested in participating. Of the eight individuals with the diagnosis of ASD responded, three who had given consent never responded to the email interviews despite a number of follow ups so five individuals with the diagnosis of ASD were interviewed. Those who were willing to participate were asked for their email address so that they could be sent an information sheet and informed consent forms to provide consent to participate in the study. Informed consent forms were provided for the parents of the individuals with ASD (Appendix F) and individuals with ASD (Appendix H) to sign. The demographic questionnaire (Appendix A) was also emailed to them, for them to fill in as well as the detailed information sheet regarding the research (Appendix G). An explanation was clearly given to potential participants that they had a right to withdraw from the study at any time even after the informed consent had been signed. Consent to record the interview (Appendix H) was also asked from them for face to face interviews. Once the participants had returned the forms, an appointment for semi structured face-to-face interview was made with the parents, and the individuals with ASD were sent e-mail interview questions so they could reply to these via email (Appendix C).

3.5.1 Data collection

The participants first filled in the demographics forms and on return of the forms, the appointments for interviews were made.

3.5.1.1 Email interviews

The individuals with ASD received semi-structured email interviews. The questions were asked to all participants the same way of using the interview guide (Appendix B). The researcher did follow-up on answers provided by participants. Thus, there was a forward and backward email conversation between the researcher and the participants until rich, thick data was collected and the interview topics had been exhausted. This meant that there was a daily exchange of emails. All emails were copied to the researcher's supervisor to allow for an audit trail of responses. Email responses were downloaded off the email server and saved in a separate, password protected folder on the researcher's computer. The content of each email was copied into a PDF document for data analysis as the participants responded. All emails were then deleted off the email server (McCoyd and Kerson, 2006.)

3.5.1.2 Face to face interviews

The face to face interview context (Brink et al., 2012) for the purpose of this study, was the place chosen by the participants to conduct interview as an initiative for them to start voicing their needs (Galler, 2013). Interviews were conducted at the participants' homes or a selected quiet restaurant as these were environments where the participants felt comfortable and free to communicate their thoughts, perceptions and needs without a fear of being interrupted, judged and ignored (Creswell, 2007; Moustakas, 1994).

In-depth semi-structured, face to face interview were used for parents by the interviewer to ask the questions, and additional probing was used, to obtain more clarity as well as thick rich data (Appendix C). Open-ended questions were included (Brink et al., 2012) to allow for elaboration on asked question. The questions were created in conjunction with objectives of the study and they were not amended during the development of the study as data gathered through them was adequate to answer the objectives of the study.

The interviews were conducted in English as all participants were fluent in spoken English. The interview sessions were conducted individually to avoid any disruptions from

a third party. They were scheduled to last for approximately 90 minutes with each participant to allow ample time for participants to process information (Atkison and Shiffrin, 1968) before they voice their perceptions. A voice recorder was utilized to capture all interview sessions and notes were written to capture what couldn't be captured through a recorder such as emphasis, body language and context. All interviews were transcribed for data analysis.

3.6 Data analysis

Six steps of data analysis as stated by (Creswell, 2009:185) regarding inductive thematic analysis (codes, categories and themes) were used in the study.

Step 1. The researcher *organized and prepared* the data for analysis. Audio recordings of the interviews were listened to and transcribed verbatim immediately after the interviews by the researcher herself. Email interview data were saved in a PDF document as text for data analysis. When analysing the data for this research Test's method of qualitative data analysis was used, as explained in (Creswell, 2007). Thereafter, the researcher read the transcripts carefully, when new ideas were identified, they were noted down on the margin of the transcripts.

Step 2. Data was read through over and over in order to obtain the sense or the feel of the data gathered.

Step 3. All the documents were uploaded onto the MAXqda program which is a software research tool that assists with analysis of qualitative data (Kuckartz and Kuckartz, 2002). The codes were identified from carefully reading the transcripts of the participants.

Step 4. Both the face to face interviews and e-mail interviews documents were combined into a cohesive integrated description of data (Magan, 2018). Data in the form of quotes taken from the face to face interviews and the e-mail interviews were placed onto MAXqda, printed and separated into different codes. MAXqda program was used to generate a description of the categories or themes for analysis by classifying the data into categories and subcategories by grouping it. The researcher met with her supervisor with the original codes and that a co-coding session was held. During this session her supervisor checked the accuracy of codes and then helped code into categories and themes.

Step 5. A description of the themes, categories and subcategories were represented in the qualitative narrative. Peer review of the codes and themes was used to confirm that the researcher included all views in the data analysis (Creswell, 2009). A final analysis was presented after repeated refining and naming of the main themes, categories and subcategories.

Step 6. Finally, an interpretation or meaning of the data was made. In this final step, the researcher and her supervisor had a meeting in which they reviewed all the data from MAXqda for re-coding, categorising and creating themes. The subcategories, categories and themes were being analysed numerous times to ensure the meaning was captured correctly. Two broad themes were identified from the interviews namely “Transitioning was really hard”, and “Occupational therapists can do more”. Both of these themes consisted of a number of categories and subcategories.

3.7 Trustworthiness

Trustworthiness in qualitative research is concerned with adding rigor to the study by the methods used by the researcher in the design, data collection and analysis of the findings to ensure the data truly represent to voices of the participants (Thomas and Magilvy, 2011). The following strategies of trustworthiness were used as advised by (Creswell, 2014).

3.7.1 Member checking

This is a technique used for discovering the credibility of results (Birt et al., 2016). Member checking was used to determine the accuracy of the project findings by sending through summary of themes after data analysis by email to the participants in order to ensure data analysis truly reflected the opinions and perspectives of the participants. The participants were asked to indicate whether they agreed with summary of the themes created from data analysis or if changes should be made. All those who responded, stated that they concurred with the summary of themes provided to them. It was found suitable to use as it is most often used to optimize the validity of qualitative research findings (Given, 2008).

3.7.2 Use a rich, thick description to convey the findings.

This is a process of making detailed analysis of a phenomenon in qualitative research to yield the highest level of reliability as well as research validity (Richard, 2006). The collection of rich, thick data from individuals with ASD occurred when using email interviews to allow the individuals the opportunity to process information and to remove the experience of social anxiety or awkwardness. Emails were sent back and forth (between three and five times with each participant) between the researcher and the individuals with ASD until there were no more probes from the researcher and there were no new answers from the individuals with ASD. The support group meetings were still continuing during the period when the researcher was collecting data therefore it cannot be confirmed if they had discussion about the research process, before or after the meetings. Probes were also used in face to face semi structured interviews with the parents, where they were asked to elaborate on their answers until there was no more forthcoming information. This is done to assist readers in deciding if the situation defined in the qualitative study applies to the reader's situation and gives meaning to their situation as well (Graduateway, 2017).

3.7.3 Clarify the bias.

The researcher and the supervisor had regular meetings where they visited the objective of the study in order to guarantee that the objective view was maintained (Creswell, 2009). The supervisor and researcher discussed the topic and the researcher reflected on her own expectations and biases (the objective researcher being in position of moving from the participants' descriptions of facts of the lived experience and their perceptions of their unmet needs) (Neubauer, Witkop, and Varpio, 2019). This was done so she was aware of her bias before interviewing the participants so as not to influence the participants in any way. The researcher kept a journal of her views regarding literature read, her own impressions and thoughts and the responds from the participants, it was recorded immediately after each and every face to face interviews.

3.7.4 Presentation of negative or discrepant information

The researcher was aware of her own biases when analysing information from the individuals with ASD as well as their parents. The presentation of negative or discrepant views that runs counter to the literature and expectations was ensured. The researcher achieved this by critically discussing themes of the data collected with the supervisor for this study and the participants (Creswell, 2009).

3.7.5 Peer debriefing

Peer debriefing has been described as a process to improve the credibility or validity of qualitative research (Spillett, 2003). The purpose of peer debriefing is to improve the reliability, or truth value, of a qualitative study, by providing "an external check on the inquiry process" (Lincoln and Guba, 1985: p. 301). Peer debriefing was used to enhance the accuracy of the account. The researcher conferred with a colleague and her supervisor in the development of the interview schedule to ensure that the questions were representative of the objectives of the study.

3.7.6 Data saturation

Previous literature, has recommended that qualitative studies require a minimum sample size of at least 12 to reach data saturation (Clarke and Braun, 2013; Fugard and Potts, 2014; Guest, Bunce, and Johnson, 2006). Data saturation means the collection of qualitative to the point where new data tend to be redundant of data already collected (Saunders et al., 2018). Data saturation is reached when no new analytical information arises anymore, and the study provides maximum information on the phenomenon (Moser and Korstjens, 2018). The development of categories and themes in the analysis process was used as the criterion for additional data collection. Analysis of the interviews was completed after 13 interviews and coding into categories and themes was completed to determine if saturation have been achieved and that no additional data were being found (Guest, Namey, and Chen, 2020).

3.8 Ethical Considerations

The researcher obtained approval from the University of Witwatersrand Human Research Ethics Committee (M170928) (Appendix D). Permission was obtained from the

chairperson of the support group (Appendix E) and each member of the support group who participated in a research was provided with an information sheet (Appendix H). The right to self-determination and full disclosure which are the main elements of informed consent were adhered to. An outline of the study and its purpose were explained to them and those who were willing to participate were asked to sign the consent form (Polit and Beck, 2012: p.154), to be interviewed (Appendix F) and audio recorded (Appendix G). The following ethical principles were adhered to in this study.

3.8.1 Beneficence

Mugenda (2011), stated that beneficence is associated with the Hippocratic “be of benefit, do not harm”. The research was for the benefit of the participants as it was exploring their perceptions about their unmet needs (Fouka and Mantzourou, 2011). This was done to give those that are often unheard a platform to voice their perceptions. There were no perceived or documented risks for participants for this research project.

3.8.2 Informed consent

The participants give their consent voluntarily after reading the information sheet. All participants were made aware of their right to choose to participate or not again at the beginning of each interview. Participants were given an opportunity to ask questions and all participants indicated that they clearly understood and knew what they going to engage in (Nusbaum et al., (2017). In this study the participants had the right to voluntarily decide whether they wanted to participate in the study including the right to withdraw at any time without penalty.

3.8.3 Non-maleficence

The participants were not subjected to unnecessary risks for harm or discomfort. Research should not harm participants in any way (Polit and Beck, 2012). No true names were used in any data analysis and none of the participants were caused any harm. The researcher ensured that the participants’ privacy was ensured throughout the study and information was given to all participants equally and feedback was provided on request.

3.8.4 Justice

Justice is more about giving voice to marginalized people and the individuals with ASD were given an opportunity to explore their perceptions (Pieper and Thomson, 2018). The individuals with ASD took part in this study so that their experiences could be heard.

CHAPTER 4: RESULTS

4.1 Introduction

The results from both the individuals with Autism Spectrum Disorder (ASD) and their parents will be dealt with in this chapter. The research sample will be described, followed by the demographics of the study participants. The themes and categories that explore perceptions of individuals with ASD who have finished their formal education or training and those of their parents about their unmet needs in terms of transitioning into the labour market are presented. The role that the occupational therapist can play in addressing these unmet needs, will be described. The quotes of the individuals with ASD and those of their parents are differentiated by colour and are coded by participant number.

4.2 The research sample

A total of 18 people agreed to participate in the study, but only 13 participants eventually responded to interview requests. A total of nine individuals with ASD and nine parents were originally recruited into the study. From the nine participants with ASD, five individuals participated in the interviews, while four individuals who had given consent never responded to the email interviews despite a number of follow ups. Eight parents of nine who consented to the study participated in the interviews.

