THE MEANING OF OCCUPATION IN ADULT AUTISTIC INDIVIDUALS' EVERYDAY LIVES

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

DECLARATION

I Arisha Magan declare that this Dissertation is my own, unaided work. It is being submitted for the Degree of Master of Science in Occupational Therapy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

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(Signature of candidate)

On 12 day of May 2018 in Australia.

DEDICATION

To my participants and all the autistic individuals, whose voices are yet to be heard.

ABSTRACT

Autistic individuals have been stigmatised and branded as individuals with limited contributions to society. Through various interactions with autistic individuals, a discrepancy between what autistic individuals hold as meaningful and what the neurotypical society think is meaningful for them became evident. This study evaluated the lived experiences and the meaning of occupation in the everyday lives of five adult autistic individuals. This qualitative study was done in two sequential phases. The first phase evaluated blogs by the participants to gather information about their lives and the second phase consisted of an E-mail interview, which provided an extension of information about their everyday lives. This study found that the participants demonstrated a fierce desire to be successful and realise their hopes and dreams however, due to their behavioural challenges they have been unfairly ostracised and deemed unfit to positively contribute to society. They have faced significant barriers to participation in their occupations due to poor awareness and acceptance of ASD by the neurotypical society. The participants are calling out to the world to hear their voices regarding what is important to them and what can assist them in allowing improved participation in their occupations. This has culminated in the participants becoming self-advocates for autism to promote autism and enlighten the neurotypical society on their capabilities. A major part of this study revolved around using technology to communicate with the participants and this reiterated the benefit of technology-mediated communication in the participants.

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LIST OF ABBREVIATIONS AND DEFINITIONS

Adult autistic individuals: Individuals in this study prefer to be referred to using this term and thus it has been used throughout this research report.

NAUWU: Nothing About Us Without Us.

ABA: Applied behavioural Analysis.

DTT: Discrete Trial Training.

SARRC: Southwest Autism Research and Resource Centre.

AAC: Alternate Augmentative Communication.

ANI: Autism Network International.

DRM: Disability Rights Movement.

AUTOCOM: Autism National Committee.

DSM V: Diagnostic and Statistical Manual of Mental Disorders.

UCLA: The University of California at Los Angeles.

DIR: Developmental, Individual-Differences, Relationship-Based.

ADHD: Attention Deficit Hyperactivity Disorder.

ASAN: Autistic Self-Advocacy Network.

LOL: Laugh Out Loud.

ASD: Autism Spectrum Disorder is a neurodevelopmental condition that is characterised by difficulty with social interaction, communication and by restricted or repetitive behaviour (Audet, 2010).

ASD individuals: The general autistic population.

Participants: ASD individuals in this study.

Underemployment: The under use of a worker due to a job that does not utilise the workers skills (Nord et al. 2016).

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

Occupation: Meaningful activities that individuals engage in on a daily basis (Dickie, 2009).

Occupational justice: An extension of social justice. The term justice is used to discuss occupational well-being and inclusion that takes various people and contexts into account.

Occupational deprivation: When individuals are excluded from opportunities to participate in meaningful occupations due to factors outside their control. Ethnic, cultural and religious minority groups, prisoners, unemployed people, child labourers and women are globally experiencing occupational deprivation in the sense of occupational choice and opportunities (Townsend et al. 2004).

Occupational alienation: A social condition of injustice when individuals feel alienated or isolated. People with disabilities, either physical or mental, and those who live in senior citizen homes are among the few who experience occupational alienation (Townsend et al. 2004).

Occupational apartheid: Situations where some individuals are offered the opportunity to participate in occupations, while it is restricted to others. This is a result of the individuals’ race, disability, gender, age, nationality, religion, social status and sexuality (Durocher et al. 2014).

Occupational marginalisation: When individuals are excluded from occupational participation based on hidden norms that decide who should participate in the occupations. These individuals are denied in decision-making and the choice to participate in occupations that are meaningful to them (Durocher et al. 2014).

Occupational balance: A balance in engagement in occupations that lead to well-being. For example, the balance may be among physical, mental and social occupations, between chosen and obligatory occupations, between strenuous and restful occupations, or between doing and being (Wagman et al. 2012).

Occupational imbalance: The preoccupation of time in one area of occupation at the expense of others (Durocher et al. 2014).

APPENDICES

PROLOGUE

During my community service year, I treated two autistic children and developed a relationship with them. Many treatment sessions proved to be unsuccessful as it resulted in meltdowns and not achieving the aims of the session. As a therapist I felt helpless. It was not until I attended a course on autism held by autistic individuals that motivated me to pursue a master's degree with a focus in autism. After joining the *Ask me, I'm Autistic* group on Facebook, and reading posts by autistic individuals, I began conversations with the group administrator.

Arisha Magan: ***"…I found all your posts extremely interesting and I want to now actually find out what is important to autistic individuals…" "The way I will structure my research is to have discussions with people through blogging and through fb, thereafter sift through the information and then conduct interviews."***

I requested to join many groups on Facebook to propose my idea and encourage participants to engage with me. There were groups that refused to allow me to post my research idea. This became stressful until someone told me that autistic individuals are wary of researchers because they believe that researchers exploit them.

Arisha Magan: ***"My main aim in the research is to give autistic individuals a voice about what is important to them."***

I believe talking to autistic individuals about their experiences and needs is the first step to achieving an integrated and inclusive society.

CHAPTER 1: INTRODUCTION

1.1. Introduction to research problem

Many autistic individuals go through life unheard and misunderstood. Through electronic discussion with autistic individuals, they have raised the idea that they are judged based on society's expectations on how one should act and behave without any consideration for the creation of a meaningful life for the individual (Ask me 2016). It is true that most of the time these individuals do what is expected of them. However, this does not mean that it is valuable to them as an individual. Occupational therapists believe that people create meaning in their lives through *doing*. It is not only the absence of disease that provides a sense of health and well-being but also being able to engage in occupations that are meaningful and important within an individuals life (Hocking 2009). This is an occupational definition of health and underpins all of occupational therapy. To achieve successful intervention and outcomes therapists and clients work together to develop a suitable treatment plan (Cohn 2009). Autistic individuals have unique barriers to sharing their perspectives and needs with therapists due to their social, behavioural and communication difficulties, making collaborative treatment difficult and complex (Cohn 2009) (Kuhaneck et al. 2010). Treatment options often focus on moulding behaviour to appear acceptable, rather than dealing with occupations that are meaningful to the individual. To stay true to occupational therapy philosophy it is imperative to understand what value autistic individuals place on occupations. Limited research has been done to understand the lived experiences of autistic individuals and what they hold as meaningful in their life. Therefore, the perception of what a "normal healthy lifestyle" is may differ for a therapist and for an autistic individual. Technology has opened new ways of communicating with autistic individuals from which their perspectives can be obtained. Thus it is critical to investigate their experiences in order to ensure meaningful, collaborative client-centered therapy.

1.2. Research Problem

Adult autistic individuals have raised concerns of the stigma attached to the diagnosis of Autism Spectrum Disorder (ASD). It was suggested that there might be a misconception between what occupational therapists view as meaningful for autistic individuals and what they themselves experience as meaningful. It was important to explore autistic individuals' experiences and perceptions of *doing* in the world and environment that they live in to understand how occupation creates meaning in their lives.

1.3. Research question

What is the meaning of occupation in the lives of autistic individuals?

1.4. Purpose of the study

The purpose of the study was to explore the experiences of autistic individuals in an attempt to understand the value and importance of occupations in their lives. The study intended to observe the amount of *doing* within their activities of daily life and how this contributes to their development of self-actualisation and individualism.

1.5. Aims and objectives

The aims of the study were to explore the lived experiences of autistic individuals in order to understand the meaning of occupation in their lives.

1.6. Objectives of the study

The objectives of the study were:

- To explore the nature and range of occupations in which autistic individuals participate.
- To explore the meaning of occupation within the everyday lives of autistic individuals.

1.7. Justification for the study

This study could be beneficial to therapists, as it will give them an opportunity to look deeper into the autistic mind and gather information on what autistic individuals find meaningful and valuable. In occupational therapy models, there is a strong focus on client-centered therapy and this is only possible if the client is part of the process. This study will provide autistic individuals with a voice to allow for a deeper understanding of what they view as meaningful.

CHAPTER 2: LITERATURE REVIEW

This literature review will attempt to summarise current literature on autism and occupation. The researcher made use of some older references as this was the primary scientific sources found. The review will begin with a discussion of occupation and its relation to health and well being. This will be followed by a discussion of the diagnosis of autism and its relationship to meaningful occupation. Disability awareness and advocacy will be briefly reviewed and finally the use of technology as a means for understanding the inner lives of autistic individuals.

2.1 "To be is to do" ~Jean Paul Sartre

2.1.1 Occupation and Health

Jean Paul Sartre, a French philosopher believed that man is responsible for himself and that man is free to create the world in which he lives and make his own decisions. Sartre believed that relationships are important to us because we need others to see us and make us real (Casmiro 2016). In conjunction with this philosophy, occupational therapists believe that *doing* in life is the embodiment of being human (Wilcock 1999). It is not only the absence of disease that provides a sense of health and well-being (Hocking 2009), but also being able to engage in occupations of everyday life that are meaningful and important to an individual (Dickie 2009). To be is to do best summarises the philosophy of occupational therapy.

When one *does* a sense of *'being'* is formed. This means that they are true to themselves. For an individual to *be* who they are in different situations and in participating in activities of daily living is dependent on the environment, which can either enable or disable the individual (Mallinson et al. 2010). This leads to *becoming*, which describes self-actualisation and ultimately the constant state of *becoming* different. Essentially, occupation is the natural biological mechanism for health (Wilcock 1999). *Doing* maintains and develops physical and mental capacities. *Doing* provides opportunities for social interaction and societal growth (Wilcock 1999). There are three levels related to what a person *does* in their life. These levels are known as occupational participation, occupational performance and occupational skill. Individuals seek meaning and fulfilment in their lives and set goals with the intention of achieving happiness and satisfaction (Emmons 2003) (Reilly 1961). This goal directed behaviour is a direct reference to occupation as goals serve as motivators to how individuals want to lead their lives (Christiansen 1999). There needs to be a balance between *doing* and *being* to achieve a healthy lifestyle. When *doing* and *being* are in balance it leads to *becoming*, which is a reference to personal growth. Occupational therapists facilitate talents and abilities by enabling people to *do* and to *be* (Wilcock 1999). These levels come together to allow a person to form an occupational identity such as who they are and who they wish to become in their everyday life through *doing*. If one is unable to participate in meaningful occupations it changes their occupational identity (Klinger 2005) (Vrkljan et al. 2007) (Christiansen 1999).

Individuals with physical, mental or neurological difficulties experience occupational dysfunction in *doing, being* and *becoming* (Wilcock 1999). Despite what most of these individuals enjoy doing, they face external barriers that place their well-being at risk. An example of an external barrier is the perception given to the public by medical science, which has generally laid the foundation for the way one views a disorder. Health professionals use the terminology of medical science to describe the meaning of disability, illness, dysfunction and health and wellness. The words ‘normal’ and ‘abnormal’ have been used to judge and describe people with disabilities and in particular autistic individuals. This view is obscuring the influential relationship between occupation and health as using these words to judge people with disabilities, including autistic individuals, based on their physical, mental or behavioural challenges has been reported as hurtful. However, they are forced to live with it as these are the professional terms used (Causton-Theoharis et al. 2009). Essentially, this undermines the individual with the disability and portrays them as inferior beings (Hocking 2009). The social, political and ecological environment such as the financial state of the individual, the amount of resources available and whether they are employed or not exacerbates occupational dysfunction when it fails to allow them to participate in their meaningful occupations (Wilcock 1999) (Price et al. 2002).

It is this occupational dysfunction that can result in occupational injustice, which demonstrates itself through occupational deprivation, occupational alienation, occupational apartheid, occupational marginalisation and occupational imbalance (Townsend et al. 2004). The concept of occupational justice includes occupational rights with a focus on promoting inclusion and participation in meaningful occupations (Durocher et al. 2014) (Townsend et al. 2004). In viewing an occupational 'just' world, speculation arises over how individuals can develop as equal citizens within their daily lives.

2.1.2 Becoming an occupational being

An occupational being encompasses two aspects; the biological need for occupation and tempo and temporality. This means that human beings need to be occupied to meet their human needs. These human needs include the need for self-care and shelter, the development of social skills and to strengthen personal capabilities. It has been established that when an occupational being *does* it impacts positively on their health and well-being however, the speed at which this *doing* takes place is another impacting factor. If occupations are done hastily rather than slowly it would be more difficult to create a deeper and fulfilling experience (Clark 1997). How one crafts their occupational life is dependent on how they form and maintain their occupational identity and competence. For an occupational being to evaluate or create meaning in their life they integrate their past, present, and future selves. An occupational being makes sense of the present through interpretations of the past, and the experience of the present shapes the path for the future (Clark 1997).

When individuals participate in occupations they develop roles pertaining to that occupation. A role is defined as a concept that gives someone an identity and a sense of obligation. That is, individuals can view themselves as a parent, sibling or friend and would fulfil certain obligations to meet these roles. This leads to internalising the role (Kielhofner et al. 2009). Roles shape what one does in their life and inhabiting roles happens at different times depending on the day or week and what the individual is meant to do at that given time. Roles guide occupation by influencing how one acts, dresses or relates to others (Kielhofner 2008). There is a need to understand the diagnosis of ASD so that autistic individuals will not be restricted to what they can or cannot *'do'*, and therefore give them the opportunity to develop as occupational beings.

2.2 "Autism … offers a chance for us to glimpse an awe-filled vision of the world that might otherwise pass us by" ~ Dr. Colin Simbleman

2.2.1 Autism Spectrum Disorder: The Diagnosis

Autism spectrum disorder (ASD) is a neurodevelopmental disorder, which is believed to cause significant disability for the rest of an individual's life (Pajareya et al. 2012). The prevalence of ASD is on the increase due to changes in diagnostic criteria and early screening (Spreckley et al. 2009). In a systematic review and meta-analytic article, it was reported that 38.9 per 10 000 children from a population-based sample in South East England are diagnosed with ASD (Williams et al. 2006). Fombonne (2003) reported that 34 per 10000 children are diagnosed with ASD in the United States of America, and concluded that the rate of ASD is 3 to 4 times higher than what it was 30 years ago (Fombonne, 2003).

Henry Maudsley, a Victorian-era psychiatrist was the first person to notice developmental process difficulties in young children. He initially thought their difficulties to be psychoses. However this viewpoint changed with Leo Kanner in 1943, when he published "Autistic Disturbances of Affective Contact" which produced the word "autism", derived from the Latin word auto, which refers to the self (Causton-Theoharis et al. 2009). Kanner, a psychologist working at John Hopkins suggested that autism had been misclassified as mental retardation or childhood schizophrenia. The characteristics identified at the time included a child's lack of responsiveness to environmental input and their inability to relate to other people (Glennon 2010). Kanner also identified another core feature of autism such as the persistence on sameness (Volkmar 2015), which means insistence on the same thing that the autistic individual finds interesting.

There has been constant debate around the causes of autism. Early theories developed the term “refrigerator mothers”. This insinuated that the mothers of autistic individuals were cold and had unfeeling relationships towards their children. Bruno Bettelheim, the director of the Sonia Shankman Orthogenetic School at the University of Chicago from 1944-1973, agreed with this idea even though Kanner dismissed it. In 1964, Dr. Bernard Rimland, a psychologist in San Diego, California and father to an autistic individual published a book called *Infantile Autism*, where he challenged the concept of refrigerator mothers and brought about a new dimension to autism. Dr. Rimland, who founded the Autism Society of America concluded that autism is more of an organic disorder with a possible genetic component (Glennon 2010).

Research on autism was supported by parents, advocacy groups and the engagement of groups such as Autism Speaks, the Autism Science Foundation, and the Simons Foundation (Volkmar 2015). Evidently, research on autism has increased substantially over the years, shedding light on the confusion regarding previous diagnostic validity (Schaaf et al. 2010). A recent article by (Rice et al. 2017) mentioned that the causes of ASD have been linked to multiple genetic variations, which include rare gene mutations, chromosomal deletions or duplications and methylation differences. Even though environmental influences are also likely to cause autism, there is limited information on what predisposes one to an ASD diagnosis. With this information, there is more widespread knowledge regarding diagnosis, intervention and outcomes for autistic individuals (Schaaf et al. 2010).

The Diagnostic and Statistical Manual of Mental Disorders (DSM V) differs from its predecessor the DSM IV as it no longer defines autism as a stand-alone diagnostic entity. Instead it is a diagnosis consistent with other neurodevelopmental conditions such as pervasive developmental disorder. The DSM V has also created a symptom severity scale which describes the severity of the individuals diagnosis and places autism on a continuum or spectrum (Carpenter 2013). Autism is characterised by difficulties in social interaction and communication throughout everyday life. Further, it includes limited ability to display emotions and interests and trouble in understanding both verbal and nonverbal cues and gestures. Other features are indicated by an insistence on sameness and preoccupation with particular behaviours to extremes where individuals engage in repetitive behaviours and that autistic individuals do not understand the cognitive science of religion and are generally atheist. This results in having restricted interests (Kielhofner 2008) (Kuhaneck et al. 2010) (Spiker 2012) (Caldwell-Harris et al. 2011).

According to the DSM V, autistic individuals face sensory processing difficulties in addition to social difficulties. These difficulties have been identified in autistic individuals since the initial description of autism and its associated features. A few examples of this include increases in pain tolerance, hypersensitivity to sounds, touch, taste, light or smells. Experiencing sensations are an integral part of our lives as it allows the brain and body to communicate with the world. Sensations are experienced and organised through our neural system and are known as energies that stimulate nerve cells and initiate neural processes. The sensory input provides an individual with information about the physical aspects of the body and the environment after which the neural system is able to inform the body what to do. This influences behaviour and competence in the tasks of daily life (Ayers 2005).

Autistic individuals will either overreact or show little attention to sensory stimuli depending on their sensory processing abilities (Ayers 2005). The sensory processing difficulties experienced by autistic individuals occur when sensory input is not registered correctly resulting in too much or limited attention on a phenomenon. Further, sensory input is not modulated well especially with the vestibular and tactile sensations (Ayers 2005). Autistic individuals struggle with sensory modulation which can result in the individual being under responsive or over responsive to the sensory stimuli. The thalamus and brainstem are parts of the central nervous system that house sensory integration. When an individual experiences stress because the sensory processing system that should be happening automatically is not, an autonomic nervous system response takes place which results in the activation of the sympathetic nervous system. This is commonly known as the fight or flight response (Case-Smith et al. 2010) (Kushki et al. 2013). As a result, the individual will shut down and this may present itself in the form of self-stimulation such as rocking or spinning, avoiding behaviours such as placing their hands over their ears to eliminate the auditory input or sensory seeking and tuning out behaviours such as ignoring environmental cues (Schaaf et al. 2011). This is known as a meltdown. Autistic individuals experience meltdowns when there is sensory overstimulation, for example strong smells from chemicals, emotional stresses, and changes in the environment (Greenspan et al. 2006). Meltdowns can be caused by a number of factors such as a build up of frustrations, sensory issues, interactions with others or being away from home (Attwood et al. 2015) (Lipsky 2011).

A study that examined sensory processing and autism reiterated that autistic individuals face sensory difficulties, but that these difficulties do not persist into adulthood (Kern et al. 2007). Another study that evaluated sensory processing in adults found that adult autistic individuals have abnormal levels of responding to sensory stimuli and these sensory abnormalities manifests itself uniquely among all adult autistic individuals (Crane et al. 2009). Research into sensory processing has mainly focussed on children rather than adults however, (Crane et al. 2009) highlights that sensory processing difficulties continues from childhood into adulthood. Other areas of dysfunction include anxiety, sleeping and eating disturbances, temper tantrums and self and other-directed aggression (van Steensel et al. 2017) (Spreckley et al. 2009) (Realmuto 2015).

2.2.2 Autism spectrum disorder- the reported problems

Autistic features have been reported to interfere in the participation of occupation including social participation, routinsation of activities of daily living, work and leisure time pursuits.

There has been a significant body of literature detailing the challenges faced by autistic individuals, a large part of which is dedicated to challenges regarding their social skills. Social skills are generally viewed as socially acceptable learned behaviours that are important for social participation. When individuals develop these social skills they are able to participate in meaningful occupations and develop comfortable relationships with others. This in turn impacts positively on a person's self-esteem (Hilton 2010). Social participation is a challenge experienced by autistic individuals. Research has suggested that there is a marked deficit in social interaction among autistic individuals as they have difficulty in forming relationships and defining what a relationship is. This social deficit is identified by their lack of non verbal behaviors, the difficulty experienced in establishing and maintaining a relationship, as well as not enjoying the same interests as neurotypical individuals or having poor verbal skills. The nature of these social challenges culminate in the exclusion of autistic individuals from participation in social and recreational activities (Orsmond et al. 2004). Social interactions that come naturally to other people can be daunting to autistic individuals which can lead to the development of social anxiety (Grandin 2006) (Orsmond et al. 2004).

Sensory processing difficulties have been reported to cause difficulties with the routine of an individual (Schaaf et al. 2011). The routine of an individual is dependent on their roles and habits and the characteristics of the temporal, social and physical environments. Routine behaviour is achieved when behaviour is repeated in a stable environment. Habits include how one performs their daily routine. What an individuals does, how they do it and when they do it is a reflection of their habits. Habits are influenced by routine behaviour, the use of time and one's occupational performance (Kielhofner 2008). (Kuhaneck et al. 2010) noted that autistic individuals face difficulties in following routines and (Schaaf et al. 2011) explained that this difficulty is evident through their ritualistic behaviours which affects participation in daily life. These ritualistic behaviours occur when autistic individuals struggle to regulate their behaviour when the environment presents multiple stimuli (Schaaf et al. 2011) (Rodger et al. 2011). Performing routines are shown to be stressful among some autistic individuals. The stress associated with these experiences can, at times result in catatonia, which is a manifestation of behavioural experiences such as mutism, akinesia and maintenance of a forced posture (Wing et al. 2000).

Individuals engage in occupations that are meaningful, and this is guided by an individuals' unique occupational choice (Kielhofner 2008). Occupational choice is present in the leisure occupations that individuals engage in as it provides them with an opportunity of free choice and to determine which interests they would like to pursue which creates an oasis to recharge themselves physically, psychologically and emotionally. This includes dealing with stress as engagement in leisure serves as a balancing function that counteracts stress (Iwasaki et al. 2005). It has been reported that autistic individuals have a preoccupation with restricted interests (Spiker 2012) (Kuhaneck et al. 2010) and therefore have limited occupational choice. This insinuates that autistic individuals will not achieve the social inclusion, self-expression and rejuvenation that leisure pursuits offer (Caldwell 2005).

Free choice of engagement in occupations applies to the occupation of work. Human beings have the right to work as stated in Article 23 of the United Nations' Universal Declaration of Human Rights. Individuals have a right to favourable and fair working conditions and to protection against unemployment. The occupation of work provides daily structure and having a purpose however, the percentages of unemployment rates for people with disabilities remains high (Enable 2007). Nord et al. (2016) explains that although employment has positive influences on autistic individuals, as it improves their social, emotional and financial well-being, autistic individuals experience difficulty in finding and maintaining a job as well as face underemployment due to their social, communication and behavioural challenges (Nord et al. 2016). Holwerda et al. (2012) justifies that unemployment rates for autistic individuals are high however, employment opportunities are available in the form of sheltered employment, voluntary work or regular work, which includes supported employment. Individual supported employment is known to be effective for people with significant disabilities as it addresses individual barriers, support and career planning, assessment, social capital development and employment customisation (Holwerda et al. 2012).

A lack of employment may cause adverse effects on self-esteem, self-efficacy and ultimately a sense of belonging. Accommodations or adjustments that can be made at work can also be made at university. A systematic review by (Gelbar et al. 2014) showed that limited research has been done on autistic individuals and tertiary education. Although there seemed to be increased awareness into autism, relatives of the autistic individuals reported bullying, being easily distracted, and difficulty in prioritising tasks and schedules among these students. To support this accommodations included breaking tasks down into smaller pieces, providing clear instructions and expectations of the work to be submitted and assistance in making plans. Extending deadlines and allowance of extra time on examinations were other helpful accommodations.

Communication is a key concept in understanding what people want or need in their life. It is a way to express feelings or emotions. When individuals connect with people on a social and emotional level communication plays a key role. Communication can be divided into the use of language and non-language behaviours, (which includes eye contact, gestures, body language and voice tone), and one should be competent in both to achieve effectiveness and independence in a social and cultural environment. It is reported that all autistic individuals experience difficulty in communication, as their speech may often sound parrotlike and lack typical intonation but they are able to communicate using both or one of these aspects of communication. Occupational therapists and other therapists can contribute positively to the development of an autistic individual if the therapists are able to understand both ways of communication (Audet 2010). If one can understand these different methods of communication, there is a better opportunity for intervention to be tailored to autistic individuals' specific needs.

