

**TRANSITION FOR ADOLESCENTS WITH AUTISM
SPECTRUM DISORDER**

PARENT AND PROFESSIONAL PERSPECTIVES

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ABSTRACT

Adolescents with Autism and their families experience a significant increase in the number and nature of challenges faced when leaving the structure of the formal education system. Increased support and planning is required in order to prepare for and better manage this period, as a successful transition is associated with family well-being. An ecosystemic approach was used in order to better understand the experiences of the individual, the family, the school and the community during this period. The purpose of this study was to gain an understanding of parent and professional perspectives on various elements of the transition process, including planning and support, predicted outcomes and the feelings experienced, in order to develop awareness, improved planning and consequently; outcomes. A sample of 14 participants (7 parents and 7 professionals) was engaged in semi-structured interviews. The results indicate that both parents and professionals feel an overwhelming sense of fear and uncertainty with regards to the future of the adolescent with Autism; however a sense of optimism and hope also exists, as participants reported effective interventions were beginning to occur. The knowledge and understanding of the needs of these individuals is continuously growing within the parents and professionals who are directly involved in the lives of adolescents with Autism; however increased awareness is required within the community and government sectors in order to gain increased access to resources and services. With the appropriate support, individuals with Autism can experience increased quality of life within residential, employment, social and community settings. The results of the current study are discussed with reference to previous research studies, and recommendations for further research are provided.

Key words:

Autism Spectrum Disorders, Transition, Adolescence, Adulthood

DECLARATION

A research project submitted in partial fulfilment of the requirements for the degree of Masters in Educational Psychology in the faculty of Humanities, University of Witwatersrand, Johannesburg.

“I declare that this research project is my own, unaided work. It has not been submitted before for any degree or examination at this or any other university.”

Meagan Meiring

Date:

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TABLE OF CONTENTS

| | Page |
|----------------------------------------------------|------|
| 1. CHAPTER 1 INTRODUCTION | |
| 1.1. Research rationale | 9 |
| 1.2. Overview of the report | 11 |
| 2. CHAPTER 2 LITERATURE REVIEW | |
| 2.1. Definitions | 12 |
| 2.1.1. Autism Spectrum Disorder | 12 |
| 2.1.2. Transition | 13 |
| 2.2. Ecosystemic framework | 14 |
| 2.2.1. The individual level | 17 |
| 2.2.2. School and education level | 20 |
| 2.2.3. The Family level | 25 |
| 2.2.4. Collaboration between the school and family | 28 |
| 2.2.5. Community involvement | 30 |
| 2.3. Future quality of life | 31 |
| 2.3.1. Residential factors | 32 |
| 2.3.2. Employment factors | 34 |
| 2.3.3. Social and leisure factors | 36 |
| 2.4. Conclusion | 37 |
| 3. CHAPTER 3 METHODOLOGY | |
| 3.1. Introduction | 39 |
| 3.2. Context of the study | 39 |
| 3.3. Research questions | 40 |
| 3.4. Research design | 40 |
| 3.5. Procedure | 41 |
| 3.6. Participants | 41 |

| | |
|------------------------------------------------------------------|----|
| 3.7. Pilot study | 44 |
| 3.8. Data collection and analysis | 45 |
| 3.9. Ethical considerations | 46 |
| 3.10. Self reflection | 47 |
| 3.11. Conclusion | 49 |
| 4. CHAPTER 4 RESULTS AND DISCUSSION | |
| 4.1. Overview of Chapter | 50 |
| 4.2. Themes | 50 |
| 4.2.1. Factors that influence transition into adulthood | 51 |
| 4.2.2. Support and planning during transition process | 57 |
| 4.2.3. Residential and Employment possibilities following school | 60 |
| 4.2.4. Thoughts and feelings experienced | 65 |
| 5. CHAPTER 5 CONCLUSIONS | |
| 5.1. Overview of Chapter | 70 |
| 5.2. Implications of research findings | 70 |
| 5.3. Potential limitations of research | 71 |
| 5.4. Direction for future research | 71 |
| 5.5. Final conclusion | 72 |
| 6. REFERENCES | 74 |
| 7. APPENDICES | |
| Appendix 1: GDE consent to conduct the study | 78 |
| Appendix 2: Information letter and consent from the Principal | 80 |
| Appendix 3: Information letter for participants | 82 |
| Appendix 4: Participant consent | 84 |
| Appendix 5: Consent to be recorded | 85 |
| Appendix 6: Interview questions for parents | 86 |
| Appendix 7: Interview questions for professionals | 88 |

8. FIGURE

| | |
|--------------------------------------------------------------------------------------------------------------------|----|
| Figure 1: Conceptual model of transition to adulthood: Mental retardation, families and culture (Blacher, 2001) | 16 |
|--------------------------------------------------------------------------------------------------------------------|----|

9. TABLES

| | |
|--------------------------------------------------------------------------------------------------------------------------|----|
| Table 1: Comparative importance placed on areas of transition between young adults and caregivers (Hanish, 2011) | 19 |
| Table 2: Employment types as outlined in the literature (Hagner & Cooney, 2005; Howlin, 2004; Taylor & Seltzer, 2010) | 35 |
| Table 3: Demographic information of study sample | 42 |
| Table 4: Education and employment of parents | 43 |
| Table 5: Job title and involvement in ASD of professionals | 43 |
| Table 6: Experience of ASD of parents and professionals | 44 |

NOMENCLATURE

ADL – Areas of Daily living

ASD – Autism Spectrum Disorder

IDEA – Individuals with Disabilities Education Act

IEP – Individual Education Plan

FET – Further Education Training

LSEN – Learners with Special Education Needs

NAS – National Autism Society

NCS – National Curriculum Statement

NQF – National Qualification Framework

OSERS – Office for Special Education Rehabilitation Services

SANASE – South African National Association for Special Education

SES – Socio-Economic Status

USA – United States of America

CHAPTER 1

INTRODUCTION

Challenges experienced by individuals with Autism and their families increase when facing adolescence and the need for transition out of the structured formal support of the schooling context and into adult life. Alongside increased stress and uncertainty, families experience reduced support from formal education structures and reduced access to appropriate resources required by the individual and the family (Howlin, 2004). Transition into adulthood for adolescents with Autism requires support in areas of education, social interaction, communication, daily life skills, vocational possibilities and community involvement. Planning needs to begin at an early stage in order to increase the likelihood of a successful transition and consequently, family well-being. Individual, family, school and environment factors thus need to be taken into account and involved in order to increase support for the individual. An ecosystemic understanding and intervention planning is thus required. Ongoing training and support in all areas could result in improvement and quality of life for an individual with Autism into adulthood.

1.1 Research rationale

Autism Spectrum Disorder (ASD) is becoming more prevalent and the statistics suggest that there is an increase in the diagnosis of ASD worldwide, in every racial, ethnic and social group. As reported by Lotter (1966) in the National Autism Society (NAS), the prevalence of Autism when first published about 20 years after Kanner's description of Autism in 1943 was given as 4.5 per 10,000 children. Currently, the estimated prevalence of children diagnosed with Autism is approximately 1 per 88 children (CDC, 2012).

The number of individuals diagnosed with ASD is unfortunately not proportional to the availability of resources and schools. Although the number of individuals diagnosed continues to increase, the number of schools providing for learners with Autism is severely limited. Jacklin and Stacey (2010) conducted a study to determine accessibility to education

for autistic children in South Africa and found that only 30% of LSEN (Learners with Special Education Needs) schools in South Africa provide for learners with ASD. Using the standardisation of 10 cases of ASD in every 1000, it is estimated that there are currently between 2-21% of learners with ASD that are being schooled in South Africa (Jacklin & Stacey, 2010). The number of schools that educate and support senior learners with Autism are very limited, and alternative placements for this age range are also limited (Howlin, 2004). The increase in diagnosis has resulted in a 'bottle-neck' effect in most schools and the demands placed on senior education are increasing. Based on current trends, in time more and more demands will be placed on adult services and facilities. Existing adolescent and adult services need increased support in terms of a pool of trained professionals in order to better benefit this age group specifically.

Ongoing research exists (locally and internationally) in the field of Autism and related disorders, and effective strategies used when educating these individuals; however this research is often limited to international practices and relates mostly to children (Howlin, 2004). It has been recognised that early intervention is most important when working with individuals with Autism; this does not imply however that later intervention is not needed or beneficial to adolescents and adults. With appropriate education and intervention, adolescents with ASD are able to manage in society, possibly find employment, live with some independence, and integrate into the community (Hendricks & Wehman, 2009). Support and training is however required in order for education facilities to help these adolescents reach their potential, and for parents and professionals to support them in the process of transition into their new roles as adults, outside of formal education structures. Research conducted by Rosenblatt (2008) in England, has shown a discrepancy in the services needed compared to the services being received, therefore if parents and professionals of adolescents can identify the skills that might be required in adulthood, the education and development of these skills can be taught within formal schooling and therefore increase the likelihood of 'success' or increased quality of life for these adults.

Parents and professionals within the field of Autism have the biggest influence on adolescents with ASD and a teamwork approach is required with advanced planning in order to increase the possibilities for an adolescent's transition (Holmes, 1997). It is essential that these adolescents receive ongoing education and development training in order to maintain learnt skills and to adapt to adult life. The majority of the life of an individual with Autism is

spent outside of formal education and training, and thus it is important that the educational programs in the latter years of their education equips them with the skills required throughout their adult lives. Since the availability of adult services for Autism within South Africa is currently limited and the availability of these services in the future, is unknown, it becomes very important that facilities for senior learners, working alongside parents and professionals in the field, are able to identify the needs of their adolescents and in order to skill them towards managing adulthood to the best of their potential.

1.2 Overview of the report

Chapter Two of this research report includes a review of the literature pertaining to Autism and the transition into adulthood. In particular factors which influence the transition and are in turn influenced during this period; the individual, the school, family and community settings are the core focus, along with residential, employment and social context which are found to influence quality of life for an adult with Autism. In Chapter Three, the research methodology; procedure, sampling, data collection and analysis are outlined and Chapter Four presents a detailed record and discussion of the results of the study. Finally, Chapter Five discusses the limitations of the study, future research possibilities and the conclusion.

CHAPTER 2

LITERATURE REVIEW

The literature review begins with a definition of Autism Spectrum Disorders, and the explanation of term ‘transition’ within the context of this study and the values used to determine skills of adulthood. These definitions are followed by a review of existing literature and previous studies conducted on this subject, internationally and locally.

2.1 Definitions

2.1.1 Autism Spectrum Disorder

“Autistic Disorder (historically called *early infantile Autism, childhood Autism, or Kanner’s Autism*) is characterized by symptoms from each of the following three categories: qualitative impairment in social interaction, impairment in communication, and restricted repetitive and stereotyped patterns of behaviour or interests” (Sadock & Sadock, 2007, p. 1191). For the purposes of this study, the terms Autism, Autism disorder and ASD (Autism Spectrum Disorder) are used interchangeably as the reasons for the different terminology are not significant to this study. As a pervasive developmental disorder, Autism exists as a spectrum ranging from mild to severely autistic, and thus for the purposes of this study, the adolescents referred to as having Autism or an ASD (Autism Spectrum Disorder) are not included or excluded on the basis of the severity of their Autism, as they attend an Autism specific school however, it can thus be assumed that the degree of their Autism is their primary obstacle to mainstream education.

Alongside disturbances in communication, social interaction and stereotyped behaviours, individuals with Autism are also known to exhibit instability of mood and affect, difference in responses to sensory stimuli, behavioural manifestations due to difficulties in the environment, such as temper tantrums, self injurious behaviours, hyperactivity and sleeping and eating difficulties, as well as below average cognitive ability. According to Sadock & Sadock (2007, p. 1195) “[a]bout 70 to 75 percent of children with autistic disorder function

in the mentally retarded range of intellectual function”, and alongside impaired intellectual functioning to various degrees, adolescent onset of epilepsy and seizures is also common in individuals with Autism. Past adolescence, individuals with ASD are not predisposed to disorders that differ from those of mainstream society, and adults with ASD appear to have normal predicted life spans (Holmes, 1997). Although a normal lifespan is expected, ASD is a lifelong disorder and the prognosis is not optimal. In fact Sadock & Sadock argue that:

“In general, adult-outcome studies indicate that about two thirds of autistic adults remain severely handicapped and live in complete dependence or semi-dependence, either with their relatives or within long term institutions” (2007, p. 1197).

2.1.2 Transition

Transition is the process or a period of changing or movement from one state or life stage to another (Brotherson, Berdine & Sartini, 1993). This study uses the term transition to describe the passage from formal education as an adolescent, into post-school adult life, after age 18. According to Hendricks & Wehman, “[t]ransition typically includes completing school, gaining employment, participating in postsecondary education, contributing to a household, participating in the community, and experiencing satisfactory personal and social relationships” (2009, p. 77). In general, transition from school to adulthood is a challenging time for many adolescents with various disorders and their families (Blacher, 2001; Brotherson et al., 1993; Chambers et al, 2004; Hendricks & Wehman, 2009; Howlin, 2004; Krauss, Seltzer & Jacobson, 2005; Sterling, 2008). This is especially true for adolescents with ASD, when seeking post-secondary and employment possibilities.

According to Whetstone and Browning (2002), in 1984 Madeleine Will, assistant secretary of Office for Special Education Rehabilitation Services (OSERS) defined transition as: “an outcome oriented process encompassing the broad array of services and experiences that lead to employment” (Whetstone & Browning, 2002, p. 1). In 1985, Halpern broadened Will’s definition to include community adjustment, and not just employment, as a desired outcome. Thus the expanded definition of transition according to Halpern’s model; includes ‘components of residential adjustment and the establishment of desirable social and interpersonal networks’ (Whetstone & Browning, 2002, p. 1). Halpern went on to propose

that developing a person's self-esteem and empowering the individual to make decisions and select his or her own goals would enhance community adjustment.

The reauthorized *Individuals with Disabilities Education Act (IDEA)* of 1990 was signed as public law in 1994. This is one of the series of documents prepared by OSERS addressing changes in regulations that would have an effect on the implementation of services. Within this document is a revised definition of transition services, consistent with Halpern, which now states:

“The term ‘transition services’ means a coordinated set of activities for a child with a disability that is designed to be within a results-orientated process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation; is based on the individual child’s needs, taking into account the child’s strengths, preferences and interests; and includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation.”

(Whetstone & Browning, 2002, p.2)

This definition has been used to inform the study due to the fact that it takes all elements of transition into account and can be used in order to plan the curricular needs of adolescents with Autism.

2.2 Ecosystemic framework

Skills required by adolescents with Autism when in the process of transition rely on the dynamic interplay between intrapersonal, interpersonal and situational variables. The ecosystemic framework is thus the most appropriate approach to this study. The approach is based on constructivism and systems theory in which the systems theory views the functioning of an individual as dependent on the interaction between different groups of people or systems. Bronfenbrenner's ecological and bio-ecological models can be used to facilitate understanding, and place focus on multimodal systems, within which transactions occur and affect an individual in society in a reciprocal nature (Swart & Pettipher, 2005).

Based on this notion, and for the purposes of this study, the school system comprises different subsystems such as staff, learners, the curriculum and the administration. In addition, the family is another system, with which the school system interacts, both of which interact with each other and impact on the functioning of the child (Donald, Lazarus & Lolwana, 2010).

