

THE EMPLOYMENT EXPERIENCES OF AN ADULT WITH DOWN SYNDROME

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requirements for the degree**

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The crest of Stellenbosch University, featuring a shield with a blue and gold design, topped with a red and white figure, and a banner below with the motto "Pacta sunt servanda".

**Educational Psychology
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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and has not previously in its entirety or in part been submitted at any university for a degree.

A handwritten signature in black ink, appearing to read 'Mallikarjuna', written over a horizontal dotted line.

.....
Signature

5 November 2008

.....
Date

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This study is dedicated to persons with intellectual disability throughout the world, and especially to unique and inspiring individuals who contribute to making our world a more enriching place, including in particular the individual adult within this study, my father Paddy McAllister and my fiancé David Warren, without who's support this study may not have been possible.

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ABSTRACT

The research aims to investigate the employment experiences of a South African adult with Down syndrome, and to explore whether this improves the quality of life for this adult across several areas of functioning.

This qualitative research design is situated within an interpretive research paradigm. A Case study method was used. Data have been produced using multiple sources and techniques to enhance validity. These include interviews, observation, field notes and questionnaires. Full account has been taken of ethical considerations.

The case study shows that this adult with Mosaic Down syndrome and intellectual disability, who is permanently employed in the open labour market, is seen as an asset by the company. Training and support have benefited him and extra supervision and attention needed are minimal. His skills, attitudes, and family support have also enhanced his quality of life. This adult's employment experiences have contributed to a culture of acceptance of and openness to intellectual disability in the formal industrial sector. This is an example of what can be accomplished regardless of intellectual disability.

As this is a case study the generalisation of the findings are limited.

OPSOMMING

Hierdie studie ondersoek 'n Suid-Afrikaanse volwassene met Downsindroom se werkservaring, en of sy lewenskwaliteit oor verskeie gebiede hierdeur verbeter word.

Die kwalitatiewe ondersoekontwerp is geleë in 'n verklarende navorsingsparadigma. 'n Gevallestudie metode is gebruik. Data is verkry deur gebruik te maak van verskeie bronne en tegnieke om die geldigheidsvlak te verhoog. Dit het onderhoude, observasie, veldnotas en vraelyste ingesluit. Hoë etiese oorwegings is deurgaans gevolg.

Die gevallestudie toon dat hierdie volwassene met Mosaïek Downsindroom en intellektuele gestremdheid, wat 'n permanente werker in die oopmark is, deur die maatskappy as 'n bate beskou word. Hy het baat gevind by opleiding en ondersteuning in soverre dat ekstra toesighouding en aandag minimaal is. Sy vaardighede, ingesteldheid en ondersteuning deur sy familie het ook sy lewenskwaliteit verhoog. Hierdie volwassene se werksvermoë en gesindheid het bygedra dat 'n kultuur van aanvaarding en gemaklikheid met intellektuele gestremdheid in die formele industrie gevestig is. Dit is 'n voorbeeld van wat bereik kan word ongeag intellektuele gestremdheid.

Omdat hierdie 'n gevallestudie is, is veralgemening van die bevindinge beperk.

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CHAPTER 1

INTRODUCTION, RATIONALE AND CONTEXTUALISATION

1.1 INTRODUCTION OF THE STUDY

Down syndrome is a congenital cause of mental disability (Barlow & Durand, 2005). It was named after Langton Down, who first conceptualised it in 1866 (Newton, 1997). Its recognisable physical features have contributed to it being the most commonly occurring genetic condition associated with mental disability (Newton, 1997; Hardman, Drew & Egan, 2005).

Many parents of learners with Down syndrome in the Western Cape have expressed concern over the employment possibilities and opportunities for their children. Parents and educators of these learners are concerned how they can best prepare them for potential employment and thus the best quality of life possible. This concern has often been reflected in discussions between parents, educators, and university students during the 'Intellectual Disability Quality of Lifespan Development Project' meetings at the University of Stellenbosch in 2006. As Jobling and Cuskelly (2002) and Henwood and Dixon (2004) point out, there is a need for further research into the transition of young adult learners with intellectual disability into employment. This case study attempts to address this need by examining the employment experiences of a young South African adult with Down syndrome.

1.2 PURPOSE OF THE STUDY

The study aims to address the need for further research by providing descriptive information on employment experiences for parents, carers and educators of learners and adults with Down syndrome. This can help them to have some insight into the challenges, opportunities, and support structures that may assist the transition of a young South African adult learner with Down syndrome into employment. In turn this can also assist and other multi-disciplinary team members

to decide on ways of enabling adults with Down syndrome to enjoy a better quality of life.

While the study concentrates on a single case study, it aims to contribute to a better understanding of these employment experiences in relation to the current literature reviewed, as well as new research and legislation paradigm shifts, general international attitudes of inclusion and approaches to intellectual disability, and our current ever-changing South African context.

Down syndrome has become one of the most researched and best-documented genetic conditions, with over 6000 publications by 1980 alone (Christianson, 1996). Only 25 of these papers have, however, dealt specifically or even in passing with Down syndrome in African populations south of the Sahara (Christianson, 1996). Whilst there does appear to be an increase in research interest in Down syndrome within developing countries, I have found that South African literature on this topic is sparse. Particularly, when consulting electronic databases such as ERICebscohost, and Google Scholar amongst others. This study therefore also aims to further the South African research literature available on this topic.

Improved research interest in developing countries, appears to have resulted in the recent research trend among well-known international Down syndrome researchers to place an emphasis on the importance of cultural attitudes and influences, which have an impact on the quality of life of an adult with Down syndrome.

Whilst this literature will be explored and examined in greater detail within the literature review, it is noteworthy to the purpose of this study that the employment experiences of an adult with Down syndrome relate to experiences within the adult's working environment. Furthermore, the impact and understanding of the experiences, explored in this study are in fact also in line with the environmental and cultural approach of Roy Brown (Editorial forward in McConkey & Timmons, 2004:vi).

We now recognize that the impact of Down syndrome in terms of individual behaviour and development is deeply influenced by the person's environment. Culture represents an important part of the environment and can determine whether people with Down syndrome flourish or deteriorate, whether they are regarded as full members of society or restricted to the fringes of society.

These influences are not simply related to low income countries but to all multi-cultural societies (Brown, 2004:vi).

This study aims to contribute to the multi-cultural context of both developing and developed countries, applicable to a broad spectrum of international research, and is not limited to the South African context.

1.3 CONTEXT OF THE STUDY

The incidence of Down syndrome in South Africa is sufficient to warrant further research (Molteno, Smart, Viljoen, Sayed & Roux, 1997). About 5% to 6% of people with mental disability have Down syndrome (Beirne-Smith et al., cited in Hardman et al., 2005) However, according to the March of Dimes Global report on birth defects, the incidence and prevalence of Down Syndrome, varies across the world, according to the income bracket of the country: the higher the income bracket of the country the greater the prevalence, and the lower the income bracket the greater the incidence (Christianson, Howson & Modell, 2006). The complex reasons for these differences as influenced by economics will be discussed in more detail in Chapter 2. However, since the above statistic was calculated from a study within a high income bracket, it may not apply to South Africa (Christianson et al., 2006). Both the incidence and prevalence of Down syndrome are relevant and important in contextualising the role and potential impact of this study. Their complex and multi-levelled relationship to culture, economics, and this study, will be discussed in greater detail in Chapter 2, the literature review.

In the context of employment in South Africa, Nicolas, Naidoo and Pretorius (2006) argue that economic downturns in South Africa over the last three decades have also eroded possibilities of long-term employment, with underemployment and unemployment being widespread. It is therefore most likely that an adult with Down syndrome, just like any adult, would have experience of the competitive nature of the workplace, even within their experience of sheltered and protected employment. In this competitive South African work environment, more people have sought to work from home or to work in corporations on a temporary or contractual basis, rather than in the formal work sector. Education and training have become vital in their aim to develop the skills of our youth in building capacity for the future growth and

development of our country. More individually, education and training aim to prepare, equip, and develop youth towards independence, future employment, and sustainable integration into society. In this study, the education and training experiences of the employed adult with Down syndrome are considered in context of the changing climate of education.

Both employment and education contexts in South Africa have changed considerably, particularly with regard to policy changes as a result of a changing political climate (Green, 2001; Nicholas et al., 2006). The political climate in South Africa resulted in a new constitution in 1996, which is founded on principles of democracy, equity, non-discrimination and a respect for the rights and dignity of all. In turn, the new constitution has affected education policies and paradigms (Green, 2001; Donald, Lazarus & Lolwana, 2002). In line with the constitution, the South African schools Act published in 1996 asserts the rights of all learners to have equal access to basic quality education, based on the Bill of rights (RSA, 1996 cited in Le Grange & Newmark, 2002). Further key documents that resulted from this changing political climate, include the white paper on an integrated national disability strategy (office of the Deputy President, 1997 cited in Le Grange & Newmark, 2002), as well as the National Committee of Education Support services (NCESS) entitled "Quality education for all: Overcoming barriers to learning and development" (Department of Education, 1997a, cited in le Grange & Newmark, 2002). More recently the Education White Paper 6: Special needs education: Building an inclusive education and training system, has provided a map of these education goals (Department of Education, 2001). The emphasis on these constitutional principles and their link to the transformation of education (Department of Education, 2001) can be clearly understood as a means to transform South Africa as a Society (Green, 2001).

Similar, employment policies have been transformed in the light of these constitutional principles. For example, the Employment Equity Act No. 55 of 1998, is one of many acts, which aim to redress discrimination against previously disadvantaged people in the workplace (Nicholas et al., 2006). In terms of this act, no person may unfairly discriminate against an employee on one or more grounds including race, gender, pregnancy, marital status, and people with disabilities. When viewed in this context, the educational and employment experiences of adults with

Down syndrome could reflect the degree to which new constitution principles are being, or have the potential, to be successfully implemented.

The type of employment experiences that a South African adult with Down syndrome are likely to encounter may reflect the degree to which this adult has either been successfully integrated into education and training opportunities, giving them leverage into employment, or the degree to which they have succeeded in overcoming some or all of the challenges presented in this changing socio-political-economic climate within the last two decades, and have entered into employment despite them. This situates the employment of an adult with Down syndrome in the context of career psychology as well as inclusion within the field of educational psychology.

Stead and Watson (2006) are career psychologists that have outlined changes in career theory that apply to the South African context. According to them, career theories, have in recent decades, shifted from approaching the term 'career' as a developmental concept that views career in terms of a sequence of jobs, occupations and positions throughout a person's working life, towards viewing it as a combination of a sequence of roles played by a person over the course of a lifetime. In this way the role of work is considered as one of many roles (e.g. spouse, citizen or leisurite) that make up a career. Richardson (1993 cited in Stead & Watson, 1996) has further developed these views. She, however, considers that the term 'work' should replace 'career' since it includes work outside the employment context. These considerations have implications for this research study, for example in line with these theories, perhaps the topic of this study would more appropriately be called: "The work experiences of an adult with Down syndrome". By including the term 'employment' as opposed to the term 'work', one is in fact further narrowing these 'work' experiences to their economic context, and highlighting a limitation for this study as excluding consideration for the value of work experiences outside of their monetary contexts.

In 1997 Dr Richard Newton a researcher on Down syndrome, based in the United Kingdom, wrote that it is disappointing to learn that only about 1% of adults with Down syndrome are in gainful employment – far fewer than could be expected if one

predicts the potential usefulness of people of their ability. According to Newton (1997:107),

... a wide range of semi-skilled and unskilled jobs such as kitchen work, gardening, and portering are within the intellectual competence of most school leavers with Down syndrome, however most adults with Down Syndrome in the United Kingdom are currently in local adult training centres and sheltered workshops, and while there are advantages to this, the environment is often not rich enough for them to reach their natural full potential, as full flourished members of society.

Contardi (2002) and McGuire and Chicoine (1999) note several benefits of employment on self esteem and autonomy. Furthermore, as employees, people with Down syndrome often prove to be more punctual, reliable, and malleable than other people employed in the same type of work (Newton, 1997). This study, therefore, also aims to illustrate the necessary role of the educational psychologist in facilitating the management of the individual with Down syndrome as full member of society, from the careful management of education and training to the transition into reaching individual potential in carefully selected employment, by means of the implementation of appropriate career theory, sensitive to cultural community contexts.

1.4 DEFINITION OF CONCEPTS

1.4.1 Down syndrome

The description of Down syndrome was first made by an English physician Langdon Down in 1866, and was based on the physical characteristics associated with mental disability (Barlow & Durand, 2005). It is the commonest recognisable form of mental disability (Newton, 1997). Down Syndrome is particularly relevant to the field of mental disability, since most people with the syndrome are moderately to severely mentally disabled, with only a few individuals with the syndrome having an IQ above 50 (Kaplan & Saddock, 1998). The physical characteristics include slanted eyes, epicanthal folds, and flat nose (Kaplan & Saddock, 1998; Hardman et al., 2005). In 1959, Lejeune showed that Down Syndrome was due to extra genetic material on the human chromosome 21 out of 23, and since that time it has been shown that the characteristics of Down syndrome are due to a relatively small part of the long arm of

chromosome 21 (Newton, 1997). There are three known types of Down syndrome, of which the most common type is Trisomy 21, identified by Lejuene in 1978 (Newton, 1997; Kaplan & Saddock, 1998; Hardman et al., 2005). However, although new research gives an indication that the incidence of DS increases with the age of the mother (Barlow & Durand, 2005), it is still not known what predisposes dividing cells to retain extra chromosome material, or why extra chromosome material negatively impacts normal development and functioning (Newton, 1997; Poeschel, 1999b).