Some of these participants use English as their second language, however all participants were fluent in English therefore English was used as a mode of interview. There was a good understanding between the researcher and the participants during both written and verbal interviews. It must be noted that the majority of the participants were Afrikaans speaking.

Demographic information regarding participants is summarized in table 4.1 and 4.2.

Individuals with ASD ranged in age from 25-37 years. These participants had completed their formal schooling and they had an experience with labour market. The rate of employment amongst the individuals with ASD was 92% with only one participant looking for a job. They all understood English language which was used as a means of

communication and they could communicate verbally and via technology (email-interviews). They included two females and three males (Table 4.1). “A” under language stands for Afrikaans and “E” stands for English

Table 4.1: Demographic Characteristics of individuals with the diagnosis of ASD (n = 5)

	Pseudonym	Gender	Use of language		Age	Race	Employed	Duration and nature of employment	Level of education
			A	E					
A 1	Warwick	M		1 st	32	White	Yes	Currently working as a geologist for 2 years	Doctorate in Geology
A 2	Matthew	M	1 st		37	White	Yes	6 years South African National Defence Force	Matric Certificate
								3 years project manager	
								Currently working as a support specialist	
A 3	Marietta (parents did not participate)	F	1 st		34	White	Yes	4 years Admin clerk	Matric Certificate
								6 years manager at private company	
								3 years working as a secretary currently	
A 4	Hope	F	1 st		27	White	No	Worked as a nurse for 6 years and resigned but now looking for a job	Certificate in Nursing
A 5	Carlo	M		1 st	25	White	Yes/self-employed	Piano tuning for 3 years	Piano technology certificate

Parents ranged in age from 45-71 years and included six females and two males. Four of these parents' children participated in this study and five did not. Those that participated have their children's names listed in the table below. Isabella's, Thabiso and Hattie's children have Grade 12 certificates. Hattie's son passed with four distinctions and he worked at the video shop but he was not coping with the job. Isabella's son is still looking for a job. Thabiso's child is busy with basic computer courses. Annemarie's son went to special school and completed the final level, he fixes electrical appliances and does paper recycling. All these parents have been members for more than five years.

Table 4.2: Demographic Characteristics of the parents of the individuals with the diagnosis of ASD (n = 8)

	Pseudonym and child's name	Gender	Use of language		Age	Race	Parental Employment
			English	Afrikaans			
P1	Nadia(Carlo)	F	1 st		45	White	Teacher
P2	Annemarie Son	F	2 nd	1 st	54	White	Secretary
P3	Isabella	F	2 nd	1 st	47	White	Accountant
P4	William(Matthew)	M	2 nd	1 st	56	White	IT support engineer
P5	Annemarie Daughter(Hope)	F	2 nd	1 st	54	White	Secretary
P6	Thabiso	M	2 nd		66	Black	Doctor
P7	Regina(Warwick)	F	1 st		71	White	Pensioner
P8	Hattie	F	2 nd	1 st	53	White	Unemployed

Two major themes emerged from the data in relation to the objectives of the study. These themes are described and supported with the quotes from the interviews with both the individuals with ASD and their parents. The interviews were done to explore perceptions of individuals with ASD who have finished their formal education or training and their

parents about their unmet needs in terms of transitioning into the labour market. The interviews were again about the role that the occupational therapist can play in addressing these unmet needs.

4.4 Themes

Two broad themes were identified from the interviews namely “Transitioning was really hard”, and “Occupational therapists can do more”. These themes came from combining the data from adults with ASD and their parents. Both of these themes consisted of a number of categories and subcategories which are presented in Table 4.3.

Table 4.3: Themes, categories and subcategories

Theme	Category	Subcategory
4.3.1. Transitioning was really hard	4.3.1.1 Finding a job is really hard	a. We did not understand the process and we had unrealistic expectations
		b. Finding the right fit was not easy
		c. We experience stigmatization in the work place
		d. We lack job seeking skills
		e. Schools do not equip our children with any transitioning skills
	4.3.1.2 Keeping the job is even harder	a. We just don't fit in
		b. We find life changes difficult
		c. We struggle with work place attitudes
		d. We don't get reasonable accommodations
	4.3.1.3 Parents have needs too	a. We support our children as best as we can
b. It can be very difficult on us and we feel unsupported: <ul style="list-style-type: none"> i. Emotional needs ii. Financial needs 		
4.3.2. Occupational therapists can do more	4.3.2.1 Participants perceptions of occupational therapy	a. Negative perceptions
		b. Positive perceptions
	4.2.2.2 Ways in which the occupational therapist can assist in preparation for transitioning to labour market	a. Case managers
		b. Skills training
		c. Job coaching
		d. Adaptation in a work place

4.3.1: Transitioning was really hard (objectives 1 & 2)

The theme “Transitioning was really hard” describes the experiences of individuals with ASD and their parents in seeking and maintaining employment. This theme highlighted a number of unmet needs for both individuals with ASD and their parents and thus answered objectives one and two.

This theme was summed up by Warwick:

“Moving to the labour market is, from my perspective, is difficult, for everybody is difficult but I think for people with ASD it is even more difficult as they don’t know what to expect.” (A1)

Participants described a number of difficulties in their transition from education into the labour market by emphasising the main issues that led to a challenging transition for individuals with ASD. Difficulties clustered around the issue of finding a job and being prepared for the job seeking process, keeping a job, and the needs and challenges that parents of individuals with ASD also faced.

4.3.1.1 “Finding a job is really hard”

Four subcategories contributed to this category and are summarized in the table below.

Table 4.4: Theme one and category one: Finding a job is really hard.

4.4.1 Transitioning was really hard	4.4.1.1 Finding a job is really hard	a. We did not understand the process and we had unrealistic expectations
		b. Finding the right job fit was not easy
		c. We lack job seeking skills
		d. We experience stigmatization in the work place
		e. Schools do not equip our children with any transitioning skills

These subcategories elaborated on why individuals with ASD found it difficult to find a job and thus contributed to difficulties in transitioning into the workplace after school.

a. We did not understand the process and we had unrealistic expectations

Participants expressed difficulty in understanding the process of finding a job and therefore had unrealistic expectations about the process. As a result, they could not obtain the jobs they hoped to have. The following statements encapsulate their views:

Matthew “Understanding how the job market works was a challenge. I expected jobs to ask me, not me having to look for a job that I could ask for. I misunderstood the job market – I thought jobs would come asking” (A2)

As Thabiso explained “These people do not have a clue of what is expected of them, when they are looking for jobs, nothing, nothing at all. They think you just show up at the work place and start working, uh! So yah!” (P6)

Marietta added; “I am of the opinion that a job should find you, not you the job.” (A3)

These comments demonstrate a misunderstanding of how the job seeking process works and led to disappointment and difficulties transitioning. The individuals with ASD therefore struggled to find a right job fit.

b. “Finding the right job fit was not easy”

From the interviews, it was clear that individuals with ASD don’t see themselves as “fitting” into society. Both individuals with ASD and their parents stated that it was a struggle for them to find a right fit in the job market and that individuals with ASD appeared socially awkward. As a result, they felt like they were left out of the job market. This is encapsulated in the following statements:

Warwick “It is easier for non-ASD individuals to get jobs than it is for ASD individuals, even though ASD individuals may be more qualified or have more insight / experience. In most cases companies are looking for a “team player”, which is causing issues for ASD individuals as they don’t fit in.” (A1)

Isabella “I think the biggest challenge is finding the suitable occupation, that suits my child’s strong points, that gives him a comfort zone where he feels safe but will also challenge him in a sense. And I think it’s like that for any other child. Finding a right suit um, for a child. I think that is a biggest challenge or rather a concern.” (P3)

A lack of social skills required to find a job was an issue that was of concern to many participants.

Thabiso commented, “They tend to say me and mine and as a result they become loners and nobody wants to integrate with them. Because other people think that they are aloof and other people think that they are arrogant and they don’t integrate too well.” (P6)

Nadia added that, “It has been a difficult task because you know, he is still autistic and for him to be surrounded by too many people is a challenge. You know autistic people are introverts and they don’t like to be around too many people, they don’t talk too much, they like to be in their little hole” (P1)

Marietta, “..... And you can just think that being a person with social awkwardness and not connecting with other people, you can imagine that ASD individuals end up being lonely.” (A3)

Hattie concurred “They have immense problem to function out of their comfort zone, they are socially awkward and they don’t integrate. Their emotional response is not at their age. Their emotional level makes it difficult for them to adapt in many situations.” (P8)

William “Our biggest problem is; mentally he is fine, intellectually he is fine but social interaction and social maturity, he is struggling, and because of that he misses the content of what is expected of him.”

Hope added “It was difficult for me to find a job, I was emotionally very young and struggled to fit in with my peer group.” (A3)

The large number of comments that spoke to “fitting in” emphasized that this was an important issue influencing the successful transition from schooling (where perhaps more accommodations were made) into the job market. Apart from struggling with the right fit between a person and a job, individuals with ASD reported that they are lacking in job hunting skills such as job applications and interviews.

c. “We lack job seeking skills”

Participants stated that they relied on other people to get jobs regardless of how skilful they are in certain jobs. They reported that they did not know how to apply for jobs. Their social awkwardness impacted on successful interviews and their job choices were limited

due to their lack of job seeking skills. They supported the above statement in the following ways:

Carlo stated that due to their lack of job seeking skills they have to rely on other people for jobs, “Autistics who do get jobs tend to be the ones that have a big support system, especially within their fields of interests, and “expedition assistants” helping to get jobs through the back door.” He continued to say, “As a group and in general, Autistics tend to be round pegs and the typical job search application submission and especially the interview are square holes. Trying to fit the round peg in a square hole is grounds for some problems cropping up.” (A5)

Marietta shared the same sentiment with Carlo as she said, “All the successful jobs I have ever had, people that I knew gave me..... I’m not really successful with job interviews and corporate job finding styles.” (A3)

Warwick concurred with others, “I relied mostly on my professional network to carry me through and vouch for me during job interviews..... I misunderstood interview questions, which cost me the jobs I was hoping for.” (A1)

Matthew even reported that at times they accept some jobs because they don’t have a choice, “I went from school directly to National Service and from there to Permanent Force in the Army. The transition was therefore forced and had to be accepted. I found the promotional interview very stressful as it involved speaking to a panel of people. It is the same situation that I experience when being interviewed for a regular job” (A2)

William “I think for people with ASD it is even more difficult as they don’t know what to expect. They struggle to present themselves as the ideal candidates when they go for an interview” (P4)

Isabella “And the biggest challenge is he is struggling with communication skills.” (P3)

In addition to lacking job seeking skills, participants described stigmatization of ASD as a big challenge when trying to find a job. They were concerned that individuals with ASD are treated as outcasts in most of their work environments.

d. “We experience stigmatization in the work place

The participants expressed their concerns about how ill-treated they feel in the job markets just because they are diagnosed with ASD. They reported that the diagnosis of ASD itself makes it difficult to be appointed to the kinds of jobs they would like to do.

