

**EMPLOYMENT IN DOWN SYNDROME:
THE EXPERIENCES OF INDIVIDUALS WITH DOWN SYNDROME, THEIR
EMPLOYERS AND FAMILIES IN KWAZULU-NATAL**

A RESEARCH REPORT PRESENTED TO
THE DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY
SCHOOL OF HEALTH SCIENCES

UNIVERSITY OF KWAZULU-NATAL

SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

MASTER OF COMMUNICATION PATHOLOGY
(SPEECH-LANGUAGE PATHOLOGY)

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NOVEMBER 2013

Declaration

As the candidate's Supervisor I agree/do not agree to the submission of this dissertation



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I, COURTNEY JAYNE TOD, declare that:

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30 November 2013

Courtney Jayne Tod

Date

This study is dedicated to all individuals with Down syndrome and especially those whose paths I crossed in conducting this research. Thank you for inspiring me and enriching the lives of so many of those around you. May your opportunities in employment and life continue to grow.

To quote a family member participant in this study
and mother of an individual with Down syndrome:

“They’ve got an extra chromosome, an extra chromosome in every cell of their body but I wonder if we just are missing something because maybe that should make them more brilliant!”

Acknowledgements

I would sincerely like to thank the following people who have made valuable contributions to this study and who have provided support throughout the research process:

- The University of KwaZulu-Natal for so generously assisting with funding for this research study
- The staff at the University of KwaZulu-Natal for all of the faxing, emailing and calling on my behalf
- Down Syndrome South Africa and especially Vanessa Dos Santos and Caroline Willis who helped me to locate participants and provided me with further contacts. Thank you for sharing the knowledge, respect and the love Down Syndrome South Africa has for those with Down syndrome
- Durban and Coastal Mental Health staff, especially Carmel Murugen who assisted me in finding participants and provided me with insight into the wonderful work that you do
- My translator, Zama Khuzwayo, my cross checker, Nokukhanya Maphanga, and my interpreter and dear friend Hlumela Silimela. Ngiyabonga kakhulu!
- My supervisors, Jenny Pahl and Saira Karrim, for your wisdom. I admire you both so much and am grateful that I had you to guide me through this journey.
- My parents and family for your support and motivation. Thank you for being proud of me and for your unconditional love.
- My husband, Matt, for allowing me to have my “research time” and reminding me to take a break. Thank you for having such faith in me and for loving me the way you do
- Most importantly:

All of my participants! Your contributions have made this research possible. Thank you for being so welcoming. I am forever grateful that you shared your stories with me. You have inspired me as a therapist and as a person.

Abstract

Employment is viewed as one of the pinnacle factors in enhancing quality of life. Despite being a right in South Africa, the employment opportunities available to individuals with Down syndrome are limited. This study aimed to explore the employment experiences of individuals with Down syndrome, their employers and their families in KwaZulu-Natal. This research provided valuable information for Speech-Language Therapists on enhancing communication in the workplace as effective communication in the workplace is crucial for employment. A qualitative approach and phenomenological design were used within the context of International Classification Framework, biopsychosocial model and critical paradigm. Individual semi-structured interviews were conducted and thematic analysis was used to analyse the data. Results revealed that individuals with Down syndrome valued their employment for the emotional and financial support it provided and the skill development opportunities available. Gaps were evident in legislation specific to the employment of individuals with Down syndrome as well as the implementation of these limited policies. Communication is necessary in the workplace; however, it is one of the areas that is severely impacted in individuals with Down syndrome. Employers and family members' experiences indicated variability in speech intelligibility, language and literacy skills among the participants with Down syndrome linked to cognitive ability, intervention, education received, mood swings and memory loss. Intriguing trends relating to the positive use of technological devices for social and recreational purposes were evident. Employment success can be linked to successful job selection, visual and emotional support. Speech-Language Therapists, employers, family members and the Down syndrome association were found to have crucial roles in providing this support. The role of the Speech-Language Therapist continues to evolve and is required across the lifespan for different purposes.

Keywords: Down syndrome, employment, Speech-Language Therapy, intellectual disability

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Introduction

This study aimed to explore the employment experiences of individuals with Down syndrome, their employers and their families in KwaZulu-Natal. This is necessary in order to guide Speech-Language Therapists on how to enhance the workplace communication skills of individuals with Down syndrome.

Communication whether verbal or nonverbal, spoken or written, is a necessary tool in the workplace to receive and pass on information, share ideas, learn new tasks and provide a message (Mallett-Hamer, 2005). Language problems in individuals with Down syndrome¹ are frequently more severe than would be predicted from cognitive level, and persist into adulthood (Kumin, 1996). Levels of reading and writing may not be sufficient for certain types of employment (Abbeduto, Warren, & Conners, 2007). Pragmatics and nonverbal skills are generally a relative area of strength for individuals with Down syndrome (Kumin, 1996; Mundy, Sigman, Kasari, & Yirmiya, 1988; Roberts, Price, & Malkin, 2007). Verbal communication is one of the areas that is severely impacted in individuals with Down syndrome (Buckley, 2000; Kumin, 1996). Individuals with Down syndrome may present with delayed or disordered speech and language skills which may impact their ability to communicate in the workplace. Speech problems, especially those reducing intelligibility often persist into adulthood (Kumin, 1994).

A person's ability to communicate influences their level of participation which ultimately impacts their quality of life, thus their daily ability to partake and communicate in workplace activity affects their social participation (Buntinx & Schalock, 2010; ICD10Data, 2012). There is much research into the barriers to participation and what can be done to address these barriers (Balandin, 2011). Adults with intellectual disability, which includes individuals with Down syndrome, often present with communication difficulties which may impact how they communicate in the workplace (Trembath, Balandin, Stancliffe, & Togher,

¹ The terms Down syndrome, Down Syndrome, Downs syndrome and Down's syndrome are all used in literature to refer to the same congenital disorder. The researcher has chosen to use the term Down syndrome as this was used frequently in the readings sourced for this research study.

2010). Personal and employment opportunities allow for a person with Down syndrome's communication skills to develop (Kumin, 1994). Employment can be defined as a person being involved in activity for a set period of time (Hassmanns, Mehran, & Varmā, 1990). However, the level of communication and understanding of an individual with Down syndrome may prevent people from hiring him/ her even though each individual with Down syndrome has a right to employment. Although there is no set figure the employment rate of individuals with Down syndrome is described as low (Jans, Kaye, & Jones, 2011). Vocational training, Speech-Language Therapy, adequate job placement and adaptations in the workplace have been suggested as helpful in enhancing the ability of the individual with Down syndrome to communicate effectively in their workplace (Battaglia & McDonald, 2010; Down's Syndrome Association, 2012; Murray & Heron, 1999).

Framework

The International Classification of Functioning, Disability and Health (ICF) designed by the World Health Organization (2001) was used as a framework through which the researcher viewed this research. The ICF views the impact that the body structure and functioning has on an individual's ability to partake in an activity and how this further impacts participation in society (Buntinx & Schalock, 2010; World Health Organisation, 2001). In the present study the impact of Down syndrome and the related cognitive and communicative difficulties on an individual's employment and participation in the workplace were explored. The ICF also seeks to view an individual's functioning within a context along with the environmental factors that impact that context (World Health Organisation, 2001). This was an ideal framework through which to view the individual with Down syndrome in this study as the work context was explored and the factors of social interaction and communication were investigated in greater detail. The ICF seeks to view the individual as an individual with a disability and not as a disabled individual (Buntinx & Schalock, 2010; World Health Organisation, 2001). The researcher wished to view individuals with Down syndrome in this manner and for prospective employers that review this study to see the individual through this lens. This perspective is also shared by the social model of disability where the focus shifts from the individuals and their disability to the barriers in society that prevent the individual from functioning optimally (The United Nations Children's Fund: Innocenti Research Centre, 2007). The social model emphasizes equality and decreasing environmental barriers such as people's attitudes, poor accessibility to infrastructure and the

necessary policies required to bring about change in education, health care and employment (The United Nations Children's Fund: Innocenti Research Centre, 2007). This is in keeping with the changing view of disability in South Africa (McKenzie, 2012).

The biopsychosocial model is another framework through which to view an individual and their interaction with the world (Borrell-Carrió, Suchman, & Epstein, 2004). This model takes into account the differences in biological, psychological and social interaction and how these interact and impact an individual's understanding of themselves, their disorder/disability and the intervention they require (Engel, 1980). It is a model that governs clinical practice and care by understanding how a disease, disorder or impairment impacts an individual (Borrell-Carrió, et al., 2004). What is unique about this model is that it recognizes the role of the individual's subjective experiences on their diagnosis, outlook to life and attitude towards intervention (Borrell-Carrió, et al., 2004; Engel, 1980). In this way the individual's employment experiences add to their vision and understanding of themselves and their role in society. The biopsychosocial model promotes self-advocacy and education (Borrell-Carrió, et al., 2004; Engel, 1980). This research study seeks to explore the biopsychosocial experiences of individuals with Down syndrome in relation to employment and what effect employment has on the individuals' perceptions of themselves, communication and social skills.

A critical paradigm was also applied as it seeks to both understand the social world as well as to encourage change (Blaxter, Hughes, & Tight, 2001). The researcher wanted to understand and highlight the strengths and difficulties of the individual with Down syndrome in the workplace in order to bring about a change in society's views towards the employment of individuals with Down syndrome. The study also sought to understand the employment of individuals with Down syndrome in the South African context.

Rationale

It is crucial to find out about a specific population by gaining access to them and by seeing their perspective (Preece & Jordan, 2009). Few studies on individuals with any form of an intellectual disability involve the individuals as either researchers or participants (Turk et al., 2011). Individuals with an intellectual disability can be included as participants in research if the appropriate methodology and resources are utilized and team work is

employed (Turk, et al., 2011). Further research is required to understand the support and services required by the individual with intellectual disability across the lifespan (Chadwick et al., 2013).

The majority of studies involving Down syndrome have focused on the infant with Down syndrome or childhood development (Abbeduto et al., 2004; Adams, 1998). Adults with any form of barrier to learning are often excluded from research due to communication difficulties (Brewster, 2004). Little research has been done to enquire about adults with Down syndrome especially with regard to employment and independent living (Adams, 1998; Down syndrome Federation India, 2013). Society has become more proactive in supporting people with any form of barrier to learning in becoming more independent and productive (Bond & Hurst, 2009; Ware, 2004). Therefore, there exists a need to identify and describe the adjustments to adulthood (Adams, 1998). As employment may form part of an individual becoming more independent it is vital to explore the experiences of those individuals that have been employed in order to understand what effect employment has had in their lives and how they have functioned in the workplace. Communication is crucial in the workplace and communication is an area of difficulty for individuals with Down syndrome. Speech-Language Therapists are the professionals that are trained to assist individuals with any form of difficulty communicating or to enhance the communicative abilities of the individual, yet adults with Down syndrome often do not receive therapy (Kumin, 1994). Communication is delayed or disordered in individuals with Down syndrome, thus therapy is warranted in the majority of cases (Buckley, 2000; Kumin, 1996). This research therefore provides valuable information for Speech-Language Therapists on enhancing communication in the workplace.

Reviewing the services a population receives is vital in improving services and considering the individual's experiences of everyday life indicates the support these services provide (Preece & Jordan, 2009). These services are viewed as a necessity in legislation in some countries such as the United Kingdom (Preece & Jordan, 2009). This is not the same in legislation for individuals with Down syndrome in South Africa. Literature notes that it is imperative for therapists to have an understanding of how the disability impacts an individual's quality of life (Buntinx & Schalock, 2010). This research study therefore highlights the communicative constraints of Down syndrome on an individual's ability to function effectively in the workplace and what was done to overcome this.

Minimal research on individuals with any form of barrier to learning and his/her employment relationships, dynamics and practices is recorded (Manthorpe, Moriarty, & Cornes, 2011). Furthermore, many of the studies done have viewed employment or adulthood from the perspective of the parent of the individual with Down syndrome and few studies have delved into the experiences from the individual's perspective. There is a growing body of literature on disability and intellectual disability from the viewpoint of the individual to gain a fuller understanding of disability (Preece & Jordan, 2009). Individuals who are successfully employed should be viewed as valuable resources in sharing experiences to assist other individuals who may be seeking a job or experiencing difficulty in the workplace (Jans, et al., 2011).

Research related to Down syndrome in general pertains to the United States of America and various countries in the European Union (Abbeduto, et al., 2004; Adams, 1998). Research related specifically to South Africa is limited. In order to improve the employment opportunities for citizens with disabilities, one first needs to review the cases and current outcomes of those employed (Adams, 1998). This research was therefore necessary for improving service delivery and employment opportunities for individuals with Down syndrome in KwaZulu-Natal.

Outline of Chapters

Chapter one is entitled “An Introduction to Down syndrome” and defines Down syndrome and reviews the cause, prevalence and associated characteristics. The variety of medical, cognitive, speech, language and literacy characteristics associated with Down syndrome are discussed. Education and the transition from school to employment are reviewed.

Chapter two evaluates employment for the individual with Down syndrome in South Africa with regard to rights, employment rate and the experiences of employment. Communication in the workplace, workplace accommodations, forms of support and the benefits for each of the individuals involved are reviewed both locally and internationally.

Chapter three outlines the methodology of the study. The aims and objectives, participants, procedure for data collection and analysis are discussed. The ethical considerations are also reviewed.

Chapter four is the results section of the study where the data has been analysed and grouped into themes and subthemes. The results were described qualitatively and compared to literature.

Chapter five provides the conclusions deduced from this study and highlights the limitations of the study. Suggestions for future research studies and implications for clinical practice are provided.

Chapter One: An Introduction to Down syndrome

This chapter introduces Down syndrome through various definitions with a specific focus on the life of an adult with Down syndrome. The communicative strengths and weaknesses associated with Down syndrome are discussed in relation to the impact on employment. Other education based skills that contribute to employment and employability are reviewed. The remainder of this chapter follows a chronological timeline beginning with the role of schooling and the transition from school to adult life.

1. Definition of Down syndrome

1.1. Medical Definition

The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) is used in the diagnosis of intellectual disability and related disorders. Version IV of the DSM classifies Down syndrome as a cognitive disorder with a variety of physical features (PsychNet-UK, 2013). Although a later version of the DSM is available, no changes have been made to the Down syndrome classification (American Psychiatric Association, 2012).

Down syndrome is a congenital disorder that is caused by an abnormality of the 21st chromosome (Hayes & Batshaw, 1993; Layton, 2000). There are three categories of Down syndrome namely Trisomy 21, translocation and mosaicism (Layton, 2000; National Down Syndrome Congress, n.d.). Individuals with Trisomy 21 Down syndrome have an extra 21st chromosome in each cell of the body (National Down Syndrome Congress, n.d.). In the case of translocation Down syndrome, individuals have an additional 21st chromosome attached to another chromosome in each cell (National Down Syndrome Congress, n.d.). The third type of Down syndrome, mosaic, is least common and occurs due to an additional 21st in only some of the cells of the body (National Down Syndrome Congress, n.d.). Although the male to female ratio is dependent on the type of Down syndrome, overall Down syndrome is more prevalent in males (Kovaleva, 2002).

The cause of any of the types of Down syndrome is unknown, however, there is a link between the mother's age when pregnant and an increased likelihood of having a child with Down syndrome (Cunningham, 1996; National Down Syndrome Congress, n.d.). It is well documented that Down syndrome occurs across all racial groups and socio-economic backgrounds (Cunningham, 1996; National Down Syndrome Congress, n.d.).

1.2. Prevalence

International statistics indicate that one in every 800 to 1000 children born in the United States of America is born with Down syndrome (National Down Syndrome Congress, n.d.). An exact statistic for South Africa is not available, however, literature suggests that in developing countries, such as South Africa, one in every 650 children is born with Down syndrome (Down Syndrome South Africa, 2011a). With such a significant number of individuals with disabilities, it is necessary for each country to have guidelines, policies and opportunities for individuals with disabilities to function optimally in society (The United Nations Children's Fund: Innocenti Research Centre, 2007). Some examples of such policies include international standards such as the 1989 Convention on the Rights of the Child, Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights and further policies specific to people with disabilities such as the Declaration on the Rights of Mentally Retarded, the Declaration on the Rights of Disabled Persons and the UN Convention on the Rights of Persons with Disabilities (The United Nations Children's Fund: Innocenti Research Centre, 2007).

1.3. Cognition

Cognition, communication, motor development and behaviour may be delayed due to the presence of Down syndrome (Cunningham, 1996; Hayes & Batshaw, 1993; National Down Syndrome Congress, n.d.). A communication deficit is particularly evident as the language abilities of an individual with Down syndrome are considerably below the expectations for his/her mental age while other areas of development may not exhibit such a lag in development (Long, 2005). The most common characteristic of Down syndrome is an impairment in cognition, which may range from mild to profound, and causes a global developmental delay (Layton, 2000). A mild intellectual disability classifies an individual

with an Intelligence Quotient (IQ) of between 50 and 70 while a moderate impairment ranges between 35 and 50 (Bosch, 2003). The intellectual disability is an integral part of a definition of Down syndrome; however, it should not define an individual and his/her opportunities for learning (Bosch, 2003). The mental age of an individual with Down syndrome is said to go through growth spurts and plateaus at three stages namely when the individual is chronologically four to six years, eight to 11 years and 12 to 17 years of age (Gibson, 1978). There are various factors that stimulate cognitive development (National Down Syndrome Congress, n.d.). According to the American Association of Mental Retardation (AAMR), Down syndrome is also classified by the level of support required namely intermittent (support is not always needed), limited (support required consistently), extensive (daily support that is needed in some environments) and pervasive (daily support required across environments) (American Psychiatric Association, 2000). There is no typical level of support required by adults with Down syndrome as some individuals are employed while others are not; some individuals live independently while others require more support from family members (Down syndrome Federation India, 2013).

1.4. Physical Characteristics

Physically, a short stature, skin folds over the eyes, brush field spots on the iris, small ears, a protruding tongue, brachycephaly and broad hands are associated with a diagnosis of Down syndrome (ICD10Data, 2012). Other characteristics include oblique palpebral fissures, a flat nasal bridge, ear abnormalities, a single palmar crease and a gap between the big and second toes (Bosch, 2003). Low muscle tone (hypotonia) and hyperflexibility of joints throughout the body is a common characteristic and this affects the precision of movement and articulation (Bosch, 2003; Kumin, 1996).

1.5. Mental Health and Health

What is perhaps considered to be most significant when comparing the child with Down syndrome to the adult with Down syndrome are the aspects of emotional well being and mental health (Brown, 2004). There is a prevalence of depression in approximately 6 to 13% of individuals with Down syndrome (Bosch, 2003). Individuals with specific disorders such as Down syndrome may be at an increased risk for mental health conditions such as depression (Mental Health Special Interest Research Group of the International Association

for the Scientific Study of Intellectual Disabilities to the World Health Organisation, 2001). Obsessive Compulsive Disorder (OCD) is also evident in the Down syndrome population (Bosch, 2003). Dementia, Alzheimer's and memory loss are associated with adults with Down syndrome (Bosch, 2003). Self-talk, regardless of age or a diagnosis of Dementia, is used with approximately 81% of individuals with Down syndrome and should not be confused with Dementia, memory loss or diagnosis of psychosis (Bosch, 2003). Deterioration in the intelligibility of speech is also characteristic of Dementia and may therefore impact some individuals with Down syndrome as they age (Evenhuis, 1990).

Health concerns that are associated with Down syndrome include cardiovascular abnormalities, diabetes, vision difficulties, hearing impairments, seizures, thyroid disease, sleep apnea and gastrointestinal difficulties (Bosch, 2003; Smith, 2001). The various elements of the adult with Down syndrome's life, such as health, recreation and employment, are considered to be interrelated with health being the central link that impacts on other areas (Brown, 2004; Rondal, Rasore-Quartino, & Soresi, 2004).

1.6. Social Characteristics

Independence and communicative abilities impact an individual's ability to socialize and build relationships (Buckley, Bird, & Sacks, 2002). Good social skills impact an individual's employability which further impacts their overall subjective wellbeing (Cummins & Lauy, 2003). Most individuals with Down syndrome are socially appropriate; however there are a percentage of individuals who are classified as being socially difficult and having developed manipulative behaviours due to a good understanding of social relationships (Buckley, Bird, & Sacks, 2002). These individuals are often described as "naughty" or "manipulative" (Buckley, Bird, & Sacks, 2002). This may be further enhanced by the severity of the intellectual disability (Buckley, Bird, & Sacks, 2002). There are also a portion of people with intellectual disabilities that find social integration very difficult (Cummins & Lauy, 2003). A goal for working with individuals with intellectual disability should be to achieve community connectedness as opposed to integration into the community at large (Cummins & Lauy, 2003).

The development of social skills is dependent on the individual with Down syndrome's family upbringing as well as their personality and temperament (Buckley, Bird, & Sacks, 2002). There are therefore individuals with Down syndrome that are moody, just as there are individuals without Down syndrome that are moody. Parents of individuals with Down syndrome are considered to have an "advantage" over parents of individuals with other intellectual disorders as individuals with Down syndrome are said to be less stressful to raise (Esbensen & Mailick Seltzer, 2011). Parents of individuals with Down syndrome are therefore said to present with a better psychosocial well-being (Esbensen & Mailick Seltzer, 2011).

2. Speech Abilities of an Individual with Down syndrome

The intelligibility of speech of individuals with Down syndrome is affected by the physical factors specific to Down syndrome discussed under the definition of Down syndrome. Speech is further impacted by secondary factors such as whether therapy was received (Buckley & Le Prévost, 2002) and if appropriate education was provided. These secondary factors and activities ultimately implicate the individual's level of inclusion in society. This shows clear correlation with the ICF where there is a link between the structure and functioning of the body, how this affects the individual's level of activity which then further impacts his/her participation in society (World Health Organisation, 2001). Below is a description of the areas of the speech mechanism and speech production and how these may be impacted if there is a diagnosis of Down syndrome:

2.1. The Structure and Function of the Oral Mechanism

With regard to structural variations, individuals with Down syndrome may present with atypical articulators such as enlarged adenoids, a small oral cavity, a narrow or high arched palate, a large tongue in relation to the size of the mouth or dental deviations (Kumin, 1996; Roberts, et al., 2007; Stoel-Gammon, 2001). The structural differences and the size of the tongue may affect the lingual sounds in speech (Stoel-Gammon, 2001). Functional variations may include muscular abnormalities and low tone throughout the body including the oral musculature (Kumin, 1996; Roberts, et al., 2007; Stoel-Gammon, 2001). Low muscle tone affects all aspects of speech production (Stoel-Gammon, 2001). Low muscle tone of the facial and labial muscles affects the precision of bilabial consonants and rounded

vowels (Stoel-Gammon, 2001). The rate of speech is affected as individuals with Down syndrome experience difficulty making rapid alternating speech movements (Rosin, Swift, Bless, & Kluppel Vetter, 1988).

2.2. Intelligibility

Intelligibility is an area of great concern with individuals with Down syndrome and problems generally persist throughout the life span (Kent & Vorperiana, 2013). It is also hypothesized that anatomical differences in the structure of the brain such as a reduced brain size and fewer sulci may also have an effect on intelligibility (Stoel-Gammon, 2001). Intelligibility of speech throughout the lifespan has been recorded as an area of concern (Kumin, 1994). The speech of individuals with Down syndrome is more intelligible with those that regularly spend time with the individual than with unfamiliar people (Kumin, 1994). Factors such as articulation, phonology, resonance, dysfluency, prosody and vocal quality may contribute to the individual's level of intelligibility (Kent & Vorperiana, 2013).

2.3. Speech Sound System

Errors in both articulation and phonology may be evident in the speech sound system development of an individual with Down syndrome (Layton, 2000; Roberts, et al., 2007). The speech of individuals with Down syndrome is less intelligible than individuals with other forms of intellectual disability (Dodd & Thompson, 2001). This may in part be due to a co-occurring hearing loss often due to otitis media. It is agreed by some authors that this would be an explanation behind articulation errors in the speech development of children with Down syndrome (Kent & Vorperiana, 2013). Other authors suggest that articulation errors are due to an impaired sequencing of fine motor movements and a central deficit in speech-motor control (Layton, 2000).

Structural differences affect the production of many speech sounds. Studies vary on the list of phonemes that are identified as articulation errors in the Down syndrome population (Kent & Vorperiana, 2013). Many studies indicate that articulation errors are more frequently observed in the adult Down syndrome population than the general population (Kent & Vorperiana, 2013). Of particular concern are the sibilant sounds namely the phoneme /s/ which will result in a lisp (Gibson, 1978; So & Dodd, 1994) and the lingual consonants (Stoel-Gammon, 2001).

The type of speech errors evident include incorrect articulation of consonants and phonological processes which are similar to those with the same cognitive age; however these processes are eliminated at a slower rate (Layton, 2000; Roberts, et al., 2007). The phonological processes evident in children with Down syndrome are a combination of delayed phonological development and atypical errors (Kent & Vorperiana, 2013). The pattern of phonological errors is comparable to the patterns observed in younger children (Shriberg & Widder, 1990). Individuals with an intellectual disability are likely to make speech sound errors as part of developing speech and these may persist into adulthood (Bunton, Leddy, & Miller., 2009; Shriberg & Widder, 1990). Inconsistency is also noted in speech productions (Kent & Vorperiana, 2013; Layton, 2000; Shriberg & Widder, 1990; So & Dodd, 1994). Such inconsistency may be viewed as characteristic of phonological disorders in those with Down syndrome (Martin, Klusek, Estigarribia, & Roberts, 2009). Individuals with Down syndrome may present with atypical substitutions such as vowel substitutions and omissions such as initial consonant deletion (Bunton, et al., 2009; Layton, 2000; So & Dodd, 1994). Some literature suggests that the omission of consonants is the most frequent error (Shriberg & Widder, 1990).

2.4. Resonance

Nasality has been described in some studies concerned with the speech of individuals with Down syndrome; however further investigation is required (Kent & Vorperiana, 2013). Nasality may implicate the harsh vocal qualities associated with Down syndrome (Kent & Vorperiana, 2013). Some studies offer abnormalities in the sinuses and nasal cavities as the cause behind a perceived nasality in the speech of individuals with Down syndrome (Kent & Vorperiana, 2013).

2.5. Dysfluency

Stuttering is another speech difficulty that may be associated with Down syndrome (Bunton, et al., 2009; Kumin, 1996; Roberts, et al., 2007). Stuttering and cluttering may occur in approximately 10-45% of the Down syndrome population which is considerably high when compared to the occurrence of 1% of those without Down syndrome (Kent & Vorperiana, 2013).

2.6. Prosody

Prosody may be atypical in the speech of individuals with Down syndrome (Kent & Vorperiana, 2013). This may be due to motor difficulties, profound articulation errors and difficulty controlling speech errors (Kent & Vorperiana, 2013). The rate of speech has been much debated in literature with some studies showing decreased Diadochokinesis rates and others indicating a rapid rate of speech as being associated with Down syndrome (Kent & Vorperiana, 2013).

2.7. Vocal Quality

There are many studies that highlight vocal abnormalities linked to a diagnosis of Down syndrome; however, few studies report on the nature and incidence of such disorders (Kent & Vorperiana, 2013). Individuals with Down syndrome are often described as having a hoarse or harsh vocal quality and being breathy or low-pitched (Bosch, 2003; Kent & Vorperiana, 2013; Layton, 2000; Patton, 2002). This may be due to a range of physiological factors such as a short neck, a high palate, obstructed nasal passages, deviated facial bones, a high larynx, a large tongue in relation to the size of the mouth, muscle hypotonia or a thickened laryngeal mucosa (Layton, 2000). Vocal quality and resonance may further contribute to reduced intelligibility levels (Bunton, et al., 2009; Kumin, 1994).

2.8. Childhood Apraxia of Speech

The research indicating an impairment in motor control and motor planning as the cause of articulation errors in the speech of individuals with Down syndrome has lead some researchers to investigate a co-occurring diagnosis of childhood apraxia of speech (CAS) (Kent & Vorperiana, 2013). Such a diagnosis is difficult as CAS is a complicated diagnosis when it occurs independently and is further complicated when it is co-morbid with the other speech and language difficulties associated with Down syndrome (Kent & Vorperiana, 2013). The three central characteristics of CAS include inconsistent errors, impaired transitions between sounds and syllables and atypical prosody (Kent & Vorperiana, 2013). These three characteristics may be evident in the speech of an individual with Down syndrome; however they may be accounted for by characteristics of Down syndrome such as abnormal muscle tone and dysfluency (Kent & Vorperiana, 2013). Differential diagnosis is therefore required (Kent & Vorperiana, 2013).

3. Language Abilities of an Individual with Down syndrome

There are various studies reporting mixed findings regarding the development of communication skills of individuals with Down syndrome from childhood to adulthood (Roberts, et al., 2007). Communication delays or disorders may be attributed to the intellectual disability associated with Down syndrome or to a hearing loss, during the developmental period affecting language acquisition, as hearing loss commonly occurs in individuals with Down syndrome due to disorders of the Eustachian tube (Abbeduto, et al., 2007; Kumin, 1996; Roberts, et al., 2007). Intellectual disability can range from mild to profound; however, all individuals with Down syndrome present with a gap in language skills (Partin Vinson, 2012). A language deficit manifests even before spoken language begins as an individual with Down syndrome will make fewer nonverbal requests (Long, 2005). Language, both receptive and expressive, and pragmatics may be affected and severity of the delay or disorder varies from individual to individual (Kumin, 1996). Ineffective communication may prevent the individual from participating in everyday activities which will affect his/her ability to participate in society at large (Mpofu & Oakland, 2010).

3.1. Receptive Language

Receptive language skills are more advanced than expressive abilities in individuals with Down syndrome (Kumin, 1996; Layton, 2000). These skills may be described as being delayed, however, in some individuals receptive language may not be impaired according to the cognitive age (Long, 2005). The level of receptive language may be accounted for in the difference between an individual's chronological age and mental age (Chapman, Schwartz, & Kay-Raining Bird, 1991). There has also been some suggestion that auditory processing may be linked to Down syndrome in that information is not processed as quickly as it enters the auditory system with specific difficulties with auditory memory and sequential processing (Chapman, et al., 1991).

3.2. Expressive Language

Adults with Down syndrome develop language skills according to the vocational and personal experiences they encounter (Kumin, 1996). Verbal expression develops in the same way in individuals with Down syndrome just as in individuals without a diagnosis of Down syndrome, however, stages of development last longer in individuals with Down syndrome due to the cognitive delay (Roberts, et al., 2007). The pre-linguistic stage of communication, when individuals communicate through gesture, vocalization and facial expression, which usually occurs between the ages of 12 to 18 months in typically developing children, may last much longer in individuals with Down syndrome (Roberts, et al., 2007; Stoel-Gammon, 2001). This stage may even be lifelong in some severe cases (Roberts, et al., 2007). Research has found the use of gesture to be a particular strength of individuals with Down syndrome, however, the use of gesture may differ in communicative function (Roberts, et al., 2007). Research has indicated that gesture may be used less frequently to request in those with Down syndrome (Kumin, 1996; Roberts, et al., 2007).

3.3. Semantics and Vocabulary

Individuals with an intellectual disability such as Down syndrome have a smaller receptive vocabulary, compared to a child of the same mental age (Long, 2005). With regard to reception at word level, individuals with Down syndrome require more exposure to a new word in order to understand and learn it (Abbeduto, et al., 2007). This may also be affected

by a limited memory span for auditory information (Abbeduto, et al., 2007). Receptive vocabulary does, however, increase as an individual with Down syndrome develops through adolescence and adulthood (Abbeduto, et al., 2007).

On average the first word is generally spoken around 18 months (Partin Vinson, 2012). The onset of the first word is generally delayed in individuals with Down syndrome (Abbeduto, et al., 2007; Roberts, et al., 2007). Expressive vocabulary continues to develop throughout childhood and development is noted as being slow (Abbeduto, et al., 2007; Roberts, et al., 2007). Individuals with Down syndrome do not reach a plateau in vocabulary development during adolescence and adulthood (Abbeduto, et al., 2007; Kumin, 1996; Roberts, et al., 2007). As vocabulary continues to develop, it may become an area of strength for adolescents and adults with Down syndrome depending on exposure and life experience (Roberts, et al., 2007). Typically children with Down syndrome have a smaller vocabulary when compared to peers with the same chronological age but a larger vocabulary when compared to peers with the same cognitive age due to life experience (Partin Vinson, 2012). Employment may provide life experience for the individual with Down syndrome and may therefore assist in developing vocabulary development.

3.4. Syntax and Morphology

Receptive syntax is a significant area of difficulty and becomes weaker as the length of utterance increases (Rosin, et al., 1988). Individuals with Down syndrome have been described as having a similar syntactic development to individuals presenting with a specific language impairment as his/her syntactic comprehension is worse than his/her receptive vocabulary and this gap widens with age (Long, 2005).

Within syntax, morphology is an area of particular difficulty for individuals with Down syndrome (Lázaro, Garayzábal, & Moraleda, 2013; Roberts, et al., 2007). Morphology develops throughout the childhood and adolescent years; however it continues to be an area of relative weakness (Roberts, et al., 2007; Rondal & Comblain, 1996). In English, children with Down syndrome do not frequently use auxiliaries and copulas (Roberts, et al., 2007). Markers indicating tense and third person singular are also challenging (Adams, 1998; Roberts, et al., 2007). There is therefore some overlap with the morphological difficulties evident in an individual with a diagnosis of Specific Language Impairment (Bishop, 1994).

Language production and syntactical difficulties are particular areas of deficit in the expressive language abilities of an individual with Down syndrome (Abbeduto, et al., 2007; Roberts, et al., 2007). A decreased length of utterance is a significant difficulty in expressive form (Kumin, 1996; Rosin, et al., 1988). The typical mean length of utterance of children with Down syndrome is 1.5 words at four years, 3.5 words at six years and five or more at 15 years of age which is well below the normative values for individuals who are not cognitively impaired (Partin Vinson, 2012). Complex sentence forms are an area of difficulty (Adams, 1998). Syntactical abilities are more advanced in narratives as opposed to conversation (Roberts, et al., 2007). Syntax continues to develop by increasing in mean length of utterance and complexity of sentences until at least 20 years of age (Roberts, et al., 2007). An individual with Down syndrome may be employed during this time thus employment may have an impact on the expansion of syntactical skills. Overall, poor syntactical skills are evident in most adults with Down syndrome (Rondal & Comblain, 1996).

The delay in expressive syntactical development further supports a form of specific language impairment in individuals with Down syndrome (Long, 2005). Literature suggests that the failure to use syntactic devices effectively results from the individual not being able to mentally represent ideas (Long, 2005). Further difficulty arises in constructing a sentence that conveys the intended meaning (Abbeduto, et al., 2007).

3.5. Pragmatics

Social pragmatic skills are a precursor to language acquisition and development (Martin, et al., 2009). Pragmatics and nonverbal skills are generally a relative area of strength for individuals with Down syndrome (Kumin, 1996; Mundy, et al., 1988; Roberts, et al., 2007). Nonverbal language is more advanced than verbal language skills in individuals with Down syndrome (Buckley, 2000). These skills are crucial for team work and interpersonal relations in the workplace (Darling & Dannels, 2003). These pragmatics skills may deteriorate over time should the individual with Down syndrome develop Alzheimer's or Dementia, which is often associated with adults with Down syndrome (Nelson, Orme, Osann, & Lott, 2001).

Individuals with Down syndrome are able to use communication effectively in that they use communication to fulfil the same functions as typically developing individuals (Roberts, et al., 2007). They use communication to answer, comment and protest (Beeghly, Weiss-Perry, & Cicchetti, 1990). Fewer requests have been observed in some studies (Beeghly, et al., 1990; Roberts, et al., 2007). Individuals with Down syndrome are also less likely to initiate a new topic (Martin, et al., 2009; Roberts, et al., 2007). They can often turn take effectively in conversation and maintain the conversation over a number of exchanges (Roberts, et al., 2007). Conversational difficulties and break down occur because of poor understanding of what the listener has comprehended and adjusting expressive language according to the listener's needs (Abbeduto, et al., 2007; Roberts, et al., 2007). Individuals with Down syndrome may also experience much difficulty in indicating that they do not understand (Martin, et al., 2009). They therefore signal less frequently that they have not understood (Abbeduto et al., 2008). This is linked with poor receptive vocabulary and syntactic skills as individuals with Down syndrome may be able to select the referent but experience difficulty putting into words a signal to request for clarification (Abbeduto, et al., 2008). Conversational repair is therefore more likely if the listener identifies the conversational breakdown and requests clarification (Abbeduto, et al., 2008; Roberts, et al., 2007). Narrative skills are adequate especially if a visual referent is provided (Roberts, et al., 2007). Content in the narrative is appropriate to the mental age of the individual with Down syndrome but the linguistic structure generally is not (Long, 2005; Martin, et al., 2009).

Differences in social language have been noted in individuals with Down syndrome (Adams, 1998). This view may stem from society viewing individuals with Down syndrome as being highly sociable (Adams, 1998). Pragmatics may be severely affected if a co-occurring diagnosis of Autism Spectrum Disorder occurs as pragmatics is adversely affected in individuals with any form of Autism (Bosch, 2003). Approximately 7% of individuals with Down syndrome also present with Autism Spectrum Disorder (Bosch, 2003; Martin, et al., 2009).

If an individual experiences difficulties with elements of their language skills supportive or augmentative methods may be required to support the individual's communication skills (Roberts, et al., 2007). In more severe cases, alternative methods of communication may be required (Roberts, et al., 2007).

4. Augmentative and Alternative Communication

Individuals with Down syndrome who have severe communication difficulties may be candidates for Augmentative and Alternative Communication (AAC) to replace or supplement verbal communication (Roberts, et al., 2007). AAC has been found to be successful when used with a number of populations with cognitive and communicative impairment (Bornman, 2011). AAC may be considered for some individuals with Down syndrome to assist and develop speech and language abilities (Roberts, et al., 2007). It may be used as the main method of communication or it may be used on a short term basis to supplement verbal communication (Roberts, et al., 2007). Suggested unaided systems include gestures and signing while suggested aided systems include Bliss symbols and Picture Communication Symbols as part of a communication board or combined with a voice output communication aid (Roberts, et al., 2007).

5. Literacy

The literacy skills of an individual with Down syndrome vary depending on their cognitive and communicative skills (Abbeduto, et al., 2007; Boudreau, 2002; The Centre for Developmental Disability Health Victoria, 2008). Those educated in mainstream schools obtain higher levels of literacy when compared to individuals educated in special education (Buckley, 2001). Additional support is required to encourage the development of reading and writing in individuals with Down syndrome in order to overcome spoken language and memory difficulties (Buckley, 2000). Reading and writing may impact on the individual with Down syndrome's overall quality of life by encouraging independence and enhancing employability (Miller, Leddy, & Leavitt, 1999). Literacy skills therefore directly impact an individual with Down syndrome's level of activity and participation.

5.1. Reading

Many but not all individuals with Down syndrome acquire the skill to read (Kay-Raining Bird, Cleave, & McConnell, 2000). Studies from the United Kingdom and Australia indicate that 60-70% of individuals with Down syndrome attain a functional level of reading by adulthood (Buckley, 2001). Cognition and verbal language are good indicators of an individual with Down syndrome's ability to develop reading, with language being the

stronger predictor of the two (Boudreau, 2002). Individuals with Down syndrome will not be able to read until their cognitive and linguistic age reaches that of a six year old, however, many with Down syndrome do not reach this level (Layton, 2000). There are mixed opinions on whether reading skills are in line with cognitive ability or not (Martin, et al., 2009).

There is much variability in the early literacy abilities and reading performance of those with Down syndrome (Boudreau, 2002). Although many individuals with Down syndrome acquire the ability to read, many do not develop strong underlying phonological awareness skills (Baylis & Snowling, 2012). Since phonological awareness skills are poor, it is believed that individuals with Down syndrome predominantly learn to read through visual recognition (Baylis & Snowling, 2012; Fowler, Doherty, & Boynton, 1995). Letter-sound correlation and the acquisition of phoneme awareness are crucial in the development of reading in any individual yet these are relative areas of weakness in individuals with Down syndrome (Baylis & Snowling, 2012; Martin, et al., 2009). This may be due to the methods of teaching used to educate individuals with Down syndrome as many were taught using a whole word approach so that functional reading skills were obtained (Baylis & Snowling, 2012). Rhyme is suggested as being one of the most difficult concepts of phonological awareness for individuals with Down syndrome to acquire (Baylis & Snowling, 2012).