Life expectancy is determined by various factors, which will be discussed and considered in more detail in Chapter 2. Intensive Studies in British Columbia reveal that generally it appears to be improving overall, but is still much poorer than the general population approximately: 44.4% and 13.6% of live born Down syndrome individuals will survive to 60 and 68 years, respectively, compared with 86.4% and 78.4% of the general population (Baird & Sadovnick, 1996, cited in Anneren & Poeschel, 1996). Kaplan and Saddock (1998) note that studies have indicated that individuals with Down syndrome live until about 30 years of age on average.

1.4.2 Educational experiences

In this study the employment experiences of adults with Down syndrome are described. These relate to the educational context, including school education; education in job training, and education in support of preparation and training for employment. Whilst, these adults may or may not yet be affected by changing educational and political contexts; it is important to the value of this study that descriptions of their experiences be considered in terms of these climates.

1.4.3 Employment experiences

The employment experiences are explored based on the nature of the experiences, the historical background, and the physical setting according to the guidelines of Stake (2000 cited in Mertens, 2005). In 2006, the National Down Syndrome Society highlighted the following types of employment, to which 'employment experiences' could refer (WWW.NDSS.ORG.UK, 2006). These include: sheltered employment, in which individuals work in a self-contained setting with others who have disabilities (Jobling & Cuskelly, 2002); supported employment, in which the individual works in integrated settings with support services such as a job coach (Contardi, 2002);

competitive employment, in which the individual works in integrated settings with support services such as a job coach, and entrepreneurship, in which, many ventures are artistic in nature, including water colour artistry, music, acting and photography amongst others (Henwood & Dixon, 2004).

1.5 THE RESEARCH PROBLEM

In South Africa although there appears to be a growing interest on this topic (Down Syndrome Society of South Africa, 2006, intellectual disability quality of lifespan development project, 2006), there is still a dearth of academic literature and research in the South African setting.

This study involved research into the employment experiences of an adult with Down syndrome in the Western Cape in order to answer the following primary research question:

What are the employment experiences of the adult with Down syndrome?

The secondary questions are:

- 1) What are the emotional employment experiences of the adult with Down syndrome?
- 2) What are the cultural employment experiences of the adult with Down syndrome?
- 3) What are the economic employment experiences of the adult with Down syndrome?
- 4) Was training and support implemented in preparing the adult with Down syndrome for employment? If so, what were the training and support experiences, and to what extent did they affect the employment experiences?
- 5) To what extent do the employment experiences assist in the development of an improved quality of life for the adult with Down syndrome?

Thus, the aims of this study are:

- To use the quality of life criteria provided by Cummins (2004) as a guide to investigate the employment experiences of an adult with Down syndrome within his place of work in South Africa in order to see whether the employment experiences affect quality of life and how these experiences were able to come about.
- To investigate the emotional experiences of employment for the adult with Down syndrome in terms of the effects of the employment experiences on self-esteem and reaching potential, in order to understand the degree to which the employment experiences enhance emotional wellbeing, according to one of the criteria for quality of life listed by Cummins (2005).
- To investigate what the cultural employment experiences are with regard to integration into the community, and a feeling of cultural belonging for the adult with Down syndrome, in order to gain insight into the adult with Down syndrome's experience of inclusion.
- To investigate the effect of the economic experience of employment of gaining a degree of self-reliance and basic means on the adult with Down syndrome, according to the criteria for quality of life listed by Cummins (2005).
- To explore generally to what extent the employment experience leads to an improved quality of life for the adult with Down syndrome, according to the criteria for quality of life, as noted by Cummins (2005).
- To look into the possible types of training and support implemented in preparing the adult with Down syndrome for employment experiences, in order to provide insights for parents and carers into the kind of preparation for employment and the transition necessary for the employment that occurred.

1.6 RESEARCH DESIGN AND METHODOLOGY

1.6.1 Introduction

Within this study the research design integrates the research method of a case study, with each of the procedures of the research methodology. In this way the

research design can be considered as the plan of how the researcher intends to conduct the research process (Mouton, 2005; Babbie & Mouton, 2001). The research design blueprint directs the research process by not only focusing on the end research product and the kind of results aimed at, but also by considering the most important aspect; the research questions (Mouton, 2005; Louw, 2006). Research design focuses through the logic of research on evidence that will address the research questions adequately (Mouton, 2005; Louw, 2006). The most important aspects within the research design blueprint, refer to the questions and objectives stated in 1.5, and these will be implemented using important combination aspects of research methodology discussed in 1.6.2.

While the research design provides the blueprint of the study, the methodology refers to the steps needed to address the research problem, or to carry out the plan (Mouton, 2005). This study is a descriptive qualitative case study. In recent decades, case study research design and methodology have been, gradually gaining more and more scientific respect (Babbie & Mouton, 2001). This is particularly because case study has been found to become increasingly valuable in social research (Kratochwill & Levin, 1992).

1.6.2 Case study method

In this study the research methodology takes the form of a single case study. Case study is an intensive investigation of a unit of analysis (Runyan, 1988; Yin, 2003). Case study methodology commonly involves four general design principles: conceptualisation, contextual detail and in-depth description, multiple sources of data, and analytical strategies (Babbie & Mouton, 2001). These design principles will be used throughout the study and integrated into the methodology by means of the three step process of constructing case studies described by Patton (2002). This three step process includes: assembling the raw case data, constructing a case record, and writing a final case study narrative. The manner in which this step by step process and general design process are implemented and integrated will be described and discussed in more detail in Chapter 3.

1.6.3 Literature review

According to Louw (2006) the literature review is useful in answering the research questions. Through allowing the researcher to locate his or her study within the bigger picture of what is known about the research topic, the literature review aims at contextualising the study, and creating an opportunity for the researcher to engage critically with the literature (Henning, 2007; Mertens, 2005 cited in Louw, 2006). The literature review also assists with later research steps, as it helps to ascertain the relevance of the research findings in relation to the existing body of literature, which is needed when explaining the research data (Henning, 2004 cited in Louw, 2006).

Within the context of the main aims of the study, the literature review provides insight into the field of Down syndrome and employment, and provides criteria, for consideration regarding life areas and aspects for exploration that give insight into quality of life. Within this study, the qualitative definition and evaluation of quality of life uses the comprehensive quality of life scale for intellectual disability (Cummins, 2005), which considers overall sense of satisfaction and contentment along the lines of material wellbeing, health, productivity, social intimacy, safety, place in community, emotional wellbeing, sense of importance and satisfaction. The literature review also introduces the context of inclusion.

1.6.4 Participant(s)

Since this is a single case study, the depth and rich descriptive detail of the study will take the form of multiple sources or interviewees, in providing data regarding the same unit of analysis. In this way this case study will still remain an intensive investigation of a single unit of analysis. In this case, of a single individual, an adult with Down syndrome (Handel, Runyan & Yin cited in Babbie & Mouton, 2001:280; Ruane, 2005). Thereby, in order to gain more insight into the experiences of this individual, further participants were interviewed who were able to contribute rich information regarding the adult's employment experiences. In this way, this study like most other case studies involved the investigation of multiple variables, through the interaction of the unit of study (in this case the adult with Down Syndrome), with his context, and the people within his context (Babbie & Mouton, 2001). Thus each interviewee contributes as a participant in the study of the single case.

1.6.5 Methods of data production

The term 'data production' rather than data collection has been used in this study to reflect the idea that: *"... an ultimate reality does not exist, but that reality is constructed according to one's own unique perceptions of experience"* (Gough, 1999:264 cited in Hill, 2002:50).

The subjective reality of this study is seen as being situated within the context of my own life experiences, which have informed my interpretation of the study.

Although my interpretation of the findings is informed by my own life experiences, great efforts are made within this study to take this into account and attempt to see things from the perspective of each of the participants. In order to best accomplish this task, a thickly described case study of the employment experiences of an adult with Down syndrome is produced through aiming to answer each of the research questions. A thick description makes it possible to take multiple perspectives into account in an attempt to understand the influences of multi-level social systems on an adult with Down syndrome's perspectives and behaviours (Shaughnessy, Zechmeister & Zechmeister, 2000; Babbie & Mouton, 2001). Data production in this study included information concerning the nature of case, its historical background, and physical setting (Stake, 2000 cited in Mertens, 2005). The methods used to produce the data are detailed in Chapter 3.

In short, data were produced using the qualitative method of observation and basic individual interviewing in which the interviewer does not necessarily have a specific set of questions, but rather establishes a general direction for the conversation and pursues specific topics raised by the respondent (Babbie & Mouton, 2001; Henning, 2007). An interview guide is drawn up based on the recommendations made by Stake (2000 cited by Mertens, 2005), as well as the main focus of the research questions (see Addendum A). In conducting the interviews, use was made of the seven stage interview process outlined by Kvale (1996:88 cited in Babbie & Mouton, 2001), which is described in more detail in Chapter 3, as well as the observation noted above (especially with regard to observing the individual adult within the employment context where possible). Multiple data sources such as personal and related documents and questionnaires to assist with background information, as well

as tape recording, were used as far as possible to assist in creating a rich description (see Addendum E).

1.6.6 Ethical considerations

Ethical considerations are essential to research methods (Ruane, 2005). Ruane (2005) outlines four primary ethical considerations: research should not cause harm to subjects; the informed consent of subjects should be obtained; the privacy of subjects should be respected; and conflict of interests should be avoided. Ethical considerations will be discussed further in Chapter 3 of this study.

1.6.7 Validity

The validity in this case study research will be explored using two main considerations classified by Burgess (1984 cited in Babbie & Mouton, 2001) namely authenticity and distortion and deception. The first consideration is that the participants may lie, presenting a false front to try to impress the researcher in some way. The other is that the researcher may hold certain assumptions or prejudices that may influence the questioning and selection of material, thereby contributing to the limitations of the study. These considerations will be addressed and in more detailed discussion in Chapter 4.

1.6.8 Qualitative Data Analysis

Data were analysed using a combination analysis specific to case study method, integrating the three step process of constructing case studies as outlined by Patton (2002). In the first step the raw case data was assembled using the data production techniques. In the second step a case record was constructed using the basic technique of content analysis which refers to any technique used for making inferences by objectively and systematically identifying specified characteristics of messages (Holsti, 1969 cited in Babbie & Mouton, 2001; Sedlack & Stanley, 1992). The original content analysis formed the original set of start codes, whereby various concepts were coded (see Addendum B). In the third step of Patton's (2002) three step process, a final case study narrative was written based on more in-depth coding that came about as a form of inductive thematic analysis, which developed from the original start codes. More thematic-based pattern analysis emerged from this. These

forms of analysis were used as they allowed for richer descriptions and made it possible to construct an in-depth discussion of the findings through the ultimate development of a more inductive style of analysis (see Patton, 2002). This will be discussed in more detail in Chapter 3 and 4.

1.7 RESEARCH PARADIGM

The interpretive paradigm was used in this study. According to Babbie and Mouton (2001), interpretive methods are used by us continuously as we interpret, create, give meaning to, define, and justify our actions, and since we are constantly changing these everyday interpretations of our worlds. The interpretive approach relies on personal accounts given by participants (Kelly & Terre Blanche, 1999:124 cited by Jervis, 2007). The interpretive approach could be used in this study because the adult with Down syndrome was able to use his words to express and describe his employment experiences. The approach was extended through the contribution of individuals who were able to relate their own accounts of their interpretation of employment experiences. As the researcher in this study, I was careful not to allow my own personal experiences of having come from a more privileged background to the research subjects, and also a different cultural and racial background, influence my relationship and understanding of the participant in any way. I feel I was able to develop 'clearer lenses' for observation through my background in anthropology and cross cultural travels abroad. The results of these clearer lenses became evident through the close relationship I was able to develop with the participant's father. Thus the way in which the accounts within this study are interpreted, and the meaning attributed to them is seen as requiring more special care to take account of the foundational assumption of interpretivists, as I hope to have achieved in this study. Most of our knowledge is gained or at least filtered through social constructions such as language, consciousness, shared meanings, documents and other artefacts, which can be affected on a daily basis:

... research focuses on the understanding of individual participant's experience and perceptions of their professional role as experienced in their day to day working environment from the standpoint of their unique backgrounds (Henning, 2007:20).

The individual adult with Down syndrome and the contributing participants in this study who were also involved in his employment experiences were able to convey their understanding of the employment experiences of the adult with Down syndrome: they experienced them in their day to day environment from the standpoints of their unique backgrounds, as parent, supervisor, manager, employer, and community supporter. Ultimately, the interpretivist paradigm strives to produce descriptive analyses that emphasise deep interpretive understanding of social phenomena through the meanings that people assign to them (Henning, 2007).

According to Neuman (2000), there are several varieties of interpretive social science, including hermeneutics, constructionism, ethnomethodology, cognitive, idealist, phenomenological, and subjectivist. In general, the interpretive approach can be referred to as the:

... systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at understandings and interpretations of how people create and maintain their social worlds (Neuman, 2000:71).