This is how Marietta expressed herself “The diagnosis mentioned, alone, is enough reasons for “others” not to trust or to not want to give you equal opportunities. Same as racism. Due to stigma – probably spread by well-meaning parents and organisations that love telling the world what a tragedy autism is.” (A3)

Nadia added this concerning her son “The problem that he experienced with the open labour market is that, the employers are not really willing to take on people with disability especially people who have cognitive disability because as you know for work ratio you have to perform at the certain level and unfortunately they can’t work at the same pace as the individual without disabilities can work. Therefore, open labour market for some of these young adults is very difficult because the employers don’t have the patience and they don’t have time you know.” (P1)

Warwick added that, “It is very sad, I promise! Just after confiding in a colleague about my autism, all my responsibilities were taken. I was demoted, only after they knew that I was autistic, so what does that tell you. Yah! You are autistic and you can’t be trusted....” (A1)

These quotes suggest that individuals with ASD felt they were not trusted to be good workers and as a result lost out on job opportunities. Thus individuals with ASD and their parents felt that the diagnosis of ASD alone was enough to exclude individuals from the job market and make the transition even more difficult.

This is therefore suggestive that the participants’ lack of job seeking skills, particularly job applications and interviews, resulted in participants being unsuccessful in obtaining the jobs they were hoping for. They indicated that their lack of job seeking skills is a result of many issues including the lack of preparation from schools.

e. Schools do not equip our children with any transitioning skills

The parents of the individuals with the diagnosis of ASD are concerned that the schools which their children attended, did not equip their children enough with necessary skills to function in the labour market. Parents indicated there is a need for programmes that will help individuals with ASD to develop different life skills.

It was indicated that due to lack of preparation from schools, the individuals with ASD struggle to perform different tasks in the jobs. They do not present with necessary skills for transitioning.

Parents' concerns were encapsulated in the following statements;

Nadia "Yah it's kind of tough you know, because when they finish with their school, they don't really have any job skills and stuff like that." (P1)

Hattie "...they don't learn at school, not to side-track, to finish one thing before they can move to another thing. They also need to learn to multitask. They must learn to organise their day because if they are in a work area, they will need to follow multiple instructions. And they don't know how to do these things you know!" (P8)

Thabiso "..... And the schools do not train them for any opportunity to go and work. They train them mostly to be able to be functional and to be self-sufficient so that they can almost become adult like. But there isn't anything of specific, be of type of training or any type of situation" (P6)

It was clear therefore that finding gainful employment was really hard for this group of individuals with ASD. They lacked preparation from school in job seeking skills and pre vocational skills required in the work place which made it harder to find jobs. However, the difficulty did not end with the successful job application in transitioning successfully into the workplace. Keeping a job was even more difficult than finding a job in the first place.

4.4.1.3 We struggle to keep jobs even if we get them

This category contributed to the theme of "Transitioning was really hard" by describing the difficulties individuals with ASD had in keeping a job once they found one. The four subcategories are summarized in table below.

Table 4.5: Theme one and category two

Transitioning was really hard	4.5.1.1 We struggle to keep jobs even if we get them	a. We just don't fit in
		b. We find it difficult to adapt to change
		c. We struggle with work place attitudes
		d. We don't get reasonable accommodations

In cases where the individuals with ASD were successful with getting a job, they expressed the difficulties to effectively incorporate and associate with their colleagues and employers.

a. We just don't fit in

Issues around “fitting in” were not only raised in relation to finding a job, but also seriously affected individuals with ASD's ability to keep a job. Participants identified this as one of the biggest reasons why individuals with ASD struggled to transition successfully into the job market. Issues identified by the participants were a struggle to read verbal cues, and a lack of social and communication skills.

William “I just think that the autistic people even those who are very educated, I mean some of them are very intelligent but they struggle to either get a job or keep a job because they don't fit in and that is a big challenge for them.” (P4)

Hope's statement concurs with William's statement as she said, “It was difficult for me to find a job, I was emotionally very young and struggled to fit in with my peer group.” (A4)

Annemarie (Daughter) said the following about her daughter, “Every single job that she gets does not last.... But at work, she goes well for a month or so. At about six weeks or so, she comes home and I see a closed face and there is obviously some complains and she is always a victim and other people are wrong. And by the end of month two, it is not working...” (P5)

Hattie added, “.... It makes it difficult because they can't fit in. They just don't fit in and my son doesn't fit in, and that's it. He does not have friends and does not mingle with others.” (P8)

Not “fitting in” the work place environment can cause considerable strain and stress. Added to this strain is the difficulty individuals with ASD have adapting to changes within the workplace.

b. We find it difficult to adapt to change

Having to adapt to a new environment is one of the challenges that participants identified. The participants indicated a need to get out of their comfort zones, which is a struggle to manage and causes stress. Individuals with ASD find it difficult to quickly adjust when

they are confronted by a new situation and this makes it difficult to adjust to workplace demands, especially if there are changes in those demands.

The participants said these about their struggle to adapt to change:

Isabella “I think if it’s a person that had already built a relationship with the individual with ASD, it will help them, as the transitioning into labour market is a big adjustment for the individual with ASD. Any change to them make them to be unsettled.....” (P3)

Nadia “So for Carlos going into an open labour market was extremely stressful. You know, he doesn’t know anybody and when he has been with unfamiliar faces he gets total meltdown.” (P1)

Hope “I am not certain if I have the courage to get back into the work environment, it will bring a big change in my life and I am scared of change. People with ASD have difficulty to adapt to a new environment because we lack certain social skills and most of us have sensory issues.” (A4)

Marietta “Because we have so many social difficulties it takes a lot of effort to adapt into the working environment, many people with ASD fear judgement because of their diagnosis.” (A3)

Individuals with ASD admitted that there are certain skills they feel they need to learn in order to combat some of the challenges they are faced with, such as life skills. Warwick summed it up by saying:

“People with ASD will have to get training on people skills, conflict resolution and office etiquette.” (A1)

The first two subcategories focussed predominantly on the difficulties individuals with ASD have in meeting the social and work requirements in the workplace. However, keeping a job was also influenced by attitudes and practices within the workplace that create discrimination and feelings of stigmatization.

c. We struggle with work place attitudes

Participants reported that workplace attitudes could be positive or negative; not everyone in the workplace treated them unfairly. However, even though some participants described supportive employers, most felt they were not being treated fairly by their co-

workers. As a result of negative treatment, many participants were not comfortable disclosing their diagnosis. They found themselves settling for menial jobs and they overworked themselves just so that they could be accepted. This was captured in the following statements.

Regina reported “My son has a very supportive boss though. Once they know about his problem and what it is, it makes it easier for people from work to accommodate a person.” (P7)

Carlo concurred with her as he said: “At my work place, I principally work individually on “my” projects but with help and input with other colleagues who go on to be listed as co-authors. I would call this environment “quasi-collaborative”. Office environment/ colleagues are very supportive/friendly and understanding.” (A5)

Nadia added. “.... They are very objective at first because they are unaware of his disability. They haven’t been exposed to this disability. But the minute they are exposed, they accept them.” (P1)

Concerning the negative attitudes that the individuals with ASD encountered this is what was reported,

Thabiso “Obviously these people don’t have labour unions as they are part of minority. And whatever they do they will always find themselves engaged in a minimum wage jobs irrespective of their qualifications.” (P6)

Marietta “Autistic people have to be double as good in what they do to prove themselves.... Or that they should do lowly work.” (A3)

Carlo “I worry that too many of my neurotype don’t have such a support system that grants them opportunities in skilled positions.” (A5)

Finally, the actual workplace environment seemed to remind the individuals with ASD that they were different.

d. We don’t get reasonable accommodations

Participants were concerned about the lack of reasonable accommodation within the workplace and felt that this seriously impeded their ability to successfully keep their jobs and thus make a success of the transition into the job market.

Nadia stated the following concerning the environmental threat: “They need to be in an environment where there are people that they know so that they feel safe because when they don’t know people around them, they don’t feel safe. And we also have to remember that they are vulnerable, people don’t understand them. And we all know that, there is too much stimuli for them and we see that in the open labour market.” (P1)

Warwick reported “And then also the work environment accommodation such as light, sound and so on. That is also an educational part to the employers to keep the environment conducive.” (A1)

Carlo seemed to agree with them that accommodative environment is vital: “I am very fortunate to work in an environment that is protective of my sensory issues. Light and noise are of great tolerance for me.” (A5)

Apart from environmental challenges, participants feel that they are not being accommodated as they should be in a working environment. This makes it hard for individuals with ASD to keep the jobs they get.

Hope stated that “People are totally ignorant about what Asperger Syndrome and what Autism is, it could help if employers could be better informed about what it is and what the person with Asperger’s are capable of doing.” (A4)

Annemarie for son, emphasised that: “There are some residents where these people are being treated as though they can’t do a thing for themselves.... There was no accommodation for his personal routine. He had to fit in with their routine or else he was deemed naughty. And eventually I realised that my child is being used as a cheap, in fact as a free labour.” (P2)

Thabiso indicated that it is so bad that: “Other people even put their children in a sheltered home where their children do either menial jobs or recycling or stamping (which is a repeated type of job) which is something that we cannot really call sustainable. Just for them to be accommodated elsewhere” (P6)

Thus, from the interviews it was clear that getting a job was only the first step in transitioning successfully into the working environment and that actually keeping a job was in some cases even more difficult than finding one. Fitting in, struggling to adjust to change, attitudes and stigma, and finally lack of reasonable accommodation all contributed to the failure of individuals with ASD to navigate this transition successfully.

Apart from the above mentioned challenges and the problems, parents of individuals with ASD reported that they also had unmet needs when it came to trying to support their children through the transition from school to workplace.

4.4.1.4 Parents have needs too

It was evident from interviews with the parents of the individuals with ASD that a strong support system is of great importance in helping their children during the transition period in order to maximise their children’s success. Parents indicated that, in the process of helping their children to transition successfully to the open labour market, they often fail to meet their own needs on top of those of their children. They reported that, much as they supported their children, they suffered as parents both emotionally and financially.

This category was captured in the following sub-categories: we support our children as best as we can, it can be very difficult on us and we feel unsupported concerning our emotional and financial needs.

Table 4.6: Theme one and category three

4.6.1 Transitioning was really hard	4.6.1.1 Parents have needs too	a. We support our children as best as we can.
		b. It can be very difficult on us and we feel unsupported: <ul style="list-style-type: none"> i. Emotional needs ii. Financial needs

a. We support our children as best as we can

Parents indicated that, difficult as it can be; they have to support and help their children as much as they can in order for their children to successfully transition into the labour market. This was encapsulated in the following statements:

Regina “He was lucky that he had parents who could support him..... I was just there to support him when he needed it. Oh well, one has to accept it and try to support him” (P7)

Isabella “I think for our son what makes it easier is the fact that he has got a very strong support system within our family and I think that is what makes him different from the other kids.” (P3)

Parents felt that it was their unwavering support that made the difference in their children’s lives. They indicated that it is their responsibility to take care of their children, but they also felt overwhelmed at times by this responsibility. Parents stated that they also needed support from society for themselves.

b. It can be very difficult for us and we feel unsupported

The parents of individuals with ASD stated that they feel unsupported from government or society, both emotionally and financially. They feel like they are on their own with their children and that the world is against them. Due to this general lack of support, there is a concern from some of the parents regarding whether they are doing enough to help their children with ASD to transition into the labour market. The parents are not certain of what will happen to their children in their (parents’) absence, as society does not seem to accept them. In conjunction with their unmet emotional needs, the parents of the individuals with ASD reported the following;

Regina “And try not to get cross with him because he does get frustrated and I have to stay calm even if I’m cross with him. And I think staying calm and praying about it really helps because a lot of help I believe comes from upstairs. I don’t think I could have managed without God’s help and staying calm. But it’s hard, it’s hard because you don’t always know how to handle him.” (P7)

Annamarie daughter, “This shows that, there is no support at all for these kids. They get out of school and they are all by themselves. Either they get pushed somewhere or they get left out completely. That is my opinion.” (P5)

Hattie seemed to be very concerned and worried of what will eventually happen with her son, as she added; “They again get mature very late. There is not enough (in my opinion) opportunities for these kids and I don’t know what is going to happen to my son. I don’t know. As far as I am concerned, I would stay with him until he is an old man but that is not how it works in life (**sadness and concern could be seen on her face**). But I don’t know what to do, I don’t know.... we cannot even go to anyone to cry for help, I just don’t know.” (P8)

Thabiso added, “It can even cause marriages to disintegrate if partners play a blaming game. So it is a very sad environment.” (P6)

In addition to emotional suffering, there is a financial challenge. The parents indicated that there were many costs incurred in raising the individuals with ASD, for example; education, therapy and medical expenses. This was summed up in the following statements:

Thabiso said, “It is not just challenging but it is very costly because the institutions out there are very expensive. And in most cases you can’t even show why you were paying such a lot of money. It is financially straining. I promise you, if God wants to challenge you financially, He will give you a child with autism.” (P6)

Regina said “Taking these children for therapy, it is very expensive and we cannot always afford it....” (P7)

Hattie added that “it is always sad you know, there is not enough support for these kids, there are not enough schools for them, the government is really not helping..... The private schools are also very expensive. It is difficult, very difficult, yah!” (P8)

Overall, parents felt that there is a great need for both individuals with ASD and their parents to be supported. Parents did not want their responsibilities removed, but were asking for understanding and help from the broader society.