An ecosystemic model refers to the different levels of a system in a social context and describes how these levels impact the child's development. There are four interacting factors that are central to this process: person factors (in this case ASD, and the resulting behavioural manifestations), process factors (the interactions between the school and family), the context (school, family and community), and time (changes existing because of adolescence and the changes required in intervention). The interactions within these dimensions are important in shaping lasting aspects of development (Donald et al., 2010). Assessment and interventions using a systemic approach focus on providing support for the various systems which function as barriers to development (Blumenthal, 2007). The further along in the development of the adolescent the sub-systems are supported and empowered, the more likely the access of the individual into learning, working and socialising environments. This is as opposed to educational systems teaching the individual directly while barriers in the home and community remain. The use of an ecosystemic and systems approach to the process of transition for adolescents with ASD is appropriate to the South African educational framework of democracy and inclusion, where the individual is assessed and supported while taking into account their context and without discrimination (Swart & Pettipher, 2005). It is generally recognised that behaviour cannot be understood outside of a context; rather development occurs within a dynamic process in which the individual and the environment continuously interact (Gormly, 1997). Every individual life occurs within economic, social, community and family contexts, which will offer opportunities and impose constraints on the individual (Engelbrecht & Green, 2001). Both the real and perceived influences of context will have an impact on the functioning of an individual.

Successful transition into adulthood impacts the individual and family well-being, thus Blacher (2001) proposed a conceptual model of transition into adulthood (*figure 1*) in order to understand the various factors which influence transition success for individuals with mental retardation and consequently family well-being.

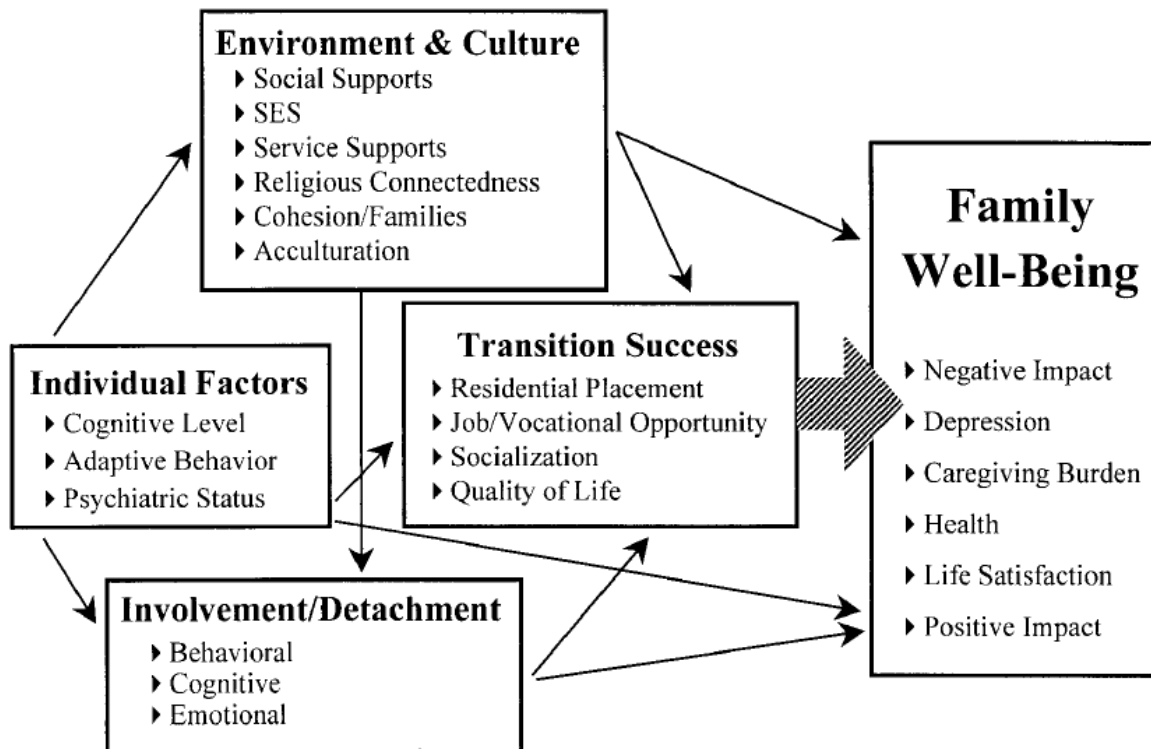


Figure 1. Conceptual model of transition to adulthood: Mental retardation, families and culture (Blacher, 2001, p. 175).

This model, designed for individuals with mental disabilities provides insights into the situation of adolescents with Autism since a high percentage have comorbid cognitive impairments, and difficulties experienced with transition to adulthood often equate to those experienced by families with children with other disabilities. In this model, transition is a complex process through which direct and indirect influences occur (Blacher, 2001). Individual factors, family involvement or detachment and the influence of environment and culture need to be taken into account when determining transition success, and will be discussed in further detail below. Autism reflects the disordered relationship between the person and the environment more than individual characteristics (Seltzer et al., 2003). Transition into adulthood is also known as the launch phase into adulthood, and is experienced by all parents, regardless of ability or disability of their child, and is mostly accompanied by heightened opportunities and increased risks and challenges for the individual, the family and the social service system (Blacher, 2001).

According to Blacher (2001) Transition occurs within three areas which each need to be taken into account: (a) status transition (individual turning 18 or 21); (b) leaving school and home and getting a job; (c) family life transition (established routines that make life

manageable, undergo change); (d) and bureaucratic transition (including the shift from school to adult service providers). The characteristics which are associated with successful transition services and planning include early planning, collaboration between home and school environments, individualised transition planning, focus on integration and a community-relevant curriculum and community based training, as well as links to businesses and job placements, as well as ongoing staff development and program evaluation (Grigal, Test, Beattie, & Wood, 1997). There is thus a need to consider the ecosystem in which the individual functions when determining the experience of transition. Transition success, or more broadly defined, quality of life most commonly involves four areas of functioning: residence, education, employment and social areas. Increased involvement in most, if not all, of these areas, correlates with increased perception of the success of the transition (Blacher, 2001). Since ASD involves both the presence of qualitatively abnormal behaviours and a deficiency in behaviours related with normal development, developmental paths can be affected by both characteristics (Seltzer et al., 2003). During adolescence, an individual matures and experiences progression towards an adult body; however their immature functioning is ongoing, and demands on care giving responsibilities increase, whilst age appropriate social and respite services become more difficult to locate (Blacher, 2001). Factors that influence each of these levels are not exclusive and independent, but rather interconnected and reciprocal. Emphasis placed on various levels will be discussed in the sections below.

2.2.1 The individual level

Individual characteristics such as gender, age, physical health, cognitive functioning and psychiatric status, as well as adaptive and maladaptive behaviours need to be taken into account when planning for transition and evaluating their level of success in transition to adulthood (Blacher, 2001). The difficulties that individuals with Autism experience during transition into adulthood, into a state of independent or supported living and purposeful vocation, is made difficult by cognitive and behavioural characteristics that are much broader than the triad of impairments that lead to diagnosis. Clements, Hardy and Lord (2010) highlight the characteristics of ASD that impact the ability or create difficulties for these individuals during transition. These characteristics include: difficulty with and motivation to engage with other people, a high need for control and a difficulty in asking for help, impaired

understanding and regulating emotions, often resulting in extreme and inappropriate behaviours, information processing difficulties resulting in communication breakdowns, literal understanding and difficulties with problem solving in novel situations, difficulty in understanding that life requires flexibility and consideration for the needs and intentions of others, etc.

The ability of a person to engage in choosing how to live their life results in independence, and therefore increased quality of life (Brotherson et al., 1993). Through choosing the activities with which they want to engage, individuals are communicating possible interest in skills that can be developed for future vocational, social and independent activities, and increase the amount of control they have over their own lives. Motivation increases the likelihood of success in any area; therefore it becomes important that parents and professionals take the wants, needs and interests of the individual into account when planning for them. Rosenblatt (2008) suggests that according to the experiences of adults with Autism in England, the support that they want or claim to need varies from the actual support provided and received. This study shows that the areas in which adults with ASD receive the most support are in daily living support, psychology and psychiatry, whereas the areas in which the adults with Autism indicated they need the most support are in social skills training, social groups, employment support, and befriending. Some of the specific areas that were identified by adults with ASD as support they needed, in order of importance, were dealing with letters, managing money, paying bills, preparing meals, as well as shopping, laundry, house work and personal care (Rosenblatt, 2008, p. 29).

Hanish (2011) compared the perspectives of young adults and their caregivers on the secondary school and postsecondary experiences. Many similarities and differences were found in the perspectives of ability to complete specific tasks, transition and barriers encountered. This information is significant to the present study because caregivers often speak on behalf of the adolescents with Autism. Young adults viewed themselves with more confidence in their ability to perform complex tasks, such as financial issues, preparing meals, leisure activities and relationships, than their caregivers. The study also suggests that most young adults had very little awareness of the transition component in their IEP (Individual Education Plan). The table below compares the top five components identified by the two groups:

Table 1: Comparative importance placed on areas of transition between young adults and caregivers

| Caregivers | Young Adults |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Structured social activities (89%) • Focus on employment after completion of the program (85%) • Independent living skills (84%) • Social skills (80%) • Work skills (79%) | <ul style="list-style-type: none"> • Structured social activities (75%) • Independent living skills (75%) • Individual choice in curriculum (75%) • Certificate, diploma or other recognition of completion (69%) • Focus on employment after completion of the program (65%) |

(Hanish, 2011).

Thus the individuals place higher importance on independent living skills and personal involvement in curriculum choice. It should be noted that the participants in this study were individuals with high functioning Autism or Aspergers Syndrome. Both parents and young adults expressed high levels of interest in postsecondary programs, however the likelihood of attending such a program was found to be fifty percent less than the level of interest in the programs (Hanish, 2011). The results of the study suggest that the key players in the transition, the viewpoints of the young adults and their caregivers, while both convergent and divergent are vital and cannot be overlooked.

In order to derive the greatest benefit for the individuals with ASD in a period of transition into adulthood, it is important to know which skills are required by these individuals and greater emphasis needs to be placed on the needs from the individual's viewpoint (Renty, 2006). ASD is a spectrum disorder and thus the needs of each individual will vary, however the parents and professionals should be aware of the needed skills of the individual they work with. As seen in the study conducted by Hanish (2011), the needs as seen by the individuals and the caregivers are more in tune than the comparison of needs suggested by the individuals and the government, as presented in Rosenblatt (2008). It is increasingly important that parents and professionals give voice to the needs of the individuals, and that

these requirements are recognised in schools, as curriculums, and acknowledged by the government in the type of support they offer.

2.2.2 School and education level

Curriculum outcomes for learners with Autism should include general special education, communication and active physical education, because learners with ASD often have intellectual impairment, impairment in communication abilities, and disruptive or withdrawn behaviours which interfere with their abilities to function independently in society. Curriculum areas should therefore include learning readiness, pre-academics, academics, prevocational, self-care, domestics, speech/language, adaptive physical education, social skills. Learning readiness and pre-academic skills are not included on in the prevocational and vocational phases, due to increased emphasis placed on functional skills. Additional programs might include extended school year programs, respite programs, home consultant programs, after-school programs, outreach and support services, parent training programs, behaviour technology workshops, consultation and evaluation services, and research activities (Holmes, 1997). It is thus clear that education authorities should work to include policies that ensure the provision of appropriate support for learners with Autism including: identification of learners with ASD, outreach services for mainstream schools, training and advice for all staff, implementation of environmental adaptations, collaborations between school and families, development of individual education plans and careful preparation for work placements (Howlin, 2004).

Adults need a similar approach to ongoing education as younger children; however there are some areas that differ, such as the change in focus on academics. Holmes (1997, p. 221) explains that this approach encompasses “teaching those skills that most directly enable adults to function independently. These are predominantly life skills and domestics, such as washing and cooking, as well as recreation, communication, behaviour management, and employment skills”. They need to be able to generalise the skills learned to home and work and community, instead of only in the classroom, and they need to be prepared for the changes that will occur in their bodies –such as menstruation, hair growth, diet, etc. There must also be a focus on teaching age appropriate recreational activities, such as going for a jog instead of playing on the swings.

Occupational therapists trained in evaluation instruments can expand on school based practices by evaluating in the areas of transition planning, specifically in areas of daily living skills, work and leisure, and community participation. Transition services are currently not addressing all areas of need of learners in all life areas, including community and personal and social relationships (Kardos & White, 2006). Successful teaching programmes must also include detailed individual assessments, restructuring of teaching strategies, environmental adaptations and significant attitude change (Howlin, 2004).

Transition services should assist the individual in achieving goals identified in the areas of training, education, employment and independent living skills, by age 16 or younger if deemed appropriate by the Individual Education Plan (IEP) team. One of the difficulties experienced in transition services is the lack of adequate evaluation strategies targeting functional performance across all essential life domains. Kardos and White (2006) aimed to develop instruments for evaluation that could answer three questions: how much knowledge the student had in transition areas; what behaviours the student could possibly display in work and community environments; and what the student's current level of performance was in basic Activities of Daily Living (ADL). The interest in these assessment instruments for the present study are the areas that are taken into account when assessing the individuals, as these areas are not limited to numeracy, literacy and life skills. Life skills, as a learning area, needs to be defined more specifically in order to include further educational or functional academics, employment, activities of daily living –independence, personal hygiene and home management skills, as well as community participation, and recreation and leisure. Increased and enhanced training of educators and educational psychologists would greatly benefit the quality of intervention for adults with Autism, as effective teaching strategies do exist; however flexibility and support from higher educational authorities would be required in order to implement these adaptations widely (Howlin, 2004).

In 2001, the White Paper 6 on Special Needs Education was introduced in South Africa, restructuring the education system in order to remove barriers to learning and include children with disabilities into the mainstream education environment. According to this new framework, autistic students should be included into mainstream schools but there is little research on the feasibility and practical implementation of this (Roberts, 2007). Education White Paper 6 further suggests that the curriculum needs to be made more flexible so that it is accessible to all learners, irrespective of their needs. Barriers to learning arise from within the

curriculum, and more specifically the content of learning, the language, the medium of teaching, management of classrooms, available materials and assessment methods and techniques. Importance should not be placed on whether mainstream or specialised education would be more beneficial, as the individual needs to be taken into account; however increased emphasis needs to be placed on how the mainstream curriculum can be adapted in areas of social, emotional and educational support (Howlin, 2004).

The South African National Association for Special Education (SANASE) has prepared a document that proposes an adapted vocational curriculum for learners with mild intellectual disabilities, based on the assumption that one of the most significant barriers to learning at present for this population is the national curriculum statement (NCS). There is a need for a vocationally orientated curriculum that will enable learners with difficulties to become economically active and independent. The proposed adaptations to the NCS would partly impact on the learning areas of the NCS, as well as requiring additional skills training or vocational programs that might result in the learners exiting with a National Qualification Framework (NQF) level one certificate. The purpose of this new structure of a curriculum for learners with intellectual disabilities is to enable them to be ‘recognized for their ability to demonstrate skills in basic literacy, numeracy as well as life-skills and vocational training, leading to general education and vocational training certified career paths’ (SANASE, 2010). The proposal for the adapted curriculum also highlights that this adaptation might benefit learners with barriers to education other than mild intellectual impairment, such as auditory or visual impairment, physical disabilities, poverty and underdevelopment, socio-economic factors etc. The general characteristics include mild learning disabilities, as well as negative self concepts, feelings of inferiority and negative perspectives of others, due to an inability to access the national curriculum. The proposed curriculum envisages a child who is confident, independent and literate, with the means to access the formal or informal economic sector, and who will participate in a social and working life (SANASE, 2010).