Interpretive social science is related to hermeneutics, a theory of meaning, as mentioned above. This variety of interpretive social science used in this study assumes that true meaning is rarely simple or obvious on the surface; one only reaches it, through a detailed study of the experiences, contemplating many perspectives, and seeking the connections between each of the accounts (Neuman, 2000).

1.8 ASSUMPTIONS

'Realities' reflected in research can only refer to the subjective constructions of the particular researcher's reality, applicable to research within the interpretive paradigm (Jones, 1992:18 cited by Hill, 2002). It seems only fitting, from the perspective of this paradigm that I assume the first person "I", where appropriate within the study since it conveys a greater sense of responsibility for the thoughts and ideas expressed (Le Guin, 1998:68 cited by Hill, 2002).

1.9 OUTLINE OF THE STUDY

This chapter is followed by a literature review in Chapter 2. It provides an overview of the theoretical background and also focuses on the developmental stages of Down syndrome, life expectancy and cultural, social, and economic influences and approaches to Down syndrome. The management of Down syndrome, the prevalence, incidence and outcome of the syndrome, as well as associated features and new research focuses will be discussed. Chapter 3 discusses the research design and methodology, as well as the research paradigm. In Chapter 4 the results will be presented and discussed. Chapter 5 concludes the research study with a discussion of the conclusions based on the results, as well as the limitations of the study and recommendations.

1.10 SUMMARY

Chapter 1 contextualized the study, and provided a rationale for research into the employment experiences of an adult with Down syndrome as the knowledge gap lies within our knowledge of his experience. It also defined the concepts pertaining to the study, described the research problem, and situated the study within the interpretive paradigm, which acts as a lens through which the assumed reality of the experience will be interpreted. The proposed research design and methodology were outlined, including the methods of data production and data analysis, which would enable the data to be interpreted and compared to what is revealed in the literature review. Ethical considerations and validity were also outlined.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter explores the nature of Down syndrome. It begins by exploring the historical development of Down syndrome as well as the influence on it of scientific research developments. Next it explores both the known and unknown etiological factors of Down syndrome. The chapter then discusses the incidence, life expectancy, prevalence, outcome, diagnosis, associated features, co-morbid disorders, treatment and management of Down syndrome. Literature on the employment experiences of adults with Down syndrome is discussed, and an overview of the theoretical background and role of quality of life is outlined. The purpose of this chapter is to provide the reader with the contextual theoretical background and scientific research that informs the goals of this study and guides the exploration of the research problem that is outlined in Chapters 1 and 3.

2.2 HISTORICAL CONCEPTUALISATION OF DOWN SYNDROME

2.2.1 Role of Dr Down in the conceptualisation of Down syndrome

In 1866, Dr Down, first identified a group of people in an institution, and gave the collection of characteristics he observed, an identity (Newton, 1997). When Langdon Down named the condition of Down syndrome, it was already well known. Because this particular combination of chromosomes is documented on many occasions prior to Langdon Down naming the syndrome, researchers claim that the condition must have been established earlier than its nineteenth century references, even as early as the beginning of man's history (Stratford, 1996). When Down was alive it was thought that the foetus went through developmental stages in which different racial characteristics were assumed (Newton, 1997). These so called 'racial characteristics' were identified as being similar to a person from Mongolia, including for example, Mongolian-like eyes and a snub nose, hence the term 'Mongolism' was used interchangeably with 'Down syndrome' as recently as 1978 (Newton, 1997; Thomson, 1971; Wingate, 1972). Down syndrome has replaced the term 'Mongolism'

in scientific literature, and scientists are now aware that the 'racial characteristics' of the syndrome that Dr Down referred to are what is today termed the phenotype of Down syndrome (Newton, 1997). The phenotype refers to the observable features of a genetic condition including physical appearance, behavioural and intellectual function (Newton, 1997; Sinet, 1999). The physical appearance and identifying symptoms were previously briefly outlined in section 1.4. Further phenotype characteristics, relevant to an understanding of Down syndrome will be explained in more detail in 2.3 and 2.4.

The way Down syndrome has been approached has also changed radically over the years. These new culturally sensitive and shifting approaches have been influenced both by developments in scientific thinking, as well as the beginnings of a shift away from traditional medical models in recent decades (McConkey & Timmons, 2004; Swart & Pettipher, 2005). These influences will be explored in more detail in the section to follow since they have a bearing on the way Down syndrome came to be conceptualised. When Dr Down first named it, he saw this group of people as a subspecies of the human race, which was in line with the scientific beliefs of this Victorian era of the time (Newton, 1997; Pueschel, 1999b).

2.2.2 The role of French Geneticist Lejeune

In line with exciting discoveries of DNA, and chromosomes, and other developmental scientific breakthroughs of the twentieth century, in 1959, Lejeune showed that Down syndrome was due to extra genetic material carried on chromosome 21, and that this extra chromosomal material is retained as the cells divide. This finding was a revelation at the time, because it was the first evidence that Down syndrome was in fact genetic in its origin (Newton, 1997).

Lejeune's scientific findings brought a new understanding of Down syndrome, providing opportunities to show what people with this syndrome could achieve despite their inherent learning difficulties and the disadvantage of others' ignorance. (This study aims to follow in his footsteps). His work brought about a stronger move towards integration, and the beginnings of a shift of changing attitudes towards individuals with Down syndrome (Newton, 1997).

2.2.3 Developing scientific research

The vast majority of people have normal cell structures arranged in 23 chromosomal pairs. Basing their research on Lejeune's original scientific findings, Hardman et al. (2005), were able to show that Down syndrome arises from genetic 'error' which occurs around the moment of conception. The identification of this error and subsequent mapping of genes on chromosome 21 is progressing exponentially, according to Sinet (1999). An increasing number of genes are being identified on chromosome 21, relating to the way they directly influence the phenotype. More details of this research will be more clearly explained in later sections (see 2.4.4).

Since the conceptualization of Down syndrome in 1866, it has received widespread attention in medical and special education literature and research. This is partly due to its known and identifiable genetic causes, its recognisable physical features, and its being the most commonly identifiable cause of mental disability (Newton, 1997; Miller et al., 1999; Devlin & Morrison, 2004; Hardman et al., 2005).

More recent research has confirmed these original findings in greater detail, showing that Trisomy 21 is the most common type of three possible types of Down syndrome, in which the chromosomal pairs simply do not separate properly during the formation of sperm or egg cells resulting in an extra chromosome on the 21st pair (Hardman et al., 2005). The degree to which these genetic influences play a role in the etiology of Down syndrome and the role of these three known subtypes of Down syndrome are outlined and explained in the section below.

2.3 THE ETIOLOGY AND PREVENTION OF DOWN SYNDROME

Scientific developments in the field of genetics have played a large role in our current understanding of Down syndrome. In order to clearly and adequately explain and outline the role of genetics, it is necessary to define the following terms first:

2.3.1 Clarification of terms:

DNA (Deoxyribonucleic Acid)

Scientists refer to DNA as being one of the secrets to life itself. It is composed of nucleic acids linked with sugars, capable of forming very long chains. It has the

important property of being able to reproduce and replicate itself. It appears in human cells as a double stranded helix spiral, and is usually concentrated in the cell nucleus (Newton, 1997; Webster's New World Medical Dictionary, 2003).

Cell division

A person inherits 23 chromosomes from each parent, which come from the egg and sperm cells. When they combine, they produce a cell with 46 chromosomes. During cell division to create a germ cell (either sperm or egg), which is also known as Mitosis. According to Webster's Medical Dictionary (2003), a cell containing 46 chromosomes divides into two identical germ cells each containing 23 chromosomal pairs, with the 23rd pair characterising the sex of the foetus (Newton, 1997; Kirk, Gallagher & Anastasoiv, 2000).

Chromosomes

Within cell nucleus DNA strands are divided up into very small structures called chromosomes. Each chromosome is made up of two strands of DNA (Newton, 1997). "Our chromosomes contain the genetic code which controls and instructs cell division, growth, and function. They are the structures inside the nucleus of living cells that contain hereditary information" (Newton, 1997; Webster's Medical Dictionary, 2003).

Genes

The chromosomes can be divided up into segments. Smaller segments on the DNA molecule which code for particular proteins are known as genes (Webster's Medical Dictionary, 2003).

Genome

The Genome refers to all the genetic information in the chromosomes of an organism (Webster's Medical Dictionary, 2003).

2.3.2 Scientific evidence in support of maternal age

A vast number of researchers have found that the incidence of Down syndrome increases significantly in children born to mothers age 35 and older (e.g. Thomson,

1971; Molteno, Smart, Viljoen, Sayed & Roux, 1997; Newton, 1997; Kirk et al., 2000; Christianson, 2004; Malini & Ramachandra, 2006).

According to Newton (1997), the incidence in women under 20 years age is less than 1 in 2000, rising to approximately 1 in 20 at the age of 45. The steepest point of change within incidence with maternal age occurs at the age of 35. Increasing maternal age leads to an increase in the number of cells with an abnormal number of chromosomes, as the chiasmata formation (the chiasmata refers to the non-genetic strands that help paired chromosomes adhere to each other) reduces with age, making it more likely for genetic material to split off in an abnormal way. Nevertheless, about half the mothers who give birth to a child with Down syndrome are younger than 35 years old. According to Newton (1997), there has been an increasing incidence amongst younger mothers partly because women are choosing to have their families earlier.

2.3.3 Scientific evidence in support of paternal age

There is limited scientific evidence in support of paternal age as an etiological factor in Down syndrome. Newton (1997) speculates that the reason that paternal age is not as marked as that of maternal age is because the effect seems to be derived from aging of sperm, rather than the age of the father. According to Newton (1997), this may be a possible reason for increasing number of DS babies born to unmarried teen couples. However research findings published more recently suggest that advanced paternal age over 55, although associated with an increased rate of mutations and a slightly higher birth prevalence of auto-somal dominant disorders, is not considered a significant influence on the overall birth prevalence of birth defects (WHO, 1996 cited in Christianson et al., 2006). The reason for this is that it has even become possible to determine the origin of the extra chromosomal material by studying chromosomal variants known as (heteromorphisms) (Newton, 1997). The father is only known to contribute the extra chromosome in 20 to 25% of all cases (Abroms & Bennett, 1980 cited in Kirk et al., 2000). Therefore the age of the father does not seem to be nearly as significant as the age of the mother (Christianson et al., 2006).

2.3.4 Scientific evidence in support of age of maternal grandmother

A relatively recent study in the field of genetics, which was conducted in India, has broken new ground in suggesting that in more and more cases, young age mothers rather than advanced age mothers are giving birth to Down syndrome children. Research that was done to investigate this finding showed that young age mothers (18-29 years) born to their mothers at the age of 30 and above produced as high as 91.3% of the children with Down syndrome. This suggests that the effect of the age of the mother and father was smaller than the effect of the age of the maternal grandmother. Therefore, for every year of advancement of age of the maternal grandmother, the risk (odds) of giving birth to a Down syndrome baby increases by 30% (Malini & Ramachandra, 2006). More scientific research will have to be done on the role of the maternal grandmother, however, before it would be safe to draw firm conclusions in this regard.

2.3.5 Scientific evidence in support of genetic influences and subtypes

Scientific research has shown that not only is the extra chromosome 21 a leading factor in the development of Down syndrome, but in more detail the extra chromosomal material that leads to the features of Down syndrome is found on this chromosome between the first and third parts of the 22nd segment on the long arm of the chromosome 21 (Newton, 1997). This small portion of the whole human genome accounts for perhaps only 50 to 100 genes, the function of only a few of which have been identified to date (Newton, 1997). The influences of this finding on our understanding and management of Down syndrome will be discussed in sections below.