Summary of Theme 1:

The perceptions of parents of adult individuals with ASD and those of the individuals with ASD who have finished their formal education or training about their unmet needs in terms of transitioning into the labour market were explored in the first theme. The results suggest that there are several matters and issues that have to be dealt with in preparation for the transition process for individuals with ASD and their parents. Participants did not feel ready for the job seeking process and experienced finding a job as very difficult. It was evident that the participants of this research were not exposed to transitioning programmes to facilitate the job seeking process. Difficulties did not resolve once individuals with ASD were successful in finding jobs as keeping these jobs proved equally, if not more challenging. Throughout the interviews it became clear that both individuals

with ASD and their parents feel unsupported and need assistance to successfully navigate the transition period between schooling and entering the labour force.

4.4.2 Occupational therapists can do more

The theme “Occupational therapists can do more” encompassed both positive and negative views of occupational therapy and what could be included in an occupational therapy role from the perspective of the participants.

Having gathered all the information by interviewing the participants, it was evident that occupational therapists have a role that they need to fulfil in the lives of the individuals with ASD during the transition into the labour market. Occupational therapists are trained to implement vocational rehabilitation programs and these form part of transitioning programs. This brought the researcher to answering the third objective which addresses the role that the occupational therapists can play during transition process.

Participants indicated that the occupational therapists have the potential to do much more than what they are offering at the moment. They stated that with the skills and nature of the occupational therapists’ personalities, the individuals with ASD could be well assisted through their transition into the labour market.

This is encapsulated in the following categories: Participants perceptions of occupational therapy and ways in which the occupational therapist can assist in preparation for transitioning to adult life. These categories assisted in identifying some of the areas where the occupational therapists are lacking and the areas where they can effectively assist in order to facilitate transitioning process.

Table 4.7: Theme two and its categories - Role of the occupational therapist

4.7.1. Role of the occupational therapist	4.7.1.1 Participants perceptions of occupational therapy.	a. Positive perceptions
		b. Negative perceptions
	4.7.1.2 Ways in which the occupational therapist can assist in preparation for transitioning into the labour market	a. Case managers
		b. Skills training
		c. Job coaching
		d. Adaptation in a work place

4.4.2.1 Participants perceptions of occupational therapy.

When answering a question whether participants have ever received occupational therapy intervention, this is what was found:

Three of the five participants (individuals with ASD) did not receive occupational therapy intervention. Three of the parents whose children did not participate in the study indicated that their children received occupational therapy intervention (two individuals while in primary school and one when she was 20). Of the three who received occupational therapy: one received it while he was in primary school and one received it when he was 22 years old. The one who received it at the later age, reported some benefits.

Parents indicated that they were expecting more from their occupational therapists with regard to service, than what they got.

Some parents of the individuals with ASD indicated that, empathy from the therapists could have been highly appreciated as the diagnosis was not well known to them and therefore, they were uncertain of how to handle the individuals with ASD. The parents also reported that the individuals with ASD gained some skills useful to transition into the labour market from receiving occupational therapy intervention. Thus participants expressed both negative and positive perceptions about occupational therapy.

Table 4.8: Theme two, category one

4.8.1. Role of the occupational therapist	4.8.1.1 Participants perceptions of occupational therapy.	a. Positive perceptions
		b. Negative perceptions

Regina smiled at the end of our interview and said, “I think a research that you are doing is really needed because there is almost a perception out there that autism is a childhood condition and it will be out grown at some stage. The reality is, it’s not and I think people tend to forget about the ASD children when they leave school, and they are left to try and figure out the way to survive in the adulthood world. And I think it is very important to try to get a support system in place”. (P7)

a. Positive perceptions

The participants indicated that the individuals with ASD benefitted from attending occupational therapy services. The participants could not measure the value of occupational therapy intervention, but they mentioned that it was of a great help. It was stated that occupational therapists assisted to improve functionality of individuals with ASD. It also assisted individuals with ASD to understand their diagnosis and taught them some life skills that are of benefit during their transition into the labour market.

The participants' perceptions were encapsulated in the following statements;

Nadia "The value of occupational therapy is finding something that works for them. But I mean there is definitely value for occupational therapy intervention but I think that, occupational therapist should go to the next level." (P1)

Carlo "OT brought about the truth and proof of my autistic behaviours. I think without OT I wouldn't be able to function or have my diagnosis" (A5)

Regina "I mean the last time he got occupational therapy was 3 years ago and I believe if he got more it could have helped him a lot as he seems to be coping much better now.....I think most of the therapy that he had after being diagnosed was greatest. I asked him if he felt like it was helping and he said it was beneficial.....But I do feel that occupational therapists, their personalities are such kind that they can deal with a person's problem and manage to help them with whatever skills in order for a person to cope in life. I have seen a lot of it in many occupational therapists." (P7)

Annamarie for her daughter, added: "Oh yes. It's like drinking vitamin A, you know, you can't really measure your health because you are taking vitamins, you can't really say the measurements like you are doing research, you can just imagine how it would be if you did not drink vitamins." (P5)

Regarding her son, Annamarie said, "He would even say his OT encouraged him not to wear more than one hat at the same time. She would tell him he had to look good. So she had a good influence on him. She taught him accountability which is great and she did it better than I did it." (P2)

Even though some parents indicated that occupational therapy services had a positive influence, they also had some negative perceptions about occupational therapists.

b. Negative perceptions

Participants reported that sometimes it was difficult to work with some occupational therapists. They stated that some occupational therapists showed no interest in helping the individuals with ASD. Some occupational therapists were reported to be impatient and others did not believe in the abilities of individuals with ASD. Overall, participants felt that some occupational therapists did not see the individuality of the individual with ASD and only saw the diagnosis.

Nadia said the following about one of her child's occupational therapists; "So for that therapist to say "you might as well put him in a home and forget about him" was totally the wrong approach and that already tells me that, he is not interested in helping me but he is just there to make money." (P1)

Annemarie for daughter added that: "You must have patience as a therapist. Take your time to do an assessment. These standardized tests, autistic people don't like them. Another thing we were not included in my child's therapy process." (P5)

About her son, Annamarie (P2) said with a sad tone, "They underestimated his abilities and because you are autistic you can't do this, you can't do that and therefore he was not very much involved. The other OT who was also working with him when he was doing recycling as he was really into it, he still does that even today and he likes it and understands it. That occupational therapist did not see this as an opportunity to venture into as she complaint that my child scratches into the dustbins. She couldn't get pass the autistic person has abilities. She just believed that you are autistic therefore you can't do this and that. You should only be doing this and that and that, instead of taking what we have at that point and making the best of it." (P2)

Marietta also added that, "Professionals that keep on hampering on normalcy – they try to get everybody as much to the same as possible, instead of developing the individual's personal experiences of their world into something workable." (A3)

Isabella added, "I understand that as a therapist you can't get emotional with cases but I think a lot of parents even me will need sympathy. You as a parent get this diagnosis and think "what to do?" and you kinda of coming to a therapist on a sympathetic expecting way. You are not necessarily expecting them to feel sorry for you. You are just expecting them to be there for you. I think a patient will appreciate it if the therapist was more understanding than being stiff neck and saying sorry but I can't help. They must be encouraging and helpful." (P3)

Regardless of some negatives, the participants still believed that there are ways in which occupational therapists can play a big role in the transitioning process of the individuals with the diagnosis of ASD into the labour market. These ways were perceived to be lacking in individuals with ASD.

4.2.2.2 Ways in which the occupational therapist can assist in preparation for transitioning to into labour market

Table 4.9: Theme two, category two

4.9.1 Role of the occupational therapist	4.9.1.1 Ways in which the occupational therapist can assist in preparation for transitioning into labour market.	a. Case managers
		b. Skills training
		c. Job coaching
		d. Adaptation in a work place

The participants reported that occupational therapists can play a role in helping the individuals with ASD transition into the labour market. There are a number of perceived roles which participants reported that occupational therapists could play. Their perceptions were summed up under the following subcategories; case managing, skills training, job coaching, and adaptations in the workplace. These are discussed below.

a. Case managing

It was evident from the participants that occupational therapists, as the experts in the field of vocational rehabilitation, are expected to exercise their roles as case managers. This includes tasks such as assessment of the client, identification and placement of a client in an identified suitable job for client’s skills as well as raising awareness about mental health issues. The participants addressed the issue by saying the following:

Thabiso said, “So OTs should be able to go out there and say which menial type of job is there, which advanced type of job is there, where is it available and how can we access them. Then they can mediate for which labour marked is suitable for these children. They must be a lead agency that says we find suitable jobs for these people and correlate with other professionals. Then place these people accordingly.” (P6)

Nadia added to what Thabiso said as she stated; “I mean advocacy for these individuals will be really great. Getting people more exposed to people with this disability as it still has more negative connotation that people with disability can’t do anything. Advocacy that these people may have disabilities but they do have abilities.” (P1)

Regina as she concurred with other participants “People seem to put children with autism in a generalised box. So occupational therapists can help in addressing those issues. Another thing will be teaching their bosses at their work place about autism so that they know why do the person with autism behaves in a certain way.” (P7)

Annemarie for daughter “The occupational therapist could have advocated for my daughter at the college on how she could have been managed. There is a lot of things that the occupational therapist could have assisted her with.” (P5)

Hope “It could help if employers could be better informed about what it is and what the person with Asperger’s are capable of doing. If this comes from professionals like you it may carry more weight than the word of the person who has Asperger’s or autism” (A4)

Participants asked that occupational therapists be advocates for individuals with ASD in the workplace. They wanted occupational therapists to help ease the transition and help both individuals with ASD and the people who employ or work with them to understand what is needed during the transition in to the labour market.

To further this assistance, participants suggested skills training as there seemed to be a need for life skills training, as the participants indicated during interviews.

b. Skills training

The participants expressed a need for the individuals with ASD to be trained in certain skills that will assist during transition process. They indicated that there were skills necessary for successful transition into the labour that the individuals with ASD lacked. It was therefore suggested that occupational therapists are well trained to assist in this aspect.