Many of what we know about individuals with Down syndrome and reading development comes from studies conducted with English participants (Baylis & Snowling, 2012). Reading in English depends on an understanding of the alphabet thus an individual requires a good understanding of letter-sound correlations or alternatively a whole word approach must be used (Baylis & Snowling, 2012). In a study conducted with children with Down syndrome who speak Oriya, an alpha syllabic language used in India, as their mother tongue, it was identified that phonological awareness skills had less of an influence on reading skills and that the children demonstrated more knowledge of syllables than of phonemes (Mishra, 2007).

Reading comprehension and being able to extract information from a passage is dependent on lexical and syntactic skills (Martin, et al., 2009). Receptive and expressive language abilities are expected to extend to literacy skills (Kay-Raining Bird, et al., 2000). Both of these aspects may be impaired in individuals with Down syndrome therefore impacting reading comprehension and their ability to inference (Kay-Raining Bird, et al.,

2000). Receptive language namely receptive vocabulary impacts the development of decoding and identification skills (Kay-Raining Bird, et al., 2000).

Many young and adolescent individuals with Down syndrome develop the ability to read but the level of competency differs (Boudreau, 2002). Reading may develop to be a considerable strength for individuals with Down syndrome (Baylis & Snowling, 2012). Learning to read will have positive effects on the language and memory skills of the individual with Down syndrome and advance his/her speech, language and educational abilities (Kay-Raining Bird, et al., 2000; Partin Vinson, 2012). This in turn may provide more opportunities for job tasks and employment (Martin, et al., 2009).

5.2. Written language

Many individuals with Down syndrome will develop functional writing skills by adulthood (Buckley, 2001). The areas of writing namely spelling, vocabulary and grammar are all affected by the poor phonological skills and delayed communicative development associated with an intellectual disability and Down syndrome (Byrne, Buckley, MacDonald, & Bird, 1995). Better access to education and quality of language intervention have improved reading abilities of adults with Down syndrome (Fowler, et al., 1995). Literacy abilities, even if minimal, expand the employment opportunities available for an individual with Down syndrome (Boudreau, 2002; Layton, 2000). The development of literacy skills also impacts further development of language and communication (Boudreau, 2002). Individuals with Down syndrome may develop the ability to express written language on the computer (Feng, Lazar, Kumin, & Ozok, 2008).

6. Technological Skills

Technology such as computers, tablets, telephones and cell phones have a role in the lives of individuals with Down syndrome just as they do in the rest of the population. Computers and technological devices have the ability to assist individuals with Down syndrome in developing their career opportunities and independence (Feng, et al., 2008). They can therefore be used for employment or social purposes such as emailing. Functions on the computer such as calculators and calendars can be used to assist with numeracy and as visual support.

Many adolescents and adults with Down syndrome use cell phones for safety and social purposes (Buckley, Bird, Sacks, & Archer, 2002). Telephone and cell phone skills assist in developing independence (Buckley, Bird, Sacks, et al., 2002). Individuals with Down syndrome may have difficulties conversing over the telephone due to decreased speech intelligibility (Rondal & Comblain, 1996). There is little research on the use of cell phones to text and send messages; however cell phones may be used to develop independence and for social communication. The other functions on a cell phone such as a calculator or calendar may assist with day to day functioning and a cell phone with a radio may be used for leisure purposes.

Understanding of computer usage amongst the Down syndrome population is limited (Feng, Lazar, Kumin, & Ozok, 2010). They are able to effectively operate and use a computer mouse, screen and keyboard and very seldom require any alterations or modifications (Feng, et al., 2008). Research indicates that typing may be slow and include errors because of difficulty with fine motor skills, however this is not a consistent finding in literature (Feng, et al., 2008). There is potential for individuals with Down syndrome to be educated on computer skills especially to expand the career opportunities available (Feng, et al., 2008). Computer skills that these individuals may exhibit in the workplace include data entry, communication and creating, editing and printing word documents (Feng, et al., 2008). Individuals with Down syndrome make use of a variety of computer or related devices and applications for these (Feng, et al., 2008). Other technological devices that are increasingly used in the workplace by individuals with Down syndrome include iPads and tablets (Kumin, Lazar, Feng, Wentz, & Ekedebe, 2012). These are used in non working contexts as well (Kumin, et al., 2012). Some studies argue that not being able to use these technological devices may isolate the individual with Down syndrome socially and decrease the work opportunities available (Kumin, et al., 2012).

7. Working Memory

The phonological component loop of working memory is said to have a role in learning verbal language by allowing an individual to hold the sound patterns of words in order to link these with meaning (Buckley & Le Prèvoist, 2002). This component of working memory is said to be impaired in individuals with Down syndrome thus causing speech and language difficulties (Buckley & Le Prèvoist, 2002). This is further compounded by

conductive hearing loss which affects 80-90% of individuals with Down syndrome or auditory processing disorders (Buckley & Le Prèvest, 2002). Visual short-term memory is however viewed as a strength with individuals with Down syndrome (Buckley & Le Prèvest, 2002). Visual impairment may also impact an individual's communicative methods and needs (Janicki & Dalton, 1998).

8. Numeracy

Numeracy and mathematic skills are areas of difficulty for individuals with Down syndrome (Brigstocke, Hulme, & Nye, 2008; Buckley & Bird, 2002). Individuals with Down syndrome have difficulty understanding the meaning behind numbers and mathematical concepts (Buckley & Bird, 2002; Byrne, et al., 1995). Numeracy skills are required for reading, education and functional daily tasks such as shopping or telling the time (Bochner, Outhred, & Pieterse, 2001). Difficulty understanding numbers will in turn impact understanding of money and the value of money (Buckley & Bird, 2002). Difficulty with telling the time may impact time keeping and time management skills. The development of numeracy skills is critical in all adults, including those with Down syndrome (Brigstocke, et al., 2008; Faragher & Brown, 2005). Well developed literacy and numeracy skills are predictors of success and independence in adulthood (Bochner, et al., 2001). Literature has suggested that numeracy education should be functional in order to accommodate for numeracy being an area of difficulty e.g. focusing on the five times table as it has a link to telling the time (Buckley, 2007).

9. Education

The Education White Paper 6 (The Department of Education, 2001) discusses the inclusion of learners with special needs in mainstream schooling and providing special needs services to each district (The Organisation for Economic Co-operation and Development, 2008). This model, as previously defined, views the individual in terms of the amount or level of support they require as opposed to the level or severity of his/her disability (The Organisation for Economic Co-operation and Development, 2008). This has been described as the ideal model, but the goal has not yet been reached in South Africa resulting in learners with severe disabilities being turned away from even special needs schooling (The Organisation for Economic Co-operation and Development, 2008). In most schools the

amount of physical resources and staff available is inadequate (The Organisation for Economic Co-operation and Development, 2008). It has been documented that learners with severe disabilities, such as Down syndrome, require much support and should therefore attend a special needs school or a school for Learners with Special Educational Needs (LSEN) (The Organisation for Economic Co-operation and Development, 2008). Learners with less severe difficulties who require less intensive support (level four) may attend a full service school which is regular schooling with additional support staff (The Organisation for Economic Co-operation and Development, 2008). Support staff may consist of Occupational Therapists, Speech-Language Therapists, Psychologists, Physiotherapists and vocational trainers (Segev & Hellman, 2001). There is no direct indication as to which category learners with Down syndrome fit in, however, most attend special needs schooling as only 0.26% of learners in mainstream schools are classified as learners with special educational needs (Education Statistics at a Glance, 2005/2006 cited in Vlachos, 2008). Literature remains divided as to whether mainstream school placement is beneficial for all learners with special needs (Wagner & Blackorby, 1996). Mainstream placement has resulted in both better and worse learning and future outcomes for individuals with barriers to learning (Wagner & Blackorby, 1996). Learners with sensory or physical disabilities found mainstream education beneficial; however, for learners with other disabilities such as intellectual impairments, the higher expectations of a mainstream school environment may impact failure rates and self esteem (Wagner & Blackorby, 1996). Parental education impacts the rate of schooling and rate of employment of individuals with special needs (Ireys, Salkever, Kolodner, & Bijur, 1996).

Currently most teachers use the Revised National Curriculum Statement and adapt this for learners with special needs (Vlachos, 2008). This curriculum is not specifically designed with the intellectually impaired in mind (Vlachos, 2008). There is currently no vocational training outlined in the national curriculum (The Department of Education, 2005). The vocational foundation in schooling and in institutional living has an impact on an adult with Down syndrome's level of employability (Adams, 1998; Brown, 2004; Cuskelly & Jobling, 2002).

The promotion of self-determination in the school context is necessary for vocational success after schooling (Stang, Carter, Lane, & Pierson, 2009). Out of this line of thinking the Self-Determined Career Development Model was developed which is a model that was developed for working adults that receive vocational training (Western New York Independent Living, 2012). Goal setting and problem solving are viewed as crucial skills that need to be developed and nurtured in order to make a person a successful employee (Western New York Independent Living, 2012). Setting up a school based enterprise has been proven to be beneficial for learners in the special education environment in developing work based skills through work experience in a contained environment (Gugerty, Foley, Frank, & Olson, 2008). Skills such as leadership, business logistics, team work, use of technology and responsibility are promoted thus making a person with special educational needs more employable and the concept promotes academic development as a method to success (Gugerty, et al., 2008).

In the South African context the relevance of training received at school and the work opportunities available for individuals with disability have been described as weak (The Department of Women, Children & People with Disabilities, 2011). Teachers in special needs education have specifically identified a lack of vocational training at dedicated needs schooling (Vlachos, 2008). Any vocational training a child receives at school has been as per a teacher or a school's adaptation of the curriculum (Vlachos, 2008). Vocational training at school is strongly associated with employment success (Wagner & Blackorby, 1996). It should involve training in natural, realistic environments (Wilson Kamens, Dolyniuk, & Dinardo, 2003). A new curriculum specifically for learners with special education needs was designed in 2005, however, vocational training and transition planning were not included in this (Vlachos, 2008).

Increasing the opportunities for individuals with Down syndrome is not just the responsibility of the individual with Down syndrome, their family and school. Society has to shift in its understanding of disability and particularly on inclusion and understanding the capabilities and limitations of individuals with Down syndrome. Some growth has been noted in this regard in the South African context; however further development is required (McKenzie, 2012).

10. Transition from School to Adult Life

Individuals with Down syndrome have hopes and dreams for their lives just as any adolescent or adult would (Segev & Hellman, 2001). The transition period between schooling and obtaining employment is crucial in any individual with Down syndrome (Adams, 1998; National Down Syndrome Society, 2012). It is particularly important to acknowledge the views of the individual and to make them central in the transition process even if they have communication difficulties (Cameron & Murphy, 2002).

Ideal preparation before employment should involve assessment of vocational options, skills training, guidance before placement, promotion of skills needed for job-seeking, work experience and trials of on-the-job work (Murray & Heron, 1999). Transition planning should involve goal setting for adulthood and devising methods of obtaining such goals (Powers, Geenen, & Powers, 2009). Individuals with Down syndrome have been found to be more unrealistic than the average adolescent in terms of their aspirations and planning for their future (Segev & Hellman, 2001). Benchmarks should thus be formulated to measure progress and satisfaction (Powers, et al., 2009). The adolescent period of transition is stressful for most individuals but may be heightened for individuals with Down syndrome due to a decreased level of cognition and various behavioural factors (Adams, 1998; Merrick, Kandel, & Vardi, 2004). They are often reliant on parents to assist in seeking employment and accessing community life (Chadwick, et al., 2013; Cuskelly & Jobling, 2002). Social workers may also assist in finding employment (Keating, 2007). This information suggests that there is insufficient support to assist an individual with Down syndrome for adulthood and independence (Cuskelly & Jobling, 2002). Accurate planning should involve inquiring what the individual with Down syndrome wants for his/her life, assessing if it feasible for the individual and then advising them on how to go about it (Powers, et al., 2009).

Learners with disabilities who come from impoverished backgrounds are less likely to obtain further education and training after school (Wagner & Blackorby, 1996). They are also likely to earn less than individuals from wealthier backgrounds (Wagner & Blackorby, 1996). Both of these impact the individual with disability's ability to break out of the cycle of poverty (Wagner & Blackorby, 1996).

In many first world countries, such as the United States of America, the United Kingdom and Canada, there are programmes to assist the individual with a disability in transitioning from school to employment (Brookes, 2012). A particular programme known as SEARCH, was developed in Cincinnati and has been established in over 200 places (Brookes, 2012). SEARCH involves the individual developing his/her areas of strength through a one year programme that incorporates on site job experience (Brookes, 2012). This is beneficial as the job is created or adapted around the individual's physical and intellectual capabilities as opposed to the individual merely shadowing someone (Brookes, 2012). Individuals are often employed permanently after the work experience period as employers are able to see firsthand how the individual copes and develops in the workplace (Brookes, 2012). KARE in Ireland offers similar support systems but focuses specifically on individuals with intellectual disability and on support from early childhood to employment in adulthood (KARE, 2013b). There are few skills development centres available in South Africa for individuals with an intellectual disability (Vlachos, 2008). Post schooling options that may be pursued include secondary education (such as academic courses or vocational training), employment or independent housing (National Down Syndrome Society, 2012). The option chosen depends on the individual's capabilities, finances and the choice made by his/her caregivers or guardians.

11. Past studies on individuals with Down syndrome

Research that involved individuals with Down syndrome or other intellectual disabilities has often centred around medical issues and health concerns (McKenzie, McConkey, & Adnams, 2012). Many studies included Down syndrome under the umbrella term of intellectual disability and did not focus specifically on Down syndrome (Buntinx & Schalock, 2010; Do2Learn, 2011; Trembath, et al., 2010) or other studies compared individuals with Down syndrome to other syndromes such as Williams syndrome or Fragile-X syndrome (Abbeduto, et al., 2008; Abbeduto, et al., 2004) or compared individuals with Down syndrome to individuals without Down syndrome (Cuskelly, Hauser-Cram, & Van Riper, 2008). Furthermore most studies did not focus on the personal characteristics and experiences of the individuals with Down syndrome (Wishart, 2001). Studies that have looked further into individual characteristics and experiences have often focused on the child with Down syndrome and specifically in first world countries (Brown, 1993; Cuskelly, et al., 2008). Gaining further insight into individuals with Down syndrome from various cultural

backgrounds is needed in future research as minimal data has been collected for non English speakers (Cuskelly, et al., 2008).

When gaining family members views, many studies have used questionnaires as the predominant source of data collection (Brown, 1993). An increase in the variety of methods of data collection is required specifically more qualitative studies and studies that include observation (Cuskelly, et al., 2008). Many recent studies have successfully adopted qualitative research methods and this should be further explored (Brown, 1993).

Summary of Chapter

Chapter one provided an introduction to the main topic of this research by defining Down syndrome. Specifics relating to the speech and language strengths and weaknesses were discussed in detail so as to draw focus to these areas. The schooling period, school based skills and the transition from school to employment was expanded on to highlight the journey that the individual with Down syndrome embarks on in order to be employed.

Chapter Two: Down syndrome and Employment

This chapter will focus on employment for the individual with Down syndrome from a variety of angles. Firstly insight will be provided into the South African policies and legislature that promote the individual with Down syndrome's right to be employed and to equality in the workplace. The rate of employment of individuals with Down syndrome will be reviewed in relation to relevant legislature from an international and local perspective. The role of employment in improving an individual's quality of life will be discussed. The possibility of leading a typical adult lifestyle will be considered in light of the general difficulties and disordered communication patterns typical to an adult with Down syndrome. Speech-Language Therapy, accommodations in the workplace and vocational and family support will be discussed in detail. The broad categories of employment of individuals with Down syndrome will be reviewed with regard to international and national trends. Sheltered, supported and open employment will each be reviewed in detail. Finally, the benefits of employment from the perspective of the employer and the employee will be considered.

1. The Rights of People with Disabilities

Disability is defined as individuals that have a long-term disorder or impairment that impacts intellectual, mental, physical or sensory functioning (The Department of Women, Children & People with Disabilities, 2011). This in turn impacts a person's ability to effectively integrate into society (The Department of Women, Children & People with Disabilities, 2011). As per the social model, functioning affects society's views on people with disabilities and obtaining equal rights for individuals with disabilities (The United Nations Children's Fund: Innocenti Research Centre, 2007). Participating in society is crucial in optional functioning and an individual's wellbeing as outlined in the ICF (World Health Organisation, 2001). A range of 5-12% of South Africa's population consists of individuals who are disabled (The Department of Women, Children & People with Disabilities, 2011). In South Africa, substantial advances have been made to improve the circumstances of individuals with disabilities so that more than custodial care is made available for the individual and his/her family who were previously disadvantaged under apartheid (van der Westhuizen, 1990). This development can be attributed to the efforts of parents and changes in legislature which support people with disabilities and have improved the economic

circumstances of people that were previously disadvantaged due to race (van der Westhuizen, 1990).

The rights of people with disabilities are well documented in a number of policies to enforce inclusion in society such as the South African Constitution (108 of 1996), the Promotion of Equality and Prevention of Unfair Discrimination Act (2002) and the White Paper on Integrated National Disability Strategy (1997) (South African Government Information, 2009, 2011). It is acknowledged by Government that what is documented in legislature is not completely implemented in the area of inclusion to meet the needs of those with disabilities (The Department of Women, Children & People with Disabilities, 2011). National policies are slowly addressing the source behind inequalities in employment (Metts, 2000). In some European cities, organizations specific to Autism Spectrum Disorder are lobbying for employment ambassadors to assist with the employment of people with this disorder (Healing Thresholds, 2013). Some countries have associations dedicated to the employment of individuals who require supported employment, for example the Irish Association of Supported Employment which works in conjunction with the government to promote supported employment (Irish Association of Supported Employment, 2008).

New models of understanding disability have emerged in the past decade (Buntinx & Schalock, 2010). These models impact our understanding of disability and validate the importance of professional assistance that is individualized (Buntinx & Schalock, 2010). The first new model is the shift from viewing the disability as a defect to a socio-ecological mismatch where the person's environment does not sufficiently support him/her (Buntinx & Schalock, 2010). Another recent model addresses the change in society's views on people with disabilities and acknowledges their rights and social, physical and emotional well-being as well as their material well-being which includes work and employment (Buntinx & Schalock, 2010).

It is suggested that, ideally, opportunities of employment should exist along a continuum so as to cater for the needs of any individual with a disability (The Department of Women, Children & People with Disabilities, 2011). This view therefore supports the concepts of sheltered employment workshops, vocational training centres, incentive schemes and subsidies for such programmes (The Department of Women, Children & People with Disabilities, 2011). For individuals with Down syndrome a sheltered employment workshop

may be suggested for individuals with a more profound intellectual disability while individuals with more cognitive ability may function in open employment which may be subsidised by the government. Individuals with any form of disability have the right to earn an income which is sufficient in covering their day to day necessity expenses (Matthews & Matthews, 2012).

Individuals with Down syndrome in South Africa are entitled to a government grant which is defined as a monthly monetary subsidy to be used to enhance the life opportunities of the individual with Down syndrome (South African Government Information, 2011). For individuals with Down syndrome between the ages of 18 years and 59/60 years the grant is termed a disability grant and for 2011/2012 the amount was R 1140 per month (South African Government Information, 2011). The terms of the disability grant stipulate that individuals over 18 years earning more than R 44880 per year no longer qualify for a disability grant (South African Government Information, 2011). This works out to approximately R 3740 per month. It is therefore evident that the salaries of adults with Down syndrome in South Africa may be designed with these figures in mind so as not to prevent an individual from obtaining their disability grant.

2. Employment Rate

In first world countries such as the United Kingdom, it is estimated that one in every five or 15-20% of individuals with Down syndrome between the ages of 18 and 60 years have had the opportunity to be employed, not necessarily on a full time basis (Down's Syndrome Association, 2009b; Keating, 2007). In Italy only 10% of individuals with Down syndrome are reported to be employed (Bertoli et al., 2011). Individuals with any form of disability reported a 22% employment rate in Kenya (Mugo, Oranga, & Singal, 2010). Exact statistics of the number of individuals with Down syndrome that are employed in South Africa are not known, however, these are estimated to be low (Watermeyer & Human Sciences Research Council: Child; Youth and Family Development Research Programme, 2006). Individuals with disabilities, such as Down syndrome, make up less than 1% of the work force in South Africa (The Department of Women, Children & People with Disabilities, 2011). In South Africa, there is a direct correlation between disability and poverty as individuals with a disability are exposed to a greater amount of discrimination and inequality (The Department of Women, Children & People with Disabilities, 2011). This injustice is

heightened by cultural beliefs and perceptions whereby individuals with disability are ostracized (The Department of Women, Children & People with Disabilities, 2011). The low employment rate of people with a disability in South Africa is of great concern as it contradicts the freedom of equality stipulated in the Constitution (Down Syndrome South Africa, 2005). Furthermore, those that have obtained jobs have only been able to do so through the persistence of carers and parents (Keating, 2007). Low employment rates worldwide can be attributed to poor understanding of what Down syndrome is and how it will affect the individual in the workplace (Keating, 2007). Although the physical appearance of those with Down syndrome is similar, the mental capacity, intelligence quotient and learning capabilities vary, however, individuals are often labelled and judged based on their outward appearance (Keating, 2007).

3. Down syndrome and Employment

The progress made in early clinical identification and intervention as well as the medical advances in today's world allow individuals with Down syndrome to enjoy a fulfilling life (Down Syndrome South Africa, 2011b; National Down Syndrome Congress, n.d.). The improvements in medical and therapeutic care of individuals with Down syndrome allow for individuals to function more effectively in society (Hayes & Batshaw, 1993). Children with Down syndrome therefore develop into individuals that are creative, relatively independent and contributing members of society should they be granted the opportunity and skills development to do so (Alderson, 2001). If legislation is followed and adequate policies are put into place, individuals with Down syndrome should be provided with opportunities so as to increase their skill base, develop social skills and increase independence.

Individuals with disability seek employment just as those without disability to gain independence, earn a living and create social bonds (Murray & Heron, 1999). Work is viewed as an expression of one's personality in society as it allows an individual to gain independence and socialize with a variety of people (Bertazzi, 2010). Independence and developing social roles are important factors in improving well-being and happiness (Haigh et al., 2013). Travelling to work independently, being able to complete a job task, learning new skills or earning a salary may all contribute to developing a sense of independence. The workplace also allows for individuals with Down syndrome to meet new people from various

backgrounds as well as the opportunity to develop relationships that may provide support both inside and outside of the workplace.

Individuals with Down syndrome share in the fundamental right to employment. Employment is viewed as one of the pinnacle factors to enhancing quality of life (Cuskelly & Jobling, 2002). It is natural for adults to seek employment for the purpose of increasing self esteem and dignity (Matthews & Matthews, 2012). There is no link between those individuals with Down syndrome seeking employment and employers that are willing to hire them thus resulting in a low rate of employment of individuals with Down syndrome (Down's Syndrome Association, 2008). Many individuals with Down syndrome want to work as they feel it part of a typical adult lifestyle (Down's Syndrome Association, 2009b; Jans, et al., 2011; Webber, 2011). When asked in a survey, two thirds of the United Kingdom's population of individuals with Down syndrome indicated that they would like to be employed (Keating, 2007).

There are both internal and external barriers that may impact the employment of an individual with Down syndrome. Internal barriers include literacy and numeracy skills as well as confidence in oneself (McGlinchey, McCallion, Burke, Carroll, & McCarron, 2013). External barriers may include stigma and discrimination from others in the workplace (McGlinchey, et al., 2013).

Individuals with Down syndrome may experience substantial health complications and difficulties with various aspects of daily functioning thus impacting the financial status of the family (Schieve, Boulet, Kogan, Van Naarden-Braun, & Boyle, 2011). It may therefore be necessary for individuals with Down syndrome to seek employment to assist the family financially (Webber, 2011). These medical conditions do not generally prevent an individual with Down syndrome from being employed or from generating an income (Smith, 2001).

The typical job descriptions that have been noted as being most suitable for the intellectual profile of an individual with Down syndrome include administration work, manual labour such as packaging and craftwork (Henwood & Dixon, 2002). Job tasks should be reviewed on a regular basis to ensure that both the individuals and employer are satisfied and to reflect on the individual's development and abilities (Matthews & Matthews, 2012). A study conducted in the United Kingdom indicated that a majority of individuals with Down

syndrome that were employed were in retail, administrative, cleaning or catering jobs (Down's Syndrome Association, 2008). These jobs are considered most suitable considering the cognitive and physical limitations that may be present with Down syndrome. Individuals that are physically able are generally considered for more manual based work such as cleaning, gardening and factory work while individuals with more cognitive ability or those with health concerns such as cardiac conditions and other concerns linked with Down syndrome are said to be suited to administrative work. Furthermore, the study indicated that individuals were generally employed for 7 to 21 hours per week (Down's Syndrome Association, 2008). This was said to be applicable because of the individual with Down syndrome feeling fatigued or because the employer was unable to afford a full time salary (Down's Syndrome Association, 2008). The study also indicated that most individuals with Down syndrome that are employed have found employment through family or family friends (Down's Syndrome Association, 2008). This has been found in other research (Chadwick, et al., 2013). It has also been suggested that employment brought about in this manner, leads individuals to be employed in jobs in which they may not be interested or a field in which they may not have employment strengths (Down's Syndrome Association, 2008). It is necessary for a job to be suitable and interesting in order for individuals to be satisfied in their work (Jans, et al., 2011). This situation is true of South Africa too where we have much in policy and law dictating what should happen but not necessarily the methods and resources or people power to implement these.

There are three types of employment for individuals with Down syndrome namely: open employment, supported employment and business services (Down Syndrome Western Australia, 2009). Intellectual ability is the strongest predictor of employment success (McGlinchey, et al., 2013). An individual's level of independence in terms of the skills and living status is also a predictor of employment success and which type of employment may be most suitable (McGlinchey, et al., 2013). Open employment is described as working without additional support thus the individual is employed independently (Down Syndrome Western Australia, 2009). Open employment is also known as competitive employment as it involves the individual competing in the general job market and having a proactive role in job seeking (National Down Syndrome Society, 2012). Often the individual's parents and family play an active role in this type of job recruitment (Down's Syndrome Association, 2008). The private sector is largely involved in partnerships, organizations and employing people with

disabilities (Metts, 2000). Many individuals with intellectual disability that are employed and paid are seldom employed in a full time capacity (McGlinchey, et al., 2013).

Supported employment involves the individual working in an environment with disabled and nondisabled co-workers and receiving support to assist him/ her in developing the skills necessary to function in the workplace (Down Syndrome Western Australia, 2009). This form of employment promotes the development of technological skills, specific task training and individualized attention which promotes overall empowerment (McGlinchey, et al., 2013). A job coach is involved in supporting the individual by initially accompanying the individual on all work related tasks and then later consulting with the individual on a regular basis to maintain progress (National Down Syndrome Society, 2012). Crucial elements of supported employment are personalizing the support strategies for the individual and assisting with social integration with co-workers, suppliers and customers (Down Syndrome South Africa, 2011b). Supported employment has been shown to improve the cognitive capabilities of employees with disorders such as Autism Spectrum Disorder (Garcia-Villamizar & Hughes, 2007). This is the most popular type of employment for people with Down syndrome (National Down Syndrome Society, 2012).

Business services involves the individual working in a sheltered work environment with other individuals who have disabilities (Down Syndrome Western Australia, 2009). This type of employment is also referred to as sheltered or protected employment as the individual is employed in a self contained environment (National Down Syndrome Society, 2012). Sheltered employment is generally obtained through a job agency and is the lowest paying type of employment in comparison to open or supported employment (National Down Syndrome Society, 2012). Further, workshops on transport, meals, social functioning and self help skills may be provided by the institution (Vlachos, 2008). There are some countries where individuals with intellectual disability attend a day service and are under the pretence that it is employment (McGlinchey, et al., 2013). This is so as to encourage the emotional benefits of employment (McGlinchey, et al., 2013).

Scholars with any form of intellectual disability are less likely to receive post school education or have goals of competitive employment (Grigal, Hart, & Migliore, 2011). These factors are crucial to obtain further job opportunities and increased wages (Grigal, et al., 2011). These students are more likely to have sheltered employment with employment goals that require support from other people (Grigal, et al., 2011).

Job agencies specific to individuals with disabilities may assist in finding suitable employment for those with Down syndrome. These are more frequent in some countries in Europe and in the United States of America (Vlachos, 2008). There are a limited number of job agencies in South Africa specifically for individuals with some form of disability (Vlachos, 2008). Examples of such include Bradshaw LeRoux Consulting, Progression, Abantu Benthu Consortium, Inclusive Solutions and Employability Vulindlela (Vlachos, 2008). The agencies assist with job placement and review the employee's, employer's and co-workers' satisfaction on a regular basis (Vlachos, 2008). For their services, job agencies require up to 15% of the individual's annual salary (Vlachos, 2008). Agencies should promote employment of individuals with disabilities and provide a link between government policies and the employment market (Murray & Heron, 1999). Literature suggests that it has become preferable to promote strategies that allow for employment in the mainstream labour market as opposed to obtaining employment through specialized agencies (Metts, 2000). Some organizations specifically for Down syndrome in South Africa e.g. Down Syndrome South Africa have some branches that also assist in employment opportunities (Webber, 2011). There is a wide variety of skills in the communicative, social, academic and physical abilities of individuals with Down syndrome thus adequate profiling is necessary for the selection of suitable employment (Bertoli, et al., 2011).

An alternative form of employment that has seldom been researched is volunteering (Trembath, et al., 2010). Volunteer work does not necessarily lead to permanent employment, however, it may provide the individual with the same sense of purpose that paid work offers and involvement in the community (Trembath, et al., 2010). Volunteer work may be viewed as a stepping stone between schooling and permanent employment or as an alternative to paid employment (Trembath, et al., 2010).

Ignorance as to how to go about finding a suitable employee with a disability or how to assist the employee in functioning optimally in the workplace is a concern on the part of the employer that prevents them from actively seeking and employing individuals with Down syndrome (Down's Syndrome Association, 2008). Employers may also be concerned as to how they should go about preparing the other staff members for working with the individual with Down syndrome (Down's Syndrome Association, 2008). Transport to and from work was found to be an additional barrier as many individuals with Down syndrome are unable to travel independently (Down's Syndrome Association, 2008; McGlinchey, et al., 2013). One would expect that in South Africa this will be heightened by limited public transport in some areas and the high cost of public transport being used on a regular basis (Khosa, 1995). There are specialized transport services designated for individuals with disabilities with decreased rates (Dial-a-ride, 2012). The cost is R 2 per kilometre and the average trip costs R 0 to R 14 per way (Dial-a-ride, 2012). This may be too expensive for some individuals.

Internationally, there are a variety of organizations that assist and support individuals with Down syndrome and their families in addressing concerns related to health, education and employment. These organizations have provided an increased number of employment opportunities for the adult with Down syndrome to gain a sense of independence (Hayes & Batshaw, 1993). A well known organization, KARE, started in Ireland in 1967 (KARE, 2013a). It was founded by parents and family friends of individuals with intellectual disability in order to promote inclusion of people with intellectual disability in the workplace (KARE, 2013a). Specific to adulthood, KARE provides support for lifelong learning, supported employment, sport and leisure, independent living, health and short breaks from family (KARE, 2013b). Such organizations can also provide mediation between the employer and employee on how best to meet both parties' needs (KARE, 2013b).

4. Communication in the Workplace

Research has revealed that a person's life experience, including experiences in the workplace, impact how they communicate in the home environment (Ritchie, 1997). A person is more conversation orientated if there is a high degree of openness and autonomy in the communication in the workplace (Ritchie, 1997). This indicates that the level of communication in the workplace helps to shape a person's overall communicative abilities and life experiences.

Central to communication in the workplace are the concepts of oral skills, written skills, team work and interpersonal relations (Darling & Dannels, 2003; Shmerling, 1996). Effective communication in the workplace may therefore be a challenge for individuals with Down syndrome who present with difficulties in some of these areas. The oral skills comprising of the speech and language skills of an individual with Down syndrome are affected by the articulation errors, difference in vocal quality, persistence of phonological processes and delayed language development (Kumin, 1996). Written or literacy skills among individuals with Down syndrome are also an area of concern as many individuals are not taught to read and write or they do not reach their potential with regard to literacy development (Fowler, et al., 1995). Society generally views individuals with Down syndrome as being very sociable (Adams, 1998). This may encourage team work and development of interpersonal skills. However, not all individuals with Down syndrome present with adequate social skills. Some individuals experience difficulties because of restricted interests and difficulties with creating and understanding social relationships (Laws & Bishop, 2004). This indicates that not all individuals with Down syndrome have well developed social skills to utilize in the workplace. The sociable nature associated with Down syndrome may however be lacking should there be a co-occurring diagnosis of Autism Spectrum Disorder. This would then affect team work and interpersonal relations in the workplace (Bosch, 2003).

Additional communication skills that may be required in the workplace are intelligibility, negotiation and listening (Darling & Dannels, 2003). It is well documented that the intelligibility of individuals with Down syndrome is decreased by articulation, vocal quality and persisting phonological processes (Kumin, 1994). Individuals with Down syndrome have difficulty adjusting their expressive language based on what another person has said (Abbeduto, et al., 2007). This may therefore impact one's ability to negotiate where required. Individuals with Down syndrome have relatively good receptive language skills in comparison to expressive language skills; however difficulties arise as receptive syntax is limited (Long, 2005).

Verbal expressive communication is also required in the workplace as a means to promote ones credibility and promote oneself (Kelly, 2006). Expressive syntax is an area of difficulty for individuals with Down syndrome thus impacting their ability to express themselves to their co-workers and employers (Abbeduto, et al., 2007). This is further

impacted on by poor conversational repair skills (Roberts, et al., 2007). Nonverbal communication is an area of relative strength therefore promoting skills such as turn taking (Buckley, 2000) These are crucial for communication and discussion in the workplace.

It is therefore evident that many of the skills necessary for effective communication and social communication in the workplace may be challenging for an individual with Down syndrome. They may require Speech-Language Therapy, accommodations in the workplace and additional support to assist them.

5. Speech-Language Therapy for Adults with Down syndrome

Individuals with complex disabilities that affect multiple areas of functioning may present with multifaceted communicative needs (Workinger, 2005). These needs change as the individual ages and develops throughout the lifespan thus therapy may be required at different stages of life for different purposes (Workinger, 2005). Speech-Language Therapy for the infant or young child with Down syndrome may focus on articulation and phonological errors while therapy for a school going child may also include literacy aims. Speech-Language Therapy for an adult may include aims of social communication and communication in the workplace.

Individuals with disability have the right to therapy and to receive multi-disciplinary care (Matthews & Matthews, 2012). The role of the Speech-Language Therapist in the lives of individuals with lifelong disabilities is seldom explored (Balandin, 2011). A Speech-Language Therapist is part of the multi-disciplinary team that is involved in intervention of an individual with Down Syndrome (Coelho, DeRuyter, & Stein, 1996). There is literature to support the notion that Speech-Language Therapy is the most crucial therapy for individuals with Down syndrome in order to promote cognitive and communicative development (Buckley & Le Prèvest, 2002). The Speech-Language Therapist assesses all aspects of communication such as speech, language and social skills and estimates areas of cognition that may impact communication such as attention, memory and executive function (Coelho, et al., 1996). Speech-Language Therapy may then involve a combination of speech or language therapy, counselling and social-skills training (Coelho, et al., 1996). The role of the therapist includes providing emotional support for the individual with an intellectual disability and their family and families have found this form of support beneficial (Chadwick,

et al., 2013). In a study conducted in the United Kingdom, individuals with intellectual disability and their families indicated that external support such as Speech-Language Therapy should be person-centred, provide choice for the individual and their family and should balance the individual's rights and their responsibilities (Chadwick, et al., 2013).

A majority of studies indicate that early Speech-Language Therapy is beneficial and that each individual's strengths and weaknesses should be profiled (Roberts, et al., 2007). Early intervention will assist with the acquisition of language or a form of communication which in turn allows for the individual to develop cognitively as they begin to verbally interact with the world around them (Buckley & Le Prèvest, 2002). The provision of Speech-Language Therapy for individuals with Down syndrome may be dependent on the therapists available in the geographical location as the knowledge and interest of therapists may vary from area to area (Buckley & Le Prèvest, 2002). A lack of specialized therapeutic services has been described in many countries even more developed countries such as Ireland (Chadwick, et al., 2013). Therapy should begin as early as possible and studies have shown that individuals benefit from therapy even in adult years, however, locating therapy services for this age group is even more challenging (Buckley & Le Prèvest, 2002). Therapeutic services are accessed less frequently by the adult population with Down syndrome (Chadwick, et al., 2013). Individuals may access services less frequently during adulthood due to dissatisfaction with the services provided in childhood. This may be caused by the individual and family being left out of decision making, a lack of respect, impersonal therapy planning and a lack of understanding about the eligibility and need for services throughout the lifespan (Chadwick, et al., 2013).

A Speech-Language Therapist is needed at various stages of the individual with Down syndrome's life, including when adjusting to the transition from education to employment, and for social and employment needs in adulthood, through deteriorating communication with advancing age (Kumin, 1994; Stoel-Gammon, 2001).

6. Accommodations in the Workplace

Traditionally employers have focused on employing individuals into the mainstream marketplace without taking into account how to make the workplaces more accommodating and accessible (Metts, 2000). The focus has been on the disability as opposed to accommodations that could be made in the workplace to encourage participation (Mpofu & Oakland, 2010). This lack of accommodation may prevent the individuals with Down syndrome from participating effectively in their environment (Mpofu & Oakland, 2010). The ICF indicates that some accommodations may be necessary to allow better participation (Mpofu & Oakland, 2010).

There are two views regarding accommodations in the workplace: firstly, the North American approach where employers must accommodate the limitations of the individuals with a disability and the European approach where the workplace is changed to be completely accessible (Metts, 2000). The presence of Down syndrome does not indicate that a person is unable to work but rather that they may require additional support in the workplace (Down's Syndrome Association, 2009a). Although various physical, cognitive, communicative, memory and health difficulties may occur, adjustments can be made in the workplace to assist individuals with Down syndrome in functioning optimally in the environment. The individual's social, communicative and physical difficulties need to be considered when an employer seeks prospective employees as these are areas of difficulty for individuals with Down syndrome (Henwood & Dixon, 2002). It is crucial to enforce person-centred planning methods when attempting to improve the independence of individuals with a barrier to learning (Ware, 2004).

There are some methods of AAC that may assist the individual with Down syndrome in functioning effectively in the workplace even if they do not use AAC to communicate. Individuals with Down syndrome are strong visual learners thus showing them how to do a task is of great benefit in assisting with understanding (Down's Syndrome Association, 2009a). Colour coding systems may also be of assistance especially when introducing a new task (Down Syndrome South Africa, 2011b; Henwood & Dixon, 2002). Individuals with Down syndrome work well in jobs where there is a set daily routine (Webber, 2011). They do not always cope well with unexpected events thus visual timetables have been found to be beneficial in the school environment (Down's Syndrome Association, 2008). It has been

suggested that these also assist in the workplace in preparing the individual with Down syndrome for his/her daily tasks (Australian Government, 2012; Down's Syndrome Association, 2008). A handheld prompting device has been proven beneficial in assisting individuals to transition between work tasks (Cihak, Kessler, & Alberto, 2008). Choosing one area for the individual with Down syndrome to learn may be beneficial to facilitate understanding and to develop skills (Australian Government, 2012). The use of memory aids to assist in remembering important details may be beneficial in the workplace or with a specific job task as receptive language is an area of concern with individuals with Down syndrome and difficulties in receptive language affect understanding and retention of information (Australian Government, 2012). Suggested memory aids include cue cards, alarms, visual prompts, computer alerts, a list of tasks or a breakdown of tasks (Australian Government, 2012). A Speech-Language Therapist or Occupational Therapist may be involved in the selection and creation of such AAC resources.