It should be noted that although clearly genetic, Down syndrome is not hereditary (except in rare cases of translocation Down syndrome as discussed in the section to follow): the problem results from chromosome division. According to Kaplan and Saddock (1998), Down syndrome is known to be caused by three types of chromosomal aberrations. This can be best understood in context of the subtypes outlined below (Kirk et al., 2000).

a) Standard Trisomy 21 Down syndrome

Standard Trisomy 21 Down syndrome occurs when the extra chromosome 21 comes from either the egg or sperm cell. Seventy five per cent of the time, it is the egg cell which carries the additional chromosomal material; 25% of the time it is the sperm cell. Between 90% and 95% of all Down syndrome is Standard Trisomy 21 (Devlin & Morrison, 2004). This Standard Trisomy 21 subtype is illustrated in the figure below, as there are three chromosomes on the 21st pair instead of two, following the arrow, as outlined below:

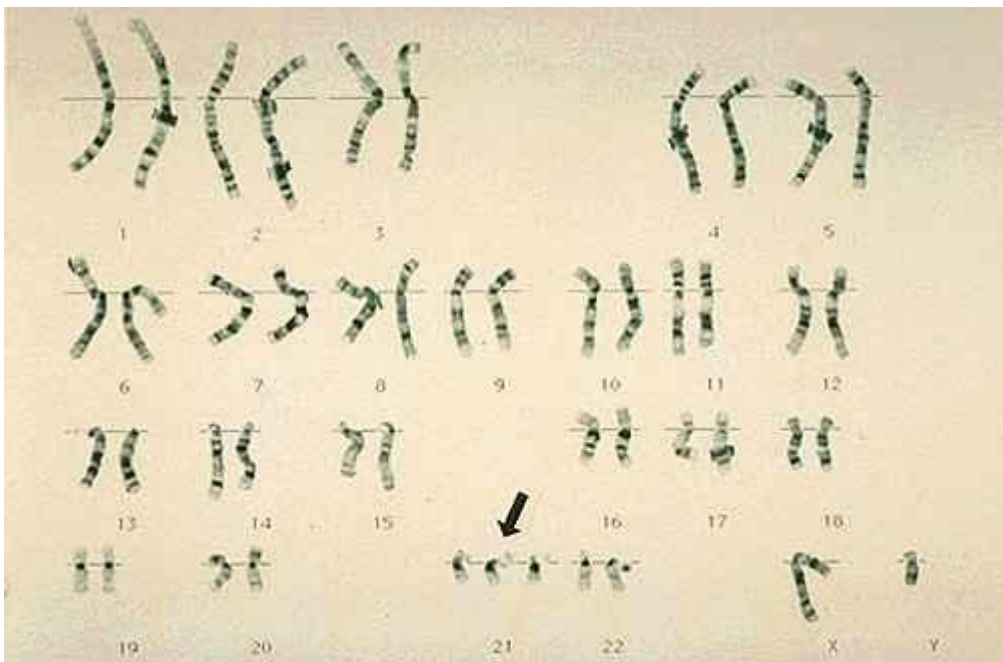


FIGURE 2.1: STANDARD TRISOMY 21 DOWN SYNDROME IN A BOY (AS INDICATED BY THE EXTRA CHROMOSOME 21) [Excerpt from Down syndrome for New Parents {WWW.Downsyn.com}]

b) Translocation Trisomy 21 Down syndrome

Translocation Trisomy 21 Down syndrome occurs when a piece of chromosome 21 is located on another chromosome (usually chromosome 15) resulting in a total of 46 chromosomes (Kaplan & Saddock, 1998). The person with Translocation Trisomy 21 will have 46 chromosomes but will have the genetic material of 47 chromosomes. Therefore, despite the presence of the additional chromosome making up the normal expected total of 46, the person with Translocation Trisomy 21 will exhibit all the

same characteristics of a person with Standard Trisomy 21 since they also have three copies of chromosome 21. Translocation 21, unlike standard Trisomy 21, is usually inherited, and the translocated chromosome may be found in unaffected parents and siblings (Kaplan & Saddock, 1998). Interestingly, the asymptomatic carriers are known to have only 45 chromosomes. Translocation occurs in between 2% and 3% of cases of Down syndrome (Devlin & Morrison, 2004).

c) *Mosaic Down syndrome*

Mosaic Down syndrome occurs when the chromosomes have failed to disjoin or split-up in a process known as non-disjunction (Devlin & Morrison, 2004). This can happen if the chromosomes do not properly separate and instead "stick together" (Devlin & Morrison, 2004). Sometimes this division does not happen properly and one cell may contain 22 chromosomes and the other may contain 24 chromosomes. Some of the resultant cells contain 46 chromosomes and some contain 47 chromosomes. These normal and trisomic cells are then found in various tissues (Devlin & Morrison, 2004). A person with Mosaic Down syndrome may exhibit all, some, or none of the characteristics of Down syndrome depending on the percentage of cells carrying the extra chromosome and the tissues in which these cells are located (Kaplan & Saddock, 1998). Other conditions arise if the duplicated chromosome is a different chromosome (Newton, 1997). If the trisomy is chromosome 13, the person will have Patau's syndrome. If the trisomy is chromosome 18, the person will have Edward's syndrome. These conditions are rarer than Down syndrome and have their own characteristics which are different from those of Down syndrome (Newton, 1997). Mosaic Down syndrome can occur because 46 chromosomes were received at fertilization, but somewhere during early cell division the chromosome 21 cell pairs failed to split. This results in a cell with 47 chromosomes and a cell with 45 chromosomes (Newton, 1997). The cell with 45 chromosomes cannot survive, but the cell with 47 chromosomes will continue to divide. All cells that come from this cell will then contain the 47 chromosomes. Alternatively, Mosaic Down syndrome can also occur when 47 chromosomes were received at fertilization, but later during cell division the extra chromosome is lost (Newton, 1997). According to Newton (1997), Mosaicism occurs in 2% to 5% of cases of Down syndrome. However, according to Devlin and Morrison (2004), cases

of mosaic Down syndrome are more common than previously recognized, since they often do not have dysmorphic features, and they tend to either be under-diagnosed or are diagnosed only later. Mosaic Down syndrome is the featured sub-type applicable within this study.

2.3.6 Current scientific limitations on etiology of Down syndrome

Despite incredible scientific developments with regard to the research of the genetic etiology of Down syndrome, the exact reasons behind these well understood and documented causes of Down syndrome are still not certain. These uncertainties may also be influenced by the fact that Down syndrome is genetic but is in fact mostly not hereditary (Kirk et al., 2000). Scientists in medical genetics are working hard to identify all of the numerous genes, which influence the various aspects of Down syndrome, yet the original cause, in determining these genes, is still not yet known. Theoretical discourses have begun to develop with regard to some of the yet unknown factors as to why some mothers conceive babies with Down syndrome and others do not. Some of these are outlined below:

a) *The discourse of environmental factors*

Environmental factors such as X-rays, chemicals and viruses may play a role on chromosomes, yet this remains unproven. Men working in areas where they are exposed to radiation, may suffer abnormalities at the first and second paternal meiotic division. This is because new sperm production goes on throughout life (Newton, 1997).

b) *The discourse of inherent vulnerability factors and their prevention*

There appears to be little chance of preventing Down syndrome as yet. However, scientific research is constantly being undertaken to develop information on that would make prevention possible as a result of ever-increasing scientific knowledge derived from more genes being identified (Sinet, 1999). According, to Newton (1997), the incidence of Trisomy 21 of paternal origin might be reduced by increasing and sustaining coital frequency or frequency of masturbation. The resultant regeneration of newer sperm cells would then have fewer tendencies for non-disjunction. However, according to Christianson et al. (2006), a decrease in Down

syndrome of paternal origin would not be statistically significant in impacting the decrease in the global incidence of Down syndrome.

Since there is little scope for effective prevention, genetic counselling is seen as second best in line (Christianson et al., 2002; Christianson et al., 2006). Medical practitioners could identify those with contributing etiological factors as outlined in the sections above, as well as genetic predisposition. They would then be in a position to give appropriate counselling, as well as decision making tools, which parents can use to better equip and prepare themselves. This section has provided an understanding of the causes, and limited ways of preventing Down syndrome. The next section offers a deeper understanding of the impact of Down syndrome within the South African context, as well as internationally.

2.4 INCIDENCE, LIFE EXPECTANCY, PREVALENCE, AND OUTCOME

2.4.1 Clarification of terms

The difference between prevalence and incidence needs to be clarified as it can be easy to misunderstand. Generally the term, 'incidence' refers to the number of live births and 'prevalence' refers to the number of babies surviving. However, perhaps because Down syndrome is considered as a congenital birth defect rather than a disease or a disorder, the words 'incidence' and 'prevalence' appear to be used interchangeably within the literature, as they will be in this study also. It seems that, in using the term 'birth prevalence' as opposed to 'incidence', medical science researchers convey a basic appreciation of the full-term survival journey abilities of the Down syndrome foetus. In this study the term 'incidence' will thus be used interchangeably with the word 'birth prevalence', and the term 'prevalence' will be used to refer to 'population prevalence'. In the section below 'birth prevalence' will be described in the context of the field of Down syndrome.

2.4.2 Birth prevalence of Down syndrome in context

It is understandable that researchers have an appreciation for the Down syndrome foetus's ability to survive, because the vast majority of pregnancies involving abnormal foetuses miscarry (Newton, 1997). This is because foetuses showing a reduced number of chromosomes cannot survive; the effect on the growing

metabolism is too great (Newton, 1997). Similarly hyperploidy (too many) of the larger chromosomes with their great effect on body metabolism also seem to lead to foetal elimination. However, hyperploidy of the smaller chromosomes with a lesser effect is often compatible with survival, and as chromosome 21 is one of the smallest (as can be seen in figure 2), Down syndrome has come to be the commonest form of chromosomal abnormality and as a result also the commonest recognizable form of mental disability (Newton, 1997).

2.4.3 Background to the integrated relationship of the terms

The relationship between prevalence and life expectancy in Down syndrome appears to be a sensitive one. The current number of people affected with Down syndrome in South Africa and around the world is more difficult to ascertain than birth prevalence or incidence. This is further complicated by the fact that when the birth prevalence is lower, the population prevalence is often higher where the life expectancy is higher. Similarly if the birth prevalence is high, yet the population prevalence is low, this can be as a result of a very low life expectancy. However, South African researchers have found reason to suggest that many low and middle income countries, including South Africa could improve their life expectancy of Down syndrome, and lessen their birth prevalence, simply with better training as well as better implementation and use of these improved medical and surgery advances (Christianson & Modell, 2004; Christianson et al., 2006). McConkey and Timmons (2004) note that the role of cultural factors and their impact on the outcome, development, and management of Down syndrome have been given little research attention, and as a result the impact of cultural factors on outcome and life expectancy could be greatly underestimated. Clearly, there is a need for further research on several aspects of this important topic.

2.4.4 Incidence

According to research published in the March of Dimes Global report on Birth defects (2006), prevalence, incidence, outcome and prevention of Down syndrome appear to be influenced by factors such as the economic status of the country of the person(s) with Down syndrome as well as the country's political ability to manage health care in terms of prevention, education, and care (Christianson, Howson & Modell, 2006).

March of Dimes Global report notes that Down syndrome has been identified as the fourth of five most common serious birth defects of genetic or partially genetic origin in 2001, totalling 217 293 globally of an estimated 7.9 million children born annually (Christianson, Howson & Modell, 2006). However, about 3.3 million children under the age of five die each year from birth defects (Christianson, Howson & Modell, 2006). The March of Dimes Global report classifies countries in terms of their Gross National Income per capita and notes that low income countries which have a GNI of less than \$826 account for an estimated 60% of the world's serious birth defects in 2001. Middle income countries have a GNI of between \$826-\$10,065 and account for about 33.5% of the world's total serious birth defects (Christianson, Howson & Modell, 2006). High Income countries have a GNI per capita per year of more than \$1 065 and account for an estimated 6.3% of the world's total (Christianson, Howson & Modell, 2006). So, for example, in both the United States and the United Kingdom, Down syndrome occurs in one in every 800 to 1000 live births (Newton, 1997) and (Hardman et al., 2005). This figure is an average based on the one in every 1 000 live births in developed countries, and one in every 650 live births in developing countries (Down Syndrome South Africa, 2004; Newton, 1997). According to March of Dimes report, the incidence of Down syndrome in South Africa is relatively high at 2,1 per 1000 live births, making its incidence in South Africa approximately double that of high income countries such as the U.S.A and England (Christianson, Howson & Modell, 2006).

2.4.5 Life expectancy

Life expectancy in individuals with Down syndrome appears to be directly related to a number of factors; including manifestation of associated medical anomalies, access to medical services, level of medical treatment, integration and interaction in community (Leonard, Bower, Petterson & Leonard, 2000). The exact age and quality of life, and life expectancy appears to differ in research, as a result of the varying influence of these factors. However, it seems that researchers generally agree that life expectancy in persons with Down syndrome appears to have increased over time (Jobling & Cuskelly, 2002).

Life expectancy has increased in recent decades from approximately 9 years in 1929, to approximately 50% of the population surviving until the age of 60 in more

recent decades (Carr, 1997 cited in Jobling & Cuskelly, 2002; Rasore-Quartino, 1999). This may be directly related to the 50% chance of individuals with Down syndrome having congenital heart disease (Rasore-Quartino, 1999). Subsequently these considerations have been confirmed through research revealing that the median life expectancy of persons with Down syndrome in the western world (i.e. high income countries) has increased to more than 55 years (Baird & Sadovnick, 1989 cited in Anneren & Pueschel, 1996; Christianson & Modell, 2004). Therefore, better medical care and changing attitudes during the last 20 to 30 years have had a profound effect on the health of individuals with Down syndrome in many countries (McConkey, 1996). Despite the increase in life expectancy, Down syndrome individuals still have a general lower life expectancy than that of the general population (Richards & Siddiqui, 1980; Steele, 1995 cited in McConkey, 1996).

Brown (1996) argues that research suggests that the more normal the lifestyle of the developing youngster with Down syndrome, the more opportunities exist for societal success in all dimensions of functioning (Firth & Rapley, 1991; Brown & Hughson, 1993 cited in Brown, 1996; McConkey & Timmons, 2004). More success in functioning makes it more likely that individuals with Down syndrome are capable of living more independent lives and therefore outliving their parents (Brown, 1996). Research also appears to suggest that life expectancy and success in functioning in adult life is directly related to the ability to detect and correct adverse physical problems such as circulatory defects, as well as an interactive and inclusive lifestyle (Brown, 1996; Perera, 1999). In the light of these findings, researchers argue that it is more than likely that people with Down syndrome will in the end approach the life span of the rest of society as they experience increasingly more effective and better quality lifestyle (Brown, 1996; Perera, 1999; Hardman et al., 2005). The quality of life model will be further outlined in the sections that follow.