Annemarie for son “They need to be assisted in developing life skills e.g., developing friendships, participating in activities of everyday, engaging in productive conversations.” (P2)

Marietta added that, “Training, advocacy, networking, serving opportunities; like conferences, media representation, working environment assistance, family wellness, the needs are all over the place, changing from day to day and person to person” (A3)

Hope “.... if only I can be empowered in self-advocacy in a gently and orderly way. Self-regulation (e.g. what to do if you get emotional, if you feel a meltdown coming, when you get angry, etc.)” (A4)

Mathew “Definitely people skills and personal interaction.” (A2)

Isabella “It will be beneficial for occupational therapist to continue guiding them. They can help by identifying behaviours that can be activated by transitioning changes and provide them with the skills that will help them settle in those transitioning changes. Therefore, the occupational therapist can play a big role in helping them settle in a new way of life.” (P3)

Hattie “So maybe you guys can help him to develop socially. Maybe in groups as this will help them to integrate with others. Not one on one session, that one is easy. They need to integrate with others. Teaching them to do things in groups as that is where the problem is. That will help them act appropriately in a neurotypical group. To get these kids to learn to socially integrate with others” (P8)

William “The therapist can assist these individuals with interview skills.” (P4)

Annemarie for daughter “Little group works and techniques should be done with then in time because when they become young adults it gets difficult to start them. And I am sorry young adults with autism can’t work on their own.” (P5)

Isabella “I think preparing them for what to expect in life after school in a sense and teach them skills on how to cope with difficult situations that they have not encountered as yet.” (P3)

Apart from skills training, the participants desired to receive job coaching during transition process into the labour market. It was stipulated that, individuals with ASD get into different jobs not knowing what is expected of them. Therefore, it was considered necessary to job coach them in order for them to transition smoothly to the labour.

c. Job coaching

The participants expressed the need to coach the individuals with ASD on how the job markets operate and how they must carry themselves. They stated that their transition could be better if they are trained concerning job market.

William “Err, I think it is basically just preparing them for open labour market. Guiding them through the process. Even if the therapist can be with them at the job side initially and then wining them off later on. Assist them to get comfortable in the work place.” (P4)

Warwick “Explain the reasons for having to actually look for a job. Coach us in confidence for interviews and what to expect.” (A1)

Hope “Yes, training in how to conduct yourself in an interview, how to sell yourself and social integration as well as sensory issues.” (A4)

The participants were also concerned that individuals with ASD struggled to adapt in a work environment. They therefore indicated a need for the individuals with ASD to be taught how to adapt into the labour market itself.

d. Adaptation in a work place

There is a need to teach the individuals with ASD skills that will assist them to adapt in a working environment. This was captured in the following statements:

Warwick “I also think that it would have been much easier for most people with autism if there were someone that could help them with the adaptation into a new work environment.” (A1)

Isabella “They need skills to keep themselves calm and how to cope in a work environment. Teach them to be independent in a way.” (P3)

William “And on the job side a therapist can help to assist them into the jobs because there are other employees who don’t understand the autistic person and everything around autistic person. So the therapist can ease them into the job and also to help them understand the job environment; that there are set rules and regulations to be followed.” (P4)

Marietta “The OT could identify places where people with autism could work.” (A3)

Summary of Theme:2

The perceptions of adolescent and adult individuals with ASD who have finished their formal education or training and their parents about the role that the occupational therapists can play in facilitating the unmet needs of individuals with ASD in transitioning into the labour market were explored.

The participants had both negative and positive perception about the occupational therapists. They indicated that some therapists were not empathetic and that caused the participants feel rejected and not supported. On the other hand, the participants indicated that the occupational therapist were helpful in their children's development however they felt that occupational therapists could provide more services than what they were providing currently.

It is therefore evident from the participants' responds that vocational rehabilitation as one of the occupational therapists' roles is an area that is in dire need of development which is not explored adequately at the moment. This area has been suggested as a lacking area for individuals with ASD who participated in this study.

4.5 Summary

Participants expressed a need for support through the transitional stage from school to workplace.

This study suggests that, while transitioning is a challenging period of life for anyone, individuals with the diagnosis of ASD appear to face even greater challenges than the general population, yet services to this specific group appear to be very limited at this point in South Africa (Pretoria to be specific). The experience of the participants of this study reflected a number of challenges in the transition in the labour market. Moreover, it was suggestive that the occupational therapists' role as the vocational rehabilitation specialists is in dire need.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter will discuss the results of this study. The first part of the discussion will focus on the challenges that the individuals with ASD experienced during the transition from formal schooling into the labour market. This will be linked to relevant literature. The second part of the discussion will focus on the role that the occupational therapist can play during transition of the individuals with ASD in the labour market.

5.2 The research context

The researcher noted the context within which the study was done in South Africa with members of Pretoria Autism support group based in the Gauteng Province where the unemployment rate is similar to the national average. Generally, transition into the open labour market in South Africa can be difficult as unemployment is officially at 29.1%, and possibly in reality higher in the last quarter of 2019 (Statistics South Africa, 2019). Finding and retaining employment is thus a tremendous concern for typically developing adolescents and even more so for individuals with ASD as they are less likely to be employed (Lindsay, Hartman, and Fellin, 2016).

It was evident in this study that although most of these participants with ASD were employed, they felt that it was harder for individuals who had disabilities (especially individuals with ASD) to find jobs. This difficulty was due to their lack of necessary skills allowing them to easily keep the jobs if they were employed (Hendricks, 2010).

5.3 The research sample

The study consisted of 13 participants, five individuals with ASD and eight parents of individuals with ASD. All the participants had an experience of the open labour market and therefore had a chance to look for jobs. The individuals with ASD were of different ages, gender and cultures, and had support from their parents. The parents were professionals, employed or were once employed in their life time and they were of middle

socio-economic status with resources to assist their children. This might have contributed to the high employment rate amongst the individuals who were interviewed for this study.

The rate of employment amongst the individuals with ASD was 92% with only one participant looking for a job. This was much higher than the 25% to 63.2% range of adults with ASD having ever been employed (Wei et al., 2018). This was due to the purposive sampling since individuals with ASD and parents of individuals with ASD who had experience with job seeking and employment in the open labour market that were selected and agreed to participate in this study.

All the participants except one had been employed since their early 20s. Two had have multiple jobs which had lasted three to six years. This supports research that indicates adults with ASD who were from higher-income households, who had better conversational or functional skills, or who had attended post-secondary schools have more positive employment prospects (Roux et al., 2013). These participants thus formed a very select sample purposely selected and represented high functioning individuals who had an opportunity to complete school and who could afford post-secondary training and who had worked in the open labour market. This sample appears to reflect those individuals with ASD who find employment in the open labour market in South Africa as they are similar to the sample described by Soeker (2020) in his study on transition for this population into work. Thus, the research findings cannot be generalised to other individuals with ASD in South Africa.

5.4 The perceptions of the individuals with ASD and their parents regarding their unmet needs when entering labour market

The main finding from this study indicates that individuals with ASD and their parents voiced the opinion that it was a real struggle to navigate the transition from schooling into the labour market successfully. This was encapsulated by the first theme that emerged from the research interviews: “Transitioning was really hard”. In general, transition periods can be difficult for all sectors of the population (Hendricks, 2010). However, analysis of the data seems to suggest that individuals with ASD experience more difficulties than the general population, thus supporting the idea that these individuals

require more support both preparing for the transition as well as while navigating the transition itself (Wehman, et al, 2014). These ideas will be discussed in more details below.

5.4.1 Theme 1: Transitioning Was Really Hard.

Participants in this study (both individuals with ASD as well as parents) reported that the transition from school to the labour market was a difficult and stressful time. The process of finding a job as well as keeping a job were plagued by misconceptions, unrealistic expectations, discrimination, struggling with change and feelings of being poorly prepared. Over and over again during the interviews, the participants with ASD emphasised they struggled to find jobs and to keep the jobs if they found them. The parents of individuals with ASD indicated that they also had unmet needs in terms of assisting their children in the transition into work.

5.4.1.1 Category 1: Finding a job was really hard

The first step in navigating the transition to the labour market successfully is finding a job. Participants in this study found the job seeking process really difficult. The literature confirmed that regardless of their education level, individuals with ASD struggled to get employed and spend a significantly longer time looking for a job (Chen et al., 2015; Wei et al. 2018). Firstly, there were many misconceptions of how one goes about finding a job. Many of the participants with ASD stated that they felt that job opportunities should come knocking on their doors and were surprised by the need to actively look for a job. This means that they either did not understand the process or they were never prepared for the process and were not trained before leaving school in terms of job seeking. This was an implication that there was not enough preparation from the education systems for individuals with ASD.

Chen et al., (2015) reported that although a higher educational level contributed to better employment of individuals with ASD it has been suggested that their lack of job seeking skills and prevocational skills necessary for labour market as a result of a lack of preparation from school system cost some individuals with ASD jobs they wished for. Thus, even after post-secondary training the participants reported that they generally

struggled to find jobs. Even with a qualification they still needed skills necessary to look for a job. They had unrealistic expectations about job seeking as supported by Hudson (2004) and Shattuck et al. (2012) who stated that individuals with ASD were faced with lack of support from formal education systems and lack of other resources important for a successful transition into the worker role in adulthood. Some participants in this study indicated that special support and services were available to them in South African post-secondary education institutions but this was to assist with their education and did not include preparation for the workplace. Their perceptions were supported by study conducted by Roux et al. (2015), looking at the transition into young adulthood. However, he found that even though services existed in the United States, in secondary education institutions, these offered guidance on understanding the effect of ASD and specific related needs in social situations and environmental accommodations and skills required for the workplace were not provided. Hendricks (2010) also found that VR services outside of education institutions in the United States did not accommodate the needs of individuals with ASD, often refusing to assist them. The situation reflected in this study indicates a similar issue with a non-availability of services for specific work transition needs of individuals with ASD, both in and outside the education system.

This lack of specific training to enter the workplace appears to have led to the misinterpretation of job seeking process and lack of skills. Individuals with ASD found it difficult to find a right job fit. They therefore accepted what was offered to them and were often placed in menial jobs such as non-qualified electricians, recycling and supermarket attendant. If they did manage to get a job, their social awkwardness and lack of communication abilities and skills, became more of a barrier since these are not accommodated in a job market, as they were in a school situation. This means that throughout their school years, expectations in relation to their communication were lower and these difficulties were not addressed in relation to what is expected in the workplace. Therefore, they felt unprepared and did not always understand the importance of communication for the transition to employment. According to Briel and Getzel (2014), communication and social difficulties of individuals with ASD presents one of the greatest obstacles to finding and maintaining work, particularly related to engaging in interactions with co-workers and supervisors.

The participants admitted that due to being socially awkward, and lacking in communication abilities, they always seemed to struggle to find a right fit in the job market. A lack of career preparation services and a poor knowledge about suitable careers, the work environment and employment activities related to these was reported by the participants with ASD as well as their parents. Thus, as long as these individuals' social skills are perceived as awkward, they will often find themselves in job markets where they are not happy and performing to their full potential. The literature indicated that matching the interests, skills and strengths of these individuals with a particular job could improve outcome performance of individuals with ASD (Nicholas et al., 2018). A poor match might lead to failure for the employee and disappointment for the employer (International Society for Research, 2018). Scott et al. (2019) report that only two studies in their scoping review considered the skills and abilities of individuals with ASD in the job matching process. Briel and Getzel (2014), indicate the importance of career guidance that will support an individual with ASD in choosing a career in a field that does not rely on good interpersonal skills but accommodates their strengths.