Miscommunication in the workplace may occur due to the receptive and expressive language difficulties and decreased speech intelligibility levels that are evident in an individual with Down syndrome (Down's Syndrome Association, 2008). It is crucial that practical tools are put in place to facilitate communication (Down's Syndrome Association, 2008). This involves making sure the employee knows up front what his/her job entails and exactly how they are to go about the duties of the job (Down's Syndrome Association, 2008). The employer must also carefully explain the expectations for the individual (Down's Syndrome Association, 2008). Other employees should be educated about Down syndrome and the strengths and weaknesses associated with the syndrome and specific to the individual (Australian Government, 2012). Employers should also explain to co-workers how best to communicate with the employee with Down syndrome and to assist in teaching them new skills as receptive language is an area of difficulty (Australian Government, 2012). The individual with Down syndrome may require more time to process instructions or to complete tasks (Rondal & Comblain, 1996). Using a screen reading system whereby information on a computer screen is read aloud, may be beneficial for individuals with Down syndrome that are not literate (Australian Government, 2012).

Employers must ensure that the equipment that the individual is required to use should be safe and easy to use (Henwood & Dixon, 2002). Adaptations to the office furniture (desks, chairs, shelving) can be made should the individual with Down syndrome be short or have short limbs as these are common physical features of individuals with Down syndrome (Australian Government, 2012). Marking the edge of stairs, additional lighting and tactile stimuli can be used for individuals with co-occurring visual difficulties (Australian Government, 2012). Adjusting the work station may also be beneficial in improving concentration as it reduces visual distraction and may decrease external noise (Australian Government, 2012).

A job coach may be beneficial in providing support for the individual and nurturing the efforts of fellow employees in assisting the individual with Down syndrome (Down's Syndrome Association, 2009a). Issues related to the use of a job coach pertain to recruitment, training, cost and accommodation in the workplace (Dowler, Solovieva, & Walls, 2011). Job coaches have been found to be beneficial particularly when other accommodations in the workplace do not provide sufficient support (Dowler, et al., 2011). Co-workers may be paired with the individual with Down syndrome as part of a “buddy system” so that the experienced worker can assist the individual with Down syndrome who may be a new employee or simply an employee that requires additional assistance (Australian Government, 2012). Job clubs have been suggested as being beneficial in allowing those with a disorder to socialize and share with other people with the same disorder who are also employed (Healing Thresholds, 2012). This occurs at events such as the World Down Syndrome Congress. At the most recent Congress in Cape Town in 2012, individuals from all over the world spoke about their road to employment success e.g. Sheri Brynard from South Africa and Jaspreet Sekhon of Singapore. This time allows individuals to build a support network and may be a time to acquire new skills (Healing Thresholds, 2012).

7. Vocational Support Courses

There are a variety of websites and online courses that provide tips for individuals with disabilities, such as Down syndrome, on applying for a job, evaluating his/her personal strengths, skill development and job maintenance (Do2Learn, 2011). These websites also assist the prospective employer in channelling the strengths of the individual, supporting the individual with Down syndrome in the workplace and managing conflicting situations

(Do2Learn, 2011). The four main steps outlined in the online courses are determining interests, finding a job, getting a job and then keeping the job (Do2Learn, 2011).

Vocational courses for individuals with other disorders such as Autism Spectrum Disorder are available in some countries such as the United States of America (Battaglia & McDonald, 2010). These could be accessed by individuals in South Africa granted that they have internet access which may be a barrier for many individuals. These courses focus on the cultivating of the participant's vocational and social skills within a community-based setting (Battaglia & McDonald, 2010). Various skills such as budgeting, computer work, diarising, planning and time management are enhanced, and the use of technology such as computers and iPods are encouraged to support learning (Battaglia & McDonald, 2010). Some courses are affiliated with universities or corporate companies which attempt to assist with employment opportunities for the individuals that participate in the courses (Battaglia & McDonald, 2010). There is also, however, evidence to suggest that sheltered workshops prior to employment of a person with Autism Spectrum Disorder do not have a positive effect on rate of employment or the level of salary (Cimera, Wehman, West, & Burgess, 2011). These courses are run by governmental organizations overseas so as to be in line with the legislature of the country, however, in South Africa, many of the organizations that assist in skill development and vocational training are non-governmental organizations or private institutions. There are a minimal number of training and occupational centres in South Africa, particularly in rural areas (van der Westhuizen, 1990).

An initiative specific to Down syndrome and employment has resulted from extensive research by the Down's Syndrome Association in the United Kingdom (Down's Syndrome Association, 2012). "WorkFit" is an initiative of the Down Syndrome Association of the United Kingdom to provide a link between individuals with Down syndrome who seek employment and employers who would like to employ someone with Down syndrome (Down's Syndrome Association, 2012). "Workfit's" website supplies information and contact details for volunteer work, apprenticeships and paying jobs (Down's Syndrome Association, 2012).

8. Family Support

Family support is the most consistent form of support for any individual with an intellectual disability and this support is needed throughout the lifespan (McKenzie, 2012). The support that is offered by family and people in the individual with Down syndrome's environment dictates how the individual will function in the community (The Centre for Developmental Disability Health Victoria, 2008). Support from the family can range from support in the home context, assistance with money, personal care, hygiene and planning or organization of daily tasks (The Centre for Developmental Disability Health Victoria, 2008). In most cases the family of individuals with Down syndrome supports the development of social skills (The Centre for Developmental Disability Health Victoria, 2008). In more profound cases the family members may be responsible for verbalizing or clarifying the individual with Down syndrome's needs or wants, assisting others in understanding the individual and developing alternative communicative systems should the individual be nonverbal (The Centre for Developmental Disability Health Victoria, 2008).

9. Benefits of Employing an Individual with Down syndrome

There is much literature to support the fact that individuals with Down syndrome want to be employed and that employment has a great impact on self esteem and sense of worth (Brown, 2004; Webber, 2011). Employers have indicated that the individuals with Down syndrome employed at their workplace are very motivated to learn and to become independent thus making them ideal employees (Down's Syndrome Association, 2009a). Employers also reported that their employees with Down syndrome are very reliable with the tasks entrusted to them (Down's Syndrome Association, 2009a). Other employers have described their staff with Down syndrome as being neat, well presented, hard working and with good time keeping skills (Down Syndrome South Africa, 2011b; Henwood & Dixon, 2002). Research indicates that employees with disabilities tend to stay in their jobs for a longer period than employees without disabilities (Down's Syndrome Association, 2009a). A large drugstore chain in the United States of America has attributed its efficiency above other stores in the chain to the 42% employment rate of individuals with physical and cognitive difficulties (Keating, 2007). Studies done in the United Kingdom indicate that having a job will impact positively on the confidence levels of most individuals with Down syndrome as well as decrease the likelihood of depression in adulthood (Keating, 2007). There is also a

financial benefit to employers who hire employees with disabilities (Metts, 2000). In South Africa, employers who employ individuals with disabilities receive a tax deduction from the government to assist in paying the individual's salary thus the individual's salary "costs" the employer less (Finance and Accounting Services Sector Education and Training Authority of Department of Higher Education and Training, 2012).

10. Employment Successes in South Africa

Potential employers must consider training costs, salaries and co-worker perceptions before employing an individual with Down syndrome (Adams, 1998). Various associations both locally and abroad have documented the successful employment of individuals with Down syndrome. The stories and triumphs of people who are further disadvantaged due to poverty or previously disadvantaged due to race are especially noted in the South African media (Down Syndrome South Africa, 2011b). These articles highlight the individuals' abilities to seek out public transport to get to work, function optimally in the workplace, socialize effectively and obtain respect from their employer and co-workers for their high standards (Down Syndrome South Africa, 2011b). Individuals with Down syndrome who are successfully placed in a workplace that provides support are often able to generate more income than a disability grant would have allowed them (Down Syndrome South Africa, 2011b). Some individuals from rural areas have been able to earn more than other members of their family who are either unemployed or employed in a low-income job (Down Syndrome South Africa, 2011b).

11. Past studies on Down syndrome and Employment

The daily realities that individuals with Down syndrome face are seldom researched and documented (Mckenzie, et al., 2012). These may include housing, employment and support. The experiences of others are crucial in developing opportunities for other individuals (Brown, 2004). Self advocacy is a crucial element in improving the rights and opportunities available to individuals with Down syndrome (Borrell-Carrió, et al., 2004). Individuals with Down syndrome have seldom been made the centre of studies that involved housing, employment and rights. Studies tended to focus on the strengths and weaknesses of individuals with Down syndrome as opposed to their experiences and views about daily life.

Summary of Chapter

Chapter two focused on the other main theme of this research project, namely employment. Definitions of the types of employment were provided. This chapter reviewed the international legislature and closely observed the national legislature that endorses the employment of individuals with Down syndrome as well as the rate of employment which indicated that legislature is not always enforced. The role of employment in the lives of those with Down syndrome was reviewed as well as the necessary adjustments and aid required by the individual with Down syndrome in order to be successful in the workplace.

Chapter Three: Methodology

This chapter focuses on a detailed description of the methods and procedures that were used for the study. The aim, objectives, study design, data collection method, data collection instrument, method of analysis and explanations for these are discussed. Reliability, trustworthiness and ethical considerations with regard to data collection and analysis are reviewed.

1. Aim

To explore the employment experiences of individuals with Down syndrome, their employers and their families in KwaZulu-Natal.

2. Objectives

- 2.1.** To explore communication used in the workplace from the perspective of the individual with Down syndrome, their employer and their family
- 2.2.** To explore social interaction required as part of work between the individual with Down syndrome and their employer and co-workers
- 2.3.** To explore the types of employment and responsibilities undertaken by individuals with Down syndrome
- 2.4.** To explore the opportunities and challenges that employment provides the individual with Down syndrome and their family
- 2.5.** To explore the therapeutic, occupational and vocational support provided to the individual with Down syndrome prior to employment
- 2.6.** To explore the employer's understanding of Down syndrome and the adaptations made by the employer to support employees with Down syndrome in the workplace
- 2.7.** To explore the communicative challenges and strengths of the employee with Down syndrome as seen by employers
- 2.8.** To explore the feelings and perspectives of the family of the individual with Down syndrome regarding their family member being employed.

3. Research Approach and Design

The appropriate research approach and design allows for the gathering of accurate and valid data which seeks to answer the research question (Leedy & Ormrod, 2010). The qualitative approach was selected in this study. The qualitative researcher seeks to illuminate and understand a phenomenon (Golafshani, 2003), in this case the employment experiences of individuals with Down syndrome. Qualitative methods of data collection are yielding valuable information fields such as Speech-Language Pathology (Hammer, 2011). A qualitative approach to research allowed the researcher to gain an in-depth understanding of the topic by looking at the perspectives of various individuals (Pope & Mays, 2000). Rich data was obtained by analysis of the perspective of the individual with Down syndrome, their employer and their family. This assisted in expanding the current knowledge base on the topic (Hammer, 2011). The nature of a qualitative approach to research allowed for all participants to express themselves freely which further enriched the data obtained (Leedy & Ormrod, 2010). This approach endorsed the researcher being actively involved in data gathering (Creswell, 2009). This allowed the researcher to accurately reflect the experiences as reported by the individual with Down syndrome, their employer and their family.

A phenomenological study design was used in this study. This design describes the experiences of participants (Creswell, 1998; Leedy & Ormrod, 2010). The personal experiences of the participants involved in the research were then analysed in an attempt to answer the research question (Leedy & Ormrod, 2010). This is also in keeping with the biopsychosocial model that was used as a framework for the study whereby the individual's subjective views are established in order to structure intervention (Borrell-Carrió, et al., 2004). This design was appropriate for the study as it documented the employment experiences of individuals with Down syndrome, their employers and their family.

4. Participants

4.1. Study Population

The study population can be described as the individuals that participate in the study and provide information that contributes towards findings (Goddard & Melville, 2001). It is important to look at topics affecting independence from the viewpoint of the individual with a disability as well as through the eyes of peers and familiar adults (Preece & Jordan, 2009). The views of familiar adults are not always accurate; however, the familiar adults can be considered ‘proxy informants’ as they provide information that is of value (Preece & Jordan, 2009). The population of this study therefore consisted of three categories of individuals namely: individuals with Down syndrome who are employed, their employers² and their families. These three categories of participants were selected as they have exposure to the experiences of an individual with Down syndrome in the workplace.

4.2. Participant Recruitment

Participants were recruited through reputable associations that are linked to individuals with Down syndrome. Down syndrome South Africa, Durban and Coastal Mental Health, schools for individuals with an intellectual disability and facilities with supported employment were contacted to obtain a list of individuals with Down syndrome that they know of who were currently or have been employed (Appendix A). Purposive sampling was used to select the participants for the study. This sampling technique was used to select participants from the population according to various characteristics (Patton, 2002). This was necessary in order to select participants that best represent the population being researched and those that assisted in achieving the aim of the study (Patton, 2002). Purposive sampling

² The term employer in this study is not necessarily the overall employer who pays the individual’s salary but rather the person who oversees and supervises the individual with Down syndrome on a regular if not daily basis. In the workshop setting it would be the person who is usually termed the “supervisor” and in the open labour market is generally a person who is some form of manager or head of a team.

allowed for recruitment of participants who were both relevant to the study and provided diversity to the sample (Ritchie & Lewis, 2003). Typical case sampling was the approach used whereby cases that represent typical cases were selected (Patton, 2002). The researcher also chose to select certain participants to provide diversity with regard to ethnicity, gender, age, language and type of employment. This type of information was obtained from the biographical questionnaire that was completed by all those individuals willing to participate in the study (Appendices B, C, D, E, F and G).

Additionally, snowball sampling was also used where participants directed the researcher to possible participants (Trochim, 2006). This form of sampling is useful when researching populations that are difficult to access (Trochim, 2006).

4.3. Sample Size

There is no universally agreed upon normative value on the number of participants required for interviews. Some research suggests that the number of participants may depend on the aim of the study (Patton, 2002). The number of participants must allow for adequate data to be obtained in order to answer the research question (Kvale & Brinkmann, 2009). Participants must also represent the diversity of the population in terms of language, ethnicity, gender, type of employment and socio-economic status. Patton (2002) suggests a smaller sample size in order to get rich, in depth data and insight into the phenomenon being investigated. The sample consisted of 15 participants, 5 being individuals with Down syndrome employed in KwaZulu-Natal, 5 employers and 5 family members.

4.4. Participant Selection

Specific participant selection criteria were used to select participants for each of the three categories of participants. The selection criteria for each category are tabulated in Tables 1, 2 and 3 on the following pages.

Table 1

Selection Criteria for Individuals with Down syndrome

Number	Selection criteria and motivation for these
1	Have a medical diagnosis of Down syndrome as the study focused specifically on the employment experiences of those with Down syndrome.
2	Reside in the province of KwaZulu-Natal as one of the parameters of the study was that it focused on individuals who are employed in this province.
3	Be over the age of 18 years as in South Africa, individuals over this age are viewed as adults by the government as per The Children's Act (38 of 2005) (South African Government Information, 2009).
4	Be employed for a least one to 20 hours per week as this was described as a moderate intensity (Mortimer, Finch, Ryu, Shanahan, & Call, 1996).
5	Currently employed in the job they were discussing or have been employed within the past six months.
6	Employed in the current/ previous job which they referred to in the interview to for at least six months as this is the minimum period of time required to adequately acquire work skills (O'Reilly, Caldwell, & Barnett, 1989). This was necessary to allow for the individual to settle into a routine and become familiar with their duties in the workplace and their colleagues as well as to provide the employer with sufficient time in which to get to know the individual and their strengths and weaknesses.
7	Able to converse in an interview in order for an adequate amount of data to be gathered and for rich detail to be obtained (Coyle & Wright, 1996).
8	Able to converse in either English or isiZulu as these are the two dominant languages in KwaZulu-Natal (Statistics South Africa, 2011)

Table 2

Selection Criteria for Employers

Number	Selection criteria and motivation for these
1	Directly oversees and provides instructions to the individual with Down syndrome in the workplace, and not necessarily the most senior level of management.
2	Have direct contact with the individual with Down syndrome at least once a week (Manz & Sims, 1987). This allowed for regular meetings where the individual or employer could raise concerns and discuss issues. In South Africa, the typical working week is five days as per the Basic Conditions of Employment Act (1997) (South African Government Information, 2009).
3	Have been an employer in the context for a minimum of six months in order to obtain adequate work skills and become familiar with staff (O'Reilly, et al., 1989).
4	Works within the province of KwaZulu-Natal as one of the parameters of the study is that it focused on individuals who are employed in this province.
5	Be able to converse in either English or isiZulu as these are the two prominent languages used in KwaZulu-Natal (Statistics South Africa, 2011).

Table 3

Selection Criteria for Family Members

Number	Selection criteria and motivation for these
1	Directly related to or have guardianship of the individual with Down syndrome as this ensured that only family members who interact with the individual on a regular basis were included.
2	Over the age of 18 years in order to provide information on the individual with Down syndrome prior to their employment.
3	Reside in the province of KwaZulu-Natal as one of the parameters of the study was that it focused on individuals who are employed in this province.
4	Able to converse in either English or IsiZulu as these are the two most frequently used languages in the province of the study (Statistics South Africa, 2011).

4.5. Description of Participants

With regard to participation selection, it was preferred if the employer and family member involved were different people. If one parent was the employer then it was preferable that the other parent, a sibling or other close family member was interviewed as the family member. Preference was given to cases where there is an individual with Down syndrome, their employer and family member who were all willing to participate in the study.

Each potential participant was supplied with an information letter, consent form and biographical questionnaire (Appendices B, C, D, E, F and G). These documents clearly indicated the selection criteria. Only individuals that completed the consent document and biographical questionnaire and met the criteria indicated in the letter were considered for the study.

The first participant with Down syndrome (PDs1)'s employer (E1) did not respond to the invitation to participate in the study. A potential participant with Down syndrome (PDs5) and her family member (FM5) responded to the information letter to participate in the study; however they could not be interviewed due to practical constraints. Altogether six individuals with Down syndrome, six employers and six family members were interviewed.

Table 4

Coding of Participants

Set	Person with Down syndrome	Employer	Family Member
Pilot	PPDs ³	PE	PFM
1	PDs1	-	FM1
2	PDs2	E2	FM2
3	PDs3	E3	FM3
4	PDs4	E4	FM4
5	-	E5	-
6	PDs6	E6	FM6

This study comprised of five individuals with Down syndrome, two males and three females. Four of the individuals with Down syndrome were first language English speakers and one was a first language isiZulu speaker. Three individuals with Down syndrome were employed in open employment with various support systems while the remaining two participants with Down syndrome were employed in a workshop environment. All except one of the individuals found their employment with the assistance of their parents. The remaining participant was assisted by a social worker. Job types ranged from physical work involving factory labour, gardening and packing to craft work and administrative assistance in a library. All individuals worked between 20-40 hours per week and receive a monthly salary. One individual receives a monthly government disability grant in conjunction with her salary. All of the participants own a cell phone and some own other forms of technology such as laptops,

³ **Key for Abbreviations**

PDs: Participant with Down syndrome

E: Participant who is an Employer

FM: Participant who is a Family Member

R: Researcher or **I:** Interpreter (Spoke on researcher's behalf)

*: The name of the participant or company has been removed for confidentiality

(The alphabetic numbering links to the coding of each individual described in Table 4 of the Methodology section of this study).

iPads and computers. Three of the participants rely on their parents for transport to work while one uses public transport and another drives himself. Two of the participants attended mainstream schooling and are proficient in reading and writing. One individual attended an LSEN school only and has basic literacy skills. The remaining two participants attended a period of mainstream school followed by a period of LSEN schooling and their literacy skills were basic and nonexistent. Four of participants received Speech-Language Therapy during childhood and the other participant did not receive any therapeutic interventions. This is illustrated in Table 5 on the following page:

Table 5

Description of Participants with Down syndrome

No.	Gender	Age (years)	Language	Type of employment ~ How Job was Found	Job type ~ Time at current job (years)	Working hours per week (hours)	Monthly Income	Technology Usage ~ Transport to Work	Schooling, Years at school, Literacy level (according to participants)	Speech- Language Therapy
PDs 1	Male	32	English	Open ~ Father	Factory labourer ~ 12	40	Salary	Cell phone Laptop ~ Drives a car	LSEN, Did not specify, Basic	During childhood
PDs 2	Male	24	English	Open ~ Mother	Gardener ~ 4	30	Salary	Cell phone iPad ~ Mother	Mainstream 5 years and LSEN 5 years, Basic	During childhood
PDs 3	Female	62	English	Workshop ~ Sister and Self	Crafts ~ 10	20-30	Salary	Cell phone Computer ~ Sister	Mainstream, 10 years, Proficient	During childhood
PDs 4	Female	28	English	Open ~ Parents and Employer	Library assistant ~ 11	20	Salary	Cell phone Computer ~ Parent	Mainstream, 8 years, Proficient	During childhood
PDs 6	Female	26	isiZulu	Workshop ~ Social Worker	Packaging ~ 5	30	Salary and grant	Cell phone ~ Public transport	Mainstream 2 years and LSEN 14 years, Illiterate	None

Five employers were involved in this study. All employers were female and ranged from 29 to 62 years old. Four of the employers were first language English speaker and one employer was isiZulu. The workplaces that were incorporated ranged from an old age home to a library and a workshop. Three of the employers were supervisors in the workshop context while the other employers held managerial roles. This is portrayed in Table 6 below:

Table 6

Description of Employer Participants

No.	Gender	Age (years)	Language(s)	Place of work	Job title
E2	Female	62	English	Old Age home	Manager
E3	Female	40	English	Craft workshop	Workshop Supervisor
E4	Female	47	English	Library	Head Librarian
E5	Female	63	English	Workshop	Workshop Supervisor
E6	Female	29	isiZulu	Workshop	Workshop Supervisor

Five family member participants were interviewed. The sample comprised of one male and four females. Four of the participants were interviewed in English and one in isiZulu. Most of the participants were the parents of individuals with Down syndrome and the remaining one participant was the sister of an individual with Down syndrome. This is depicted in Table 7 below:

Table 7

Description of Family Member Participants

No.	Gender	Age (years)	Language(s)	Relation to participant
FM1	Male	55	English	Father
FM2	Female	52	English	Mother
FM3	Female	66	English	Sister
FM4	Female	59	English	Mother
FM6	Female	67	isiZulu	Mother

5. Data Collection Process

Possible participants (individual with Down syndrome, employer and family member) were each sent an information letter, an informed consent document and a biographical information questionnaire via fax or electronic mail before the day of the interview. Alternatively, if the potential participant indicated that they would like to participate but did not have access to these facilities then the documents were provided on the day of the interview. These were made available in English or isiZulu depending on what the potential participant indicated as their preferred language for communication. English and isiZulu were chosen as the two languages of the study as these are the predominant languages of the province in which the study was conducted (Statistics South Africa, 2011).

The information letter instructed those participants who were interested in participating in the study to complete the informed consent document and the biographical questionnaire and return both of these documents to the researcher via fax or electronic mail. The documents supplied to the individuals with Down syndrome were designed to accommodate the cognitive and communicative levels of the individuals as jargon was avoided and simple sentences were used (Alzheimer's Disease & Association Disorders, 2004).

For this study, qualitative data was gathered through individual qualitative, semi-structured interviews as this is a dominant method of qualitative research (Golafshani, 2003). Qualitative interviews involve the gathering of information through an informal question and answer session (Gubrium & Holstein, 2001). Semi-structured interviews are best suited for gathering data for individuals with a mild to moderate form of barrier to learning as it best allows the individual to share their opinions and comment on their life style (Boyden, Muniz, & Laxton-Kane, 2012). The advantages of individual interviews are that they allow for a multitude of questions, the researcher may clarify or request further information if needed and nonverbal communication can be noted for interpretation (Neuman, 2009). The flexible nature of a qualitative interview allowed for in-depth data to be gathered (Kvale, 1996). Qualitative interviews were used with all three categories of participants who met the participant selection criteria. Interviews that are semi-structured merge the use of a structured instrument with direction and an agenda with the flexibility of open-ended questions (Schensul, Schensul, & LeCompte, 1999). Predetermined questions are used to guide the interview together and are expanded by the researcher and enhanced by the use of

probe questions (Schensul, et al., 1999). A semi-structured nature is optimal for studies where the aim is to explore (Schensul, et al., 1999). An interview that is semi-structured allows for the researcher to focus on certain areas if they become seemingly important in an interview and flexibility to enquire further should a participant not supply sufficient information on a given question (Patton, 2002). The nature of such an interview allowed for each interview to start in the same way and branch into various directions dependant on the information the participant supplied (Schensul, et al., 1999).

The interview was divided into three stages: an introduction or briefing, the main part of the interview where content was gathered and a closing or debriefing (Neuman, 2009). The researcher began the interview by reminding the participant of the aim of the study and the interview (Sansosti, Lavik, & Sansosti, 2012). Confidentiality was assured (Sansosti, et al., 2012). The participant was reminded of the consent form they signed and how the data was to be used (Sansosti, et al., 2012). Open-ended questions were used to gather data and additional questions were used to prompt and probe (Rubin & Rubin, 2005). The research problem was divided into parts so that each part was covered in a question. This prevents predetermining the information that will be gathered (Rubin & Rubin, 2005). This allowed for multiple themes to be explored (Rubin & Rubin, 2005). The researcher was flexible and followed where the conversation lead (Rubin & Rubin, 2005). The main questions allowed for content to be mapped, new dimensions and perspectives to be broadened (Rubin & Rubin, 2005). Prompts and probes were used to acquire further detail (Gillham, 2001). Prompts and probes are necessary if information has been misinterpreted (Leedy & Ormrod, 2010). Follow up questions allowed for elaboration, explanation, continuation, clarification and evidence (Rubin & Rubin, 2005). The meeting concluded with a vote of thanks and the researcher indicated that the study was to be made available should it be requested by the participant.

The interviewer needed to be sensitive, professional and patient at all times in order to facilitate the interview in the best possible manner (Neuman, 2009). The researcher became a crucial part of the data collection instrument as consistency was maintained from interview to interview (Golafshani, 2003). Additional factors such as tone and wording of questions remained the same in each interview to eliminate bias (Neuman, 2009). The researcher had previous experience in conducting qualitative interviews as part of an undergraduate study and therefore had developed knowledge and skills to conduct interviews effectively.

The interviews were conducted in English or isiZulu depending on the preference each participant indicated on their biographical questionnaire form. An interpreter and a translated version of the interview schedule were used in the interviews conducted in isiZulu. The interpreter was then considered the interviewer which allowed for a flow in conversation during the interview (Farooq & Fear, 2003). The interpreter involved in the study was a first language isiZulu speaker and had obtained a degree in Speech-Language Pathology. The interpreter was briefed beforehand on conducting the interview and on the aims of the study (Langdon & Cheng, 2002). The interview schedules were carefully explained so that the interpreter understood the type of information that the researcher was attempting to gain from each question. The interpreter asked the question from the interview schedule, listened to the participant's answer, interpreted the answer for the researcher and then the researcher indicated further prompts and probes to be used.

The interviews were held on a date and time specified by the participant and at a venue of their choice which promoted participation. A venue that was quiet and conducive to conducting an interview was requested by the researcher. There is no specified length of time for an interview as factors such as the method of data collection, the participant and the topic being discussed impact the time needed (Holloway & Wheeler, 2009). Permission to record the interview was obtained from the participant as part of the consent form and each interview was recorded for analysis (DiCicco-Bloom & Crabtree, 2006). Responses were recorded using two Olympus WS-110 digital voice recorders which were set on high quality. Field notes were kept by the researcher throughout the interviewing process. Field notes helped the researcher to connect with the participant and data in a new way (Wolfinger, 2002). They assisted in reconstructing the events when the recordings were transcribed and recorded additional observations of body language, facial expressions and communication (Wolfinger, 2002). The field notes assisted the researcher in identifying her own personal assumptions thus assisting in the process of eliminating bias in the interviews (Wolfinger, 2002). The salience hierarchy was used so that only information that stands out as being unusual or interesting was recorded (Wolfinger, 2002). The type of information written down depended on what the researcher noticed (Wolfinger, 2002).

6. Data Collection Instrument

Biographical information of each participant was collected before the interview on a biographical information questionnaire. Each participant was contacted via fax or electronic mail to complete the biographical information questionnaire which was sent with the information letter and informed consent document (Appendices B, C, D, E, F and G). The instrument for the individual with Down syndrome gathered information pertaining to personal biographical details, educational information, employment information and their ideal specifications for the interviews e.g. a suggested date. The instrument for the employer focused on personal biographical details, employment information and their ideal specifications for the interviews. The instrument for the family member addressed personal biographical information, information regarding the relationship between the individual with Down syndrome and the family member and their ideal specifications for the interviews.

The main data collection instruments for this study was three interview schedules, one for each of the three categories of participants (Appendices H, J and L). These instruments were translated into isiZulu (Appendices I, K and M). The isiZulu versions of these instruments were translated by a Speech-Language Therapist who was also a first language isiZulu speaker. It is recommended that translation was verified by someone who was not involved in the study and whose first language is the language of translation (Maneesriwongul & Dixon, 2004). A few typing errors were rectified and minimal wording was changed.

The instrument outlined the topics to be initiated and discussed in the interview (Leedy & Ormrod, 2010). With the participants with Down syndrome, the instrument had questions and probing questions covering the topics of educational and therapeutic history, employment history, perceptions in the workplace, job tasks, communication and social interaction in the workplace and family support. The instrument used with employers had questions and probes to promote discussion regarding understanding of Down syndrome and employment, perceptions in the workplace, job tasks and communication and social interaction in the workplace. The instrument for interviewing family members contained questions and probe questions that enquired about educational and therapeutic history, understanding of Down syndrome and employment, employment history, perceptions in the workplace, job tasks, communication and social interaction in the workplace and family support.

The interview schedules consisted of sections pertinent to the category of participant being interviewed. All questions were open-ended questions in line with the nature of qualitative research and the aim of exploring the experience of employment (Rubin & Rubin, 2005). Questions focused on the core areas which emerged during a review of the literature (Adams, 1998; Adkins, 1995; Buckley, 2000; Down Syndrome South Africa, 2005, 2011a, 2011b; Henwood & Dixon, 2002; Kumin, 1994, 1996; National Down Syndrome Society, 2012; Schall, 2010; Smith, 2001; Thönia & Gächterb, 2005; Vlachos, 2008; Webber, 2011). Special consideration was made with regard to the wording and explanation used in instrument, namely the information letter, informed consent document and interview schedule, for the individual with Down syndrome as the researcher was aware of the possible intellectual and language delays that may have been present. The sections that were included in the interview schedule are tabulated in Table 8 below.

Table 8

Sections Included in the Interviews with Motivations for These

Sections	Motivation
Educational and therapeutic history	Inquiring about schooling was crucial in establishing the vocational support the individual with Down syndrome received as well as in ascertaining whether they were assisted in the transition from school to employment. Both of these areas have been established as predictors of success in employment (Adams, 1998; National Down Syndrome Society, 2012; Vlachos, 2008). From the perspective of the Speech-Language Therapist it is crucial to know when and what Speech-Language Therapy was received as it may be beneficial in improving various aspects of communication (Kumin, 1996; Smith, 2001). Speech-Language Therapy may have been received privately or at the school either as part of a vocational training programme or not.

Perspective of Down syndrome	An employer's perspective of Down syndrome is what encourages them or discourages them from employing someone with a disability (Down Syndrome South Africa, 2005). This has a direct influence on the low employment rates of individuals with disabilities and prevents the rights of the individual with Down syndrome from being reached. This section uncovered the thoughts of employers regarding their employees with Down syndrome in an attempt to highlight the reality for prospective employers.
Employment history	It is important to understand how the individual with Down syndrome found their job, how difficult a task was for them and if the current employment options and assistance available when seeking employment are sufficient. Previous employment opportunities and experiences may also assist them in their current employment (Adkins, 1995).
Perceptions in the workplace	The employer's and co-workers' perspective of Down syndrome in the workplace impacts the role and responsibilities of the individual with Down syndrome in the workplace. Socialization amongst colleagues is also affected. Job and life satisfaction are affected by the relationships formed with other individuals (Vlachos, 2008). The employer's and co-workers' understanding of the strengths and challenges of Down syndrome is crucial (Buckley, 2000). Understanding impacts on the job tasks given to the individual with Down syndrome and the accommodations in the workplace (Buckley, 2000).
Communication and social interaction in the workplace	Listening and speaking form the basis for interactions in the workplace (Vlachos, 2008). It has been noted that communication, intelligibility and voice are areas of difficulty with individuals with Down syndrome (Kumin, 1994, 1996; Smith, 2001). This therefore impacts on the individual with Down syndrome's ability to communicate in the workplace. Communication over the telephone was also discussed.

	<p>Literacy skills, including reading and writing, usually develop in individuals with Down syndrome depending on their level of cognition and their educational exposure was explored (Abbeduto, et al., 2007). Communication has also been identified as a critical skill in an individual's level of self-determination (Vlachos, 2008). Nonverbal skills are an area of strength with individuals with Down syndrome thus these were investigated (Mundy, et al., 1988). Social interaction is required in the workplace for success in the work environment (Schall, 2010; Thönia & Gächterb, 2005). Individuals are influenced by their co-workers' opinions and actions thus it is necessary to have a positive work environment (Thönia & Gächterb, 2005).</p>
Job tasks	<p>This section uncovered the typical job tasks and duties given to individuals with Down syndrome as well as how employers went about selecting tasks applicable to employees with Down syndrome and the individuals themselves. It has been well recorded that accommodations are made in the workplace to assist the individual with Down syndrome (Down Syndrome South Africa, 2011a, 2011b; Henwood & Dixon, 2002; Webber, 2011). The accommodations specific to the job tasks the individual with Down syndrome undertakes were revealed. The use of technology such as computers and telephones was discussed in order to find out whether they form part of the individual with Down syndrome's skill base and how they are used in the workplace.</p>
Family support	<p>Family involvement in seeking and maintaining employment has been identified as one of the key elements in successful employment of individuals with intellectual disabilities (Vlachos, 2008). This section of questions identified to what extent the individual with Down syndrome requires family support and how they communicated their need for this.</p>

7. Pilot Study

A small scale version or trial run of the data collection method is known as a pilot study (Schreiber, 2008). It is necessary to address logistical, feasibility and integrity constraints of the data collection instrument and process before data collection takes place (Schreiber, 2008). The integrity of the data collection instrument is strengthened if it is administered to a few participants, who met the selection criteria of the study, prior to data collection so that the instrument may be edited if necessary (Leedy & Ormrod, 2010; Phillips & Stawarski, 2008).

The consent forms, biographical questionnaires and interview schedules were each piloted with an individual from one of the three categories of participants. The first set of participants who met all the selection criteria were selected to participate in the pilot study. The pilot interviews were conducted before data collection on dates and at a venue convenient to each of the pilot study participants. The Table below describes the participants of the pilot study.

Table 9

Description of Pilot Study Participants

Type of participant	Gender	Age (years)	Type of Employment	Language	Venue
Individual with Down syndrome	Male	24	Administration	English	Participant's home
Family member (mother)	Female	45	House wife	English	Participant's home
Employer	Male	52	Business owner	English	Participant's home

The participants of the pilot study interviews were questioned following the interview to provide feedback on the data collection instrument and the facilitation of data collection (Phillips & Stawarski, 2008). The researcher enquired about the nature of the questions, phrasing of the questions, the participant's ability to understand each question, the tone used

in asking the questions and the length of the interview. The data and feedback obtained from the pilot study allowed for the researcher to practice the method of data analysis, note the areas covered by the questions and to ascertain if the instrument allowed for gathering of sufficient applicable information (Schreiber, 2008). Changes were made to the data collection instrument and the manner of interviewing based on a review of the audio recordings and electronic feedback from the participants. These are tabulated in Table 10 below.

Table 10

Description of Changes Made Following the Pilot Study Interviews

Area of focus	Feedback from pilot participant and from researcher	Action taken
Consent and biographical questionnaire forms	The participants indicated that these forms were straightforward and easy to complete.	No changes were necessary.
Quality of audio recording	The noise of television and people could be heard thus affecting the clarity of the participants' verbal responses on the recordings.	The level of background noise needed to be checked at the beginning of each interview and where necessary further effort needed to be made to encourage a quiet environment.
Length of interview	The interviews were shorter than the researcher had anticipated because the researcher did not provide the participants with adequate time to think over the questions and respond.	More time was provided to the participants when they were answering questions.
Questions in data collection instrument	The participants indicated that they saw the relevance in all of the questions asked and found them to be fair.	No changes were necessary.
Wording of questions in data collection instrument	The researcher noticed some confusion and hesitation with some questions.	Some wording was edited on the data collection instrument in the main questions (see Table 11 below).
Researcher's manner during interview	The participants noted the researcher's manner as being professional, compassionate and respectful.	No changes were necessary.

The interview schedules were edited to provide clarity for the participants and to assist in administering of the questions. For ease of reference, the questions were renumbered so that the numbering went throughout the document as opposed to restarting the numbering system under each subheading in the interview schedule. The question and probe question changes made to the three interview schedules have been summarized in Tables 11, 12 and 13 below. A detailed description of each of these changes has been tabulated in Appendix N.

Table 11

Summary of the Changes Made to the Interview Schedule: Individual with Down syndrome

Type of Change Made	Questions that were Changed
Questions reworded for clarity or accuracy of information elicited	3, 5, 8, 9, 14, 15, 22, 23, 24, 25
Questions added	24 and two concluding questions
Questions omitted	3
Probe question added	1, 3, 9, 14, 30
Probe question omitted	14

Table 12

Summary of the Changes Made to the Interview Schedule: Employer

Type of Change Made	Questions that were Changed
Questions reworded for clarity or accuracy of information elicited	3, 16, 22, 23, 24, 25
Questions added	Two concluding questions
Questions omitted	One due to duplicated information
Probe question added	16, 23, 25
Probe question omitted	-

Table 13

Summary of the Changes Made to the Interview Schedule: Family Member

Type of Change Made	Questions that were Changed
Questions reworded for clarity or accuracy of information elicited	2, 3, 4, 5, 13, 21, 22
Questions added	-
Questions omitted	Two due to duplication and one was made a probe
Probe question added	4
Probe question omitted	-

8. Data Analysis

Data generation was continuous until saturation was reached (Cohen & Crabtree, 2006; Siegle, 2002). The point of saturation was reached when sufficient data was present and no new themes emerged in analysis (Cohen & Crabtree, 2006; Siegle, 2002). The researcher then immersed herself in the data by analyzing the data closely for details as well as intermittently surfacing from the process to identify larger themes (Cohen & Crabtree, 2006). The researcher then searched for meaning from what was said (Cohen & Crabtree, 2006).

Data analysis was continuous throughout the process of data generation (Siegle, 2002). The data analysis spiral was used to analyse the data in a step by step format (Creswell, 1998) (See Figure 1 on page 72). This process involved working through the raw data in a systematic fashion but also constantly reverting back to the data to gain depth and insight as opposed to working through the data in a linear manner (Creswell, 1998). Raw data was organized and prepared to make it more manageable before being broken down to extract content (Creswell, 1998). The raw data, which in this study was a series of audio recordings, was organized in an electronic filing system (Creswell, 1998).

Each recording was then transcribed in order to prepare for analysis of the content (Creswell, 1998). Data that was collected in isiZulu was transcribed in isiZulu and translated into English by a first language isiZulu speaker and then back translated by another first

language isiZulu speaker to ensure accuracy (Brislin, 1970). Both individuals used in translation had a University degree, one in Speech-Language Pathology. A few word selection changes were made to avoid jargon; however, a majority of the translation was in agreement.

After organization, the data was perused which allowed the researcher to gain an overall idea of the content and gain a preliminary impression of the possible themes that emerged (Creswell, 1998). Sections of data were extracted and categorized with other data representing a similar thought (Creswell, 1998). This was a manner of condensing the information into themes so that the data became workable and the researcher began to find meaning in the content (Creswell, 1998).