The special curricular needs of these learners include a curriculum that is flexible and/or adapted to the diverse range of their needs, with a technical or vocational core that requires a significant shift away from the academically oriented curriculum. It is suggested that the instruction time is amended to allocate as much as fifty percent to vocational training, and more in the senior grades. Certification would benefit these learners so that they are recognised for their skills outside of the formal schooling system, also allowing access

opportunities in the Further Education and Training (FET) band. The curriculum should meet the emotional, moral and physical needs of the learners, not only the academic or cognitive needs. The pace of teaching and time required to complete the curriculum needs should provide for their needs, and it must acknowledge, respect and meet the different learning needs of learners with barriers to accessing the NCS. Barriers to learning would then be minimised, and participation of learners in the curriculum would be maximised. The Education White Paper 6 on Special Needs Education recognises the ‘inability of the system to recognise and accommodate the diverse range of learning needs’ (Department of Education, 2001). The presentation of an adapted curriculum including academic learning programmes and vocational-oriented learning programmes, suggests that both programmes could be offered within the same school, however assessment would differ. The framework of this proposed curriculum includes four levels, and a learner to be admitted to the programme at 14 years old. The first level/year would be an orientation or bridging phase, the following two levels/years a training phase, and the fourth level/year a qualification phase. The system is proposed to be learner-based and learner-paced, and as such the classes would not be allocated according to age groups.

This proposed curriculum would appear to be a step towards the needs of individuals being met by a curriculum that is flexible to individual needs, as well as resulting in a qualification, which most learners with ASD have difficulty achieving and is consistent with recommended best practice in this field. It is this evident that some professionals recognised the differing needs of learners with disabilities, and that the inclusion policy in theory is lacking in practical applicability. The next step would include government endorsement of the proposed adaptations and obtaining the resources required in order to put this proposal into practice within the South African schooling system.

When teaching adolescents with Autism, parents and/or professionals need to take into account the individual’s strengths and difficulties, their interests, their autistic traits and sensitivities, as well as their age and sex. A team is needed in order to understand the curricular needs of the individual with Autism in the context of the home, school, community and possible job and living contexts, and an individualised plan needs to be created by the team. Hendricks & Wehman (2009, p. 78) argue that:

“As adolescents with ASD prepare for life after school, transition planning is needed to dictate goals, courses of study, services, and supports. Effective plans

require active involvement and participation from a multidisciplinary team (National Council on Disability, 2000)”

Multidisciplinary teams are an integral part of most schools and education systems, especially when working with learners with special needs, as special education became the vehicle for promoting collaboration within schools, and multidisciplinary teams were acknowledged for their importance in maximising the learner’s development (Dettmer, Thurston & Dyck, 2005). Multidisciplinary teams often include the parents, educator, head of department and any therapists and specialists working with the learner, such as occupational therapist, speech therapist, physiotherapist, psychologist etc. The involvement of trans-disciplinary teams in the transition process is limited (Grigal et al., 1997) and the extent to which this team is involved in the planning is determined by the school, therefore the level to which they are involved with the learner when leaving school is limited.

Hendricks and Wehman (2009) investigated transition from school to adulthood for youth with Autism in a meta-analysis study, and found that team member participation varied, however approximately 96 percent of meetings were attended by the special educator, and 90 percent by parents. Active participation by other members such as service personnel, general educators and external support agencies however was much lower, ranging from 58 to 30 percent respectively. In mainstream schooling, less emphasis is placed on the team when an adolescent chooses his or her subjects and begins to plan for a career or university entrance; however, the individual is in charge of making the decisions. In specialised educational systems, there is increased emphasis placed on the team, however the individual is rarely consulted when choosing an educational program or possible career. The presence of a disability should suggest that the team create an individualised and accessible plan that the learner with Autism or other disability can contribute to, according to his or her interests and wants in his or her life. Involvement of the learner in his/her IEP would create an opportunity for them to learn about themselves and plan for their futures, by helping them understand the process and lead the meetings will assist them in self-advocacy, goal setting, self determination and self-evaluation (Glor-Scheib & Telthorster, 2006; Hendricks & Wehman, 2009). The number of learners actively participating in the team is low, with the minority attending meetings and only three percent of learners were found to be leading the team discussion (Grigal et al., 1997; Hendricks & Wehman, 2009). This raises the question of how many specialised schools consider the opinion of the individual in planning and choosing

their living and working environments, and how parents and professionals have exposed them to future possibilities in a medium in which they can understand.

Successful transition, to the best of each individual's ability, requires thorough preparation and implementation and overlap of school and adult services. Each individual, with his or her individual needs of support, to varying degrees in varying areas, requires assistance with transition into an adult role within the community, and the earlier these structures and planning programs are put into place, the more likely the adolescent will gain the needed support. Services required by learners in order to make successful transitions need to be included in the IEPs, and a designated component of the IEP should be in place by age 16 if not before (Grigal et al., 1997). The need for early planning and overlapping services is important in order to support the individual transition, as well as creating a more smooth transition for the service providers. "It is not enough to document the need for support services, but timely contacts to service agencies must be made to align programming between school and adult providers" (Hendricks & Wehman, 2009, p. 79). It has been recommended that planning for transition should begin between ages 10 and 13 years, so that more detailed planning begin at age 14, and implementation of the transition plan can become a part of the activities for 16 to 18 year olds when the individual is expected to exit the formal education system. Sufficient time is then allowed for support from the formal education, and information gained from adult services to overlap, into order to increase the likelihood of smooth transition from one service to the next. Although transition plans are found mostly to comply with the four areas of the transition requirements as stated in the IDEA (education, employment, residence and recreation), the quality of these goals were found to be minimal and step-by-step plans in achieving such outcomes often absent. Since special educators are often responsible for creating the curriculum they use to plan, the list of skills in the curriculum often lack knowledge of skills required in adult life (Grigal et al., 1997).

2.2.3 The family level

Transition into adulthood is a particularly stressful time for most parents, and research has shown that caregivers of children with developmental disabilities face increased and unique stressors, such as additional financial burdens, more restrictions in social activities, and heightened parental stress (Lecavalier, Leone, & Wiltz, 2006; Seltzer, Krauss, Orsmond &

Vestal, 2001; Taylor, 2009). Families experience an increased amount of stress when their son or daughter enters into adolescence as changes occur, and that stress increases again during transition or leaving high school and making the transition into adulthood (Taylor, 2009). Most parents worry about how much independence their child can attain and how they will cope when they can no longer be available to care for them (Howlin, 2004). Over and above these, parents also have concerns about behaviour, and social interactions and communication (Seltzer et al., 2003). In general, the transition period is accompanied by increased challenges and risks for parents and family members.

Seltzer et al. (2001) describe four reasons for which few disorders pose a greater threat to the psychosocial well-being of families than ASD. The authors argue that since ASD is relatively rare, obtaining diagnosis and evaluation is a prolonged process, secondly, behaviours are often extremely difficult to manage, third a low tolerance for and public understanding of the disorder exists, and lastly there is no cure –with treatments requiring extensive time, energy and patience from the parents. Specific stressors exist around concerns about finding appropriate residential and vocational placements, the quality of support, limited social lives, and reduced opportunities, as well as financial concerns and problems within the family. Parents whose children were in the last year of high school, stated that they were unfamiliar and uncertain about the adult service world, and felt uninformed about post-high school employment and residential possibilities (Brotherson et al., 1993; Chambers et al., 2004; Taylor, 2009).

Parents whose young adults had already exited the school system cited that the lack of options were a significant source of stress, as well as the dependency of their son or daughter; lacking self help skills, mobility and independent functioning (Taylor, 2009). In addition to a lack of services available, there are long waiting lists for entrance into the existing services, the community also lack age appropriate alternate services, and parents experience reduced acceptance and therefore greater isolation, and parenting burnout (Brotherson et al., 1993). In addition, parents report an impact on their recreation activities, finances, physical and mental health, marital relationships and personal development. For some, the experience of adolescence is accompanied by a realisation of the permanency of the daily management demands, increasing the difficulty during this period (Seltzer et al., 2001). With reduced formal structure of school, informal support systems via school educators and other parents diminish as their uncertainties and anxieties increase (Howlin, 2004). Individual differences

in experience occur during the period of transition, some families experienced reduced stress when their child exited school due to reduced social pressure placed on them; however those who were dissatisfied reported insufficient transition planning prior to their leaving school (Taylor, 2009).

The perspectives and input of siblings are also crucial during the transition period, because it is not only the individual and the parents who are affected during the time of changes and increased concern for the adolescents with ASD. Increased involvement of siblings should result in increased understanding and therefore a more active role assumed in planning and implementing interventions and decisions for the adolescent and later the adult. Siblings have reported an expectation to be involved in caring for their sibling later in life, therefore should be increasingly involved in planning (Chambers, 2004). Sibling involvement will also increase support for parents (Blacher, 2001) and result in additional continuity of service should an unexpected event occur and parents are unable to make decisions for their child (Chambers, 2004).

Professionals are responsible for organising a team that can prepare and support an individual with Autism for transition with skills required in adulthood, however in the years following formal education, the responsibility falls on the parents to organise a team that can support them and their child, ongoing learning and movement into living and working opportunities. A child with ASD within the family places a strain on a family's financial resources and social possibilities, through need for early intervention, specialised schooling, behavioural challenges and intensive therapy at times, therefore the added responsibility of organising a team and further placements in residence or vocational positions adds further strain to a family. Parental psychological resources, formal and informal social support can buffer the stress of having a child with autism, or account for the toll the stress takes on the parent's psychological well-being (Seltzer et al., 2001). Some families seek the support of paraprofessionals in order to manage the child, however some families do not have access to added support, and thus children have to stay home and parents need to take care of them, resulting in additional financial strain due to lack of employment for a parent (Hendricks & Wehman, 2009). In a study conducted by Rosenblatt (2008, p. 29), when parents and carers were asked what support their son/daughter would need to live independently '40% indicated 24-hour support, 22% said significant support, 20% indicated some support daily, 10% said

some support weekly, 6% occasional support and 2% suggested no support was needed'. The need for support is thus high, and parents cannot manage the demand placed on them alone.

2.2.4 Collaboration between the school and family

Hendricks and Wehman (2009) suggest that professionals have difficulties in designing and maintaining appropriate programs for these individuals based on limited research and access to information, and parents have difficulties in working alongside services in order to best meet the needs of their child. Preparing adolescents for the transition requires professionals to be knowledgeable of a variety of teaching strategies to apply to each individual despite the lack of research on curricula for these individuals. Parents, however report frustration at a lack of information and services of poor quality, as well as high levels of effort required in order to assure a placement for their child in the services provided (Hendricks & Wehman, 2009). Studies further suggests that interventions that can alleviate stress and concern regarding the period of transition should include increased information for families about available services, as well as skills being taught that increase autonomy (Taylor, 2009).

It becomes increasingly important that parents and professionals working with an adolescent with Autism are in agreement and are working together to support the individual in transition. Since information on the needs of the individuals during this phase is limited, it becomes essential that communication between parents and professionals is open and ongoing in order to share the already limited knowledge. When parents receive support from the education provider and the school receives information and support from the parents, the individual will ultimately gain from the team approach. If parents and professionals experience obstacles in working together towards common goals, the individual will not benefit and much time and resources will be wasted.

A relationship of collaboration and reciprocal understanding and participation does not occur naturally between home and school settings, and thus Brotherson et al. (1993) have suggested five strategies that special educators can use in supporting parents and young adults in making the transition into adulthood more successful. Firstly educators should encourage early expectations of involvement from parents, thus enhancing their understanding of the scope of skills required in transitioning and increasing their participation in making such goals a reality. The earlier goals are set, the more likely small steps and activities can be put into place at home and at school in order to work towards these goals. Secondly, educators

need to assist parents in realising the importance of their contributions. Parents have often experienced negative responses to their involvement in the past and their low energy levels and high stress levels result in reduced involvement with the school case management of their child. Educators need to present information to parents at meetings and then ask for understanding of their specific needs and expectations, and work to increase community involvement and reduced dependence on the family by discussing available and appropriate service opportunities for the adult and engage actively in decision making. Parents are often unsure of how to be involved and thus a parent involvement policy might assist both parties in working together (Brotherson et al., 1993).

Thirdly, educators should increase strategies in which they gain understanding of the choices and preferences of adults with Autism, and then share these strategies with the parents. Increased personal decision making in all areas of functioning results in increased independence and self-advocacy; which will ultimately reduce the stress and pressure of decision making placed on the parents. Fourth, educators need to assist parents in increasing the role of social support networks in their family functioning. Natural support networks for families with a member with a disability are often limited. Schools can increase the availability of information and understanding for extended family members, neighbours, friends and community acquaintances, in order to increase their availability to parents in times of need. Social support creates a link between community presence and community involvement or participation, and also reduces the stress and increases the emotional wellbeing of family members. Lastly, educators can begin to address family concerns regarding employment, as oftentimes parents fear failure and discrimination which can be reduced or avoided when planned for (Brotherson et al., 1993). The importance in defining the role for parents and professionals and how they can work in collaboration from the time that the individual with ASD needs to begin preparation, is crucial in order to create a period of reduced stress for the individual and his/her team members. Through better understanding of the perspectives of parents and professionals during the period of transition, each team member could better understand the emphasis or importance placed by and on other team members and therefore be able to work more effectively as a team.

In conclusion, challenges faced by parents with a child with intellectual disability are shared with those with a child with Autism; however additional unique stressors also exist. These are due to the social impairment and restricted interests inherent in the diagnosis, as well as the

difficulties of fitting into adult services which increase the stress and burden placed on the families of these individuals (Taylor, 2009). Family involvement and increased social support is critical to planning for an adolescent and increasing the likelihood of transition success (Blacher, 2001; Brotherson et al, 1993; Chambers, 2004). If sufficient planning and awareness can be accomplished with adolescents aged 16 to 18 whilst preparing for a period of transition into adulthood, the levels of stress and strain placed on the individual as well as the family can be alleviated and reduced, and this might mean that parents are more at ease during this period and experience reduced distress.

2.2.5 Community involvement

Individuals who are able to engage in community activities and events are more likely to live a more fulfilled life. Community involvement benefits the individual in engaging in a variety of experiences outside of a residential environment, but also exposes the community members to the abilities of the individuals living within a residence. The limited social imagination and inability to entertain themselves in an age appropriate context of adolescents and adults with ASD, results in the need for them to be instructed specifically in possible leisure activities and exposure to age appropriate norms that typical adolescents might receive through their friends (Holmes, 1997). Social and recreational skills such as going to the movies, eating at a restaurant, swimming, dancing etc, need to be taught in order to broaden future possibilities in the community. Involvement in increased community settings can support an individual in developing social interactions, support networks, and increased opportunities to engage in activities of interest (Howlin, 2004).

Contexts which might benefit an individual in terms of community involvement and social interaction, as well as overall wellbeing include special interest groups which enable sharing of particular interests with like-minded individuals, sports activities and church or religious groups which allow social interaction within structured activities and routines. Engagement in sport and religion can also buffer and reduce stress in individuals (Blacher, 2001; Howlin, 2004). Decreased stress and increased recreation activities with exposure to a broader possible support network would also decrease the likelihood of feelings of isolation and rejection, and also reduce the risk for depression (Howlin, 2004). Lack of social understanding and increased inappropriate pursuit of obsessive interests can result in individuals with ASD committing offences, violating other's rights, privacy and property.