2.4.6 Prevalence

Christianson and Modell (2004) have found evidence to suggest that in high resource countries, the population prevalence of Down syndrome is decreasing as a result of family planning, available information on age-related risk, antenatal screening, prenatal diagnosis and selective abortion, while the average age of survival and quality of life have both increased, as mentioned in the sections above.

According to Christianson et al. (2004), in middle and low income countries, Down syndrome was previously considered rare, particularly in Africa. However, this was because of high mortality and low life expectancy rather than low birth prevalence. During a personal conversation that I had with geneticist Dr Christianson (2007), he made the prediction that due to a history of racial capitalism in South Africa, and in turn a racial stratification of economic groups, it would be less likely that an employed adult with Down syndrome from an economically disadvantaged socio-cultural group would be available for this research; since they would have less chance of survival into adulthood, purely as a result of socio-economic factors than their white South African Down syndrome counter parts. This prediction is perhaps in line with findings from Australian researchers Leonard, Bower, Petterson and Leonard (2000), who found that the difference in survival between lower socio-economic aboriginal and higher economic non-aboriginal children with Down syndrome was particularly disturbing, mirroring the pattern in the general population. Their overall findings on the prevalence of Down syndrome in Australia suggest that for infants born between 1980 and 1996 survival to one year is now 91%, and 85% can expect to survive until the age of 10 years.

According to Christianson et al. (2004), in rural South Africa in the early and mid-1990s the birth prevalence (in other words the incidence) of Down Syndrome was reported to be 2,09 per 1000 live births (as noted in also in more recent research). However, the population prevalence was only 0,75 per 1000 children aged between 0 and 9 years (Christianson et al., 2002; Venter et al., 1995 cited in Christianson et al., 2006) This difference suggests that 65% of the infants and children with Down syndrome had died by the age of two. Experience has shown that as effective care becomes available, population prevalence rises gradually to resemble birth prevalence (Christianson & Modell, 2004 cited in Christianson et al., 2006).

Research in the United States has revealed that their incidence represents approximately 5 000 births per year, and the research studies on prevalence in recent years suggests that Down syndrome currently affects approximately 350 000 American people in total (Hardman et al., 2005). These results imply that a substantial number of individuals with Down syndrome in the United states survive into adulthood, suggesting an overwhelmingly greater prevalence of Down syndrome

in the states as compared to their rural African, and lower income country counterparts (Hardman et al., 2005; Kirk et al., 2000; Newton, 1997; Christianson et al., 2004).

2.4.7 Outcome

Due to chromosomal abnormalities that result in Down syndrome, persons with Down syndrome run an increased risk of developing disorders in various organs and having multiple congenital malformations, as the defects that result from these abnormalities are typically severe (Anneren & Peuschel, 1996; Hardman et al., 2005). Individuals with Down syndrome have benefited from access to increased medical knowledge and research that has allowed treatment programmes for intellectual and motor difficulties, as well as special medical care to prevent treatable disorders from remaining undiagnosed within individuals with Down syndrome (Anneren & Pueshel, 1996). Thus with both knowledge of, and access to, treatment and surgery the course and outcome for Down syndrome can be significantly improved as opposed to when these associated problems and disorders go undetected and untreated. Furthermore, cultural understanding and integration are more likely to allow people in the community to care for individuals and in turn integrate them fully into society and community. This in turn improves quality of life, life expectancy, and the course of life (McConkey & Timmons, 2004).

However, community cultures which marginalise individuals with Down syndrome may exclude them economically and often place them in institutions. As a result they have less chance of reaching their potential and being integrated into the community to lead a full and happy life (McConkey & Timmons, 2004). Thus although a great deal of the literature points to the influence of socio-economic factors on outcome of Down syndrome, there is literature (albeit scant) that emphasises the role of cultural factors on the outcome of Down syndrome. Within the context of this study, both are seen as important.

2.5 DIAGNOSIS

2.5.1 Screening and diagnosis

The diagnosis of Down syndrome has changed remarkably over the years. In the last few decades, non-invasive as well as invasive technologies for the pre-natal detection of foetal anomalies and genetic diseases have made the diagnosis of Down syndrome possible long before the baby is born (Steele & Bred, 1956 in Fortuny, 1999). It was not until the mid 1960s that successful culture of amniotic cells to perform cytogenetic analysis was made possible. This is now commonly known as amniocentesis, whereby foetal cells in the amniotic fluid are analyzed for karyotyping, and the extra chromosome 21 can be clearly seen (see figure 2) (Kirk et al., 2000). The relative disadvantages are a very small risk of foetal loss, and diagnosis is not available after 17-18 weeks. Since the 1980s however, screening measures are becoming increasingly safer and more accurate, through improved ultrasound definition (Steele & Bred, 1956 in Fortuny, 1999; Christianson & Modell, 2004). For example, an increase in thickness of the foetal neck, more commonly observed in Down syndrome, can be used in conjunction with other ultrasound findings such as congenital heart defects, before the amniocentesis is required to confirm the diagnosis (Steele & Bred, 1956 cited in Fortuny, 1999). Down syndrome can also be diagnosed after birth through the professional identification of its characteristic features. However, this can be more difficult in newborn infants, as discussed in section 2.5.3 below.

2.5.2 Diagnostic challenges

There has been speculation that within more rural parts of South Africa, as within other developing countries, where access to quality medical care and the latest medical research and screening procedures is difficult, Down syndrome and other syndromes and disorders can go completely undetected not just during pregnancy, but also after birth (Venter et al., 1995; Christianson, 1996, 1997; Christianson et al., 2002; Christianson & Modell, 2004). When the diagnosis is not made and medical checks, treatment and care are not followed up, these individuals have a minimal chance of survival (Venter et al., 1995; Christianson & Modell, 2004; Christianson et

al., 2002; Christianson et al., 2006). This may explain why fewer adults with Down syndrome exist in developing countries.

2.5.3 Criteria for diagnosis

A diagnosis of Down syndrome is usually made by a medical practitioner. Since Down syndrome is a congenital birth defect, a diagnosis can be made through pre-natal screening, as discussed above. However, without the prenatal screening and diagnosis, a diagnosis of Down syndrome can be difficult to make in newborn infants (Kaplan & Saddock, 1998). The most important signs in a newborn include general hypotonia, oblique palpebral fissures, abundant neck skin, a small flattened skull, high cheekbones, and a protruding tongue (Kaplan & Saddock, 1998; Devlin & Morrison, 2004). The hands are both broad and thick. Once developmental stages begin to occur, it becomes easier to detect through a variety of symptoms (Kaplan & Saddock, 1998). More than 100 signs or stigmata are described in Down syndrome, but are rarely all found in one person (Kaplan & Saddock, 1998).

2.5.4 Ethical dilemmas of pre-natal diagnosis

Prenatal screening and diagnosis of Down syndrome and the possibility of selective abortion raises ethical dilemmas such as the right of the child to be born as opposed to the financial burden viewed in terms of a loss of output because individuals with Down syndrome can be seen as unemployable, or they die prematurely, or they require an excess of educational and residential expenses (Peuschel, 1999a). Pearl S. Buck (cited in Peuschel, 1999a) describes the current practice of prenatal diagnosis and selective abortion as a threat to basic human rights. Deciding that a foetus with Down syndrome should be aborted can be seen as a social judgment about the place of individuals with developmental disabilities in society (Peuschel, 1999a).

2.5.5 Primary features

Primary features of Down syndrome are its physical and mental features. Intellectual disability is the overriding feature of Down syndrome.

a) Intellectual disability

'Mild mental retardation' as described in the DSM IV-R is considered to be representative of an IQ between 50-55-70. Moderate mental retardation is considered to be representative of an IQ level of 35-40 to 50-55, and severe 20-25-35-40 and profound below 20 or 25. A diagnosis of mental retardation is also characterised by deficits or impairments in present or adaptive functioning. In other words, the person's effectiveness is measured in terms of meeting the standards expected for his or her age by his or her cultural group in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work leisure, health and safety, with an onset before 18 years of age.

b) Medical complications

Medical complications as a result of Down syndrome are common, and these complications often help to confirm the accuracy of diagnosis.

c) Identifying characteristics

These have been outlined previously in the section on criteria for diagnosis 2.5.3 above.

2.6 ASSOCIATED FEATURES AND CO-MORBID DISORDERS

Common associated medical disorders with Down syndrome include congenital anomalies of the heart and of the gastrointestinal tract, which carries an increased risk of leukaemia, defects of the immune system and Alzheimer's disease (Rasore-Quartino, 1999). Sensory defects such as hearing and ocular (visual) abnormalities are also common, and can have an important effect in the general pattern of mental development, and rehabilitation possibilities if they occur in first years of life (Rasore-Quartino, 1999). Other characteristics of perceptual motor behaviour associated with Down syndrome include muscle activation time and general motor movements (Weeks, Chua & Elliot, 2000). Children with Down syndrome appear to have higher social and adaptive skills than would be expected given their slow intellectual

development, and less developed language and communication skills (Kirk et al., 2000).

2.6.1 Cognitive deficits

According to Hardman et al. (2005), studies conducted in high income countries reveal that most people with Down's syndrome have IQ's that fall in the mild to moderate range of retardation or intellectual disability, and the remaining few fall into the severe or profound range of retardation or intellectual disability. However, limited studies in lower income regions and developing countries such as rural sub-Saharan Africa suggest that, severe or profound retardation or intellectual disability are more common (Christianson, 1996; Christianson, 2002).

Buckley (1999) has noted that it is the slow cognitive development of mental abilities such as talking, thinking, reasoning and remembering which provide the foundation for intelligence or intelligent behaviour, are what mostly concern parents of children with Down syndrome, especially as these functions assist individuals to meet demands and expectations of the world around them. Buckley (1999) and Peuschel (1999) describe a considerable amount of research into promoting the development of cognition in children with Down syndrome in recent years, including visual supports for learning including signing and reading while talking. Furthermore, research suggests that reading instruction leads to useful levels of functional literacy for a majority of children, and also mildly improves functional intelligence by improving speech, language, and short term memory skills (Buckley, 1999).

2.6.2 Language problems

Speech intelligibility, language difficulties and delays are particularly prevalent among persons with Down syndrome, because, as a group, persons with Down syndrome typically display more severe language impairments than comparison groups matched in age and overall level of cognitive function (Fowler, 1999; Miller et al., 1999; Kirk et al., 2000; Hardman et al., 2005). Comparisons across a variety of neuron-developmental syndromes provide further evidence that Down syndrome puts individuals at particular risk for language difficulties (Fowler, 1999), and therefore linguistic problems are greater than would be expected solely on the basis of overall cognitive function (Scarborough, 1991 cited in Fowler, 1999; Miller et al.,

1999; Fowler, 1999). Research on a group of adolescents with Down syndrome in the United Kingdom has revealed that language impairments appear to manifest mainly in phonological problems; and although parents can usually understand their children, strangers frequently find it difficult to understand them (Buckley & Sacks, 1987 cited in Fowler, 1999).

Miller et al. (1999), have published and documented comprehensive research on the communication challenges of people with Down syndrome including the assessment of communication skills, and have found that progress in speech and language performance is linked to factors including hearing status, speech motor function status, non-verbal cognitive level and chronological age.

2.6.3 Clinical/medical problems and physical difficulties

Cohen (1998) has outlined associated clinical problems and physical difficulties that can be expected in adults with Down syndrome. These will be discussed below:

Cardiac problems

These include cardiac problems particularly congenital heart disease, which is reported to occur in 30-60% of children with DS. Timely surgery, treatment and ongoing check-ups are recommended in the first six months, preferably before three months of age.

Ear problems

Most children with Down syndrome have very small ear canals making it difficult to examine them properly. If checked and treated properly in early development, major hearing difficulties can be avoided later.

Nose and throat problems

Obstructive airway disease has been recognised as a significant problem for children and adults with DS. Therefore, physical examination of tonsils and airways is done to determine if surgery is necessary to avoid major obstructions and breathing difficulties.

Eye/Vision

Congenital cataracts are a serious problem for infants with DS leading to vision loss if not detected and treated.

Atlantoaxial Instability problems

Term used to describe increased mobility of the cervical spine at the level of the first vertebra, a condition found in 14% of person with Down syndrome. This can lead to compression of the spinal cord, which can lead to symptoms such as neck pain, loss of upper body strength, and change in bowel functioning amongst others.

Oral-motor function difficulties

Infants with Down syndrome have been known to have difficulty feeding from birth as a result of oral-motor function difficulties. DS persons have been known to benefit greatly from physical and occupational therapies.

Immunology

Auto-immune conditions are common in persons with Down syndrome.

Endocrine

Incidence of thyroid disease is significantly increased among individuals with Down syndrome of all ages, and research suggests that children with Down syndrome have an abnormality of growth hormone secretion. Further research is being done in this area.

Neurodevelopment issues

The frequency of seizure disorders such as epilepsy in persons with Down syndrome is greater than that seen in the general population but lower in persons with intellectual disability. This increased incidence of seizures is seen as not solely the result of abnormal brain development but also of cardiac defects, infections and irregularities of one or more neurotransmitters.