Participants reported due to their struggles to find jobs, they as individuals with ASD attained their jobs through the help of known others, even those who were highly qualified. This was supported by Baldwin, Costley and Warren (2014), as they indicated that 41% of the participants in their study were assisted by the people they know to obtain jobs. Wei et al. (2018) also reported that young adults with ASD were significantly less likely to find jobs themselves than other PWDs with 32% relying on friends and family and 20% on teachers to find them a job. Participants followed this route due to the negative attitude they experienced from prospective employers once it was realised that they were diagnosed with ASD. This proved to be an obstacle for their employment.

They reported that disclosing a diagnosis of ASD cost them a number of job opportunities even those jobs that they qualified for. This was supported by Nicholas et al. (2018) in their study who also found that that when an employer learned about the individual's diagnosis of ASD, they subsequently tended to not be hired. This may be due to the awareness and knowledge on the part of employers. Their negative attitude was commonly quoted as a limitation to successful employment as this also heighten existing

social anxiety of the individuals with ASD during the job application process (Briel and Getzel, 2014; Harmuth et al. 2018). It seems when family and friends or teachers assist with finding a job, employers may have better knowledge about ASD and this confirms the need to inform employers more widely about the ability of individuals with ASD to overcome the negative connotation attached to being autistic experienced in this study.

The participants indicated that there was no support system in preparation of individuals with ASD to transition into the labour market. They reported that they could not find any institution in South Africa that provided individuals with ASD with vocational services such as those described in the literature (Brooke et al., 2018). Parents' perception was that at LSEN schools, their children were used as cheap labour and their individual needs and interests were never supported. Their children were taught just daily basic skills and not work preparation skills which could benefit them in transitioning in to the workplace. There was lack of strategies for individuals with ASD entering into their junior and senior years of high school as suggested in the literature to warrant a smooth transition after they graduate was never put in place in the South African schools (Shattuck et al., 2012). The strategies suggested in the study by Frank (2015), include life skills, employment skills and other skills that apply to adapting to either college life or adult life. No published research on the programs offered to individuals with ASD in South Africa was found to support what the participants reported. However, it is evident that the Programme-to-Work Linkage suggested by the Department of Basic Education, for LSEN schools, in which learners should be able to develop using learning content specific to them and "master the required skills at school level to enter adulthood with sufficient education, in order to obtain and maintain successful employment", is not being implemented (Moosa, 2014: p33).

In the process of assisting the individuals with ASD to transition into the labour market, it is suggested they should be taught different social skills together with job seeking skills (Wehman et al., 2014). It is therefore necessary that specific services which can empower individuals with ASD are provided (Wehman et al., 2014).

Due to the mismatch and the unmet needs as well as other environmental and personal issues the participants with ASD not only struggled to find a job but to keep their jobs once they found employment.

5.4.1.2 Category 2: Keeping the job was even harder

The parents of individuals with ASD reported that their children were just not fitting in at work. This indicates that an individual with ASD's transition process needs to occur over a prolonged period, not just during job seeking. As the literature stated, individuals with ASD have difficulty with adapting to life changes and "Fit" of the job, therefore extended job supports that are suited to the individual with ASD are necessary for improving their job retention and satisfaction (Nicholas et al., 2018). Participants in this study reported both personal and environmental factors to contribute to their inability to keep their jobs if they happened to get them. The literature concurred with them as it suggested that the low employment rates seen globally are potentially related to both these factors (Brownlow, 2010; Gal, Ben Meir and Katz, 2013) and both should be addressed for smooth transition and retention of employment into the labour market (Wehman et al., 2014).

As in the process of finding a job, on the personal level, poor social communication and interpersonal skills were commonly reported as challenges to maintaining employment (Brownlow, 2010; Gal, Ben Meir and Katz, 2013). Other personal factors that also affected individuals with ASD such as cognitive functioning, behaviour management, stress, and anxiety when they are looking for jobs, still affected them regarding their job retention (Scott et al., 2019). The parents of individuals with ASD indicated their children were socially awkward, lacked communication skills and struggled to form relationships with their counterparts. The individuals with ASD themselves agreed with their parents as they said they struggled to fit in with their peer groups, they felt emotionally immature and could not make friends, as well as struggled in adapting to change. "some people with autism find change and transition difficult". This means it is important to understand how ASD affects each person individually in order to assist these individuals to deal with their needs from as soon as they start a job for achievement of a smooth transition.

Added to the personal challenges was the environmental challenge of workplace attitudes. The participants in this study indicated that, they were being stigmatised for having a diagnosis of ASD as once they had a job and they experienced negative attitudes at work place. Sometimes if they disclosed their ASD at their work places, rather than being well accommodated they were ill-treated, got demoted or certain responsibilities were taken away from them. They thus indicated that disclosing their diagnosis of ASD presented limitations for employment retention and promotion, which was reason enough for them to resign from their job.

There is controversy in the literature about disclosure by the individuals about ASD to their employer. The act of disclosing requires a level of emotional, and social conversation that may be difficult for an individual with ASD due to their communication deficits and social anxieties (Neely and Hunter, 2014). Ohl et al. (2017), however reported that disability disclosure actually contributed to successful employment retention in the United States since disclosure opened communication to the employers and allowed for reasonable workplace accommodations. These findings were supported by some of the participants in this study who indicated that they were still in their jobs because their immediate supervisors knew of their ASD diagnosis and therefore provided them support they needed

This experience was reported by a limited number of participants in the current study and other participants compared stigmatisation of individuals with ASD in work environment to racism. These findings confirm as some have posited in the literature that the real barriers to employment and job retention for this group lie not only in the socially atypical mannerisms of ASD but instead in society's labelling of the peculiarities associated with ASD as "deficits" instead of positive attributes in the workplace (Lorenz et al., 2016). Thus, society needs to learn to accommodate individuals with ASD with regard to their abilities not diagnosis and recognise their many strengths (Armstrong, 2010). de Schipper et al. (2016), suggest a strengths-based approach which can be used to assist those in the workplace understand the positive aspects that an individual with ASD such as "punctuality, low absenteeism, high quality work, prompt task commencement and strong work ethic" (Scott et al., 2019: p 882).

In this study stigmatization in the work place was reported even though under the constitution of South Africa employers were legally bound to support individuals with the ASD and to make reasonable adjustments, improving understanding of the colleagues and manager (The Constitution of South Africa, 1996). An awareness of ASD and the implementation of accommodations could prevent individuals with ASD from hiding their diagnosis (International Society for Autism Research, 2018). The employers, managers, supervisors and colleagues lack knowledge regarding ASD, and their negative attitudes also resulted in poor adaptations of the works environments in which individuals with ASD work. Flower et al. (2019), in their scoping review on the barriers and facilitators to employment for adults with Autism, stated that the individuals with ASD face numerous obstacles to maintaining meaningful employment, one of which is a lack of appropriate modifications to their work environments.

Reasonable accommodation for individuals with ASD is necessary in work environments (Thompson et al., 2018). Some of the participants indicated that they sometimes got frustrated as they struggled to cope with environmental structures such as light, noise and the office set-up that were “too much” for them. This occurs even if their colleagues and employees accommodate them. Since sensory input does affect their work performance it would be vital that they are placed in a building in which they will not be overwhelmed by sensory input. Participants in Baldwin, Costley and Warren (2014), study are of the view that their workplaces are often unsuccessful in providing accommodations and adjustments appropriate to their sensory, environmental and other needs of individuals with ASD. This again emphasised the importance of the selection of appropriate types of work where this type of environment can be achieved. However, as Thompson et al. (2018), indicated the maximization of the “person-environment fit” of the individuals with ASD in the workplace is poorly understood. This lack of understanding is impacted by societal expectations and the stigmatization that the individual with ASD faced since according to Hendricks (2010), successful employment of individuals with ASD is dependent on employers and co-workers who make an environment user friendly for them. In this study some participants who were employed reported that they were fortunate enough to work in environments which were not negatively affecting their work performance. Their work stations were conducive for their work performance and

participants reported that environments where they were working were accommodative and they could perform their work without environmental distraction. They had been accommodated by work environment's adaptations and support with regard to social interaction. These accommodations including changes to communication processes were necessary for them to be successful at work. It has been suggested that people who supervise, interact, or collaborate with the individuals with ASD need to be patient, flexible and tolerant in order for those individuals to keep their employment (Hendricks, 2010). Therefore, finding the just right fit in an employment situation can be difficult since it depends not only on the work but most importantly the people in the work environment. Capitalizing on this fit then includes employers and colleagues being educated about the characteristics of people with ASD, so they appreciate the specific accommodations required such as minimizing external stimuli and a workplace that is predictable and supportive (Hendricks, 2010).

As confirmed by Nicholas et al. (2018), the unmet needs in relation to employment support for the increasing population of adults with ASD presents with many challenges for this community. Although literature indicated VR programs provide training and supported employment for individuals with ASD internationally (Scott et al., 2019), these programs were not available to the participants in this study to assist them in overcoming the challenges they faced in employment. For example, one of the parents indicated that her child could hardly keep any job as her child got frustrated with the work environment and had no skills on handling labour market challenges.

It was from the view of the participants in this study that the individuals with ASD also experienced numerous unmet needs during their transition into the labour market. They managed to keep their jobs because some had supportive employers or a mentor and parents reported that they were very involved and had to support their children. One parent indicated that she had to travel with her son on his business trips. It was also clear that not only the individuals with ASD were in need of support in this regard, but their parents as well.

5.4.1.3 Category 3: Parents have needs too

The parents in this study reported that they supported their children as best as they could. That support according to the parents, assisted their children through transition process. Unfortunately, these parents have had to continue to support their children for long periods and it is fortunate they had the resources to do so. As the literature indicated that ASD is a lifetime disorder and parents often continue to be the primary caregiver until individuals with ASD reach well into their adulthood years (Hodgetts, Zwaigenbaum, and Nicholas, 2015). Which means these parents also need support in order to meet the challenges they face. The literature concurs as it suggested that in order to cope with the symptoms and co-occurring behaviour problems, to assist their child with the activities of daily living as well as deal with and cope with family-wide effects, parents often rely on both formal and informal supports (Hartley and Schultz, 2015). Research indicated that the diagnosis of ASD in the family may break marriages. Hartley et al. (2010), concurred that couples of children and adolescents with ASD are at an increased risk of divorce which may further affect the ability of the family to assist their child with ASD and provide continued support for the child. As the parents voiced in this study, they were in dire need of social and emotional support from government agencies and other services in terms of caring for their child and assisting with their child's transition into the workplace. Nicholas et al. (2018), in their study on evaluation of employment-support services for adults with ASD, found as a rule that families could not access the necessary community support systems. Their participants mentioned that there were numerous times when they searched for such resources which were unavailable, and this resulted in serious mental health outcomes and/or the end of their child's employment.

Hodgetts et al. (2015), in their study, profile the service needs for families of children with ASD, found that parents' greatest identified need was for information, followed by community services, and social support and they reported financial assistance as the lowest identified need. This indicates that enhancing social support should be another equally-valuable (if not more valuable) avenue for promoting positive parental well-being, since social support predicted changes in psychological well-being, above and beyond the impact of child behaviour problems (Smith, Greenberg and Seltzer, 2012).