Criminal acts are mostly engaged in with naïve ignorance and no intention to harm another person; however lack of understanding, and misinterpretation of social rules, combined with limited or no evidence of guilt or empathy, can result in problematic situations and legal action (Howlin, 2004). Increased exposure to and education in engaging within community activities which might increase appropriate interactions and acceptable forms of following special interests and reducing stress will therefore benefit the individual and the family as a whole.

As seen in Blacher's (2001) conceptual model of transition into adulthood, environment and cultural influences also include socio-economic status (SES) and service support. Individuals within a family context of lower income and lower SES, experience greater barriers to accessing service support and therefore show increase behavioural problems (Taylor & Seltzer, 2010). SES therefore plays a predicting role in the well-being of a family with a child with a disability (Blacher, 2001). Reduced access to support services and networks and increased maladaptive behaviours result in decreased individual and family well-being. Communities, through discrimination or ignorance, are often unaware of the impact they have on the family of an individual with a disability.

2.3 Future Quality of life

The outcomes for adults with Autism are extremely variable, dependent on the abilities and difficulties of the individual, the family and the context and might include residence at home or elsewhere, employment or day activities, isolation or socialisation and family involvement. In order to maximise the possibilities of any individual within their areas of interest and potential, appropriate support structures are required to reduce barriers and difficulties and enhance strengths and areas of interest (Howlin, 2004). According to the factors which have begun to define the successful transition into adulthood discussed previously, areas of residence, employment and social interaction need to be taken into account, and thus these areas are discussed in more detail below.

2.3.1 Residential factors

Opportunities to enter into residential and employment services enable adults with Autism to have similar experiences as their non-disabled peers –living independently from family, social independence and monetary rewards, as well as self-esteem and pride. As much as it is important to keep in mind the capabilities of each individual and build on specific skills for employment within their interests, it is also important to teach and develop skills that will enable adults with Autism to live a more independent life, which might include residential placements (Holmes, 1997). If schooling systems can work to develop and improve an individual's ability in independence and life skills, behaviour management, improved physical health, as well as domestic abilities and self-care, as opposed to focusing only on academics, the chances of success in being accepted for residential facilities will improve, as will the quality of life of the individual.

The decision that needs to be faced is whether the adult with Autism will live at home or in a residence. This is reported to be one of the most difficult issues that families need to confront, and consequently the decision impacts all family members. This phase of launching an adolescent out of home is often postponed due to family preferences or due to lack of adult services available; however parents of adolescents and adults with intellectual disabilities experience increased involvement in decision making and support, as compared to families of typically developing children, who begin to experience reduced involvement with their child (Krauss et al., 2005). The increased needs of adolescents when leaving school result in increased demands and stress placed on families which generally result in increased need for a home placement (Blacher, 2001).

Krauss et al. (2005) studied the perspectives of mothers on the impact on living at home or moving out of home for the family, for the son or daughter and for the mother. It was found that positive and negative impacts were experienced in both circumstances; however the benefits of an adult living at home were experienced as 46.2% beneficial to the family, 34.7% beneficial to the son/daughter and 19.1% beneficial to the mother. In contrast, the experiences of an adult living at a residence showed 20.5% beneficial for the family, 50.6% beneficial for the son/daughter and 22.9% beneficial for the mother. It clear from this study that the family found it more beneficial for the adult to live at home, mostly through being good company and a good influence on parenting styles; however increased benefits were perceived for the adult if they were to move out of home, through acquiring new capabilities and increased

confidence and independence, a more structured and age appropriate life and increased social life. Some of the negative aspects of an adult moving out of home included; fear of their vulnerability and an insufficient service and support being provided, lack of communication and interaction between home and parents, and guilt experienced by the parents for not providing adequately. The negative aspects experienced when an adult resided within the family home included; increased stress of constant care-giving and dealing with problematic behaviours, limitation of activities available to the adult and reduced access to activities for the family, social isolation for the adult and the family, and increased concerns regarding the future when parents aged (Krauss et al., 2005).

Families of recently placed adults reported an intense emotional experience with increased stress; however increased family and parental well-being (Blacher, 2001), and maternal appraisal of changes which occurred in the family life situation included 90.5% more free time and 44.6% reduced fatigue (Krauss et al., 2005). Since benefits do exist for parents as well as for adults when moving out of home and residing in a group home or community residential programme, it is important to understand what obstacles occur to the arrangement of suitable placements. The child's ongoing dependency, continual vulnerability, lack of autonomy and the need for constant supervision were reported the most prevalent. In addition, behavioural concerns, such as aggression, obsessions and tantrums, as well as social and communicative concerns were reported. Concerns regarding the availability of appropriate services and the need for effective communication required with services were also expressed (Krauss et al, 2005).

Due to the lack of alternate possibilities or dissatisfaction with available services, most adults with Autism continue to be dependent on their parents long after the expected age of launching for most young adults. Nearly half of the population with Autism continue to reside at home and only approximately 11% live in semi-supported or independent residences. Over extended dependency has been found to foster feelings of resentment and numerous relationship problems within families, and no matter how successful, the plan is not sustainable as most adults with Autism will outlive their parents (Howlin, 2004). With a complex network of support and prior planning and training, most adults with Autism are able to attain semi-supported living arrangements, with support in finances, domestic and travel arrangements, shopping and leisure possibilities and emotional support, and the well-being of the adult and the family would most likely increase. A wide range of provision is

required alongside possibilities for change as the individual's wants and needs change (Howlin, 2004).

2.3.2 Employment factors

Underemployment of individuals with Autism spectrum disorder is currently an ongoing challenge for most families. In addition, those who are able to gain employment are commonly underpaid; however this is an international phenomenon and not exclusive to the South African setting (Taylor & Seltzer, 2010). Despite evidence that individuals with Autism can achieve successful work lives within the community, many challenges to gaining and maintaining employment remain (Hagner & Cooney, 2005). Individuals without an intellectual impairment have been found to have increased social functioning and independence and therefore increased chances of employment (Taylor & Seltzer, 2010). Comorbid intellectual impairment creates a barrier to employment as well as impaired verbal and nonverbal communication abilities, inappropriate social behaviour and difficulties with social relationships and social rules, obsessive special interests, difficulty with changes in routine and sensory impairment which result in increased sensitivity or insensitivity and behavioural difficulties (Hagner & Cooney, 2005; Howlin, 2004) severely hampering employment prospects. The correlation between intellectual impairment and employment opportunities were interesting because although reduced competitive employment was accessible if a comorbid intellectual impairment was present, the individuals without an intellectual impairment were three times more likely to engage in activities with a frequency of less than ten hours a week. Intellectual impairment thus hampers employment possibilities; however the lack of intellectual impairment does not guarantee suitable work can be sought, due to inconsistent abilities. Sheltered employment services were most common amongst adults with intellectual impairments and resulted in the lowest functional independence and the highest levels of maladaptive behaviour. Supported employment was engaged in by approximately 12% of the participants and the presence or absence of a comorbid intellectual impairment was not significant (Taylor & Seltzer, 2010). Supported employment should offer assistance within the regular workplace through a job coach, and although the initial cost of implementing this level of support is high, the long-term benefits result in the programme being worthwhile. Supported employment has been found to result in increased job

satisfaction, sustainability and increased social interaction with non-disabled workers (Howlin, 2004).

Assessment and support for an individual with ASD are required, beginning with access to the structure and expectations of an interview and selection process, modifying the tasks required and the working environment (such as increasing structure and organizers). Appropriate behaviours during work breaks and times of reduced structure (such as alternate activities and time constraints) need to be taught, adapted communication strategies (such as increased specific instructions and reduced figurative speech) and routine and predictable activities need to be implemented (Hagner & Cooney, 2005). Social and emotional deficits are the main barrier to successful employment (Howlin, 2004), thus ongoing support is required in these areas. It is important to note that from an employers' perspective, employees with Autism mostly exceeded expectations and were commended on their high accuracy in visual perception, concentration ability (reduced distraction by social stimuli), long term memory, high tolerance for repetitive activities, methodological and high quality work, and a consistent, punctual and dependable presence. Overall, the job modifications were reported to work with employees other than the individual with Autism, and that the modifications required were more attitudinal than technical (Hagner & Cooney, 2005), thus the placements were viewed as beneficial not just to the individual but for the organisation as a whole.

In the literature surveyed for this study, examples of suitable employment for people with Autism are outlined in the table below:

Table 2: Employment types as outlined in the literature

| Hagner & Cooney (2005) | Howlin (2004) | Taylor & Seltzer (2010) |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Cashier • Assemblers • Recycling • Dishwashers • Data entry • Sensor installer • Stocker • Cleaner, • Deli assistant, • House keeper, • Maintenance • Clerical assistant | <ul style="list-style-type: none"> • Manufacturing jobs • Retail • Printing and mailing • Food services • Warehouse work • Recycling and delivery • Office clerks • Janitors | <ul style="list-style-type: none"> • Bus boy or wrapping silverware at a restaurant • Replacing dirty glasses or folding towels at a hotel • Working at salvation army • Beading • Shredding confidential information • Working at a grocery store • Working in the community in groups |

Increased emphasis needs to be placed on the suitability of the employment for the individual rather than the type of employment; however reduced emphasis on social interaction and flexibility increases possibilities for adults with Autism.

2.3.3 Social and leisure factors

Social deficits, as included in the triad of impairments needed for diagnosing Autism, are an integral part of the difficulty experienced by individuals with Autism in accessing community and support networks. Social deficits are often characterised by impairment in verbal and nonverbal behaviour, difficulty establishing and maintaining peer relations, lack of shared enjoyment of interests, repetitive one track communication about own interests, and general lack of social and emotional reciprocity. During adolescence, increased interest in social interaction and improved communication with adults occurs; however continued difficulty with social interactions with peers exists and difficulty in developing and maintaining friendships continues into adulthood (Orsmond, 2004). Increased exposure to and awareness of social difficulties, often results in lowered self esteem, which alongside inability to adjust to their incapability in this area, result in increased risk of depressive symptoms (Sterling, 2008). With increased interest in social interaction, as well as increased societal expectations and increased stress during transition, adolescents and adults with ASD are more likely to experience depressive symptoms. Psychiatric conditions such as depression are thought to exacerbate existing Autism characteristics, and result in social withdrawal, reduced communication, increased agitation and self injurious behaviour, stereotypic, obsessive and aggressive behaviour, as well as sleep disturbances (Sterling, 2008).

Inability to manage change and unstructured periods of time, as experienced by individuals with ASD, results in decreased ability to engage with others during work breaks. Impairment in communication abilities creates an inability to express their difficulties, which causes withdrawal from situations in which social and peer relations often originate. Supervisors in an employment context have realised the need for support that extends beyond work tasks and includes supporting social inclusion and acceptance, understanding of non-verbal communication, acceptable activities in which to engage in idle time and encouraging others to initiate conversation (Hagner & Cooney, 2005).

Contexts such as community, employment and residential environments all have an impact on social interaction and participation. Individual characteristics such as age and social ability are also predictors of peer relationships, however both individual and environmental factors impact on predictions of social and recreational participation, such as increased maternal involvement in social activities, increased services received and extent of inclusion in school settings (Orsmond, 2004). The functional independence and degree of maladaptive behaviours of an individual with Autism impacts on their ability to engage in social and community recreational activities, as well as impacting the isolation and social support opportunities for families of the individual with Autism (Krauss et al., 2005). Support networks for families not only assist with emotional well-being, but help with transition as a significantly high percentage (82%) of adult employment is often found to be found through family relatives and friends (Brotherson et al., 1993).

2.4 Conclusions

In summary, sufficient literature exists relating to the definition of ASD and transition. The existing literature has given insight into various areas in which the perspectives of participants can be explored. Areas of individual, family and school influences and residential and employment potential were thus addressed in interviews. Research has been conducted internationally in order to better understand the skills needed in order to improve the period of transition as well as improve the quality of life as an adult with a developmental disorder; however few studies have focused on the benefits of intervention for older adults. It is clear increased emphasis needs to be placed on how the skills identified can be incorporated into the existing curriculum in South Africa in order to increase planning and preparation from an early age in order to avoid costly intervention needed for long established maladaptive behaviours. A proposal for an adapted curriculum is examined, in which increased emphasis is placed on the development of skills and exposure to adult life, as opposed to the focus on academics; however this curriculum has not yet been recognised as relevant and applicable. In order to place increased emphasis on the skills identified, it would be beneficial to further explore the importance and meaning that the development of such skills in preparation for a period of transition would create for parents and professionals, as well as for the individual with ASD. Existing literature suggests that the stress experienced by parents during this period is higher than during other periods or when working with other disabilities. This study

seeks to further explore the skills needed or seen as beneficial through the perspectives of parents and professionals, and the meaning that these skills would create, in order to further justify their inclusion in the curriculum and school activities.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter will describe the research process carried out for this study. The aim is to describe the methods used for data collection and analysis, taking into account ethical considerations and impact on the trustworthiness of the results of the study. The chapter includes details with regards to the context in which data was collected, the questions the research aims to answer, and the research design used to best explore the perspectives of participants. The procedure is explained in detail, as well as the information regarding the demographics and involvement of participants. Data collection and analysis procedures have been described, as well as a self reflection, in order to increase awareness of and reduce the impact of the personal involvement of the researcher. Ethical considerations are also outlined.

3.2 Context of the Study

The Johannesburg Hospital School was identified as an appropriate source of participants because it is the only Autism specific ASD School with a senior section for learners up to and including 18 years old, in Johannesburg. The school accepts fees on a sliding scale and some learners are exempt from paying school fees, and thus the sample does not exclude participants from various socio-economic groups. Purposive sampling was chosen as most relevant approach to developing a sample for the study sample. Participants were approached through the Johannesburg Hospital School, Senior Section for learners with Autism, in Braamfontein. Parents were approached based on certain characteristics of their children (diagnosis of ASD, attendance of ASD specific school, and age) and the professionals were approached based on their working at an Autism specific school, and with adolescents in particular.

3.3 Research Questions

1. What factors on an individual, family, and school levels influence transition into adulthood?
2. How is planning for transition being managed and what supports exist during this period of change?
3. What are parent and professional perspectives on an individual with Autism leaving home and gaining employment?
4. What thoughts and feelings are parents and professionals currently experiencing during preparation of adolescents for adulthood?

3.4 Research Design

A qualitative approach, using semi-structured interviews was used to explore the perspectives of parents and professionals. The qualitative approach was identified as the most appropriate given the aim of the study which is to explore and understand the perspectives of the participants, and how their experiences have created meaning for them (Haslam & McGarty, 2003). A realist method was used in order to report on participants' experiences, meanings and realities (Braun & Clarke, 2006). The realist perspective views reality as existing independently of the researcher's mind; social phenomena are fragile in nature and causal impacts are not fixed but are dependent on their environment (Sobh & Perry, 2006). Direct causality links very rarely appear because any links are strongly influenced by context, and therefore it is more beneficial to seek a group of answers that cover several contexts and reflective participants (Sobh & Perry, 2006). Realist researchers enter the field with prior knowledge of existing theories, in order to better choose the interviewees and assist the process. For instance by knowing a little bit about the topic they have chosen to study, they will have increased insight into how to gain further information without causing frustration or confusion for the participants of the study. Researchers can seek to triangulate many sources in order to better understand the realities, such as asking several interviewees the same questions hoping that the different sources will provide the same perception. Should these different triangulation sources provide different perceptions, however these should not be viewed as confusing glimpses of the same reality, but rather a window into the complexity of that reality which needs to be understood (Sobh & Perry, 2006). The participants thus have

common characteristics; however a joint reality is hoped to be revealed through asking them the same questions through which differences of perceptions discovered may account for the complexity of the topic due to differences in context. Limitations exist within qualitative research methods, such as the subjective influence of the researcher on the participants and personal bias within data analysis. Additional limitations of the study have been explained in Chapter 5.