Data was then synthesized in order to offer hypotheses and connections drawn between themes (Creswell, 1998). Triangulation of data took place. Data triangulation is the process by which data from various sources, researchers, methodologies or theories is compared to validate and cross-check findings (Holloway & Wheeler, 2009). Data triangulation was used in this research study to compare data supplied by different sources which in this study was the three different categories of participants (individual with Down syndrome, employer and family member). This form of triangulation may also be referred to as person triangulation as the information comes from different groups of people (Denzin, 2006). Gaining and triangulating information from various people provided insight and wisdom on the topic (Denzin, 2006). Triangulation improved the validity of findings and assists in overcoming bias (Holloway & Wheeler, 2009). This assisted in confirming a view point and added a different dimension to findings (Denzin, 2006). Analysis of data and thematic analysis was cross checked by a colleague who was familiar with the topic. This was termed as peer debriefing and enhances the validity of qualitative research (Sansosti, et al., 2012). This allowed for an unbiased opinion on the analysis to be obtained and allowed the researcher to cross check analysis so that all data was sufficiently analysed (Cutcliffe & McKenna, 2001). The outcome of this indicated that analysis was thorough and the themes derived from the data were an accurate representation of findings. The quality of qualitative research was measured through the thoroughness of data analysis, the believability of data and transparent processes of data collection and analysis (Rubin & Rubin, 2005). The final report was compiled as a representation of the themes identified from the data analysis (Creswell, 1998).

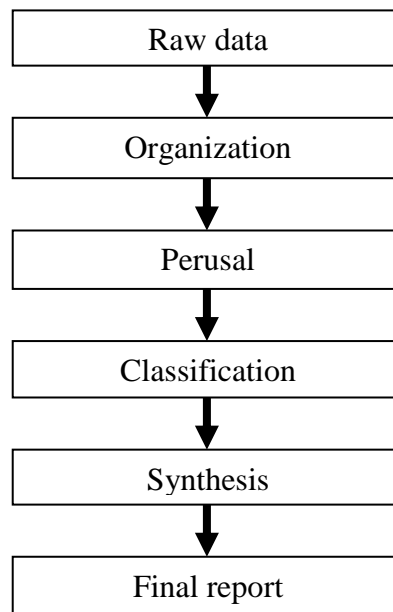


Figure 1: The Data Analysis Spiral (Creswell, 1998).

9. Issues of Reliability and Trustworthiness

Reliability is used to describe when the same outcomes of the study may be achieved if the study were to be repeated (Neuman, 2002). In qualitative research, reliability is evident in the quality of the data collected (Golafshani, 2003). Quality is measured by the credibility, conformability, consistency and transferability of the study (Lincoln & Guba, 1985).

Research that is consistent should be dependable and reliable in the manner in which the data was collected and analysed (Golafshani, 2003). Various methods were employed to ensure and enhance the reliability of this study. The data collection instrument that was used was developed based on current literature to ensure relevant information was included. The information letter, consent form and data collection instrument were translated into isiZulu. Translation was done by a first language isiZulu speaker and verified by a first language isiZulu speaker who is also a qualified Speech-Language Therapist and therefore had exposure to the terminology and concepts involved in the study. The data collection instruments were piloted to strengthen reliability.

In both the pilot study and the interviews, the researcher ensured the manner and tone in which questions were presented to participants remained consistent (Neuman, 2009). This was crucial in making sure that each participant had the same experience of the interview

instrument and data collection method (Golafshani, 2003). In interviews that were conducted in isiZulu, as per the request of the participant, the interpreter functioned as the facilitator who was briefed beforehand on methods of facilitation and the importance of accuracy. The interpreter was briefed before the interview and debriefed after the interview to enhance the validity of the study (Langdon & Cheng, 2002). The interpreter was briefed on the nature of the study, the various questions as well as how to interact with the participants (Langdon & Cheng, 2002). The interpreter was debriefed after the interview to confirm what was said by the participant, to restate the purpose of the information gathered and its accuracy as well as to be thanked (Langdon & Cheng, 2002).

Trustworthiness is a term used specifically in qualitative research to encompass the values of credibility and dependability of research (Lincoln & Guba, 1985; Welman, Kruger, & Mitchell, 2005). Credibility involved the researcher ensuring that the results obtained are an accurate reflection of what was gathered from the information supplied by the participants (Welman, et al., 2005). Dependability referred to the processes of data collection, integration and analysis (Lincoln & Guba, 1985).

All participants selected met the selection criteria thus the authenticity of their contribution towards the study was increased (Behar & Borkovec, 2003). All interviews were audio recorded on two digital recorders each set on the highest quality. This allowed the researcher to have multiple, clear copies of each interview (Modaff & Modaff, 2000). Background noise at each venue was closely monitored by the researcher and avoided (Modaff & Modaff, 2000). The researcher conducted member checking by checking important data with the participant during and after the interview which insured that information was accurately understood (Burke Johnson, 1997). All interviews were transcribed verbatim so that participants were accurately represented. Transcriptions were verified by an independent researcher and the supervisors to make sure that the information was dependable. Field notes were kept during the pilot interview and all of the study interviews. These notes assisted in keeping record of the events of the interviews (Mulhall, 2003; National Science Foundation, 2011). Analysis was done by the researcher and peer debriefing with an additional researcher who was not involved in the study (Sansosti, et al., 2012). This ensured that data had been sufficiently and accurately analysed.

10. Ethical Considerations

Ethical principles are prescribed values and morals that are to be followed to prevent any form of harm to the participants (Health Professions of Council South Africa, 2008; Leedy & Ormrod, 2010). The researcher completed an on-line course to gain understanding in ethical principles and practice (Appendix O). Ethical clearance to conduct the study was obtained from the University of KwaZulu-Natal School Research, Ethics and Higher Degrees Committee (Appendix P).

Each possible participant was provided with an information letter, consent form and biographical questionnaire in either English or isiZulu depending on their language of preference (Appendices B, C, D, E, F and H). The three documents (letter, consent form and biographical questionnaire) for each of the three categories of participants were compiled as individual documents and were on separate pages. The three documents per category were combined into one appendix and were sent together as a unit. The letter informed participants on the nature of the study, provided an explanation of their involvement, indicated the use of an audio recorder during interviews, notified that recordings and data would be kept for five years and then destroyed through deleting and shredding, assured of confidentiality and indicated that participation was voluntary and that they were able to withdraw at any stage without penalty (Barrett, 2006; Health Professions of Council South Africa, 2008). The letter indicated the benefits of the study and also clearly indicated that the study would in no way result in employment, a change in employment status or increased income so as not to falsely raise the hopes of the individual with Down syndrome as well as his or her family. The letter also indicated to participants that they were to keep their original copy of the letter, signed consent and completed biographical questionnaire documents. Copies of these were kept by the researcher. The consent form required the participant to sign indicating that they had read the information letter and were giving their consent to participate, permitted audio recording in the interview, were to provide accurate information and indicated that they were aware that participation was voluntary and participation would not benefit them directly. An information letter was provided to the interpreter and he/she was required to complete and sign a document of informed consent and confidentiality and complete a biographical questionnaire (Appendix Q).

Participants, who were employers and family members were required to read an information letter, sign a consent form and complete a biographical questionnaire. These documents and the interview schedules for these participants had been written in language that is easy to understand so as to avoid confusion. The letter to the family member indicated that their signed consent form indicated their permission to access the individual with Down syndrome's employer. The employer's details were accessed through the family member and the researcher contacted the employer to establish rapport and deliver the employer's individual information letter, consent form and biographical questionnaire.

Individuals with Down syndrome may be considered a vulnerable research population due to the presence of an intellectual disability (Health Professions of Council South Africa, 2008). Individuals with an intellectual disability should be included as researchers or participants when topics involving people with intellectual disabilities are researched (Turk, et al., 2011). These individuals should not be considered as passive members when research is done into services with which they are involved (Boyden, et al., 2012). Research with such a population should be inclusive and encourage the participation of those being researched (Boyden, et al., 2012). This is in keeping with the biopsychosocial framework chosen for the study where the individuals' subjective views about their disorder and related issues are explored (Borrell-Carrió, et al., 2004). The appropriate methodology, data collection instruments, partnerships and focus were developed (Turk, et al., 2011). Gaining informed consent from such a population raises various ethical issues (Bond & Hurst, 2009). Information needs to be presented in a meaningful manner (Bond & Hurst, 2009). Assent can be defined as identifying if a person is willing to participate should they be too young to complete the consent form but are able to understand the proposed research (MedTran, n.d.). Individuals with Down syndrome may provide assent if they are unable to comprehend and complete the written consent form. Parents or caregivers had to undertake the responsibility of finding out if the individual with Down syndrome wanted to participate in the study. The parent or caregiver was responsible for reading the information letter, understanding its content, following through with instructions, gaining assent from the individual with Down syndrome and signing the consent form on the individual with Down syndrome's behalf. Consent was an ongoing process to ensure that the individual with Down syndrome was aware that participation was voluntary and so that they were not stressed by the process of the interview (Preece & Jordan, 2009).

The researcher adjusted various elements of the research method, instrument and procedure accordingly. Interview schedules for the interview of the individuals with Down syndrome were developed with the cognitive and linguistic levels typical of an individual with Down syndrome in mind. Research involving individuals with an intellectual impairment has indicated that anyone providing a service to the individual should communicate at an appropriate level, have a welcoming approach and be open to discussion (Boyden, et al., 2012). The researcher kept in mind that each individual is unique with their own personality traits, strengths and weaknesses (The Centre for Developmental Disability Health Victoria, 2008). The researcher took some time to have an introductory period before the interview commenced which allowed the participant to feel comfortable in the situation (Preece & Jordan, 2009).

Working with any population with intellectual disability requires the researcher to supply support (The Centre for Developmental Disability Health Victoria, 2008). The researcher supported the participants' cognitive level, their expectations in the environment and any other co-occurring disabilities with which the individual presented (The Centre for Developmental Disability Health Victoria, 2008). The individuals' cognitive and communicative abilities are strong predictors of the level of support the individual requires (The Centre for Developmental Disability Health Victoria, 2008). Strategies to enhance communication with the individual with Down syndrome included attitude, communication and working with the family (The Centre for Developmental Disability Health Victoria, 2008). With regard to attitude, the researcher conveyed respect for the individual with Down syndrome through appropriate body language and verbal communication (The Centre for Developmental Disability Health Victoria, 2008). The researcher used an appropriate tone of voice remembering that she was conversing with an adult regardless of the cognitive ability of the individual (The Centre for Developmental Disability Health Victoria, 2008). To support receptive communication the researcher spoke slowly, paused regularly to allow for the individual to process the information, kept sentences short and clear and asked one question at a time (The Centre for Developmental Disability Health Victoria, 2008). Questions were appropriately worded and provided examples and analogies to facilitate understanding (Perry, 2004). Participants with Down syndrome were given time to respond to questions which allowed for processing and clarification and any difficulties in expression (Preece & Jordan, 2009).

If the researcher did not understand the individual with Down syndrome when they communicated, the researcher asked the individual to repeat themselves, asked the individual to explain in another way, asked a family member for clarification or asked closed ended questions to clarify their understanding (The Centre for Developmental Disability Health Victoria, 2008). The researcher did not pretend to understand the individual but rather took the responsibility for a communication breakdown and apologised if she had attempted to understand but still did not (The Centre for Developmental Disability Health Victoria, 2008). Overall communication was enhanced by the researcher making sure they had the individual's attention by using their name, eye contact or a light touch on the shoulder (The Centre for Developmental Disability Health Victoria, 2008).

Interviews were conducted on a date and at a time and place convenient to the participant and in a venue that was conducive to interviewing. Interviews were conducted in isiZulu when the participant indicated this as their language of preference on the consent form. This was necessary as the researcher wanted to interview a variety of participants from various linguistic and cultural backgrounds. It was also necessary that the participants were able to speak in their first language in order to feel comfortable sharing their experiences. An interpreter was used to assist in communication in isiZulu and an isiZulu version of the data collection instrument was used. The instrument in isiZulu assisted the interpreter in interviewing participants whose first language was isiZulu. The interpreter was also briefed on the aim of the study and methods of effective interpretation before conducting the interview.

Participants were coded to ensure confidentiality e.g. Participant 1, Employer 1, Family member 1 (Health Professions of Council South Africa, 2008). All participants were treated equally and with respect. Transcriptions were recorded accurately and results were analysed and reported honestly (Institute of Medicine (United States) Committee on the Responsible Conduct of Research, 1989). Recordings and data will be kept for five years (Creswell, 2009). Hard copies of data will be kept in a locked cupboard at the University of KwaZulu-Natal in the Speech-Language Pathology department. This will be destroyed via shredding after five years. Electronic data will be stored on a computer that is password protected. This will be deleted after five years.

The researcher has a social responsibility to make sure that research findings are shared with the appropriate parties involved in the study and to ensure the perspectives of the participants are shared with society at large (Health Professions of Council South Africa, 2008; Marczyk, DeMatteo, & Festinger, 2010). In keeping with the critical paradigm of the study, the findings of the study will be freely shared or summarized and shared with all participants. Each participant will receive an electronic or hard copy of the findings if indicated on the returned consent document. Preliminary findings were presented at the World Down Syndrome Congress in Cape Town in August 2012. Complete findings were sent to organizations in South Africa that assist with the employment of individuals with Down syndrome, schools that educate learners with intellectual impairment and the associations, schools and individuals that assisted in locating participants.

11. Procedure

- 11.1.** The research proposal and ethics course certificates were submitted to the University of KwaZulu-Natal School Research, Ethics and Higher Degrees Committee for ethical clearance
- 11.2.** Letters were sent to Down Syndrome South Africa, Durban and Coastal Mental Health, various schools that educate learners with special needs and places of supported employment in KwaZulu-Natal to assist in identifying possible participants
- 11.3.** Possible participants were contacted telephonically to identify whether they would be interested in participating in the study
- 11.4.** Information letters and consent forms were sent to all interested participants
- 11.5.** The pilot study was conducted
- 11.6.** The interview schedules were adjusted according to the information obtained in the pilot study
- 11.7.** Each participant completed a form prior to the interview to capture biographical details
- 11.8.** Interviews were conducted with each of the participants
- 11.9.** The recording of each interview was transcribed by the researcher
- 11.10.** The transcriptions were analyzed and the data categorized into themes
- 11.11.** Transcription and analysis was verified by an impartial researcher
- 11.12.** The study document was compiled based on results and discussion of relevant literature.

Summary of Chapter

The methodology chapter of the dissertation described the procedure undertaken to complete the study. The aims, research design, selection criteria for participants and details of the participants were explained. Data collection and data analysis were described in detail. The chapter concluded with a review of the issues relating to validity, reliability, trustworthiness and ethical undertakings of the study.

Chapter Four: Results and Discussion

This study aimed to explore the employment experiences of individuals with Down syndrome and people who are directly involved in the individuals' employment, namely family members and the employers. The participants include five individuals with Down syndrome, five employers and five family members. The individuals with Down syndrome comprised of those employed in the open employment market as well as those employed in the workshop context. Male and female participants were represented in the individual with Down syndrome category and family member category; however all employers were female. Both English and isiZulu participants were included. The results and discussion reflect information gathered during the interviews. All results are described qualitatively in terms of the themes that emerged from analysis of the data. The results will be interpreted and related to literature. Results will be presented according to main and subthemes that are consistent with the objectives of the study and emerged during data analysis. These are outlined below:

1. "I think they understand her"- The Variability in Speech and Language Skills
2. "Washing the Chairs"- The Cognitive-Linguistic Link
3. Deteriorating with Age- "a little bit of deterioration as she's gotten older"
4. "She's also a bit moody"- Variability from Day to Day
5. "Talk slowly" or "repeat myself" - Tackling Conversation Breakdown and Repair
6. "And his reading went..."- School Involvement and Literacy Development
7. Contributors to Independence
8. Differences in the Workshop Context
9. The Technological Era- "He's picked up...rapidly with modern technology"
10. Positive Effects of Employment- "His employment ... a better life for all of us"
11. Comparing Cases- The Variability from Person to Person
12. The Role of Early Intervention
13. The Roles of the Game Players
14. Gaining Employment: Does Law Match Reality in South Africa?
15. Selecting Job Tasks- "he does anything and everything"
16. Job Challenges
17. The Role of a Speech-Language Therapist in Working with Adults with Down syndrome
18. A Pot of Gold at the End of the Rainbow- Types of Support
19. The Journey to Successful Employment

1. “I think they understand her”- The Variability in Speech and Language Skills

Speech may be a challenge for individuals with Down syndrome due to poor articulation, decreased intelligibility, persisting phonological processes, differences in vocal quality and differences in prosody (Kent & Vorperiana, 2013). Adequate speech skills are necessary for intelligible communication in the workplace (Darling & Dannels, 2003; Shmerling, 1996). Individuals with Down syndrome in this study varied in their level of intelligibility. Family member participants felt that they were able to understand the individuals but explained that unfamiliar individuals, such as in the workplace situation may experience difficulty understanding their speech. Some employers shared in concerns relating to poor intelligibility. No consistent findings on the clarity of speech were obtained thus conclusions about the intelligibility of speech of individuals with Down syndrome in the workplace could not be made other than intelligibility being affected by any combination of the above mentioned factors to various degrees. These speech difficulties are not specific to Down syndrome and could affect an individual without Down syndrome; however their combination, in various degrees, is linked to the profile of an individual with Down syndrome.

FM4: “I think they understand her. Mostly I think. And I mean I very seldom have to go in and sort anything out. So I think that they do”

E2: “Um his speech is not a hundred percent clear but he’s quite a he makes himself understood”

E5: “I do understand her. I listen carefully and the others listen carefully ‘cause we know she’s got that impairment with her speech”

FM2: “If he’s tired ja you can’t always understand him and if he’s excited you can’t always understand him but generally his speech is ok.”

Family members and employers described the anatomy of the tongue as impacting the precision of articulation and thus the individual’s speech. They spoke of an enlarged tongue as though it was a common characteristic of Down syndrome and was the cause behind any articulation difficulties. The size of the tongue but in relation to the oral cavity has often been described as a structural difference that impacts articulation and intelligibility (Stoel-Gammon, 2001). The position and protrusion of the tongue may be the cause of articulation difficulties (Kumin, 1996). Low muscle tone may also be responsible for poor articulation (ICD10Data, 2012).

FM6: “I told them about her tongue, that it has a problem, she can speak but it is not clear.”

PDs1: You see because my tongue is thick

“Lisps” were described by two of the participants. This was consistent with literature as individuals with Down syndrome may experience difficulties with the production of sibilant speech sounds and therefore are classified as having a lisp (Gibson, 1978; So & Dodd, 1994). Rate of speech is another aspect that was mentioned in the interviews that may impact speech intelligibility. This may be due to a difficulty in sequencing the fine motor movements needed for speech (Kent & Vorperiana, 2013; Layton, 2000). Individuals were described as speaking too fast, possibly because they had difficulty monitoring their speech, they felt the need to have their say in order to discourage notions of discrimination or they were attempting to cover up for insufficient expressive language abilities to express themselves more effectively. Family member participants indicated that rate and articulation were negatively affected when the individual with Down syndrome was tired or excited. Some individuals with Down syndrome were able to identify this characteristic in their own speech. It is reported in literature that intelligibility is affected to some degree throughout the lifespan (Kent & Vorperiana, 2013). Lingual sounds may be impacted due to low muscle tone or tongue positioning and this too may impact intelligibility (Stoel-Gammon, 2001). This is consistent with findings in this study as all individuals with Down syndrome were reported to have speech that is at times less intelligible. Four out of the five individuals with Down syndrome had Speech-Language Therapy when they were younger. Some of the individuals presented with intelligible speech while others experienced poor intelligibility. This may be because therapy was received for a short period of time only or because therapy focused more on language as opposed to speech intelligibility.

PDs3: “‘Cause I’ve got a lisp and people say ‘scuse me’ especially family. ‘Talk slowly’

E5: “Well she does have that sort of like a lisp”

~

FM3: “Lately, and that’s when we have to say slow down, ‘cause sometimes she’s so keen to get her point across or tell you something that she speaks too fast”

PDs3: “‘cause when I talk I talk like a galloping horse... ‘cause I get very emotional and very excited”

FM3: “not only for spelling but for speech as well, pronunciation and that was where we would hear the words over and over and over”

1.1. Talking is tough so you have to “become attuned to that accent”

One employer suggested that it is possible for the employer to improve their understanding of the individual with Down syndrome’s speech by training one’s ear to listen carefully to pick up what the individual is saying as though adjusting to listening to a person speaking with a foreign accent. The concept of getting used to the speech techniques and pronunciations of an individual with Down syndrome has been described in other studies which found that it takes people who are unfamiliar with the individual’s speech, some time to understand the individual with Down syndrome (McAllister, 2008).

E4: “I can understand her perfectly...Some people do say they can’t but it’s just like anything. You hear an Italian speaking English, your ear’s got to become attuned to that accent and then before long you’re enjoying what he’s saying.”

Vocal quality was not discussed by any of the participants in the study; however some individuals with Down syndrome were observed as having a hoarse voice. Differences in vocal quality have been described in some studies concerned with the speech of individuals with Down syndrome (Kent & Vorperiana, 2013).

Poor speech intelligibility and difficulty with expressive language affected some of the individuals with Down syndrome. They therefore experienced communication difficulties in the workplace, which impacted the job tasks and opportunities available to them. Some employers and family members encountered difficulties understanding the individuals with Down syndrome but through experience have created their own coping strategies.

1.2. The “communistration” in communication

Expressive language is an area of great concern in the majority of individuals with Down syndrome (Abbeduto, et al., 2007; Roberts, et al., 2007). Expressive vocabulary develops around the employment experiences to which an individual with Down syndrome is exposed (Kumin, 1996). Syntactical difficulties are prominent in most adults with Down syndrome (Rondal & Comblain, 1996). Some of the individuals with Down syndrome or their family members in the study spoke about the difficulties in expressing themselves. Others were not able to express their difficulties in words; however, their language during the interviews indicated that they may experience difficulty expressing themselves as they

pronounced long words incorrectly (e.g. “communication” pronounced “communistration”), some spoke in short one or two word utterances, repetition of words and concepts was noted, the use of interjections such as “uh” and “um was evident and some individuals left out words in sentences, often the subject (e.g. PDs2: “Play angry birds” instead of “I play angry birds”).

FM2: “I don’t think he that he’s always able to communicate what he’s thinking although it’s better now.”

FM4: “it’s been very hard for her to be able to express herself because she doesn’t want to be seen to be um rude or disrespectful”

1.3. “He’s picked up a bit of Zulu”- Learning Another Language for Social Interaction

All individuals with Down syndrome who were involved in the study spoke one language only although some knew a few words or basic sentences in another language, namely Afrikaans, isiZulu or English, because of the work environments to which they are exposed. Individuals with Down syndrome picked up common words and phrases from observation of communication between fellow co-workers. Knowledge of the new language was then used in order to socialize, in hopes of being more socially accepted because of the effort they had made. This would be a form of Basic Interpersonal Communication Skills (BICS) whereby the individual learns a second language in order to be able to converse on general everyday topics (Cummins, 1984).

E2: “He can help himself in Afrikaans.”

E2: “The two of them work really well together and I don’t know whether he’s picked up a bit of Zulu”

E3: “She’ll try and tell me something about somebody in Afrikaans.”

E6: “Other employees speak English. I don’t know how she does it, but she is able to catch the conversations of those speaking in English and understand when they talk to her”

2. “Washing the Chairs”- The Cognitive-Linguistic Link

There are no consistent findings about the receptive language skills of individuals with Down syndrome (Roberts, et al., 2007). This was evident in this study as receptive language was found to be an area of relative strength in the workplace with most participants

provided that vocabulary was kept simple and the sentences were not too complex or linguistically loaded. The development of receptive language may or may not be delayed and this is dependent on the individual's cognitive abilities (Abbeduto, et al., 2007; Kumin, 1996; Long, 2005; Roberts, et al., 2007). This was evident in this study as those with reported weaker cognitive skills often remained quiet when they did not understand or responded with a short answer that indicated poor receptive language and that the individual had not understood the question such as one participant with Down syndrome talking about washing chairs when she was asked about what it is like to have Down syndrome. Receptive language did not impact employability as employers were not aware of the individual's receptive language abilities before employing them. Receptive language was however linked to the type of employment as those with weaker levels of receptive language were generally employed in a sheltered workshop environment. In terms of receptive language in the workplace, employers and co-workers need to be aware of the individual's receptive language skills in order to ensure effective communication and ability to understand instructions for job tasks.

FM1: "he's got a good sense of understanding, he understands quite well"

FM3: "she's always had a very good understanding"

E2: "He understands instructions."

E6: "She understands me and I understand her."

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I: Now we are going to talk about what it is like to be a person with Down syndrome who works...How is it to do you think...?

PDs6: Wash the chairs

Individuals with Down syndrome found that people simplify communication when speaking to them. This occurred with some co-workers in some of the workplaces represented in the study. In such instances, the individuals with Down syndrome had not requested such a change in communication but rather this stemmed from misunderstandings and myths about the abilities of someone with Down syndrome and their personal communicative abilities. Interestingly, both of the individuals that described such events were noted by their family members and employers as being cognitively able and with developed linguistic and communicative skills. These cognitive and linguistic abilities may also be the reason that allows the individuals with Down syndrome to reflect on such experiences while others may not have the abilities to do so.

PDs1: “That if I’m talking to them very calm. They talk nice sometimes they talk proper to me”

FM4: “I think that for me there are times where *PDs4 is the child in that place”

Some individuals with Down syndrome presented with difficulties with receptive language and this was further impacted on by the severity of intellectual disability. This impacted the type of employment the individuals were placed in and in this way impacted their employment experience. Some individuals with Down syndrome experienced discrimination in the workplace as co-workers would oversimplify communication in these instances. Receptive language is therefore an area for Speech-Language Therapists to develop; however the individual’s intellectual functioning must be taken into account.

3. Deteriorating with Age- “a little bit of deterioration as she’s gotten older”

Memory loss and deteriorating speech intelligibility are associated with aging in the Down syndrome population (Evenhuis, 1990). One participant, who was older than the others, was described as starting to forget things and her speech intelligibility was described as sometimes being affected.

E3: “Well she her verbal skills is going backwards. It’s sometimes a little bit harder to understand what she’s saying”

Social skills may deteriorate with age if the individual does not retain the understanding of social behaviours or due to embarrassment pertaining to decreased speech intelligibility or memory loss (Nelson, et al., 2001). PDs2’s employer noted that PDs2’s memory has started to deteriorate and this was evident in the workplace as she would forget the steps for a job task and easily became frustrated with herself and others. This affected her morale in the workplace and also her social interaction with others. Here the employer had to intervene so that the individual’s job performance and job satisfaction were not affected.

E3: “over the last couple of years obviously we’ve seen a little bit of deterioration as she’s gotten older... At this stage she gets a bit confused at times... but she is getting older. Her memory is not as good as it was.”

E3: “she’s not doing the right thing and she’s blames it on herself and that is very very hard. It breaks my heart when that happens”

FM3: “she does get a little bit frustrated now with the younger ones”

The individual with Down syndrome that reported memory loss experienced frustration in the workplace due to not being able to remember instructions. This also affected her relationship with co-workers and therefore impacted her and her co-worker's social experiences in the work place.

4. “She’s also a bit moody”- Variability from Day to Day

Many of the family members spoke of the individuals with Down syndrome having mood swings or moody days and noted that communication may appear to be poorer on such days. Literature notes that mood swings are not characteristic of Down syndrome and occurs in the Down syndrome and non Down syndrome population alike (Buckley, Bird, & Sacks, 2002). There is however a link between mood swings and personality type or the severity of the intellectual disability (Buckley, Bird, & Sacks, 2002). This was evident in the study as the participant who was described as being moody was also described as being less cognitively able. Colleagues and employers needed to be mindful of this to ensure effective communication. Management of emotions is crucial in maintaining well-being (Haigh, et al., 2013). In one instance, E5 described how an individual with Down syndrome's mood swings prevented her from taking part in a training programme. The individual was upset on the starting day of the training course and did not want to participate. Her defiant mood on the first day prevented her from being allowed to attend subsequent days of the training course. If her employer had been aware of how to deal with such mood swings, the individual would have taken part or alternatively allowance could have been made for the individual to miss one day of the course and continue on the following day.

<p>E5: “she’s also a bit moody and sometimes she just doesn’t want to interact with the others”</p> <p>E5: “We actually did um have her sent to training and then she went for one day and then she objected.”</p>
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It was evident that not all individuals with Down syndrome found it as natural to socialize with other people at work and at times felt intimidated by situations or having a lot of people around them. At break times some individuals take their break by themselves instead of interacting with other staff in the staff room. They indicated that being with many other staff members all at once can be overwhelming. Some participants found it difficult to make friends because of their shy personalities or if they felt isolated because of having a disability. Others experience mood swings which influence their ability to socialize in the

workplace. Social interaction, regardless of how difficult for the individual, was viewed as beneficial in developing the individual's social skills. Communication difficulties may impact social interaction and ultimately impact how an individual is able to participate in society (Mpofu & Oakland, 2010).

E4: "there's no interaction. She doesn't go to the staff room at lunch time for instance and sit because there's no conversation level"

PDs4: "Hmmm it's a bit scary hey? 'cause sometimes I guess it's a bit too much"

PDs4: "I don't know if I have friends"

E5: "she's also a bit moody and sometimes she just doesn't want to interact with the others"

Mood swings and personality differences affected individuals with Down syndrome in the workplace just as they would impact individuals without Down syndrome. A majority of the individuals found socializing an area of strength except on days where they experienced mood swings.

5. "Talk slowly" or "repeat myself" - Tackling Conversation Breakdown and Repair

Miscommunications and conversation breakdown in the workplace occur regardless of Down syndrome or the communicative context and environment. Participants with Down syndrome experienced a breakdown in conversation in the workplace due to poor intelligibility and expressive language skills. This is in keeping with findings in other studies on expressive language skills and communication breakdown (Down's Syndrome Association, 2008; Rosin, et al., 1988). Similarly literature indicates that pragmatic skills develop but topic initiation, topic maintenance and conversation repair do not occur as frequently in comparison to individuals without Down syndrome (Beeghly, et al., 1990; Martin, et al., 2009; Roberts, et al., 2007). Communication breakdowns were evident in the interviews. For example, when asked about his job tasks, PDs1 spoke about having a back injury and not being compensated, but later in the interview when the researcher spoke about support in the workplace he indicated that consideration had been made for his injury.

Some individuals with Down syndrome are aware of conversation breakdown and are able to employ strategies, such as repetition or rewording, to repair the communication. For individuals with a more severe intellectual disability, the other speaker may need to assist the individual in identifying that there has been a breakdown in communication and how to rectify this. Some employers and co-workers were noted as being very negative when breakdown occurred due to frustration or confusion and this is not conducive to effective communication in the workplace. The speaker may need to assist in gaining clarification as individuals with Down syndrome experience difficulty expressing that they have not understood (Martin, et al., 2009).

R: “what happens if someone at work doesn’t understand you when you talk, what do you do?”

PDs3: Talk slowly.

R: Talk slowly. Do you ever have to repeat yourself or explain in different words?

PDs3: Ja I try to”

~

FM6: “Sometimes I can’t understand her, when I ask her to repeat, she just signals me not to bother.”

PDs4: “I do sometimes repeat myself when they go like I say ‘pardon’ and then they say it again and then I find they maybe understand.”

FM4: “we’ve been able to understand her uh but if we don’t we ask her to repeat herself... And then we have to say ‘slow down!’”

PDs6: “They scold at me.”

One employer noted that conversation needed to be kept to work specific information otherwise the individual may experience some difficulties comprehending while others made comments of talking about social topics such as television stars and rugby matches. In contrast to this, some of the individuals with Down syndrome spoke of how they felt they could discuss a variety of work and social topics with co-workers but that most of their social communication took place outside of the work environment. The need for thorough explanation was suggested by one employer to encourage understanding and encourage focus. New tasks need to be handled with particular caution and the employer may need to try a variety of methods to promote understanding. A job coach may be beneficial in this regard but in South Africa, job coaches are not readily available. A Speech-Language Therapist may also assist in this transition and provide support for employment in this regard.

E4: “As long as it is work specific. I think if they had to start to speak outside of ‘where is that book?’”

E3: “I think the employer just needs to know they when they explain you know when there’s a new task at hand to explain it properly...Um if you know I think if you can find ways of explaining something the best that you can then the chances of them getting what they’ve got to do right is almost hundred percent”

Family members suggested that if someone is unable to understand the individual with Down syndrome or a misunderstanding occurs then it may be beneficial to bring a third party in as a mediator. Misunderstandings need to be talked through in order to prevent tension in the workplace. In a case study conducted in KZN, an individual with Down syndrome was suspended due to a misunderstanding and breakdown in communication resulted in a hearing being necessary in order to work through the incident (McAllister, 2008).

FM1: “Get someone to help you to mediate that and say ‘you know what I need to talk to you so probably if you understand me better then you could say to him’”

Many individuals with Down syndrome experience communication breakdown in the workplace. Some individuals experienced negativity in the workplace because of communication breakdown and this can impact their perception of their workplace. In one instance this also impacted the social experiences of the individual with Down syndrome.

6. “And his reading went...”- School Involvement and Literacy Development

Spoken communication is not the only aspect of communication that impacts an individual with Down syndrome’s life after schooling. Literacy also has an impact on the social, leisure and employment pursuits of an individual with Down syndrome in adulthood. There was much variability in reading and writing skills of the individuals with Down syndrome involved in the study. In terms of reading, the range varied from those who read novels for entertainment to those who are unable to read at all. With regard to writing, those with more developed writing skills were able to write letters to family overseas while others were unable to write at all and used their thumb stamp as a signature. This variability in

literacy abilities is consistent with findings in literature (Kay-Raining Bird, Cleave, & McConnell, 2000).

The two main prerequisites in the development of literacy skills are largely dependent on an individual with Down syndrome's cognitive and communicative development as these increase the individual's educational opportunities (Abbeduto, et al., 2007; Boudreau, 2002; The Centre for Developmental Disability Health Victoria, 2008). The participants in the study indicated that they believed literacy development was dependent on the individual with Down syndrome's cognitive level and educational opportunity at school. All participants went to schools in KZN. Two of the individuals (PDs3 and PDs4) went to mainstream schools only where literacy was a large part of the curriculum and literacy development was a prerequisite for passing a grade. These were the participants that were able to read and write to some degree. Two participants (PDs2 and PDs6) started at mainstream schooling and then moved to LSEN schools. One stated that they moved to receive on site intervention while the other moved because they could not cope with the syllabus. A decline in reading skills was noted with one of these participants due to being under stimulated in the special school context and a decrease in what was expected from the learners. The other participant (PDs1) went to an LSEN school only where the curriculum encouraged literacy but focused more on functional and vocational skills development. The participants who had been exposed to LSEN schooling were unable to read and write to the same level of proficiency as the other participants. Inclusion into mainstream education as opposed to special school education/ LSEN assists in developing the literacy skills (Buckley, 2001).

FM2: "I think being in a normal environment also assisted his speech."

FM2: "When he was in the normal school, his reading was really coming on nicely. Then he left *(name of mainstream school), which is a private school, and he went to * (name of special needs school) and his reading went... I don't think they put as much emphasis on the reading"

6.1. "Basic" to "Literate"- The Variability in Literacy Skills

Many but not all individuals with Down syndrome acquire the ability to read (Kay-Raining Bird, et al., 2000). Cognition and language skills are required to develop the ability to read (Boudreau, 2002). These precursors were evident amongst the participants of the study as individuals with Down syndrome with poor language skills, who spoke in shorter

sentences with a smaller vocabulary, were unable to read even at a sight word level. Participants who were more proficient during conversation were noted as reading for enjoyment and being able to read for a purpose in daily functioning such as reading instructions. Reading fluency was noted as being an area of weakness of the individuals in the study.

FM1: “his reading is not so fluent uh that’s where he struggles a little bit but uh he identifies.”

FM2: “Basic very very basic. He can’t pick up a book and read it. Word recognition”

E3: “she’s probably as literate as I am”

FM4: “in fact was reading earlier than some of the kids in the class”

PDs4: “Oh I love reading ‘cause that’s part of fun and imagination”

Written language skills whether hand written or on the computer were generally an area of weakness for most participants but again variability in skills was evident. Most participants were able to write a few words or basic sentences in order to write notes or cards. The intellectual disability associated with Down syndrome may influence the written language areas of spelling, vocabulary and grammar (Byrne, et al., 1995). In the study individuals with Down syndrome with a more profound intellectual disability, as reported by the family member or employer, were described as being unable to write or unable to write more than their name or a few everyday words while those with more developed cognitive and communicative skills were able to spell more accurately and write longer utterances.

FM2: “*PDs2’s writing skills are not very. He can physically write but to write a sentence... doesn’t exist”

PDs4: “No I don’t write anything for work but if someone wants me to write something for that person, I will do it.”

FM4: “her writing skills...her neatness isn’t as good”

FM4: “her spelling is very good (giggles). Kids today you think like ‘oh what does that mean?’”

FM3: “She’s a very good speller. She wrote well and she can write letters.”

E6: “When they receive their salary, they have to sign, she does not sign but rather puts her thumb as signage”

Literacy experiences in the workplace were limited regardless of the individual's level of proficiency in reading and writing. The schooling experiences of an individual with Down syndrome impacts his/her literacy skills. Literacy development impacts the job opportunities and job tasks that are available to individuals with Down syndrome. It is therefore evident that schooling experiences impact employment experiences. Schooling should therefore be compulsory for all individuals with appropriate support for those individuals that require it.

7. Contributors to Independence

Being independent contributes to an individual's level of participation and ultimately their contribution to society which is in keeping with the ICF (World Health Organisation, 2001). Literacy development assists the individual in being independent. This is beneficial in the workplace and enhances the individual's employability and independence (Miller, et al., 1999). Writing did not form part of a job task for any of the individuals involved in the study thus it did not enhance their employability but impacted on the variety of jobs that were available. Other people's perceptions therefore prevented the individuals with Down syndrome from participating which goes against the notion of the optimal functioning identified in the ICF (World Health Organisation, 2001). This is in alignment with literature that indicates that society's barriers prevent participation and in contradiction to the social model (The United Nations Children's Fund: Innocenti Research Centre, 2007). However, this discrimination in the workplace is against the policy and legislature of South Africa (South African Government Information, 2009, 2011). One participant writes in the workplace of her own accord to make notes for the employer of what occurs in the workplace when the employer is not in the vicinity. Her ability to write and the level at which she is able to present written language therefore affects the independence the individual is able to display in the workplace.

<p>E4: “she'll write me notes often you know? In fact I'm trying to think there's probably dozens lying round here but I have lots of notes from her. So she can write exactly what she feels. She's got no problem with putting it onto paper.”</p>

For many individuals in the study, employment was a chance to interact. This further developed social skills and independence. In the workshop environment individuals with Down syndrome have the opportunity to interact with other people with disabilities as E6 describes below. It also supplies individuals with Down syndrome employed in the open employment market opportunity to interact with adults outside of their family.

E6: “I think it helps them socially, to interact with others like them and they are not left to stay at home.”

FM4: “We wanted her to learn to fit in um to a social sort of environment and have good role models. Learning also to stand up for herself”

FM4: “I think that’s good for her because um she’s had to interact with adults um other than her parents”

There is a sense of self esteem that comes from employment and individuals with Down syndrome want this for themselves (Brown, 2004; Webber, 2011). All participants were found to respond positively when asked how they feel about people with Down syndrome being part of the work force. This was because employment provides some form of income that can contribute to medical expenses and general household expenses but more importantly it provides a sense of belonging in society and influences their feeling of self-worth. Employment provides cognitive and social stimulation which is equally important. Family members described concerns that unemployed, the individual with Down syndrome would be at home and not participate in something that stimulates personal growth. Society can therefore benefit from having persons with Down syndrome in the workforce.

FM2: “it’s independence um and he feels important... he feels he is functioning and he feels he can do something. He’s very proud of his work”

FM1: “And at least now he’s given employment and a sense of belonging and at least build his self esteem as well and at least he is part of society, he’s part of employment, he can earn something of his own.”