Developmental disorders

Co-morbid disorders such as Autistic disorders are more prevalent in person with Down syndrome.

2.6.4 Psycho-social issues

Cuckle and Wilson (2002) have found that the social relationships and friendships among people with Down syndrome are an important part of interpersonal development, and are very dependent on opportunities created by families for their social life. They found evidence that the development of peer groups in special schools allow real, reciprocal, supportive relationships to flourish among peers with similar interests and abilities, because more truly reciprocal relationships and friendships were noted to exist between them and other young people with special needs (Including those with Down syndrome) whose interests, social life, emotional maturity, and communication skills were more equally matched. However, Cuckle and Wilson (2002) also note that despite these findings there were more obvious advantages for young people experiencing both groups of friends, since the social skills learned in mainstream schooling were considered important for the future, in terms of increasingly independent living and developing a wider range of more independent relationships.

2.6.5 Behavioural problems and disorders

Marital Stress has been associated with an increase in behaviour problems in children with intellectual difficulties (Floyd & Zmich, 1991 cited in Cuskelly & Gunn, 1997). Cuskelly and Gunn (1997) have found that often the extent of the behaviour problems in a person with Down syndrome is frequently dependent on how the behaviour is perceived by their parents, particularly with regard to parental expectations.

Individuals with Down syndrome who have impaired speech and language face many trying situations and therefore what may be regarded as problem behaviour may stem from frustration either because their communication was not understood or because they could not understand a spoken request or demand (Cuskelly & Gunn, 1997).

2.7 INCLUSION OF INDIVIDUALS WITH DOWN SYNDROME

a) Inclusion into school and society

While I was completing my internship year with the Western Cape Education Department recently, I found that the term 'Inclusion' is a 'hot topic' within the context of South African schooling. The South African schooling system makes sincere attempts to move toward the implementation of inclusion in the education system (Department of Education, White Paper 6, 2001), this is based on the theory that schools often mirror societies, and consequently that inclusive schools lead to inclusive societies. Education plays a clear role in preparing individuals for work, and better quality of life through developing skills that will enable a successful transition from school to community. Within the field of Down syndrome, these skills are seen to relate to independence, self-help, work experience and training and leisure (Jobling & Cuskelly, 2002).

The approach, philosophy and attitude to inclusion of people with disabilities in western cultures have developed over changing paradigms across time (Swart & Pettipher, 2005). Attitudes to people with Down syndrome have varied considerably within different cultural, community groups and even within families (Stratford, 1996). For example, an indication of these cultural influences is better illustrated when contrasting western perceptions of persons with Down syndrome during the time of Dr Down, when mental disability was viewed in the derogatory terms of being sub-human (Newton, 1997), with more recent models and attitudes tending towards human rights and inclusion. Today, paradigms, perceptions, and policies are steadily shifting towards human rights, equality, and inclusion. Within these contexts there are far more opportunities for a person with Down syndrome to be included as a full member of society than previously.

b) Inclusion into the workplace

The underlying assumption of inclusion is the degree to which the person with Down syndrome is employed, reflects the degree to which they are included into society. Inclusion is likely to be experienced by the adult with Down syndrome indirectly to the work experience, and will probably be reflected in their more concrete explanations of work experiences (Hardman et al., 2005; Swart & Pettipher, 2005).

Within the context of inclusion, the ultimate form of inclusive employment could naturally be considered within competitive mainstream employment. Most societies still appear to reflect varying levels of attempting to implement inclusion in attitude and policy, amongst others (Swart & Pettipher, 2005). Within the newly developing field of inclusive employment, these levels of inclusion into employment can be considered in terms of four types of employment, for adults with Down syndrome (see National Down Syndrome Society in the United Kingdom website). As mentioned in Chapter 1, these typically include:

Sheltered employment in which individuals work in a self-contained setting with others who have disabilities; **supported employment** in which the individual works in integrated settings with support services such as a job coach; **competitive employment** in which the person works independently in the open labour market without support; **entrepreneurial business** in which, many ventures are artistic in nature, including watercolour artistry, music, acting and photography amongst others (WWW.NDSS.org National Down syndrome Society).

According to the Western Cape Down Syndrome Association at the time of this study, there seem to be an extremely limited few individuals with Down syndrome employed in competitive employment, and the majority of these had access to a job coach. The most popular type of employment, according to the Down Syndrome Association, was sheltered employment, and the waiting lists for places at these workshops appeared to be extremely long.

2.8 RESEARCH ON EMPLOYMENT EXPERIENCES OF ADULTS WITH DOWN SYNDROME

Very little research has been conducted on the lives and employment experiences of adults with Down syndrome (Jobling & Cuskelly, 2002). There is even less research, if any, on South African adults with Down syndrome.

2.8.1 A London study

A study in London in 1995 conducted by Carr (1995) followed up on a sample of 35 young adults with Down syndrome aged 21 years (cited Jobling & Cuskelly, 2002). Carr found that 15% of the group were at home full time, and only 10% of the sample

worked (all were part time) and this work was on farms, in family businesses, with one individual working in hairdressing. Most could not get to work independently. The remaining 75% were all found to be attending local day centres. Carr noted that ability alone was not sufficient for the young adult to reach a level of independence but that rural and urban factors as well as the mother's beliefs influenced the adult's life style.

2.8.2 An Australian study

Jobling and Cuskelly (2002) conducted a study on 72 employed individuals with Down syndrome living in Queensland Australia. Unlike Carr (1995), Jobling and Cuskelly (2002) did not find that urban and rural factors influenced life style opportunities and subsequently found that there were no significant differences between the responses of the metropolitan, regional or country participants, so the data was combined for analysis. They found that the main types of work in which the adults with Down syndrome engaged in, were packing, collating, and associated mailroom work. Eight adults were employed doing outdoor work. Thirteen were employed in private enterprise, 12 had a variety of work with employment services, and the rest were in sheltered workshops. Forty eight adults were paid for their work. Most of the young adults worked between 20 and 40 hours a week and the others worked less than 10 hours. These employment opportunities were mainly accessed through employment support agencies and school transitional work experience programs. Similar to Carr, and the situation revealed in conversations with the Down syndrome association within the Western Cape, they found that the main avenue for employment remained the sheltered workshops (Jobling & Cuskelly, 2002).

2.8.3 Effect of work motivation on employment experiences

There appears to be a growing expressed need on behalf of individuals with Down syndrome wanting work (Jobling & Cuskelly, 2002; Botroff, 2002; Brown, 1996). The reasons for wanting work were in having the opportunity to perform specific tasks or valued roles in employment and to a lesser extent, establishing friendships and improving their personal well-being. Their parents or carers expressed reasons emphasizing the need for personal development in terms of independence, and self-esteem. Thus parents were more concerned about the person and their level of

satisfaction than about the type or status of employment, whereas the people with Down syndrome on the other hand were more concerned with the type of work they would like to perform. Thus their thinking was more concrete (Botroff et al., 2002). The motivating factors influencing the reasons to work and the reason for certain types of work, play a role in the experience of employment. This not only affects the type of employment experience, but also the degree to which that employment experience may be considered as a satisfying one, thereby influencing the potential positive effect on overall quality of life.

2.8.4 Quality of life

Simply put, one's quality of life is influenced by several factors at any one time: political factors, economic factors, emotional factors, amongst others. The term has become increasingly loaded amongst researchers over the last two decades. According to Perera (1999), the concept of quality of life applies to the planning and evaluation of services for disabled people, in developed countries, originating in the late 1980s. The term 'quality of life' is practically impossible to talk about in developing countries when all too often the focus is more on day to day survival and the struggle to have basic human rights recognized such as access to basic health care, education, personal safety, and work. However, this term has gradually been introduced into the world of people with Down syndrome for three reasons: the application of inclusion, longer life expectancy, and scientific advances in the genetic understanding of Down syndrome (Perera, 1999).

Nearly two decades after the origin of 'quality of life' research, and researchers finally agree that any evaluation or definition of quality of life is essentially subjective, and can be extremely difficult to determine given the challenge of ensuring the reliability of comparisons over time and between different geographical contexts (Blatt 1987; Edgerton 1990, cited in Perera, J, 1999; Barbotte et al., 2001; Cummins 2005). Within this study, the qualitative definition and evaluation of quality of life is taken from the comprehensive quality of life scale for intellectual disability (Cummins, 2005), which considers overall sense of satisfaction and contentment along the lines of material wellbeing, health, productivity, social intimacy, safety, place in community, emotional wellbeing, sense of importance and satisfaction. The personal Wellbeing Index was used in this study to gain a comparative insight into the quality

of life of the adult with Down syndrome, which is based more simplistically along the same lines (Cummins, 1997). Barbotte, Guillemin, Chau and the Lorhandicap group (2001) have highlighted the importance of accurately defining concepts of impairment, disability, and handicap, and integrating the environmental context in more accurately contributing to the challenging field of quality of life research. The role of language and the way that words are used to effect meaning are seen as an important means in conveying an accurate understanding of quality of life, and thereby creating a way for research data to contribute to this important field.

According to the new WHO classification (11) cited in Barbotte et al. (2001:1047), in view of the need for careful use of language within this field, these concepts should be defined within the following ways:

- "Impairment is seen as a disturbance affecting functions that are essentially mental (Memory, consciousness) or sensory, or the limbs."
- "Disability is seen as a restriction or inability to perform an activity within the range considered normal for a human being mostly resulting from the impairment."
- "Handicap is seen as a result of an impairment of disability that limits or prevents the fulfilment of one or several roles regarded as normal depending on age, sex, and social and cultural factors."

Careful attention has been paid to the use of language within this study, as far as possible, due caution has been exercised when undertaking subjective interpretation of data as pertaining to quality of life, especially in terms of employment experiences. More specifically, Botroff et al. (2002) view the role of employment experiences within the quality of life model stating that another challenge of the quality of life model is to recognise that young people with Down syndrome need to be helped to understand the more complex reasons for work, and that employment is only likely, if they get an experience of real work. They found that parents tend to select the more traditional types of jobs whereas people with Down syndrome suggest a wider range of employment possibilities (Botroff et al., 2002). For example, there was more variation in job choice amongst people with Down syndrome, and these frequently

included jobs where people with Down syndrome are actually employed (e.g. dancer, waiter, factory worker, shop assistant).

Botroff et al. (2002:131) found that most parents hoped for open employment with or without support, though about a third thought that sheltered workshops were the most likely option. Interestingly, Botroff et al. (2002) found that given the data on the individual's skill levels this would most likely underestimate what individuals could do. Botroff et al. (2002) concluded that educational authorities need to broaden experiences in employment while the child is still enrolled in school, in order to aim toward improved quality of life. In a South African setting there are several challenges to achieving this, even in the case of mainstream children, given the nature of our overall status as a middle income country or developing country, and what that naturally implies in terms of quality of life, as described by Perera (1999) at the beginning of this section.

2.8.5 Effect of the South African employment context on experiences

Nicholas et al. (2006) reviews the situation in South Africa. Here there has been a shortage of skills experienced by employers, in keeping up with a rapidly growing economy. Although South Africa has several characteristics of a 'first world' country it still has a very high rate of unemployment in comparison to many high income countries. Consequently, there is a growing emphasis on entrepreneurship within a variety of training centres. Temporary work, contract work, and casual work are frequently easier to obtain in comparison to the welcome security of permanent employment. New legislation and policies impacting on education, training and labour, have also brought about many changes affecting the employment context in South Africa. For example, the Labour Relations Act of 1995 was created to resolve disputes. It aims to give employees more of a voice and assist them through the organisation of trade union representation, as well as providing conciliation, mediation and arbitration. Another new piece of legislation with far reaching career implications is the Employment Equity Act no 55 of 1998, which aims to redress discrimination against previously disadvantaged people in the work place. The act makes provision for black people, women, and people with disabilities, and applies to all employers with more than 50 employees (Nicolas et al., 2006). It requires the employer to draw up an employment equity plan suitable to their context.

2.8.6 Affects of training on work experiences

It is Interesting that Botroff et al. (2002) consider further training to be necessary for individuals with Down syndrome in order for them to attain these potential reaching and quality of life fulfilling work and employment experiences. Yet they also acknowledge that additional training could be done within the work context. It appears that their concern is with creating the work and employment opportunities most suited for adults with Down syndrome rather than the training required to prepare for these experiences. The implication of their thinking is that there should be a focus on the creation of employment opportunities in the school context, with a possible need for the educational psychologist to assist in the development of on-the-job training. In the South African setting where there are a great many challenges to employment for the majority of individuals, there appears to be an increasing need for the role of the educational psychologist and career psychologist to change from being mainly concerned with educational factors, to playing more of a role within the team involved with the creation of job opportunities and work experiences.

2.8.7 Examples of work experiences

The work experiences of one worker of Down syndrome as reflected by Contardi (2002):

"My first day of work was on Monday at 4'o'clock. I saw the restaurant and the manager and I tried on the uniform and met my colleagues. I was nervous. On Monday, Thursday and Friday and Sunday I work from 3'o'clock until 7 o'clock. On Wednesday I work from 10 to 2 (because in the afternoon I go swimming), and Tuesday and Saturday are my free days. Every day I clock in when I arrive and I clock out when I finish work before I go away.