3.5 Procedure

Firstly consent was received from the principal of the school, then participants were approached with information on the study, and then interested parties were interviewed at the school. Approval of application to conduct the study was obtained from the Gauteng Department of Education (GDE) in order to approach participants from the government educational services (see Appendix 1), and an information letter and request for consent, was signed by the principal of the school (Appendix 2). An information letter (Appendix 3), and consent form was allocated to each participant in order to gain consent to participate (Appendix 4) and to be recorded (Appendix 5), in advance of interviews conducted. Self-created, semi-structured interviews were used (Appendix 6 and 7). Interviews took place at the Johannesburg Hospital School after schooling hours, for professionals, and during or after schooling hours for parents. This setting was chosen as convenient and accessible to participants; however time slots were allocated in order not to interfere with the school activities. Participants were offered access to the results of the study following completion, in the information letter; they had the opportunity of giving their contact information should they want to be contacted with the results.

3.6 Participants

As outlined in Table 3 below, the sample comprised 7 parents and 7 professionals (teachers, head of department, principal and consultant) working with learners between the ages 16 and 18 years old. Of the 14 participants, only one professional was male and no male parents were represented; which might be due to the fact that the field is feminized, and the participation of more females is in line with stereotypical roles. The ratio of male/female

participants creates an interesting bias, specifically with regard to the parents. As evident in Krauss et al. (2005), the impact of an adult with Autism also focuses more on mothers than fathers. Ages of parents ranged between 34 years and 53 years (mean =47.1) and professional’s ages ranged from 34 to 79 with an overall mean age of 49. Parents and professionals thus shared a similar mean age, resulting in possible similarities in life stages. The majority of overall participants were first language English speakers, and the majority of professionals were second language English speakers.

Table 3: Demographic information of study sample

| | | <u>Parents</u> | | <u>Professionals</u> | | <u>Overall</u> |
|------------------------|--------|----------------|-------|----------------------|-------|----------------|
| | | N | % | n | % | % |
| Participants | | 7 | 50 | 7 | 50 | 100 |
| Gender | Male | | | 1 | 7.14 | 7.14 |
| | Female | 7 | 50 | 6 | 42.85 | 92.8 |
| First language English | | 6 | 42.85 | 3 | 21.42 | 64.28 |
| Child’s age | 16 | 4 | 57.14 | | | |
| | 17 | 1 | 14.28 | | | |
| | 18 | 2 | 28.57 | | | |
| Siblings | Yes | 6 | 85.71 | | | |
| | No | 1 | 14.28 | | | |

The levels of education and current employment status of parents (see Table 4 below) give indication to the restrictions placed on employment possibilities for parents despite the level of education achieved. Two mothers, representing a third of the sample, reported that they were not currently employed due to the need to be at home to support their child with Autism.

Table 4: Education and employment of parents

| | | <u>Parents</u> | |
|--------------------|----------------|----------------|-------|
| | | N | % |
| Level of Education | Grade 11 | 1 | 14.28 |
| | Matric | 1 | 14.28 |
| | Diploma/Degree | 4 | 57.14 |
| | Postgraduate | 1 | 14.28 |
| Employed | Yes | 4 | 57.14 |
| | No | 3 | 42.85 |

Professionals within various positions within the school and with various levels of experience with learners with Autism were interviewed (see Table 5). The majority of professionals had not worked with adults with Autism, giving indication to the limited awareness of the needs and experiences of adults with ASD and their families.

Table 5: Job title and involvement with ASD of professionals

| | | <u>Professionals</u> | |
|-------------------------------------------------------|------------------------|----------------------|-------|
| | | N | % |
| Occupation | Principal | 1 | 7.14 |
| | HOD | 1 | 7.14 |
| | Educator | 3 | 21.42 |
| | Skills trainer | 1 | 7.14 |
| | Educational consultant | 1 | 7.14 |
| Number of adolescents with ASD currently working with | 0 to 5 | 2 | 28.57 |
| | 5 to 10 | 2 | 28.57 |
| | More than 10 | 3 | 42.85 |
| Contact with adults with ASD | Yes | 1 | 14.28 |
| | No | 6 | 85.71 |

When describing their experience of Autism, the participants expressed ASD as occurring on various levels of the spectrum (see Table 6 below); however the majority felt it could be explained as a severe disorder. Some felt it existed between two levels depending on the context and level of demand, and some professionals felt it would depend entirely on the individual. The majority of participants felt they were knowledgeable about ASD; however the majority of formal training in Autism was described as courses, conferences and

workshops on intervention strategies. This articulates the need for further training and formal access to evidence-based intervention strategies.

Table 6: Experience of ASD of parents and professionals

| | | Parents | | Professionals | | Overall |
|-----------------------------|--------------------------------------------------------------------------|---------|-------|---------------|-------|---------|
| | | n | % | n | % | % |
| Level of Autism on spectrum | Mild | 1 | 7.14 | | | 7.14 |
| | Moderate | 1 | 7.14 | 1 | 7.14 | 14.28 |
| | Severe | 3 | 21.42 | 3 | 21.42 | 42.85 |
| | Individual | | | 3 | 21.42 | 21.42 |
| | Mild- moderate | 1 | 7.14 | | | 7.14 |
| | Moderate -severe | 1 | 7.14 | | | 7.14 |
| Knowledgeable of ASD | Yes | 7 | 50 | 5 | 35.71 | 85.71 |
| | No | | | 2 | 14.28 | 14.28 |
| | None | 2 | 14.28 | 1 | 7.14 | 21.42 |
| Formal training in ASD | Reading material | 1 | 7.14 | | | 7.14 |
| | Courses, conferences and workshops | 4 | 28.57 | 5 | 35.71 | 64.28 |
| | Tertiary education in psychology, psychiatry and special needs education | | | 1 | 7.14 | 7.14 |
| | | | | | | |

3.7 Pilot Study

Two participants were invited to participate in a pilot study in order to evaluate the effectiveness of the questionnaires. The participants included a facilitator who has worked in the senior section for four years, and a grandmother of an adolescent with Autism. These participants were chosen as relevant due to their involvement within the school and with adolescents with Autism. Through the pilot interviews, it was decided that a paragraph needed to be included in the introduction in order to explain that although the researcher is familiar with the participants and the context of Autism, that their responses would need to be given in as much detail as possible, without relying on presumptions of knowledge, in order to decrease possible influence of the researcher on the information collected. Some rewording

of questions was needed at times in order to increase the understanding and flow of the questions, such as replacing the word ‘adolescent’ with ‘teenager’, and using the child’s name when speaking to parents, in order to gain more insight into personal experience rather than expected responses. It was found more beneficial to introduce the question and then let the participant speak and probe for further information with sub-questions if needed, rather than asking the full question, with sub-questions included.

Themes that emerged were summarised in terms of the questions asked. Questions were based on areas including: demographic information and experience of Autism, factors on various levels which would impact the experience of transition, planning and support received during transition, residential and employment possibilities, and thoughts and feelings experienced by participants regarding transition into adulthood. The themes emerging from the interview questions resulted in an adaptation required in the research questions, and an extended literature review to cover a broader scope than the merely skills required by the adolescent.

3.8 Data Collection and analysis

The data was collected using semi structured interviews (Appendix 6 and 7). As a pre-designed questionnaire or interview template had not previously been devised, the researcher designed interview questions for each of the sample groups in order to gain understanding of the perspectives of the participants based on existing knowledge and experience. The interviews were thus guided by a common interview schedule; however allowing the freedom for the participants to express themselves in areas they felt was beneficial for understanding and the freedom for the researcher to pursue interesting information which emerged. Interviews were conducted in English due to the school being English medium. The time allocated for the interviews was forty five minutes to an hour and the interviews lasted between twenty minutes and an hour, depending on the amount of information given by the participant. The questions which guided the interview are presented in Appendix 6 and 7. The interviews were recorded using a Dictaphone for accuracy.

Recorded data were analysed using thematic content analysis, based on themes gained through the literature review, as well as remaining open to the idea that data gathered at times generated new insights and themes (Haslam & McGarty, 2003). Due to the interest in the

meaning of transition through the perspectives of professionals and parents, the analytic process often progressed from descriptive themes summarized, to interpreting the significance of patterns and their broader meanings and implications (Braun & Clarke, 2006).

3.9 Ethical considerations

Ethical clearance was requested from the University of the Witwatersrand and the ethical protocol number allocated was MEDP/12/006 IH. The principal of the school was approached with information and consent forms to conduct the study from within the Johannesburg Hospital School (Appendix 1). The participants received information on how the study would be conducted and how the data would be collected and used (Appendix 2). Confidentiality of information given by the participants was maintained throughout the study. Due to the study taking place within a school, as well as the material being recorded in interview format, anonymity was not guaranteed as face to face interviews were used. The identity and information gained by the participants was protected as far as possible, with the documents and audio recordings kept in a locked cupboard, to which only the researcher and supervisor had access.

The possibility of the study being placed on the Wits library system, as well as possible future publications and presentations, were mentioned in the participant information letter. The names of the participants and learners mentioned have been coded, and no real names were used in the research report. Consent for participation and recording were gained from all participants (Appendix 3 and 4). Participation in the study was voluntary and therefore participant's rights to refuse participation in the study or certain aspects of the study were explained. Access to further information sources, such as contacts for service providers for adults with Autism (residential, day care or transition services) and support services, were available in case of observed distress; however the need for such services was not experienced by participants and further support of free counselling services (lifeline: 011 715-2000, lifeline online counselling 0861 322 322) was not required. Accessibility of the study to professionals and parents of a variety of cultural, educational and /or language backgrounds was ensured through the minimal use of jargon or professional terms. The possible use of information and verbatim quotations was explained to participants, as well as the purpose of the study.

3.10 Self Reflection

Self awareness of the researcher is important in order to ensure that the research information is impacted minimally by the personal involvement of the researcher. Specifically when collecting, coding and analysing the data, researchers can never be completely free of their theoretical commitments (Braun & Clarke, 2006), and any involvement of the researcher must be acknowledged when researching.

Concerning reflexivity, I have acknowledged that the research is conducted in an area that is of importance to me, since I have had experience working in the school in which the research took place. When interpreting the results of the study, it must be taken into account the fact that the participants know me, which might have impacted the answers given in a positive or negative way. A possible negative impact is that the participants felt the need to express themselves based on the expectations created during previous engagements, or have left out details on account of previous shared knowledge. On the other hand this knowledge might positively impact the study in that the participants already felt comfortable speaking to me and therefore expressed themselves more easily. My position as researcher was explained to parents and professionals in order to decrease any possible concerns regarding confidentiality and that my interest is related to the study of their experiences and not in order to assess their knowledge based previous experiences encountered together. A strategy that has been incorporated into my study in order to ensure my involvement did not interfere with data collection and analysis included the keeping of a journal in order to aid self-awareness and therefore minimise bias towards information gained. A summary of my reflections whilst conducting interviews is included below.

Of interest to me are the transformations in my interest in the subject of my research as I have gained information and further insight in the parent and professional perspectives. To begin with, my interest in the topic was reasonably superficial; I felt that the research would benefit me in staying in contact with the school, staff and parents and to show them that although I had left the school, that I was still involved where possible and still committed to the 'Autism cause'. Slowly my interest changed. I found it difficult to put the impact of Autism into academic writing. I felt that I was writing what I already knew, and surely then, others knew

too. In this way my research topic became something reasonably easy to engage in, but I questioned whether it would be beneficial and meaningful.

Over time and through the study, this perspective began to change; having been disengaged from the world of ASD for a few months, I have found that my passion for the subject has been re-ignited. I am not just trying to prove a point or get things down on paper; I truly feel that this project is worthwhile. I had assumed that anyone could guess the perspectives of families and staff during this time of transition, and yet now I find that by listening to the experiences and thoughts of these people who engage in this on a daily basis, I feel as if I am hearing it for the first time - really understanding it instead of just trying to manage it as I had before.

The actual process of interviewing was also more complicated than I expected. After having conducted the pilot study, small changes were needed. I enjoyed asking the research questions I have created, and felt that each question is required in order to fully understand the dynamics of the situation I am investigating. I felt that my research questions were too limiting and too narrow. I needed to work on the themes that arose from different interview questions and adapt my research questions in order to do justice to the information I was receiving.

Interviewing the staff, I found myself pleasantly surprised. I have found it very difficult to revisit the school in order to conduct the interviews, and see that things are not being managed the way in which I believed the standard should be maintained. I felt as if I was an outsider, an intruder. I felt as if I had forsaken them by leaving and now was returning for information for my own benefit. However, conducting the interviews, I found that the staff underestimate the extent to which they are experts within their own field. Although we are not managing to provide the support and teaching of skills required by these adolescents, the staff are aware of their limits and areas in which they should be doing more. What fails them is the foundation of a supporting system. Lack of coherence between the answers given, speaks to me of a lack of communication within the team. In these cases I felt myself having to remove any personal want to comment on and fix these situations. Renewed in me was a want to do more, to do better, to keep trying, and yet it was not an appropriate role as I needed be a researcher and maintain minimal influence on my participants.

Speaking to the parents has also been a more interesting process than I had anticipated. I had to step back, into the role of researcher, without trying to help or give advice. Although I

have known these parents for a number of years, I thought I fully knew and understood them, but listening to them during interviews made me realise I hadn't fully understood the breadth and scope of their experiences. It also reminded me of the sense of isolation and helplessness they feel. Before hand I thought that I knew it and that people would expect and understand these feelings, but I was taking for granted the extent to which these feelings are real and deep and ongoing, and yet these parents continue with life, get up every morning and keep trying. Encouraging them to keep talking as much as possible, without interfering or manipulating the information, was beneficial to my understanding but also reminded me of therapy. These parents need counselling, someone who can hear their pain and their difficulties and help them to cope.

Through the study, I have been reminded of my desire to be involved in the field of ASD, and how my studies have given me increased meaning and understanding of the work I was already doing to some extent. I really hope that I can help to motivate and be a part of creating change so that these parents will be further supported.

The strategy of keeping a journal enabled me to gain perspective of my influence on my research, under the guidance of my supervisor, thus ensuring the trustworthiness of my research.

3.11 Conclusion

This chapter gives an overview of the study's methodology, design and procedure, as well as ethical considerations, possible limitations and self reflections on the researcher's experience during the course of the research being conducted. The following chapter will include a detailed description of the results of the interview questions.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 Overview of chapter

The aim of the study was to explore the perspectives of parents and professionals on the transition of adolescents with Autism. The themes which emerged during data analysis have firstly been explained, followed by the results. The results and discussion of the present study will be presented concurrently, and have been arranged into four distinctive categories based on the research questions. The categories are: (a) factors on various levels which influence the process of transition, (b) the experience of planning and support during transition, (c) the perspectives of parent and professionals on employment and alternate residential arrangements for a young adult with Autism, and (d) the thoughts and feelings experienced by the study participants during this period.