2.3 “Everyone is a genius. But if you judge a fish on it’s ability to climb a tree, it will live it’s whole life believing that it is stupid.” ~Albert Einstein

2.3.1 This is how ASD is generally treated

Many methods have been put in place to obtain the highest level of functioning within autistic individuals and to provide them with the opportunity to lead a healthy lifestyle (Case-Smith et al. 2008). A meta-analytic study by touched on the types of treatments related to autism. These treatments include ABA, DIR/Floortime and sensory integration approaches. Other therapies include specific diets such as gluten and casein free diets, which evaluate behavioural and physiological aspects of the individual. The main focus of this article was on ABA as it appears to be the most researched intervention method (Peters-Scheffer et al. 2011).

Applied Behavioural Analysis (ABA) has been the traditional method of intervention for autistic individuals as it has the largest evidence base for best practice (Sherrod 2016). ABA was developed by psychologist Ivar Lovaas, a graduate from the University of Kansas and who developed the UCLA Young Autism Project. Lovaas published a number of articles in the 1960’s regarding his system for coding observed behaviours and what led to problem behaviours within children. He proposed reinforcements and teaching children imitation will assist non-verbal children to speak. Electric shocks played a role in reducing aggressive behaviour including self-injury however, these methods did not prove to be effective. This led Lovaas to begin intervention at earlier ages, involving parents in the treatment program and applying the intervention within the home setting as opposed to an institutional setting. Behaviour modification progressively turned into behaviour analysis. The function of behaviour, what promoted it and maintained it, was analysed so that it could be replaced by successful behaviour (Wikipedia 2017) (Speaks 2017).

ABA uses a method known as Discrete Trial Training (DTT). DTT is used to help autistic children to learn and think like neurotypical children, to improve communication, creativity and critical thinking. This method is used through repeating a command or instruction and thereafter providing the answer. Once the child repeats the answer they receive a positive reinforcement. The child is expected to gradually provide the answers with fewer clues given (Pearson 2017).

Developmental, Individual-Difference, Relationship-based (DIR®) therapy offers an alternate perspective on therapy. DIR® offers a different intervention approach for autistic individuals. Dr. Stanley Greenspan developed this method in the 1970's. Developmental refers to six stages of development, individual-difference is the way in which a child processes information and relationship-based discusses the learning relationships that allows the child to progress in his development. This approach is also referred to as Floortime™ however, it should be made clear that Floortime™ is a component of a comprehensive DIR® based intervention program (Greenspan et al. 2006). Floortime™ has a primary focus on creating learning interactions that are emotionally meaningful. To complete a comprehensive DIR® program, occupational therapy, speech therapy, semi-structured problem solving activities and peer play opportunities are included. This model has aided children in creating a more intimate and warm environment as well as a high level of abstract reasoning and empathy (Greenspan et al. 2006).

A comparative study by Hilton et al. (2007) described the effectiveness of ABA and Floortime™. With one-step instructions the presentation of 60 minute ABA therapy was done through discrete tasks such as 'point to the cow.' There were 5 activities involved with 10 correct responses set as criterion. Primary reinforcements were first offered and later reinforcement schedules were used which included a choice of activities (e.g. blowing bubbles). The reward system usually lasted for 3-5 minutes after which the stimulus-response-reward cycle was repeated. During the DIR/Floortime® sessions, the same materials were used as the ABA sessions however, the children were able to choose the activities. The clinician followed the child's choices with comments such as 'Let's play with the cow'. Prompting for gestures, vocal or verbal were used. Different to ABA reinforcement, Floortime used high-fives, clapping and praise (Hilton et al. 2007).

The results from Hilton et al. (2007) revealed that ABA and DIR/Floortime® both showed results but in different categories. ABA proved to be more successful with the autistic individuals in social-affective signalling, while DIR/Floortime® showed improvement in reciprocity and symbolic behaviours. No improvement was noted in communicative function. Both DIR/Floortime® and ABA strives to improve the way in which a child develops. DIR/Floortime® seems to offer a more welcoming approach to autistic children compared to the firmer approach from ABA (Hilton et al. 2007).

Behavioural intervention is not necessarily an occupational therapy approach to intervention with autistic individuals however, occupational therapist's may consult with behavioural therapists and propose strategies that best suit the individuals physiological or sensory needs. Behavioural techniques make use of reinforcement and punishment, which have proved to be beneficial in reducing problem behaviours. These techniques are generally used interchangeably and have shown positive results in the management of autistic individuals (Case-Smith et al. 2008). The intervention strategy of DIR/Floortime® corresponds to the philosophy of occupational therapy, particularly in the social skills domain. This intervention uses prompting and cueing to facilitate peer interactions and to create suitable environments to support social interaction (Case-Smith et al. 2008).

Jean Ayers developed an approach known as sensory integration. Sensory integration describes both the basic and essential neurological functions that involves organising sensory information for use. Sensory integration is a frame of reference, which is unique to occupational therapy. Sensory integration aims to tackle sensory issues and encompasses engagement in occupation to achieve a general sense of health and participation in life (Mailloux et al. 2010). This approach encompasses the idea that if a child engages in individually tailored sensory- motor activities, their nervous system is better enabled to modulate and organise their senses appropriately and thereby work towards more meaningful participation in social situations.

Case-Smith et al. (2008) described that a goal of sensory integration intervention is to improve a child's ability to modulate arousal to achieve well-organised adaptive responses. In a systematic review of sensory and motor intervention for autistic children, Baranek (2002) identified positive changes in social interaction, purposeful play and decreased sensitivity. Although sensory integration therapy has demonstrated positive results, Case-Smith et al. (2008) discussed that this intervention does not promote overall functional and educational outcomes (Case-Smith et al. 2008) (Baranek 2002).

Mulloy et al. (2009) described other interventions. It was suggested that the use of a gluten and casein free diet was not effective in autistic children, but should only be used if the autistic individual has a food intolerance or allergy (Mulloy et al. 2009). Music therapy is another form of therapy that involves music therapists using 'response evoking techniques'. This involves musical interactions in relation to the child's expression and focus of attention, which results in joint musical engagement (Kim et al. 2008). To work on social-communicative skills in autistic children the Picture Exchange Communication System (PECS) was used. Six instructional phases were used where phases I and II involved exchanging pictures for preferred items and activities. Phase III assisted autistic learners to discriminate between preferred and non-preferred items. Phase IV requested using complete sentences, phase V involved instruction in answering the questions and lastly in phase VI, autistic individuals learned to make comments (Lerna et al. 2012).

With regards to the occupation of work, occupational therapists play a role to find the most suitable employment opportunities for people with disabilities. They assist these individuals to enhance their vocational potential in an attempt to improve their vocational outcomes (King et al. 2009) (Kirsh et al. 2005) (Mukaetova-Ladinska et al. 2016). This contributes towards developing a suitable quality of life, one's self-esteem, developing a sense of who they are and who they wish to become as an occupational being (Phelan et al. 2009) (Gerhardt et al. 2011).

Essentially, in occupational therapy, the therapist together with the individual being treated usually guides intervention (Case-Smith et al. 2008). Despite the success of these intervention strategies it is difficult to assess the extent to which intervention and outcome is meaningful and valuable to them. Due to the limited amount of research on an autistic individuals' perception of occupation and what they attach meaning to (DePape et al. 2016), it can be seen that most research on intervention has predominantly focussed on children and behaviour and it is questioned whether this level of functioning and description of what a healthy lifestyle should be is important to an autistic individual.

2.4 "If you think I'm puzzling, imagine what the world is like for me."

~Unknown

2.4.1 What is normal?

The general conception of the idea of being human revolves around a person having distinct characteristics where each person is expected to function according to a set template with a given set of rules. One should assess being human by their positive contributions to society rather than by specific characteristics, which the general public deems to be normal (Rochat 2006). In a narrative by an adult autistic individual, it was explained that any deviation from society's view of 'normal' leads to punishment and isolation from those who are regarded as 'normal' (O'Neill 2000). The challenges that autistic individuals and people with disabilities have faced resulted in many of them being ignored and excluded from participation in society. They were judged as inferior to others because of their differences and because they may not have behaved in a socially appropriate way (Ward et al. 1999). In essence, they were not valued or believed to be able to contribute to society in any way. It was further suggested that the longing to feel a sense of belonging was ignored as people who act differently to what is considered normal are kept on the fringes of society (Blank et al. 2015). This denial of equal moral worth is a feature of discrimination (Hellman 2008) (Thornicroft 2009).

2.4.2 The concept of neurodiversity

While it is believed that autistic individuals have different behaviour traits to neurotypical individuals, Judy Singer, a sociologist who was diagnosed with Asperger Syndrome, created the term neurodiversity. Neurodiversity is referred to as a philosophy based on social acceptance and equal opportunity for all individuals who have a different neurology. The neurodiversity movement was developed in the 1990's by an online group of autistic individuals and are gaining civil rights for individuals diagnosed with neurological conditions. This movement follows the belief that atypical neurological development is a normal human difference. In particular, autism among other neurological conditions is a natural variation of being human and should therefore be respected. Secondly, neurodiversity emphasises recognition and acceptance of the neurodiversity condition which is related to rights and non-discrimination (Jaarsma et al. 2012).

Neurodiversity includes conditions such as dyslexia, autism and attention-deficit/hyperactivity disorder (ADHD). One should look at the strengths and values that these conditions have contributed towards today's society in terms of evolving technology and promoting cultural awareness and acceptance, (Silberman 2015) rather than as a dysfunction. Neurodiversity encourages people to use the term *autistic individuals* as opposed to *individuals with autism*, as the latter term insinuates that autism is separate from the individual. The neurodiversity movement is trying to emphasise that autism is part of an individual and influences the way they lead their lives (Jaarsma et al. 2012).

2.4.3 The Model of an Integral Human Science

The concept of neurodiversity is redefined in Yerxa (2009) where it is suggested that in order to understand and view all individuals as human beings it is imperative to unite the *'I'* of intention with the *'it'* of behaviour, the *'we'* of cultures and the *'they'* of social systems. To describe the connotations of these pronouns, the Model of an Integral Human Science, developed by the contemporary philosopher Ken Wilber was used. The Model of an Integral

Human Science uses four quadrants to understand an individual. *'I'* lies in the upper left quadrant, and this refers to the conscious self, who thinks, feels and perceives, and further includes goals, emotions and interpretations. This includes personal experiences and is therefore integral to an individual. The *'it'* of an individual lies in the upper right quadrant, and this refers to the behaviour of the individual. The *'it'* relates to an external perception of the individual, who interprets the significance of the behaviour. *'We'* exists in the lower left quadrant and encompasses the values, habits and rules emerging from a community. Lastly, *'they'*, which is situated in the lower right quadrant includes society and social systems. The article by Yerxa (2009) highlights the dilemmas caused by focusing on the *'it'* factors as a means of improving an individuals occupational life. This results in dismissing the conscious experience of the individual, which leads to ignoring the *'I'* of the individual culminating in reducing their autonomy and self-respect (Yerxa 2009). How then can one sincerely help another if they do not understand their internal experiences?

By applying the Model of an Integral Human Science to autism, a study by DePape et al. (2016) suggested that most of the literature has focussed on parents, teachers, siblings or caregiver perspectives (DePape et al. 2016). This implies that focus has incorporated the *'it'* and *'they'* factors, while less attention has been on the *'I'* factors (Griffith et al. 2012). This study which examined the lived experiences of autistic individuals through a qualitative meta-synthesis, emphasised the importance of gaining the lived experiences of autistic individuals as it clarifies any misunderstandings, as well provide insight on methods to improve services for autistic individuals.

A further example on the dilemmas faced when focusing on the *'it'* factors comes in the form of neurotypical individuals attaching labels to autistic individuals by referring to what they can or cannot do. The negative implications of attaching labels onto autistic individuals was described by Amy Sequenzia, a non-speaking autistic individual with co-morbid conditions of epilepsy, cerebral palsy, dyspraxia and insomnia. Sequenzia is a multiple disabled activist and writer about disability rights, civil rights and human rights and is well accomplished despite her setbacks. In a blog written by Sequenzia she mentions that she has been labelled as ‘low functioning’ all her life and that she refuses to accept this label as it does not make sense, even though others have graded her. This brings in personal causation, which describes one’s sense of capacity and effectiveness (Yerxa 2009). Sequenzia knew her worth and ability and disagrees with labels (Sequenzia 2012). Sequenzia explains how doctors and teachers labelled her as being ‘not smart’ because of her diagnosis. Sequenzia (2017) states, “As for having an intellectual disability, I taught myself how to read at a very young age, but even if I am intellectually disabled, I still have value, I demand to be respected, I am a person.” (Sequenzia 2017). This statement is profound as it emphasises that each person is unique and has their own experience of their strengths and weaknesses.

Sequenzia is proud of who she is, and she emphasises that the journey was not easy without the help and support she received. Once her worth was recognised she was respected and seen as a whole person. This helped her confidence grow and fight for autism acceptance (Sequenzia 2017). Many people think autistic individuals are autistic savants meaning they exhibit strange behavioural mannerisms but they do have the ability to be brilliant in some field for example music or art. Despite their ability to be extraordinary, there are some individuals that may behave differently, but should not be deemed unfit to be able to lead a “normal” life (Sacks 2006). We as human beings face challenges, which may impact negatively on our confidence and self-worth and ultimately our personal causation (Audet 2010) (Yerxa 2009).

2.5 “If you’ve met one person with autism, you’ve met one person with autism,”~ Dr. Stephen Shore

2.5.1 The lived experience

Georg Simmel, a German sociologist whose focus was on social individuality and fragmentation sees human experience as endlessly creative and most meaningful when in the service of being an individual. Individuality makes someone unique (Simmel 1971). Our uniqueness drives the development and progression of society and history is littered with individuals who through their identity changed the world. These individuals, most of whom are deceased did not have the diagnosis of autism, but displayed the characteristics of an autistic individual. Examples of these individuals include Albert Einstein who improved the worlds understanding of physics. He spoke at the age of three, had limited social interaction and was able to concentrate on an interest with much intensity. Other individuals include Wolfgang Amadeus Mozart, who was a musical prodigy, Marie Curie, an excellent scientist and Thomas Jefferson, the third president of the United States of America to name a few. These individuals serve as mentors for many autistic individuals in an attempt to improve their self-esteem. These examples argue against the common perception of normalcy. These famous individuals have significantly contributed to the world and it is this very contribution that makes one human (Ledgin 2002).

2.6 "Without individual experience and meaning coupled with doing, there is no occupation" ~Gary Kielhofner

While the difficulties in social interaction experienced by autistic individuals are true, most of this literature is based on observation or parent reports. Müller et al. (2008) draws on the perspectives of autistic individuals themselves on how they experience their social worlds (Müller et al. 2008). These autistic individuals emphasised that although they face difficulties in communication and initiating social interactions, they long to develop relationships and desire work, romantic and social connectedness. This was reiterated by an autistic man named Birger Sellin who described loneliness as an enemy and the longing he had for social connection (Causton-Theoharis et al. 2009). Hilton et al. (2010) reported that the autistic population do not have many friends despite the observation that they were aware of and interested in friendships (Hilton et al. 2010) (Orsmond 2004). The way the social world works remains complex to many autistic individuals (Holwerda et al. 2012). This can lead the autistic individuals to be bullied. The psychological effects of bullying can result in deterioration of well-being, health and low self-esteem (Kowalski et al. 2013). A study that evaluated social skills training programs with autistic individuals was conducted to understand their experiences, responses and opinions. The study indicated that autistic individuals were not given a voice or able to state their preferences. Their needs, autonomy and opinions were not considered (McLaren et al. 2014).

Ward et al. (2000) describes the lived experiences of an autistic individual. The article described that due to the diagnosis of autism the individual was bullied and teased, which caused the individual to become frustrated. The individual emphasised that he worked very hard at school and university as he had goals in life and that accommodations made it easier for him to cope. He also explained that he had various interests and hobbies and this also comforted him in stressful situations. In this article, sensory difficulties such as the lack of eye contact was described where he reported that eye contact can be a painful experience and this contributed to people thinking that he was not serious or not paying attention. This individual also emphasised that not all autistic individuals are the same as they each have their own set of strengths and weaknesses. He also explained how working in suitable conditions based on sensory needs can be beneficial. Lastly, the individual emphasised that he is proud of who he is despite the challenges that he faces (Ward et al. 2000).

O'Neill et al. (2000) discusses another description of an autistic individual. She sheds light on the pride she feels to be autistic and that one should not view having the diagnosis of autism as a negative one. She emphasises that people through different therapies should not try to change an autistic individual into someone who is more socially acceptable, but rather accept and love the person as they are. She further explains that rejection and lack of understanding from her teachers were hurtful. She explains that the concept of normalcy is a social and subjective concept and any deviation from this leads to punishment. This autistic individual communicates through writing and she describes that one should not judge an autistic individual based on their ability to speak as the innate nature of a person is more meaningful. This individual explains that she endured many adversities in life that have scarred her, but she chose to rise above this and *do* as neurotypicals *do* by not renouncing her individuality. She does not blame autism for her suffering, but rather the ignorance of society. She further emphasises that one should show love towards people with disabilities as everyone needs to feel a sense of belonging and to feel valued. This individual also described that she had goals, but was labelled as someone who could not achieve this based on her challenges, affecting her chances of employment (O’Neill et al. 2000).

There is limited research on sexual autonomy for the autistic individuals (Travers et al. 2010). In a personal account of an autistic individual she expressed that many people feel that it is not necessary to educate autistic individuals about sex. However, this can be damaging and depressing for most autistic individuals and may also lead to sexual vulnerability (Lawson 2005). As human beings, we all go through the process of puberty around the same age however, the way this is experienced differs as autistic individuals’ cognitive and emotional stages may be delayed compared to their physical changes (Sevlever et al. 2013). In a study by Cridland et al. (2014), it was suggested that most studies have focussed on autistic male individuals, and therefore not much is known about female sexuality. This study, which examined mothers and their autistic daughters, highlighted the difficulties faced during puberty and sexual relationships with a major concern towards the risk of sexual exploitation (Cridland et al. 2014). Sexuality develops throughout one’s lifespan and has an occupational dimension as it influences identity formation, contributes towards self-esteem and influences one’s feelings and thoughts. Sexuality further embraces occupations such as grooming or dating (Sakellariou et al. 2006) (Rogers et al. 2017).

2.7 “Courage is what it takes to stand up and speak. Courage is also what it takes to sit down and listen.” ~Winston Churchill

2.7.1 Becoming an advocate

Autistic individuals are proud of who they are and are aware of their abilities. This pride has given them the courage to become advocates for autism to clear the misconceptions about autistic individuals (Reid 2000) (Taylor 2016). Müller et al. (2008) stated that there are limited studies that describe the perspectives and unique nature of autistic individuals and thus there is an absence of their voice. They are calling out to the world to hear their voices, but the question as to what extent are their voices being heard still resonates deeply (Müller et al. 2008).

This feeling of gaining equal rights and getting their voices heard was expressed from the 1960s with the evolution of the humanisation of disabled people, which started in the United States of America and is still continuing today. This evolution started by giving children with disabilities a form of education. The second step came from the Independent Living and Disability Rights Movement to give people with disabilities equal opportunity. Since then, individuals with disabilities realised that they were marginalised and oppressed and as a result became angry. They were made to feel less intelligent, had poor decision making skills and were incapable of making decisions regarding their life. These individuals started movements that encompassed the belief that they have rights, could choose, belong and participate as an equal member in society (Ward et al. 1999).

Previous viewpoints about people with disabilities are changing and people are starting to accept and welcome them with more ease than before. This change is also influenced by the disability rights movement and Nothing About Us Without Us (NAUWU). The NAUWU draws its philosophy from the Disability Rights Movements. There are numerous self-advocates who want their voice heard and who continue writing articles or posting information about what works for them or what does not (Charlton 1998).

Ed Roberts, one of the leading figures of the international Disability Rights Movement (DRM) that started in the 1960’s redefined what independence means. He rephrased independence as the control people with disabilities have over their lives and that this independence should be measured by one’s quality of life rather than the tasks they can perform without assistance (Ward et al. 1999). He further went on to say, “it’s that when others speak for you, you lose” (Charlton 1998).

Thus came about the birth of self-advocacy, which was started by Benget Nirje in Sweden and was initially started as a civil rights movement. This movement rebelled against being underestimated and deprived of choices in decision making (Ward et al. 1999). Herbert Lovett, an autism and disability advocate founded the Autism National Committee (AUTOCOM), which is a self-advocacy group. This group consisted of parents advocating on behalf of their adult autistic children. When these parents were not willing to work on an equal footing with able autistic individuals, three autistic individuals formed the Autism Network International (ANI) in February 1992. One of the founders, Jim Sinclair, explained the purpose of this group. He highlighted that the main focus of the group was for self-advocacy and self-efficacy. He went on to say that parents and professionals acting on behalf of autistic individuals is not the same as them speaking for themselves. He explained that parents and professionals are more concerned about taking care of disabled people rather than the rights and freedom for them. He stated, “Also, I think that people who are living with the condition know better what their needs are” (Sinclair 1992).

2.7.2 Autism awareness

Autism awareness is increasing throughout the world. Autistic individuals have created groups and communities as a form of a support system. There are many other groups on Facebook that claim to support autism awareness. Denise Resnik, co-founder of the Southwest Autism Research and Resource Centre (SARRC), mentioned that autistic individuals need communities that consist of a support system. This includes supporting social activities, a place of worship, healthcare, jobs and transportation. It is essential that autistic individuals be included in mainstream society rather than excluded to become part of a community (Speaks 2016). Silberman also noted in his book *Neurotribes,* that if the general public as well as companies understand autistic people their contributions to society will be noticed (Silberman 2015).

This emphasises the importance of understanding what is meaningful to people and how they go about achieving their maximum potential within their everyday life (Kielhofner 2008). This reiterates the importance of acceptance and understanding the adversities individuals face and how it impacts on their occupational performance. When thinking and acting from the perspectives of one's occupational nature happens, then can their occupational health be addressed (Wilcock 1999).

2.8 "Tech gives the quietest student a voice" ~Jerry Blumengarten

2.8.1 The role of technology in giving Autism spectrum disorder individuals a voice

It has been established that autistic individuals face communication impediments (Rosenhall et al. 1999). Autistic individuals are comfortable and become more motivated by using computers and the internet as a way of expressing themselves (Goodwin 2008) (Gillespie-Lynch et al. 2014). Technology has assisted them in overcoming the social challenges they may experience when engaging in face-to-face interaction. Using computer-mediated communication, autistic individuals are given the opportunity to immediately relate what is on their mind, rather than wait for others to finish. In this way, communication is uninterrupted and they are given control over their communication (Gillespie-Lynch et al. 2014).

The recent revolution of technology is being utilised in ways that can enhance autistic individuals' abilities and provide a supportive method of treatment. The Internet, audio and video recorders as well as electronic sensing technology, computer architecture, hardware and software, virtual reality and robotics are the technological means that are currently being used. These technological methods are useful strategies in the treatment of autistic individuals. In support of technology using the Internet and in particular, online services, can offer immediate support to autistic individuals when they are facing a crisis as opposed to waiting for appointments (Goodwin 2008). Some individuals face difficulty in certain areas of their life at various times during the day. Posting on an online site may offer immediate response that can help the individual promptly (Ask me 2016). Many individuals who are non-verbal are able to "speak" and communicate using social media sites (Zurcher 2016). Another benefit of technology is the accessibility autistic individuals have to it. In effect, secure online environments have been developed to support families and allow professionals anywhere in the world to access it (Goodwin 2008).

Using E-mail interviewing in qualitative data has been able to provide more detail and understanding of social and cultural processes. This is achieved through in-depth interviewing, which is generally unstructured in nature, to allow space for probing questions (Meho 2006). There are generally three methods of qualitative research done through E-mail interviewing namely online synchronous interviews, online asynchronous interviews and virtual focus groups. Asynchronous interviews are characteristically semi-structured. It takes place over multiple E-mail exchanges and not necessarily done at the same time between the interviewer and interviewee as done with synchronous interviews. Further asynchronous interviews are not influenced, shared or viewed by other participants, which is done in virtual focus groups. Asynchronous interviews are more favourable with individuals who do not prefer to be interviewed face to face and are geographically dispersed (Meho 2006). It has been shown that using this method of E-mail interviewing for qualitative studies is encouraging and therefore the use of this method is significantly increasing (Meho 2006).

E-mail interviewing has considerable advantages. E-mail interviews are more cost effective than interviews via telephone or face-to-face interviews, especially for participants who are geographically dispersed. Additionally, using E-mail interviews removes the demand for synchronous interviews, and thus more than one participant can be interviewed at a time. A difficulty with this is the time period for responses. The time period the researcher may wait for responses may vary from days to weeks, which will ultimately effect data collection time. In addition, this method of research is favourable as it extends to individuals and communities that otherwise would not and could not have been studied. It is also true that with E-mail interviews, the researcher may not be able to read nonverbal cues such as facial expression and body language however, E-mail interviews eliminate difficulties that are experienced during face-to-face interviews. To accommodate non-verbal cues the researcher may use abbreviations such as ‘LOL’ (laughing out loud), as well as using emoticons as a means for participants to express themselves online (Meho 2006).

Technology has provided assistance in communicating with people and serves as an outlet when one feels overwhelmed. Technology has provided meaningful occupations to certain participants by giving them a voice. Augmentative and Alternative Communication (AAC) allows for the expression of thoughts, needs and ideas without using oral speech. Augmentative aids include pictures and symbol communication boards and electronic devices (Association 2017). The participants may struggle to express themselves through words, gestures or expressions however, this does not mean that they are incapable of doing so (Kuhaneck et al. 2010).