With my colleagues everything is fine. They work different shifts, the night shift too. I do my job by myself and they help me when I need it. I prepare all the kinds of burgers and I do the training – till the manager helps me and explains how the till works. I prepare the drinks, the chips, the ice-creams, the apple pies and I make the cream. When I work in the morning I do the salad bar, where the salads are sold, I take the orders, I put them on the plates, I take the money at the till."

Another says: *"My salary is paid into the bank so when I need money I use bancomat. I buy myself things- smart clothes, shoes with high heels, jackets*

and shirts, and I go to the theatre and to the cinema or have a pizza with my friends. Since I've been working my life has got better – I've changed as a person, I've grown, become an adult. I've become a woman. "

The work experiences, particularly those reflected in the latter, imply that they serve to greatly enhance the quality of life and independence of the adult with Down syndrome.

The work experiences such as the ones mentioned above, do not usually come about without a high level of family support, both in the job creation and the integration into the working environment. This high level of family involvement in the management, care and lifestyle of the adult with Down syndrome has been described by various researchers on the subject (Carr, 1995; Fujiura & Smith, 1997 in Jobling & Cuskelly, 2002). Naturally not all families are in a position to offer such high levels of support, or to respond to such high demands of support. Jobling and Cuskelly (2002) propose that if the unmet needs of this 'often invisible' group of adults are recognised by the wider community, the demands on these parents will most likely lessen.

2.9 REFLECTION

This chapter attempts to give the reader a contextual overview of our current understanding of Down syndrome. In light of this understanding, and given that the literature available on the employment experiences of adults with Down syndrome is limited, it is assumed that the reader may have developed a deeper appreciation for the amazing achievement of an employed adult with Down syndrome, within any type of employment, and within any type of context.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This chapter situates the research design and methodology within the perspective of the interpretivist research paradigm, followed by a description of the research problem and the aims of the study. The research design and methodology are then discussed in detail, including qualitative research techniques of data production, data analysis, as well as ethical considerations, and validity and reliability.

3.2 RESEARCH PARADIGM

The research paradigm guides the way in which the research is contextualised within the nature of social enquiry, and the way in which the research is approached (Babbie & Mouton, 2001). The interpretive approach (which is also known as the phenomenological approach, and the constructivist perspective) is centred on the notion that all human beings are engaged in the process of making sense of their "life worlds" (Babbie & Mouton, 2001). In this approach people are seen as shaped by, and as active shapers of, their social context (Donald et al., 2002). The interpretive paradigm acknowledges the notion of multiple realities, and therefore multiple truths (Babbie & Mouton, 2001).

As outlined in Chapter 1, the theoretical paradigm that informs the research is the interpretive approach to social science research, also known as interpretivism. This approach is centred on the notion that all human beings are engaged in making sense of their "life worlds" (Babbie & Mouton, 2001). This study describes the social reality of an individual adult with Down syndrome.

3.3 RESEARCH PROBLEM

As mentioned in Chapter 1, this research study seeks to explore the employment experiences of an adult with Down syndrome, an area where little research has been

done in South Africa. However, there does appear to be a growing interest on this topic (Down Syndrome Society of South Africa, 2006; Intellectual disability quality of lifespan development project, 2006).

3.4 AIMS AND PURPOSE OF THE STUDY

This research set out to create awareness and understanding of the employment experiences of an adult with Down syndrome. It also set out to gain insight into the factors which have influenced these experiences on various levels (including emotional factors, influences on quality of life, parental and community support amongst others), and the degree to which the various challenges to employment were overcome within the South African context as well as within the context of the physical constraints as a result of the Down syndrome. The researcher attempted to achieve the purpose of the study by meeting the following aims (as outlined in more detail in Chapter 1):

- To investigate the employment experiences of an adult with Down syndrome in South Africa.
- To investigate what the emotional experiences of employment for the adult with Down syndrome are in terms of the effects of the employment experiences on developing self-esteem, and reaching potential.
- To investigate what the cultural employment experiences are in terms of integration into the community, and a feeling of cultural belonging for the adult with Down syndrome.
- To investigate what the economic experience of employment is with regard to gaining a degree of self-reliance and basic means for the adult with Down syndrome.
- To explore to what extent the employment experience has led to an improved quality of life for the adult with Down syndrome.
- To look into the possible types of training and support implemented in preparing the adult with Down syndrome for the employment experiences.

These aims were addressed through the research questions as outlined in Chapter 1, and below:

The primary question was:

- 1) What are the employment experiences of an adult with Down syndrome?

Secondary questions were:

- 2) What are the emotional employment experiences of the adult with Down syndrome?
- 3) What are the cultural employment experiences of the adult with Down syndrome?
- 4) What are the economic employment experiences of the adult with Down syndrome?
- 5) Was training and support implemented in preparing the adult with Down syndrome for employment? If so, what were the training and support experiences, and to what extent did they affect the employment experiences?
- 6) To what extent do the employment experiences assist in the development of an improved quality of life for the adult with Down syndrome?

3.5 RESEARCH DESIGN AND METHODOLOGY

The research design is a qualitative study that is situated in the interpretive research paradigm (as discussed in the section 3.1 above) and uses case study methodology.

Case study method is often characterised as exploratory in nature. It has also been viewed as complementary to other research methods in psychology, and as such can provide new ideas and hypothesis, as well as opportunities to develop new techniques, and a chance to study unique phenomena (Kazdin, 1998, cited in Shaughnessy et al., 2000). Bolgar (1965 cited in Shaughnessy et al., 2000) underlines the power of the case study method to open the way for discoveries. In psychology, the development of psychoanalytic theory is a classic example of hypothesis formation based on case study method. Case studies are also able to

provide a means of challenging scientific theory when the behaviour of a single case contradicts theoretical principles or claims. Furthermore, case studies also make idiographic research (the study of individuals to identify what is unique) possible, which complements the traditional nomothetic research (the study of groups to identify what is typical). Since psychology is largely a nomothetic discipline (like science in general), It aims to establish broad generalisations and universal laws that will apply to a wider population, in this way the researcher hopes to be able to predict on the basis of this mean performance what the population group will be like in 'general' (Shaughnessy et al., 2000). However idiographic research does not aim to predict the aggregate, but instead aims to describe a unique ideal for any one individual. In reaching this ideal, an actual predication may sometimes then help universal groups. For that reason, this case study does not aim to establish broad generalisations that may then be applied and expected from the average adult with Down syndrome or even their average employment experiences. Instead it sets out to describe what one adult with Down syndrome experienced through his employment. This example of what can be experienced may in turn inspire and even enable a universal group of Down syndrome adults living in developing countries to become more aware of what they could achieve, given certain factors. In this way case study method permits the kind of detailed observation that has the power to reveal various subtleties of behaviour that a 'group approach' might miss. Thus, case studies have the ability to teach us about possible typical or average behaviour by studying what is not average and is atypical (Shaughnessy et al., 2000).

A case study is characterised by its focus on a phenomenon that has identifiable boundaries, the phenomenon within the identifiable boundaries is also known as the bounded system (Henning, 2007). For example, the bounded system of this case can be defined in terms of the adult with Down syndrome as well as his interaction with his community, family, and employment context through the action of his employment. Another characteristic of case study as a methodology is that the context is also more than part of the case, thus it is the case and the interaction between context and action that is usually the unit of analysis (Henning, 2007:41).

Using Henning's 2007 guidelines, the phenomenon that was studied was the employment experiences of an adult with Down syndrome (Henning, 2007). The time

involved in the study was the time taken to conduct the research methods, this will become clearer as it is discussed further in the following section below.

The actions, activities and events that may be included within the study refer to those applicable to the employment experiences of an adult with Down syndrome. Data that are not applicable to the case are not utilised unless they indirectly reflect the nature of the case (Henning, 2007:41). The process is therefore more important than the outcome (Merriam cited in Henning, 2007).

In practice a case study is an intensive investigation of a unit of analysis as mentioned above (Runyan, 1988, Yin, 2003). Although the form and content of case studies vary greatly (Shaughnessy et al., 2000), case study commonly involves four general design principles (Babbie & Mouton, 2001), which integrate the three step process of constructing case studies as described by Patton (2002) and mentioned in chapter 1. These include the following:

3.5.1 Conceptualisation

The first principle includes the role of conceptualisation in the research. This includes defining concepts, the purpose of the study, research questions, and the literature review. In this study, the phenomenon that is studied refers to the employment experiences of an adult with Down syndrome.

3.5.2 Contextual detail and in-depth description

The second design principle includes the importance of contextual detail and in-depth description. In this study, like most other case studies, this principle was applied through involving the investigation of multiple variables, through the interaction of the unit of study (in this case the adult with Down syndrome) with his context (Babbie & Mouton, 2001). This main focus of the study is the individual adult with Down syndrome, which is the defining characteristic of the case study (Babbie & Mouton, 2001). Thus an employed adult with Down syndrome and his interaction with his community, family, and employment context through the action of his employment represent the bounded system which was the unit of analysis. It is during the process of condensing, organising and classifying the rich descriptive raw case data that step 2 of constructing a case record can take place (Patton, 2002).

3.5.3 Using multiple sources of data

The third design principle includes using multiple sources of data. In this study, multiple sources of data, involving multiple interviewing and observation occasions, and a variety of informants were used as methods to investigate for the purpose of gaining a more reliable and valid outcome. It is during the process of producing the rich details of the raw data, from these multiple sources, that step 1 of assembling the raw case data could take place (Patton, 2002).

3.5.4 Analytical strategies

The fourth design principle includes analytical strategies. Analytical strategies for this case study research involved organising the findings, using modes of analysis such as pattern matching, and more specifically, content analysis, which could identify research themes in communications according to the conceptual frameworks in this study identified in the literature study. Furthermore, in using analytical strategies to organise the findings appropriately, the question of generalisation could be considered, which could potentially be demonstrated through showing links between findings and previous knowledge (Babbie & Mouton, 2001). It is after this analysis has taken place that a final case study narrative can be presented completing the third step in the process of constructing case studies (Patton, 2002). This step is taken in Chapter 5.

3.6 METHODS OF DATA PRODUCTION

"When the data collection tools of interviewing, observation, document analysis and artefact analysis act as basic equipment in the researcher's toolkit, the researcher may set out to gather purposeful data, record them in detail and prepare them for scrutiny" (Henning, 2007:100).

In setting out to produce purposeful data in a case study, Stake (2000 cited in Mertens, 2005) recommends data production of information concerning the nature of case, its historical background, and the physical setting. These three main types of information are gathered using the methods of data production outlined below.

3.6.1 Interviews

According to Babbie and Mouton (2001), the basic individual interview is one of the most frequently used methods of data gathering in the qualitative approach. They describe a qualitative interview as an interaction between the interviewer and the respondent in which the interviewer has a general plan of inquiry but not necessarily a specific set of questions. This enables the interviewer to establish a general direction for the conversation and to pursue specific topics raised by the respondent, whereby ideally, the respondent does most of the talking (Babbie & Mouton, 2001:289). Therefore, in this study careful consideration was given to the responsibility of the interviewer, especially with regard to sensitivity of the potential emotional and intellectual demands that the interview might inherently make on the adult with Down syndrome (King, 1996). Babbie and Mouton (2001) emphasise that careful wording of the questions is necessary in order to prevent potential bias on the part of the interviewer. The use of probing has been suggested as a useful way to get answers in more depth without biasing later answers. Babbie and Mouton (2001) advise that the basis of effective qualitative interviewing is to be interested rather than interesting. Steven Kvale (1996:88 cited in Babbie & Mouton, 2001) details seven stages in a complete interviewing process;

- 1) Thematising: Clarifying the purpose of the complete interviewing process
- 2) Designing: Laying out the process through which you will accomplish your purpose including a consideration of the ethical dimension
- 3) Interviewing: Doing the actual interviews
- 4) Transcribing: Writing a text of the interviews
- 5) Analysing: Determining the meaning of gathered materials in relation to the purpose of the study
- 6) Verifying: Checking the reliability and validity of the materials
- 7) Reporting: Telling others what you have learnt.

3.6.2 Observation

According to Babbie and Mouton (2001), there are two types of observation, namely simple observation, where the researcher remains an outside observer and participant observation where the researcher is also a member of the group she or he is studying (Babbie & Mouton, 2001). Since the researcher was an outside observer of the employment experiences, this study can be said to have employed simple observation. According to Kelleher (1993 cited in Babbie & Mouton 2001), in simple observation there are a variety of major types of observable data, including for example; exterior physical signs, expressive movement, physical location, language behaviour, and time duration.

Observation as a method of research has several advantages in that it forces researchers to familiarise themselves with the subject, and it allows previously unnoticed or ignored aspects to be seen (Babbie & Mouton, 2001). People's actions are probably more telling than their verbal accounts and observing these are valuable (Henning, 2007). Furthermore observation is usually the most unobtrusive, and as a result the researcher is less likely to affect what is being studied (Kelleher, 1993 cited in Babbie & Mouton, 2001).

Simple observation can have the disadvantage, as a method of research in that especially in the role of a complete observer, there is less chance of the researcher developing a full appreciation of what is being studied, and as a result observations may be more sketchy and transitory (Babbie & Mouton, 2001).