Although the parents in this study did receive some social support from the Autism support group, they reported that they did experience financial strain in conjunction with their social needs (Clasquin-Johnson and Clasquin-Johnson, 2018). They complained about paying for expensive medical and school funds on their own to support their children. They reported a lack of public special schools which could accommodate their children. It is only since 2016 that the Gauteng Department of Education (GDE) has opened ASD units in LSEN schools (Evans, 2016) to reduce waiting lists. The parents in this study were unable to benefit from these recent changes but while these do provide as suggested more accessible and financially affordable public schools for individuals with ASD (Erasmus, Kritzinger and Van Der Linde, 2019), problems with accommodating all children still exist.

The participants reported that they felt that there was no support at all for them and their children in terms of preparing them for employment and supporting them in employment. They voiced the need for vocational services (Brooke et al., 2018) so that their children could be trained and prepared for suitable future professions and work endeavours. These services would be of great support for them and their children as the parents it will decrease the burden of parental support (Camarena and Sarigiani, 2009).

The participants believed therefore that occupational therapists have a role in supporting the individuals with ASD to transition smoothly into the labour market. This will be discussed in the categories below

5.5 Occupational therapists can do more

The participants indicated that there was value to occupational therapy interventions even though they could not measure it. This opinion is supported by literature that states that occupational therapists have expertise facilitating individuals' engagement in self-determination and building goals based on their strengths and preferences during transition between development milestones into adulthood (Clark, 2019). The American Occupational Therapy Association (2017), added that occupational therapists use client-centred approach which improves occupational participation. Occupational therapists

could therefore play an important role in effectively assisting individuals with ASD during their transition phase to the workplace.

5.5.1 Category 1: Participants perceptions of occupational therapy

The participants voiced their expectations with regard to the roles that the occupational therapist could play during the transition of individuals with ASD into the labour market. Both negative and positive perceptions were expressed by the participants in this study about occupational therapy.

The participants reported that some occupational therapists were not at all supportive and sympathetic of the individuals with ASD. Only one article in occupational therapy literature in South Africa was found which considered skills training for older individuals with ASD (Soeker, 2020). This was suggestive that occupational therapists may not provide intervention for older individuals with ASD. This was reported by the participants in this study in which in their experience occupational therapists appear not to render their services to individuals with ASD during transition period into work.

On the other hand, some participants reported that there was value to occupational therapy services. They indicated that occupational therapists could play a number of roles such as case managers, coaches as well as assist with skills training and adaptation in job market. Literature supported their opinions by indicating that occupational therapists may play a key role in enhancing the service delivery to elevate employment outcomes for individuals with ASD (Harmuth et al., 2018).

5.5.2 Category 2: Ways in which the occupational therapist can assist in preparation for transitioning to labour market

According to American Occupational Therapy Associations (2017), occupational therapists have been trained, to assess worker capacities, task performance, and the work environment, and to provide interventions related to these areas. Those roles are in line with what the participants in this study expected from the occupational therapists, namely case managers, skills trainers, job coaching and adaptation in work place. Research indicates that individuals with ASD that receive these VR services have more

positive employment outcomes (Burgess and Cimera, 2014). Part of occupational therapists training is to evaluate among other body functions the individual's psychological, and cognitive functions then link the individual's functional abilities to those required by the job. "In addition, occupational therapists have the observational skills, training, and expertise to perform complex task analysis and assessment of the environmental factors affecting work performance" (American Occupational Therapy Association, 2012: p1). Nicholas et al. (2018), stated that a determinant of success in supported employment appeared to be a good relationship between ASD job coaches and employers in exploring appropriate job opportunities and matching individuals' skills to the job. Therefore, this suggested that occupational therapists can indeed play a role in the life of the individual with ASD in transition into the workplace, since they are well equipped and trained to provide such services.

Skills training was also suggested in terms of the services that the occupational therapists were believed to be capable of providing. Parent participants seemed concerned that those individuals were lacking in independent living skills and were scared to think of what will happen to the individuals with ASD when they (the parents) were no longer around. Camarena, and Sarigiani (2009), supported this, as they reported that parent participants in their study stated that development of personal living skills would help their children to be independent and cope better at work. Rogen (2018), in a guide named: Life Skills Programs, indicated that individuals with ASD need well-structured and practical training on how to conduct their lives on daily basis. It was indicated that the individuals with ASD also need a step by step training in these skills, since they struggled with multitasking. The life skills training should occur in natural environments including the work environment, where the skills being taught related directly to the type of environment in which the individual was going to utilize them.

This supported the participants' perception that the individuals with ASD also needed intense skills training in terms of prevocational and skills related to coping in the workplace during the transition period. The participants reported that it was important that occupational therapists coached the individuals with ASD as a preparation to the labour market. They suggested that occupational therapists should provide work practice on

different job types in order to address and prepare the individuals with ASD for the challenges associated with job market. Employment training could also include on-site experiences in a variety of work settings, both paid and non-paid. Scaffolding techniques and referral to job coaches or professional supports should also be utilized to ensure proper transition in the work place (Rogen, 2018).

According to literature, in preparation to get adolescents with ASD ready for a career, it is essential to expose them to the job market through positive career development and early work activities (Lee and Carter, 2012). Thus, it is important that the individuals with ASD get skills training in preparation for transitioning into the labour market. Lee and Carter (2012), concurred that during the preparation of adolescents for their transition into the world labour market, after high school, it was important to teach social and employment related skills during the school years. This is a service which occupational therapists could provide as it involves activities related to career assessment and planning, exploration, instruction, and making connections to the potential employers (Frank, 2015). As a result, this practice provides meaningful opportunities to improve general employment skills and career readiness (Lee and Carter, 2012). It was also indicated that early exposure to work experience, gives individuals with ASD a better representation of what the job market will be like and what is expected of them (Frank, 2015).

Other literature, added that as much as the individuals with ASD reported a need to be trained in different life skills, training explicit to ASD, to increase the understanding and support of co-workers and supervisors about the diagnosis of ASD is also required (Lynas, 2014; Wehman et al., 2016). The participants agreed with this and emphasised that not only individuals with ASD would benefit from skills training but also their employers, colleagues and community members. This implies that individuals with ASD believe that most of their colleagues and employers are not informed about ASD and therefore do not understand the impact of ASD diagnosis in the workplace. It was suggested that occupational therapists could work together with employees and supervisors to improve adaptation of individuals with ASD in different labour markets. The American Association of Occupational Therapists (2017), stated that occupational

therapists facilitate success in the workplace by encouraging the fit between the person, the job tasks, and the environment. They work with employers and employees to adjust the environment or duty, in order to promote participation, productivity, and satisfaction in the workplace. In their study, evaluation of employment-support services for adults with ASD Nicholas et al. (2018), indicated that it was recommended that employees of individuals with ASD, receive guidance on how to optimally work with those individuals. International Society for Research (2018), added that instead of using “blanket training,” training of employers and co-workers concerning the unique needs of each individual with ASD and how to support them should be considered.

Apart from skills training, the participants indicated that the occupational therapists could take on the role of a case manager, and that they could be aware of the kind of jobs into which individuals with ASD could fit. They believed that occupational therapists have skills for advocating for individuals in the workplace as well. They felt that if the occupational therapists exercise this role the individuals with ASD will not find themselves in the work environments where “they don’t fit” and fail to keep their jobs. Advocacy in terms of guidance to employers in general by the occupational therapist on how to optimally work with employees with ASD was recommended (Nicholas et al., 2018). Literature suggests that providing advocacy is a traditional role in occupational therapy (Sachs and Linn, 1997; Smith, 2005). This suggested that the participants perceived the occupational therapists’ role in case management as advocates, was vital and needed.

Thus, findings of this study implied that the participants understood the challenges and their children’s unmet needs during transition to the labour market and had ideas of how these should be addressed. The participants suggested that the occupational therapist could assist the individuals with ASD with these skills necessary to adapt in the labour market. Individuals with ASD who were employed for at least one year or more suggested that individualized services, support from a coach, and focus on social and cognitive skills were important to successful work experiences. These services need to be started in the academic years and continued through pre-vocational and vocational training (Muller et al., 2003) for the survival of individuals with ASD, in a job environment. This often means

specific individualised assistance from a mentor and help if they are to perform successfully in their job and advance their careers.

5.6 Summary

The findings of this study suggest that the transitioning into the labour market is difficult for individuals with ASD. The participants had unmet needs that they need to see addressed. They experienced with stigmatisation and reported that finding and maintaining employment was impacted by their poor communication and social skills. They were not prepared for entry into the labour market in terms of the necessary skills to look for and keep jobs.

The parents of the individuals with ASD needed to be supported both emotionally and financially. The parents expressed the lack of support from professional services and their communities when their children are transitioning into work. In South Africa, access to VR services were very limited with poor implementation of laws in South Africa for PWDs. Franz et al. (2017), in their scoping review reported the urgent need for research in implementation of policies related to work for individuals with ASD in sub Saharan Africa.

The participants in the study also indicated that occupational therapists have a role to play during this transition process. They stated that with their skills occupational therapists could assist the individuals with ASD through their transition into the labour market. They identified some of the areas where the occupational therapists were not offering services and the areas where they can effectively assist in order to facilitate transitioning process (e.g. Case management, job coaching, skills training and advocacy).

CHAPTER 6: CONCLUSION

A qualitative explorative descriptive research method was used to explore perceptions of individuals with ASD and those of their parents on their unmet needs in terms of transition into the labour market and how occupational therapists could assist with the process. The study used a phenomenological approach by exploring the lived experiences of the participants, through giving them time to describe the problem from their perspective (Creswell. 2014:239). Semi-structured, face to face interviews were used with parents of individuals with ASD, while Email interviews were used with individuals with ASD to collect data. Data was analysed using inductive thematic analysis to develop themes, categories and codes.

The main findings of this study were transitioning was very hard, as the participants described a number of difficulties in their transition from education into the labour market by emphasising the main issues that led to a challenging transition for individuals with ASD. Difficulties clustered around the issue of finding a job and being prepared for the job seeking process, keeping a job, and the needs and challenges that parents of individuals with ASD also faced. Finding and keeping a job presented a challenge for most participants in this study and these challenges were similar to those reported internationally and were related to both personal and environment issues. It was indicated that the school system did not prepare the individuals with ASD for transition into adulthood and along with post-secondary educational institutions did not prepare them for the work place. Participants indicated that in South Africa services related to VR that supported individuals with ASD specifically, were unavailable. This lack of support placed a burden on the parents emotionally and financially and resulted in most of the participants relying on parents and friends to find them jobs.

There was little guidance as to which jobs would best suit individuals with ASD so that they had a better fit in the workplace. Participants reported varying levels of understanding about their diagnosis and accommodation being provided for them in their jobs. The lack of awareness about ASD and the social and environmental adjustments

needed for successful employment. It was suggested that not only was training needed in terms of skills required for work but that support was offered on a longer term basis once the individual with ASD had a job.

As a result, the participants suggested that occupational therapist have a role to play during the transition into work for individuals with ASD. The participants believed that “Occupational therapists can do more” and that encompassed both positive and negative views of occupational therapy and what could be included in an occupational therapy role from the perspective of the participants. Participants indicated that the occupational therapists have the potential to do much more than what they are offering at the moment. They stated that with their skills occupational therapists could assist the individuals with ASD through their transition into the labour market. They identified some of the areas where the occupational therapists were not offering services and the areas where they can effectively assist in order to facilitate transitioning process (e.g. Case management, job coaching, skills training and advocacy).