Scott Michael Robertson is an autistic self-advocate and vice president of the Autistic Self-Advocacy Network (ASAN), which is an international autistic-run organisation that aims to expand societal acceptance and community understanding for individuals across the autistic spectrum. He mentioned that media attention mainly focuses on young children while ignoring autistic adolescents and adults are ignored. Volkmar (2015) reiterated this by explaining that it is more common to hear a person talking about autistic children rather than autistic adults, which implies that these children never grow up, or that no concern is given to the individuals once they have grown up (Volkmar 2015). Robertson, a doctoral candidate at Penn State University, considered how online communities are able to empower autistic self-advocates and in particular he studied how online collaborations with educational professionals helped develop autistic specific accommodations and transition resources for autistic college students (Van Pelt 2008).

3. Conclusion to literature review

Much of the research conducted in autism has focussed on the features of autism and in particular how this can be treated in children. While health professionals acknowledge the importance of *‘doing’* in every day life, the meaning of occupation in autistic individuals’ lives have not been dealt with in much depth, especially in adult autistic individuals. Adult autistic individuals, through the use of technology, have tried to express what would add meaning to their lives however, their voices have not been addressed formally. This study took advantage of the positive influence technology has in communicating with autistic individuals and sought to understand the meaning of occupation in adult autistic individuals everyday lives.

CHAPTER 3: METHODOLOGY

3.1. Philosophical foundations for research method

This study was based on the social constructivist worldview. The researcher explored the minds of autistic individuals aiming to give them the opportunity to form subjective meanings of their lived experiences. The study was strongly dependent on the individual’s views of the situation being studied, that being the meaning of occupation in their lives. Open-ended questions played an integral part of the study, since in the social constructivist worldview individuals should evaluate the meaning of the situation through interactions with other individuals. The social constructivist worldview embraces the contexts of individuals in terms of where they live and work and therefore understanding the cultural settings of the participants. This tied in well with the aim of this study, as it gave the researcher a clearer idea of what the individuals held important in terms of their occupations. The social constructivist worldview interprets the values each individual places on the world in which they live. Each individual has experienced life differently. This embraced the social constructivist worldview as it linked to the assumption that qualitative researchers should understand the context of these individuals through gaining the information personally (Creswell 2009).

3.2. Overall study design

This study reflected a descriptive qualitative research design. This design was selected as the study was directed towards discovering personal experiences of the meaning of occupations within the lives of autistic individuals (Creswell 2009).

The study consisted of two sequential phases, which will be described separately.

3.3. Phase 1: Micro-blogging through social networks

3.3.1. Population:

The population consisted of autistic individuals who were 18 years and older, either verbal or non-verbal, but who were able to communicate through some form of typing through social media. The researcher used a closed Facebook group, which is only available to members, to source participants. The participants on the group were from all over the world however, an attempt was made to sample only South African participants, however this was unsuccessful. A survey was created on the Facebook group by the group admin, requesting individuals who would like to participate in the study. This consisted of check boxes, which the members of the group were required to mark. Those who were willing to participate were sent E-mails by the researcher detailing the information of the study. Once the participants were happy to continue with the study, the researcher E-mailed the consent forms for phase 1.

3.3.2. Sampling:

The sample consisted of a selection of blogs collected from a private group on Facebook, of which the researcher is a member, and from the participants' own website used for blogging. This group consists of autistic individuals and related caregivers or health professionals who are 18 years and older from around the world. The sample was directed towards autistic individuals who shared their personal views and ideas on how to improve autism awareness. The blogs were sampled based on their applicability to the study. Blogs that were included in the study were required to meet the following two criteria:

(a) Obtained consent from the blogger to include the blogs in the study; the blogger should have a formal diagnosis of autism and is a member of the Facebook group.

(b) The content of the blog included information or writing about any of the following topics: participation in occupations of daily living, the meaning or value of occupations in daily living.

One hundred and ninety-six blogs were sampled from the last 6 months, for 2 months. Thereafter, the researcher chose one hundred and ten blogs from the one hundred and ninety-six blogs, which were re-sampled for an additional three weeks until data saturation was achieved. This was achieved as no additional data was found to develop new categories.

3.3.3. Data Collection:

Data was collected by downloading the blogs that met the inclusion criteria. The blogs were saved as a soft copy on a hard drive. The blogs were also printed and filed. The blogs served as transcripts that were used during data analysis.

3.3.4. Data Analysis:

Text data, in the form of transcripts, were analysed and subjectively interpreted through qualitative thematic analysis. This was done through a systematic classification process such as coding resulting in the emergence of themes. Inductive thematic analysis was used and a clearer understanding of the importance of occupations in an individuals' life was obtained (Hsiu-Fang et al. 2005). When analysing the text data, a general idea of the information obtained from each blog was read and understood. The initial impressions and ideas of the text data was identified and noted in a journal by the researcher (Creswell 2009). Thereafter, each blog was re-read allowing the researcher to place all information into the MAXqda program, which is a popular software research tool that allows for this type of analysis to be done (Kuckartz et al. 2002). This was used to interpret and evaluate the text allowing for the emergence of codes (Creswell 2009). The codes were then placed into a table of categories based on similarity (Hsiu-Fang et al. 2005). Through thematic analysis these categories were placed into themes (Fereday et al. 2006). The researcher interpreted each of the themes and thereafter created an open-ended questionnaire, (which will be discussed in Phase 2) to understand the meaning of the statements made in the blog.

3.3.5. Outcome of Phase 1:

Phase 1 explored and described the lived experiences of an autistic individuals' life. The descriptions of their lived experiences gave insight into and informed the E-mail interviews that took place in Phase 2 of the study.

3.4. Phase 2: Semi-structured e-mail interviews with autistic individuals

3.4.1. Sampling:

This sample consisted of the individuals who participated in phase 1 of the study. The participants were sent an E-mail of invitation to participate in the E-mail interview. They were required to complete a second informed consent form (Appendix D) (Meho 2006). The individuals were given the opportunity to confirm the information obtained in phase 1 and broaden or ensure the depth of information through the E-mail interviews. This provided more self-reflection on the meaning of occupations in their lives (McCoyd et al. 2006).

3.4.2. Data Collection:

Data was collected through semi-structured asynchronous E-mail interviews with the autistic individuals. The individuals were required to complete a demographic questionnaire, which confirmed their diagnosis (Appendix E). This was followed by open-ended questions in accordance with the themes (Appendix F). Through E-mail interviews, the researcher was able to obtain ample information on a group that is geographically dispersed and who have difficulties with verbal and face-to-face interactions (McCoyd et al. 2006). E-mails were sent out with the original open-ended questions developed from Phase 1. The research supervisor was Carbon Copied on the E-mail. This ensured more than one view on the E-mail and that no tampering with the E-mail answers were done. Once the responses were collected, probing questions were sent to the individuals to obtain thick, rich descriptions. This broadened and deepened the information given. There were continuous back and forth communications throughout the E-mail interviews, which indicated that communication, was not done at only one point in time. Engaging in multiple interactions with participants has been advantageous in gathering more information about an experience (McCoyd et al. 2006) (Meho 2006). Autistic individuals are generally candid in their responses and due to their social barriers open-ended e-mail interviews gave them the opportunity to provide a greater sense of self-reflection and meaning in their occupations. When data saturation had been reached and the researcher was clear that participants were no longer providing new information regarding the interview questions, the researcher thanked participants for participating in the study and informed them that the interview was at an end. However, as the researcher had built up relationships with participants over the course of the interview, she remained in E-mail contact with participants after the conclusion of the interview until the participants felt comfortable terminating this relationship.

3.4.3. Data Analysis:

Phase 2 data analysis followed the steps as in Phase 1 data analysis discussed in point 3.3.4. Inductive thematic analysis was used to obtain a greater understanding of the discussions and answers obtained. This offered more insight into the minds of autistic individuals. The researcher analysed the text data by reading and understanding the information and answers provided by the participants. The information that corresponded to the blogs as well as other additional information was highlighted. The text was then loaded onto the MAXqda program which assisted in the development of codes (Creswell 2009). These codes were categorised according to similarity (Hsiu-Fang et al. 2005). Themes were formed using thematic analysis (Fereday et al. 2006).

3.4.4. Outcome of Phase 2:

Phase 2 aimed to understand and take heed of what autistic individuals held as important and meaningful in their lives and how the environment supported or inhibited them to participate in these occupations.

3.5. Final Data Analysis

The final data analysis combined the information from phase 1 and phase 2 into a cohesive integrated description of data. The research supervisor acted as a co-coder. Data in the form of quotes taken from the blogs and the E-mail interviews that were placed onto MAXqda were exported into an excel document and printed. The researcher and research supervisor triangulated the data from the blogs and the E-mail interviews. As the data frequently overlapped, the data was combined to create two major themes namely, *I Want To Be Accepted As a Human Being* and *Facilitators and Barriers.* Categories and codes were then developed under each theme. The quotes from the data were then organised to create a story. These themes assisted in formulating what occupations autistic individuals expressed as meaningful in their daily lives and the extent to which they could participate in their occupations.

3.6. Maintaining trustworthiness throughout the project:

Trustworthiness was maintained throughout the study, as this is essential in qualitative research. This was achieved through:

Triangulation: This was done by intersecting the two inferences to find a common ground to substantiate the data obtained (Krefting 1991). These inferences include the blogs which were converged with the answers and discussions obtained in the E-mail interviews. These inferences were assessed against each other and interpreted.

Member checking: This was used to ascertain the accuracy of the data obtained (Creswell 2009). Once the coding process was completed in Phase 1, the researcher developed themes and constructed open-ended questions based on the themes. This formed Phase 2 of the study. This proved to be a form of member checking, as the questions in phase 2 were a reflection and elaboration of the themes obtained in Phase 1. The answers and discussions obtained served as confirmation of the blogs. The researcher developed a table detailing the themes, categories and codes of the findings, which were E-mailed to each participant to evaluate if the table was a reflection of their views.

Rich, thick description: This maintained validity throughout the study as it contained the shared experiences of the autistic individuals through blogging. Different perspectives on the importance of occupations to each person were obtained. To ensure rich data, E-mail interviews were done through open-ended questions and constant back and forth communication. This extracted numerous perceptions and ideas about the value of occupations to autistic individuals (Creswell 2009).

Clarifying the bias of the researcher: In guaranteeing a good element of qualitative research, the researcher ensured that she maintained an objective view (Creswell 2009). The researcher made use of journaling to bracket her own views from what literature mentions and from what autistic individuals mentioned. There were regular meetings with the research supervisor and the researcher to ensure an objective view throughout the study and to avoid bias.

3.7. Ethics

The study dealt with autistic individuals and therefore ethical considerations played an integral part of the study.

- An information sheet (Appendix B) and informed consent forms (Appendix C and Appendix D) were sent as attachments on the E-mail interview. This included information about the study and noted that should the participant wish to withdraw, they will be given the opportunity to do so at any given time. The participants attached their signatures onto the documents. Those who faced difficulty with this were given the opportunity to type their names onto the document or send an E-mail noting that they have read and understood the requirements. The participants were given the opportunity to ask questions.
- Confidentiality was maintained when showing excerpts of the blogging. All participants received a participant code. Data collection was identified through this code. During data analysis, the researcher used pseudonyms to ensure complete anonymity.
- The E-mail interview document began with self-disclosure, which provided information about the researcher, followed by a request to interview the individuals. The researcher was transparent when explaining the reason for the E-mail interview. All participants' questions were answered (Meho 2006). Confidentiality was ensured during the E-mail interviews, as the researcher checked her E-mail on a daily basis. Once a corresponding E-mail came through, the text was copied and pasted onto a separate word document and saved onto a hard drive

including the date and time it was sent but excluding any identifying information. A hard copy for back up was printed and the word document was stored in a separate folder titled ‘E-mail conversations’. The initial e-mail was deleted. All folders containing discussions with the participants had a password to ensure primary access from the researcher. The researcher ensured clarity when asking the questions to prevent confusion or misunderstandings and to ensure that the autistic individuals were able to give detailed answers. The researcher clarified any confusion regarding the questions. The questions were rephrased when participants did not understand. A wide range of 5 questions was asked first, followed by probing questions. The autistic individuals were made aware that there are no incorrect answers and no concern will be made on incorrect spelling or grammatical errors. The researcher indicated a one-week deadline each time questions were asked however, the researcher was cognisant of the needs of the participants if more time was needed (Meho 2006). Veracity was maintained by submitting the facts and true experiences of the individuals.

- The researcher was aware of the participants’ feelings when engaging through back and forth E-mail conversations by asking the participant if they were comfortable to answer certain questions or to continue elaborating. Dr. Nicola Powell, an educational psychologist was on standby throughout the E-mail interviews to provide emotional support should the individual become distressed, but this did not happen. Contact details: (082 899 6108), e-mail address: npowell@netactive.co.za.
- This study depended on the honesty of the respondents and trusted that the respondents were who they said they were.

CHAPTER 4: RESULTS

This chapter will present the final integrated results from both phases of the study. In the first part of this chapter, the demographics of each of the five participants will be described. A framework that summarises the themes and categories that describe the meaning of occupation in their lives will follow this. The quotes from the blogs are in purple text and quotes from the E-mail interviews are in blue text.

4.1. Demographics of the participants

Five participants participated in this study. Two participants currently live in South Africa. One participant moved from South Africa to Korea. The other two participants live in the United States of America and New Zealand. These participants have all had different experiences in their lives. Four of the five participants were females. Four of the five participants were diagnosed with a range of comorbid conditions, of which ADHD was the most common followed by anxiety. These comorbidities reflect the conditions most commonly diagnosed together with ASD (Levy et al. 2010).

Participant 1

Participant 1 is a 32-year-old Asian male who lives in the United States of America. He speaks both English and his home language of Cantonese. He has been diagnosed with Asperger's syndrome and has received occupational therapy as well as speech therapy. He is currently working as an occupational therapist, specifically in the field of geriatrics. He is extremely passionate about his job and has received his doctoral degree. He has participated in two TEDx talks to date. He enjoys travelling and golf. He has no co-morbid conditions and is currently not on any medication.

Participant 2

Participant 2 is a 38-year-old Caucasian female. Her home language is English. She was born in South Africa. She has worked in England from September 2004 to July 2006. She has been living in Korea for the past four years. She has received her BMus from Stellenbosch University, BMus Honours in vocal performance from University of Cape Town, PGCE (Senior phase and FET) from UNISA and CELTA Cambridge Certificate for teaching EFL to adults. From March 2008-2009 she worked at CDI Academy and from March 2014 she has been working at Haba Kindergarten. She enjoys reading, writing, classical music, yoga, culture, languages, and current affairs. She enjoys travel and has visited more than ten countries. She has been diagnosed with autism, anxiety and has been re-diagnosed with ADHD in 2012. Pre-morbidly, Participant 2 was diagnosed with ADHD and dyslexia as a child. She has a history of anxiety, suffers from depression, allergies and migraines. She also has asthma, PMDD and IBS. The medication that she takes is to control her PMDD and anxiety and depression. The other therapies that Participant 2 receives include seeing a psychologist twice a month. She has a mentor and regularly goes to Church. She also does yoga two or three times a week.

Participant 3

Participant 3 is a 31-year-old white female who currently lives in Pietermaritzburg, South Africa. Her home language is English. She has received a BA degree in journalism and media studies and anthropology from Rhodes University. She is currently employed as an online content developer and quality assessor for a website that teaches foreigners to speak English. She was diagnosed with autism, ADHD in 2003 and bipolar disorder in 2010. She had epilepsy from 11 months old to 11 years old. She suffers from food intolerances, candida and low serotonin. She still has mild asthma, hay fever, insomnia, irritable bowel syndrome and skin problems. She is currently taking Risperidone and Lamotrigine. She has received cognitive behavioural therapy, occupational therapy and relationship counseling. Participant 3 is happily married and continues to live life in a positive manner by believing that Jesus Christ cured her of autism before her wedding, when she was 30 years old. Participant 3 was on Autism South Africa's (ASA) national executive board and on the Kwa-Zulu Natal Provincial Disability Forum. She has given many talks on autism around the country, including national autism conferences.

Participant 4

Participant 4 is a 38-year-old white female currently living in Parow, Cape Town. Her home language is English. She has received a degree in prophetic ministry from the Team Impact Christian University. Participant 4 has been diagnosed with autism spectrum disorder and ADHD. She is on anti-depressants and used to see a psychologist. She enjoys art, and works as an online English teacher.

Participant 5

Participant 5 is a 29-year-old European woman who lives in New Zealand. Her home language is English. She has received her Certificate in Arts. She is a disability benefit student and part time worker. She has been diagnosed with autism (catatonia related to autism), ADHD, SPD, Irlen Syndrome, Auditory Processing Disorder, mild intellectual disability, PTSD and possible seizures. She is currently on Gabapentin, Concerta, reflux medications, B6, zinc, melatonin, oral contraceptive pill, iron and anti-fungal medication. Participant 5 has presented at conferences on autism and has previously been on the New Zealand Expert Advisory Group. She enjoys working with children with special needs. She has a deep love for God and has therefore lived with her diagnosis of autism in a positive manner and attempts to help other autistic individuals, especially women. She has a goal to educate people and prevent sexual abuse and/or assault and rape affecting autistic individuals.

During data analysis, two major themes took precedence. These themes will be discussed in detail below. Quotes from participants will be used to substantiate the argument and give the findings substance. These quotes will be in bold and italicised. It must be noted that spelling mistakes may be visible during direct quoting from the participants.

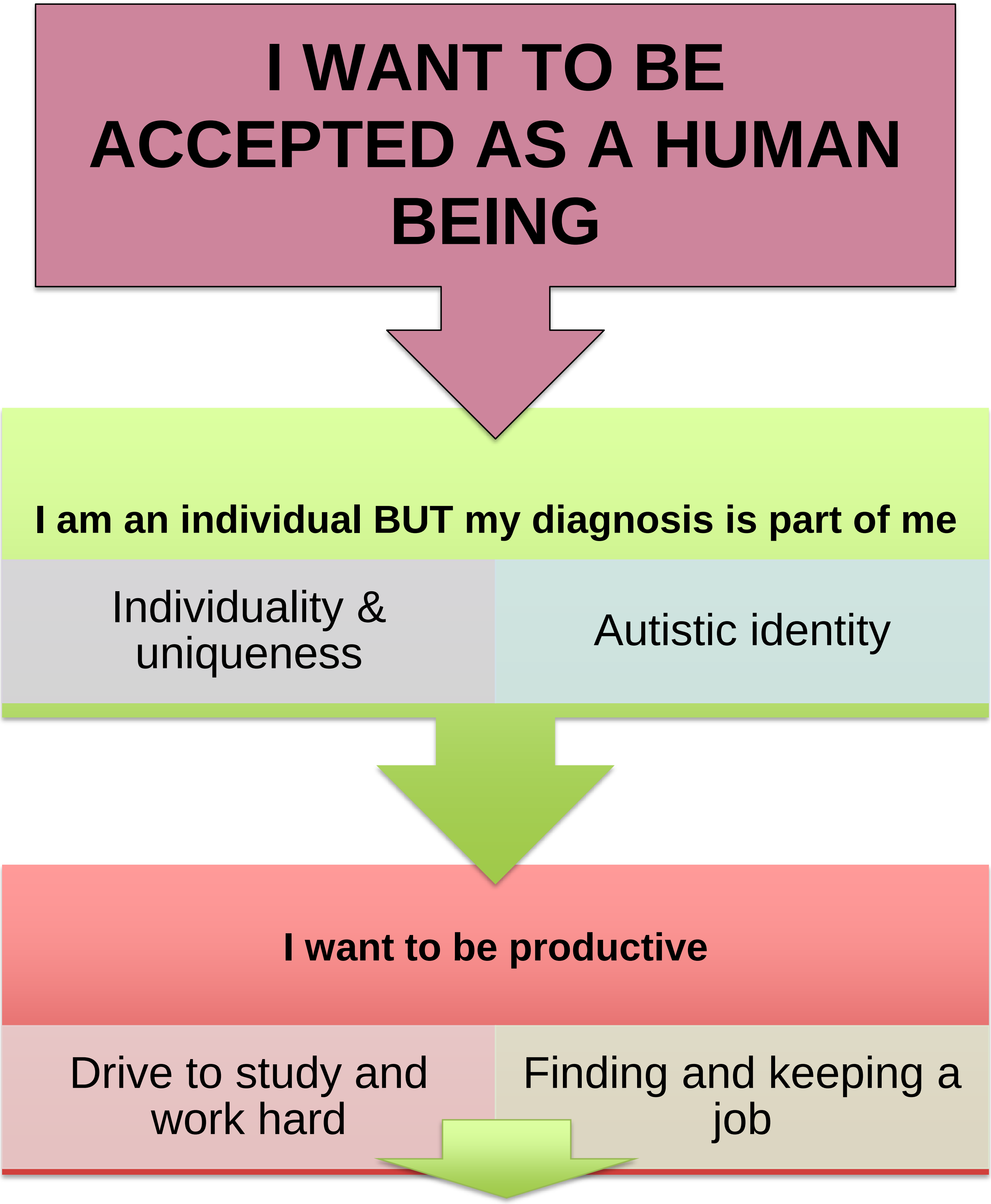
This chapter mainly focuses on how autistic individuals experienced life and how this leads to understanding the meaning of occupation in their life.

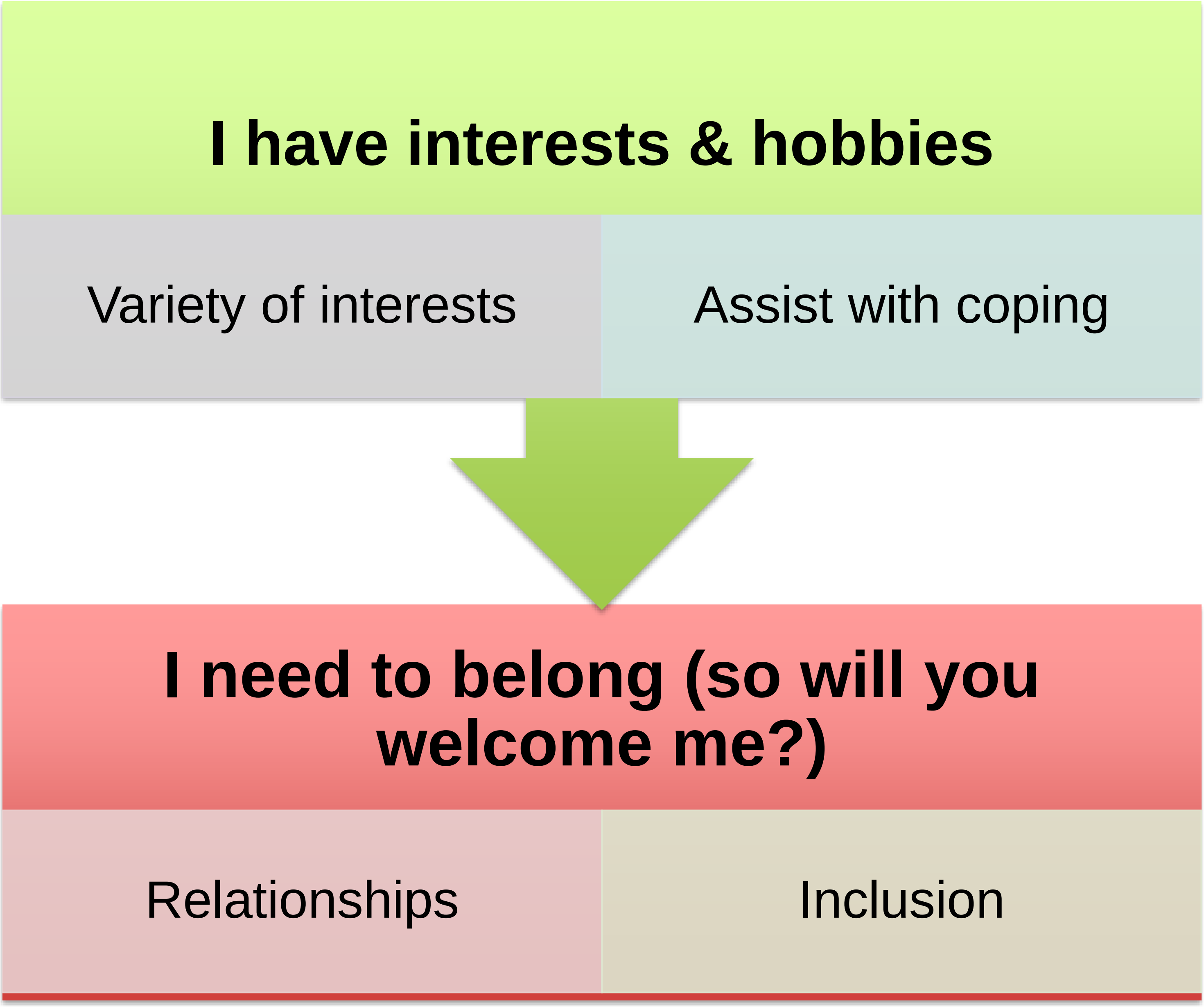
Participant 4: ***"I may not be a social butterfly or know how to develop deep friendships well. I may sometimes talk widely about MY interests and have to remind myself about the other person and their interests and stressors. I may not always pick up on signals that are overt to others in speech and body language. I may not be able to always interpret emotions. I may not always share the interests of everyone I talk to or am around.***
I may not always have a subject to talk about in every social situation.
BUT
I can be very creative with the food that I make. I can think deeply about many things. I can draw and paint on my own for hours. I can learn new craft activities and get really good at them fairly quickly. I can feel emotions and I can get overwhelmed by picking up on the emotions of most people in the room. I can make an effort to learn about what someone else is interested in and learn a lot more about someone that way. I can be quiet and listen well.
I can sit alone at a party and feel OK as long as I don't feel the pressure to mingle for the entire time of the party."