4.2 Themes

Several themes emerged from the data obtained by means of interviews. Four themes emerged as perspectives and three themes emerged as feelings which together influenced all areas of transition. The perspectives are explained, followed by the feelings which emerged throughout the interviews. Firstly, participants perceived a lack of available resources, facilities and services required by adolescents with Autism and their families for successful transition to occur. Secondly, it emerged that although a theoretical understanding of what is needed to prepare for transition exists, the practical application of the knowledge is limited. Although most participants are aware of the existing needs of individuals with Autism, they have difficulty implementing the strategies. Thirdly, there is a need to take the individual and his/ her context into account in order to assess transition possibilities. There cannot be a predicted or standardised strategy or outcome for all individuals with Autism, as the individual's strengths, interests, level of functioning and possibilities need to be understood. The final theme includes the need for an ecosystemic or multidisciplinary approach when planning for transition. Collaboration and the need for various members to play various roles in planning and implementing intervention was repeatedly mentioned, with reference to family, school, community and government influences all impacting the potential of an individual with Autism. The themes which emerged as feelings experienced by participants

include fear and uncertainty, secondly a feeling of isolation, lack of support and understanding, and thirdly, a glimmer of hope and the possibilities which exist should support be achieved.

4.2.1 Factors that influence transition into adulthood

Participants were asked what areas of learning were required by adolescents with Autism when transitioning into adulthood, what they perceived as predicted areas of strength or difficulty, and with regards to the people involved as a ‘team’, what planning and preparations were being made for the transition out of school. The various levels of impact on the transition preparation that resulted directly or indirectly from various people and contexts were in line with the ecosystemic framework that is predominant in the literature (Blacher, 2001; Blumenthal, 2007; Donald et al., 2010; Engelbrecht & Green, 2001; Gormly, 1997). The individual was only rarely referred to without reference to their family and school context, as well as the community and the country, as seen in the quotes below. As the individual with Autism is influenced by his/her context, the whole family is also affected by the demands and well-being of the individual, thus it is important to keep the entire context in mind when designing an intervention and planning the preparation for transition. Highlighting the above, a parent and a professional demonstrate the individual, family and societal influences and express the challenges of integration:

“I think she would discover more about herself and it would make our lives easier” (parent 1)

“They’re going to be a huge burden on society if we don’t enable them to be part of society, so it’s a political challenge” (professional 3)

Factors which influence the transition into adulthood occur on an individual level, a school level, and a family level, and will be discussed below according to the themes which emerged during the interviews.

Individual characteristics which impact the experience of transition, as suggested by Blacher (2001) were echoed by participants, such as age (maturing as a teenager), gender (more vulnerable as a female), SES (services more likely accessed if afforded), physical or medical well-being (which can add complications to the process) and level of ASD or level of functioning. The level of functioning, or impact of the triad of impairments exist on a

spectrum and thus affect the experience of transition in various ways for individuals. Most participants would predict the possibility of successful transition on each individual's level of self help or daily living skills. The possible success of transition could thus not be predicted for all individuals on the spectrum, but rather would have to be planned for on an individual basis according to the individual's abilities and access to support.

The themes which emerged suggest concern by participants that the result of a loss of school structure would have a negative impact causing increasingly negative behaviour, such as boredom, frustration, depression, increased anxiety, behavioural deterioration and decreased social interaction, lack of self help or purpose in life and increased vulnerability and dependence on others. As Sterling (2008) suggested, adults with Autism have a high risk of depression, which exacerbates existing Autism characteristics, such as withdrawal and aggression; justifying the fears expressed by participants.

The positive characteristics expressed by participants which served as a comfort during the transition process included strengths in visual perception and tolerance of repetition and isolation, as well as the possible manipulation of an obsession or special interest for motivation purposes. When motivated, it was noted an individual with ASD will work with persistence and accuracy. Brotherson et al., (1993) referred to the importance of motivation and the involvement of the individual as an indication of quality of life. Motivation for independence was noted as a comfort by four of parents in the present study, and as such these individual factors can be a focus area of the transition plan in order to increase the likelihood of successful transition. Motivation was also mentioned by some participants to be beneficial when individuals were encourage to be involved in family activities, which resulted in positive impact on family well-being in terms of being able to access leisure activities within the community, such as going to restaurants, shopping centres and the movies.

The change in focus from academic to functional skills taught within school and home settings as depicted in past studies (Holmes, 1997) was endorsed by participants as essential to promote the likelihood of a successful transition. Consistent with current thinking in the field, most participants (78.5%) referred to the need for independence and daily living skills to be taught, with a secondary focus placed on academic achievements. Learners with Autism were perceived to need a different curriculum (85.7%), due to a different learning style and more relevant, individual and meaningful content, such as communication, independence, coping with change, vocational skills and engaging in society. Functional learning, coping in

society and work contexts, emotional management, leisure possibilities and the characteristics of the triad of impairments were expressed as skills required by individuals with ASD. As expressed by respondents, characteristics which were perceived to create barriers to inclusion were the national curriculum, the method of learning and the lack of knowledge and understanding of Autism:

“For me it’s a life skill, ya, it’s got nothing to do with how to learn to add or even to learn how to colour in it about how to cope in society” (parent 2)

“To put it in a nutshell I would say functional learning, ... learn to manage their own autism, manage their own behaviour, manage their own learning, so that they can take responsibility for themselves” (professional 3)

“I don’t think academics make any difference, its rote learning. I think his learning has to be different; it has to be different because it has to be meaningful” (parent 5)

“The school is adapting some of the things in the national curriculum, but we made them relevant to the learners that we teach in terms of content as well as in terms of delivery” (professional 4)

“The things they require to get through their lives are not a Matric certificate, they need something else” (parent 1)

It was suggested that the learning style of an individual with Autism differs from mainstream education, as visually explicit material is required more than oral processing of information. The curriculum needs an increased focus on communication, social interaction and coping with change, as well as basic independence skills, vocational training, and other skills required to engage in society. Consistent with the IDEA (1990) proposals in the USA and SANASE (2010) discussions in South Africa, respondents in this study also felt that an alternate or adjusted curriculum was required because learners with Autism would not cope with the mainstream curriculum. The possibility for continuous teaching and accommodation is perceived as difficult due to lack of services, support and resources. Professionals are hopeful, however due to the possibility of an adapted curriculum, as proposed by SANASE (2010), with increased focus on the individual and vocational training. Participants reported that the increased support provided at the ASD specific school, which has programmes

tailored to meet the needs of individuals with ASD, results in increased access to functionality.

Family: In addition to individual and educational characteristics which impact on the success of transition, the characteristics of families also impact the individual and the process. The need for parents to be more involved in creating the team who works with their children, was congruent with the positive impact of participants who were more involved in planning. The results of the study pertain to mothers as a sample, although they refer to themselves and their partners. The perspectives of fathers would be of further interest. The families who were reportedly more involved were also observed to have reduced levels of stress and uncertainty with regard to the future absence of school support. Mothers who are more ‘involved’ attend and create meetings about their child and follow through with activities and teaching in the home environment, include extended family in the life of their child, as well as exposing them to additional environments, and continually increase the involvement of their child in daily living activities. More ‘sociable’ and ‘involved’ families were also understood to increase opportunities for involvement of their children in different contexts:

“I have to do more than being a mom, I have to help open an institution, I have to help run things, I am helping fundraise for things, you know things that it would just be so easy to take a back seat, but we can’t, we need to go forward so it’s very scary” (parent 5)

“By placing those demands, I feel that she has risen to meet them on some level which means that we’ve been able to negotiate certain things with her in terms of the community, in terms of schooling and so I feel optimistic” (parent 1)

Families provide a possible source of support; but were also viewed by professionals as possible obstacles due to their pattern of ‘doing too much’ for their child. Parents reported concern with regard to the ability of the child to cope without them and the fear of what would happen when parents are inevitably no longer available as support. An increased intensity of stress was reported by parents, alongside uncertainty due to experiencing a lack of options and a sense of being uninformed. This experience expressed by participants is associated with the decreased support from formal schooling during a period of increased anxiety, as explained by Howlin (2004). The role of siblings was also debated by some, as

seen in the literature (Blacher, 2001; Chambers, 2004), because it was felt that siblings should be more involved in planning and decision making; however should not be relied upon as responsible caregivers for the adult with Autism in the event that the adults outlive their parents:

“Maybe some of them have siblings, but I don’t think it’s right that the sibling gets to be the custodian or take on the guardian of the child.” (parent 2)

“We feel that it is important that they are a part of her development... I am not of the belief that she should live with her siblings; I will fight that.” (parent 1)

The need for collaboration between the school and family environments is crucial in working to the benefit of the individual with Autism; however the perceived involvement of a team including both parents and professionals is minimal, since the majority of participants felt there was no team (42.8%) or they were not sure of an existing team (21.4%) working with the individual. Professionals had a different view to parents however, and as such it would be beneficial for the school to consider using the strategies for collaboration, as proposed by Brotherson et al. (1993). The multidisciplinary team suggested by participants is similar to the results of studies (Dettmer et al., 2005; Grigal et al., 1997; Hendriks & Wehman, 2009) done on multidisciplinary teams, with educators (50%) and parents (28.5%) being most involved, and secondary involvement (therapists, psychologists, management, potential employers, friends and family and community members) varying according to the individual context. Little or no mention of the individual with ASD as a team member is made however, consistent with the findings of Hendricks & Wehman, 2009. According to study respondents, an ideal team would be involved in planning and discussing possibilities, teaching skills required later in life and assisting in fleshing out ideas. The need to overlap and align school and adult services is understood as a need; however this does not appear to be standard practice as neither parents nor professionals know what services are available after school:

“No, I don’t know of any” (professional 1, 2, 5, 6, parent 1, 4, 6)

“I suppose the school should go and visit other areas and see if they can align or link in” (parent 7)

“...if we could contact to see if they would take children with special needs and train them, but we couldn't find anything, and then it just comes to a dead end”
(professional 1)

Reference was also made to increased community involvement, which according to body of research (Brotherson et al., 1993; Hendricks and Wehman, 2009; Holmes, 1997; Howlin, 2004) benefits both the individual and the community, increasing awareness and exposure, education and leisure possibilities. International practices are viewed by participants as ideal due to availability of resources, services and increased awareness, and although shared difficulties exist with other disabilities, additional challenges exist for individuals with Autism and their scholastic needs and family experiences. Although South Africa is perceived to be doing well when compared to other African countries, the country is perceived to be in the ‘early stages’ with much room for development, when compared to first world countries and the services offered there. Professional 3 explained that when taking the United Kingdom as an example, it would have to be understood that the first school for Autism was opened in England in 1962 and that parents had demonstrated publicly for 40 years before the legislation was changed and Autism was acknowledged by the government as a valuable area in which to allocate time and resources.

Through general comments respondents expressed the view that South Africa does not have enough facilities with the right curriculum, and that the government does not acknowledge, understand or support Autism. Parent 5 gave the example that the government could not focus on special needs when they were not managing with successful transition within mainstream schools. It was assumed that South Africa is lacking the support and resources required for Autism-specific intervention, therefore individuals with Autism are grouped within general ‘special needs’ or disabilities. Five participants also highlighted the perception that attitudes are different in South Africa and will need to change, but that a transformation is beginning and that strategies are slowly falling into place:

“We don't have resources, so ya, I don't think we do support, I think there are pockets of... I think the schools, there are individual schools that are actually doing a good job but you've got to find the schools yourself and you've got to... I think it {school} has to fight incredibly hard to do the work” (parent 7)

“I think it’s very wrong to compare Africa with Europe, especially in view of South Africa’s history, and I think in view of everything else, we’ve got the best schools in this country, in Africa, I mean many African countries haven’t got provision at all, South Africa have certainly got schools that stand up, quality wise compared to any school overseas, and I think we’ve just got to look at getting the same quality model for our adults” (professional 3)

Therefore although felt that South Africa is lacking in support and understand of Autism and the required services, there is also a hope that things are beginning to be put into place and the potential from there is greater than the services currently available.

4.2.2 Support and planning during transition process

As highlighted above, multidisciplinary teams are required in order to engage in effective planning for an individual with Autism to transition with increase success out of school and into unstructured adult life (Dettmer et al., 2005; Hendricks & Wehman, 2009). This section will focus in more detail on the role of the team in planning, the age at which planning occurs and the amount of support offered to various team members during this phase.

The majority of the participants (42.8%) reported that no age specific plan existed, with some (28.5%) planning to encourage the school to keep the individual with Autism as long as possible, a clear indication that no transition plans currently exist. Eight participants of the study reported that team planning for transition included mostly discussions regarding ‘fleshing out ideas’ and teaching skills required later in life, and obtaining information regarding possible services available following school. Some parents felt that the school was working on skills, whereas they (as parents) were adjusting where needed as the child develops. Professionals reported that there was a plan to support the individual through different phases and thus be prepared for adulthood; however it was acknowledged that these were plans that were not being implemented at the time of the research. The plan suggested by some professionals seemed largely in line with the phases of transition explained in the proposed SANASE curriculum. Overall most participants (50%) felt that age 16 was an appropriate point for transition planning to be implemented, with some (4 participants) suggesting that earlier ages were required, with some skills being taught at the beginning of the child’s schooling intervention. Both professionals and parents agree that skills

development should be a focus from ages 13 to 15, and from age 16 to 18 vocational training or skills for after school, independence in the community, functional learning, and building confidence should be emphasised. Participants reported that interventions or people between the ages of 18 and 21 should include visiting different possibilities and making a decision with the learner, with a hope that the learner will be ready for a suitable work environment.

The majority of participants (85.7%) suggested that the interests of the individuals had been taken into account when planning as this information was vital in designing their Individual Education Plan (IEP). Of interest was that most parents responded with a hesitant answer or a 'yes, but...' scenario, using phrases such as 'I'd like to think so' or 'we're beginning to' or 'trying to, alongside teachers' or 'yes, but I need support', 'yes, at school'; however two parents were confident in saying that this was the priority or their only interest above their own interests. One parent suggested that they were taking her child's interests into account however could only comply with them at times due to the fact that they need to '*live in a typical world*' (parent 5). The desires and interests of the individuals seemed to be largely understood through observations in choosing opportunities and engaging them in various activities, or identifying their repetitive talk and engagement in tasks.