FM6: “People with Down syndrome must work, so that they can be encouraged to work and also not to isolate themselves as people with Down syndrome. This will help them be more involved in society”

E4: “I think it’s absolutely vital that she has the mental stimulation, that she has the social stimulation. I think the fact that she’s able to get dressed in the morning and go somewhere”

Social use of language and nonverbal interaction is a relative strength in individuals with Down syndrome (Kumin, 1996; Mundy, et al., 1988; Roberts, et al., 2007). Individuals with Down syndrome in the study were able to interact socially with their co-workers. This was an area of strength and a highlight of employment for individuals with Down syndrome. Most participants were able to work well in busy workplaces where there are lots of people because they are not opposed to crowds and interaction. One participant is opposed to noisy environments and prefers to not socialize at lunch breaks. Work allows an individual to socialize and in this way express a part of their personality (Bertazzi, 2010). Some individuals who were initially shy in the workplace have been described as developing communicative confidence as they became more familiar with their co-workers and each understood more about the other.

FM2: “He’s very social”

FM3: “you can’t generalize with everything but generally they very affectionate, very friendly people”

PDs4: “I know I’m different but I think everybody just enjoys having me around them because they like my company.”

E5: “She loves sitting in the crowd and then she laughs and talks also she likes to laugh out loud”

The ability to participate socially allows for the individuals with Down syndrome to build friendships and relationships in the workplace. This further promotes participation and inclusion into society, which is necessary for functioning optimally (World Health Organisation, 2001). Employment provides the individual with Down syndrome with additional opportunities to engage in social interaction and learn about the positive and negative aspects of communication and relationships. Family members spoke about individuals with Down syndrome learning about conflict and other people’s emotions because of their social exposure in the work context. This further supports the notion that employment provides an individual with Down syndrome with more experiences that are considered to be part of general social functioning.

PDs4: “Ah they lovely and they give me lots of hugs and I just enjoy that”

FM6: “It has helped her a lot, as she was a person who does not like engaging in conversations with others. But since she has been at work it has helped her to be more open and talkative”

E3: “they also benefit hugely from the social interaction that they have”

FM3: “she loves the company and the normality of it being able to come home and moan about this one having done that”

The parents of the individual with Down syndrome may play a role in developing the individual with Down syndrome’s interpersonal skills. Individuals who had been very sheltered whilst growing up required assistance with building relationships in the workplace and working through miscommunication and conflict in the workplace. Although social skills are an area of strength for individuals with Down syndrome, some individuals can be overly affectionate and this can be viewed negatively in the workplace. With some individuals, pragmatic abilities were also a cause of conversation breakdown, particularly inappropriate hugging. Conversation repair is an area of difficulty for individuals with Down syndrome who may experience difficulties with staying on topic, adding to a topic and turn taking (Layton, 2000). In one instance an employer described how a family member had to get involved to assist in dissipating the situation.

E3: “The ones...that seem to be more dependent, more unable to think for themselves, do things for themselves... if you look at the relationship between them and their parents, you can see that they’ve been sheltered.”

E2: “His mother has to stop him from being...too loving”

Individuals with Down syndrome experienced many positive benefits from employment. Employment allowed the individuals with Down syndrome to experience independence and social interaction. This promotes optimal functioning and well being. Individuals with Down syndrome experienced discrimination and therefore limited job opportunities in the workplace if their literacy skills were underdeveloped. Employed also allowed individuals with Down syndrome to experience conflict and dealing with other people’s emotions.

8. Differences in the Workshop Context

In some employment settings, individuals with Down syndrome went through a trial period of employment before being formally accepted. This was particularly evident in the workshop environment and was deemed necessary to make sure that the individuals are able to interact well with the other people at the workshop. The workshop environment is a different environment to the open employment environment as all workers have disabilities. The job tasks and work pace are therefore less demanding so that all employees are catered for. In workshops where there are people with various disabilities and various levels of communicative abilities, workshop supervisors indicated that, the individuals are sometimes without explanation, just able to understand each other. This may be because the individuals spend much time together and have therefore become accustomed to each other's communicative techniques or because the workshop supervisors have to share their time amongst all the individuals and therefore hear parts of conversations.

E3: “basically people come and enquire and then we ask them to come and spend a day there... Um and then after that day if they feel like they like the environment um then you know they would do a two week trial period where we see that they are able to um that they don't upset the group. That that they the they kind of that that the group kind of almost not blends in but if it's somebody that's really gonna irritate everybody it's gonna be a problem.”

E3: “in the workplace within the group, everybody seems to understand each other even when you sometimes like ‘what just happened?’”

The experiences of the individual with Down syndrome in the open workplace setting and the workshop setting differ with regard to the nature of their contract, contact with other individuals with disabilities, job tasks, work pace and communication in the workplace.

9. The Technological Era- “he’s picked up...rapidly with modern technology”

9.1. “She loves to phone”- Using the Telephone or Cell phone

For individuals with Down syndrome, the use of telephones and cell phones was widely discussed. All individuals own a cell phone and use this for social purposes; however none use telephones in the workplace (Buckley, Bird, Sacks, et al., 2002). Literature reports difficulty understanding individuals with Down syndrome over the telephone due to

decreased speech intelligibility (Rondal & Comblain, 1996). The participants involved in the study discussed how they enjoyed talking on the telephone; however only one individual was described as having poor intelligibility over the phone.

FM4: “speaking I mean ‘specially over the phone when you when you speak over the phone to her. She is so clear on the phone. It’s quite incredible. It’s funny. It’s almost like she has this different way of speaking over the phone”

E3: “telephone skills, she loves to phone...if she goes to... her sister in Joburg or wherever, she waits for them to leave the house so she can phone us just to ask how we are”

PDs3: “I can talk to the hind leg off a donkey”

E5: “Telephone skills she’s ok. She can handle a telephone but just that maybe other people wouldn’t understand her.”

E5: “at times I ask her to pick up the phone for me and she must just say ‘Hello. Hold on’ because ... otherwise people wouldn’t understand her on the phone.”

PDs6: “I call my mom and my dad.”

The ownership and use of cell phones was a recurring theme in the study. The use of cell phones for social purposes was noted. The initial desire for a cell phone appeared to be linked to wanting to fit in with peers and colleagues. This is similar to the peer pressure and social conformity that occurs with individuals who do not have Down syndrome.

FM1: “So he said listen he needs a cell phone. So I said ‘what do you need a cell phone?’ He reckons ‘no I need a cell phone because they got a cell phone because I need to talk.’ So I didn’t know I didn’t want to limit his dreams and his thoughts.”

Individuals with Down syndrome reported using their cell phones to make calls, send text messages/ smses, take photos, play games and communicate on social networking sites. The role of the cell phone for the individuals with Down syndrome in the study was therefore for entertainment, to provide social contact with others from work and to interact with other people. One participant also uses his cell phone as a radio to provide background music for entertainment while he works. This participant performs physical labour and spends most of his day outside in the garden. All participants pay for or contribute to the cost of their cell phone and airtime by using the money they get from their salary, workshop salary or disability grant.

FM4: “is um fantastic on the cell phone. She can sms, she can she’s got all her numbers you know she does all that. I don’t touch her cell phone. She loads her own numbers, she’s got a photograph uh camera on her cell phone. She so she’s very good with all of that um and very good at sending messages, very nice messages”

Individuals with Down syndrome also appeared to understand the social rules around a cell phone in that it is not appropriate to take your cell phone out when you are supposed to be working. One participant stated that she does not make calls in the workplace but rather smses because it is quicker and more socially appropriate to type a quick sms rather than make a phone call when in the company of others at work.

E4: “She’s never brought her phone out during work time and phoned her mother or anything. But she has shown me the phone. She’ll show me photos on the phone”

9.2. Other forms of technology

Individuals with Down syndrome use a variety of technological devices (Feng, et al., 2008). Learning to use a cell phone, in many cases, opened up the individual with Down syndrome’s perspective on technology and lead to further interest in other technological devices such as computers, laptops, iPods, other forms of communication such as email and Facebook and interest in social media such as Facebook. This has also been found in other countries (Down syndrome Federation India, 2013). iPods have become increasingly popular with those with Down syndrome for employment and recreation purposes (Kumin, et al., 2012).

Participants indicated that individuals with Down syndrome learnt how to use these devices much faster than they would have anticipated when they considered how long it took them to learn to read or write or that they do not have such proficient written language skills. Individuals who were not avid readers and writers, even though they had been to mainstream and special needs schools where these skills had been taught and encouraged, knew how to use various technological devices and programmes for social connection and entertainment. This may indicate either that technology appeals to individuals with Down syndrome and prompts learning or that the end goals of social connection and enjoyment are driving forces behind rapid learning of how technological devices work. This could also be a sign of the technological era in which we live. This may be an area for teachers to encourage in school in

order to promote the development of literacy, learning and vocational skills and better equip learners with Down syndrome for adulthood and employment.

The successful use of one device may lead to interest in other devices. These devices provide a sense of independence and often encourage a different type of socializing. Facebook proved very popular among the Down syndrome community as a means of staying in touch with friends. One participant indicated that although the Down syndrome community are a close knit community, they are widely spread across the province thus cell phones and Facebook provide a financially viable means to stay in contact with others as there is limited opportunity to see each other face to face.

FM1: “the cell phone and then ja he’s picked up himself quite rapidly with modern technology as well and then uh he wanted a computer”

FM2: “he knows how to phone. He can use his cell phone. Computer skills are average but he’s a whizz on his iPad... interactive things and he goes on his Facebook”

PDs2: “I like my iPad...I play all different games”

FM4: “she’s now just recently gone onto Facebook”

Computers and technological devices assist individuals with Down syndrome in becoming more employable (Feng, et al., 2008). It also develops independence and develops an individual’s self-empowerment and self-advocacy skills as he/she is able to use computers to further their knowledge on a topic, record their thoughts, keep record of something or create presentations. This promotes the principles of the biopsychosocial model whereby the individual’s outlook on their diagnosis is crucial in overall wellbeing (Borrell-Carrió, et al., 2004). Although computers were often mentioned by the participants, they were used for social and personal use as opposed to employment. Only one participant used the computer for employment and this was a job task that had been taught to her at her workplace to develop her skills. Limited literature is available on the usage of computers in the Down syndrome community (Feng, et al., 2010). As with language and literacy skills, computer skills varied from individual to individual and depended on a person’s exposure to computers and technology.

PDs4: “I do um sometimes I struggle with computer things”

FM2: “he’s pretty good as long as it’s um I don’t think it’s computer skills for employment purposes...it’s more social and for pleasure”

FM3: “She enjoys typing letters even if she gets cross with the keyboard”

Developing computer skills such as typing, internet usage, understanding of relevant computer programmes and email ability increases the employment and job task opportunities for individuals with Down syndrome and many individuals with Down syndrome have the potential to acquire computer skills (Feng, et al., 2008). Some workplaces are assisting their employees in furthering their education by providing computer training through the workplace or through Adult Basic Education Training (ABET) which is run by the government to support adults in developing literacy and work based skills (Adult Basic Education and Training, 2013). This assists in developing the individual’s skills and provides them with the opportunity to gain more job tasks or gain other employment due to the increase in skills.

PDs1: “I was doing the ABET with the computer”

PDs1: “maybe 30 of us they do computer and like telephone we do the computer and the telephone... All that. How to speak to people on the line.”

E4: “maybe a year and a half I’m trying to think now of time frames. I decided I’d train her on the computer”

All but one participant revealed that they do not use the computer as part of their job tasks at work because the employer had not provided them with a task that involved computer usage. The individuals’ potential was not realized as these same participants use computers at home for leisure e.g. to play games, interact on social networking sites such as Facebook and to type emails to family and friends. The computer skills that are described include data entry, communication and creating, editing and printing word documents (Feng, et al., 2008). The individual with Down syndrome who uses a computer at her workplace was trained by her employer to scan items in and out of the database. She received in-service training from the employer just as the other employees had; however the training was on a one-on-one basis so that the employer could work at the individual with Down syndrome’s pace and ensure understanding.

Telephones, cell phones and other forms of technology provided positive social and learning experiences for individuals with Down syndrome. Individuals with Down syndrome used these items regardless of their level of intellectual disability or level of literacy. These experiences provided the individuals with self-empowerment and self-advocacy skills.

Individuals with Down syndrome experienced limited use of technology in the workplace. Those that were exposed to technology in the workplace experienced a growth in job tasks.

10. Positive Effects of Employment- “His employment...a better life for all of us”

Family members experienced peace of mind, encouragement, pride and financial benefits relating to the individual with Down syndrome’s employment. Employment provided many opportunities for ongoing development of communication skills specifically literacy, numeracy and technical skills.

10.1. Personal Effects

All family members were pleased that their family member with Down syndrome was employed as they could see the benefits employment had for the individual and for the family. For the family members, employment provided peace of mind that the individual with Down syndrome was in a safe environment where they were stimulated cognitively and socially as opposed to being at home.

FM2: “For me it’s peace of mind... um and that’s he’s active and busy and doing a normal day day’s work. He’s not sitting around doing nothing... and eating and watching TV. He’s and also learning responsibility. I think for me that’s one of the things. He can’t just say to me ‘I’m not going to work today’”

FM3: “Well it keeps her occupied. It gives her a um a sense of achievement um. I said normality. That she’s like the rest of us going out to work which is important for anybody’s self esteem. Um and it’s shown how creative she can be”

FM1: “he his employment added to our lifestyle, a better life for all of us”

FM3: “we just very grateful that she does have an outlet to go to”

In two of the participating families where not everyone is employed, and the individual with Down syndrome is employed, family members describe the individual as being a role model for others in their family and others with Down syndrome or any disability. This is important for individuals who come from impoverished backgrounds and are trying to break out of the poverty cycle (Wagner & Blackorby, 1996).

Literature indicates that in the families of an individual with Down syndrome, the individual's employment makes them proud and that they consider employment successful if the individual is satisfied in their employment (McAllister, 2008). Conversely for the individual with Down syndrome, employment is viewed as a part of adding meaning to their life and contributing to society thus employment success for them is how their contribution is perceived by others (McAllister, 2008).

10.2. Financial Effects

The individuals with Down syndrome that participated in the study all earn some form of monetary compensation, whether it is in open employment or in a workshop setting. Even though individuals with Down syndrome do not always have a good understanding of money in terms of the value of money and how to count or use money, they do find emotional benefit in earning a salary (Down Syndrome South Africa, 2011b).

FM2: "he gets a salary and I think that's also good for him because when he wants to buy something, he can"

E5: "They receive their own little salary where they can um empower themselves to budget for themselves."

One individual in the study collects a social grant to supplement the income she receives from workshop employment as her salary is below the cut off point stipulated by the government. Another individual with Down syndrome openly refused a social grant as he felt he was able to work and that earning a salary was part of his social responsibility. Family members described putting part of the individual's earnings or grant money towards the household costs especially towards monthly groceries. The rest of the money is put towards savings, medical care costs and some pocket money for the individual to spend as they please.

FM1: "he said no listen I need to find a job I don't want to collect social grant if there's somebody else who deserves it more than I do"

FM6: "It does help us because she buys items that she likes to eat and that are nice and shares them with everyone. She likes to boast about what she has bought, like tomato sauce which she likes a lot."

10.3. Employer Benefits

Society benefits from having persons with Down syndrome as part of the workforce. Employers who have employed or worked with someone with Down syndrome are aware of the benefits that employment has for the individual. Employers are also aware of the benefits to the company when employing someone with Down syndrome (Down's Syndrome Association, 2009a). In literature and this research study, high levels of motivation and commitment to work were noted among individuals with Down syndrome. If it is something they feel they are able to do, they like to please people, they are energetic and they fulfil a role in the workplace that would need to be filled if they were not there.

E2: “certainly *PDs2 grew um in confidence...in self image. Um I think that it has been very good for him to earn his own living... so that he’s he feels like a man. Um because I think it must be very hard to he knows that he’s different... and this has done him the world of good so I think it’s it really is valuable um for his um maturity.”

E3: “they great committed people to have working for you and you know if you don’t give them a chance you wouldn’t know”

E3: “I think they have this want, this need to please... to do something for you and they don’t tire easily either. They they’ve got huge amounts of energy most of them.”

E4: “In fact if she left I would be devastated!”

E2: “It’s been good for everyone to have him. And I would encourage other places like us, where the degree of skill required is not very high, to appoint people like *PDs2”

E4: “If you asked me would I do it again- I’d do it again at the drop of a hat”

E4: “I think if you have somebody with Down syndrome work with you and you see their capabilities, you’d be astounded at what they can actually achieve”

11. Comparing Cases- The Variability from Person to Person

There was a vast difference between the life experiences and opportunities between PDs1 and PDs6. PDs1’s family was very involved in his development from birth and he received much private intervention and support. PDs6 also comes from a very supportive family but lacked early intervention. Most of her intervention was received through the government hospital system and received at a much later stage because of a delayed diagnosis. Early intervention impacts communication development (Kumin, 1996). PDs1 was

able to interact effectively in the interview and fewer receptive and expressive language errors were observed in comparison to PDs6.

PDs1 works independently in the open business sector while PDs6 was told by a social worker that a workshop environment would be most suitable for her as she was unable to read and write. PDs1's family member was very involved in his gaining employment and he is employed in the open labour market. This assistance from the family is in keeping with literature (Cuskelly & Jobling, 2002). In his employment, PDs1 is permanently employed with employment benefits. His employment catered towards his needs and he receives skills and job training. PDs1 has had much exposure to technology and drives himself to work. He has travelled extensively and attended many Down syndrome gatherings and congress meetings including on an international basis. PDs6's family member assisted in her employment. She works in a workshop where tasks are adapted to her abilities; however she does not receive any further skills or vocational training. She has a cell phone and is able to socialize with friends. PDs6 does not know any other individuals with Down syndrome outside of her workplace.

Literature indicated that many of the individuals with Down syndrome employed in the United Kingdom worked for 7-20 hours per week while individuals involved in the study worked between 20-40 hours a week (Down's Syndrome Association, 2008). This may be because employers in South Africa are unable to afford salaries to employ more than one individual with Down syndrome.

12. The Role of Early Intervention

Both literature and results of this study indicated that early intervention has a spiral effect on many other aspects of the individual's life. Early intervention impacts the development of language, communication and literacy skills. These in turn provide the individual with greater educational opportunities. Further educational opportunities supply the individual with avenues to develop his/her communicative, literacy and technical skills through mainstream or supported schooling. These skills may benefit the leisure and social pursuits of the individual which encourages inclusion into society. If such socialization occurs at a school going level then the individual will be better prepared for transitioning from school to work and for the work environment. Employment provides the individual with positive effects on

their leisure, social, financial, communicative, literacy and technological abilities. Age may play a role in memory and speech intelligibility thus additional supports such as visual schedules may be required.

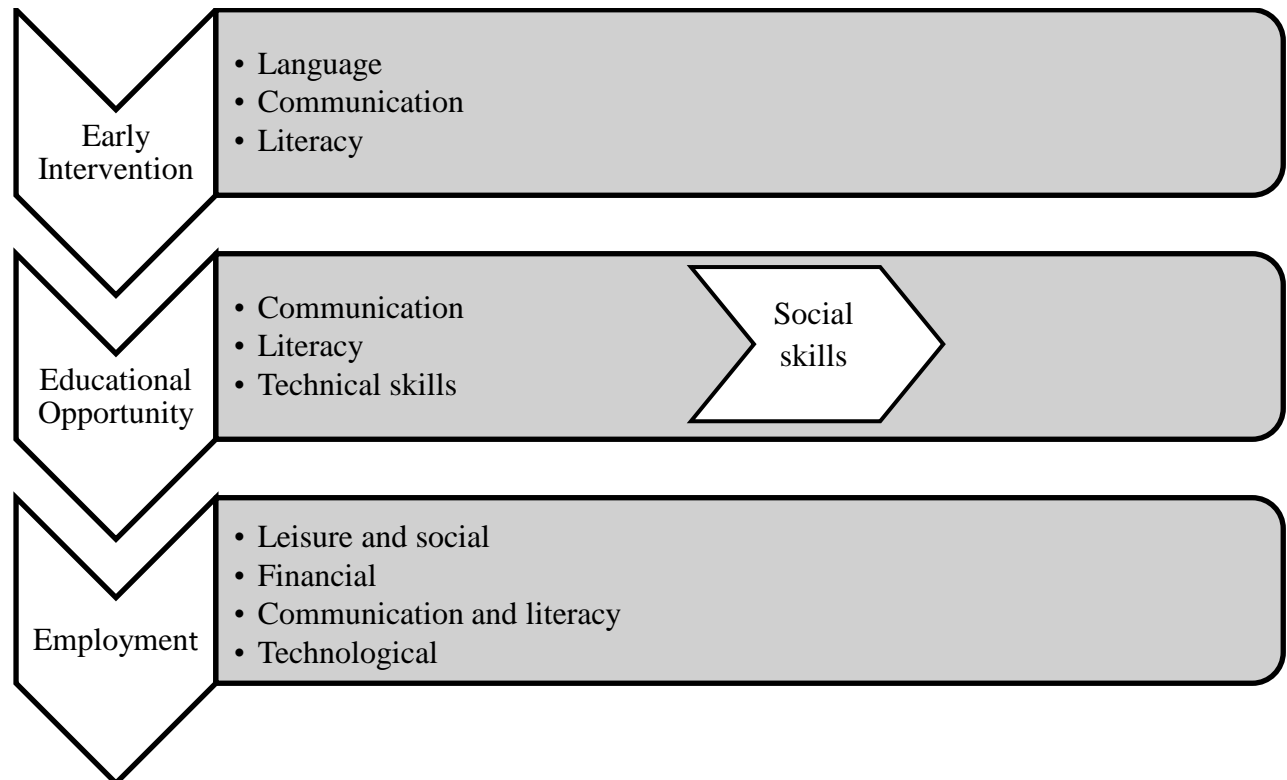


Figure 2: The Spiral Affect of Early Intervention

13. The Roles of the Game Players

13.1. Advocacy- *“I watch how people talking, respectful ways.”*

Advocacy is seen as crucial in broadening the perspectives of individuals with Down syndrome (Brynard, 2012). Self advocacy is a crucial element of how the individual views themselves and their disorder (Borrell-Carrió, et al., 2004). Advocacy requires the individual to have a positive attitude about themselves and their disability and is part of learning to cope with a disability (Brynard, 2012). Individuals with Down syndrome who are involved in advocacy stress the importance of viewing what one has as opposed to what one is lacking (Brynard, 2012). Television has broadened the perspectives of individuals with Down syndrome to what occurs in other parts of the world. It has opened up new avenues of

thinking by showing the individual not only what it is like elsewhere in the world but what it is like to be a person with a disability in other parts of the world. Television was also noted as being a form of education and a method of learning social etiquette. Some participants were aware of their rights and how these are met more fully elsewhere in the world. One participant indicated that the World Down Syndrome Congress meetings and exposure to other countries on television has assisted in allowing individuals with Down syndrome from all over the world to meet and learn from each other's experiences. These meetings and groups form support networks for people with Down syndrome all over the world. Some participants spoke of feeling they could do more in the workplace or felt they could be more suitably employed elsewhere but were not sure how to indicate this to the employer. In the framework of the biopsychosocial model, the individual is allowing their experiences to impact his/her outlook but then not taking further action to better the situation (Borrell-Carrió, et al., 2004). In such instances their level of activity has been inhibited by other people's perception of functioning and this ultimately inhibits social participation (World Health Organisation, 2001). Most important was the realisation that their employment and successful fulfilment of job tasks opens up the doors for future employment of individuals with Down syndrome. This is in keeping with literature and has been noted in other studies (McAllister, 2008).

PDs1: "See I watching TV. I watch how people talking, respectful ways."

~

PDs1: "other companies who can understand me what it is that Down syndrome I wanna move up there those other companies. Maybe like London or Switzerland"

R: ok

PDs1: Ja. I want to learn more other people. That's it

R: Do you think it's better in London and Switzerland?

PDs1: Ja it's better

R: Why is it better there?

PDs1: It's better the way the people talk to you, calm way, smart way and they tell you 'there's a job for you.' You do that job."

The eldest participant, who attended mainstream schooling, noted a change in the employment opportunities available for the youth of today's society in comparison with when she was growing up. This may be linked to the move towards inclusive education for individuals with Down syndrome or any disability as outlined in White Paper 6 (The

Department of Education, 2001). This individual with Down syndrome and her family member felt strongly about individuals with any disability being employed but particularly those with Down syndrome because of the areas of strengths that can be enhanced if the appropriate employment, workplace, employer and job tasks are encountered. The individual spoke of having to advocate for employment and having to prove herself and often being in a specific job because it was the only option and not because it was where her interests were. They noted advocacy and hearing the voices of all of the game players as being crucial in this regard but particularly the advocacy of the family of the individual with Down syndrome as proving pivotal in the change in people's mindsets.

FM3: "when we see today what the opportunities are um for youngsters, it's absolutely fantastic but we do take pride in that we know that the ground work that our folks did"

FM4: "I still think that there's many Down syndrome being born and I think they've got a better start now than they had those years back"

FM1: "It is uh times have changed a little bit it's now people are be becoming a little bit more understanding... tolerant towards people with ... Down syndrome. It's not the way they look but it's the way you see them."

It is ideal for individuals with Down syndrome to experience a trial period of the job in which they will be employed before any commitments are made (Murray & Heron, 1999). All participants in the study, whether employed or working at a workshop, experienced a trial period of employment. One participant felt employees with Down syndrome may have to go through a longer period of casual or contract work before obtaining a permanent contract so that the employer could ascertain if there was a successful pairing of individual with Down syndrome to employment. Permanent employment is viewed very highly by individuals with Down syndrome not necessarily for the medical aid, pension or company shares it may bring but because it is thought to be more towards the social norm (McAllister, 2008).

PDs1: "Then I work past eight years then I then later on then I was doing good in the company they called me in for an interview, I passed the interview I got a permanent job."

FM1: "he worked for company contract for quite some time"

In larger companies, individuals with disabilities, including those with Down syndrome, may need to educate their superiors on their disorder, their limitations, their support requirements or advocate for people with disabilities.

PDs1: “I belong to the equity meeting... I spoke to them about Down syndrome people when your guys is calling the of uh the head of the head of the what you call this the big branch from Pretoria “

Person-centred decision making should be used when deciding on a job or job tasks for an individual (Ware, 2004). Participants spoke of being happy that the individual with Down syndrome has a job and is happy with what the job entails but some also indicated a need to move into a higher position in the company or hold more responsibility.

PDs1: “work is fine and uh I enjoy working because I help. I’m very happy working there but I wanna go more further up the work in the next company”

FM1: They said packing you know like at supermarkets, packing shelves and pushing people’s trolleys and then I said you know what, I think he can do better.”

FM1: “There are certain times that he feels he needs to move on to find another job in another company and I said to him is that if you move away from the situation is that your problems may not get any better”

Employers and fellow employees should be educated on what Down syndrome is and the associated strengths and weaknesses in all aspects relative to their job (Australian Government, 2012). The employer’s understanding of Down syndrome will impact the way the individual with Down syndrome is viewed by their colleagues and how they are treated in the workplace. Based on what the employers said in the interviews, the genetic makeup of an individual with Down syndrome is an aspect that all employers knew about. Down syndrome is categorised as a genetic disorder caused by an extra chromosome (Hayes & Batshaw, 1993; Layton, 2000).

E2: “I do know that it is a chromosome problem...that is half a chromosome well one or a half chromosome... extra. Um and this is what causes problems. Uh I also know that um Downs children often have physical problems...respiratory problems and so on.”

As a result of a difference in genetic makeup, individuals with Down syndrome may present with any combination of delays in cognition, communication and motor skills (Cunningham, 1996; Hayes & Batshaw, 1993; National Down Syndrome Congress, n.d.). Employers appeared to be aware of physical limitations.

E2: “I s’pose that he is mentally challenged. Um *PDs2 is not physically challenged.”

E3: “I’ve never really gone to read up on it or anything like that um I just you know with Down syndrome there’s a variety of different levels of functionality”

13.2. Education and Training for Employers

Employers involved in the research study had not had any training specific to Down syndrome. They were aware of possible areas of delay but most employers admitted that their knowledge came from reading and hands-on experience as opposed to research and training. Employers in the employment workshop environment have access to booklets from governmental organizations and government departments on various disorders. These provide information on cause and characteristics but not necessarily practical information on cognitive and communicative difficulties and are not specific to adults. In South Africa there is no legislation requiring the employer to have any training; however this may be necessary to encourage a better understanding of the disability and the co-occurring characteristics. Legislation focuses more on the employer’s role as being educating other employees, avoiding discrimination, adapting the workplace and preventing discrimination (Finance and Accounting Services Sector Education and Training Authority of Department of Higher Education and Training, 2012). There are some local documents on effectively employing an individual with a disability but these are not specific to Down syndrome (Finance and Accounting Services Sector Education and Training Authority of Department of Higher Education and Training, 2012). There is a national diploma in disability employment practice which may assist employers, advocates for people with disabilities, therapists, placement officers and any other parties involved in the employment of individuals with disabilities in developing their understanding of how to support individuals with disabilities in the workplace (South African Qualification Authority, 2013).

E4: “I read up quite a lot about it. I’ve probably forgot a lot you know as time goes by but I did. I made it my business initially to read up about it and I got books about it and just to understand from the genetic point of view exactly what was wrong and how it would affect

her.”

E5: “I don’t know very much. We just uh got booklets”

E6: “I don’t know much about them, but what I know about them I have seen in their work here at the workshop.”

13.3. Role of the Employer

Employers need to be able to identify and work with the communicative and cognitive strengths and limitations of persons with Down syndrome. This includes knowing when and how to grow the individual and push the boundaries.

FM3: “It’s like you wouldn’t employ a cashier to go and work at a space centre you know. You’ve got to find their strong points and give them something that they will cope with and one, as a I’m sure like anybody with training, they can grow and move slowly up to to more successful...to achieve more.”

E4: “I know her capabilities so I would never give her a task that was outside of her capabilities but I do believe on that I need to stretch her and I do believe that I need to keep her cognitions going”

E2: “certainly with the degree of functionally *PDs2’s actually got, he um I think he could do even more difficult tasks than he does now”

Employers need to be able to find constructive methods to critique the job performance of individuals with Down syndrome (Down's Syndrome Association, 2008). This may be necessary as some employers noted that individuals stray from the job task and need prompting to continue or motivation to stay on task and complete it. Similarly the employer needs to be able to provide support and praise when there is job success.

FM3: “it doesn’t you don’t have to humiliate a person. You can just say we’ll have a trial period and then see what they will cope with but if they not going to fit into the situation suggest that they try something else you know. I mean it can all be handled in a in a gentle, unhurtful way”

E4: “She’s a “words person” so words support her. ‘Thank you.’ ‘That’s lovely!’ ‘Come here for a hug.’ ‘Wow I’m so glad.’”

FM4: “They’ve always been so proud of her and ...always affirmed her so much in how what she does and her strength. They’ve just loved her strengths and told her about that.”

Participants in the study indicated that the employers provided structure in the workplace to ensure there is work to do and that the individual takes a break and does not become too frustrated if they make an error. Employers need to be able to interpret the emotions of their employees so that they are aware when the individual has not understood the task at hand. It is important for job expectations to be carefully explained (Down's Syndrome Association, 2008). This is another important element in the employer's role. Repetition of instructions and training has proven to be essential in this regard.

PDs3: "I do my work and that and I'm fine after a while we I just sleep and they'll say 'ok put it away for now. Go outside and get some fresh air then come back in.'"

FM4: "we so fortunate to have *E3 because she will always say to her "ok have a break" or whatever"

E3: "Giving them opportunities to have the conversations they want to have, the interactions they need to have but saving them from themselves without making them feel guilty"

E4: "I can also read her body language because I've been with her long enough for that and I say to her 'what's the matter lovey? What is the matter?'"

FM3: "Um would have to just explain the challenges that there are sometimes not always comprehending may needing to have something being explained the second time"

An employer noted that employers need to talk individuals through a word or higher order concepts so that they are better able to process and adjust to new tasks or routines and that flexibility becomes a metacognitive process. Most employers indicated that they thought the individuals with Down syndrome felt comfortable to ask them when they needed assistance.

E4: "She's not able to do it inwardly like we do and use our inner speech and reason. She's got to reason outwardly"

PDs1: "If I need help I go call to my managers"

E3: "She'll get up and come and ask or um she'll come to you and say 'I dunno what I did' or 'I don't know what happened'"

E4: "She's not afraid to ask for help and she will very quickly ask for help"

E6: "She usually comes to me and asks me for help. She usually does not need help, but when she does she comes to me and I help her."

Various reactions were noted when the word “boss” or “supervisor” (term used in the employment workshop context) was mentioned and the employer-employee relationship was discussed in interviews. Generally individuals with Down syndrome felt comfortable with their employer and expressed feelings of respect towards them. Many describe a sense of friendship with the individuals but within the boundaries of the workplace. A good working relationship encourages open communication and allows the individual with Down syndrome to ask for assistance when needed.

PDs1: “He a respected man...But you respect but sometimes he get angry with me... if the managers go tell him I do wrong but I wasn’t doing wrong then he go tell him I doing the wrong”

FM2: “It’s very good. He knows. He knows who’s in charge and the and he also knows what their functions are”

E2: “We don’t exactly have an employer-employee relationship um although he does show me utmost respect and he knows that I’m his boss... ja we have a very good relationship um. We we’ve never I’ve never had occasion to reprimand him at all”

E4: “we get a little rapport going which just breaks down any sort of preconceived ideas”

FM4: “I think that it is really a very special relationship. I think it’s more than a boss-employee type relationship.”

For participants employed in the open labour market, employers chose to hire the individual with Down syndrome either because the individual’s parent worked within the company or if they felt a social responsibility as employment opportunities for individuals with Down syndrome are limited. The employment workshops attended by the individuals with Down syndrome that were interviewed were specifically designed for people with an intellectual disability thus the environment and tasks are specifically tailored to this. Some employers also realized the opportunities they could provide the individuals with.

E2: “I know there is protected employment people who fold cartons...and things like that but I don’t think that there’re enough jobs for people, not only with Downs but with other disabilities”

FM3: “I think in the workshop situation it is set up specifically for the intellectually challenged”

E4: “I wanted to try push the boundaries with her and find that ceiling instead of just saying well she’s not capable”

13.4. The Support of Family- “Without my father and my mother I can’t get a job”

The individual’s family may need to intervene and make sure that the employer and fellow employees have an understanding of Down syndrome. This is not typically part of the family member’s role. It goes against social models where people with disabilities should be included in all aspects of society (Borrell-Carrió, et al., 2004; World Health Organisation, 2001). However, due to stereotypes, family members have found themselves in this position.

FM1: “educate them a little further as to why they are like that, what is the situation, why they are different from you and I, intellectually...that they have an impairment with Down syndrome and this is what the expectancy is of them and if they if there is opportunity like menial task work where there’s not much machinery or danger to their lives or their fellow workers they can make them give them menial tasks.”

E4: “I’ve had her dad come in and speak about her before on the stage um on a Down syndrome day”

Family members assist in the development of social skills (The Centre for Developmental Disability Health Victoria, 2008). The family are involved in raising the individual from birth to adulthood and therefore played a huge role in how the individual perceived themselves. The family of the individual with Down syndrome, as in any family unit, need to teach the individual social, communication, self advocacy and self help skills.

FM1: “But what we did was that my wife and I, my wife played a very pivotal role in growing *PDs1 up and then teaching him things. And then what we did was that we didn’t isolate him from the rest of the family we integrated him very quickly and uh this is where he actually picked up of knowing things and uh finding his way.”

FM3: “but it’s from mum’s hard work that she’s achieved what she did over the years”

Family members are crucial in talking individuals with Down syndrome through conflict in the workplace and through some daily aspects of employment as these may be unfamiliar to them. In instances where conflict occurs the individuals with Down syndrome turn to their parents or family for emotional support and guidance. One family member spoke about feeling the need to protect their son/daughter when such conflict occurs.

FM2: “Ja he will come and speak to me.”

PDs2: “I’d phone my mom”

FM4: “I must admit I find that very hard because you just want to go in there and protect”

PDs4: “Like when I come home from work I tell them and then my mom like tells me “ok maybe you should do it the other way””

It was anticipated that most individuals with Down syndrome would rely on their family for transport to get to work every day due to limited public transport (Khosa, 1995). In this research study, three individuals with Down syndrome required lifting from family members, one caught a taxi alone and one individual with Down syndrome drives himself.

The support offered by the family of the individual with Down syndrome is crucial in promoting employment and social success (The Centre for Developmental Disability Health Victoria, 2008). This was evident in the South African context as well. Family members may need to assist in locating suitable employment for the individual with Down syndrome (Cuskelly & Jobling, 2002). Two of the participants were employed in a workplace where their family members worked and had been employed due to their family members’ advocacy in the workplace. This is beneficial as the individuals gained employment but may be contradictory should the workplace not be suitable or job tasks be in the individuals’ areas of interest. In one case the individual was happy in his employment but believed he was capable of holding more responsibility in the present workplace. Both of the family members did not get involved in the day to day running of the job. They communicated with the employer only when problems arose and in each setting the individual was placed in a section of the workplace that was separate to where their parent worked so that they could establish their own identity in the workplace. Family members indicated feeling compelled to get involved in the lives of the individuals with Down syndrome because there was not sufficient support from the government, job agencies or vocational programmes to assist in gaining employment. They reported having to read up on employment rights in order to be able to advocate for employment. In other countries there is more information specific to the working adult with Down syndrome and the information is more readily available because of the presence and advocacy of a variety of groups and associations that focus specifically on the adult with Down syndrome or the working individual with a disability such as ‘WorkFit’ in the United Kingdom (Down's Syndrome Association, 2012).

FM1: “And then we couldn’t find a suitable school for him and they said us you need to find employment for him, at that age you need to find employment. So I thought to myself where

do I find employment for a person with disabilities? ...and with all the able bodies that are looking for a job but they couldn't find a job. So I took up my management a challenge to my management and uh I challenged them in the sense that, if they say they care about my family's welfare so not would they offer *PDs1 a job?"

FM2: "'Cause obviously I spoke and told them that I've got this problem so they employed him."

PDs1: "Without my father and my mother I can't get a job anywhere. At least I got working at * (place of employment) by the grace of God."

13.5. The Role of Down syndrome Societies

Some participants mentioned the role of Down Syndrome South Africa in encouraging those with Down syndrome to meet and share experiences and also to share their life stories and lessons via a dedicated magazine. Some spoke of attending the World Down Syndrome Congress meetings or the annual dances and family days but admitted that the Down syndrome community involved in Down Syndrome South Africa are spread out over the province thus meetings are not as regular as they would like. Regular social interaction with other people with Down syndrome is important for advocacy, emotional support and for sharing experiences (Brown, 1993).

PDs3: "Once a year we when we get together"

FM3: "She goes and likes to meet all the people with new babies"

There is no set decision on who should fill the role of educating or training employers and workshop supervisors on the strengths and weaknesses of individuals with Down syndrome and employment considerations and accommodations. Down syndrome societies may be beneficial in this regard. Government, specifically the Department of Women, Children and People with Disabilities should also be involved in employer education. The booklets provided to the employment workshops appeared to provide very basic information and were based on individuals with an intellectual disability and not necessarily specific to Down syndrome.

FM1: "somebody from the association it's good that they go there"

E5: "I don't know very much. We just uh got booklets"

14. Gaining Employment: Does Policy Match Practice in South Africa?

14.1. *Lack of Opportunity*- “people don’t know enough”

Recent models of understanding disability acknowledge individuals’ rights to work (Buntinx & Schalock, 2010). Individuals with Down syndrome or any form of disability have a right to employment (South African Government Information, 2011). It is documented that what is well described in legislature is not the reality for specific individuals in South Africa (The Department of Women, Children & People with Disabilities, 2011). Thus the principles of the social model relating to necessary policies and upholding these are not evident in the South African context (The United Nations Children's Fund: Innocenti Research Centre, 2007). All participants were in agreement that it is difficult for individuals with Down syndrome to get a job and that stereotyping about Down syndrome, intellectual disability and stigmas relating to being a person with a disability were evident. This is contradictory to the equality and accessibility emphasized in the social model (The United Nations Children's Fund: Innocenti Research Centre, 2007). Employers identified that these negative perceptions are what prevent more employers from employing individuals with Down syndrome. This is contradictory to the ICF as the negative perceptions of others, in this case the employers, prevent activity and participation which are part of the ICF and optimal functioning (World Health Organisation, 2001). Intellectual disability, communicative challenges and the general level of functioning were identified as handicaps within themselves and the key aspects of what prevent employers from hiring.