This quote encapsulated the essence of this study, and truly illustrates the need to get to know autistic individuals.

Two themes namely, ***I want to be accepted as a human being*** and ***Facilitators and Barriers*** emerged from the data that told the story of the participants' experiences. This story is illustrated in the diagram below.

4.2. Summary of results (table of themes and categories can be found in appendix G)





I have interests & hobbies

Variety of interests

Assist with coping

I need to belong (so will you welcome me?)

Relationships

Inclusion

FACILITATORS AND BARRIERS

I have some unique challenges

- Routines, planning and prioritising
- Sensory processing
- Understanding my body & sexuality
- Social exclusion & bullying
- Financial strain

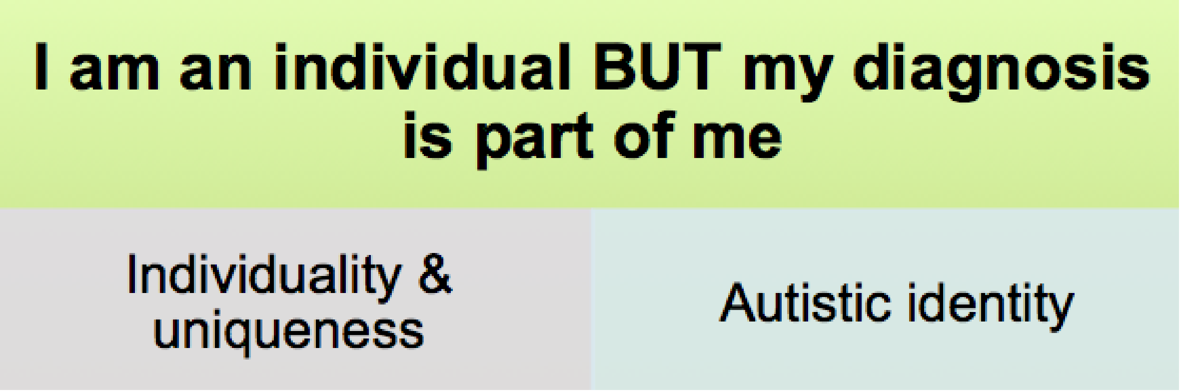
There are ways to overcome these challenges

- People
- Technology
- Advocacy

I WANT TO BE ACCEPTED AS A HUMAN BEING

4.3. I Want To Be Accepted As A Human Being

This theme captures the essence of what it means to be and to live as a human being and that the participants are proud of who they are.



I am an individual BUT my diagnosis is part of me

Individuality & uniqueness	Autistic identity

4.3.1. I am an individual but my diagnosis is part of me

The first category, *I am an individual but my diagnosis is part of me*, is divided into two codes namely *Individuality and uniqueness* and *Autistic identity.*

<u>Individuality and uniqueness</u>

The participants have been dismissed as individuals who are not ‘normal’, and they challenge the concept of what it actually means to be normal.

Participant 5: ***“just likeall the so called”normal” individuals. Welcome, I can assure you that you are already differentbecause there simplyisno such thing, as NORMAL”***

This quote emphasises the point that being ‘normal’ is a social construct. If we as a society assess people by their unique contributions to society we will strengthen their human right to be human and so add meaning to their lives through participation in occupation. This embraces the idea that all individuals are unique

All people are created differently. Each person has their own set of abilities and disabilities in varying degrees.

Participant 2: ***“Just like neurotypicals are unique, each person on the autism spectrum is unique.”***

The participants emphasise individuality through the concept of neurodiversity, in that autism among other conditions should be seen as a naturally occurring cognitive variation.

Participant 4: “I do believe in the neuro diverisity movement though because we are all different and are not and were not created the same.”

The participants are imploring the world to stop treating them differently because they act differently to neurotypicals. By neurotypicals accepting the importance of the individuality of each person, autistic individuals will be able to express themselves more confidently and so add a greater meaning of occupation in their lives.

The participants describe their hope to be given a chance to grow, develop and succeed in life.

Participant 5: ***“AUTISM IS A MIND BODY DISCONNECT***

I am not in control of my body, I need a way to show my feelings, to show I understand more then people think. I am in here."

Participant 1 mentions a famous quote about autism, which celebrates the uniqueness of an autistic individual.

Participant 1: ***"A misconception I like to clear is autism is a condition that affects people of all racial groups and socialeconomic status. That said, people who are affected by it have their own unique set of abilities. It is important for societies to discover their talents and untap their potentials. As there is a popular saying in the community, "If you meet one person with autism, you only meet one person with autism.***

Autistic identity

The participant below describes how being treated as an outcast has motivated her to rise above this unfair judgement. She refers to the harmful consequences of discrimination and is encouraging in how one should learn to live their lives through embracing their uniqueness and staying true to themselves. This positivity has given this participant a reason to create meaning in her life and hopefully it will inspire others to follow her lead.

Participant 3: ***"If I try to be what I am not, I will stumble for the rest of my life. I've learnt to embrace the things that make me different, instead of obsessing over them. Even if everyone else sees me as an outcast, I will choose to be different from the rest. I have come to understand how important it is to appreciate the things that make people different, whether it is a disability, race, gender, class etc. I try my best not to discriminate against people for any reason, because I know how it could scar them for life. Don't be afraid to express your individuality, no matter what anyone else says. If you always follow the crowd, you will end up hiding who you really are inside."***

Autism is viewed as a debilitating disorder with devastating impacts on an individual's life. The participants below have described their feelings towards autism. They emphasise that they are proud of who they are, and proud to be autistic. They have embraced their uniqueness and are constantly striving to improve.

Participant 4: *"Accept yourself."*

Participant 5: *"I am wonderfully Autiscally made."*

Participant 4: "I am not separate from my autism, it is who I am and how my brain works differently to your brain. Things are not all the same and we don't all fit into a box like a cookie cutter.I am not lazy when I am not able to do my work effectively. It is usually the environment and the perception of my abilities in the ablism* environment that holds me back. Some things I am not able to do unless certain things are in place before I start. This is to do with my brain and how I cope with things and because my autism is an "unseen" thing it makes me look like I am not different from the outside but the way I need to do things is VERY different from the inside!"

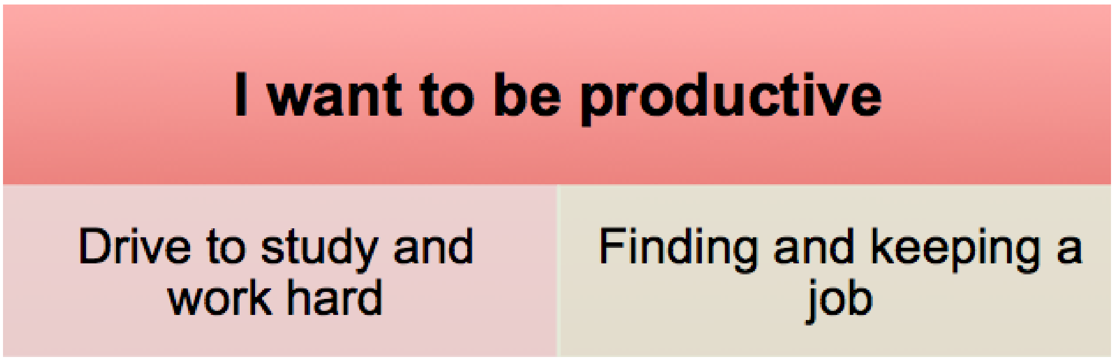
Participant 1: *"If I am offered to reset to the day when I was first diagnosed, I would have done the same things over again with no regrets."*

Participant 1: *"As I have learned as an OT... continuously being motivated despite having immense struggles is important. As long as you believe you have a reasonable chance of doing something, keep trying until you can't try any more. Sometimes it's that one more attempt can lead you to success."*

Participant 2: "However, knowing I am different, and why has helped me to connect with the right people."

Participant 5: ***"I like the way I never gave up."***

These profound statements by the participants should start changing the way neurotypical individuals view autistic individuals.



4.3.2. I want to be productive

This category, *I want to be productive*, is divided into two codes named *Drive to study and work hard* and *Finding and keeping a job*. All participants expressed the need to participate in productive occupations.

<u>Drive to study and work hard</u>

The participants in the study showed a desire to be successful and make a life for themselves. They sought jobs that best matched their abilities and stressed that they will work hard and continue to be trustworthy in what they do. Having a job is important to these individuals as it gives them a sense of purpose, which adds meaning to their lives.

Participant 3: ***"I worked immensely hard at school to get into university."***

Participant 4: ***"I am looking for a new job that matches my skills better because I'm not earning enough to live right now."***

Participant 3: ***Many employers think that I only do my own thing, that I'm not there to work, and that I'm not taking the job seriously. I'm actually a very hard worker."***

Participant 1: ***"I will work hard to continue to prove that I am a consistent and reliable employee."***

The two quotes below describe different experiences by the participants at university. The first quote describes how limited knowledge by the general public of autistic individuals impacted on their university experience and that this 'condition' was hurtfully described as an 'array of emotional conditions'. The second quote however, explains how necessary accommodations were made to cater for the required needs. This indicates how awareness into ASD can assist individuals into better achieving their goals.

Participant 3: ***"I applied for extra time for exams. I was refused, on the grounds that the university "does not cater for an array of emotional conditions."***

Participant 5: ***"the plan for my disability needs for my classes is stuff like i have note takers , separate exams use of computer, sensory modulation, one on one in science lab, and allowed to do work at home etc. I've had to leave science labs cause of meltdowns lately I've just been changed to a noise friendly class on a tuesday morning for the rest of the semester, the lecturer was sorry that she didnt think of the sensory environment at the beginning of the semester."***

<u>Finding and keeping a job</u>

The participants have said that interviews can be daunting for the interviewee and in particular for autistic individuals as they struggle with eye contact, which makes face-to-face interaction difficult.

Participant 2: ***"Many asd people also struggle with interviews, and an online interview, without face to face contact, may be more beneficial, or perhaps giving the interview questions as an assignment to complete." "I***

can manage interviews, but really dislike them, however some autistics, cannot even manage interviews..."

The participants expressed the need to have an employer who understands what autism is as well as what accommodations are needed for the individual to perform at their optimum capacity.

Participant 3: "He said none of the staff except the owners are allowed to take time off work at any time. He said because I asked about that he thinks I am not serious about working and won't be committed to the job. He refused to let me explain myself and did not want to understand me. He ended the interview abruptly and told me I can't work for him."

Participant 4: ***"I think (from my experience) you need a boss is willing to listen and who is also able to adapt your working environment to get the best out of your skills. Communication that is done piece by piece and in a clear way (and written down in a doable list if needed) will also assist in lowering the stress level in the working environment."***

The participants expressed the importance of getting concrete, straightforward and step-by-step instructions by the employer, as this will lead to improved productivity.

Participant 4: ***"I did keep asking for clearly written goals and steps to follow in order to finish the tasks set out for me but I never received this detailed input which would have reduced my stress levels immediately and made me feel more secure."***

Participant 4: ***"Once an autistic person has the right instructions in the right order and done in the right way, they won't ask you again. It's worth the extra time spent to teach someone the right way of doing things to spare the time later."***

Participant 3: ***"However my boss did not understand that Aspergers makes me very literal, so I couldn't understand his abstract phrases of speech which he often used. Near the end of my time at the job he would get very irritated and sometimes angry with me when I did not understand what he said because he thought I was playing stupid with him."***

The participants have suggested that once employers are aware and understand ASD they will be able to make the necessary accommodations that the individuals need and be better equipped to deal with sensory sensitivity, including meltdowns.

Participant 2: ***"In my opinion all employers should ask if the applicants are neurodiverse, what they need support with, and what their sensory issues are."***

Participant 4: ***"One thing that would continue to affect an autistic person in their working environment are the smells, sounds and lights in particular. The need to sometimes have a dark room to go to to recover from the light and over stimulation is necessary."***

Participant 3: ***"…the company did not allow me certain accommodations for the disabilities I had. Eg. They wouldn't allow me to go outside if I had a mental breakdown. Many of my colleagues complained about me and some bullied me."***

Participant 3: ***"They need to make an effort to get to know the disabled employee's needs and do whatever they can to reasonably accommodate them. A lot of employers make lame excuses as to why they won't make accommodation for our needs. The employers need to explain to the rest of the staff what the person's diagnosis is and how it will affect them at work. They need to give the person a mentor and/or assistant/job buddy. They need to have a plan of action when someone complains about the disabled person."***

The participants have the aspiration to work hard and should not be denied accommodations at work as this is unfair. Awareness into autism, support and understanding of autistic individuals are values that all companies should practice.

Participant 3: ***"I tried to avoid showing my colleagues that I had a meltdown."***

Participant 3: ***"My conditions have greatly hindered my work opportunities. I can't work in an open office like most newsrooms have, because there are too many distractions and noise for me to concentrate. Most media companies tell me they do not have a spare office for me."***

Participant 3: ***"I suppose the difficulties I had at work made me try even harder to be good at what I did. I read books on spelling, grammar etc and my mother helped me edit some stories via email. The situation did greatly decrease my self-esteem and made me frustrated, depressed and sometimes angry."***

In every day life and in particular at work, things do change unexpectedly. The participants mentioned that they struggle with unexpected changes. The quote below sheds light on how this can be handled in the work place.

Participant 1: ***"A common trait that autistic individuals have is struggles dealing with sudden and/or unexpected things."***

Participant 1: ***"Embrace change when it happens. I understand it is hard that I have to change places sometimes as I began to get a feel of the flow of one place in terms of work for whatever reason. But I also know that showing my willingness to be flexible is a long term asset at my job. So, I just focus on doing the best I can each day rather than worrying about where I am going the next day."***

The participants have needs, desires and goals as neurotypicals do. At times neurotypicals fail to see the motivation autistic individuals have in achieving their goals due to their limited knowledge of ASD. It is clear from the participant's experiences that the ability in achieving their goals and fulfilling their job requirements is influenced by the amount of knowledge and support a neurotypical has on autism, as well as the extent to which they accept them, and how willing they are to accommodate them.

I have interests & hobbies

Variety of interests

Assist with coping

4.3.3. I have interests and hobbies

This category, *I have interests and hobbies*, is divided into *Variety of interests* and *Assist with coping,* and explains the importance of interests in the participants lives.

<u>Variety of interests</u>

All of the participants have expressed a wide variety of interests and participation in different activities.

Participant 1: "*Traveling (to conferences and leisure), golf, and social media*

Participant 5: *"The things that i really love to do are knitting, researching autism particular genetics and nutrition and sensory issues and i love to write and i love my science studies and i love being a aunty, i love getting*

out in the out doors and i love swimming and the movies and ten pin bowling.”

Participant 2: ***“I enjoy***
A. Reading
B. Yoga
C. Playing classical music
D. Travelling
E. Writing
F. Intellectual discussions
G. Being with small groups of friends
H. Watching movies
I. Going to the beach or just being near large bodies of water”

Participant 3: ***My husband and I enjoy cuddling, watching TV or movies together, hiking at nature reserves, cooking, exercising, socialising, and eating at restaurants when we can afford it.***

These quotes suggest that the participants, like many people have various interests and enjoy doing some things more than others. Each participant displayed unique interests due to what they have experienced in their life. Autism is generally associated with autistic individuals having limited interests however, from the participants above it is indicative that they have interests in activities that are important to them. The participants participate within their interests when they have the opportunity to do so, with the intention of bringing meaning into their lives.

Assist with coping

Anxiety and stress are mental states experienced by the participants, but are not limited to them only.

Participant 1: ***“Anxiety wise, I definitely do have some. But then again, who doesn't…”***

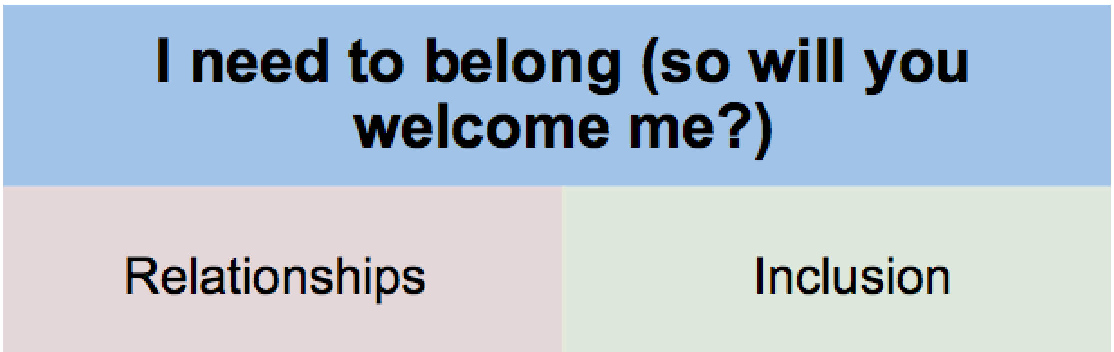
Many participants experience stress when people do not understand them, especially when they express a need to be heard.

Participant 4: “Emotional stress comes in when someone doesn’t make the effort to understand my point of view no matter how I explain it to them and even when I myself don’t understand my emotions of the moment.”

Each person deals with stress differently and the quotes below describe some ways that the participants deal with stress related to their interests.

Participant 3: ***“When I get the opportunity I swim. It helps me a great deal by de-stressing me…”***

Participant 1: ***“Golf for me at a minimum is an opportunity to release stress for work.”***



I need to belong (so will you welcome me?)

Relationships

Inclusion

4.3.4. I need to belong (so will you welcome me?)

In this category, *I need to belong (so will you welcome me)*, a deep need for social inclusion, for being welcomed and accepted by society was expressed. This will be explained by two codes namely *Relationships* and *Inclusion*.

Relationships

All participants expressed the need for relationships with others. Three important social role types emerged namely work relationships, friendships and romantic relationships. The participants in this study voiced their desire for relationships but explained the difficulties they encountered during this process.

Work Relationships:

The participants explained that forming work relationships can be stressful. Despite the difficulties found in social situations, the individuals must try to form relationships in an effort to ensure a more suitable working environment.

Participant 4: *“Stress adds to the equation of challenging work environments and relationships. Generally interacting with people is very challenging for me for various reasons.”*

Participant 1: *“The more close knit your line of work is amongst people who work there (even applies if they work at different locations), the more you must make an effort to make friends. While being social is a choice, I feel that having friends automatically reduces my stress when I try to do my job, especially at unfamiliar locations.”*

Social Relationships:

Autistic individuals are generally expected to follow the social norms of a neurotypical society and a failure to do so creates a difficulty to connect. The participants below describe how they struggled to develop the friendships that they longed for, and how they felt when these relationships did not last.

Participant 5: ***"I wanted and needed friends." "I lacked the social and communication skills to be heard."***

Participant 3: ***"I struggled to relate to other people my age…All I knew was that most the times I had the opportunity to connect with people and develop friendships, I'd mess it up. Then I'd hate myself for it."***

The inability to maintain relationships is not isolated to autistic individuals. The participants may need extra support when developing and maintaining relationships. However, as the second participant points out, one does need to make the effort to create long-lasting relationships.

Participant 4: ***"…as well as of course further analyses of my own boundaries and how to make them constructive and healthy to building (and keeping) long term friendships. This is a human struggle, an autistic struggle and one that can be overcome!"***

Participant 1: ***"I feel that a key reason my social skills have improved is because I have a motivation to work hard at it. I not only wanted to improve on it because of my career related needs, but also the fact that my support system won't build itself if I don't build relationships with people who might potentially support me in my journey as an occupational therapist. Of course, consistently getting positive feedback has helped. In the autism context, I feel that motivation to improve social skills is important, and successes will breed confidence. Over time, successes can help encourage autistic individuals to expand their social skills skill set. But they might need extra effort and support in doing so."***

Romantic Relationships:

In the same way that most neurotypicals long to be loved, the participants share the same feelings. However, since they behave differently from neurotypicals, they doubt whether they will be able to find the right person.

Participant 4: *"Relationships are very complicated, I hope to have a romantic relationship sometime…"*

Participant 2: *"Being different and finding the right person, is not easy, maybe I never will. Romantic novels just make me sad."*

Participant 3: *"I feel much more supported and loved since my husband came into my life"*

The participants state that when it comes to sex and relationships they do not have enough knowledge on these matters. It is imperative for them to be educated on such matters to prevent them from being taken advantage of.

Participant 5: *"I've been in what i thought were relationships but the specialist says they were guys taking advantage of my disabilities. i don't understand why people like to take advantage of people like myself when they know we don't understand."*

Participant 5: *"i don't know if sex is different for autistics but the specialists say i don't know enough to consent to sexual activity."*

Participant 5: *"But i often wonder could i cope if the guy was moderate to severely autistic too."*

Despite their longing for romantic relationships, the participants discussed potential issues that might adversely affect their chances of a long-lasting relationship. The issue of compatibility is a problem experienced by both autistic individuals and neurotypicals.

Participant 2: ***"Therefore, people in the spectrum need to be compatible in their interests, and with their sensory issues, or it could be a problem, in terms of dating."***

The need to belong was expressed more strongly in the category, *Will you include me.*

Inclusion

The participants want to be understood and are asking the neurotypical world to accept and include them in society by making an effort to understand and embrace their unique identity. The participants have tried to voice their feelings however, more often than not their pleas are dismissed and go unheard. In the quotes below they explain how their feelings are ignored and how most neurotypicals are ignorant of the difficulties encountered by autistic individuals. Such an attitude towards autistic individuals needs to be changed.

Participant 4: **"I am just learning to express how I feel in many situations in a healthy way and not being validated for what I was feeling was very de-motivating and discouraging."**

Participant 5: ***"As a person with lived experience of mental distress, I missed the chance to interact and to be included."***

Participant 5: ***"According to someone who surely doesn't understand the UNCRPD.***
I'm a:
A: diminished mind
B: im unequal because i have a disability.
C: I contribute less so I'm unequal."

Participant 2: ***"Get to know us. Do not dismiss us because we are different. Give us a chance. This is discrimination."***

Participant 4: ***"All the covers don't look the same, they never will so don't judge someone on your limited knowledge on a topic and make them feel more isolated and alone. By saying this it also shows that the person has not bothered to actually understand what Autism and being Autistic actually means. What are you doing to better understand those around you? Are you gaining knowledge or just going on what you know from second hand information?"***

Participant 3: ***"I totally agree that autistics should be included in decision making and their voices must be heard."***

A large portion of research is dedicated to evaluating the effectiveness of treatment techniques, but little has been done in actively focusing on what autistic individuals have to say. These participants are living with autism and are emphasising that their opinions needs to be respected and taken into consideration. The participants have voiced that it is vital for the neurotypical society to include autistic individuals in research concerning autism.

Participant 3: ***"I hardly ever see mention of research done by an autistic. I think this is wrong. However, I don't see anything wrong with neurotypical people doing research as long as they speak to autistics for their research."***

Participant 5: ***"when providers approach me i always wonder whether they really what my input or are they just doing it to meet the tick boxes that they have consulted "disabled people" but regardless i set aside my feelings and put my 100% into it."***

Participant 2: ***"I think people should ask autistic people what they want, and let autistic people help each other, rather than decide what we need, and tell us what to do."***

The participants are emphasising their need to advocate for autism awareness so that they are accepted into society.

Participant 5: ***"Every time we deny a disabled individual from being a citizen in any country, we are sending a clear message that we are still not ready for a fully inclusive society, where the disability is always seen, and not the ability that individual has to contribute to society."***

Participant 3: ***"I have autism awareness shirts that I wear when I am going somewhere where the people need to know about it. If I get the opportunity to go to a meeting where the government or journalists are, I try to bring up an issue that autistics need help with. I've been asked to a lot of public talks about autism over the years."***

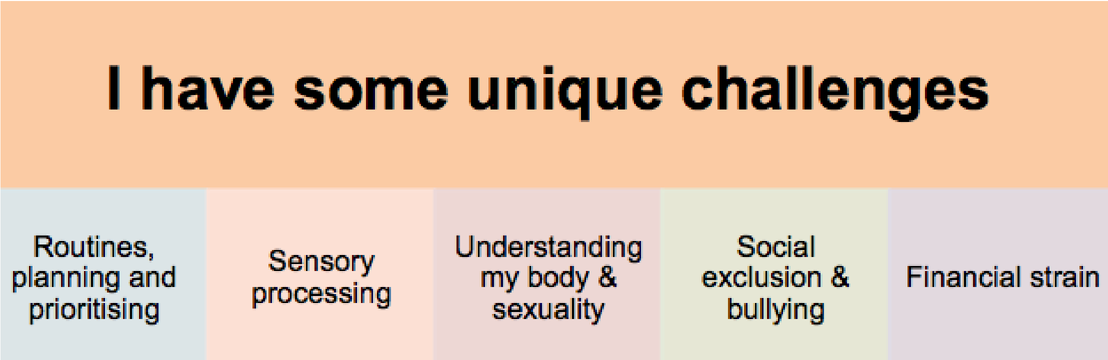
Participant 4: ***"Worldwide this month its "Autism Awareness Month". Awareness is a good thing, a better thing is not only starting with awareness but going one step further to also being ACCEPTING of those with a different neurology than yours."***

Participant 1: ***"At the same time, I also want to promote more autism awareness in public and more autism acceptance…"***

FACILITATORS AND BARRIERS

4.4. Facilitators and Barriers

This theme describes many of the challenges that the participants have faced in their lives as well as what support they received.