In general, the importance of learner-centred planning was acknowledged; however participants reported no strategy making use of this information when moving forward. Although the process of planning for transition is understood theoretically, support is obviously required in putting this knowledge into practice. The lack of support for adolescents, families and adults with Autism is consistent with the international studies reviewed as part of this research (Blacher, 2009; Brotherson et al., 1993; Hendricks & Wehman, 2009; Howlin, 2004; Rosenblatt, 2008). Most parents (71.4%) felt that they were their child's only support, although some (28.5%) used external professionals, in their view this support was secondary to the support of the parents. Generally professionals (42.8%) however reported that the school was supporting the adolescents, with parents called in if necessary. Overall, participants reported that adolescents receive very little support, and the school team could not be relied upon as a support structure once the individual with Autism had left school, resulting in many families with no support due to no team existing outside of the school environment:

“It’s a very very scary thought, it’s a very sad situation, to be very honest, there is nobody, after us (parents) there is really nobody” (parent 3)

“The school has got a big support system if you need to access it... there’s no support kind of after the school environment” (parent 7)

“I don’t think there’s a lot of support, it’s just the teachers, the educators which support them... in the community there’s no support system” (professional 6)

Support for the parents followed a similar trend; with the general consensus (57.1%) being that not a lot of support existed. Parents felt they were alone and had to rely on each other for support:

“I can’t count on a single person, either from my side or from my husband’s side, nobody” (parent 3)

“I don’t think we have any; we go on day by day, doing what you think is right for the child” (parent 6)

Some professionals reported that they were available as a support for parents, through meetings and workshops. It was recognised however that very little support existed apart from contact with the school. Alternate suggestions for support for parents included external professionals or counsellors, friends or other parents with children with Autism; however these supports systems were viewed as beneficial for emotional support and information rather than support in forward planning. Increased anxiety was reportedly experienced by the parents facing the end of support through the school structure for their children. Over 50 percent of participants indicated that there was no support for adults with Autism, although 28,5% reported having heard of some that were not appropriate or Autism specific. It seems that although minimal support exists for adolescents during transition, even less support is perceived to exist for adults and their families and although support centres are known to professionals and parents, they were perceived as inaccessible:

“I don’t think there was any support for them after school. It’s basically at 18 they are the parent’s responsibility” (professional 6)

“No I don’t know of any. I have ‘googled’, I have looked, it’s only overseas where I see there is so much support systems” (parent 6)

“After school? Not a lot” (professional 7)

Increased awareness of the needs of adolescents and young adults is being produced through increasing bodies of research (Brotherson et al., 1993; Hanish, 2011; Hendricks & Wehman, 2009; Holmes, 1997; Howlin, 2004; Kardos & White, 2006; Rosenblatt, 2008; Taylor, 2009; Whetstone & Browning, 2002) however support is required in making this knowledge available in South Africa. Families, schools and services need support in implementing existing knowledge into practical strategies for these individuals.

4.2.3 Residential and employment possibilities following school

Participants were asked to reflect on their perspectives of an adolescent with Autism leaving home and gaining employment after having left school. The responses have been grouped into four areas of interest: (a) their thoughts on moving out, (b) the possible benefits and (c) the obstacles which are perceived to prevent the possibility. The perspectives on (d) employment possibilities follow. Participants report mixed feelings with regard to residential and employment possibilities; although predominantly fear and uncertainty.

(a) The thought of moving out

The decision with regard to alternate residential possibilities seems to be approached with great difficulty. Participants express feelings of fear and concern, as well as uncertainty with regard to available supports. Although benefits of moving out of home have been highlighted by participants, many obstacles are perceived to interfere with the possibility:

“Half of me thinks it’s a brilliant idea... one of the biggest concerns is that, I so worry about care and what happens when I’m not there to guard him” (parent 5)

“No I’m not ready for that... I do know that at some point she will have to transition to something... I’m not really sure how it’s going to pan out, so I do feel safer saying no” (parent 1)

“When he’s older and more adult, I think I would have to look at it” (parent 5)

Participants reported that learners with Autism have the same rights as other adolescents to move out; however the implementation was perceived as difficult. Previous studies are in line with the participants’ responses, as increased independence from the family is viewed as beneficial for quality of life of the individual and the family; however the decision and process is difficult, and therefore is often delayed (Blacher, 2001; Howlin, 2004; Krauss et al., 2005).

“To some extent I think it is beneficial, although it will be very tough, both for the parents and the person. You know the parents are used to supporting the person in every step of the way, and letting go can be very traumatic. But on the other hand I can say it’s beneficial because maybe when they have to be responsible for their things” (professional 4)

(b) Possible benefits in moving out

The benefits of alternate residential placements include independence and responsibility, exposure to increased opportunities and social interactions with similar aged peers, increase confidence and self-esteem, and improved family relationships. The majority of professionals (71.4%) reported that parents need to encourage more independence within the home environment, since they will be unable to provide intensive full time care when parents become elderly. Independence is perceived as the overall aim of the education program, and alternate residential placements would create a safe environment with increased independence opportunities and some sheltered exposure to society. Parents expressed concerns over a perceived lack of suitable services and collaboration, as well as fears of vulnerability and inadequate management of their child. Krauss et al. (2005) suggest the benefits of residential placements include decreased stress of constant care-giving, limiting activities and social isolation, and decreased concerns when parents aged. The theoretical

understanding of the benefits are thus hindered by the fear and uncertainty felt by family members. Increased awareness of the positive impact on the family is needed, alongside a wide range of possibilities for residential provision. Once again, quality of life is perceived to be possible; however increased support is required in order to implement the planning.

(c) Obstacles perceived to be preventing moving out

Compared to the possible benefits, the obstacles were more easily identified by the parents and professionals. The most common obstacles reported by participants included concerns that there is no available support for the learners with Autism, as services provide for special needs generally but are not Autism specific. Participants feared that the individual with autism might be misunderstood or taken advantage of. Communication difficulties; and the inability to express discomfort or abuse on the part of the individual with Autism, added to the perceived vulnerability. Parents also feared a lack of communication and collaboration with adult services:

“I wouldn’t know if someone was hurting him or not, I wouldn’t know if he’s okay or not, and nobody else would understand him, nor have the patience with him”
(parent 2)

“I haven’t heard or seen anything yet that makes me think, this would be a good idea” (parent 1)

Some professionals pointed out how the characteristics of Autism could create obstacles in alternate environments, such as impairments in social interaction. Such difficulties were expressed as problematic through an example in which a possible misunderstanding of social appropriateness could result in a charge of sexual harassment. Individual characteristics which could create obstacles include self help skills, behavioural and sensory difficulties and factors in the broader context which could limit possibilities include financial constraints and a lack of governmental support.

(d) Perspectives on employment possibilities

Similar results have emerged for the possibility of employment for adults with Autism, within the literature (Hagner & Cooney, 2005; Howlin, 2004; Taylor & Seltzer, 2010) and the experiences of participants. Overall, it is perceived that employment is a need and a possibility with the right support and structure; however obstacles exist and are rarely overcome:

“I think it’s a possibility and I think it’s fair and I think why should they not have employment, I think if it’s reasonable, and I think it’s important. I think everybody wants to be valued in that way” (parent 1)

As highlighted in the studies outlined in Chapter 2 (Hagner & Cooney, 2005; Howlin, 2004; Taylor & Seltzer, 2010), appropriate employment for an individual with Autism would depend on the individual’s interests, the level of functioning and the job type. An employer would need to be understanding, patient and accommodating, and a facilitator would need to support the employer and the employee during the transition. Support is required in modifying tasks and environments, aiding communication and teaching appropriate behaviour. Hagner and Cooney (2005) suggest options for methods of modification and preparation which would support communication and structured tasks in the workplace, and overcome some obstacles. In general, respondents agreed that adults with Autism would not cope within a fast pace, demanding or high pressure position, and would engage in a task with increased ease and precision if not reliant on social interaction. Employees with Autism were thought by respondents to be valuable employees due being dependable, reliable, trustworthy, honest, methodological and with limited interest in social distractions.

“Employ an Autistic person; I think you won’t regret it” (professional 5)

“Personally, I would think they would be the best person to employ, depending on the work” (parent 1)

“Given the right support, given the right attitude they can do things that maybe you and me wouldn’t do” (professional 4)

“Once he’s taught, he will never take a short cut, he will never try to, he will do it exactly as they showed him” (parent 5)

It emerged in the study that job types which were thought to be more appropriate included: part time work, within the specific area of interest where motivation would increase, predictable and routine tasks, few interaction requirements and positive reinforcement applicable to the individual. The type of work would depend on the individual, but that any work would be frustrating if no benefit is achieved. Consistent with international research (Hagner & Cooney, 2005; Howlin, 2004; Taylor & Seltzer, 2010), some examples of job types given include office work (filing, photocopying, laminating, scanning and general admin or messenger), restaurant work (kitchen preparation, catering or washing dishes, cleaning tidying or bed-making), computer work (copy-typing, data processing or printing), packing or filling bags according to a template, laundry, library, carpentry, car wash or working with animals.

Some parents and professionals highlighted that employment is needed and important. That it is only fair to give young adults with Autism the opportunity to work and that employment would help them to feel valued, would help to change their attitude. Employment would be expected to give them access to spending money, a hobby and a possible platform for interacting with others. These benefits expressed are consistent with those referred to in previous studies (Howlin, 2004).

“Employment and residential facilities are extremely needed, especially for autistic people, because they need to survive and need semi-independent set up later on in their life because parents are not going to be with them forever”
(parent 3)

The perception of financial support for individuals with Autism could gain through employment however seems to be minimal. Most participants (8 of 14) suggest that the financial reward would depend on the job type, on the hours worked, the outcome of their work, the duties and support required, on the employer and the country and law. Some reported that the work would not be expected to support them financially, and that the earnings would purely be spending money. Taylor and Seltzer (2010) suggested this difficulty occurs worldwide, that even if employment is gained, the employee will most likely be underpaid; due to only menial jobs being acquired as a result of the inadequacy of the service system to accommodate for the needs of individuals. Work was more likely to be part

time, and financial possibilities were thought to increase if working as a part of a team, as this would reduce the possibility of them being taken advantage of. In theory participants felt that the employee should be paid according to their job duties, and not penalised on the basis of their disability. When taking into account the fees required for the support and the job most likely including menial tasks completed on a part time basis however, expectations for financial support are low.

“I don’t think the public or the state, do they really care? I think they’re scared, they don’t have the time, they don’t have the knowledge to accommodate, they haven’t got the facilities, whatever is needed, so why would they employ them?”
(professional 2)

The investment in training and supporting individuals with Autism in employment and residential possibilities is perceived to be beneficial in the long term. Increased prevalence of dependent adults with Autism in society can be assumed to burden the government and society more than the cost of earlier support and training would impact.

“The support that you would pay for, for one or two people, is far less than the support you would have to pay for one person for a lifetime without employment, without being in an assisted living program” (professional 3)

Since the concept of Autism and the support required is still perceived to be new and only beginning within South Africa, parents and professionals involved with Autism and aware of the high demand and the minimal support, should begin to lobby government for better services, raise public awareness and seek amendments to legislation, to the rights of individuals acknowledged.

4.2.4 Thoughts and feelings experienced

Blacher (2001, p. 177) states that “[t]he future, when parents seriously begin to think about it, approaches with a barrage of challenges”. This statement is observed to be true when participants begin to explain their thoughts and feelings with regard to the autistic learner’s period of transition out of the formal school structure. Once again, mixed feelings emerge due to the predominant fear and uncertainty with regards to the future and the high demand with

little accompanying support. It is important to note however that a sense of hope or optimism cannot be overlooked, as participants feel that the work that is currently being done with these adolescents is a step in the right direction.

“Well the predominant feeling is fear, confusion, what will happen? Feeling of, very strong feeling of helplessness, what am I going to do? I can’t do, because I myself can’t do much, alone by myself without any support...And yet there is hope, and I have to focus on her positives, harness that and help her to become independent as much as I can do. So hope, and also determination that okay, this is what I can do and this is what I will do as a mother. That’s it, so it’s a mixed feeling. But the predominant feeling is of uncertainty and fear” (parent 3)

“It’s very exciting, to see our learners transition, because some of them are, they are transitioning, but it’s nerve-wrecking. I am so scared” (professional 6)

“I find it the most scary thing to even contemplate, I just think, what the hell is going to happen to my son, that is frightening.... I just think that in time that he will, in time I will also get myself there” (parent 2)

“I think in the first half of this year I was very very frustrated, just felt that not enough was being done and I felt that in terms of her schooling and I felt that we have worked very hard to get to a blank wall. And it really made me angry... [now] I am actually really optimistic for her, I have to say that does not mean that I have put all my faith in the school or in people, but I just think that there are lots of avenues” (parent 1)

As evident from the quote above, the predominant feeling is fear, concern and terror (57.1%) however a substantive proportion of participants (42.8%) felt a sense of hope and optimism. Both these responses were given by equal amounts of parents and professionals, with some explaining an experience of both fear and optimism. Some participants explained feelings of anger and frustration, mostly feeling that not enough was being done, or that all the work put in would come to nothing after school. Other feelings suggested included confusion, helplessness, unpreparedness, and being tired and having less energy to focus and put things

into place. Some parents also mentioned more positive feelings alongside hope and optimism, such as determination, excitement and interest in seeing the adolescent mature.

“It’s fearsome sometimes, I am afraid, but it’s interesting also, noticing certain differences and similarities with the normal teenagers, and I think you know that is what gives me strength, to see him maturing from a young child to being a teenager, it makes me think there is a hope somewhere” (Parent 4)

Studies conducted by Taylor (2009) suggested a range of experiences, as some families experienced reduced stress, whilst others were not satisfied with the process. The concerns which emerged include the need for a long term plan and an alternative when parents are not longer capable of providing care. The study also suggested a possible delay in taking action due to an underlying hope that things will be better in the future, and a need for support for fear of not managing the demands of a dependant adult, or not being around to care for them. These reported feelings were echoed in the responses of participants in the current study:

“I just think that in time that he will, in time I will also get myself there... I keep thinking that there’s time, so I think okay, so I go and I live somewhere where it’s quiet... where I don’t have to get to work, I don’t have to do this, then maybe I’ll have time to go sit with my son and do those things that he needs to do, maybe that’s the time I’ll spend with him getting it right. That’s why I’m not fretful over it to a point; I’m fretful over if something should happen to us” (parent 2)

When discussing the meaning that would result for all parties involved, it was found that successful transition would result in great importance for the individual, the family, the school, the community and the country overall. Professionals reported a determination to continue with the strategies which have resulted in observed progress, and a need to realize the potential of the individuals and give credit to the potential allowed through intervention with adolescents with Autism.

“We owe it to ourselves and them to do everything in our power to help them... I’m absolutely passionate about the fact that there should be real focus on this period” (professional 3)

“The support that we are giving here, in the short time that I’ve been here, I can see a change” (professional 2)

Professionals reported that they would have succeeded in providing a good service and would be proud to know that they would be a part of the process. They predicted that the individuals with ASD would be able to feel good about themselves because they would feel worthwhile, they would be able to settle in the community and be happy. The school would be offering a service that is not readily available in the country and would be able to give parents hope.

Parents reported that if they could succeed in transition, they would experience a burden being lifted and reduced worry, stress and guilt, as described by some as ‘life changing’. The individual would gain a sense of satisfaction, self worth, independence, pride, confidence, self esteem and meaning. The family would experience relief in observing progress in the individual with ASD. The community and country would be expected to benefit; although it seems that the potential impact of adults with Autism have not been realized by the community. A huge burden on society will result if professionals do not manage to enable individuals with ASD to transition successfully. Departments need to work together and parents need to lobby and the political sectors need to be challenged to acknowledge the rights of individuals to education and to be a part of society.

“It’s terrifying (laugh) it’s very scary... when they’re little its forgiving, they’re cute and they can do strange things and its forgiving, now that he’s big and the future is out there, its daunting... the scary thing is that we know we are not here forever, so I need to prepare him so that in some way he’s independent, or in a home or whatever his future is, it needs to be put into place a lot sooner than I would like to do it or think about it because the future, I mean I could be dead tomorrow” (professional 5)

It was reported that transition was very important, in knowing what skills are needed and how they can be used, in aligning the school and ‘*what is out there*’ (parent 7), in preventing the child from ‘*going astray*’ (parent 6). Support is required however as this was described as ‘*not an easy journey*’ (parent 5). When asked what support and successful transition would mean to participants, the overall consensus was that it would mean a lot.