FM2: “I think that it’s very difficult. I don’t believe they giving given opportunities... because they people don’t know enough”... “I think that he could work in a lot of other places but the opportunities are not there. People don’t employ them easily.”

FM2: “It’s a pity there’s not more of them working but then there’s other handicaps, if they don’t speak properly or you can’t understand them, it’s also a handicap.”

FM3: “I think to start with I think the first thing is the stigma”

E4: “I think that it [having Down syndrome] does it affects their employability no matter which way you look at it. I think it’s also lack of education in business”

E3: “it would depend on how severe their Down syndrome is how high functioning are. Um and then obviously also the from the employer’s point of view, somebody’s gonna be open minded enough”

The unemployment rate in South Africa is particularly high. It is difficult for an able bodied person to find employment in today's economic climate but even more so for those with disabilities. Although the employment equity act indicates that individuals with disabilities should be included in the workplace, it does not specify a quota for Down syndrome or even for intellectual disability at large (McAllister, 2008). Individuals with Down syndrome and families are therefore often left to find employment by themselves and have to advocate for equal employment rights. Much of the literature indicates the importance of the role of the school, government and employment services in assisting individuals to find employment; however in the South African system the responsibility appears to fall on the family and the individual themselves. This is an area where South Africa appears to differ to some of the other countries in the world. For example in the United Kingdom research has shown that employment for individuals with Down syndrome is found through family/friend contact, specialist employment services and through work experience while at school (Down's Syndrome Association, 2008). All of the individuals indicated that the school the individual attended did not assist in locating employment opportunities. One school provided the individual with employment after her family member enquired if there was anything that they could do to assist the individual as she had become comfortable in the school environment and the family were hesitant that she would find this sense of belonging elsewhere.

14.2. I'm the "Only One"

In South Africa, individuals with disabilities are said to make up less than 1% of employees in the country (The Department of Women, Children & People with Disabilities, 2011). Despite all of the laws and policies in South Africa relating to equal rights to employment for individuals with disabilities such as Down syndrome, employment rates are well below the 2% employment rate per workplace target (Finance and Accounting Services Sector Education and Training Authority of Department of Higher Education and Training, 2012). In most instances, in both the open labour market and the workshop context, the participants with Down syndrome were the only people with Down syndrome in their workplace or workshop and in some instances they were the only person with a disability. This has also been noted in other third world countries such as India (Diversity and Equal Opportunity Centre, 2009).

PDs1: “Only one only one only one like us that’s me. I work in the company”

PDs4: “What it’s like to have Down syndrome at work? It’s a bit different. Um well everybody just loves me as I am”

15. Selecting Job Tasks- “he does anything and everything”

Individuals with Down syndrome who participated in the study were involved in all three of the different types of employment. Those involved in open employment were the individuals that found employment because of the involvement of their family members and were given job tasks based on what needed to be done in the workplace as opposed to where their strengths lie. Those involved in supported employment were given job tasks based on their strengths and they were provided with job specific training. Those with a more profound intellectual disability or who were older than the other employees with Down syndrome were employed in workshops where the job tasks are specifically adapted for individuals with disabilities.

It has been suggested that individuals with Down syndrome benefit from having one area of employment to learn and focus on (Australian Government, 2012). It was evident that some of the participants with Down syndrome are employed to perform a number of smaller tasks and generally take on tasks based on what needs to be done in the workplace as opposed to receiving a specific role adjusted to their interests and strengths. If an individual does not grasp a task, it is important that their attention and efforts are directed elsewhere. This needs to be handled in a sensitive manner. Part of ensuring job satisfaction is ensuring the individual understands what the job entails and tailoring the job to suit the individual’s limitations (Ware, 2004). For example in an employment workshop where job tasks involve labelling, cutting, counting, packing and bar-coding, the employer knows that the individual with Down syndrome is unable to cut and is able to count to five only. In some instances their limitations or interests were not taken into account such as an individual who is physically capable but with a back injury whose job involves heavy lifting. This is not true for all individuals with Down syndrome. Some individuals have reported job success, enjoying their employment, maintaining a balance of job tasks and are employed to do tasks that are suitable to their interests and strengths (Schoeman, 2012).

E2: “If leaves need to be swept, *PDs1 will sweep the leaves. If um if a wall needs to be scrubbed, *PDs1 will scrub the wall. Uh if there’s weeding to be done, he will do it. He is told on a daily basis what he has to do.”

FM2: “he does anything and everything. He his main job is to sweep and rake and weed and maintain a few flower beds”

E3: “we don’t tell her ‘well you not getting ceramics again.’ We just keep her busy with something else”

E5: “a simple uh counting, gluing uh wire rolling up of little ear plugs and stuff like that.”

E6: “There are numerous jobs that we get from different customers, but she cannot do all of them. She is able to do the small jobs, like packing items into fives and bar-coding items.”

PDs1: “But I the other work other work to do it’s like a painting you have to go push it out because I gotta pain nerve on my back...and there they don’t gimme an ID (injury on duty) nothing for my back and I said to myself you know what, the company can’t give me an ID I will stay away and be quiet and do my job”

Interest and a level of job skill are crucial for job satisfaction (Jans, et al., 2011). Appropriate job placement and task selection is a form of support as choosing a task that is appropriate for an individual’s strengths will allow for success at a task and build morale (National Down Syndrome Society, 2012). Individuals with Down syndrome are often employed in jobs that are not necessarily in their field of interest (Down's Syndrome Association, 2008). Ideally there should be multiple employment opportunities with jobs available at various levels so that any individual is satisfied (The Department of Women, Children & People with Disabilities, 2011).

E3: “I think just with the craft thing again you know we I feel that we I give her something that she can cope with instead of giving her something that she’s trying her best to do but failing to accomplish.... I’ve just adapted whatever she’s doing to accommodate that because there’s no reason for her to have to struggle through things.”

E2: “No he would do exactly the same task as our other um cleaners”

Individuals with Down syndrome may experience difficulties with physical tasks or manual labour as some individuals present with low muscle tone (hypotonia) and hyperflexibility of joints (Bosch, 2003; Kumin, 1996).

E4: “physically carrying heavy things. That’s a challenge. She can’t really carry heavy things.”

Recreational activities and the types of job tasks an individual with Down syndrome will take part in are interlinked with their health and level of cognition (Brown, 2004; Rondal, et al., 2004). Physical, communicative and social constraints need to be considered when allocating job tasks (Henwood & Dixon, 2002). Individuals with Down syndrome who were noted by their family and employers as being physically stronger but with a cognitive delay tended to take part in physical hobbies such as swimming and going to the gym and had job tasks that involved manual labour such as machine operating, cleaning, gardening, painting and handiwork. Individuals who were physically of poorer health but linguistically more capable enjoyed hobbies such as playing an instrument, crocheting and reading. Their job tasks included light cleaning, administrative work and arts and crafts. The participants’ employment therefore corresponded to previous literature findings (Down's Syndrome Association, 2008; Henwood & Dixon, 2002). In this way employers were cognisant of the strengths and weaknesses of the individual with Down syndrome and provided them with job tasks accordingly.

16. Job Challenges

16.1. Other People’s Perceptions

It was evident that in some workplaces there is discrimination towards those with disabilities such as Down syndrome. Participants in the study indicated that once a job is obtained they had to prove themselves to the employer and justify their employment or the salary that they are paid. Discrimination was also evident in the manner in which co-workers spoke to the individual and the level of respect their communication showed.

FM1: “their mind set and perception of people with disabilities uh they couldn’t be trained or else they have limited uh sense of thinking and limited mentality and he proved them wrong”

E4: “I think she was getting a little R 150 or R 200 a month or some ridiculous amount like

that. And then so it wasn't really an official employment capacity where we had all sorts of forms or anything set up at all in place"

PDs1: "Ok the people the people I would like to change because nice communistration [sic] (communication) to me and uh I want them to get better to talk nice to me. Respective way and stand like the managers they mu must show me the respect... See there as I told you the manager they got no respect, they treat me like an animal at work."

PDs6: "They say that I am lazy and do not want to work."

16.2. Health

There are a variety of health concerns that an individual with Down syndrome may present with (Brown, 2004; van Allen, Fung, & Jurenka, 1999). Certain mental and physical health concerns are commonly associated with Down syndrome such as cardiovascular abnormalities, diabetes, visual impairment, hearing impairment, seizures, and gastrointestinal problems (Bosch, 2003; Smith, 2001). Just as in the neurologically typical population, these are all conditions that may impose on the individual in the workplace and may therefore limit employment opportunities. Individuals in the study spoke of back pain, cardiac defects and being easily fatigued when doing too much physical work.

FM4: "has a cardiac um defect and so she is limited um with um you know what type of work she would have to do"

E2: "very careful with him because if he gets sick he can very easily get an infection and become very ill"

16.3. Numeracy

Numeracy skills are an area of weakness for individuals with Down syndrome (Brigstocke, et al., 2008). The use and understanding of numbers and particularly money and monetary value appeared an overall area of weakness and something that requires assistance in all of the participants with Down syndrome. This is linked to the level of intellectual disability (Byrne, et al., 1995). This may also be linked to the educational opportunities provided; however, all individuals in the study, regardless of type of schooling, had some difficulties with money whether it is counting money, keeping money or understanding monetary value. Variability amongst participants was evident as some were able to count and work with money while others with a significant intellectual disability were unable to count

past five. This impacted the individual in the employment workshop as the individual was unable to work with an item from start to finish. She could package items but then had to pass them on to someone else to count out for packaging. It is therefore evident that poor understanding of numeracy and money limits job tasks and employment opportunities.

PDs1: “My dad and my mum want me to learn about money and how to spend the money”

FM3: “she never had a good understanding of the value of money”

FM4: “I mean she knows she understands certain money and she ja but we haven’t like pushed her to be an absolute star at working out um money”

FM2: “he knows what money what it is, what it physically is but he wouldn’t know if he’s getting the right change or not”

E6: “she can only count up to five, beyond that she has difficulty”

17. The Role of a Speech-Language Therapist in Working with Adults with Down syndrome

17.1. When to start?

Early intervention is crucial in assisting development of speech, language and literacy skills (Buckley & Le Prèvest, 2002). Most participants received Speech-Language Therapy, mostly in the private sector, however it was reported that they were considerably younger and the focus was on articulation. There was one individual who did not receive speech therapy because her family was not aware it was available.

There are a variety of speech, language, reading and writing delays and difficulties that may occur (Kent & Vorperiana, 2013; Kumin, 1994; Stoel-Gammon, 2001). A Speech-Language Therapist may therefore be needed throughout the lifespan (Kumin, 1994; Stoel-Gammon, 2001), but at different stages for different reasons. Some family members felt that Speech-Language Therapy should occur at a later stage in the individual’s life because of the cognitive delay associated with Down syndrome. This is contrary to what is recommended in literature (Kumin, 1994; Stoel-Gammon, 2001). The participants did however note the early intervention as also being beneficial. This reinforced the need for therapy to be ongoing and targeting different aims at different stages in the individual’s life.

Early intervention would focus on speech and language stimulation then later include early literacy as an aim. At a school going age reading, written language and spelling could be targeted as well as social and vocational language. As the individual enters adolescence and adulthood the focus would shift to communication in the work and leisure environments. Therapy aims therefore develop as the individual ages and he/she encounters new environments where communication is required and various people may be included in shaping the therapy aims and meeting them.

PDs4: “I did go to I think a speech therapist ...Oh that was a long time ago”

PDs3: “It’s so far back I can’t remember”

FM6: “Yes, I don’t remember as she was so young at the time”

FM2: “I think because he was older it was easier because he could participate and it was sort of in the house and because he was already talking. So it wasn’t that we were teaching him to talk. It was correcting the speech”

FM3: “she was 8 or 9 probably when mum started with. But the general development was a little slower so that was probably then the right time”

17.2. What Happens in Therapy?

Little is written about the role of the Speech-Language Therapist in adulthood with individuals with disabilities (Balandin, 2011). None of the individuals interviewed attended Speech-Language Therapy during adolescence or adulthood and therefore did not receive this form of intervention to assist with employment. Family members were not aware that Speech-Language Therapy was available for the adult population with Down syndrome in order to assist with preparation and adaptation in the workplace and in general to assist with communication in adulthood. Therapy did not necessarily have an influence on employment because of the young age at which it was received. These benefits were not directly linked to the individual’s employment and communication in the workplace but rather to communication skills as a whole. Should Speech-Language Therapy be attended in adulthood, the Speech-Language Therapist could assist with the development of literacy skills, intervene with social communication difficulties and encourage the use of technology in the workplace.

R: “Do you think the therapy has assisted him in any way in his employment?”

FM2: No. It helps that he can speak and he can be understood. That helps.

R: How long did he have that therapy for?

FM2: I think he had around four three or four years he went to speech”

~

FM3: “I’m sure just her general abilities as well as the speech would’ve have been beneficial to her”

The benefits of therapy were noted by family members. Aims of articulation, intelligibility, vocabulary, expressive language and speech rate were described. Participants described methods of phonetic placement, vocabulary development and encouragement of communicative competence. Although benefits were reported, the same areas that were targeted in therapy when the individual was younger were reported as areas of concern in the individuals’ current communication. This indicates that further therapy is required as the individual ages to continue with the progress achieved in childhood intervention.

FM1: “Most definitely yes because it did help him to articulate himself and to speak uh apart from could’ve learnt from home and then but at least that enhanced him a little bit... because the speech therapy professionally yes it does with the vocabulary because he could just be learning English at home but with the Speech therapists there was a technique”

PDs3: “For me to slow down and think you know talk and things like that”

PDs4: “I learnt a lot of words at the time and it was like quite interesting”

Individuals with Down syndrome may present with atypical speech articulators, anatomical differences and frequent otitis media which impacts on speech intelligibility (Kumin, 1996; Roberts, et al., 2007; Stoel-Gammon, 2001). In one case the individual with Down syndrome received speech therapy and much medical intervention; however, it was some time before anyone noted that the individual with Down syndrome had a cleft of the soft palate. This had an effect on articulation and was only repaired at six years of age.

FM2: “he did like a scope thing down his nose and he had a soft um palate cleft”

There is evidence that Speech-Language Therapy for adults with Down syndrome assists in employment and successful communication in the workplace. None of the individuals with Down syndrome involved in the study received Speech-Language Therapy or any form of therapy in adulthood therefore indicative of a gap in service delivery for adults with Down syndrome.

18. A Pot of Gold at the End of the Rainbow- Types of Support

18.1. Accommodations

South Africa has adopted the North American approach to employment of individuals with disabilities. In this approach employers must accommodate the limitations of the individual (Metts, 2000). Various accommodations were described by the participants of the study. Individuals with Down syndrome benefit from having a visual referent to support their understanding and retention of information (Down's Syndrome Association, 2009a). Detail is better retained when a visual referent has been provided (Martin, et al., 2009; Roberts, et al., 2007). Visual supports may include colour coding, labelling items, visual examples, timetables and visual schedules. Examples of these were reported and evident in some of the workplaces visited. In some instances these were developed especially for the individual with Down syndrome and in other instances they were developed for any employee with an intellectual disability or who would benefit from a visual support. Timetables and visual schedules are other forms of visual support that have proven to be beneficial in the employment of individuals with Down syndrome (Down's Syndrome Association, 2008). Individuals with Down syndrome also enjoy this form of support because they appreciate routine and structure (Webber, 2011). These may be developed by a Speech-Language Therapist or Occupational Therapist as they have experience in working with people with Down syndrome and visual schedules; however they could also be developed by a family member, the employer or another person in the work place as these individuals will have an understanding of the specific individual with Down syndrome and their needs in the workplace.

Colour coding:

FM1: “We work on a colour coded system at the moment where you say listen, I want 10 boxes of red so you give them a box of red and they put 10 boxes with so many in a box. So they can they can easily catch on”

PDs4: “I just they have a green label with the numbers on and I look at that number and ok that’s where it goes”

Labelling:

E4: “So she’s got her own little set of cloths. They labelled Monday to Friday so she’s got one for each day.”

Visual examples:

E3: “I mean within the workshop if I can say if I see that somebody’s not understanding what I’m saying, I will find something to let help them understand that... You know you know like say um *PDs3’s just made a cushion cover. To let her understand what it’s gonna actually look like when it’s finished sewing, I’ll get a cushion and I’ll wrap it over so she sees what she’s just made, what it’s gonna be turned into.”

E4: “She looks at the time table. There’s one stuck up down there”

E4: “we’ve got an “A” brick and a “B” brick so that helps her but that helps anybody who’s filing”

PDs4: “sometimes they leave reminders about things out for me”

Timetables and visual schedules:

E4: “She had a little roster and she’d go off to different classes and she’d dust shelves or she’d pack a few books or she’d be like a little errand girl”

E4: “Her other jobs are every morning when she arrives, I’ve written it up for her so she knows”

FM2: “You can’t give him give them something that they don’t know. Plus they also have know that it’s gotta be repetitive and routine. *PDs2 doesn’t take kindly to anything that’s not routine.”

Individuals with Down syndrome do not always manage to cope when routines are changed (Down's Syndrome Association, 2008). Employers therefore needed to encourage flexibility in the workplace even if it meant explaining the term “flexibility” and providing examples.

E4: “I’ll pick a word and then work through it with her.... So we’ve worked on that word for a while and I’d say to her ‘ok I need you to be what for me now?’ then she’d say ‘flexible.’ Then I’d say ‘right now listen to what I need you to do.’”

Additional time may be necessary for the individual to complete a task (Rondal & Comblain, 1996). Difficulties comprehending instructions and in being able to form syntactically appropriate expressive communication may take individuals with Down

syndrome more time thus employers were mindful of this when evaluating performance on job tasks and forming their expectations.

E6: “She is slow, every task she does, she completes the task at a very slow pace.”

E4: If she takes mugs for instance, she can only carry two and she’ll make four trips with two at a time. So what?

FM3: “not expecting things to happen at the same speed as others would do. It’d just depends on the type of job and uh ask the person what their understanding is you know”

18.2. Training and Support- “expand what she knew because ... she was far more capable”

South African literature has described the vocational/ employment training received at school and the work opportunities available for individuals with any disability as poor (The Department of Women, Children & People with Disabilities, 2011). Ideally individuals should receive guidance before they are placed in a job and have some experience in the skills necessary for the job (Murray & Heron, 1999). Many participants indicated that school did not adequately prepare them for adulthood and employment as there was minimal vocational experience or variety in training. Vocational training focused on cleaning and gardening which only one participant does as part of employment.

FM2: “the only thing that really I think *PDs2 learnt that was work skills was they did cleaning up outside in the garden at school and they also did cookery”

PDs2: “A bit of gardening and reading...how to be a grownup”

PDs6: “To knit and crotchet only”

A lack of specific vocational experience and training necessary for employment success has been reported internationally as well as in the South African context (McAllister, 2008; Vlachos, 2008). Without sufficient vocational training, many individuals are left to learn skills only once they have been employed. It has been suggested that a good technique of skills development in the workplace is through observation as individuals with Down syndrome benefit from having a visual referent (McAllister, 2008). Once employed, some individuals were taught skills specific to their job whilst others received general skills training through the ABET programme. ABET focuses on computer skills, language, telephone communication, reading and writing (Adult Basic Education and Training, 2013). Specific skills that were being taught to individuals in the study included painting, mixing

concrete, alphabetization, filing and factory machine operating. A skills matrix may be beneficial whereby the employer devises a list of skills the individual needs to learn and rates their capabilities to keep track of their development (McAllister, 2008).

E5: “we do have a Zulu class that we had started and with teachers... from the ABET”

FM6: “they can work if they are trained on how to do the job”

PDs2: “He’s teaching me how to paint, mixing concrete”

PDs4: “they trained me in the beginning to get my ABCs right and ja and my numbers and in the beginning I never ever scanned books in the beginning before. Now I can”

PDs1: “He teach me how to run the machine”

Some employers knew the limitations of the individual and focused on task allocation as opposed to further training even if they knew the person is capable of holding more responsibilities. Other employers recognized the individual’s potential and provided them with training thus expanding their list of job tasks.

E2: “So he really does perform the tasks that he’s given well but they are simple tasks. I mean we won’t ask him to make payments on the computer... because that’s beyond his field of expertise but the work that he does he does really well.”

E2: “At times he has a shoulder problem. Um and obviously if he comes to work and he his shoulders sore we won’t ask him to lift heavy things but that’s a physical”

E4: “I decided I was going to train her in other things and just expand what she knew because really she I knew she was far more capable of work than just dusting everyday and coming and doing the same old you know”

Job coaches have been discussed in international literature (National Down Syndrome Society, 2012). However, they were not mentioned by any of the participants. Another accommodation that has been mentioned is the use of a buddy system. One participant mentioned that they used a buddy system which assisted in their learning of new job tasks, monitored the quality of their work and provided emotional support in the workplace. The employer and family member worked together to find a fellow employee that could assist the individual with Down syndrome in their job with work based tasks and interpersonal workplace dynamics. Buddy systems have proven helpful in a variety of contexts in open and supported employment in assisting individuals with Down syndrome to learn more about their job task (Australian Government, 2012).

FM1: “what we did is what we’ve done is created a work buddy...ok a work buddy is somebody he can actually confide in. With the climate...we’ve created for *PDs1 in the workplace... amongst the employees he’s identified guys he can be friends. Some of them have got some of them have a soft spot for *PDs1. So he could actually go and confide in them.”

Support systems that may be beneficial for the individual with Down syndrome in the workplace include colour coding, labelling, visual examples, timetables, visual schedules and additional time for tasks. Employers should encourage and understanding of flexibility but at the same time work within the boundaries of the individual’s limitations. Job coaches may be beneficial in this regard.

19. The Journey to Successful Employment

South Africa in theory and policy adopts the principles of inclusion in education and employment yet this is not the reality of all of the individuals with Down syndrome that were involved in this study. For some inclusion in mainstream schooling has lead to success and inclusion in the open market and workshop environments. Those that were not exposed to mainstream schooling had limited literacy skills which impacted on employment opportunities. South Africa currently appears to be implementing a social approach whereby focus has been on policy development and developing people’s attitudes towards individuals with a disability. Clear evidence of this are the brochures government has developed about the various disabilities but not on how employers can focus on an individual’s strengths. In adopting the ICF in the South African context we need to implement the laws and policies that we describe in such detail so as to allow individuals with Down syndrome to take part in activities such as literacy development which impact their workplace participation and overall participation in society. This will impact their overall wellbeing. Furthermore if the ICF were successfully implemented and more individuals with disabilities were employed then a biopsychosocial model could be applied so that individual experiences could be used to educate others and better the services and conditions for individuals with disabilities. This research study is an example of this.

Supported employment appears to be lacking in the South African context. Individuals with intellectual disability seem to either have to go to a workshop for employment or advocate being in the open working market. Similarly Speech-Language Therapy for those individuals with Down syndrome that are employed is lacking and could benefit communication and support in the workplace.

A way forward for individuals with Down syndrome and intellectual disability in South Africa would be to be included in mainstream education or to be in a LSEN school where literacy development and technological skills are emphasized to simultaneously develop cognition and communication skills. Employment experience should be encouraged so as to ascertain each individual's areas of strength and what the types of job tasks they enjoy. Once this is determined the remaining school years should be focused on developing these skills. Speech-Language Therapy should be implemented during this time as well as during employment in order to develop workplace supports and communication skills.

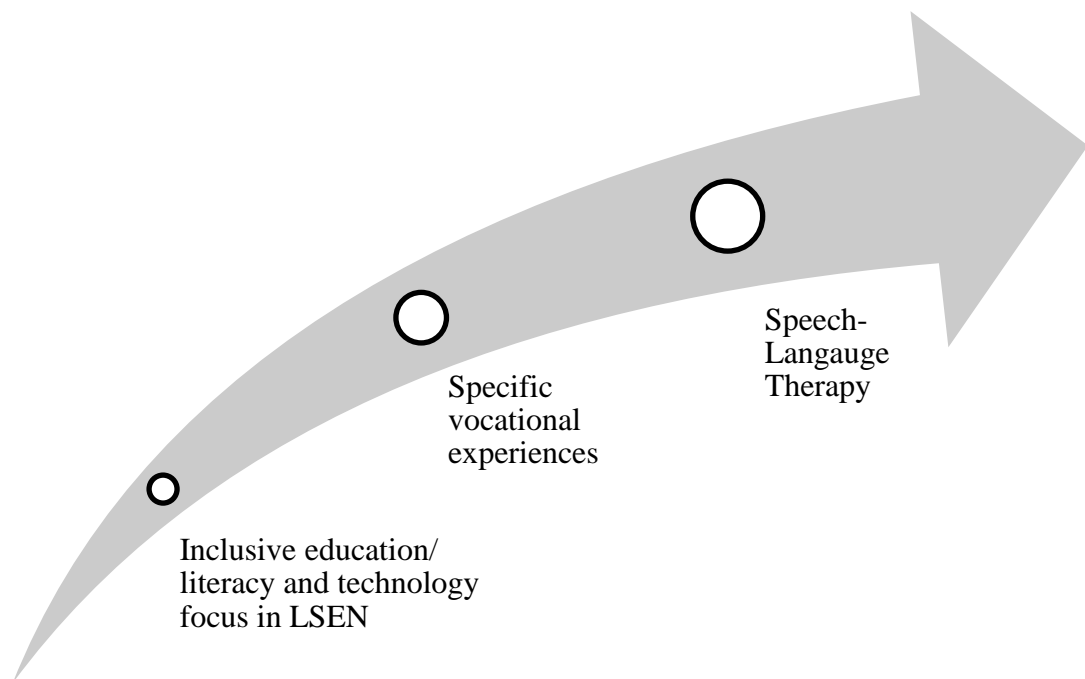


Figure 3: Journey to Successful Employment

Summary of Chapter

Findings relating to speech and language skills of adults with Down syndrome remain inconclusive and vary from individual to individual. However, it was evident that in the workplace, the more knowledgeable the employer was about Down syndrome and the individual with Down syndrome, the better they were able to understand the individual.

With regard to communication, variability in speech intelligibility of individuals was identified with a discrepancy between the family and the employer as to how intelligible the individual is. Family members were limited in identifying only one possible cause of poor intelligibility being the size of the tongue in relation to the mouth. Social skills also varied from individual to individual and the individual's mood was found to influence social interaction and participation. This impacted relationships in the workplace. The individual's mood therefore impacts his/her level of social participation which is crucial in optimal overall well-being as highlighted by the ICF (World Health Organisation, 2001).

The individual's level of cognition impacted receptive language, communicative breakdown and conversational repair. Communication breakdown in the workplace occurs with individuals with Down syndrome and the employer's experiences revealed that repair techniques such as a slower speech rate and repetition were beneficial which is in keeping with literature (Down's Syndrome Association, 2008; Rosin, et al., 1988). It was identified that some co-workers underestimated the individual's level of understanding and oversimplify communication because of this. Employers' experiences revealed that understanding the individual with Down syndrome's speech can be compared to understanding a person with a foreign accent and through this implying that one becomes accustomed to this through exposure. It was evident that individuals with Down syndrome may acquire BICS of another language if they have adequate exposure in the workplace and have the social motivation to do so.

Literacy was another element in the study that varied from individual to individual; however the type of schooling was identified as having a large impact on literacy proficiency. Even though some individuals may be proficient in both reading and writing skills, individuals with Down syndrome are seldom requested to use these skills in the workplace. Similarly, telephone skills are seldom allowed in the workplace despite the avid ownership

and use of cell phones for private use. Including job tasks with literacy elements or telephone skills may enhance the independence of those individuals with Down syndrome who are competent in these tasks.

Speech-Language Therapy was generally well accessed as part of early intervention but not during adulthood. Speech-Language Therapy may be beneficial at various stages during the life span targeting different aims as they become applicable across the lifespan (Kumin, 1994; Stoel-Gammon, 2001). The experiences of the individuals with Down syndrome indicated that speech, language, literacy and social interaction may continue to be concerns in adulthood and the individual may therefore benefit from Speech-Language Therapy especially in relation to the work context to facilitate development and promote communication. Speech-Language Therapists may also assist in with literacy, numeracy and the use of technology within the context of socializing and employment. Visual supports may form part of the Speech-Language Therapist's role working with the adult with Down syndrome. Further skills training may also be a method of workplace support; however this is lacking in the South African context.

Technology was found to be a tool for entertainment, socializing and learning. With a keen interest and an ability to adapt to the use of technology, individuals with Down syndrome should be encouraged to use these various devices to enhance their functioning in the workplace. Individuals with Down syndrome showed benefit from visual timetables and visual examples, how much more beneficial could these be made if tailored to the individual and presented digitally on a device they enjoy and understand. This may be an area for Speech-Language Therapists to assist with.

This chapter provided a description of the results deduced about employment experiences from interviewing individuals with Down syndrome and those that are involved in their employment. It provided information pertaining to the aims and objectives of this study as outlined in the methodology. Links with literature have indicated how individuals with Down syndrome and employed in KZN are similar or different in their experiences to those employed elsewhere.

Chapter Five: Conclusion, Limitations and Implications

This chapter will identify the conclusions that may be drawn from the findings of the study and theoretical and clinical implications will be deduced. This chapter will also include recommendations for areas requiring further research.

Conclusion

This study aimed to explore the employment experiences of individuals with Down syndrome from the perspectives of the individuals with Down syndrome, their employers and their family members with particular emphasis on communication. Overall, employment has a positive effect for individuals with Down syndrome if they are suitably placed according to their strengths and then accommodated for in the workplace. It has a ripple effect by improving the quality of life for the family.

South Africa has some policies in place regarding employment of individuals with a disability; however it is not specific to individuals with an intellectual disability and specifically Down syndrome. This has impacted on how the individuals with Down syndrome gained employment, the vocational opportunities they received and the vocational training available. Only one individual with Down syndrome was supported by the government in gaining employment and the remaining individuals with Down syndrome relied on family members to assist them in this regard.

Family members' experiences indicated that a discrepancy remains between the employment laws in South Africa and the reality of the laws being enforced partially due to myths and misunderstanding of Down syndrome. Employers seldom had an accurate understanding of Down syndrome and needed to research as little was provided to them. The experiences of the employers involved in this study also revealed a fairly limited understanding of Down syndrome specifically the communicative strengths and weaknesses. Employers were somewhat supported by governmental policy and receive some financial support when employing an individual with Down syndrome but do not receive sufficient specific information and personal assistance e.g. a job coach.

Individuals with Down syndrome and their families are crucial in advocating for the rights of individuals with Down syndrome. The opportunities available for individuals with Down syndrome have increased as employment rights have been promoted. In the work environment, job tasks are generally not specifically designed for the individual with Down syndrome other than being classified as physical or administrative in nature. Challenges relating to other people's perceptions, health concerns and numeracy were frequently described.

Individuals with Down syndrome that participated in the study indicated positive experiences of employment regardless of the type of employment. Employment was described as having encouraging effects on confidence and self esteem and increase financial income as well as having positive effects for the family and employer. This is in keeping with literature (Brown, 2004; Webber, 2011). Individuals experienced some discrimination in the work place and were required to advocate and prove themselves in the workplace. Some individuals with Down syndrome experienced limited job task opportunities but still felt grateful for their employment and found benefit in being employed.

Participants with Down syndrome all used forms of technology to communicate. The use of cell phones, telephones and other technological devices were discussed by many of the participants. The devices were commonly used for social and recreational purposes; however they were seldom used in the work environment. These devices have the potential to assist the individual in the workplace. Some workplaces encourage the development of their employee with Down syndrome's literacy and computer skills and in this way begin to encourage technology in the workplace to increase job tasks and independence.

Speech-Language Therapists are seldom involved in intervention with the adult population with Down syndrome yet the areas of difficulty highlighted in this study clearly link to the role of Speech-Language Therapists. The Speech-Language Therapist may be able to provide insight into the use of technological devices in the workplace to enhance communication and workplace skills considering their understanding of AAC and the use of technological devices. The question remains as to why Speech-Language Therapy services are not being accessed by adults with Down syndrome who are employed.

There are many people who influence the individual with Down syndrome's work experience. The employer impacts the learning opportunities available to the individual, provides constructive criticism and structure and emotional support. Family members play a role in finding employment, developing social skills; working through conflict and in some instances providing transport as well. Down syndrome societies advocate for those with Down syndrome and assist in dispelling myths and misconceptions in society which ultimately promotes employment.

Down syndrome is a congenital lifelong disorder that influences an individual in many ways (Hayes & Batshaw, 1993; Layton, 2000). As stated in the ICF, optimum functioning and well being is affected if the individual's body structure, ability to partake in activities and participation in society are affected (World Health Organisation, 2001). Functioning may therefore be impacted by the intellectual impairment, health concerns and communicative difficulties associated with Down syndrome. Intervention is required and the type and nature of intervention will change as the individual ages and develops. It is crucial for those involved in management and supporting the individual with Down syndrome to know how best to assist the individual in the workplace.

Limitations

1. In this study, the sample and results are only representative of individuals with Down syndrome in one district of the KwaZulu-Natal province
2. The results of the study were limited to those who are able to verbally communicate and share their experiences. The experiences of those that participated are valuable, however, it must be noted that their experiences may not represent the full range of individuals in the population as those who cannot communicate in an interview did not participate (Preece & Jordan, 2009). Communicative difficulties may also have inhibited those who participated from being able to express their experiences in their entirety
3. Cultural, gender, racial, geographical and linguistic diversity was obtained in the study sample; however, there were a limited number of participants representing each of these groups
4. The type of Down syndrome was not established and therefore could not be considered in data analysis.

Implications

Implications for research

Future research into the employment of individuals with Down syndrome should investigate:

1. The employment experiences of the individuals with Down syndrome including observation of these experiences in the workplace
2. The employment experiences of individuals with Down syndrome in other provinces and identification of regional trends across South Africa
3. The experiences of individuals with an intellectual disability in order to compare and contrast this with the employment experiences of individuals with Down syndrome
4. The knowledge base of Speech-Language Therapists on working with adults with Down syndrome and on supporting employment
5. The perspectives of adults with Down syndrome who are employed and receive Speech-Language Therapy and the benefits therapy has provided
6. The role of the Speech-Language Therapist in the management of adults with Down syndrome
7. The role of the Speech-Language Therapist in addressing written language development and promoting the use of written language skills of individuals with Down syndrome
8. The role of the Speech-Language Therapist in facilitating the use of assistive technology by the individual with Down syndrome
9. The role of other rehabilitative services such as school or vocational training programmes in assisting in the workplace
10. The rights of individuals' with disabilities and whether these are upheld in the workplace
11. The numeracy development and skills of individuals with Down syndrome
12. The social and leisure pursuits of individuals with Down syndrome
13. The leisure use of computers and other technological devices by individuals with Down syndrome
14. The work experiences of individuals with Down syndrome who have difficulty communicating in an interview

15. The views of people with Down syndrome on issues related to the lives of people with Down syndrome such as health care, strengths, weaknesses, relationships, schooling, therapies and communicative, social and literacy development.

Implications for practice

1. Work is crucial for financial, self esteem, keeping people busy, developing skills and for broadening society's understanding of Down syndrome
2. If legislation is followed, individuals with Down syndrome should be provided with employment in order to develop their skills, social skills and independence. They should therefore be provided with adequate opportunities for employment
3. The provision of vocational courses and the development of training and occupational centres is an area that the South African government need to develop to improve the services available to individuals with Down syndrome particularly in rural areas
4. Education and language intervention provide support for literacy development in individuals with Down syndrome
5. As mainstream education encourages the development of literacy skills, learners that attend LSEN schools should obtain literacy support so that they can develop literacy skills to their full potential
6. Individuals with Down syndrome benefited from Speech-Language Therapy for articulation, language and literacy concerns. Concerns continued into adulthood yet many adults with Down syndrome do not receive therapy. Speech-Language Therapists need to advocate for Speech-Language Therapy for adults with Down syndrome. Speech-Language Therapists also need to promote the benefit of therapy in assisting with employment
7. Employers should promote the use of computers in the workplace should the individual with Down syndrome possess the ability to develop computer skills and an interest in computer usage
8. Speech-Language Therapists need to increase their knowledge about working with the adult population with Down syndrome and an intellectual disability in order to develop treatment strategies and provide adequate management
9. Speech-Language Therapists should assist adults with Down syndrome in identifying conversation breakdown and how to repair this

10. Speech-Language Therapists should assist in developing work related vocabulary and develop the individual with Down syndrome's ability to use this vocabulary effectively in the workplace
11. Speech-Language Therapists should assist in developing AAC resources and memory aids to benefit the individual with Down syndrome in the workplace
12. Referral to an Occupational Therapist would be beneficial to encourage adaptations to the workplace and vocational support
13. In-service training or input from a job coach is necessary for employers and prospective employers on communicative strengths and weaknesses of individuals with Down syndrome. The job coach may also take on the role of liaison between the person with disability and the family
14. Job coaches should be encouraged in enhancing the employment success of individuals with Down syndrome
15. Having a mediator may be necessary when misunderstandings occur in the workplace
16. Governmental input is required to develop skill based vocational courses particularly in rural areas of South Africa
17. Technological devices such as iPads and cell phones should be incorporated into therapy and as support in the workplace
18. Exposure to technological devices such as computers, cell phones, iPads/tablets etc. should be encouraged in the home context to increase the understanding and use of such devices so that they can be used for social and employment purposes
19. The use of computers should be encouraged as they can be used for social and employment purposes
20. Family should be included in discussion involving employment for the individual with Down syndrome to determine the individual's strengths and weaknesses, adequate allocation of job tasks and support that may be needed
21. Families of individuals with Down syndrome require support from medical professionals and Down syndrome associations to cope with the changes that develop with aging such as memory loss, health concerns and a decrease in social skills
22. Individuals with Down syndrome should share their experiences with each other in order to learn from each other and to promote advocacy self-skills. Local and international Down syndrome seminars and congress meetings are ideal forums for such discussion.

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Appendix A: Letter to Associations

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

Dear Association that works with individuals with Down syndrome,

REQUEST FOR ASSISTANCE IN A RESEARCH STUDY

Research study title: Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal.

I am a Masters student at the University of KwaZulu-Natal (Westville Campus) conducting research in the field of Down syndrome. The focus of my research is on adults with Down syndrome and employment in KwaZulu-Natal. This is a topic of interest as there is a lack of information in this area in South Africa. I am conducting research to gain understanding on the types of jobs available, accommodations in the workplace and specifically communication in the workplace from the perspective of the individual with Down syndrome, their employer and their family. This information will draw awareness to the employment of individuals with Down syndrome as well as indicate the employment options available and what employers could do to assist individuals with Down syndrome in the workplace. I have received ethical clearance to conduct my study from the University of KwaZulu-Natal School Research, Ethics and Higher Degrees Committee (Reference: HSS/0274/012M).

My study involves interviewing the individual with Down syndrome, their employer and a family member. Involvement would include interviews with each participant, lasting approximately an hour, at a date, time and venue that is convenient. The interview questions will relate to Down syndrome in the workplace. Confidentiality will be maintained at all times and the names of individuals or institutions will not be reported. Each individual will be required to read their own information letter and sign their own consent form. Participation is voluntary and participants have the right to withdraw from the research study at any time.

Participation will not result in employment, a change in employment status or an increased income for the individual with Down syndrome.

I kindly request your assistance in obtaining names and contact details of people who are members of your organization that may be interested in participating in my study. If you know of people that may be interested then please complete the contact details document attached to this letter and return via email to courtneytod@gmail.com or fax to the University of KwaZulu-Natal Speech-Language Pathology Department on (031) 260 7622 with “Attention: Courtney Tod” written at the top. I will then contact the individuals personally. The individuals and their caregivers can then decide if they would like to participate in the study. I look forward to your correspondence and will greatly appreciate any information you are able to supply me with. Should you have any queries regarding the research study, kindly contact the researcher or one of the research supervisors.

Thank you for your assistance.

Yours faithfully,

Courtney Tod (Researcher)

Email: courtneytod@gmail.com

Phone: 083 317 6790

Ms. Jenny Pahl (Research Supervisor)

Email: pahlj@ukzn.ac.za

Phone: 031 260 7624

Ms. Saira Karrim (Research Supervisor)

Email: karimsb@ukzn.ac.za

Phone: 031 260 7550

For further queries, please contact the School of Health Science Research Office.