4.4.1. I have some unique challenges

This category, *I have some unique challenges*, explains the barriers in occupational participation and is divided into *Routines, planning and prioritising, Sensory processing, Understanding my body and sexuality, Social exclusion and bullying* and *Financial strain.*

<u>Routines, planning and prioritising</u>

The participants have described the difficulties they experience when performing their daily routine.

Participant 4: ***"For most people setting an alarm, getting up, putting on a geyser, then having breakfast, showering, tidying up and taking the right things to work is quite an easy routine in the morning to follow. For most autistic people this is not necessarily so true.***

Participant 4: ***"A struggle with autistic people and me in particular is being able to prioritize tasks."***

Participants have described how support can assist them in carrying out their occupations in a more efficient way.

Participant 5: “*with the personal cares i really struggle with remembering how to wash and in the order. i do have a visual aide steps i chart but there are times i freeze up and need physical support to move on etc.”*

Sensory processing

Many participants experienced difficulties processing sensory input in their daily lives.

Participant 4: *“Sensory sensitivity and sensory overload are a big struggle for me in many ways. This affects us in multiple ways.” “I can share and think better when I am talking to someone if I make LESS eye contact than the “normal” person is required to do…” “…I still find the sensation of water on my skin a both exhilarating and painful experience. I like swimming in the sea and in pools but showering and bathing are a struggle. Once I’m in it’s ok but getting in is a struggle.”*

Participant 4: *“…sensory problems made it too difficult to drive.”*

When sensory experiences become difficult for autistic individuals to cope with, it may result in meltdowns. The quotes below explain what the participants go through when having a meltdown. Due to their sensory difficulties, the way in which they handle their meltdowns differ from person to person.

Participant 5: *“I have challenging behaviours and meltdowns so severe that I head bang and self bite, all due to not having functional speech and not being in control of my body.”*

Participant 4: *“Autistic people are affected in many different extremes because all bodies are different. One may not want to be touched at all*

during a meltdown and another will need a bear hug to stabalize the body system."

Participants deal with their sensory sensitivity in their own unique ways.

Participant 2: ***"The sound of watee is always calming, and the color too, especmally the colour of the ocean. I love sand. I mean walking in soft sand, and the sound of seagulls."***

Participant 5: ***"well i like my weighted blanket and my weighted cat (not a real cat), swimming and the therapressure brush - but need to train my carers into using the therapressure brush correctly."***

Participant 2: ***"I do not really enjoy hugging as I feel like I am being crushed from a sensory point of view, but with kids it is not too bad." "I like holding hands or putting my arm around someone or touching their shoulder."***

It is important to understand how sensory sensitivity affects an autistic individual as knowledge on this may bring about better ways for autistic individuals to cope.

Understanding my body and sexuality

The participants expressed the importance of educating autistic individuals on how the male and female body functions. Sex education is crucial to autistic individuals as they are vulnerable to sexual abuse. Even though autistic individuals have difficulty communicating, they should be educated on such matters

Participant 5: ***"watching a live birth is the best education for an autistic woman because for myself seeing it in real life teaches us that the baby***

comes out where the blood comes out and yeah blood comes out when the baby comes out and for the fact that the baby comes out attached to the polcenta cord (spelling), before this i thought babies came out really easy at the hospital. as thats all i had known. high school didnt teach me anything I'm still way behind in how a baby gets to be in the utuerus. still learning."

Participant 5: ***"i think hospitals should have specialist nurses that work specifically with developmental disabilities that can develop individual sex education , one on one as be different for all of us etc. they should be the ones to assess our capabilities."***

The participants explained that individuals who wish to have children should be supported and educated by the government or an agency, as this is a human right.

Participant 5: ***"Autisticandbeing a womancan beextremely hard at times."***

Participant 5: ***"our government tends to take babies of autistic mothers that have high support needs and put them in foster care. i don't want to be a mother if I'm not supported to be a mother if it will just get taken of me."***

Participant 2: ***"Kids are not for everyone. I do not want kids, because of sensory, and hormonal issues. I also tbink that genetically, they may be neurodiverse, which is fine, if you have a lot of money."***

Participant 3: "I tell woman I don't want to have children."

<u>Social exclusion and bullying</u>

The participants have faced barriers to social inclusion and have therefore endured the struggles of social rejection, which were experienced as extremely hurtful.

Participant 4: ***"This is a daily struggle as well as an ongoing struggle. In the "neuro-typical" world if you do not look the same, speak the same and follow the rules the usual result is either bullying (why aren't you like us?) or being ignored. Both of these are painful for the person on the receiving end."***

Participant 3: ***"Ever since I started mainstream school, I was bullied and teased. Some called me a retard, without knowing I have a syndrome. The kids spread rumors about me and criticised me. But I couldn't see what I was doing wrong. I was made to feel inferior, like something all the kids could walk over when they pleased. They would verbally abuse me. Some of them would tell the other kids that I have a virus, so many of the kids would avoid coming near me if they passed me in the passage way. Kids would stomp on my bags or throw balls of paper at me. They would make jokes at my expense and gang up on me. No one in my grade would let me sit with them at break time. They would either refuse me verbally, or walk off as soon as I approached them. I ended up sitting by myself at break in Matric. This did great damage to my self esteem and my emotions. It actually caused me to develop a personality disorder, because I was not accepted as a person."***

The participants describe how society places lables on them, which unfairly determines what they are capable of. This ignorance is harmful to personal growth and self-worth. Such an attitude is another form of bullying. Also, we have seen that each individual is endowed with his or her own unique abilities and categorising an autistic individual on what a neurotypical deems appropriate is damaging.

Participant 5: ***"And after this speech the facilitator said you would of done better if you used your own voice, I wanna see you use your own voice tomorrow! And I'm thinking is this not my own thoughts, are my experiences any less because right then and there my AAC was my voice***

as I couldn't speak myself right then and there in that moment, although the other participants really liked what I had to say."

Participant 5: ***"Does society perceptions of autistic individualslimits our ability to achieve and make us more disabled over time. I believe so Society sees the labelsand gives up hope on us ever achieving anything in life.We start of with a neuro diverse needa different way of thinking and being."***

Financial strain

The participants in the study have experienced financial difficulties. Their financial strain increases as they may find it more difficult to find a job as well as to maintain one.

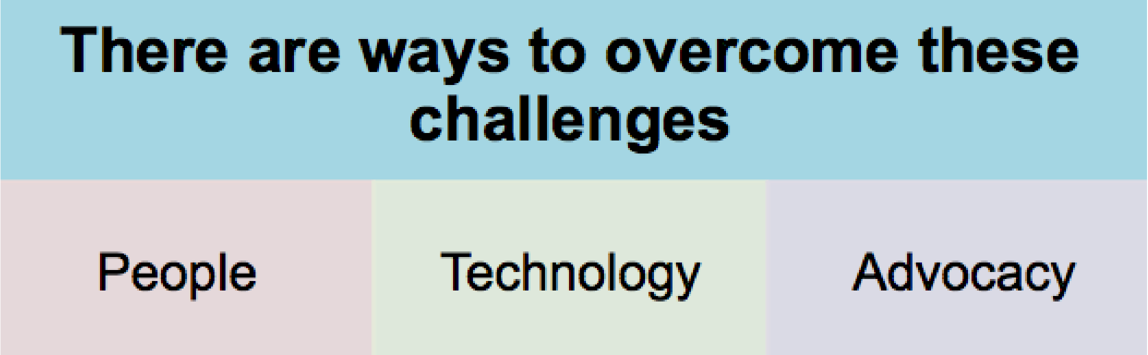
Participant 4: ***"I have stress when I am not sure about finances because I need to use finances to help me get to places and pay for electricity, food and airtime to contact people."***

The participants explained how financial strain leads to the inability to participate in their interests, which leads to increased levels of stress and anxiety.

Participant 4: ***"I don't go out often with friends, I'd like to go out more often but money prevents me from doing a lot of things right now."***

Participant 5: ***"swimming at the moment, no where yet , price gets in the way"***

Participant 3: ***"I can't afford to pay for sewing lessons."***



There are ways to overcome these challenges		
People	Technology	Advocacy

4.4.2. There are ways to overcome these challenges

This category, *There are ways to overcome these challenges,* describes the support autistic individuals received and is divided into People, Technology and Advocacy.

<u>People</u>

Three of the participants had caregivers who influenced their participation in performing their activities of daily living. The support offered by personal carers should not go unnoticed as their involvement in their life can positively influence their occupational participation.

Participant 4: ***"She helps with: Time management and life management."***

Participant 4: ***"The support that I have had from many people has helped me to continue until I see the end in sight."***

Participant 5: ***"…there are lots of physical stuff i really struggle with, i.e. with baking and cooking i need full supervision and assistance and personal cares i need assistance with. I guess this is the reality of Autism..."***

Participant 5: ***"the majority of these things are done with supervision and assistance accept for well I'm pretty good at charging my electronics"***

Participant 2: ***"I talk and she never judges me. She always remains calm. She helps me to make good decisions, by asking the right questions. I feel more rekaxed after talking to her. Aload off my shoulders."***

It is important that the supervision and assistance given to the participants be given with caution and sensitivity. They should also be given a chance to say and to do what they are capable of and supported as much as possible in the tasks they find difficult in accomplishing.

Participant 5: ***“I'm too scared that i will hurt myself in the kitchen when I'm alone but then wihen my carers are with me sometimes i feel they take over in areas i can do well and sometimes that can be frustrating . i need to be supervised, supported but i need a element of independence as well. not sure how to find that balance yet.”***

Participant 5: ***“support workers i like to see them go on training so they understand that I'm their boss not the other way around.”***

Technology

Participants emphasised the need to be able to communicate effectively and this was identified as one of the key areas of difficulty in gaining acceptance.

Participant 4: ***“Do elephants communicate with cheetahs in the same way that elephants communicate with elephants?”***

Participant 5: **“but did you know that if you asked me to read a chapter out loud i will stumble over the words and people wont really understand what I'm saying and it will be so slow…”**

Participant 4: ***“…and then the communication gap between autistic people and neuro typical people who like things done a certain way.”***

Participant 4: ***“I wonder how many “neuro-typical” people actually take the time to realise that the way that they communicate to other people who are “not the same” can be confusing and sometimes very***

patronizing. (Patronizing because the other person who is not like you is expected to communicate like you.)”

The participants, either verbal or non-verbal, are trying to find ways to communicate with neurotypical people. From the above quote, it seems that the neurotypical population are not adapting their way of communication to accommodate an autistic individual. This may create misunderstandings and an uncomfortable environment for them. However technology has opened up a new way of communicating that makes it easier for the participants to relay their message to the next individual and to offload burdening emotions. Some of these communication methods include the use of technology such as E-mail or social media.

Participant 5: **“…it will be good for them to see a autistic person in action who uses AAC…”**

Participant 5: ***“My best mode of communication is with typing.”***

Participant 2: ***“About how my psychologist and mentor. You asked how do they help. Whenever I feel upset about something, I write emails to them. Psychologist rarely replies, and mentor does once a week, or once every 2 weeks, but it helps to write it all down, and send it to them. My emotions are very strong, so it helps to let off steam...”***

Participant 2: ***“Hooray for technology”***

The use of technology is beneficial to the participants. It assists with communication, but also with their activities of daily life. As Participant 2 mentioned, letting off steam through the use of technology allows her to participate more efficiently and effectively during the day.

In many ways technology assists individuals in social networking and participating in social groups.

Participant 1: ***"Social media is my outlet to network and set up professional networking opportunities."***

However, the advertisements of happiness on social media can result in further feelings of loneliness.

Participant 2: ***"Social media is good and bad. It helps me connect with other autistics worldwide, so that is good and helpful, but I am also inundated with pictures of happy families, and couples, this makes me feel lonely."***

Both participants agree that social media is beneficial in forming connections however it can cause distress and sadness.

Advocacy

The participants have expressed the desire for their voices to be heard, but they have gone unheard for the most part. As a result, they have become advocates for autism.

Participant 1: ***"I know there are autism self advocates out there who use themselves as barometers in autism acceptance in society. I definitely see a point of that because autism (or other disability) acceptance is a major issue in societies today."***
Participant 5: ***"here in new zealand i don't believe we have much autistic voices, there are too many people that want to talk on our behalf rather then enabling us…"***

Participant 2: ***"Somewhat of an advocate myself…"***

Participant 4: ***"Well, I'm not sure if I'm an "advocate" it's more about getting people to understand and accept than something else."***

Participant 5: ***“…i encourage the younger autistics to be vocal. and support others to be vocal.”***

The participants do not appreciate terms that are negatively associated with autism. Neurotypicals must be mindful of the language used when referring to an autistic individual.

Participant 3: ***“I also feel my blood boiling when someone calls me or a disabled person a ‘retard’. I prefer the term ‘person with autism’ although I sometimes use ‘autistic person’ when I need to speak or write quickly.”***

Conclusion to results

In this chapter each of the participants expressed emotions over their diagnosis and a belief in their personal ability and capability to *‘do’*. It has been shown in this chapter that there is a discrepancy between what autistic individuals hold as important and what neurotypicals perceive to be important to them. A major issue that emerged from this chapter is the longing from autistic individuals to be heard and respected.

CHAPTER 5: DISCUSSION

This chapter will present a discussion of the results of the study. The first discussion will focus on the participants need to be accepted as a human being and how this relates to the literature. The second part of the discussion will focus on the facilitators and barriers to participation in occupation within their lives.

5.1.Theme: I Want To Be Accepted As A Human Being

Throughout the execution of this study, the researcher became more aware of the urgent cry for acceptance from the participants. This plea was present in every interaction, every interview, every transcript, and every email. When embarking on this project, the researcher had set out to understand the meaning of occupation within autistic individuals' lives with the assumption that these individuals may experience and value occupation differently to neurotypical individuals. This study provided a window into the lives of five participants living with ASD and thus is not necessarily representative of the entire autistic population. However, the results from this study suggest that the participants of this study are not significantly different to neurotypicals in terms of what occupations they hold as important.

The results from the interviews with participants indicated that they have similar wants and needs to neurotypical individuals and that these are universal human needs that characterise us all as human beings. The participants in this study expressed the need for productivity, the need to relax through participating in activities that stimulate their own interests, the need to belong and to have a place in society. These three needs form the very core of an occupational definition of being human (Yerxa 1998). To live is to engage in occupations, which are activities that an individual participates in within their every day life. It is through *doing* that we create our own identities and it is through *doing* with others that we form a space where we belong (Kielhofner 2008).

In this discussion, the researcher would like to tell the story of the participants being human through occupation, and in the end not being that different from you or me. The researcher will use the terminology *'I'* and *'it'* from the Model of Integral Human Science developed by the contemporary philosopher Ken Wilber to understand human beings. *'I'* relates to the individual while *'it'* refers to the behavioural aspects of the individual (Yerxa 2009).

5.1.1. I am an individual but my diagnosis is a part of me

The participants in the study expressed their desire to clear the misconception around the meaning of 'normal' and to not be discriminated against or judged against a set of characteristics that does not allow for diversity and tolerance. Autism is part of the participants' identity and while they have been branded as 'not normal', they are trying to communicate their want to be accepted into society as human beings and to be treated with the same respect as one would treat neurotypical individuals. The participants feel they have been wrongfully distinguished based on their unique attributes and have been denied equal moral worth by neurotypical individuals. They are therefore emphasising that each person is created in a unique way and endowed with their own special capabilities. They would like to convey the message that although they have a diagnosis of autism they should not be treated as inferior human beings, but rather that society should try to get to know them and understand their unique abilities, potential and talents when engaging in their occupations.

This parallels literature, as it is suggested that every human being has the need to express their unique occupational identity through participation in their specific occupation, which ultimately allows for the creation of a meaningful life (Christiansen 1999). The participants longing for respect is not a recent plea, but as literature suggests, has been in motion from the 1960s. This began with the development of humanisation of disabled people in the United States of America and the Independent Living and Disability Rights Movement since people with disabilities have been excluded from society and have been ignored (Ward et al. 1999). Essentially, people with disabilities were subjected to discrimination. Another study that gathered information by people with mental illnesses explains how society's lack of knowledge, negative attitudes and discriminatory behaviour have shaped their personal and social experiences (Thornicroft 2009) (Hellman 2008). It is evident that a distorted view on the participants' unique abilities and who they are can have severe implications on who they *become* as occupational beings as it restricts opportunities for engagement. It is also important for society to understand what autism means and what it means to live with autism from the participants themselves, and in so doing give them a voice.

The participants are *doing* and are expressing a desire of wanting to *do* more. Their desire to *do* highlights the fact that they are evolving as human beings and as literature suggests, *doing* is a core concept in occupational therapy as *doing* embodies occupation (Wilcock 1999). Anthropologists have suggested that human beings are different, not only in what they *do*, but that they have choices in what they want to *do*. These occupational choices emphasise the participants' uniqueness and individuality and they would like the world to understand that they too can uniquely contribute to society (Wilcock 1999). This is closely linked to being human as each individual's contribution to society is equally important. Rochat (2006), justifies that the participants should not be branded as people who are not 'normal' (Rochat 2006). Embracing this view will allow for the creation of a more profound meaning of occupation in their lives as they will be provided with the opportunity to engage positively within their occupations and create a meaningful occupational identity. Effectively, the true meaning of what it means to be human will be captured (Dickie 2009). Passing, which as literature suggests means that individuals successfully hide their limitations in an attempt to display their competence to appear 'normal' or 'able-bodied' (Christiansen 1999), has been dismissed by the participants as they have chosen to rejoice their uniqueness.

The lived experiences of other autistic individuals reported in the literature also touched on the concept that being normal is a subjective thought and if one deviates from this perception of normal it generally leads to isolation (O'Neill et al. 2000). They were treated as inferior and believed to have no contributions to society (Hellman 2008) (Ward et al. 1999). The participants have brought about the topic of neurodiversity, which encompasses the idea that autism is a naturally occurring cognitive variation and that there is no single way for the brain to be normal (Silberman 2015) (Baron-Cohen 2017) (Jaarsma et al. 2012). Ideally, the participants want to feel accepted to form a positive occupational identity and in so doing develop a positive personal and social identity. This concept relates to Blank et al. (2015), which explains that it is a universal human trait to have the feelings of wanting to be approved and accepted to form a personal and social identity (Blank et al. 2015).

The participants have faced many hurdles in their life but the first step in overcoming any challenge or obstacle is acceptance. The participants have placed positive views on autism and this has helped and encouraged them to be proud of who they are and what they have achieved. All the participants shared a willingness to rise above their challenges and to be competent in their occupations to create a positive occupational identity. However, in a study by DePape et al. (2016), some autistic individuals felt indifferent about being autistic and showed no desire to understand what being autistic meant, as they associated ASD as having a negative impact on their sense of self (DePape et al. 2016). Other participants felt a sense of pride as being autistic contributed to their identity formation. These findings reiterate that autistic individuals are unique human beings who all have different feelings. In the same way that feminism is a movement that supports equality for both males and females and is an ideology that women are proud of, stand for and have embraced in shaping their identity, the participants are calling for equality and acceptance of a neurodiverse population.

5.1.2. I want to be productive

One of the strongest needs expressed by the participants was that of productivity. Participation in work is a universal phenomenon as it not only offers financial stability, but also opens doors towards social engagement, developing new skills and the feeling of being valued. This contributes to the occupational definition of health (Kielhofner 2008) (Nord et al. 2016) (Holwerda et al. 2012) (Yerxa 1998). A famous quote by Mary Reilly, *“Man by the use of* *his hands, as they are energised by the mind and will, can influence the state of his own health"*, means that we as individuals are responsible and have the capabilities for creating a healthy lifestyle by ensuring that we have a positive mind-set to do so. This quote celebrates human nature, and that human beings have the ability to make themselves at home in this world, and to make this world their home by having a sense of purpose and feelings (Reilly 1961). The participants by showing motivation to achieve their goals and the need for productivity shared this sentiment.

Literature has suggested that employment opportunities for people with disabilities are a struggle. As proposed by the United Nations, in globally developing countries 80% to 90% of people with disabilities are unemployed and in industrialised countries the percentage of unemployment ranges between 50% and 70% (Enable 2007). It was further suggested in the literature that autistic individuals had lower odds of being employed or maintaining a job due to their behavioural, social and communication challenges (Nord et al. 2016). While these unemployment percentages are significant and should not be ignored, there are opportunities for employment, that being, regular work, which includes supported employment, sheltered employment or voluntary work. The participants in this study were all engaged in productive occupations of regular work or furthering their education. This highlights that there are inconsistencies among neurotypical employees in being accepting of autism as some autistic individuals are employed, while others have not been given the opportunity to be employed. The education and awareness of autism is therefore vital for neurotypical employees so that all autistic individuals will be given a fair and equal employment opportunity.

The importance of supported employment is emphasised in literature as it provides accommodations to suit the skills and needs of people with disabilities (Holwerda et al. 2012) (Nord et al. 2016). For the participants, supported employment was not completely addressed as most participants explained that they had to overcome barriers independently in order to find and maintain a job, since the support was not available. This corresponds to Gerhardt (2011), which stated that many autistic individuals remain without the appropriate services. To overcome this challenge it is important to address and accommodate the specific needs of the participants and all autistic individuals so that they are able to utilise their skills fully (Gerhardt et al. 2011). The fact that participants in this study were overcoming barriers independently suggests that they all had fairly good ability to problem solve and to take responsibility for their own lives, which speaks to a high level of functioning and motivation. Unfortunately, this study did not probe the level of motivation and skills in this sample. It would be interesting to further explore how levels of motivation in ASD individuals affect their ability to function independently using motivation theories such as Vona du Toit's Model of Creative Ability (VdTMoCA) or Self Determination Theory.

The participants in the study possess internal motivation and have set goals in their life with the intention of adding meaning to their lives. The participants have a fierce desire to be successful and competent. The participants in the study had awareness into their personal causation and in conjunction with literature, this allows for more successful work participation (Holwerda et al. 2012). The participants' motivation to work opposed literature as it suggests that many autistic individuals lack the drive and initiative to find employment and that many individuals do not achieve their goals (Holwerda et al. 2012) (Barnard et al. 2000). These literature studies were done as surveys with parents of autistic children and as a systematic review of studies looking at overall social outcome including employment. The findings in the literature did not incorporate the views of autistic individuals themselves, while this study gathered the feelings and experiences of the participants. When an individuals' personal experience is not addressed the perceptions about them can be distorted.

Like many people in the world the participants have experienced the need for self-sufficiency and the need to earn money. The participants have discussed that their right to work has been disrupted due to their employers' lack of understanding of autism. The participants also mentioned that at times, they tried not to show their colleagues that they were struggling with sensory difficulties and DePape et al. (2016) substantiated this (DePape et al. 2016).

The participants in the study explained that autistic individuals need to be employed in a tolerant work place where their co-workers will not condemn them for their behaviours. Coping with meltdowns due to their sensory processing difficulties also proved to be a challenge for the participants. Further literature supports this by touching on the lived experiences of autistic individuals, who explained the importance of employers understanding autism and in particular their sensory difficulties. For example, if an autistic individual does not make eye contact this does not necessarily mean that they are not paying attention to what needs to be done, but merely avoiding the high sensory stimulation that making eye contact demands (Barnard et al. 2000) (Ward et al. 2000). These findings represent a call from autistic individuals for employers to understand autism and to be accepting of them in the workplace.

According to literature, people with disabilities, who have the desire to work, face challenges in actually acquiring and retaining a job because employers are hesitant to hire people with disabilities as they feel that these individuals will not be able to manage with the increasing work demands (Gerhardt et al. 2011). This is unfair to people with disabilities. If given the chance, through making necessary accommodations, the participants have demonstrated that they too have the capacity to contribute positively. The lived experiences of autistic individuals also substantiate this by explaining that when the necessary accommodations were made, coping with the tasks became easier to handle (Ward et al. 2000). Employers are also preoccupied with the *'it'* factors and the belief that autistic individuals are unable to lead an independent life, rather than on the *'I'* factors such as the awareness of their personal causation and what would match their skill set more effectively leading to better productivity (Holwerda et al. 2012).

The participants have further validated this as finding and maintaining a job has been a challenge, due to the unfavourable experiences of interviews and in communication. Communication proved to be a key factor in the participants finding employment. The way in which instructions were communicated influenced the way the task was completed. Holwerda et al. (2012) explained that communication in terms of language abilities and level of speech influenced employment opportunities (Holwerda et al. 2012). Literature detailing the lived experiences of autistic individuals further substantiated this as they explained the drawbacks they had during the job application process or contacting potential employers (DePape et al. 2016). From an occupational therapy perspective, it is important to view individuals holistically. Therefore it is important to understand the different ways in which individuals can communicate to better enable them to engage in their work occupations. Autistic individuals are able to communicate through typing or using electronic devices such as Augmentative and Alternative Communication (AAC). The various ways of communication will be further discussed in the category *'how technology helps me'*. Barnard (2000) has shown that adult autistic individuals need support when preparing their job applications and during interviews and the clarity of language is important when working with them (Barnard et al. 2000).