“I would feel that the purpose of my existence is served” (parent 3)

Successful transition would then create a service for the individual, the family and the country. Increased awareness and ongoing determination when working with an adolescent with Autism, whether as a parent or professional, is required in order to make a difference to the individual and the ecosystem in which they function.

CHAPTER 5

CONCLUSIONS

5.1 Overview of chapter

This chapter discusses the implications of the study, the limitations and directions for future research, followed by the conclusion.

5.2 Implications of research findings

The results of the present study combined with understanding gained from previous research, indicates that increased consideration is required for the importance of transition for adolescents with Autism. Attention needs to be given to each person or level within the ecosystem impacting the individual with Autism. The adolescent, requires increased planning and preparation for transition, as well as involvement in the planning process. Importance placed on choice-making and involvement is expected to increase motivation and likelihood of success in transition out of school. Improved training is required in order to support professionals, to understand and work effectively with the adolescent, the family and the community. Families need increased support and understanding in order to better manage this period of stress. Better access to information would benefit parents in decision making and coping strategies. Collaboration techniques are required in order to align school and home interventions and goals. The research has indicated that strategies for collaboration exist, but need to be accessed by the professionals and parents. Increased awareness and understanding from the community would result in increased involvement of the individual with ASD, and therefore more successful transition, which has been suggested, would benefit society as a whole.

Evidently increasing bodies of knowledge are being produced internationally as well as within South Africa; however this information needs to become more accessible to the public. Practical implementation techniques are required so that parents and professionals can apply this knowledge to their individual contexts. Increased support, such as information, options, involved teams, adapted curriculums and relevant IEPs, and planning during the time of

transition out of formal education would prove to be beneficial for not only the individual, but for the family, professionals, the community and society.

5.3 Potential limitations of research

Although the study allowed for a variety of contexts within the selected participants, some common variables and shared experiences, such as the school, could influence the perspectives and experiences of the sample and thus the study is limited in terms of generalising the result of the data to the broader population. The small sample size also precludes generalisation to the entire South African population with ASD. Further limitations might include the fact that parents and professionals of adolescents were asked questions based on their current experiences of expected outcomes. The perspectives of parents and professionals who have already experienced the transition period might add depth and further understanding to the topic. The experiences of fathers have not been taken into account directly, due to only mothers responding to the participation letter. The sample does not include parents whose children are not receiving education, nor from professionals from a remedial or mainstream education setting. Limitations therefore exist in the study due to shared experiences. It would be beneficial to gain understanding of a broader range of perspectives.

5.4 Direction for future research

The results of this research has been beneficial in providing insight into the perspectives of parents and professionals into the practical implication of existing theoretical knowledge on transition, and the planning required in order to benefit the quality of life of the family as a whole. More research would be beneficial in many related areas, including increased understanding of the perspectives of parents and professionals within a variety of educational settings, as well as possible differences in perspectives of those with experience with adults who have already exited the formal school structure. If perspectives are found to change over time, it would be of interest to discover whether the occurring changes are negative or positive in nature and the possible factors which contribute to the changes. Perspectives of other family members would also be of interest, such as perspectives of fathers and siblings.

Additional research would also be beneficial in understanding the perspectives of community members on their awareness of Autism, and their acceptance of differences and willingness to adapt to others with special needs within the community setting. Further understanding would be of interest within the difficulties which exist in the collaboration between school and home settings, and the obstacles which interfere with the process. Research in support of the development of policy or program interventions supporting further collaboration would also be beneficial. Increased understanding of adapted curriculum content and methods would also be of interest in order to support adolescents and families in preparing for transition within community, social, residential, employment and daily living skills. Further research is also required in order to develop strategies for practical implementation of existing knowledge within a resource limited community such as South Africa.

5.5 Final conclusion

Transition of adolescents with Autism into adulthood is a challenging and stressful time for parents and professionals involved in trying to prepare them, mostly due to fear and uncertainty with regards to what the future holds, as well as a sense of not having done enough to support them, as a result of the scarcity of resources and support. Early intervention for individuals with Autism is acknowledged; however the need for ongoing intervention designed specifically for adolescents with Autism, cannot be underestimated. With the prevalence of Autism continually increasing, and the normal life expectancy of individuals with Autism, increased awareness of the possible implications on society is required. With appropriate attention, structure and support, individuals with Autism can attain a reasonable quality of life, including residential, employment and social opportunities. Positive outcomes for the individual would result in a positive impact on family, school, community and country.

Currently the interests of the individuals with Autism are being taken into account; however these individuals are not considered as valued members of the team planning and preparing for their future. Both parents and professionals are gaining understanding of the needs of these individuals as well as their potential if allowed the appropriate support; however they are not collaborating as a team and are not working together to raise the awareness of the public and the government with as much vigour. Increased awareness of possibilities within

residential, vocational and adult services are required, and training facilities and universities could play an increasingly important role in preparing professionals to better understand and support adolescents with Autism and their families.

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Appendix 1: GDE consent to conduct the study



education
Department: Education
GAUTENG PROVINCE

For administrative use:
Reference no. D2012/255

GDE RESEARCH APPROVAL LETTER

| | |
|--------------------------------|-------------------------------------------------------------------------------------------------|
| Date: | 23 March 2012 |
| Validity of research Approval: | 23 March 2012 to 30 September 2012 |
| Name of Researcher: | Meiring M.G. |
| Address of Researcher: | 4 Corfu Island |
| | 360 Surrey Avenue |
| | Ferndale |
| | Randburg |
| | 2194 |
| Telephone Number: | 011 787 0291 / 082 714 3176 |
| Email address: | meagan.meiring@gmail.com |
| Research Topic: | Transition for adolescents with Autism spectrum Disorder: Parent and professional's perspective |
| Number and type of schools: | ONE LSEN School |
| District/s/HO | Johannesburg South |

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*

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Office of the Director: Knowledge Management and Research

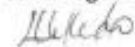
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za

Makhado

2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards



Dr David Makhado

2012/03/23

Director: Knowledge Management and Research

Appendix 2: Information letter and consent from the principal



Transition for adolescents with Autism spectrum disorder; Parent and professional perspectives

Dear Mrs R. Van Biljon

My name is Meagan Meiring, and I am conducting research for the purpose of obtaining a Masters degree in Educational Psychology at the University of the Witwatersrand. The focus of this research is on exploring the perspectives of professionals and parents on the requirements of transition into adulthood. The study aims to determine the skills that would be most beneficial to adolescents in order to transition into adult life, as well as the meaning of the development of these skills for the parents and professionals.

I wish to request your permission to conduct my research within your school. In order to do this, I would like to approach professionals who are working with learners with Autism from age 16-18 years old, as well as the parents of these learners. Each participant who agrees to participate in the study will be interviewed using a semi-structured questionnaire, each requiring approximately an hour. The times for interviews for professionals will be scheduled in order not to interfere with teaching or working hours.

Participation in this study is voluntary. Should professionals or parents choose not to participate in the study, they will not be discriminated against. Apart from my supervisor and myself, no one will have access to the data received, however verbatim quotes might be used in the research report. Names will not be used in the report, and codes will be given, such as Professional A, Parent B etc.

Confidentiality of information gained will be assured to the best of my ability, the documents and recordings will be kept in a locked cupboard and destroyed following final hand in and grading.

Should you allow the study to take place within your school, would you please be so kind as to sign the consent letter attached, granting me permission to conduct the study.

Thank you

Meagan Meiring

Cell: 0827143176

Email: meagan.meiring@gmail.com

Supervisor:

Mr. Joseph Seabi

011 717 8331

joseph.seabi@wits.ac.za



Principal consent form

I....., the principal of the Johannesburg Hospital School, do hereby grant Meagan Meiring permission to conduct her research in my school.

(Please print) at
on

Signature:

Appendix 3: Information letter for participants



Transition for adolescents with Autism spectrum disorder; Parent and professional perspectives

To whom it may concern

My name is Meagan Meiring, and I am conducting research as a part of my Masters degree in Educational Psychology at the University of the Witwatersrand. The focus of this research is on exploring the perspectives of professionals and parents on the skills needed by adolescents with Autism during transition into adulthood. In this study I want to know the skills that you think would be most important for adolescents when leaving school and if possible working and becoming independent. I am also interested in understanding the meaning that the development of such skills would mean for you.

It is hoped that this study will bring increased understanding on the topic of skills required by adolescents with ASD when entering a period of transition, and with increased understanding of what these skills would mean to yourself and the individuals with ASD, more importance can be awarded to the need to teach these skills before these learners reach 18 and need to exit school. My interest in this project is in order to gain and therefore share understanding of your perspectives. There are no right or wrong answers, because each individual has had different experiences and has different hopes for these individual learners. It would be most beneficial if you would answer the questions as honestly as possible, without regard for other's thoughts. If the experience of sharing this information is distressing or upsetting in any way, please let me know and we can move onto another question, or stop, or if persistent I can refer you onto counselling possibilities. It is not expected that the study should cause negative consequences, and the benefits of documenting your opinion on the current context, is in my view, important; however if you disagree please say so.

I would like to interview professionals who work with adolescents with Autism from age 16-18 years old, and the parents of these learners. Each participant who agrees to be a part of the study will be interviewed using a structured questionnaire, that shouldn't take longer than an hour. The times for interviews will be decided when I contact you, if you allow me to.

Participation in this study is voluntary. If you choose not to participate in the study, or decide you want to stop at any stage, or not to answer any specific questions, there will be no consequences, this includes the opportunity for you to ask to have your interview to be removed even after the interview has occurred. I will be recording the auditory content of interviews in order to capture all the information. Apart from my supervisor and myself, no one will have access to the information, but direct quotes might be used in the research report –in which case your identity will be withheld. Documents and recordings will be kept in a locked cupboard during the research. Confidentiality of information gained will be assured to the best of my ability, and coded names not real names will be used in the report. Although confidentiality will be assured to the best of my ability, a risk exists in that a small number of participants (12) will be used, and all participants exist within this school and the name of the school is being revealed, thus it might be possible for those who know the school to make inferences as to the identity of the participants. A summary of results from the study can be emailed to you, if you wish, when the study is finished. If passed, it is possible that this study might be placed on the Wits library system, for further reference in future research, as well as the possibility of publication and presentation in the future.

Should you be willing to participate in this study, would you please be so kind as to sign the consent letter attached, granting me permission to contact you regarding the interview.

Thank you

Meagan Meiring

Cell: 0827143176

Email: meagan.meiring@gmail.com

Supervisor:

Mr. Joseph Seabi

011 717 8331

joseph.seabi@wits.ac.za

Appendix 4: Consent to participate



Consent to be contacted regarding participation in the interview

I....., the parent/professional of an adolescent with ASD, do hereby grant Meagan Meiring permission to contact me in order to set up an interview.

My contact number is:

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

My email or postal address is:

.....
.....
.....

I have read and understood the information letter.

(Please print) name: at

..... on

Signature:

Appendix 5: Consent to be recorded



Consent to be recorded during the interview

I....., the parent/professional of an adolescent with ASD, do hereby grant Meagan Meiring permission to record the content of the interview.

I have read and understood the information letter, understanding that recordings and information about the participants will be granted confidentiality to the best of the researcher's ability, however verbatim quotes, without reference to names, might be used in the research findings.

(Please print) name: at
..... on

Signature:

Appendix 6: Interview questions for parents

1. Age: _____

2. Gender:

Male Female

3. Use of English language

3.1 First language English

3.2 Second language English

3.3 Limited use of English

4. Are you currently employed?

4.1 What is your highest level of education? _____

4.2 What is your current occupation? _____

4.3 Do you own washing machine? _____

5. How old is your child?

5.1 16 years old

5.2 17 years old

5.3 18 years old

6. Do you have other children?

6.1 No

6.2 Yes

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

7.1 Mild

7.2 Moderate

7.3 Severe

8. Do you consider yourself knowledgeable about ASD?

8.1 No

8.2 Yes

9. What formal training have you had in supporting individuals with ASD?

10. What areas of learning need to be focused on for adolescents with Autism as opposed to mainstream adolescents? Do you feel there should be a different curriculum? Why?

11. What are your concerns or predicted areas of difficulty when an individual with ASD leaves the formal schooling system?

12. What are your comforts or predicted areas of strength when an individual with ASD leaves the formal schooling system?

13. Is there a team in place to work with the adolescent and plan for transition? Who is in the team? How are they involved? Does the team continue to work with the individual after leaving school?

14. Is there an age specific plan in place? At what age does planning for transition begin? Has the adolescent's wants and interests been taken into account? How?

15. What support systems are in place for the adolescent transitioning? What support systems are in place for the family of the transitioning adolescent? What supports exist for adults with ASD?

16. What are your thoughts on adolescents with ASD moving out of home? (is it probable? Would it be beneficial and why? What obstacles do you think would interfere?)

17. What are your thoughts on employment for adults with ASD? (is it a possibility? What kind of employment? To what extent will their employment support them financially?)

18. Do you think South Africa differs from other countries in terms of support received for transitioning an adolescent with ASD? How?

19. Can you explain some of your feelings regarding the transitioning process? (the current and future support as well as if the current skills being taught will benefit the adolescent into adulthood).

20. What would development in these skill areas mean for you and for the individual with ASD?

Appendix 7: Interview questions for professionals

1. Age: _____

2. Gender:

Male Female

3. Use of English language

3.1 First language English

3.2 Second language English

3.3 Limited use of English

4. What is your job title?

5. How many individuals with ASD do you currently work with?

5.1 0-5

5.2 5-10

5.3 more than 10

6. Have you worked with or come into contact with adults with ASD?

6.1 No

6.2 Yes

7. Do you consider ASD to be a mild, moderate or severe disorder?

7.1 Mild

7.2 Moderate

7.3 Severe

8. Do you consider yourself knowledgeable about ASD?

8.1 No

8.2 Yes

9. What formal training have you had in supporting individuals with ASD?

10. What areas of learning need to be focused on for adolescents with Autism as opposed to mainstream adolescents? Do you feel there should be a different curriculum? Why?

11. What are your concerns or predicted areas of difficulty when an individual with ASD leaves the formal schooling system?

12. What are your comforts or predicted areas of strength when an individual with ASD leaves the formal schooling system?

13. Is there a team in place to work with the adolescent and plan for transition? Who is in the team? How are they involved? Does the team continue to work with the individual after leaving school?

14. Is there an age specific plan in place? At what age does planning for transition begin? Has the adolescent's wants and interests been taken into account? How?

15. What support systems are in place for the adolescent transitioning? What support systems are in place for the family of the transitioning adolescent? What supports exist for adults with ASD?

16. What are your thoughts on adolescents with ASD moving out of home? (is it probable? Would it be beneficial and why? What obstacles do you think would interfere?)

17. What are your thoughts on employment for adults with ASD? (is it a possibility? What kind of employment? To what extent will their employment support them financially?)

18. Do you think South Africa differs from other countries in terms of support received for transitioning an adolescent with ASD? How?

19. Can you explain some of your feelings regarding the transitioning process? (the current and future support as well as if the current skills being taught will benefit the adolescent into adulthood).

20. What would development in these skill areas mean for you and for the individuals with ASD?