Contact person: Miss Phumelele Ximba

Email: Ximbap@ukzn.ac.za

Phone: 031 260 3587

Fax: 031 260 4609

Contact Details of Potential Participants

No.	Individual with Down syndrome's name	Parent's/ caregiver's name	Caregiver's relation to child	Contact number
1				
2				
3				
4				
5				
6				
7				
8				

Appendix B: Letter, Consent and Biographical Questionnaire: Individual with Down syndrome (English)
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DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

INVITATION TO BE PART OF A RESEARCH STUDY

**** As the parent/ caregiver of the individual with Down syndrome, please determine if the individual with Down syndrome is able to read, understand and complete these forms. Should the parent/ caregiver feel the individual with Down syndrome may find this too difficult, then please read and respond on the individual with Down syndrome's behalf. This will indicate to the researcher that the parent/ caregiver has asked the individual with Down syndrome if they would like to participate in the study and explained the nature and process of the study in as much detail as possible to the individual.**

Dear Sir/ Madam,

I am studying at the University of KwaZulu-Natal (Westville Campus) and I am finding out about adults with Down syndrome and their work. I have permission to do a study about adults with Down syndrome who work (Reference: HSS/0274/012M). There is not much information about the types of jobs available and how people with Down syndrome feel about the work they do.

I got your name from Down Syndrome South Africa or Durban Mental Health. I would really like to speak to you and learn about you and your work. I would need about 30 minutes of your time to chat with you on a day that you are free. I will meet you at a place that is comfortable for you. The talk will be tape recorded to help me remember the things we speak about. I will not mention your name or your work's name in my report. The tape will be kept on my computer for five years and nobody will have access to it without a password. I will

keep any written work in a locked cupboard at the University for five years so all information is private. I will then cut it up and throw the papers away.

This study may help bosses to understand more about people with Down syndrome and may help in the future for other people with Down syndrome to get work. I would also like to speak to your boss and one of your family members. They will get their own letters to read and sign.

You will not be in any trouble at work if you do not want to participate. You will not be given a job or extra money if you take part in the research study. You can change your mind at any time if you feel you do not want to be part of the research study anymore. Pages 4, 5 and 6 of this letter are forms for you to fill in if you want to be part of my research study. A family member can fill them in for you if you want. If you want to be a part of my research study, then please fill in the two forms and send them back by email to courtneytod@gmail.com or fax to Speech-Language Pathology on (031) 260 7622 with "Attention: Courtney Tod" written at the top. These forms must also be signed by one of your parents/ guardians or the person that helps you at home. Please return by 01 July 2012. Please keep your original copies of each of the forms for yourself.

I look forward to hearing from you. If you have any questions, then please call me or one of my supervisors. Our phone numbers are written below our names.

Thank You!

Yours faithfully,

Courtney Tod (Researcher)

Email: courtneytod@gmail.com

Phone: 083 317 6790

Ms. Jenny Pahl (Research Supervisor)

Email: pahlj@ukzn.ac.za

Phone: 031 260 7624

Ms. Saira Karrim (Research Supervisor)

Email: karimsb@ukzn.ac.za

Phone: 031 260 7550

For further queries, please contact the School of Health Science Research Office.

Contact person: Miss Phumelele Ximba

Email: Ximbap@ukzn.ac.za

Phone: 031 260 3587

Fax: 031 260 4609

Form of Understanding: Individual with Down syndrome

I _____(your name) agree that I read the letter about the research and understand what it says. I want to be part of the research study and will meet with the researcher for an interview. I understand that the interview will be audio taped. I understand that I do not have to participate and I can change my mind if I do not want to be a part of the research study anymore. I understand that being part of this will not harm me or my work in anyway and there is no benefit to me for being part of the research study.

Your signature

Date

Parent/ Guardian signature

Date

I would like to receive a summary of the results of this study (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/> No <input type="checkbox"/>
--	--

If “yes” please supply an email address or postal address to which the summary can be sent:

Biographical Information Questionnaire: Individual with Down syndrome

Study Criteria

Please tick one of the boxes. This will show if you are the right type of person to be in the study.

Have Down syndrome	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Lives in KwaZulu-Natal	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Is 18 years or older	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Working for at least 1-20 hours every week	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Working in current/previous job within the last 6 months	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Working in current/previous job for at least 6 months of work	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Able to be part of a conversation	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Able to speak in English or isiZulu	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Personal details of individual with Down syndrome

Name		
Phone numbers		
Date of birth		
Age		
Gender (please tick one of the boxes to show your choice)	Male <input type="checkbox"/>	Female <input type="checkbox"/>
Home language (please tick one of the boxes to show your choice)	English <input type="checkbox"/>	isiZulu <input type="checkbox"/>
Living with parents/family (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Educational details of individual with Down syndrome

Number of years of school		
Work courses at school (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Additional courses attended while at school		
Additional therapy attended at school or privately e.g. Speech Therapy, Occupational Therapy etc		

Employment details of individual with Down syndrome

Current place of employment			
Name of employer			
Contact details of employer			
Start date of employment			
Type of employment (please tick one of the boxes to show your choice)	Open: <input type="checkbox"/> you and your family found the job for yourself and you do not require assistance at work	Supported: <input type="checkbox"/> you work with other people who have disabilities and receive help in the workplace	Sheltered: <input type="checkbox"/> the job is part of a programme at an institution
Additional courses attended while working			
Number of working days per week			
Working hours each day			

Interview Details for individual with Down syndrome

Language for interview (please tick one of the boxes to show your choice)	English <input type="checkbox"/>	isiZulu <input type="checkbox"/>
Place for interview		
Date and time for interview		

PLEASE RETURN BY 01 JULY 2012

Appendix C: Letter, Consent and Biographical Questionnaire: Individual with Down syndrome (isiZulu)

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

ISIMEMO SOKUBA YINGXENYE YOCWANINGO

**** Njengomzali noma umnakekeli womuntu ophila ne Down syndrome, ngicela ubheke ukuthi lomuntu ophila ne Down Syndrome ngabe uyakwazi na ukufunda, aphinde agcwalise lamafomu. Uma ngabe ubona sengathi lamafomu angaba nzima kakhulu kulowo muntu ophila ne Down syndrome, sicela wena uwafunde bese umgcwalisela lowo muntu one Down syndrome. Lokho kuyosiza ukuthi umcwaningi abone ukuthi lamafomu agcwaliswe ngemvume yalowo muntu one Down syndrome, nokuthi lomuntu utsheliwe futhi wachazelwa ngalolu cwaningo.**

Sawubona Mnu/Nkk/Nksz,

Ngifunda eNyuvesi yaKwaZulu Natali (eWestville), ngicwaninga kabanzi mayelana nabantu abane Down syndrome nomsebenzi wabo lapho besebenza khona. Ngithole imvume yokucwaninga ngabantu abane Down syndrome abasebenzayo (Reference: HSS/0274/012M). Alukho ulwazi oloningi olukhona nayelana nezinhlalo zemisebenzi engenziwa abantu abaphila ne Down syndrome Nangokuthi abantu abane Down syndrome bazizwa kanjani ngemisebenzi abayenzayo.

Ngithole igama lakho kwi-Down Syndrome South Africa noma kwi-Durban Mental Health. Ngingakujabulela kakhulu ukukhuluma nawe, ngiphinde ngazi kabanzi ngomsebenzi owenzayo. Ngidinga nje isikhathi esingangemizuzu eyishumi nantathu (30), ukuze ngixoxe nawe ngalolo suku oyobe unesikhathi ngalo. Ngizohlangana nawe endaweni evumelana nawe. Ingxoxo yethu ngizoyoyiqopha, lokhu kuyongisiza ngikhumbule izinto esiyobe sikhulume ngazo. Angeke ngiliphathe igama lakho lapho sengibhala imiphumela yalolucwaningo, liyohlala liyimfihlo. Lokho okuqoshiwe kuyohlala ekhompuyutheni yami

iminyaka eyisihlanu, futhi akekho omunye oyoba nemvume yokulalela. Lokho engikubhale phansi ngiyokugcina endaweni evalelekile iminyaka eyisihlanu engekho omunye onemvume yokukufunda. Emuva kwaleminyaka ngiyobe sengikugoba ngikulahla ukuze kungabibikho omunye okubonayo konke lokhu. Lolucwaningo lungasiza abaphathi ukuthi bazi kangcono ngabantu abane Down syndrome futhi lungasiza esikhathini esizayo ukuthi abanye abantu abane Down syndrome bathole imisebenzi. Ngingakujabulela ukuxoxa nomqashi wakho kanye nelunga lomndeni wakho. Bazothola ezabo izincwadi abazozifunda bazisayine.

Angeke ungene enkingeni emsebenzini uma ungathandi ukuba yingxenye yalolu gcwaningo. Angeke uthole umsebenzi noma imali uma uvuma ukuba yingxenye yocwaningo. Uvumelekile ukushintsha umqondo noma inini uma uzizwa sengathi awusathandi ukuqhubeka ube yingxenye yocwaningo. Amakhasi alandelayo u 4,5 no 6 ale ncwadi angamafomu okumele uwagcwalise. Ilunga lomndeni wakho lingakugcwalisela uma uthanda kanjalo. Uma ufisa ukuba yilunga lalolu cwaningolwami, ngicela ugcwalise lamafomu bese uwathumela kimi nge-email ku- courtneytod@gmail.com noma nge fax kwa Speech Language Pathology ku (031) 260 7622 ubhale phezu uthi “Attention: Courtney Tod”. Lamafomu kumele asyinwe nguwe kanye nomzali wakho, umuntu okunakekelayo noma umuntu okusizayo ekhaya. Ngicela lamafomu abuye ngomhlaka **1 July 2012**. Ngicela ugcine lawamafomu ayosala kuwe kube ngawakho.

Ngojabula ukuthola impendulo evela kuwe. Uma unemibuzo, ngicela ungifonele noma ufonele umphathi wami. Izinombolo zethu zibhalwe ngezansi.

Ngiyabonga

Yimi ozithobayo

Courtney Tod (umcwaningi)

Thumela i-email: courtneytod@gmail.com

Phone: 083 317 6790

Ms. Jenny Pahl (umphathi wocwaningo)

Thumela i-email: pahlj@ukzn.ac.za

Fonela: 031 260 7624

Ms. Saira Karrim (umphathi wocwaningo)

Thumela i-email: karimsb@ukzn.ac.za

Fonela: 031 260 7550

Uma unezinkinga, thintana nesikole sakwa Health Science amahhovisi ocwaningo

Xhumana no: Nkz Phumele Ximba

Thumela i-email: Ximbap@ukzn.ac.za

Fonela: 031 260 3587

Thumela ifax: 031 260 4609

Ifomu lesivumelwano: Umuntu one Down syndrome

Mina_____ (igama lakho) ngiyavuma ukuthi ngiyifundile incwadi emayelana nocwaningo futhi ngiyazi ukuthi ithini. Ngiyathanda ukuba yingxenye yalolu cwaningo futhi ngizohlangana nomcwaningi ukuze sixoxe. Ngiyaqonda ukuthi ingxoxo yethu izoqoshwa. Ngiyaqonda ukuthi angiphoqelekile ukuba yingxenye yocwaningo futhi ngingawushintsha umqondo wami noma yinini uma ngingasathandi ukuba yingxenye yocwaningo. Ngiyaqonda ukuthi ukuba yingxenye yalolu cwaningo ngeke kungilimaze mina noma umsebenzi wami nanoma ingayiphi indlela, ngiyazi futhi ukuthi angeke ngithole lutho ngokuba yingxenye yocwaningo.

Sayina

Usuku

Umzali/Umbheki sayina

Usuku

Ngingakuthokozela ukuthola imiphumela emifushane yalolu cwaningo (Khetha ibhokisi elilodwa)

Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
-------------------------------	------------------------------

Uma uthi “yebo” ngicela unginike i-adilesi yakho ye posi noma ye email lapho ngizothumela khona:

Imininingwane yalowo one Down syndrome

Ukuze ube yingxenye yocwaningo

Khetha ibhokisi elivumelana nawe. Lokhu kuzongisiza ngibone ukuthi ungumuntu olungele ukuba yingxenye yocwaningo

Une Down syndrome	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uhlala KwaZulu Natali	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uneminyaka eyi-18 noma ngaphezulu	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Usebenza okungenani amahora kusukela kwelilodwa kuya ku 20 njalo ngesonto	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Ususebenze umsebenzi izinyanga eziyi-6	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Ususebenze okungenani izinyanga eziyi-6	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uyakwazi ukuxoxa nabanye abantu	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uyakwazi ukuxoxa ngesiNgisi noma isiZulu	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>

Iminingwane ephathelene nalowo one Down syndrome

Igama	
Izinombolo zocingo	
Usuku lokuzalwa	
Iminyaka	
Ubulili (Khetha ibhokisi elivumelana nawe)	Owesilisa <input type="checkbox"/> Owesifazane <input type="checkbox"/>
Ulimi lwasekhaya (Khetha ibhokisi elivumelana nawe)	IsiNgisi <input type="checkbox"/> IsiZulu <input type="checkbox"/>
Uhlala nabazali/nomndeni (Khetha ibhokisi elivumelana nawe)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>

Iminingwane ephathelene nemfundo yalowo one Down syndrome

Iminyaka owayifunda	
Ngabe wenza izifundo zomsebenzi esikoleni (Khetha ibhokisi elivumelana nawe)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
Ezinye izifundo eziseceleni owazenza usafunda	
Olunye usizo lo\dokotela owaluthola esikoleni	

noma kodokotela abazimele njenge Speech Therapy noma Occupational Therapy nokunye.	
--	--

Iminingwane ephathelene nokuqashwa kwalowo one Down syndrome

Indawo osebenza kuyo			
Igama lomqashi			
Izinombolo zomqashi			
Usuku owaqala ngalo ukusebenza			
Inhlobo yomsebenzi (Khetha ibhokisi elivumelana nawe)	Ovulelekile: <input type="checkbox"/> Wena nomndeni wakho nazitholela umsebenzi futhi awudingi usizo emsebenzini	Osizwayo: <input type="checkbox"/> Usebenza nabanye abantu abakhubazekile futhi uthola usizo emsebenzini.	Ovikelekile: <input type="checkbox"/> Umsebenzi wakho uyingxenywe yohlelo endaweni ohlala kuyo.
Ezinye izinto ozifundelayo ngesikhathi usebenza.			
Inani lezinsuku ozisebenzayo ngesonto.			
Inani lamahora owasebenzayo ngosuku			

Imininingwane ephathelene nengxoxo ezoba phakathi komcwaningi nalowomuntu one Down syndrome

Ulimi oluzosetshenziswa kule ngxoxo (Khetha ibhokisi elivumelana nawe)	IsiNgisi <input type="checkbox"/>	IsiZulu <input type="checkbox"/>
Indawo lapho kuyohlenganwa khona		
Usuku nesikhathi okuyohlenganwa ngaso		

NGICELA ULIBUYISE NGOMHLAKA 1 JULAYI 201

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

Dear Sir/ Madam,

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Research study title: Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal.

I am a Masters student at the University of KwaZulu-Natal (Westville Campus) conducting research in the field of Down syndrome. The focus of my research is on adults with Down syndrome and employment in KwaZulu-Natal. This is a topic of interest as there is a lack of information in this area in South Africa. I am conducting research to gain understanding on the types of jobs available, accommodations in the workplace and specifically communication in the workplace from the perspective of the individual with Down syndrome, their employer and their family. This information will draw awareness to the employment of individuals with Down syndrome as well as indicate the employment options available and what employers and Speech-Language Therapists could do to assist individuals with Down syndrome in the workplace. I have received ethical clearance to conduct my study from the University of KwaZulu-Natal School Research, Ethics and Higher Degrees Committee (Reference: HSS/0274/012M).

I obtained the names of individuals with Down syndrome and their families from Down Syndrome South Africa and Durban Mental Health as possible participants. The details of employers were obtained from the families of the individuals with Down syndrome. I kindly request your involvement in my research study. Involvement would include an interview, lasting approximately an hour, at a date, time and venue that is convenient to you. The interview questions will relate to Down syndrome in the workplace and no questions will have any implications for you personally. The interview will be audio recorded for the

purpose of analysis. This recording will be kept for a compulsory period of five years and then destroyed. Hard copies of data will be kept in a locked cupboard at the University of KwaZulu-Natal in the Speech-Language Pathology department. This will be destroyed via shredding after five years. Electronic data will be stored on a computer that is password protected. This will be destroyed after five years. All participants' names will be coded. Confidentiality will be maintained at all times and the names of individuals or institutions will not be reported. My study involves interviewing the individual with Down syndrome, their employer and a family member. Each individual will be required to read their own information letter and sign their own consent form.

Please note that participation is voluntary and participants have the right to withdraw from the research study at any time. Refusal to participate in the research study will in no way impact the employment of the individual with Down syndrome. Participation will not result in employment, a change in employment status or an increased income for the individual with Down syndrome.

Attached is a document of informed consent and a biographical questionnaire. If you are willing to participate, please complete the forms and return via email to courtneytod@gmail.com or fax to the University of KwaZulu-Natal, Discipline of Speech-Language Pathology on (031) 260 7622 with "Attention: Courtney Tod" written at the top. Please return by **01 July 2012**. Please keep your original copies of each of the documents for your own reference.

I look forward to your correspondence and will greatly appreciate your participation. Should you have any queries regarding the research study, kindly contact the researcher or one of the research supervisors.

Thank you for your assistance.

Yours faithfully,

Courtney Tod (Researcher)
Email: courtneytod@gmail.com
Phone: 083 317 6790

Ms. Jenny Pahl (Research Supervisor)
Email: pahlj@ukzn.ac.za
Phone: 031 260 7624

Ms. Saira Karrim (Research Supervisor)
Email: karimsb@ukzn.ac.za
Phone: 031 260 7550

For further queries, please contact the School of Health Science Research Office.
Contact person: Miss Phumelele Ximba
Email: Ximbap@ukzn.ac.za
Phone: 031 260 3587
Fax: 031 260 4609

Declaration of Informed Consent: Employer

I _____(full name of participant) hereby confirm that I have read and understood the contents of this document and the nature of the research study. I consent to participate in an interview and allow the contents of the interview to be used in the research study. I will provide the researcher with accurate information. I give my consent for the interview to be audio taped for analysis purposes only.

I understand that participation is voluntarily and I am at liberty to withdraw at any stage should I wish to do so. I understand that there is no direct benefit to me for participating in the study.

Signature of participant

Date

I would like to receive a summary of the results of this study (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
--	------------------------------	-----------------------------

If “yes” please supply an email address or postal address to which the summary can be sent:

Biographical Information Questionnaire: Employer

Study Criteria

Please tick below to indicate the participant meets the participant criteria:

Directly oversees individual with Down syndrome (not necessarily the most senior level of management)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Have direct contact with the individual at least once a week	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Has been the employer for a minimum of six months	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Resides in KwaZulu-Natal	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Able to converse in either English or isiZulu	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Personal details of Employer of individual with Down syndrome

Participant name	
Contact number	
Date of birth	
Age	
Gender (please tick)	Male <input type="checkbox"/> Female <input type="checkbox"/>

Employment details of Employer of Individual with Down syndrome

Current place of employment	
Rank or title at work	
Length of employment in current job	
Number of contact hours with employee with Down syndrome per week	

Interview Details for Employer of Individual with Down syndrome

Language for interview (please tick)	English <input type="checkbox"/> isiZulu <input type="checkbox"/>
Venue for interview	
Date and time for interview	

PLEASE RETURN BY 01 JULY 2012

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



Sawubona Mnu/Nkk/Nkz,

June 2012

ISIMEMO SOKUBA YINGXENYE YOCWANINGO

Isihloko socwaningo: Ukuqashwa kwabantu abane Down syndrome: Isipiliyoni salabo abane Down syndrome, abaqashi babo kanye nemindeni yabo KwaZulu-Natali

Ngingumfundi owenza izifundo eziphakeme phecelezi iMasters eNyuvesi yaKwaZulu-Natali (eWestville), ngicwaninga ngabantu abane Down syndrome. Ucwanningo lwami lubheke kakhulu abantu abadala abane Down syndrome kanye nokuqashwa kwabo KwaZulu-Natali. Lesi sihloko ngisikhetha ngoba lungekho ulwazi olwanele mayelana naloku lapha eMzansi Afrika. Ngenza lolucwaningo ukuze ngithole ulwazi olubanzi mayelana nemisebenzi ekhona, ukwamukeleka emsebenzini, ikakhulukazi ukuxhumana emsebenzini ngokubona kwalabo abane Down syndrome, abaqashi babo kanye nemindeni yabo. Imiphumela yalolu cwanningo izosiza ukuthuthukisa ulwazi mayelana namathuba omsebenzi akhona kubantu abane Down syndrome. Izosiza futhi abaqashi nama Speech-Language Therapists ukuthi bazi izinto abangazenza ukuze basize abantu abane Down syndrome emsebenzini. Ngiyitholile imvume ukuthi ngenze lolu cwanningo kwi komiti lezocwaningo eliphakeme, eNyuvesi yaKwaZulu-Natali (I-reference ithi: HSS/0274/012M)

Ngithole amagama abantu abane Down syndrome nemindeni yabo kwi-Down Syndrome South Africa noma kwi-Durban Mental Health. Amagama abaqashi wona ngiwathole emindenini yalaba abane Down syndrome. Ngenhlonipho, ngicela ukuthi ube yingxenywe yocwaningo lwami. Ngingakujabulela kakhulu ukukhuluma nawe. Ngidinga nje isikhathi esingaba ngange hora, ukuze ngixoxe nawe ngalolo suku oyobe unesikhathi ngalo. Ngizohlangana nawe endaweni evumelana nawe. Ingxoxo yethu ngiyoyiqopha, lokhu kuyongisiza ngikhumbule izinto esiyobe sikhulume ngazo. Angeke ngiliphathe igama lakho noma igama lendawo osebenza kuyo lapho sengibhala imiphumela yalolucwaningo, liyohlala

liyimfihlo. Lokho okuqoshiwe kuyohlala ekhompuyutheni yami iminyaka eyi-5, futhi akekho omunye oyoba nemvume yokulalela. Lokho engikubhale phansi ngiyokugcina endaweni evalelekile iminyaka emihlanu engekho omunye onemvume yokukufunda. Emuva kwaleminyaka ngiyobe sengikuqoba ngikulahla ukuze kungabibikho omunye okubonayo konke lokhu. Lolucwaningo luhlanganisa ukuxoxa nabantu abane Down syndrome, umqashi wabo kanye nelunga lomndeni wabo. Wonke umuntu udingeka ukuba afunde incwadi emazisa ngocwaningo abese esayina.

Ngicela wazi ukuthi ukuba yingxenywe yocwaningo akuphoqekile. Unemvume yokushintsha umqondo uma ungasathandi ukuba yingxenywe yocwaningo noma inini. Angeke angene enkingeni emsebenzini umuntu one Down syndrome uma ungathandi ukuba yingxenywe yalolu gcwaningo. Angeke athole umsebenzi noma imali umuntu one Down syndrome uma uvuma ukuba yingxenywe yocwaningo.

Amakhasi alandelayo ale ncwadi angamafomu okumele uwagcwalise mayelana nawe.. Uma ufisa ukuba yilunga lalolu cwaningo lwami, ngicela ugcwalise lamafomu bese uwathumela kimi nge-email ku- courtneytod@gmail.com noma nge fax kwi Nyuvesi yaKwaZulu-Natali kwa Speech Language Pathology ku (031) 260 7622 ubhale phezulu uthi “Attention: Courtney Tod”. Ngicela lamafomu abuye ngomhlaka **1 July 2012**. Ngicela ugcine lawamafomu ayosala kuwe kube ngawakho.

Ngojabula ukuthola impendulo evela kuwe. Uma unemibuzo, ngicela ungifonele noma ufonele umphathi wami. Izinombolo zethu zibhalwe ngezansi.

Ngiyabonga ngosizo lwakho

Yimi ozithobayo,

Courtney Tod (umcwaningi)

Thumela i-email: courtneytod@gmail.com

Fonela: 083 317 6790

Ms. Jenny Pahl (umphathi wocwaningo)

Thumela i-email: pahlj@ukzn.ac.za

Fonela: 031 260 7624

Ms. Saira Karrim (umphathi wocwaningo)

Thumela i-email: karimsb@ukzn.ac.za

Fonela: 031 260 7550

Uma unezinkinga, thintana nesikole sakwa Health Science amahhovisi ocwaningo

Xhumana no: Nkz Phumele Ximba

Thumela i-email: Ximbap@ukzn.ac.za

Fonela: 031 260 3587

Thumela ifax: 031 260 4609

Incwadi yesivumelwano: Umqashi

Mina_____ (igama lakho) ngiyavuma ukuthi ngiyifundile incwadi emayelana nocwaningo futhi ngiyazi ukuthi ithini. Ngiyathanda ukuba yingxenye yalolu cwaningo futhi nginika imvume ukuthi engizokusho kusetshenziswe njengengxenye yocwaningo. Ngizonika umcwaningi lokho okuyiqiniso nengikwaziyo.

Ngiyaqonda ukuthi ingxoxo yethu izoqoshwa. Ngiyaqonda ukuthi angiphoqelekile ukuba yingxenye yocwaningo futhi ngingawushintsha umqondo wami noma yinini uma ngingasathandi ukuba yingxenye yocwaningo. Ngiyaqonda ukuthi angeke ngithole lutho ngokuba yingxenye yocwaningo.

Sayina

Usuku

Ngingakuthokozela ukuthola imiphumela emifushane yalolu cwaningo (Khetha ibhokisi elilodwa)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
---	--

Uma uthi “yebo” ngicela unginike i-adilesi yakho ye posi noma ye email lapho ngizothumela khona:

Imininingwane yomqashi walowo one Down syndrome

Ukuze ube yingxenye yocwaningo

Khetha ibhokisi elivumelana nawe. Lokhu kuzongisiza ngibone ukuthi ungumuntu olungele ukuba yingxenye yocwaningo

Ungumphathi walowo one Down syndrome (Akubalulekile ukuthi uze ube phezulu enkampanini)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
Umbona okungenani kanye ngesonto lowo one Down syndrome	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
Usube ngumphathi wakhe okungenani izinyanga eziyi-6	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
Uhlala KwaZulu-Natali	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
Uyakwazi ukuxoxa ngesiNgisi noma isiZulu	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>

Iminingwane ephathelene nomqashi walowo one Down syndrome

Igama	
Izinombolo zocingo	
Usuku lokuzalwa	
Iminyaka	
Ubulili (Khetha ibhokisi elivumelana nawe)	Owesilisa <input type="checkbox"/> Owesifazane <input type="checkbox"/>

Iminingwane yokuqashwa komqashi walowo one Down syndrome

Indawo osebenza kuyo	
Isikhundla emsebenzini	
Ususebenze iskhathi esingakanani	
Inani lamahora obonana ngawo nalowo one Down syndrome ngesonto	

**Imininingwane ephathelene nengxoxo ezoba phakathi komcwangingi kanye nomqashi
walowo muntu one Down syndrome**

Ulimi oluzosetshenziswa kule ngxoxo (Khetha ibhokisi elivumelana nawe)	IsiNgesi <input type="checkbox"/>	IsiZulu <input type="checkbox"/>
Indawo lapho kuyohlanganwa khona		
Usuku nesikhathi okuyohlanganwa ngaso		

NGICELA ULIBUYISE NGOMHLAKA 1 JULAYI 2012

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

Dear Sir/ Madam,

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Research study title: Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal.

I am a Masters student at the University of KwaZulu-Natal (Westville Campus) conducting research in the field of Down syndrome. The focus of my research is on adults with Down syndrome and employment in KwaZulu-Natal. This is a topic of interest as there is a lack of information in this area in South Africa. I am conducting research to gain understanding on the types of jobs available, accommodations in the workplace and specifically communication in the workplace from the perspective of the individual with Down syndrome, their employer and their family. This information will draw awareness to the employment of individuals with Down syndrome as well as indicate the employment options available and what employers could do to assist individuals with Down syndrome in the workplace. I have received ethical clearance to conduct my study from the University of KwaZulu-Natal School Research, Ethics and Higher Degrees Committee (Reference: HSS/0274/012M).

I obtained the names of individuals with Down syndrome and their families from Down Syndrome South Africa and Durban Mental Health as possible participants. I kindly request the involvement of a family member of the individual with Down syndrome in my research study. Involvement would include an interview, lasting approximately an hour, at a date, time and venue that is convenient to you. The interview questions will relate to Down syndrome in the workplace and no questions will have any implications for you or your family member

personally. The interview will be audio recorded for the purpose of analysis. This recording will be kept for a compulsory period of five years and then destroyed. Hard copies of data will be kept in a locked cupboard at the University of KwaZulu-Natal in the Speech-Language Pathology department. This will be destroyed via shredding after five years. Electronic data will be stored on a computer that is password protected. This will be destroyed after five years. All participants' names will be coded. Confidentiality will be maintained at all times and the names of individuals or institutions will not be reported. My study involves interviewing the individual with Down syndrome, their employer and a family member. Each individual will be required to read their own information letter and sign their own consent form. It is preferable that if the parent is the employer then that parent is interviewed as the employer and the other parent, a sibling or a close family member is interviewed as a family member.

Please note that participation is voluntary and participants have the right to withdraw from the research study at any time. Refusal to participate in the research study will not impact you in any way. Participation will not result in employment, a change in employment status or an increased income for the individual with Down syndrome.

Attached is a document of informed consent and a biographical information questionnaire. If you are willing to participate, please complete both forms and return via email to courtneytod@gmail.com or fax to the University of KwaZulu-Natal, Discipline of Speech-Language Pathology on (031) 260 7622 with "Attention: Courtney Tod" written at the top. Please return by **01 July 2012**. Please keep your original copies of each of the documents for your own reference.

Please indicate on the consent form whether or not you are providing permission for the researcher to contact the individual with Down syndrome's employer. In addition, please note that your family member with Down syndrome will also receive an information letter and informed consent document that they can read and sign together with you.

I look forward to your correspondence and will greatly appreciate your participation. Should you have any queries regarding the research study, kindly contact the researcher or one of the research supervisors.

Thank you for your assistance.

Yours faithfully,

Courtney Tod (Researcher)
Email: courtneytod@gmail.com
Phone: 083 317 6790

Ms. Jenny Pahl (Research Supervisor)
Email: pahlj@ukzn.ac.za
Phone: 031 260 7624

Ms. Saira Karrim (Research Supervisor)
Email: karimsb@ukzn.ac.za
Phone: 031 260 7550

For further queries, please contact the School of Health Science Research Office.

Contact person: Miss Phumelele Ximba

Email: Ximbap@ukzn.ac.za

Phone: 031 260 3587

Fax: 031 260 4609

Declaration of Informed Consent: Family Member

I _____ (full name of participant) hereby confirm that I have read and understood the contents of this document and the nature of the research study. I consent to participate in an interview and allow the contents of the interview to be used in the research study. I will provide the researcher with accurate information. I give my consent for the interview to be audio taped for analysis purposes only.

I understand that participation is voluntarily and I am at liberty to withdraw at any stage should I wish to do so. I understand that there is no direct benefit to me for participating in the study.

Signature of participant

Date

I give consent to the employer of my family member being contacted by the researcher (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/> No <input type="checkbox"/>
---	--

If “yes” please supply an email address or phone number for the employer:

I would like to receive a summary of the results of this study (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/> No <input type="checkbox"/>
---	--

If “yes” please supply an email address or postal address to which the summary can be sent:

Biographical Information Questionnaire: Family Member

Study Criteria

Please tick below to indicate the participant meets the participant criteria

Directly related to or have guardianship of the individual with Down syndrome	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Over the age of 18 years	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Resides in KwaZulu-Natal	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Able to converse in either English or isiZulu	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Your Personal details (family member of individual with Down syndrome)

Participant name	
Contact number	
Date of birth	
Age	
Gender (please tick)	Male <input type="checkbox"/> Female <input type="checkbox"/>

Relationship with the Individual with Down syndrome

How are you related to the individual with Down syndrome?	
Do you live with the individual with Down syndrome? (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you assist with financial support? (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you assist with transport to work? (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Does the individual with Down syndrome have any co-occurring disorders, delays or difficulties? (please tick)	Autism Spectrum Disorder or another form of <input type="checkbox"/> Pervasive Developmental Disorder Sight difficulties <input type="checkbox"/> Hearing loss <input type="checkbox"/> Behavioural difficulties <input type="checkbox"/> Memory loss/ Dementia <input type="checkbox"/>

Interview Details for family member of individual with Down syndrome

Language for interview (please tick)	English <input type="checkbox"/> isiZulu <input type="checkbox"/>
Venue for interview	
Date and time for interview	

PLEASE RETURN BY 01 JULY 2012

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

Sawubona Mnu/Nkk/Nkz,

ISIMEMO SOKUBA YINGXENYE YOCWANINGO

Isihloko socwaningo: Ukuqashwa kwabantu abane Down syndrome: Isipiliyoni salabo abane Down syndrome, abaqashi babo kanye nemindeni yabo KwaZulu-Natali

Ngingumfundi owenza izifundo eziphakeme phecelezi iMasters eNyuvesi yaKwaZulu-Natali (eWestville), ngicwaninga ngabantu abane Down syndrome. Ucwaningo lwami lubheke kakhulu abantu abadala abane Down syndrome kanye nokuqashwa kwabo KwaZulu-Natali. Lesi sihloko ngisikhetha ngoba lungekho ulwazi olwanele mayelana naloku lapha eMzansi Afrika. Ngenza lolucwaningo ukuze ngithole ulwazi olubanzi mayelana nemisebenzi ekhona, ukwamukeleka emsebenzini, ikakhulukazi ukuxhumana emsebenzini ngokubona kwalabo abane Down syndrome, abaqashi babo kanye nemindeni yabo. Imiphumela yalolu cwaningo izosiza ukuthuthukisa ulwazi mayelana namathuba omsebenzi akhona kubantu abane Down syndrome. Izosiza futhi abaqashi ukuthi bazi izinto abangazenza ukuze basize abantu abane Down syndrome emsebenzini. Ngiyitholile imvume ukuthi ngenze lolu cwaningo kwi komiti lezocwaningo eliphakeme, eNyuvesi yaKwaZulu-Natali (I-reference ithi: HSS/0274/012M)

Ngithole amagama abantu abane Down syndrome nemindeni yabo kwi-Down Syndrome South Africa noma kwi-Durban Mental Health. Ngenhlonipho, ngicela ukuthi ilunga lomndeni walowo one Down syndrome libe yingxenye yocwaningo lwami. Ngidinga nje isikhathi esingaba ngange hora, ukuze ngixoxe nelunga lomndeni ngalolo suku kanye nesikhathi esivumelana nalelo lungu lomndeni. Imibuzo iyobe ikhuluma ngokwenzeka emsebenzini lapho ilunga lomndeni wakho eline Down syndrome lisebenza khona, akukho okuyobuzwa mayelana nelunga lomndeni wakho noma ngawe okuphathelene nezimpilo zenu. Ngizohlangana nawe endaweni evumelana nawe. Ingxoxo yethu ngiyoyiqopha, lokhu

kuyongisiza ngikhumbule izinto esiyobe sikhulume ngazo. Angeke ngiliphathe igama lakho noma igama lomuntu wakini one Down syndrome lapho sengibhala imiphumela yalolucwaningo, liyohlala liyimfihlo. Lokho okuqoshiwe kuyohlala ekhompuyutheni yami iminyaka eyi-5, futhi akekho omunye oyoba nemvume yokulalela. Lokho engikubhale phansi ngiyokugcina endaweni evalelekile iminyaka emihlanu engekho omunye onemvume yokukufunda. Emuva kwaleminyaka ngiyobe sengikuqoba ngikulahla ukuze kungabibikho omunye okubonayo konke lokhu. Lolucwaningo luhlanganisa ukuxoxa nabantu abane Down syndrome, umqashi wabo kanye nelunga lomndeni wabo. Wonke umuntu udingeke ukuba afunde incwadi emazisa ngocwaningo abese esayina. Uma umzali walowo one Down syndrome engumqashi kuyomele axoxe nomcwaningi njengomqashi bese elinye ilunga lomndeni lixoxe nomcwaningi njengelunga lomndeni.

Ngicela wazi ukuthi ukuba yingxenye yocwaningo akuphoqekile. Unemvume yokushintsha umqondo uma ungasathandi ukuba yingxenye yocwaningo noma inini. Angeke angene enkingeni emsebenzini umuntu one Down syndrome uma ungathandi ukuba yingxenye yalolu gcwaningo. Angeke athole ukukhushulwa emsebenzini noma imali umuntu one Down syndrome uma uvuma ukuba yingxenye yocwaningo.

Amakhasi alandelayo ale ncwadi angamafomu okumele uwagcwalise mayelana nawe.. Uma ufisa ukuba yilunga lalolu cwaningo lwami, ngicela ugcwalise womabili lamafomu bese uwathumela kimi nge-email ku- courtneytod@gmail.com noma nge fax kwi Nyivesi yaKwaZulu-Natali kwa Speech Language Pathology ku (031) 260 7622 ubhale phezulu uthi “Attention: Courtney Tod”. Ngicela lamafomu abuye ngomhlaka **1 July 2012**. Ngicela ugcine lawamafomu ayosala kuwe kube ngawakho.

Ngicela ubonakalise kulamafomu ukuthi uyavuma na ukuthi umcwaningi athinte umqashi walowo one Down syndrome. Ngaphezu kwalokho, ngicela wazi ukuthi umuntu wakini one Down syndrome uzothola eyakhe incwadi azoyifunda ayisayine kanye nawe.

Ngojabula ukuthola impendulo evela kuwe. Uma unemibuzo, ngicela ungifonele noma ufonele umphathi wami. Izinombolo zethu zibhalwe ngezansi.

Ngiyabonga ngosizo lwakho

Yimi ozithobayo,

Courtney Tod (umcwaningi)

Thumela i-email: courtneytod@gmail.com

Fonela: 083 317 6790

Ms. Jenny Pahl (umphathi wocwaningo)

Thumela i-email: pahlj@ukzn.ac.za

Fonela: 031 260 7624

Ms. Saira Karrim (umphathi wocwaningo)

Thumela i-email: karimsb@ukzn.ac.za

Fonela: 031 260 7550

Uma unezinkinga, thintana nesikole sakwa Health Science amahhovisi ocwaningo

Xhumana no: Nkz Phumele Ximba

Thumela i-email: Ximbap@ukzn.ac.za

Fonela: 031 260 3587

Thumela ifax: 031 260 4609

Incwadi yesivumelwano: Ilunga lomndeni

Mina_____ (igama lakho) ngiyavuma ukuthi ngiyifundile incwadi emayelana nocwaningo futhi ngiyazi ukuthi ithini. Ngiyathanda ukuba yingxenye yalolu cwaningo futhi nginika imvume ukuthi engizokusho kusetshenziswe njengengxenye yocwaningo. Ngizonika umcwaningi lokho okuyiqiniso nengikwaziyo.

Ngiyaqonda ukuthi ingxoxo yethu izoqoshwa. Ngiyaqonda ukuthi angiphoqelekile ukuba yingxenye yocwaningo futhi ngingawushintsha umqondo wami noma yinini uma ngingasathandi ukuba yingxenye yocwaningo. Ngiyaqonda ukuthi angeke ngithole lutho ngokuba yingxenye yocwaningo.