The same desire to work hard was not restricted to being an employee bust was shown at the university level as well. The participants have mentioned the difficulties they experienced at university when the educators were unprepared to make accommodations. This corroborates with literature, which mentions the importance of educators' awareness into autism as well as the lived experiences of autistic individuals who worked extremely hard at school and university (Barnard et al. 2000) (Ward et al. 2000). Although some of the participants have had different experiences at a university level, it is important to understand how their experiences can impact on the meaning of occupation for them presently and in the future. Clark (1997) suggests that an individuals' past experiences shapes how they wanted to lead their lives in the future (Clark 1997). Although some of the participants have experienced obstacles at the university level, this has not deterred them from wanting to achieve and accomplish their goals in the future. The participants' occupational participation was driven by personal factors such as their motivation to be productive and their desire to grow as occupational beings.

It is therefore essential that the participants be given a chance to display their unique abilities. The participants feel they have not been provided with the opportunity of fair working conditions and it seems that they have not been protected against underemployment. This underemployment obstructs individuals from forming a positive quality of life. This results in diminished self esteem, a false sense of who they are and ultimately a poor sense of belonging (Gerhardt et al. 2011) (Phelan et al. 2009). Literature has also mentioned that individuals can have a disability, but being unemployed is larger than a physical or cognitive challenge. Being unemployed results in the feeling of being disabled (Yerxa 1998).

The participants in the study have experienced occupational injustice in the form of occupational deprivation as they were unable to use their skill set to its fullest due to external factors (Townsend et al. 2004). This included employers who were not knowledgeable on autism and the challenges they faced by a lack of the necessary accommodations or provisions at work and university to assist with sensory processing difficulties. To fully live up to their potential, they needed colleagues and lecturers who would provide a more comfortable environment by a willingness to understand and accept autism. Further, the participants also faced occupational apartheid, as employment opportunities are fewer for them, due to personal characteristics and behavioural challenges.

5.1.3. I have interests and hobbies

The participants engaged in a wide variety of interests. They did not have the same set of interests, but each of their interests ranged between doing something fun, intellectual and spiritual. These different interests indicated that participants' interests were not limited or stereotypical. It further indicated that the participants understand the cognitive science of religion. Their interests were not odd or bizarre, but are activity choices that most people would engage in. Although this study offered a glimpse into five autistic individuals' lives, none of the participants displayed limited or restricted interests as mentioned in literature (Kuhaneck et al. 2010) (Spiker 2012) (Caldwell-Harris et al. 2011). However, a qualitative meta-synthesis study, which examined the lived experiences of autistic individuals found that the autistic individuals said that they thought and behaved differently from neurotypical individuals and this was evident through their repetitive and restricted interests. They did not view this as a negative characteristic, but instead explained that this attribute shaped their identity and it led to the development of their talents (DePape et al. 2016). This is an important finding as it emphasises the unique and individual nature of the participants and other autistic individuals. Phelan (2009) suggests that individual leisure choice is an influential factor when creating an identity. It can therefore be seen that the participants have and are continuing to shape their occupational identity (Phelan et al. 2009).

Although the participants are geographically dispersed and live in countries where engagement in some activities are more accessible than others, they were motivated to make engagement in their interests possible and were able to do so independently or with someone else. It is shown in Orsmond (2004) that autistic individuals enjoyed recreational activities that did not require social interaction more than activities that did (Orsmond et al. 2004). These findings were reported by families of autistic adolescents and adults and it was noted that participation in these social recreational activities were facilitated by the families of the autistic individuals, their teachers or service providers or by the autistic individuals themselves. However, information on the level of internal motivation by the autistic population was unknown. The participants in this study emphasised their enjoyment in a range of interests and showed pronounced motivation to participate in their interest. It is therefore important to understand each autistic individual’s motivation to engage in their interests as participation in their chosen activity makes occupation more meaningful. The value and importance of being able to pursue interests and participate in activities that we enjoy has been emphasised in OT literature (Kielhofner 2008). Once again, this study has shown that these participants have the same need to participate in meaningful leisure activities as neurotypical individuals do.

These participants are *doing* and it is in this *doing* that they are engaging in meaningful occupations. The occupation of pursuing interests helps to improve their health and well-being as well as their social participation. The participant’s occupational identity was emphasised through the engagement in their unique interests. The participants were not deterred from participating in their interests by determining whether they were good at it or not. They found something that they enjoy, and therefore continued to pursue their passions as often as they could. Their subjective experience of engagement in these interests is what added meaning to their occupational lives. This is confirmed in (Yerxa 1998), which suggests that engagement in any form of interests' fuels human happiness and participation in occupation as it allows for autonomy and creativity.

The participants' leisure pursuits provided them with the opportunity to rejuvenate, rest and feel better emotionally. The participants needed to develop a balance in their occupational participation of work, leisure, rest and sleep as this influences their well-being (Wagman et al. 2012). This is not always possible as work demands, social demands or emotional demands can become stressful. Stress and anxiety is not a feeling experienced solely by the participants, but is a universal feeling (Iwasaki et al. 2005). We all experience stress for different reasons however, the participants have expressed their emotional stress when their cries go unheard or when they are misunderstood. Stress has negative effects on their health and quality of life. Stress negatively influences participation in occupations and therefore how and what one *does* in their lives. This limitation in *doing* impacts the way an individual views themselves as occupational beings and ultimately hinders one from forming an occupational identity (Christiansen 1999) (Wilcock 1999).

The participants have mentioned how engagement in their interests helps to alleviate this stress and anxiety and therefore facilitates engagement in occupation. (Yerxa 1998) mentions, engagement in interests prevents mental collapse. Engagement in what the participants found exciting resulted in feelings of comfort and enjoyment. In an autobiography by Christi Brown, titled *My Left Foot,* he explained how painting helped relieve his depression, which was caused by his diagnosis of cerebral palsy (Kielhofner 2008). This emphasises the importance of engagement in interests in one achieving a sense of meaning in their lives. In a study by Iwasaki (2005), leisure in stress coping was analysed with a marginalised population who experienced stress due to their minority status. The participants were interviewed and all expressed the benefit leisure has in coping with stress and providing them with a sense of empowerment. In essence, this study gathered personal experiences of a marginalised population to provide guidance to others on how they can use leisure as a coping strategy (Iwasaki et al. 2005). This highlights the importance of gathering the participants and other autistic individuals' personal experiences so that they are given equal opportunities to participate in what they find meaningful and what will positively contribute to their well-being.

In a study by DePape (2016), the lived experiences of autistic individuals were analysed and it was further substantiated here that autistic individuals deal with on-going anxiety. However, in this study the individuals had different ways of dealing with their anxiety and this included increasing their self-awareness or withdrawing from social situations and as such the importance of understanding the lived experiences of autistic individuals cannot be underestimated (DePape et al. 2016).

5.1.4. I need to belong (so will you welcome me?)

In addition to creating their occupational identity, the participants expressed the desire to identify themselves within a role or roles. One of the roles that the participants emphasised was the social role. This social role encompassed internalising work relationships, friendships and romantic relationships. The way the participants have been treated by others and by understanding their relationships with others has contributed to the way they have internalised their social role. This is supported in (Christiansen 1999) where it is explained that our social environment drives our identities. This includes taking on family roles or being involved with the community. Blank (2015) mentioned that engaging in these roles contributes to the formation of an occupational identity (Blank et al. 2015). Another study by Phelan (2009) reiterated this by explaining that society is influential in determining what occupations are accepted and that society influences the development of occupational identity (Phelan et al. 2009).

The participants expressed a longing to be socially accepted at work, with friends and romantically. Literature suggests that the need to belong is a basic human need (Blank et al. 2015). This statement authenticates the initial remark of this study, that all beings, neurotypical or neurodiverse individuals are all human as they all display this need of belonging. The participants expressed their experience of stress when interacting with people, but were also aware of their social challenges and how this affected their interaction. This substantiates literature, which explains that autistic individuals do face social challenges (Müller et al. 2008) (Orsmond et al. 2004) (Grandin 2006). The participants realised that they themselves must make the effort to form relationships. Even though they faced challenges with forming and maintaining relationships and have been sexually exploited, they believe that with support, they can work towards building successful relationships. The participants have also described the adversities they faced when this support was not provided, and this will be discussed under the category, *'I have been excluded and bullied'*.

The participants expressed the difficulties in forming and maintaining long term relationships. This is not something that is limited to the participants or other autistic individuals, but a struggle experienced by many neurotypicals. The participants expressed how much more supported they felt when they shared a relationship with someone and Phelan (2009), Hilton (2010) and Causton-Theoharis (2009) explains the importance of belonging and engaging in social participation and the positive impact it has on an individuals self-esteem and quality of life (Phelan et al. 2009) (Hilton 2010) (Causton-Theoharis et al. 2009).

The participants in the study have similar roles to most neurotypical individuals however, their ability to fully engage in these roles particularly the social role, is disrupted because of the lack of acceptance by neurotypicals. Further they find it difficult to make eye contact and communicate with neurotypicals. When forming positive relationships, it is important to engage in socially acceptable behaviour. This behaviour comes in the form of using friendly phrases, such as *please* or *thank you*, giving compliments, helping others or asking for help. It is unfortunate that some of the participants who have faced these challenges while trying to develop relationships have had their calls for help ignored and were excluded. This eventually led to feelings of isolation. This feeling of isolation and disconnectedness culminates in occupational alienation (Durocher et al. 2014).

Causton-Theoharis (2009) and Müller (2008) studied the social challenges of autistic individuals by interviewing the autistic individuals themselves, found that feelings of isolation from childhood to adulthood were significant for them. Initiating interaction within social situations was difficult for most of the participants as they were unsure of how to include themselves. They also described their communication difficulties. The participants desired intimacy and explained that they felt distressed due to the inability to find or maintain relationships (Causton-Theoharis et al. 2009) (Müller et al. 2008). It is evident that the findings from the above studies challenge the idea that autistic individuals prefer to be alone. Making the effort to delve into the participants world by communicating with them, offered the chance to better understand them and their needs. While it is true that the participants struggle with social situations, this does not mean that they want to be excluded. Literature echoes this as in a study of the autobiographies of autistic individuals, it was found that autistic individuals have a strong craving for social interaction but due to their *'it'* factors namely their interests, ways of communication and sensory processing difficulties, the way they interact with others becomes difficult (Causton-Theoharis et al. 2009). The participants have faced occupational injustice in the form of occupational marginalisation. They have been excluded from participation in occupations and have limited opportunity for decision-making. As Durocher (2014) mentioned, this marginalisation may be due to the participant's habits and behaviours (Durocher et al. 2014).

The participants have also expressed the desire to be included when it comes to research into autism and to be involved in decision making. Literature supports this as it explains that being included in society, means having the opportunity to make decisions and participate as an equal member of society (Ward et al. 1999). The participants are emphasising that they are living with autism and are experiencing what it truly means to be autistic and should therefore be included in aspects pertaining to their life. In a study that interviewed adult autistic individuals, the need for inclusion was also expressed. This inclusion took the form of developing friendships and having the opportunity of being employed. These autistic individuals also expressed the barriers they faced with regards to inclusion, such as negative reactions from the neurotypical society (Barnard et al. 2000).

The participants are trying to increase inclusion of autistic individuals by increasing awareness and acceptance into autism. This inclusion encompasses all autistic individuals, whether they are verbal or non-verbal. In a narrative study of autistic individuals, it was explained that authors who used alternative forms of communication were included in the study as it provided the study with the voices of those with and without speech. This study emphasised inclusion by explaining that if autistic individuals are kept on the outskirts of the community, rather than being consistently involved in society, they will not understand life, work or play. Another example used was that if neurotypical individuals, particularly educators learn to understand how autistic individuals perceive their sensory and social worlds, as well as how they communicate, classrooms will be better equipped to encourage the autistic individuals to reach their full potential (Causton-Theoharis et al. 2009).

Occupational therapy follows a client centred approach, and by understanding the lived experiences of the participants, the essence of occupational therapy philosophy will be achieved. This understanding can only happen when one learns to include the autistic participants as well as all autistic individuals. This inclusion ultimately results in a better awareness into autism with the hope of accepting autism. Another study based on the lived experiences of autistic individuals emphasised the importance of understanding autistic individuals' experiences so that younger autistic individuals can transition into adulthood with better ease. This study shows the importance of such research in that it provides participants with the opportunity to speak and explain their experiences through their own perspectives (DePape et al. 2016).

5.1.5. Conclusion to theme 1:

In conclusion, the first theme of; *I want to be accepted as a human being,* has shown that the meaning of occupation for the participants is not that different from neurotypical individuals. The three categories that represent the need of productivity, of leisure time pursuits and perhaps most of all belonging are as important for autistic individuals as for neurotypical individuals. They are powerful contributors to the development of occupational identity and the experience of health and well-being. The participants in the study have experienced elements of negativity in how the neurotypical society views them. They have been dismissed as not 'normal' and trying to emphasise that this view of autism needs to change so that it does not cloud a neurotypicals judgement of an autistic individual. They are asking the neurotypical society to understand the concept of neurodiversity and embrace their uniqueness. The participants have expressed the pride they have towards autism and have used this diagnosis to form their occupational identity. The participants aspire to be successful and competent in all that they do. They have expressed the desire to be productive however, due to their associated autistic challenges and the limited awareness of autism by employers, obtaining and maintaining a job has been difficult. In addition to employers' awareness and acceptance of autism, the need for support serves as another means in which the participants regarded is helpful in obtaining and maintaining a job. There were a wide variety of interests that the participants engaged in which were done with or without social interaction. The participants further explained how engagement in their interests helped alleviate their experiences of stress. The participants have faced social challenges but are still expressing a desire to be included into society. They are aware of their autism, have lived with autism in a prejudiced society and are therefore attempting to increase awareness into autism.

5.2. Theme: Facilitators And Barriers

The second theme that emerged from the data focussed on the facilitators that promoted engagement in occupation and the barriers that prevent engagement in occupation. The participants have emphasised that they are living with autism and therefore have more insight in how autism plays a role in their everyday life. The participants have explained the internal and external challenges that they have faced. The internal challenges include following a routine, sensory processing and understanding sexuality, and the external challenges include being bullied and excluded from participation in society and financial difficulties. These difficulties have had negative implications on their self-esteem and occupational identity.

Approaches have been put into place to assist these participants in making participation in their daily life easier. This includes having support workers and using technology to communicate. The participants have become self-advocates to promote autism with the aim of achieving a more tolerant and inclusive society.

5.2.1. I need help to go through my day

Routinisation of behaviour into patterns of daily routines is a feature of all human occupation (Kielhofner 2008). The participants in this study also had daily routines that reflected the roles they fulfilled. These include getting ready in the morning to go to work or attend class at university, as they need to be presentable. Rodger (2011) focused on routine behaviour and suggested that the participation in routine behaviour contributes towards identity formation (Rodger et al. 2011). Further literature examining the lived experiences of autistic individuals caregivers shows that autistic individuals have ritualistic behaviours that impact their daily routines as they are rigid and at times refuse to deviate from their specific routine. The morning routine was reported to be the most difficult (Schaaf et al. 2011). Literature on routine behaviour and autism has mainly focused on children, with limited research done with adults (Mukaetova-Ladinska et al. 2016). The participants in this study were all adult autistic individuals and they described the difficulties they encountered whilst performing their routines. They mentioned that following a set pattern of behaviour is not as easy as it may be for a neurotypical individual.

A big challenge that the participants faced was prioritising tasks and deciding what is needed and important for the day. The participants also expressed that following this routine behaviour can become stressful. Stress, as mentioned before has negative impacts on individuals. In this study it was found that some participants, due to this stress are unable to move or speak and this causes frustration. In a study that examined catatonic features in autistic individuals, it was found that individuals would freeze while performing routines and needed support and prompting to move again (Wing et al. 2000).

To assist the participants with completing their routines, support workers or personal carers were available. The participants have mentioned the important role support workers have in assisting them complete their routines, and this was supported in (Schaaf et al. 2011). It was explained that families of autistic individuals created their own strategies with accommodations for the autistic individuals' sensory needs, so that they will be able to participate in their occupations. It is important to understand what the autistic individual needs so accommodations can be made through the use of support from families or support workers. This will give the individuals the best opportunity to participate in their occupations. The assistance that the support workers or caregivers provide to the participants in completing their routines is closely related to the category *‘how people help me’.*

5.2.2. I struggle with sensory processing

The participants mentioned the difficulty they experience in the way they process sensory information and how this impacts on their life. Experiencing sensations are an integral part of our lives as it allows the brain and body to communicate. The participants experience either heightened or decreased sensory input depending on their sensory processing abilities. They struggle with modulating their senses where the challenge is knowing what sensory information is relevant. As literature suggests autistic individuals may hear a sound too loudly, at times ignore the sound or experience a general sensory overload. For example, they may either lack eye contact or prefer to stare at a spot on the ground for a prolonged period (Ayers 2005). Literature, which examined the lived experiences of adult autistic individuals also found that sensory difficulties were ubiquitous in adult autistic individuals and that these sensory difficulties manifest differently amongst all adult autistic individuals (Crane et al. 2009). Another study suggested that sensory difficulties dissipate as autistic individuals become older (Kern et al. 2007). The study done by Kern (2007) contrasts the findings by Crane (2009) and the present study in that it reflected the perception of sensory experiences of autistic individuals from the point of view of the caregivers rather than the autistic individuals themselves. This further justifies the importance of understanding adult autistic individuals’ experiences of their sensory difficulties.

The participants expressed the difficulty they face when making eye contact. These sensory difficulties can affect participation in daily life, from making it difficult to drive to affecting the occupation of work. Sensory difficulties such as making eye contact were described as painful (Ward et al. 2000). It must be understood that these sensory difficulties do not mean that the autistic individuals are not trying to make the effort to connect or communicate with the neurotypical population, but that they have sensory difficulties that they are struggling with. The participants mentioned that they have experienced meltdowns, which is an involuntary autonomic nervous system (ANS) response when adapting to stressful situations (Lipsky 2011). The meltdowns occur when individuals struggle to modulate their senses resulting in the experience of sensory overload. This leads to shutting down and becoming under responsive (Case-Smith 2010). They reported that their meltdowns are so severe that at times they are prone to causing harm to themselves. They also emphasise that these meltdowns differ from person to person and should not be handled in the same way. It is therefore vital to understand what an autistic individual needs, to create an environment that allows for them to deal with their sensory processing difficulties in their unique way. In a book titled *'An Aspie's Guide To Living With Meltdowns: Been There. Done That. Try This'*, it was explained that meltdowns are common in autistic individuals, and it manifests itself in the form of getting angry, running away or shutting down (Attwood et al. 2015). The autistic individuals explained how they dealt with their meltdowns. This differed from each person. One autistic individual explained how modifying the environment, such as the amount of light in the room as well as the level of social interaction helped to reduce meltdowns, while another explained that emotional awareness and communication is important (Attwood et al. 2015). These examples apply to the participants in the study as it reiterates that autistic individuals are all unique and that their experiences and ways of coping are different.

The participants explain that if they are allowed to communicate with people in a way that better suits their sensory system they will be able to create more meaningful conversations. From the participants' explanations it is evident that it is not only autistic children who struggle with sensory processing, but that sensory processing is another challenge experienced by autistic adults. Again this illuminates the importance of listening to an autistic individual and understanding that each person is an individual and should be treated in ways that are fair beneficial to them.

5.2.3. I need to understand my body and sexuality

The majority of the participants in the study were female. Being a female means that one may have the role of being a daughter, wife and mother. Being a male also implies that individuals have the opportunity to be a husband, son and father. Fulfilling these roles means taking on certain responsibilities however, in accomplishing these responsibilities individuals need to know how to perform these roles. In taking up these roles, individuals are given the opportunity to develop a different occupational identity. The participants have expressed the need to understand and to be educated on the male and female reproductive system so should participation in the above mentioned roles occur, they are better equipped to deal with it.

The participants suggested that there should be health professionals available specifically for autistic individuals, to educate them on sex and which will give them the opportunity to understand their sexual autonomy. The article by Sevlever (2013) mentioned that sexual education for autistic individuals is lacking (Sevlever et al. 2013). Gerhardt et al. (2011) has emphasised that autistic individuals, just like neurotypical individuals are sexual beings however, the only time sexuality is addressed is when autistic individuals are sexually exploited (Gerhardt et al. 2011). Therefore, it is imperative that sexuality be included as another instructional area, to provide adult autistic individuals with a safer environment. The participants have voiced their need for sexual education and this has also been discussed in Travers (2010) (Travers et al. 2010). It has been established that autistic individuals struggle with social interactions and this may make them prone to sexual abuse. Autistic individuals have a right to be educated about relationships, marriage, parenthood and appropriate sexuality. The article suggests that with individual sexual education, autistic individuals will be empowered to prevent sexual abuse or be able to report incidences of abuse.

The participants have suggested that it is difficult to be autistic and to be a woman. Cridland (2014) identified that most studies have been done on autistic males and the studies that included autistic females did not fully explore the experiences of the women. This article sought to understand the experiences of autistic adolescent females and was done through interviewing both the autistic individuals and their mothers. The experiences of autistic women on sexuality stem from their adolescent years, where they experience difficulties in socialising with other girls, difficulties with puberty and sexuality and sexual vulnerabilities. A further challenge in being autistic and being a woman is the view on having children. While there were participants who felt they would like to have children, some participants felt that their sensory challenges will affect their ability to be a mother. They also felt that financial challenges pose a strain on autistic woman having children. There is much study on women having autistic children, while research on autistic women having children has not been studied in much depth (Cridland et al 2014) (Rogers et al. 2017). Autistic individuals struggle with sensory difficulties and these sensory difficulties are heightened in pregnant autistic women, which can lead to an increase in their stress levels. Health care workers therefore need to be aware of the needs of the autistic women.

Occupational therapy follows a holistic approach. This holistic approach encompasses all occupations that individuals engage in. Sexuality can be regarded as an umbrella term that describes occupations of dating, grooming or having sex (Sakellariou et al. 2006). Sexual education is therefore important so that the participants become more sexually aware and this can influence participation and give meaning to their occupations.

5.2.4.I have been excluded and bullied

The participants have experienced a lack of social acceptance, which has led to feelings of isolation. Due to lack of knowledge about autism the participants were bullied. This culminated in negative psychological effects as it resulted in low self-esteem. Kowalski (2013) highlighted the implications of bullying, which can cause adverse effects on self-esteem and health. This category is closely associated with the category ‘I want to belong’ (Kowalski et al. 2013).

The negativity experienced by the participants affected their participation in meaningful occupations. It is identified that the participants longed to feel a sense of belonging and to feel part of a society. In conjunction with the literature that are narratives from autistic individuals themselves, it was noted that autistic individuals too felt the need to belong and feel valued (O'Neill et al. 2000). Another narrative explained that belonging is a human need and allows one to form a positive sense of self-esteem (Blank et al. 2015).

This accentuates the importance of getting to know the participants and therefore allowing for their participation in society. (Yerxa 2009) further suggests that when individuals have impairments they are subjected to social prejudice. These social prejudices focus on the *‘it’* characteristics of the individuals which equates them with an ‘abnormally’ functioning body. The reduction of the participants to their *‘it’* characteristics has had a negative impact on their experience of occupations as they were not appreciated for what they were able to contribute to society which is a barrier to a sense of belonging. This study further goes on to explain that if the *‘I’* characteristics are put in the forefront, it will enable and empower individuals to challenge their difficulties and create a more meaningful environment (Yerxa 2009). Evidently, a focus on the *‘I’* characteristics will improve the participants as well as all autistic individuals’ self-esteem and therefore contribute to the formation of a positive occupational identity (Phelan et al. 2009).

To stress the importance of getting to know autistic individuals and what they are capable of, in the category, *‘I want to be an individual but autism is a part of me’* discussed the hope to dismiss terms such as ‘normal’ and ‘abnormal’. The participants have highlighted that societies misinterpretations of autistic individuals can sometimes cause poor participation in their occupations as they are then led to believe that they themselves have limited capabilities. This impedes their progress in achieving their goals and what is meaningful to them.

These labels also negatively contribute to the opportunities for acceptance and inclusion into society by neurotypical individuals. The neurotypical society should not place assumptions on how the participants should behave based on their belief of autism.

In a narrative by Dekker (1999) of an adult autistic individual, he explained the importance of understanding the lived experiences of autistic individuals and how this will allow for the creation of a unique and larger picture of what autistic individuals can actually do. He also suggested that by gaining this larger picture, one will not assume that autistic individuals are either going to be savants or that the individual will never be able to improve (Dekker 1999). Amy Sequenzia, a non-speaking autistic individual has also written about how functioning labels are not helpful. She argues that someone who is termed as ‘high functioning’ may experience difficult periods in their life, but because of this label, their struggles go unnoticed (Sequenzia 2012). In essence, the social rejection that the participants faced had detrimental effects on their self worth and confidence. Without social acceptance and support the participants found adding meaning to their lives more difficult.