6.1 Limitations and contributions of the study

6.1.1 Limitations of the study

The study had several limitations. Participants were from a middle class socioeconomic backgrounds and had access to significant financial resources to provide for training for their children with ASD. Most individuals with ASD had jobs and some form of income. Their experiences may not represent those with fewer economic resources, who are not financially stable and therefore could not access the same services as the participants of this study.

There was no diversity in cultures involved as the Afrikaans speaking people predominately participated. Some cultures might argue that they were not well presented as there are differences to different cultures. This make it difficult to justify the results for general South African population as some of the South Africans might think that the perceptions only apply to the cultural group that dominated in this study. People who failed with their employment transition and who have not got employment were not

interviewed. Participants follow mainly scientific beliefs and those who follow cultural and spiritual beliefs were not interviewed.

6.1.2 Clinical contribution

While the study sample was small, purposive sampling enabled a rich exploration of the phenomenon serving to enhance the trustworthiness of the data, specifically the transferability of the findings (Thompson et al., 2018). The study explored both the viewpoints of the individuals with ASD and those of their parents. It concurred with the literature that there is a lack of vocational services in South Africa (within Tshwane district in Pretoria) for individuals with ASD. The services are scares for these individuals when they transition into the labour market.

It is therefore, necessary that occupational therapists develop the VR programs for adolescents with ASD that will be implemented during transition process. These programs should include; case management, advocacy, skills training, and job coaching. Again, it is vital that occupational therapists, need to listen more carefully to the needs of the people they work with as this will assist in rendering better service.

6.2 Recommendations

This study implies that there is a need for more studies by occupational therapists in South Africa where the individuals with ASD are participants. These studies will assist occupational therapists to gather more valuable information which can be used in developing VR services in preparation of individuals with ASD into the labour market. Occupational therapists are encouraged to take their positions and effectively implement what they have been trained in their profession as there is a gap in transition services that they have to close. This is an indication that:

- ✚ There is a need to investigate what is currently offered and what can be added regarding transition programs in South Africa.
- ✚ To engage in collaborative research between the researcher and individuals with ASD to ensure that research focuses on issues that are relevant to the population of individuals with ASD.

- ✚ To explore the perceptions of the population within lower socio-economic class who might have not been exposed to employment.
- ✚ To have this research conducted in different geographical locations as to explore whether the perceptions are similar or different to those described in this study.

6.3 Future research

Including more members from different support groups and any member of a community who is affected by the diagnosis of ASD will be appreciated. Exploration of perceptions of people who failed with their employment transition and have never got employment. Inclusion of people who follow spiritual and cultural believes is recommended.

A follow-up study with a larger national or international sample is recommended. It is acknowledged that the study represents selected part of Pretoria; hence, it cannot be assumed to be more broadly representative. Convenience sampling with qualitative interviews imposes a risk that certain groups may be under-represented (e.g. females with ASD, individuals with a lack of verbal capacity, impoverished individuals and families who could not join support group due to transport issues, cultural minorities, and individuals and families in rural and remote geographic regions). Broader regional and population representation in samples and a more granular analysis of sample distinctions are recommended in further study.

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Appendix A

DEMOGRAPHIC QUESTIONNAIRE: INDIVIDUALS WITH ASD

1. Age: _____

2. Gender:

Male

Female

3. Use of English language

3.1 First language English

3.2 Second language English

3.3 Limited use of English

4. Tell me about your employment history:

Job title	Years of Service	Reason for leaving

5. When did you complete your formal (school) training?

5.1 0-2 years ago

5.2 3-5 years ago

5.3 More than 5 years ago

PARENTS

1. Age: _____

2. Gender:

Male

Female

3. Use of English language

3.1 First language English

3.2 Second language English

3.4 Limited use of English

4. Tell me about your employment history:

Job title	Years of Service	Reason for leaving

5. Do you consider your child's Autism to be mild, moderate or severe?

5.1 Mild

5.2 Moderate

5.3 Severe

Appendix B

EMAIL- INTERVIEW SCHEDULE FOR INDIVIDUALS WITH ASD

Good day, I am Bonang, masters' student from Wits University and I would kindly like you to answer the following questions as part of my research project.

Tell me about your experience looking for a job.

- What was easy about it? Can you tell me about any difficulties you encountered at the time you were looking for a job?

Can you tell me about what kind of job you would like to do?

- Tell me about the kind of training that you think should be provided for individuals with ASD in with their transition to job market.

Tell me about your experience regarding occupational therapy intervention.

- Tell me about the support systems that you think occupational therapist should provide in assisting individuals with ASD for their transition to job market?

Appendix C

INTERVIEW SCHEDULE FOR PARENTS

Tell me about your experience of when your child finished school and had to start working.

Tell me about the challenges that you think your child might have experiences after finishing school and started looking for a job.

Tell me about your experience regarding occupational therapy intervention for your child.

- Tell me about the support systems that you think occupational therapist should provide in assisting individuals with ASD for their transition to job market?

Appendix D



R14/49 Ms BS Mhleka

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M170928

NAME: Ms BS Mhleka
(Principal Investigator)
DEPARTMENT: School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

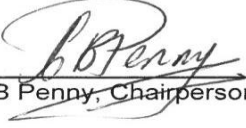
PROJECT TITLE: The perceptions and experiences of people living with
Autism Spectrum Disorder on their transition into the
labour market

DATE CONSIDERED: 29/09/2017

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Ms L Koch

APPROVED BY: 
Professor CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 23/03/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____

Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix E



Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa

Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: leilane.bogoshi@wits.ac.za | www.wits.ac.za

PERMISSION LETTER

The Chairperson
Autism Support Group
Pretoria

Dear Anna

Title: The perceptions and experiences of people living with Autism Spectrum Disorder on their transition into the labour market

My name is Bonang Sylvia Mhleka, and I am conducting research for the purpose of obtaining a Masters degree in Occupational Therapy at the University of the Witwatersrand. The aim of this research is to explore the perceptions of individuals with Autism Spectrum Disorder (ASD) and those of their parents on unmet needs in transition to labour market for individuals with ASD and how occupational therapists can assist individuals to facilitate this transition.

In order to do this, I would like to approach both the parents of individuals with Autism who have completed their formal training and the individuals with Autism who have completed their formal training. Each participant who agrees to participate in the study will be interviewed using a semi-structured questionnaire, requiring approximately an hour. Interviews will be recorded. Participation in this study is voluntary. Should participants choose not to participate in the study, they will not be discriminated against. Apart from my supervisor and myself, no one will have access to the data received, however verbatim quotes might be used in the research report. Names will not be used

in the report, and codes will be given, such as Individual A or Parent A. Confidentiality of information gained will be assured to the best of my ability, the documents and recordings will be kept in a locked cupboard and destroyed following final hand in and grading.

Should you agree to participate in a research project, would you please sign the consent letter attached, granting me permission to conduct the study.

For any ethical concerns please contact the chairperson of the Human Research Ethics Committee at the University of Witwatersrand, Prof P Cleaton-Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252, or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

Thank you

Student:

Bonang Sylvia Mhleka

Cell: 0722859127

Email: brownchurchblue@yahoo.com

Supervisor:

Ms Lindsay Koch

011 717 3701

lyndsay.koch@wits.ac.za

Appendix F

INFORMED CONSENT TO PARTICIPATE FOR PARENTS

I, _____, agree to be interviewed for the research project: The perceptions and experiences of people living with Autism Spectrum Disorder on their transition into the labour market which is being produced by *Bonang Mhlekwa* of University of *Witwatersrand*.

I certify that I have been told of the confidentiality of information collected for this research project and the anonymity of my participation; that I have been given satisfactory answers to my inquiries concerning research project procedures and other matters; and that I have been advised that I am free to withdraw my consent and to discontinue participation in the study at any time without prejudice.

I agree to participate in one or more electronically recorded interviews for this research project. I understand that such interviews and related materials will be kept completely anonymous and that the results of this study may be published for academic purposes

I agree that any information obtained from this research project may be used in any way thought best for this research project.

I would/would not like to receive a summary of results following completion of the study

My contact number is: _____

My email address is: _____

(Please print) name: _____

at _____ on _____

Signature: _____

Appendix G

INFORMATION LETTER

Title: **The perceptions and experiences of people living with Autism Spectrum Disorder on their transition into the labour market.**

My name is Bonang Sylvia Mhleka, and I am conducting research for the purpose of obtaining a Masters degree in Occupational Therapy at the University of the Witwatersrand. The aim of this research is to explore the perceptions of individuals with Autism Spectrum Disorder (ASD) and those of their parents on unmet needs in transition to labour market for individuals with ASD and how occupational therapists can assist individuals with ASD to facilitate this transition.

I would like to invite you as a parent of individuals with ASD who has completed their formal education or training to take part in this research project. I would like to ask that you agree to be interviewed using a semi-structured questionnaire, approximately an hour. I am also asking that you agree for the interview to be audio recorded.

Participation in this study is voluntary. Should you choose not to participate in the study, there will be no consequences. Apart from my supervisor and myself, no one will have access to the data received, however verbatim quotes might be used in the research report. Names will not be used in the report, and codes will be given, such as Parent A. Confidentiality of information gained will be assured to the best of my ability, the documents and recordings will be kept in a locked cupboard and destroyed after six years according to HPCSA regulations.

Should you agree to participate in a research project, would you please sign the consent letter attached, granting me permission to conduct the study.

For any ethical concerns please contact the chairperson of the Human Research Ethics Committee at the University of Witwatersrand, Prof P Cleaton-Jones at peter.cleaton-jones@wits.ac.za Contact details for the administrative offices: Ms. Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng, Tel: 011 717 2700/2656/1234/1252, or email: Zanele.ndlovu@wits.ac.za; Rhulani.mkansi@wits.ac.za; Lebo.moeng@wits.ac.za

Thank you

Student:

Bonang Sylvia Mhleka

Cell: 0722859127

Email: brownchurcbblue@yahoo.com

Supervisor:

Ms Lindsay Koch

011 717 3701

lyndsay.koch@wits.ac.za

Appendix H

INFORMED CONSENT TO PARTICIPATE FOR INDIVIDUALS WITH ASD

I, _____, agree to be interviewed for the research project titled: The perceptions and experiences of people living with Autism Spectrum Disorder on their transition into the labour market, which is being produced by *BonangMhlele* University of *Witwatersrand*.

I certify that I have been told of the confidentiality of information collected for this research project and the anonymity of my participation; that I have been given satisfactory answers to my inquiries concerning research project procedures and other matters; and that I have been advised that I am free to withdraw my consent and to discontinue participation in the study at any time without prejudice.

I agree to participate in one or more e-mailed interviews for this research project. I understand that such interviews and related materials will be kept completely anonymous and that the results of this study may be published for academic purposes

I agree that any information obtained from this research project may be used in any way thought best for this research project.

I would/would not like to receive a summary of results following completion of the study

My contact number is: _____

My email address is: _____

(Please print) name: _____

at _____ on _____

Signature: _____

Appendix I

Turn it in report

PERCEPTIONS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER (ASD)

ORIGINALITY REPORT

9%	7%	5%	5%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	journals.sagepub.com Internet Source	1%
2	www.healio.com Internet Source	1%
3	Submitted to University of Pretoria Student Paper	<1%
4	fisherpub.sjfc.edu Internet Source	<1%
5	www.tandfonline.com Internet Source	<1%
6	journals.plos.org Internet Source	<1%
7	uir.unisa.ac.za Internet Source	<1%
8	www.agasd.org Internet Source	<1%
9	digitalcommons.liberty.edu	