Sayina

Usuku

Ngiyavuma ukuthi umcwaningi athinte umqashi womuntu wakithi one Down syndrome (Khetha ibhokisi elilodwa)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
--	--

Uma uthi “yebo” ngicela unginike i-adilesi yomqashi ye email noma inombolo yocingo lapho ngizomthinta khona:

Ngingakuthokozela ukuthola imiphumela emifushane yalolu cwaningo (Khetha ibhokisi elilodwa)	Yebo <input type="checkbox"/> Cha <input type="checkbox"/>
---	--

Uma uthi “yebo” ngicela unginike i-adilesi yakho ye posi noma ye email lapho ngizothumela khona:

Imininingwane mayelana nelunga lomndeni walowo one Down syndrome

Ukuze ube yingxenye yocwaningo

Khetha ibhokisi elivumelana nawe. Lokhu kuzongisiza ngibone ukuthi ungumuntu olungele ukuba yingxenye yocwaningo

Uyisihlobo esiseduze noma ungumqaphi walowo one Down syndrome	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uneminyaka engaphezu kweyi-18	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uhlala KwaZulu-Natali	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>
Uyakwazi ukuxoxa ngesiNgisi noma isiZulu	Yebo <input type="checkbox"/>	Cha <input type="checkbox"/>

Imininingwane ephathele ngqo nelunga lomndeni walowo one Down syndrome

Igama	
Izinombolo zocingo	
Usuku lokuzalwa	
Iminyaka	
Ubulili (Khetha ibhokisi elivumelana nawe)	Owesilisa <input type="checkbox"/> Owesifazane <input type="checkbox"/>

Ubuhlobo malowo one Down syndrome

Uhlobene kanjani nalowo oneDown syndrome?	
Ngabe uhlala naye lowo oneDown syndrome? (Khetha ibhokisi)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Uyamsiza ngezezimali? (Khetha ibhokisi)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Ngabe uyamsiza ngokugibela lapho eya emsebenzini? (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>

Ngabe lo one Down syndrome unezinye izifo? (Khetha ibhokisi/amabhokisi)	I-Autism Spectrum Disorder noma olunye uhlobo lwana Pervasive Developmental Disorder <input type="checkbox"/> Izinkinga emehlweni <input type="checkbox"/> Izinkinga zokuzwa <input type="checkbox"/> Izinkinga ngokuziphatha <input type="checkbox"/> Ukulahlekelwa unqondo/ ukungakhumbuli izinto <input type="checkbox"/>
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Imininingwane ephathelene nengxoxo ezoba phakathi komcwaningi kanye nelunga lomndeni walowomuntu one Down syndrome

Ulimi oluzosetshenziswa kule ngxoxo (Khetha ibhokisi elivumelana nawe)	IsiNgisi <input type="checkbox"/> IsiZulu <input type="checkbox"/>
Indawo lapho kuyohlanganwa khona	
Usuku nesikhathi okuyohlanganwa ngaso	

NGICELA ULIBUYISE NGOMHLAKA 1 JULAYI 2012

Appendix H: Interview Schedule: Individual with Down syndrome (English)

X = individual with Down syndrome's name

Good morning,

My name is Courtney and as you know I am here today to talk to you about Down syndrome and what it is like for a person with Down syndrome to work. I am going to ask you some questions. If you don't understand or you want me to say the question again, please ask me. A while ago you/ your parent signed this letter to say that you will be part of my study and that it is ok if I tape your answers so I remember what you say. In my report I will not mention your name or the place where you work. Before we begin do you have any questions?

General

1. Tell me about yourself

Probe: Who is **X** and what you like to do?

2. Tell me about your work.

Educational and therapeutic history

3. Tell me all about what skills school taught you

Probe: Maths, computers, telephone, gardening, office skills

Let's talk about the skills you learnt at school that help you at working

4. Tell me about what your school did to help you find any jobs.

5. Tell me about any therapy you have had

Probe: Describe the things did at therapy.

6. Tell me all about what you learnt from therapy that helps you in your work.

Probe: Tell me about what you did with the therapists.

Employment history

7. Tell me about the time between you finishing school and starting your job.

8. Let's talk about how you found your job and who helped you.

Perceptions, communication and social interaction in the workplace

9. Let's talk about what it is like to be a person with Down syndrome who works.
Probe: Do you think it's easy or hard? Why?
10. Tell me about any other people who have Down syndrome or disabilities at your work.
11. Tell me about your relationship with your boss.
12. Let's talk about your relationship with other people at work. Tell me about how you get on with the people you work with.
Probe: Tell me about what they do and how that makes you feel
13. Tell me about when you talk to other people at work.
Probes: Tell me about the things you talk about
What do you do when you need help?
14. What happens when someone at work doesn't understand what you say to them?
Probe: Do you repeat yourself; do you try explaining in other words?
15. Tell me about the different languages you speak at home and at work.
Probe: Tell me about when you talk in another language, not (*insert name of first language*)
16. Let's talk about any problems you may have with speaking
17. Tell me how you cope when there are a lot of people around you to talk to.
18. Tell me about when you talk to people outside of work.

Job tasks

19. Tell me about how your day goes at work and all the things you do
Probe: How do you feel about them?
20. Tell me about how you feel about the work that you do.
21. Tell me about using a computer at work.
Probe: What types of things do you have to do on the computer?
22. Tell me the good things and the difficult things about using the phone at work
Probe: Tell me about any problems you have using the phone at work
What do you do?
23. Tell me about when your boss and the people at work help you
24. Tell me about any change/s your boss or the people at work made to make work better for you

25. Let's talk about the reading, writing, numbers and typing you do as part of your job
Probe: What types of things do you have to read or write about? (forms, notes, receipts)
26. Let's talk about any training you have received at work or are having now
Probe: Tell me about what happens when you have to learn something new at work
27. Tell me about what is hard for you at work and why.
28. Let's talk about anything you would change about your work or the people you work with.

Family Support

29. Tell me about how you and your family feel about you working.
Probe: How do you know they are (un)happy?
30. Let's talk about when your family help you if you have a problem at work.
Probe: What types of things do they help you with?
31. What other ways do your family help you?
Probe: transport, financially

Is there anything else you want to tell me about Down syndrome or work?
What do you think about people with Down syndrome working and why?

Thank you for your time! I wish you all the best with you work.

Appendix I: Interview Schedule: Individual with Down syndrome (isiZulu)

X= igama laloyo one Down syndrome

Sawubona,

Igama lami ngingu Courtney, njengoba wazi ukuthi namhlanje sizokhuluma nge Down syndrome nokuthi kunjani ukusebenza kulabo abane Down syndrome. Ngizokubuza imibuzo embalwa. Uma ungawuzwa kahle umbuzo ngicela ungitshele ngizowuphinda noma ngicacise. Abazali/abagadi bakho basayina lencwadi bevuma ukuthi ube yingxenye yocwaningo lwami, bavuma futhi ukuthi ngiyiqophe ingxoxo yethu ukuze ngikhumbule esikuxoxile. Uma sengibhala imiphumela angeke ngiliphathe igama lakho nendawo lapho usebenza khona. Ngabe unayo imibuzo ngaphambi kokuthi siqale?

General

1. Ngitshele kabanzi ngawe
Probe: Ngabe ngubani u **X** futhi yini othanda ukuyenza?
2. Ngitshele kabanzi ngomsebenzi wakho

Ezemfundo

3. Ngitshele ukuthi iskole sikufundiseni
Probe: imaths, ikhompuyutha, ucingo, ingadi, amakhono asehhovisi
4. Ngitshele ukuthi isikole sikusize kanjani ukuthi uthole umsebenzi?
5. Ngitshele mayelana nodokotela obahambayo.
Probe: Chaza ngezinto ozenziswa odokotela
6. Ngitshele ngezinto ozofundiswe odokotela bakho ezikusizayo emsebenzini
Probe: Ngitshele ngezinto obuzenza nodokotela bakho.

Umlando wokuqashwa

7. Ngitshele ngesikhathi phakathi kokuqeda esikoleni kanye nokuqala emsebenzini
8. Ngitshele kabanzi ukuthi wawuthola kanjani umsebenzi nokuthi wasizwa wubani

Imibono nokuxhumana emsebenzini

9. Asikhulume ngokuthi kunjani ukuba ngumuntu one Down syndrome osebenzayo
Probe: Ngabe ucabanga ukuthi kulula noma kunzima? Ngobani?

10. Ngitshele ngabe bakhona abanye abane Down syndrome noma abakhubazekile emsebenzini wakho?
11. Ngitshele ngobudlelwano phakathi kwakho nomqashi wakho
12. Asikhulume ngobudlelwano bakho nabanye abantu emsebenzini. Ngitshele ngabe bunjani lobu budlelwano?
Probe: Ngitshele ukuthi benzani futhi bakwenza uzizwe kanjani
13. Ngitshele mayelana nokukhuluma kwakho kanye nabantu osebenza nabo
Probes: Ngitshele ngezinto ozixoxa nabo
Wenze njani uma udinga usizo?
14. Ngabe kwenzakalani lapho umuntu osebenza naye engaqondi ukuthi uthini kuye?
Probe: Ngabe uyayiphinda into oyishoyo, noma usebenzise amanye amagama?
15. Ake sikhulume ngezilimi okwazi ukuzikhuluma ekhaya nasemsebenzini
Probe: Ngitshele ngesikhathi ukhuluma olunye ulimi (faka ulimi lokuqala)
16. Asikhulume ngezinkinga onazo ngokukhuluma
17. Ngitshele ukuthi umelana kanjani nabantu abaningi bekhuluma nawe ngesikhathi esisodwa
18. Ngitshele mayelana nokukhuluma nabantu ngaphandle kwasemsebenzini

Imisebenzi yakho

19. Ngitshele mayelana nosuku lwakho emsebenzini nakho konke okwenzayo
Probe: Uzizwa kanjani mayelana nezinto ozenza emsebenzini?
20. Ngitshele ukuthi uzizwa kanjani ngohlobo lomsebenzi owenzayo
21. Ngitshele mayelana nokusebenzisa ikhompuyutha emsebenzini
Probe: Izinto ezifana nani ozenza ekhompuyitheni?
22. Ngitshele ngezinto ezinhle nezinto ezinzima ngokusebenzisa ucingo emsebenzini.
Probe: Ngitshele ngezinkinga oba nazo lapho usebenzisa ucingo emsebenzini.
Wenzenjani?
23. Ngitshele ngesikhathi lapho abantu emsebenzini noma umphathi wakho ekusiza.
24. Ngitshele mayelana noshintsho abantu abasebenza nawe kanye nomphathi wakho abalwenza ukuthi benze umsebenzi wakho ube ngcono.
25. Ngitshele ngokufunda, ukubhala, izinamba kanye nokubhala ngekhompuyutha njengengxenye yomsebenzi wakho.
Probe: Iziphi izinto ozenzayo ezidinga ukufunda nokubhala (amafomu, amanothi nama risidi)

26. Masikhulume ngokuqeqeshwa osuke wakuthola emsebenzini noma okuthola manje
Probe: Ngitshele ukuthi kwenzakalani lapho kumele ufunde into entsha emsebenzini
27. Ngitshele ukuthi yini oyithola inzima emsebenzini wakho, futhi ngobani.
28. Ngitshele nganoma yini ongayishintsha ngomsebenzi wakho noma ngabantu osebenza nabo.

Usizo nokusekelwa ngabasekhaya

29. Ngitshele ukuthi wena nabantu bakini nizizwa kanjani ngokusebenza kwakho
Probe: Ngabe abantu bakini bajabule noma abajabulile?
30. Asikhulume ngesikhathi lapho abantu bakini abakusiza ngaso uma unezinkinga emsebenzini
Probe: Izinto ezifana nani abakusiza ngazo kini?
31. Iziphi ezinye izindlela umndeni wakho okusiza ngazo?
Probe: Ngabe bakusiza ngokugibela uya emsebenzini noma ngezimali?

Ngabe ikhona enye into ofuna ukungitshela yona mayelana neDown syndrome noma ngomsebenzi?

Ngabe ucabangani ngokusebenza kwabantu abane Down syndrome, ngobani?

Ngiyabonga ngesikhathi sakho! Ngikufisela konke okuhle emsebenzini wakho.

Appendix J: Interview Schedule: Employer (English)

X = individual with Down syndrome's name

Good morning,

My name is Courtney and I am researching the employment of adults with Down syndrome as part of my Masters degree in Speech-Language Therapy at the University of KwaZulu-Natal. As you know I am here today to talk to you about Down syndrome and the employment of X. Before we begin I would like to thank you for participating in this study. I acknowledge your opinions and experience and believe that it will make a valuable contribution to research in Down syndrome in KwaZulu-Natal. Confidentiality will be maintained at all times in my analysis and reporting of my findings. Please be reminded of the confidentiality form you signed to say you understand the aim and terms of this study and agree for today's session to be audio recorded for the purpose of analysis. This recording will be kept for a minimum of five years. If you do not wish to answer any questions or wish to leave at any time, you are free to do so. Before we begin are there any questions?

General

1. Tell me about **X** and his/ her work?

Understanding of Down syndrome and employment

2. Tell me about the people with disabilities that are employed at your place of work.
3. Tell me about your understanding of Down syndrome and the associated challenges and strengths.
Probe: Let's discuss the social, communication and literacy aspects.
4. Why did you employ someone with Down syndrome?
5. Tell me your views on how Down syndrome affects a person getting a job.
6. Let's discuss the role of employment for the individual with Down syndrome.
7. Describe any considerations that you had before employing an individual with Down syndrome.

Perceptions in the workplace

8. Tell me about how Down syndrome affects **X** in his/ her workplace.
9. What you think is important for you and **X**'s co-workers to know about Down syndrome?
10. Tell me about how you think **X** feels about his/her job and workplace.

11. Tell me about the impact **X**'s employment has had on your business?

Communication and social interaction in the workplace

12. Describe **X**'s communication in the workplace.

13. Let's talk about the language(s) spoken at work and how this affects **X**'s communication with others.

14. Describe your and other people's understanding of **X** when he/she speaks.

15. Tell me about how **X** copes in a crowd.

16. Tell me about the communication between **X** and his/ her co-workers, communication being articulation, language understanding and language expression.

Probes: How well do **X**'s co-workers understand him/ her?

How well does **X** understand them?

17. Describe your relationship with **X**.

18. Let's discuss what **X** does to get help in the workplace.

Job tasks

19. Describe a typical day at work for **X** in terms of what he/ she does.

Probe: Let's talk about how you selected these tasks for **X**.

Probe: Describe how **X** copes with these tasks.

20. Let's talk about **X**'s computer skills and telephone skills.

21. What aspects of work do you think **X** finds difficult to do at work?

22. Describe **X**'s reading, writing and numeracy abilities.

Probe: Describe **X**'s reading and writing abilities in the workplace.

23. Describe how **X** is supported in the workplace by you and their co-workers.

Probe: What do the people around them do to help them?

(Examples: selection of job tasks)

24. Tell me about how **X**'s weaknesses are accommodated for in the workplace.

Probe: What physical changes have been made to help **X**?

(Examples: furniture/ equipment altered, reminders)

Is there anything else you think I need to know about Down syndrome and work?

What would you tell other employers about employing someone with Down syndrome?

Thank you for your time! I wish you everything of the best with your business.

Appendix K: Interview Schedule: Employer (isiZulu)

X= igama laloyo one Down syndrome

Sawubona,

Igama lami ngingu Courtney, ngicwaninga kabanzi mayelana nokusebenza kwabantu abane Down syndrome njengengxenye yezifundo zami eziphakeme phecelezi iMasters kwi Speech-Language Therapy eNyuvesi yaKwaZulu-Natali. Njengoba wazi ukuthi namhlanje sizokhuluma nge Down syndrome nangokuqashwa kuka X. Ngaphambi kokuthi siqale ngizothanda ukubonga ngokuthi uvume ukuba yingxenye yocwaningo. Lolulwazi luzosiza kakhulu ocwaningweni mayelana ne Down syndrome KwaZulu-Natali. Amagama azohlala egcinwe eyimfihlo ngasosonke isikhathi. Inkulumo yethu eqoshiwe izohlala inani leminyaka eyi-5 ibe isibhujiswa. Uma ungathandi ukuphendula eminye imibuzo noma ufuna ukuhamba noma ingasiphi isikhathi uvumelekile ukwenze njalo. Ngabe unayo imibuzo ngaphambi kokuba siqale?

General

1. Ngitshele mayelana no **X** nangomsebenzi wakhe?

Ulwazi ngeDown syndrome nomsebenzi

2. Ngitshele mayelana nabantu abakhubazekile abaqashiwe lapho usebenza khona
3. Ngitshele ngolwazi lwakho mayelana neDown syndrome, nangezinkinga abanazo abantu abanayo kanye nezinto ezingcono abakwazi ukuzenza
Probe: Ake sikhulume ngokuzwana nabantu, ukuxhumana kanye nokufundiseka kwabantu abane Down syndrome
4. Yini eyakwenza uqashe umuntu one Down syndrome?
5. Ngitshele ngombono wakho mayelana nokuthi ukuba ne Down syndrome kungamsiza/noma kungamviba kanjani ukuthi umuntu athole umsebenzi
6. Ake sikhulume ngeqhaza elihambisana nokuqashwa empilweni yabantu abane Down syndrome
7. Chaza ngezinto obekumele uzibheke kabanzi ngaphambi kokuqasha umuntu one Down syndrome

Imibono emsebenzini

8. Ngitshele ukuthi ngabe iDown syndrome inamuphi umthelela ku **X** emsebenzini
9. Yini ocabanga ukuthi ibalulekile ukuthi wena nabanye abasebenza no **X** ukuthi niyazi nge Down syndrome

10. Ngitshele ukuthi ucabanga ukuthi u **X** uzizwa kanjani ngomsebenzi wakhe nendawo asebenza kuyo
11. Ngitshele ukuthi ukuqasha u **X** sekube namthelela muni ebhizinisini lakho?

Ukukhuluma nokuzwana nabantu emsebenzini

12. Chaza indlela u **X** axhumana ngayo nabanye emsebenzini
13. Ake sikhulume ngolimi/ ngezilimi ezikhulunywa emsebenzini. Ngabe zinamthelela muni endleleni u **X** axhumana ngayo nabanye
14. Chaza indlela wena noma abanye abakwazi ngayo ukuqonda lapho u **X** ekhuluma.
15. Ngitshele ukuthi u **X** wenze njani lapho abantu bebaningi kakhulu
16. Ngitshele ngokuxhumana phakathi kuka **X** nabanye asebenza nabo, ndlela aphimisela ngayo amagama, ukuqonda nokusebenzisa ulwimi.
Probes: Ngabe abanye abasebenzi bayaqonda lapho u **X** ekhuluma?
Ngabe u **X** uyaqonda lapho abanye bekhuluma?
17. Chaza mayelana nobudlelwano bakho no **X**
18. Asikhulume ngokuthi u **X** wenza njani uma edinga usizo emsebenzini

Imisebenzi

19. Chaza usuku lwasemsebenzini olujwayelekile luka **X** nokuthi wenzani
Probe: Asikhulume ngokuthi lemisebenzi ayenzayo yakhethwa kanjani
Chaza ukuthi u **X** uyakwazi yini ukumela lemisebenzi?
20. Asikhulume ngamakhono ka **X** okusebenzisa ucingo nekhompuyutha?
21. Ngabe yiziphi izingxenywe zomsebenzi wakhe ocabanga ukuthi u **X** uzithola zinzima?
22. Chaza ngamakhono ka **X** okufunda, ukubhala kanye nokubala
Probe: Chaza ngokufunda nokubhala kuka **X** emsebenzini
23. Chaza ukuthi u **X** usizwa kanjani emsebenzini nguwe kanye nabanye abasebenzi
Probe: Ngabe abantu abaseceleni benzani ukuze basize u **X**?
(Isibonelo: ukukhethwa kwemisebenzi)
24. Ngitshele ukuthi yini eyenziwayo emsebenzini ukuze u **X** asizakale nalapho enamakhono angekho mahle khona
Probe: Yini eyenziwe emsebenzini ukusiza u **X**?
(Isibonelo: ifenisha/ ukushintshwa kwempahla yokusebenza, ama-alamu okukhumbuza ngemihlangano)

Ngabe ikhona enye into ofuna ukungitshela yona mayelana neDown syndrome noma ngomsebenzi?

Ungabatshelani abanye abaqashi ngokuqasha umuntu one Down syndrome?

Ngiyabonga ngesikhathi sakho! Ngikufisela konke okuhle ebhizinisini lakho.

Appendix L: Interview Schedule: Family Member (English)

X = individual with Down syndrome's name

Good morning,

My name is Courtney and I am researching the employment of adults with Down syndrome as part of my Masters degree in Speech-Language Therapy at the University of KwaZulu-Natal. As you know I am here today to talk to you about Down syndrome and the employment of X. Before we begin I would like to thank you for participating in this study. I acknowledge your opinions and experience and believe that it will make a valuable contribution to research in Down syndrome in KwaZulu-Natal. Confidentiality will be maintained at all times in my analysis and reporting of my findings. Please be reminded of the confidentiality form you signed to say you understand the aim and terms of this study and agree for today's session to be audio recorded for the purpose of analysis. This recording will be kept for a minimum of five years. If you do not wish to answer any questions or wish to leave at any time, you are free to do so. Before we begin are there any questions?

General

1. Tell me about **X** and his/ her work?

Educational and therapeutic history

2. Let's talk about what at school, in therapy or elsewhere helped **X** to find a job.
3. Describe training, subjects or programmes at school, in therapy or elsewhere that helped **X** to learn work skills.

Probe: Training, subjects or programmes at school

4. Tell me about any speech therapy **X** has received

Probes: What was your experience of therapy?

How did the therapy assist in employment?

Describe the therapy **X** has received from the time of being employed

Employment history

5. Tell me about **X**'s road to employment and his/ her employment history from school to where **X** is now
6. Describe the process of **X** finding a job.

Understanding of Down syndrome and employment

7. Tell me about your understanding of Down syndrome and the associated strengths and difficulties including social, communication and literacy aspects.
8. Tell me your views on how Down syndrome affects a person getting a job.
9. Describe what information **X**'s boss and co-workers needed to know about Down syndrome.
10. Let's discuss what employment means to **X**

Perceptions in the workplace

11. Tell me about how Down syndrome affects **X** in his/ her workplace.
12. Tell me about how you think **X** feels about his/ her job and workplace.

Communication and social interaction in the workplace

13. Describe **X**'s communication in the workplace, including the understanding of other people's instructions and conversation.
14. Let's talk about the language(s) spoken at work and how this affects **X**'s communication with others.
15. Describe other people's understanding of **X** when he/she speaks.
16. Tell me about how **X** copes in a crowd.
17. Let's discuss what **X** does to get help in the workplace.
18. Describe the relationship between **X** and his/ her boss and co-workers.

Job tasks

19. Describe the job support **X** receives in the workplace.
20. Tell me about the accommodations that are made in the workplace to assist **X**.
Probe: given extra time, selection of job tasks
21. Tell me about **X**'s computer, cell phone and telephone skills, if required for his/ her job.
22. Describe **X**'s reading and writing abilities.
Probe: Describe **X**'s reading, writing, typing and numeracy abilities in the workplace.

Family support

23. Tell me about the family support that **X** requires in relation to his/ her employment.
24. Tell me about the challenges that the family faces in supporting **X**'s employment.
25. Tell me about the benefits that the family has found in **X**'s employment.

Is there anything else you want to tell me about Down syndrome or work?

What do you think about people with Down syndrome working and why?

Thank you for your time! I wish you and X everything of the best for the future.

Appendix M: Interview Schedule: Family Member (isiZulu)

X= igama laloyo one Down syndrome

Sawubona,

Igama lami ngingu Courtney, ngicwaninga kabanzi mayelana nokusebenza kwabantu abane Down syndrome njengengxenye yezifundo zami eziphakeme phecelezi iMasters kwi Speech-Language Therapy eNyuvesi yaKwaZulu-Natali. Njengoba wazi ukuthi namhlanje sizokhuluma nge Down syndrome nangokuqashwa kuka X. Ngaphambi kokuthi siqale ngizothanda ukubonga ngokuthi uvume ukuba yingxenye yocwaningo. Lolulwazi luzosiza kakhulu ocwaningweni mayelana ne Down syndrome KwaZulu-Natali. Amagama azohlala egcinwe eyimfihlo ngasosonke isikhathi. Inkulumo yethu eqoshiwe izohlala inani leminyaka eyi-5 ibe isibhujiswa. Uma ungathandi ukuphendula eminye imibuzo noma ufuna ukuhamba noma ingasiphi isikhathi uvumelekile ukwenze njalo. Ngabe unayo imibuzo ngaphambi kokuba siqale?

General

1. Ngitshele ngo **X** nomsebenzi awenzayo?

Ezemfundo nezodokotela

2. Asikhulume ngokuthi esikoleni, odokotela noma kuphi nje kwenye indawo, bamsiza kanjani u **X** ukuthi athole umsebenzi.
3. Chaza ngokuqeqeshwa, izifundo esikoleni noma kwezinye izindawo ezasiza u **X** ukuthi afunde amakhono omsebenzi
Probe: Izifundo noma ukuqeqeshwa esikoleni
4. Ngitshele nge speech therapy u **X** asitholayo
Probes: Yikuphi enakufunda kulodokotela we speech therapy
Ngabe ukuhamba odokotela kwamsiza kanjani u **X** ukuthi athole umsebenzi
Chaza ngokuhamba odokotela u **X** kutholayo njengoba esebenza nje

Ezomsebenzi

5. Ngichazele ngendlela ka **X** kusukela eqeda isikole kuze kufike lapho ekhona manje
6. Chaza ngezinto u **X** okwakumele azenze ukuze athole umsebenzi

Ulwazi nge Down syndrome nomsebenzi

7. Ngitshele ngolwazi lwakho mayelana neDown syndrome, nangezinkinga abanazo abantu abanayo kanye nezinto ezingcono abakwazi ukuzenza kanye nokufundiseka kwabo
8. Ngitshele umbono wakho ngokuthi ukuba ne Down syndrome kungaba namthelela muni ekutheni umuntu athole umsebenzi
9. Ngitshele ngolwazi umphathi ka **X** nabanye abasebenzi abebedinga ukuba nalo nge Down syndrome
10. Asikhulume ukuthi ukusebenza kusho ukuthini ku **X**

Imibono emsebenzini

11. Ngitshele ukuthi ngabe ukuba ne Down syndrome kunamuphi umthelela ku **X** emsebenzini
12. Ngitshele ukuthi ucabanga ukuthi u **X** uzizwa kanjani ngomsebenzi wakhe nendawo asebenza kuyo

Ukuxhumana kanye nokuzwana nabantu emsebenzini

13. Chaza ngokuxhumana kuka **X** nabane abantu emsebenzini, kuhlangukisa ukuqonda okushiwo abanye kuyena kanye nengxoxo.
14. Ake sikhulume ngolimi/ ngezilimi ezikhulunywa emsebenzini. Ngabe zinamthelela muni endleleni u **X** axhumana ngayo nabanye
15. Chaza indlela abanye abakwazi ngayo ukuqonda lapho u **X** ekhuluma.
16. Ngitshele ukuthi u **X** wenze njani lapho abantu bebaningi kakhulu
17. Asikhulume ngokuthi u **X** wenza njani uma edinga usizo emsebenzini
18. Ake uchaze ubudlelwano phakathi kuka **X** nomphathi wakhe kanye nabanye asebenza nabo

Imisibenzi

19. Chaza ngosizo u **X** aluthola emsebenzini
20. Ngitshele ngoshintsho olwenziwe emsebenzini ukuze kusizakale u **X**.
Probe: ukwengezelwa isikhathi, ukukhethelwa imisebenzi ethile
21. Ngitshele nagamakhono ekhompuyutha, iselula kanye ncingo u **X** anawo, uma edingeka emsebenzini awenzayo.
22. Chaza ngamakhono okufunda nokubhala u **X** anawo

Probe: Chaza amakhono ka **X** okufunda, ukubhala, ukubhala ngekhompuyutha kanye nokubala emsebenzini.

Ukusekelwa umndeni

- 23. Ngitshele ngosizo lomndeni u **X** aludingayo mayelana nomsebenzi wakhe
- 24. Ngitshele ngezingqinamba umndeni obhekana nazo ekusekeleni ukusebenza kuka **X**
- 25. Ngitshele ukuthi umndeni usizakala kanjani ngokusebenza kuka **X**

Ngabe ikhona enye into ofuna ukungitshela yona mayelana neDown syndrome noma ngomsebenzi?

Ngabe ucabangani ngokusebenza kwabantu abane Down syndrome, ngobani?

*Ngiyabonga ngesikhathi sakho! Ngifisela wena no **X** konke okuhle nekusasa elihle.*

<p align="center">Appendix N: Detailed Description of the Edits Made to the Interview Schedules After the Pilot Interviews</p>

Table 14

Detailed Description of Changes Made to the Interview Schedule: Individual with Down syndrome

Question	Change Made	Reason for Changes Made
1	Added prompt to the opening question “Tell me about yourself.” Probe: “Tell me about X and what you like to do”	The individual found this question overwhelming and was unable to conceptualize the type of information that the research was looking for.
3	The question “Tell me all about what school taught you about work” was combined with the question “Let’s talk about the skills you learnt at school that help you now that you are working.” A probe was added to indicate examples of work skills.	Both questions alluded to the same type of information. This was necessary to indicate to the participant about the type of information that the researcher required.
5	The wording of the question “Tell me about the therapy you had at school or after school” was changed to omit the concept of school.	This change was necessary as the inclusion of the word “school” in the question confused the participant as they had private therapy that was not at school.
8	The phrase “and who helped you” was added to the question “Let’s talk about how you found your job.”	This was added to gain insight into the individual’s motivation for finding a job and further detail about the job finding process.
9	The question was reworded for clarity and the probe “Do you think it’s easy or hard? Why?” was added when asking what it is like to be a person with Down	This was necessary to expand on the information provided as one word answers such as “nice” were provided.

	syndrome that works.	
14	<p>The probe “Tell me about how you deal with other people not understanding you” was omitted as a probe as it was asked later as a question. The question was moved so that it followed the question discussing when the individual speaks to other people at work.</p> <p>The question was then reworded to provide clarity.</p> <p>The probe asking if the individual repeats themselves was expanded to include the concept of rewording when they are not understood.</p>	<p>This information was not being supplied when it was a probe.</p> <p>The word “deal” made the question difficult to understand.</p> <p>The probe was expanded to supply the individual with more options.</p>
15	The probe was changed from a closed ended question to an opened question.	The probe was reworded to promote discussion.
22	The question “Tell me about how you find talking on the telephone at work” was reworded.	The question did not to encourage the participant to talk about the negative experiences of using the telephone.
23	The question “Tell me about the support that you receive from your boss and other people at work” was reworded.	The word “support” made the question difficult to understand.
24	<p>The probe “Tell me about any adaptations they make to your workplace or the tasks you are that help you?” was made a main question and reworded to “Tell me about any change/s your boss or the people at work made to make work better for you.”</p>	<p>This information was not being supplied when it was a probe.</p> <p>The word “adaptations” made the question difficult to understand.</p>

25	Examples were provided for the types of documents that could be read or written at work.	These were added to encourage discussion.
	The concept of numeracy was added when questioning about reading and writing abilities.	This concept was not discussed and was taught at school thus it would be beneficial to enquire about numeracy in the workplace.
30	The probe “What types of things do they help you with?” was added.	This was added to assist in prompting further discussion.
-	The questions “Is there anything else you want to tell me about Down syndrome or work?” and “What do you think about people with Down syndrome working and why?”	These questions will allow for any additional data to be shared and provide the participant with more time to share their views.

Table 15

Detailed Description of Changes Made to the Interview Schedule: Employer

Question	Change Made	Reason for Changes Made
3	This question was reworded. The word “difficulties” was replaced with the word “challenges.”	This was edited to imply that the individual experienced a challenge related to the presence of Down syndrome characteristics as opposed to a personal difficulty.
16	The question was reworded to expand on the various sub sections of communication e.g. articulation, receptive language and expressive language.	This was necessary to promote discussion on all aspects of communication.
	Two probes were added: “How well do X’s co-workers understand him/ her?”	This was added to assist in prompting further discussion.

	and” How well does X understand them?”	
22	The question was reworded to include the concept of numeracy when questioning about reading and writing abilities.	This concept was not discussed and was taught at school thus it would be beneficial to enquire about numeracy in the workplace.
23	This question was reworded. The term “job support” was changed to ask how the individual is supported in the workplace.	This edit was necessary as it was apparent that the support provided may not just be job related.
	A probe was added.	This was added to assist in prompting further discussion.
24	This question was reworded from: “Tell me about the accommodations that are made in the workplace to assist X ” to “Tell me about how X ’s weaknesses are accommodated for in the workplace.”	This edit was made to encourage discussion about the individual’s weaknesses and to allow for more direct connections to be made between the individual’s weaknesses and the accommodations made.
	The examples were omitted as they provided too much detail. A probe was added.	This was made to assist in guiding the discussion on the types of changes that could have possibly been made in the workplace.
-	An additional question regarding computer and telephone use was omitted.	This question yielded information that was previously enquired about.
-	The questions “Is there anything else you want to tell me about Down syndrome or work?” and “What do you think about people with Down syndrome working and why?”	These questions will allow for any additional data to be shared and provide the participant with more time to share their views.

Table 16

Detailed Description of Changes Made to the Interview Schedule: Family Member

Question	Change Made	Reason for Changes Made
2	The question was reworded so that the concept of “work skills” was no longer included.	The question was intended to enquire about what assisted the individual in finding employment and having the phrase “work skills” took the focus off of this.
3	The question was reworded to include therapy and the terms “subjects” and “training programmes.”	This edit broadened the question so that further discussion was encouraged.
4	The terms “privately” and “at school” were removed from this question enquiring about Speech-Language Therapy.	This was necessary to avoid confusion.
	The probe was reworded so that the experience of therapy was discussed as opposed to the results.	This edit allowed for further information to be gathered on the participant’s experience of therapy with regards to how they found the therapist, the types of activities, and the homework provided etc.
	The question “Describe the therapy X receives at the moment or when they started his/her job” was made a probe.	This was made a probe as it became apparent that therapy may have only been conducted when the individual with Down syndrome was of a much younger age.
5	The phrase “from school to where X is now” was added to this question regarding employment history.	The question initially encouraged information about the individual with Down syndrome’s job

		history of their current place of employment.
13	Communication was expanded to include receptive and expressive abilities.	This was necessary to promote discussion on all aspects of communication.
-	The question “Tell me about the communication between X and their co-workers” was omitted.	Question 13 allowed for discussion of this information.
-	The question “Tell me about how X’s co-workers relate to him/her in the workplace” was omitted.	Question 18 allowed for discussion of this information.
21	“Cell phones” were added to this question when it was reworded.	Cell phone usage has not been covered in any of the questions and there are various forms of communication via a cell phone that may provide an interesting dynamic to the information gathered in the study.
22	The concept of numeracy was added when questioning about reading and writing abilities.	This concept was not discussed and was taught at school thus it would be beneficial to enquire about numeracy in the workplace.
-	An X replaced “individual with Down syndrome” as often as possible and the term “their” was replaced with “he/she.”	This was necessary in order to use the individual’s name, to make the interview more personal and to continually centre the conversation on the individual with Down syndrome.
-	The questions “Is there anything else you want to tell me about Down syndrome or work?” and “What do you think about people with Down syndrome working and why?”	These questions will allow for any additional data to be shared and provide the participant with more time to share their views.



University of KwaZulu-Natal

HEREBY ACKNOWLEDGES THAT

Miss Courtney Tod

HAS COMPLETED A COURSE IN
RESEARCH POLICY V: RESEARCH ETHICS

Completed On
14 - 8 - 2010

Valid Until
8 - 2013



THE FOLLOWING SUBJECTS WERE COMPLETED IN THIS
COURSE

- RESEARCH ETHICS POLICY
- CODE OF CONDUCT FOR RESEARCH



University of KwaZulu-Natal

HEREBY ACKNOWLEDGES THAT

Miss Courtney Tod

HAS COMPLETED A COURSE IN

Human Subject Research Ethics

Completed On
14 - 8 - 2010

Valid Until
8 - 2013



**THE FOLLOWING MODULES WERE COMPLETED IN THIS
COURSE**

Research Ethics in South Africa - An Overview
Guiding Principles of Ethical Research
Informed Consent
Research Vulnerabilities
Researcher Responsibilities

Appendix P: Letter of Ethical Clearance



15 June 2012

Ms Courtney Tod 208505496
School of Health Sciences

Dear Ms Tod

PROTOCOL REFERENCE NUMBER: HSS/0274/012M

PROJECT TITLE: Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal.

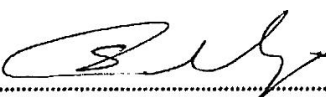
In response to your application dated 4 June 2012, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully


.....
Professor Steven Collings (Chair)
/px

cc Supervisor Jenny Pahl
cc Ms Saira Karim
cc Ms Phindile Nene

Professor S Collings (Chair)
Humanities & Social SC Research Ethics Committee
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350 **Facsimile:** +27 (0)31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

Inspiring Greatness



DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY

SCHOOL OF HEALTH SCIENCES

Tel: 031 260 7438

Fax: 031 260 7622

Email: khumalot8@ukzn.ac.za



June 2012

Dear interpreter,

INVITATION TO INTERPRET IN A RESEARCH STUDY

Research study title: Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in KwaZulu-Natal.

I am a Masters student at the University of KwaZulu Natal (Westville Campus) conducting research in the field of Down syndrome. The focus of my research is on adults with Down syndrome and employment in KwaZulu-Natal. This is a topic of interest as there is a lack of information in this area in South Africa. I am conducting research to gain understanding on the types of jobs available, accommodations in the workplace and specifically communication in the workplace from the perspective of the individual with Down syndrome, their employer and their family. This information will draw awareness to the employment of individuals with Down syndrome as well as indicate the employment options available and what employers could do to assist individuals with Down syndrome in the workplace.

I obtained the names of individuals with Down syndrome and their families from Down Syndrome South Africa and Durban Mental Health as possible participants. I kindly request your involvement in my research study by interpreting in interviews with participants who have indicated that they prefer communicating in isiZulu. Involvement would include interpreting in an interview, lasting approximately an hour, at a date, time and venue that is selected by the participant. Transport can be arranged for you or alternatively your transport fees will be covered. The interview questions will relate to Down syndrome in the workplace. The interview will be audio recorded for the purpose of analysis. This recording will be kept for a compulsory period of five years and then destroyed. Confidentiality will be maintained

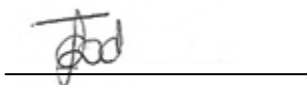
at all times. The names of individuals or institutions will not be reported and all participants' names will be coded to assure anonymity. Please note that participation your participation is voluntary and you have the right to withdraw from the research study at any time. Refusal to participate in the research study will not impact you in any way. Participation will not result in employment, a change in employment status or an increased income.

Attached is a biographical questionnaire and document of informed consent and confidentiality. If you are willing to participate, please complete the forms and return via email to courtneytod@gmail.com or fax to the University of KwaZulu-Natal, Discipline of Speech-Language Pathology on (031) 260 7622 with "Attention: Courtney Tod" written at the top. Please return by **01 July 2012**.

I look forward to your correspondence and will greatly appreciate your participation. Should you have any queries regarding the research study, kindly contact the researcher or one of the research supervisors.

Thank you for your assistance.

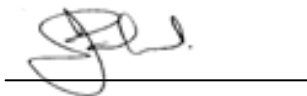
Yours faithfully,



Courtney Tod (Researcher)

Email: courtneytod@gmail.com

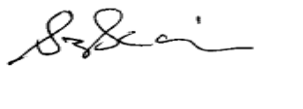
Phone: 083 317 6790



Ms. Jenny Pahl (Research Supervisor)

Email: pahlj@ukzn.ac.za

Phone: 031 260 7624



Ms. Saira Karrim (Research Supervisor)

Email: karimsb@ukzn.ac.za

Phone: 031 260 7550

Declaration of Informed Consent and Consent of Confidentiality: Interpreter

I _____(full name of interpreter) hereby confirm that I have read and understood the contents of this document and the nature of the research study. I consent to interpret in interviews and allow the contents of the interview to be used in the research study. I understand that participation is voluntarily and I am at liberty to withdraw at any stage should I wish to do so.

I agree to interpret from isiZulu to English and from English to isiZulu to the best of my ability. I will provide the researcher with accurate information. I agree to keep all names of participants and details of the interview confidential. I agree not to discuss any of the contents of the interviews with anyone other than the researcher.

Signature of Interpreter

Date

I would like to receive a summary of the results of this study (please tick one of the boxes to show your choice)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
--	------------------------------	-----------------------------

If “yes” please supply an email address or postal address to which the summary can be sent:

Biographical Information Questionnaire: Interpreter

Interpreter name	
Age	
Gender (please tick)	Male <input type="checkbox"/> Female <input type="checkbox"/>
Home language is isiZulu (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Additional language is English (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Qualification(s) and year obtained	
Current place of employment	
Contact numbers	