5.2.5. I have financial difficulties

This category is closely related to the categories, *‘I want to be productive’* and *‘I have various interests’,* as productivity is often related to remuneration and interests often require resources. The importance of having a stable financial environment is an aspect of life that most people aim to have. The participants have described that they face financial challenges, which interferes with their engagement in their occupations and activities of daily living. Poor engagement in their occupations can lead to the participants experiencing occupational imbalance. Wagman (2012) justified that occupational balance is a positive influence on an individual’s well-being (Wagman et al. 2012). In another study detailing the lived experiences of autistic individuals, finances among others were noted as a difficulty (Mukaetova-Ladinska et al. 2016).

There has been limited research done on financial challenges and autism. Finances play a major role in the active participation of occupations, as many occupations (especially those of self care and leisure time pursuits) require financial expenditure. When there is an added condition such as ASD, finances may be prioritized to attend doctor appointments, purchase their prescribed medication as well as pay their support worker fees. Thus the financial needs and daily expenses for participants can be higher than for neurotypical individuals, and can prevent ASD individuals from participating in occupations of their choice as they are using their financial resources on health care. Literature emphasises that it is an occupational right for all individuals to engage in meaningful occupations that contribute to their well-being and the well-being of their communities. It was further suggested that occupational therapy addresses how engagement in occupation influences the well-being of the individual (Whalley Hammell et al. 2012). While there are neurotypical individuals who are also struggling financially, the participants may be facing these financial difficulties due to the focus on their *'it'* characteristics such as their behavioural challenges when finding and maintaining a job. Financial strain has the ability to cause stress, which as discussed above can negatively influence participation in occupation and ultimately the well-being of the participants. This can lead to occupational dysfunction as the environment fails to enable participation in meaningful occupations (Wilcock 1999).

Whalley Hammell (2012) identified that occupational therapy theories have been developed in economically wealthy societies, while poverty stricken environments where disability, social exclusion, marginalisation and discrimination are rife have not been central to the theory development. This study recognises that disabled people are generally the poorest in most countries and occupational therapy should bring this to the forefront of theory development so that the well-being and occupational rights of these individuals are appropriately addressed (Whalley Hammell et al. 2012). Although the participants in this study are employed and are receiving an income, they have faced financial challenges, which have in some way or another influenced their occupational rights. Due to the labels attached to them regarding what they can or cannot do, or the assumption about their ability to work all culminates in focusing on the *'it'* factors. This results in not providing the individuals with the opportunities to fully live up to their potential. This may lead to underemployment causing financial strain. This financial strain negatively influences participation in occupations, which will lead to a poor sense of self-esteem and ultimately affects occupational identity (Phelan et al. 2009) (Price et al. 2002).

5.2.6. How people help me

In the category, *'I need help to go through my day',* many of the participants identified support workers or personal carers as positive influences in their lives as these people provide them with the help they need to complete their tasks of daily living. These support workers or personal carers helped participants with time management and life management, which allowed participants to participate in their occupations in a meaningful and successful manner.

This category appreciates the assistance offered by the support workers or personal carers as they have provided better opportunities for self-management. The participants emphasised that it is important for the support workers or personal carers to be trained in the field of autism so that they are aware of what needs to be done and how the specific tasks should be done. It is also important for the support workers or personal carers to be cognisant of the participant's abilities so that they do not hinder their progress in becoming independent. In a study by Griffith (2012), the lived experiences of individuals and their experience of social support were examined. It was found that the participants were unhappy with the support provided, as the support offered was not specifically tailored to autistic individuals (Griffith et al. 2012). This reiterates that support workers need to be knowledgeable on the population they wish to help. The findings from this study and Griffith (2012) suggest that all autistic individuals are unique and therefore their support needs to be matched to their unique needs. In this manner, assistance provided to autistic individuals will be better achieved.

5.2.7. How technology helps me

Technology is another form of support that has proved beneficial to the participants in the study who struggle with communication. It allows them to communicate with each other and other people with more ease and it accommodates their sensory needs. There is less pressure to make eye contact with the person on the receiving end and helps in overcoming certain social challenges.

Technology and using the computer offers the participants a better opportunity to relay their messages with more clarity, as they sometimes struggle to explain themselves verbally. The participants in the study expressed that the way a neurotypical individual may speak to an autistic individual can be patronising but such an issue is alleviated when using the computer. As Gillespie-Lynch (2014) mentioned, computer mediated communication is helpful in clearing up miscommunications and the fact that some autistic individuals prefer writing to speaking (Gillespie-Lynch et al. 2014).

Augmentative and Alternative Communication (AAC), was another form of communication used by some of the participants. This provided them with the opportunity for the expression of their thoughts, needs and ideas without using oral speech. This is another attempt that the participants are making to communicate with people around the world. The participants are hopeful that people around the world will be willing to learn about this method of communication so that they can be respected when using it and not be deemed as unfit because they are physically unable to express themselves through words, gestures or expressions.

Technology has served as an outlet for the participants to express themselves when they are feeling overwhelmed. This expression can take the form of writing blogs or E-mailing people who offer support. The participants do not need an immediate response to their blogs or E-mails, but it is a way for them to tell someone about their feelings and have control over their communication without interruptions.

Social media is a form of entertainment and communication for many individuals around the world. The participants use social media to establish relationships, be it social or career related. Social media offers social interaction. The participants stated that social media could also be an unhealthy environment as people mainly post information about their happiness. They explained that these advertisements of happiness may not be experienced by another and can sometimes cause emotional pain. The participants or other autistic individuals do not only experience this pain, but it is a feeling that can be experienced by neurotypical individuals as well. Literature discusses the implications of using computer-mediated communication in that it may cause vulnerability among its users. Further, autistic individuals may miss the immediate emotions that non-verbal cues provide (Gillespie-Lynch et al. 2014).

Wilcock (1999) has suggested that technology has negative implications on an individuals' ability to *do* as technology abandons the natural world (Wilcock 1999). However, this is not true for the participants in the study, as they have explained how technology enables them to *do*. It was also mentioned that autistic individuals mainly use the internet for gaming purposes rather than for social interactions (Gillespie-Lynch et al. 2014). This contradicts the findings of this study, as the participants have mentioned that they use the Internet to develop relationships. This discrepancy was present as Gillespie-Lynch (2014) received this information from parent reports, rather than the autistic individuals themselves (Gillespie-Lynch et al. 2014). Causton-Theoharis et al. (2009) has used autobiographical accounts of autistic individuals, to explain that the autistic individuals prefer to narrate their experiences and express their voice through writing. This study evaluated the lived experiences of the participants, which therefore justifies the importance of gaining autistic individuals' personal experiences so that misinterpretations about them do not occur (Causton-Theoharis et al. 2009).

Gillespie-Lynch et al. (2014) conducted online surveys on autistic individuals and suggested that autistic individuals acknowledged the benefits of computer-mediated communication. This form of communication gave them the opportunity to express themselves and gain control over their own communication. The article further suggested that computer mediated communication reduces the anxiety that most autistic individuals experience in face-to-face interactions (Gillespie-Lynch et al. 2014). This form of communication also gave the participants opportunities to advocate for autism through blogging.

5.2.8. I have become an advocate

Autism has not been fully accepted into society. The participants explained that they are not given a voice and there are too many people that are speaking for them. This feeling was shared by Charlton (1998) a disability rights activist, who associated personal defeat with others speaking on your behalf (Charlton 1998). The participants are proud of who they are and this pride has given them the courage to become self-advocates for autism. They are therefore trying to clear the misconceptions that neurotypical individuals have about autism and in so doing are creating a moral identity (Taylor 2016). Through their self-advocacy for autism, they want people to understand them and accept them, as they are the individuals who have first hand experience of what autism means. This ties in with Benget Nirje's belief that one should rebel against being underestimated and have the opportunity to make choices, which can be achieved through advocacy (Ward et al. 1999). Dekker (1999) suggested that there are many autistic self-advocates in the world who are attempting to create an autistic culture. People with physical disabilities have been practising self-advocacy for many years and this has left a significant mark on society such as the importance of wheelchair accessibility. However, as the communication styles of the participants are subtler their voices go unheard and it is therefore important to make the effort in understanding their ways of communication so that their voices can be expressed (Dekker 1999).

The participants highlighted that acceptance is also in the form of how neurotypical individuals refer to them. The participants have emphasised that they are also people and are asking to not be called by hurtful names. They are implying that despite their differences it does not make them or anyone who acts differently a inferior. This is further reiterated in literature, which explains that autistic individuals reject the terms ‘abnormal, delayed or impaired’ (Causton-Theoharis et al. 2009). Autism is an integral part of who they are, it is not separate from their identity, and it is with this value that they are asking to not be referred to as individuals with autism, because they are not separate from their autism (Jaarsma et al. 2012).

5.2.9. Conclusion to theme 2:

In conclusion the theme *‘facilitators and barriers’* highlighted four main barriers to participation in occupation and two important facilitators. The participants have encountered challenges in their life. These challenges affect the ability of the participants to engage in their daily routines. A support system in the form of support workers that assist with prompting enables the participants to complete their daily tasks. Evidently, through gaining the experiences of the participants it became evident that challenges in following daily routine or prioritising tasks are also prominent in adult autistic individuals and not primarily in autistic children. Another challenge described by the participants was the difficulties associated with sensory processing. They explained how their sensory processing difficulties have implications on their activities of daily living. The participants further described that when they experience sensory overload it results in them having meltdowns and that each autistic individual needs to be handled in their own unique manner. To understand the unique nature of handling these situations it is imperative to listen to autistic individuals themselves.

The majority of the participants in the study were female and they described the difficulties associated with understanding sexuality as well as the difficulties autistic women have with regards to the female reproductive system. The participants emphasised the need for sex education. They explained that they have been subjects of exclusion due to their diagnosis of autism, which has led to feelings of isolation. These feelings were heightened, as society tends to place lables onto autistic individuals in terms to what they are thought to be capable of. This assumption has negative implications on the individual as it leads them to believe in distorted vision of who they are as occupational beings. Although there has been limited research done on the financial difficulties experienced by autistic individuals, the participants in this study experienced financial difficulties. Financial strain is experienced by many people around the world, however this financial strain may be exacerbated in autistic individuals due to neurotypical individuals focusing on their *'it'* characteristics, which decreases their opportunity to engage in occupations.

The participants highlighted two key support systems. The participants mentioned how support workers assist them in coping with their self-management. However, it is essential that the support workers be educated on autism so that they do not over ride what the participants actually can do. The participants also described how the use of technology is helpful in communicating with others with more ease than face-to-face interaction. Technology provides a medium for the participants to express themselves as well as form relationships. As a result of the exclusion from society and the lack of understanding autism, the participants have become self-advocates for autism.

5.3. Implications for occupational therapy

Occupational therapy facilitates and encourages individuals to participate in meaningful occupations to their optimum capacity. Occupational therapy promotes health and well-being in all aspects of life such as in personal routines, social interaction, productivity and engaging in leisure pursuits. It was further suggested that occupational therapy focuses on what individuals *do*, and that through participation in their occupations they are in a constant state of becoming different (Wilcock 1999). However, this is mainly addressed by using techniques of splinting and aids to daily living, which although is important, individuals' experiences of their life and occupations they participate in is not put in the forefront. Yerxa (2009) explains that the *'it'* characteristics have gained precedence over many other features that encompass a human being (Yerxa 2009). Throughout this study it can be identified that due to a focus by neurotypicals on the *'it'* characteristics of the participants, their capabilities and difficulties have gone unheard. Yerxa (2009) further explained that one of the purposes of occupational therapy is to enable individuals to empower themselves and to find satisfaction within all their unique occupations (Yerxa 2009). The participants in this study have emphasised that they are trying to empower themselves through self-advocacy acts and to get their voices heard.

Another implication of neurotypicals focussing on the *'it'* characteristics of the participants led to significant challenges with regards to their opportunities to perform within their occupations. They were seen as 'unfit' or 'not normal' and due to their behavioural difficulties the neurotypical society failed to see what the participants were capable of and this affected their ability to *'do'*. This in turn contributed to their occupational identity formation. Christiansen et al. (1999) explained that while illness or injury have implications in occupational performance and occupational identity, occupational therapists are well equipped and have the knowledge to address the identity challenges and therefore help to improve the well-being among individuals (Christiansen et al. 1999). Occupational therapists have the expertise to provide individuals with the opportunity to empower themselves by providing environments that enable them to explore what is meaningful to them so that they can develop their occupational identity (Wilcock 1999). This empowerment also takes the form of listening to the participants' voices and understanding what their capabilities are, what is meaningful to them and also what they find difficult. Another form of empowerment, especially in the workplace, is for occupational therapists to ensure that there are effective assessments and interventions to assist with work participation. Wilcock (1999) explains that the occupational therapy profession should not only focus on neurological, physical or mental disorders, but also focus on individuals who are struggling with the disorders of occupational deprivation, occupational alienation and occupational imbalance (Wilcock 1999). In this study such disorders have been discussed. It is imperative that this be addressed through listening to their voices, so that they are given the opportunity to participate in their occupations.

Occupational therapists can also assist the participants and other autistic individuals through the role of being an advocate. Although the participants have become self-advocates, having occupational therapists support them may result in the achievement of an autistic utopia (Kuhaneck et al. 2010). Occupational therapy, being a profession that enables *doing* and looking into the health and well-being of individuals through viewing them holistically, can advocate for the participants by emphasising the importance of listening, accepting and respecting an autistic individuals needs and desires. They need to be respected for who they are and not be pressured to conform to the *'normalcy'* of society. Using this holistic and client-centred approach the unique nature of the participants must be celebrated and that each persons' unique nature must be dealt with individually in either the work environment or socially. Lastly, occupational therapists can assist in emphasising that all the participants and other autistic individuals are equal and that there should be no hierarchical platform on which decisions about autistic individuals are based. They should all be able to equally contribute to society and to what they need. Occupational therapists should also appreciate the use of the internet and how this assists autistic individuals to organise an alternate human society (Dekker 1999).

CHAPTER 6: CONCLUSION

This chapter summarises the main findings of the study.

In conclusion, autism has been viewed as a debilitating disorder with the belief that autistic individuals are ‘abnormal’ due to their behavioural challenges. As a result autistic individuals have been stigmatised and kept on the fringes of society. Research has generally been aimed at formulating the best possible treatment options to suppress these behavioural challenges with the intention of providing autistic individuals with a better quality of life. The participants in this study have raised concerns regarding what occupations they hold as meaningful as opposed to what the neurotypical society views as meaningful for them. They emphasised that their voices on what is meaningful to them as well as their lived experiences have gone unheard. To fully adhere to occupational therapy philosophy, it is important to explore autistic individuals’ experiences and perceptions of *doing* in the world and environment that they live in. This will enable neurotypicals to understand how occupation creates meaning in their lives and therefore contribute to therapy in achieving a client centred approach.

This study aimed to evaluate the lived experiences of autistic individuals and the meaning of occupation in their lives. A maximum of five geographically dispersed participants participated in the study. To achieve this, the study was done in two sequential phases. Phase 1 consisted of downloading and analysing blogs by the participants, which provided the researcher with information of their participation in daily life. This informed phase 2 of the study, which consisted of an E-mail interview where the questions were based on extending the information obtained in Phase 1. Both phases were analysed and interpreted through qualitative thematic analysis.

Two main themes emerged from the data namely, ***‘I want to be accepted as a human being’*** and ***‘Facilitators and Barriers’.*** These themes provided insight into how the participants have experienced the world, the challenges they faced, what provided assistance to them in overcoming these challenges and how they themselves can overcome these challenges.

Autism has been viewed with the assumption that autistic individuals are ‘abnormal’ as they do not behave in the same manner as neurotypical individuals. As a result, the participants have explained that they have been stigmatised, and their unique contributions to society have not been acknowledged. The participants have emphasised that autism is part of their identity and it is not a separate entity. They are asking for the neurotypical society to accept and respect their originality, rather than reject them as equal members of society. They want the world to understand that they are part of a neurodiverse population and are emphasising that they exist as different ways of being human.

The sensory and communication challenges that the participants face have culminated in the difficulty to find and maintain a job. All the participants in the study were employed and expressed the need for self-sufficiency however, they expressed that all employers should be aware and accept autism so that all autistic individuals will be given fair and equal employment opportunities. Poor awareness and acceptance into autism potentially leads to underemployment and financial difficulties. These challenges further resulted in difficulties when trying to interact and develop relationships with others. Due to the neurotypical society’s poor awareness and acceptance into autism, the denial of a fully inclusive society is evident. The participants have been subjected to bullying and rejection. This resulted in feelings of isolation and exclusion, which affected their self-esteem and occupational identity. Majority of the participants were female and they shed light on the challenges that are unique to women. They emphasised the need to be educated on sexuality and the female reproductive system to provide them with sexual autonomy.

Despite these challenges, the participants displayed pride in being autistic. The participants’ pride of being autistic has fuelled their desire to set and achieve goals. In essence, the participants are *doing*, and have unique occupational choices of engaging in leisure occupations, which serves to rejuvenate and revitalise them as well as their desire to be productive. This is a direct reference to occupational therapy, as it is in this *doing* that they are developing their occupational identity and becoming occupational beings, with the intention of achieving a positive sense of health and well-being.

To assist the participants in accomplishing their occupations, they require support workers or caregivers however, it is vital that these support workers or caregivers have awareness into autism so that they do not undermine the participants capabilities. Further, the participants have also explained how accommodations at work or university that are tailored to their specific needs can positively contribute to engagement in their occupations.

The participants have faced many adversities throughout their life. Their voices and pleas have gone unheard. They are asking the world to listen to them, to get to know them and to understand that they are not the ‘abnormal’ individuals neurotypicals think they are.

The participants’ call to be accepted as human beings emphasised that their experience and value of occupation needs to be understood. This has therefore influenced them to become self-advocates for autism with the intention of educating the neurotypical society about autism and that autistic individuals have the potential to contribute positively to society. It is imperative for the neurotypical society to be aware of the different methods of communication with autistic individuals. By listening to their voices, a better picture of their unique abilities and what they can contribute to society will be achieved. Technology has been used in this study to gather the lived experiences of the autistic individuals and has proved to be beneficial in this study as well as in the participants’ lives. Occupational therapists can use this information to achieve a client-centred approach and understand the true meaning of occupation in autistic individuals’ lives.

6.1. Limitations of the study

There was difficulty in recruiting participants for the study as many autistic individuals were wary of researchers and health professionals and did not truly believe that researchers had their best interests at heart. There were only five participants in the study, where the majority of the participants were female. Thus it would be difficult to generalise findings to other populations of autistic individuals, especially males.

Due to the difficulty in recruiting participants, this study did not have a geographical or cultural focus however, the majority of the population subscribed to a Western worldview. These results describe these participants' specific experiences within their own worldview. It would be interesting to explore the experiences of autistic individuals in a wide variety of geographical and cultural locations in order to truly understand the experiences of autistic individuals around the world.

Originally this research project wanted to explore the experiences autistic individuals had in occupational therapy, but due to the difficulty in recruiting participants this was not possible. It would be interesting to explore how autistic individuals experience occupational therapy and whether this therapy is truly meeting their needs.

The sample of the study included individuals who did not represent all autistic individuals, but rather those that had a strong tendency for advocacy and high levels of motivation to overcome their barriers. These individuals had access to technology, which allowed for communication between the researcher and the sample. It would be interesting to understand the opinions and levels of motivation from autistic individuals who do not have access to technology and those who do not have a tendency for advocacy.

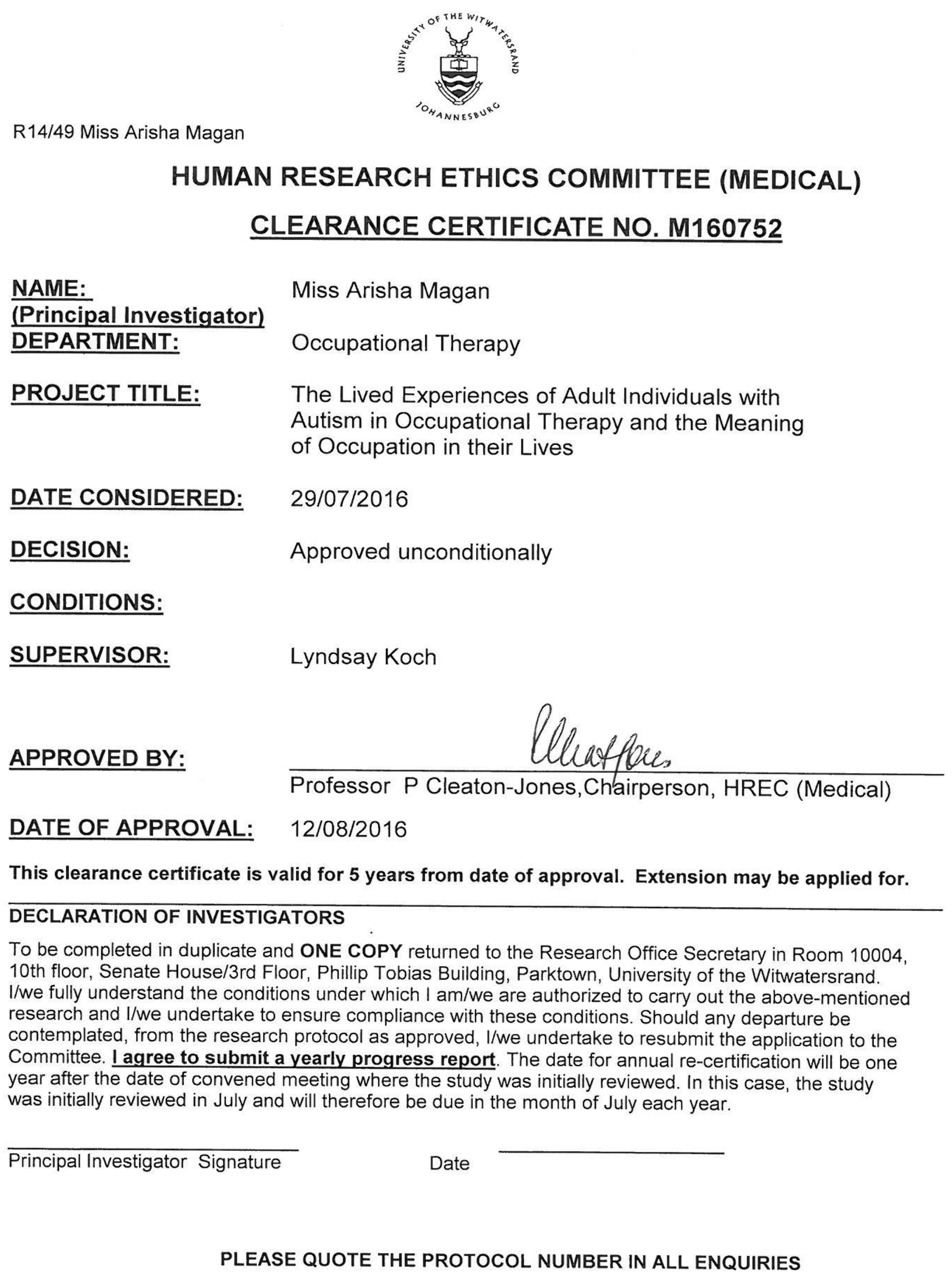
6.2. Recommendations

The following research recommendation are suggested:

- To engage in collaborative research between the researcher and autistic individuals to ensure that research focuses on issues that are relevant to the autistic population.
- To explore the lived experiences of autistic adult male individuals.
- To reproduce this research process in different geographical locations and with different cultures and communities in order to explore whether these lived experiences are similar or different to those described in this project.
- To gather the lived experiences of adult autistic individuals who have attended occupational therapy, to understand their experience of therapy and whether this therapy meets their needs. This information can be used to inform how occupational therapy techniques can be adjusted to meet their needs.
- To investigate the relationship between levels of motivation and drive in autistic individuals and their ability to overcome barriers in the workplace or to complete higher education using motivation theories such as the Vona du Toit Model of Creative Ability (VdTMoCA).

CHAPTER 7: APPENDICES

Appendix A: Ethical Clearance Certificate



R14/49 Miss Arisha Magan

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160752

NAME: **(Principal Investigator)**	Miss Arisha Magan
DEPARTMENT:	Occupational Therapy
PROJECT TITLE:	The Lived Experiences of Adult Individuals with Autism in Occupational Therapy and the Meaning of Occupation in their Lives
DATE CONSIDERED:	29/07/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Lyndsay Koch
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	12/08/2016

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 in Room 10004, 10th floor, Senate House/3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized 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 the application 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 July and will therefore be due in the month of July each year.

Principal Investigator Signature ____________ Date ____________

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Information Document

Study title: The lived experiences of individuals with autism in occupational therapy the meaning of occupation in their lives.

Good day

I, Arisha Magan am a Masters student in occupational therapy at the University of the Witwatersrand. I am completing a research study on the lived experiences by individuals with autism. This study aims to explore the minds of individuals with autism and gather information about what is meaningful and important to them with regards to their occupations.

Invitation to participate:

I am inviting you to take part in this study. Your lived experiences in occupational therapy will provide useful information on what you have found meaningful and beneficial with regards to your occupations.

What is involved in the study

The study will entail gaining clarity on your lived experiences as an autistic individual, through using the information obtained from the blogs and the open-ended e-mail interviews. The research supervisor will be carbon copied on the e-mail to ensure no tampering with the answers. There will be back and forth discussions on what is important to you as an individual and how this has been achieved in therapy. Individuals with autism from South Africa will be taking part in the study. The study will be done in two phases. The first phase includes blogging, which will take place over 2-3 weeks. As the researcher, I will collect the blogs and make reference to it when developing the e-mail interview. The second phase, which includes the e-mail interviews will take place over 3 months. All transcripts received will be saved in a separate folder, printed and stored in a file.

Risks

There is a risk of reliving negative experiences, which may cause anxiety. If at any point you do not wish to discuss the experience further because of this, you may alert the researcher and the discussion will be changed.

Benefits

This study will provide a greater depth of insight into the minds of an autistic individual. Intervention is primarily focused on what is society's expectations, therefore this study will provide information on what is actually meaningful and important to an autistic individual in terms of their occupations.

The participant will be given pertinent information on the study while involved in the project and after the results are available.

Participation is voluntary

Your participation is voluntary and any that refusal to participate will involve no penalty or loss of benefits. You are able to discontinue participation at any time during the study.

Confidentiality:

All information obtained during the study will be kept confidential.
Organisations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee.
The data from the blogging and e-mail interviews will be kept for a period of six years in accordance with the HPCSA regulations.

Contact details of researcher

If at any time during the study you have questions, please feel free to contact my research supervisor, Ms Lyndsay Koch, or the WITS occupational therapy department at (011) 717-3701.

For any questions regarding ethical issues, please contact Professor P Cleaton Jones at (011) 717 1234.

Appendix C: Informed Consent: Use of blogs

I hereby confirm that I have been informed about the study.

I may, at any stage, refuse to take part in the study or stop and withdraw from the study. I have had an opportunity to ask questions and (of my own free will) declare I am willing to take part in the study.

Participant's name: (please print) ____

Participant's signature (if able to do electronically): ____

Date: ____

Witness's name: (please print) ____

Witness's signature (if able to do electronically): ____

Date: _______________________________________

Appendix D: Informed Consent: Participation in e-mail interview

I hereby confirm that I have been informed about the study.
I may, at any stage, refuse to take part in the study or stop and withdraw from the study. I have had an opportunity to ask questions and (of my own free will) declare I am willing to take part in the study.

Participant’s name: (please print) ______________________________________

Participant’s signature (if able to do electronically): ____

Date: ____

Witness’s name: (please print) ____

Witness’s signature (if able to do electronically): ____

Date: _____________________________________

Appendix E: Demographic Questionnaire

Participant code:

UNIVERSITY OF THE WITWATERSRAND: DEPARTMENT OF OCCUPATIONAL THERAPY
PERSONAL BACKGROUND AND MEDICAL INFORMATION:

GENERAL INFORMATION

Gender:	Ethnic group:
Age:	Home language:
Highest level of education:	Occupation:

MEDICAL INFORMATION

Diagnosis:	
Doctor who made the diagnosis:	
Premorbid Medical History:	
Current Medical history:	
Precautions:	
Medication and side effects:	
Other therapies:	

Appendix F: E-mail interview initial questions

1. Can you tell me about everything you did yesterday?
2. What are things that you really love to do?
3. What are things that you do not like to do?
4. What are things that you have to do?
5. If you could relive a day, what day would that be and can you tell me why?

Appendix G: Summary of results

Theme:	Category:	Code:
I want to be accepted as a human being.	I am an individual, but my diagnosis is part of me.	Individuality & uniqueness
		Autistic identity
	I want to be productive.	Drive to study and work hard.
		Finding and keeping a job.
	I have interests and hobbies.	Variety of interests.
		Assist with coping.
	I need to belong (so will you welcome me?)	Relationships
		Inclusion.
Facilitators and Barriers	I have some unique challenges.	Routines, planning and prioritising.
		Sensory processing.
		Understanding my body and sexuality.
		Social exclusion and bullying.
		Financial strain.
	There are ways to overcome these challenges.	People.
		Technology.
		Advocacy.

CHAPTER 8: BIBLIOGRAPHY

1. Ask me, I. m. A. (2016). **2016**.

2. Association, A. Speech-Language-Hearing. (2017). "Augmentative and Alternative Communication (AAC)." Retrieved 02/08, 2017.

3. Attwood, T. E., CR; Lesko, A (2015). An Aspie's Guide To Living With Meltdowns. Been There. Done That. Try This! London and Philadelphia, Jessica Kingsley Publishers.

4. Audet, L. (2010). Core Features of Autism Spectrum Disorders: Impairments in Communication and Socialization, and Restrictive Repetitive Acts. Autism: A Comprehensive Occupational Therapy Approach, 3rd Edition. H. Kuhaneck and R. Watling. Bethesda, United States of America, AOTA Press**:** 87-113.

5. Ayers, J. (2005). Sensory Integration and the Child, Understanding Hidden Sensory Challenges. United States of America, Western Psychological Services.

6. Barnard, J. Prior, A; Potter, A (2000). "Inclusion and autism: is it working?": 1-28.

7. Baranek, GT. (2002). "Efficacy of Sensory and Motor Interventions for Children with Autism." Journal of autism and developmental disorders **32**(5): 397-422.

8. Baron-Cohen, S. (2017). "Editorial Perspective: Neurodiversity – a revolutionary concept for autism and psychiatry." The Journal of Child Psychology And Psychiatry **58**(6): 744-747.

9. Blank, A. Harries, P; Reynolds, F (2015). "'Without Occupation You Don't Exist': Occupational Engagement and Mental Illness." Journal of Occupational Science **22**(2): 197-209.

10. Caldwell, L. (2005). "Leisure and health: Why is leisure therapeutic?" British Journal of Guidance and Counselling **33**(1): 7-26.

11. Caldwell-Harris, C. Murphy, CF; Velazquez, T; McNamara, P (2011). "Religious Belief Systems of Persons with High Functioning Autism." Proceedings of the Annual Meeting of the Cognitive Science Society **33**(33): 3362-3366.

12. Carpenter, L. (2013). "DSM-5 Autism Spectrum Disorder."

13. Case-Smith, J. Arbesman, M (2008). "Evidence-based review of interventions for autism used in or of relevance to occupational therapy." American Journal of Occupational Therapy **62**(4): 416-429.

14. Case-Smith, J; O'Brien, JC (2010). Occupational Therapy for Children. United States of America, Mosby Elsevier.

15. Casmiro, P. (2016). Philosophy Crash Course. An In-Depth Overview Of History's Great Thinkers.

16. Causton-Theoharis, J. Ashby, C; Cosier, M (2009). "Islands of Lonliness: Exploring Social Interaction Through the Autobiographies of Individuals With Autism." Intellectual and developmental disabilities **47**(2): 84-96.

17. Charlton, J. (1998). Nothing About Us Without Us: Disability oppression and empowerment. Nothing About Us Without Us. J. Charlton. United States of America, University of California Press.

18. Christiansen, C. (1999). "Defining Lives: Occupation as Identity: An Essay on Competence, Coherence, and the Creation of Meaning." The American Journal of Occupational Therapy **53**(6): 547-558.

19. Clark, F. (1997). "Reflections on the Human as an Occupational Being: Biological Need, Tempo and Temporality." Journal of Occupational Science **4**(3): 86-92.

20. Cohn, E. (2009). Team Interaction Models and Team Communication. Willard & Spackman's Occupational Therapy. United States of America, Lippincott Williams & Wilkins**:** 396-402.

21. Crane, L; Goddard, L; Pring, L (2009). "Sensory processing in adults with autism spectrum disorders." autism **13**(3): 215-228.

22. Creswell, J. (2009). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Thousand Oaks, California, United States of America, SAGE Publications Ltd.

23. Cridland, EK; Jones, SC; Caputi, P; Magee, C (2014). "Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence." Journal of autism and developmental disorders **44**(6): 1261-1274.

24. Dekker, M. (1999). On Our Own Terms: Emerging autistic culture. **2017**.

25. DePape, AM; Lindsay, S (2016). "Lived Experience From the Perspective of individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis." Focus on autism and other developmental disabilities **31**(1): 60-71.

26. Dickie (2009). What Is Occupation? Willard & Spackman's Occupational Therapy. E. C. Crepeau, ES; Boyt Schell, BA, Lippincott Williams & Wilkins**:** 15-21.

27. Durocher, E; Gibson, BE; Rappolt, S (2014). "Occupational Justice: A Conceptual Review." Journal of Occupational Science **21**(4): 418-430.

28. Emmons, R. (2003). "Personal Goals, Life Meaning, And Virtue: Wellsprings Of A Positive Life." 105-128.

29. Enable, UN. (2007). "United Nations Enable." 2017, from http://www.un.org/disabilities/documents/toolaction/employmentfs.pdf.

30. Fereday, J. and E. Muir-Cochrane (2006). "Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development." International journal of qualitative methods **5**(1): 80-92.

31. Fombonne, E. (2003). "The Prevalence of Autism." American Medical Association **289**(1): 87-89.

32. Gelbar, NW; Smith, I; Reichow, B (2014). "Systematic Review of Articles Describing Experience and Supports of Individuals with Autism Enrolled in College and University Programs." J Autism Dev Disord **44**: 2593–2601.

33. Gerhardt, PF; Lainer, I (2011). "Addressing the Needs of Adolescents and Adults with Autism: A Crisis on the Horizon." Journal of Contemporary Psychotherapy **41**: 37-45.

34. Gillespie-Lynch, K. K., Steven K; Shane-Simpson, C; Smith, DS; Hutman, T (2014). "Intersections between the autism spectrum and the internet: perceived benefits and preferred functions of computer-mediated communication." Intellectual and developmental disabilities **52**(6): 456-469.

35. Glennon, T. (2010). An Introduction to the Autism Spectrum Disorders. Autism. A Comprehensive Occupational Therapy Approach. H. Kuhaneck. Bethesda, AOTA Press**:** 3-24.

36. Goodwin, M. (2008). "Enhancing and accelerating the pace of autism research and treatment: The promise of developing innovative technology." Focus on autism and other developmental disabilities **23**(2): 125.

37. Grandin, T. (2006). Thinking In Pictures. New York, Vintage Books.

38. Greenspan, S. and S. Wieder (2006). New Goals for Children with ASD. Engaging Autism. S. Greenspan and S. Wieder. Philadelphia, Da Capo Press**:** 36-53.

39. Griffith, GM; Totsika, V; Nash, S; Hastings, RP (2012). “I just don’t fit anywhere”: Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood., Bangor University.

40. Hellman, D. (2008). When Is Discrimination Wrong? United States of America, Harvard University Press.

41. Hilton, C. (2010). Social Skills for Children With an Autism Spectrum Disorder. Autism, A Comprehensive Occupational Therapy Approach. H. Kuhaneck, Watling, R, AOTA Press**:** 333-364.

42. Hilton, C; Seal, BC (2007). "Brief Report: Comparative ABA and DIR Trials in Twin Brothers with Autism." Journal of autism and developmental disorders **37**: 1197-1201.

43. Hocking, C. (2009). Contribution of Occupation to Health and Well-Being. Willard & Spackman's Occupational Therapy. E. Crepeau, E. Cohn and B. Boyt Schell. United States of America, Lippincott Williams & Wilkins**:** 45-54.

44. Holwerda, A, van der Klink; Groothoff, JW; Brouwer, S (2012). "Predictors for Work Participation in Individuals with an Autism Spectrum Disorder: A Systematic Review." Journal of Occupational Rehabilitation **22**: 333-352.

45. Hsiu-Fang, H; S. Shannon (2005). "Three approaches to qualitative content analysis." Qualitative health research **15**(9): 1277-1288.

46. Iwasaki, Y; Mactavish, J; Mackay, K (2005). "Building on strengths and resilience: leisure as a stress survival strategy." British Journal of Guidance and Counselling **33**(1): 81-100.

47. Jaarsma, P; S. Welin (2012). "Autism as a natural human variation: Reflections on the claims of the neurodiversity movement." Health Care Analysis **20**(1): 20-30.

48. Kern, JK; Trivedi, MH; Grannemann, BD; Garver, CR; Johnson, DG; Andrews, AA; Savla, JS; Mehta, JA; Schroeder, JL (2007). "Sensory correlations in autism." autism **11**(2): 123-134.

49. Kielhofner, G. (2008). Model Of Human Occupation, Theory And Application. United States of America, Lippincott Williams & Wilkins.

50. Kielhofner, G; Forsyth, K; Kramer, JM; Melton, J & Dobson, E (2009). The Model of Human Occupation. United States of America, Lippincott Williams & Wilkins.

51. Kim, J; Wigram, T; Gold, C (2008). "The Effects of Improvisational Music Therapy on Joint Attention Behaviors in Autistic Children: A Randomized Controlled Study." Journal of autism and developmental disorders **38**: 1758-1766.

52. King, PM; Olson, DL (2009). Work. Williard & Spackman's Occupational Therapy. E. C. Crepeau, ES; Boyt Schell, BA. United States of America, Lippincott Williams & Wilkins.

53. Kirsh, B; Cockburn, L; Gewurtz R (2005). "Best practice in occupational therapy: Program characteristics that influence vocational outcomes for

people with serious mental illnesses." The Canadian Journal of Occupational Therapy **72**(5): 265-270.

54. Klinger, L. (2005). "Occupational Adaptation: Perspectives of People with Traumatic Brain Injury." Journal of Occupational Science **12**(1): 9-16.

55. Kowalski, R; Limber, SP. (2013). "Psychological, Physical, and Academic Correlates of Cyberbullying and Traditional Bullying." Journal of Adolescent Health **53** (1): 13-20.

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

57. Kuckartz, A. A., FN; Kuckartz, U (2002). "Qualitative Text Analysis with MAXQDA ". 2017, from https://www.centrodeestudiosandaluces.es.

58. Kuhaneck, H. Watling, R (2010). Autism, A Comprehensive Occupational Therapy Approach, AOTA PRESS.

59. Kushki, A; Drumm, E; Mobarak, MP; Tanel, N; Dupuis, A; Chau, T; Anagnostou, E (2013). "Investigating the Autonomic Nervous System Response to Anxiety in Children with Autism Spectrum Disorders." The Anxiety Response in Autism Spectrum Disorders **8**(4).

60. Lawson, W. (2005). sex, sexuality and the Autism Spectrum. London & Philadelphia, Jessica Kingsley Publishers.

61. Ledgin, N. (2002). Asperger's and Self-Esteem. Insight and Hope Through Famous Role Models. Canada, Future Horizons.

62. Lerna, A. E., D; Conson, M; Russo, L; Massagli, A (2012). "Social–communicative effects of the Picture Exchange Communication

System (PECS) in Autism Spectrum Disorders." International Journal of Language & Communication Disorders **47**(5): 609-617.

63. Levy, SE; Giarelli, E; Lee, LC; Schieve, LA; Kirby, RS; Cunniff, C; Nicholas, J; Reaven, J; Rice, CE (2010). "Autism Spectrum Disorder and Co-occurring Developmental, Psychiatric, and Medical Conditions Among Children in Multiple Populations of the United States." Journal of Developmental Behavioural Pediatrics **31**(4): 267-275.

64. Lipsky, D. (2011). From Anxiety to Meltdown. London and Philadelphia, Jessica Kingsley Publishers.

65. Mailloux, Z., Roley, SS. (2010). Sensory Integration. Autism, A Comprehensive Occupational Therapy Approach. H. Kuhaneck, Watling, R, AOTA Press**:** 469-507.

66. Mallinson, T; Hammel, J. (2010). "Measurement of Participation: Intersecting Person, Task, and Environment." Physical Medical Rehabilitation **91**(9): S29-33.

67. McCoyd, J; Kerson, T. (2006). "Conducting intensive interviews using email a serendipitous comparative opportunity." Qualitative Social Work **5**(3): 389-406.

68. McLaren, K. (2014). Interrogating Normal Autism Social Skills Training at the Margins of a Social Fiction, Sonoma State University.

69. Meho, L. (2006). "E-mail interviewing in qualitative research: A methodological discussion." Journal of the American society for information science and technology **57**(10): 1284-1295.

70. Mukaetova-Ladinska, EB.; Stuart-Hamilton., I. (2016). "Adults with Autism Spectrum Disorder (ASD): Service User Perspective on Ageing Transition(S)." American Journal of Autism **2**(1): 1-11.

71. Müller, E; Schuler, A; Yates, GB. (2008). "Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities." autism **12**(2): 173-190.

72. Mulloy, A; Lang, R; O’Reilly, M; Sigafoos, J; Lancioni, G; Rispoli, M. (2009). "Gluten-free and casein-free diets in the treatment of autism spectrum disorders: A systematic review." Research in Autism Spectrum Disorders: **(3)** 1-12.

73. Nord, DK, Stancliffe, RJ; Nye-Lengerman, K; Hewitt, AS. (2016). "Employment in the community for people with and without autism: A comparative analysis." Research in Autism Spectrum Disorders **24**: 11-16.

74. O'Neill, J. (2000). "My View of Autism." Focus on autism and other developmental disabilities **15**(4): 224-226.

75. Orsmond, GI; Krauss, MW; Seltzer, MM. (2004). "Peer Relationships and Social and Recreational Activities Among Adolescents and Adults with Autism." Journal of autism and developmental disorders **34**(3): 245-255.

76. Pajareya, K; Nopmaneejumruslers, K. (2012). "A One-Year Prospective Follow Up Study of a DIR/Floortime Parent Training Intervention for Pre-School Children with Autism Spectrum Disorders." J Med Assoc Thai **95**(9): 1184-1193.

77. Pearson, J. (2017). ABA Applied Behaviour Analysis Managing and Defining Target Behavior.

78. Peters-Scheffer, N; Didden, R; Korzilius, H; Sturmey, P. (2011). "A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders." Research in Autism Spectrum Disorders **5**(1): 60-69.

79. Phelan, S; Kinsella, EA. (2009). "Occupational Identity: Engaging Socio-Cultural Perspectives." Journal of Occupational Science **16**(2): 85-91.

80. Price, RH; Choi, JN; Vinokur, AD. (2002). "Links in the Chain of Adversity Following Job Loss: How Financial Strain and Loss of Personal Control Lead to Depression, Impaired Functioning, and Poor Health." Journal of Occupational Health Psychology **7**(4): 302-312.

81. Realmuto G. (2015) Autism Spectrum Disorder: Diagnostic Considerations. In: Fatemi S. (eds) The Molecular Basis of Autism. Contemporary Clinical Neuroscience. Springer, New York, NY."

82. Reid, E. (2000). Structuring the Inquiry into Advocacy. E. Reid, Nonprofit Advocacy and The Policy Process A Seminar Series, The Urban Institute. **1**.

83. Reilly, M. (1961). "Occupational Therapy Can Be One of the Great Ideas of 20th-Century Medicine." **(16)** 80-93.

84. Rice, CE. Rosanoff, M; Dawson, G; Durkin, MS; Croen, LA; Singer, A; Yeargin-Allsopp, M (2017). "Evaluating Changes in the Prevalence of the Autism Spectrum Disorders (ASDs)." Public Health Reviews **34**(2): 1-22.

85. Rochat, P. (2006). "What does it mean to be human?" Journal of Anthropological Psychology(17): 48-51.

86. Rodger, S; Umaibalan, V (2011). "The routines and rituals of families of typically developing children compared with families of children with autism spectrum disorder: an exploratory study." British Journal of Occupational Therapy **74**(1): 20-26.

87. Rogers, C., Lepherd, L; Ganguly, R; Jacob-Rogers, S (2017). "Perinatal issues for women with high functioning autism spectrum disorder." Women and Birth **30**: 89-95.

88. Rosenhall, U; Nordin, V; Sandström, M; Ahlsen, G; Gillberg, C. (1999). "Autism and hearing loss." Journal of autism and developmental disorders **29**(5): 349-357.

89. Sacks, O. (2006). Foreword. Thinking In Pictures, My Life With Autism. T. Grandin. New York, Vintage Books.

90. Sakellariou, D; Algado, SS (2006). "Sexuality and Occupational Therapy: Exploring the Link." British Journal of Occupational Therapy **69**(8): 350-356.

91. Schaaf, RC; Benevides, T; Zapletal, AL. (2010). Neurobiological Basis of Autism Spectrum Disorders: An Overview. Autism. A Comprehensive Occupational Therapy Approach. H. W. Kuhaneck, R. Bethesda, AOTA Press**:** 25-44.

92. Schaaf, RC; Toth-Cohen, S; Johnson, SL; Outten, G; Benevides, TW (2011). "The everyday routines of families of children with autism." autism **15**(2): 1-17.

93. Sequenzia, A. (2012). Functioning Labels, Again. Autism Women's Network. **2017**.

94. Sequenzia, A. (2017). I Define Myself. **2017** from http://www.goldenhatfoundation.org/.

95. Sevlever, M; Roth, ME; Gills, JM (2013). "Sexual Abuse and Offending in Autism Spectrum Disorders." Sexual Disabilities **31** (2): 189-200.

96. Sherrod, B. (2016). Applied Behaviour Analysis, Montessori Method And DIR®/Floortime Early Intervention And Music Therapy. College of Music, Florida State University. **Unpublished Masters Dissertation.**

97. Silberman, S. (2015). Neurotribes. Australia and New Zealand, Allen & Unwin.

98. Simmel, G. (1971). Georg Simmel On Individuality And Social Forms, The University Of Chicago Press.

99. Sinclair, J. (1992). "Bridging the gaps: An inside-out view of autism." In Schopler E and Mesibov GB (eds).High-functioning individuals with autism, Plenum Press, New York. 294-302.

100. Autism Speaks. (2016). from https://http://www.autismspeaks.org/news/news-item/pbs-highlights-the-importance-for-adults-with-autism.

101. Autism Speaks. (2017). "Applied Behavior Analysis (ABA)." Retrieved 02/06, 2017, from https://http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba.

102. Spiker, MA; Lin, CE; Van Dyke, M; Wood, JJ (2012). "Restricted interests and anxiety in children with autism." autism **16**(3): 306-320.

103. Spreckley, M; Boyd, R. (2009). "Efficacy of applied behavioral intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: a systematic review and meta-analysis." The Journal of pediatrics **154**(3): 338-344.

104. Taylor, J. (2016). The Oxford Handbook of Hume. Hume On Pride And The Other Indirect Passions. P. Russel, Oxford University Press.

105. Thornicroft, G. (2009). "Shunned: Discrimination Against People With Mental Illness." Journal of Occupational Psychology, Employment and Disability **11**(1): 56-58.

106. Townsend, E; Wilcock, AA. (2004). "Occupational justice and client-centred practice: A dialogue in progress." Canadian Journal of Occupational Therapy. **71**(2): 75-87.

107. Travers, J; Tincani, M (2010). "Sexuality Education for Individuals with Autism Spectrum Disorders: Critical Issues and Decision Making Guidelines." Education and Training in Autism and Developmental Disabilities **45**(2): 284-293.

108. Van Pelt, J. (2008). "Autism into adulthood—Making the transition." Social Work Today **8**(5): 12.

109. van Steensel, FJA; Zegers, VM; Bögels, SM (2017). "Predictors of Treatment Effectiveness for Youth with ASD and Comorbid Anxiety Disorders: It all Depends on the Family." Journal of autism and developmental disorders **47** (3): 636-645.

110. Volkmar, F. (2015). A Brief History of Autism. The Molecular Basis of Autism. S. Fatemi. New York, Springer Science**:** 3-14.

111. Vrkljan, BH; Polgar, JM. (2007). "Linking Occupational Participation and Occupational Identity: An Exploratory Study of the Transition from Driving to Driving Cessation in Older Adulthood " Journal of Occupational Science **14**(1): 30-39.

112. Wagman, P; Håkansson, C; Björklund, A. (2012). "Occupational balance as used in occupational therapy: A concept analysis." Scandinavian Journal of Occupational Therapy **19** (4): 322-327.

113. Ward, M; R. Meyer. (1999). "Self-Determination for People with Developmental Disabilities and Autism Two Self-Advocates' Perspectives." Focus on autism and other developmental disabilities **14**(3): 133-139.

114. Ward, M. Alar, N. (2000). "Being Autistic Is Part of Who I Am." Focus on autism and other developmental disabilities **15**(4): 232-235.

115. Whalley Hammell, KR; Iwama, MK. (2012). "Well-being and occupational rights: An imperative for critical occupational therapy." Scandinavian Journal of Occupational Therapy **19** (5): 385-394.

116. Wikipedia (2017). "Stanley Greenspan." Retrieved 03/06, 2017, from https://en.wikipedia.org/wiki/Stanley_Greenspan.

117. Wilcock, A. (1999). "Creating self and shaping the world." Australian Occupational Therapy Journal **46** (3): 77-88.

118. Wilcock, A. (1999). "Reflections on doing, being and becoming." Australian Occupational Therapy Journal **46** (1): 1-11.

119. Williams, JG; Higgins, JPT; Brayne, CEG (2006). "Systematic review of prevalence studies of autism spectrum disorders." **91** (1): 8-15.

120. Wing, L; Shah, A (2000). "Catatonia in autism spectrum disorders." British Journal of Psychiatry **176**: 357-362.

121. Yerxa, E. (1998). "Health and the Human Spirit for Occupation." **52**(6): 412-418.

122. Yerxa, E. (2009). "Infinite Distance Between the I and the It." American Journal of Occupational Therapy **63**: 490-497.

123. Zurcher, A. (2016). Emma's Hope Book. **2016**. Retrieved 2017, From https://emmashopebook.com/