While researchers have noted that rich documentation can be gained on seven days of observation of a person's life, it was, unfortunately, not possible to observe the adult with Down syndrome's employment experiences over the course of seven days. Instead the adult was visited at work over a course of two days, and observed during the course of these visits of about three hours each to give as much depth as possible to the interview data (Babbie & Mouton, 2001).

3.6.3 Personal and related documents

Babbie and Mouton (2001) provide a basic list of personal documents that includes autobiographies, diaries and diary interviews, and letters. They point to ethical and

other considerations that should guide the decision as to whether or not to use them. Sometimes the documents are confidential or contain far too much material that is not necessarily relevant to the researchers concern.

However, personal and related documents are an alternative and often less biased means of giving the researcher access to further information regarding the topic studied. Furthermore, as Henning (2007) warns, omitting documents from a qualitative research study may mean that there are gaps. Although they are used mainly for their content value, documents can be used as entities of data and so follow the usual route of analysis and interpretation. Where the study uses documents as the main source of data, it may be regarded as a 'genre' on its own. In my study, documents are used to provide a rich context of the employment experiences, and are not the main source of data (see Addendum E, and skills matrix in Chapter 4).

Henning (2007:100) advises novice researchers to practise data collection in as many modes as possible, and then to select a specific method in a specific design that seems to capture data optimally and purposefully.

3.6.4 Questionnaires

A self-report questionnaire in the form of the amnesia (see Addendum F) was given to each caregiver and employer to complete the relevant background information including the developmental history of each adult where possible, relevant and appropriate. Basic leading interview questions were formulated based on Cummins's Quality of Lifespan Development questionnaire. The questionnaire formed part of the unstructured interview with the parents. Although self-report questionnaires are often quicker and easier to administer than an interview, questionnaires do not allow the researcher the means to gain access to other information which may also be relevant, and which is easier in interviews, even if it can be more time consuming (McLeod, 1994 cited in Daniels, 2005; Babbie & Mouton, 2001; Henning, 2007). Bearing this in mind, the aim of the questionnaires was to simply act as a tool to guide the direction of the interview.

Information and reports from previous health and education professionals were encouraged, and Chinton's parents were fortunately able to provide equivalent data information, as attachments to the questionnaire to a fair extent (see Addendum C).

3.6.5 Tape recording

Before recordings of any kind are used, ethical permission should be obtained from the participants in consideration of the appropriate, professional and respectful use of the recordings for an agreed purpose (De Vos et al., 2002:304 cited in Daniels, 2005). Tape recording not only allows the researcher to concentrate optimally on the interview and less on taking notes, but allows easier and more accurate access to transcribing the information later on.

3.7 DATA ANALYSIS

"The true test of a competent qualitative researcher comes in the analysis of the data ..." (Henning, 2007:101).

According to Ezzy (2002), in order to be a competent researcher, integrated research is important. For this reason data analysis in most qualitative research should in fact begin during data production. Waiting until after data have been produced to begin data analysis can be problematic as then the researcher may have precluded or made difficult certain types of data analysis. For example, during data analysis the researcher will typically discover and notice unanticipated issues that have arisen early in the data production and cannot be pursued in any depth during the data analysis. Holiday (2001 cited by Henning, 2007:15) recommends that a researcher select analysis procedures that are appropriate to the methodological position of the study and consistently and coherently manage the analysis (and interpretation) process according to the principles of design.

In the light of these considerations, content analysis seemed the best method to use for analysing data. As Ezzy (2002) argues, content analysis allows a thorough analysis of the content of the data. It is the most deductive of all forms of data analysis, and it begins with predefined categories based on the unit of analysis and the categories into which these will be placed. These are then interpreted through the help of the literature (see Chapter 5). Content analysis is useful for confirming or

testing pre-existing theory, but it is not very useful for building new theory, and restricts the degree to which the data can "speak to the researcher" and the extent to which the "other" can have a voice within the research (Ezzy, 2002). For this reason thematic analysis was considered next as it allows categories to emerge from the data (Ezzy, 2002). Thematic analysis is a more inductive methodology, and it is more sensitive to emergent categories and interpretations. Another benefit is that it can also be used in conjunction with content analysis.

Ezzy (2002) notes the advantages of content analysis for novice researchers. It can be useful as a stage of data analysis which helps the relevance of pre-existing theory to be tested, and it can be used as a way of assessing the applicability of a theory that emerges during thematic or content analysis. The skills acquired through learning to conduct content analysis provide a basis for more inductive forms of research such as thematic analysis.

Babbie and Mouton (2001) recommend unique analytical strategies which they recommend as best suited specifically to case study methodology (Babbie & Mouton, 2001). They recommend starting with at least the following questions and issues, namely: 1) how the findings will be organised, 2) whether generalisation is appropriate to case study data, and 3) the issue of theory development.

According to Babbie and Mouton (2001), while organisation of case study findings is a serious challenge, given the amount of data produced for each study, this can be tackled by developing clear conceptual categories for the empirical data, which in turn provides a focus for the findings, this step incorporates content analysis. According to Patton (1990), the discussion of the categories of the findings is separate from the presentation of the findings (Babbie & Mouton, 2001). In organising the data, the research report (as also noted as the seventh step in Kvale's (1996) interview process mentioned above) must account for the multi-dimensionality of the findings, which is done by presenting the multiple patterns of phenomena and by describing the context and conditions under which the patterns appear (Babbie & Mouton, 2001:283). This step also forms part of constructing the final case study narrative (Patton, 2002). According to Yin (1994 cited in Babbie & Mouton, 2001:283), the way to achieve this is encapsulated in two crucial modes of case study analysis, pattern matching and explanation building.

In pattern matching, patterns emerging from the data are compared with patterns in the theory. Where these patterns match, the study can be assumed to have enhanced internal validity. Explanation building refers to a specific kind of pattern building where the idea is to generate explanations about the case.

Therefore, in careful consideration of the literature on data analysis and case study, data were analysed using a combination analysis specific to case study method, integrating the above mentioned strategies of analysis such as content and thematic analysis within a simple layered approach. Bearing in mind the case study design principles described in the sections above, the three step process of constructing case studies as outlined by Patton (2002) was then implemented. In the first step, the raw case data were assembled using the data production techniques. In the second step, a case record was constructed using the basic technique of content analysis mentioned above to form the original set of start codes, whereby various concepts were coded (see Addendum B). In the third step of Patton's (2002) three step process, a final case study narrative was written based on more in-depth coding. This coding develops naturally from the content analysis into thematic analysis, as described above and that can be seen in Addendum B and tables 4.1, 4.2 and 4.3. This step developed then into pattern matching and explanation building, recorded in Chapter 5. The presentation of the findings is done in Chapter 4.

Substantive significance

Patton (2002) acknowledges this important responsibility, and advocates that it can best be managed through responsible efforts at uncovering patterns, and themes, and determining what is significant and meaningful in the data. Although the data analyst may argue for substantive significance in presenting findings, readers and users of the analysis will ultimately make their own value judgments about their significance. If the analyst is able to address three kinds of questions, as outlined in the section below, then attempts at determining substantive significance can be considered as worthwhile.

Since qualitative analysts do not have statistic tests to tell them when an observation or a pattern is significant, they must rely on their own intelligence, experience and

judgment to answer the first question of how solid, coherent and consistent the evidence is, in support of the findings (Patton, 2002:467). Secondly, analysts should take seriously the responses of those who were studied in answering the question as to what ways the findings deepen the understanding of the phenomenon studied. Thirdly the researcher should consider the reactions and responses of those who read and review results, in answering to what extent the findings are useful to the purpose of the study and consistent with other knowledge (Patton, 2002:467). Therefore, where the analyst, those studied, and reviewers can all agree, one has consensual validation of the substantive significance of the findings (Patton, 2002). This issue is addressed more fully in Chapter 5, along with triangulation to avoid bias.

3.8 ETHICAL CONSIDERATIONS

Ethical considerations are essential to research methods (Ruane, 2005). The ethics of science concerns what is wrong and what is right in the conduct of research, and because scientific research is a form of human conduct, it follows that it has to conform to generally accepted norms and values (Mouton, 2005). In keeping with codes of conduct developed by the scientific community, and more specifically the behavioural discipline of psychology (which frequently studies 'vulnerable' populations such as children, and persons with disabilities, e.g. Down syndrome) as mentioned in Chapter 1, Ruane (2005) outlines four primary ethical considerations, which help to ensure that the rights of such groups are protected, The way in which these were taken into account in this study are carefully discussed and outlined in the paragraph below.

Ruane (2005) stresses that the research should not cause emotional, physical, and verbal or any other form of harm whatsoever to the participants in the study. There are other ethical responsibilities. These include carefully respecting the time, and personal boundaries of the participants; both by means of careful communication, physical actions, as well as through appropriate, relevant and verbal wording. The informed consent of subjects should be obtained through written permission forms. These must thoroughly explain what will be expected of the subjects, and give a brief outline of the goals and purpose of the study. Mouton (2005) emphasises that the privacy of subjects must be respected either through anonymity or the possible

removal of identifiers. Furthermore, the subjects must be made aware of the full implications of their identity being revealed to the research world before they agree to do so. They must also have the right to refuse to be interviewed or complete questionnaires or forms. In sum, as Ruane (2005) points out, a conflict of interests should be avoided. The motivation of the research participants should be carefully noted and taken into careful consideration. However, as Mouton (2005) argues, it is not always so easy to avoid a conflict of interest, especially when what is right for one person is not necessarily right for other people, and he notes that in many cases, ethical choices often involve trade-off or compromise between the interests and rights of different parties. Nevertheless, the scientist's right to search for truth must never be pursued at the expense of the rights of other individuals in society (Mouton, 2005).

While Ruane (2005)'s four primary ethical considerations mainly refer to the direct interaction with the subjects of the study, Mouton (2005) also emphasises ethical considerations pertaining to the practice of science, regarding society at large, as well as the environment science, referring to the moral commitment that scientists are required to make to the search for truth and knowledge.

Mouton (2005) details how adherence to the scientific imperative translates into a number of specific rules or conventions including objectivity and integrity in research: researchers should adhere to the highest possible technical standards in their research, be careful to indicate the limits of their findings, and the methodological constraints that influence the validity of their findings, and are further obliged not to misinterpret their results in any manner. Consequently, fabrication or falsification of data is one of the most serious transgressions of the scientific code of ethics. Ethical considerations in terms of recording data imply that researchers should at all times be prepared to disclose their methodology and techniques of analysis. After completing their own analyses, researchers should ideally make raw data available to other scientists except in cases where the client's rights to proprietary information and privacy would be violated, thus it is the ethical responsibility of the researcher to record data in a durable and appropriately referenced form. Each publication must contain appropriate reference to the contributions made by all participants in the research, and one of the key ethical principles of scientific publication is that one

must acknowledge one's sources to avoid plagiarism, just as Mouton (2005) is being acknowledged as a source here.

According to Mouton (2005), the most important principle that guides the relationship between science and the rest of society is that of accountability. For example, there is a general obligation to conduct research in a socially responsible manner. This implies that there is a responsibility to the funders and sponsors of research: scientists have a responsibility to report their research findings resulting from public funding in a full, open and timely fashion to the scientific community. Society frowns upon secret or clandestine research because it undermines the commitment to public accountability

3.9 RELIABILITY AND VALIDITY

Even though the results are not generalised to a larger population, reliability remains important to the study because the results can be generalised to theory and literature outlined in Chapter 2 (Patton, 2002). The standard of reliability within this study further refers to the consistency, in which the information was documented (Yin, 2003). Validity is equally important and relevant to the study. Burgess (1984 cited in Babbie & Mouton, 2001) sees two main considerations of validity in case study research as authenticity (on the part of the participant) and distortion and deception (on the part of the researcher). The second consideration is related to the likelihood that the researcher may hold certain assumptions or prejudices that may influence the questioning and selection of material, thereby contributing to the limitations of the study.

In any scientific research there are bound to be legitimate limitations to the research, which should be carefully taken into account. Using a case study methodology also implies its own characteristic set of 'potholes' or natural disadvantages as outlined briefly in the section on methodology. Each of these 'potholes' or disadvantages outlined in the sections above has the potential to negatively affect the validity of the research. As a novice, and relatively inexperienced researcher, there is perhaps a natural relationship between enthusiasm for the research and a tendency to be a little naïve about what is involved in taking these limitations into serious account. For example, in consideration of each possible limitation, there is a strong, and perhaps

naïve, tendency to find another piece of literature and research to justify why a particular limitation cannot seriously be considered as limiting, or in seriously weakening the validity of the study. This subjective attitude on behalf of the researcher is arguably the largest limitation worthy of consideration within this study.

The subjective attitude of the researcher is also referred to as observer bias. Shaughnessy et al. (2000) underline how biases in data collection understandably lead to incorrect interpretations of study outcomes. For instance, interpretation of an outcome solely based on the subjective impressions of the observer can be a serious weakness, and can negatively affect the validity of the case study. King (1996) proposes a way in which this observer bias can be addressed through building what is known as the reflexive self. According to Mead (1994 cited in King, 1996:175), reflexivity is described as the "turning back of the experience of the individual upon her or himself". In this way awareness of possible biases is far more likely to occur and ever increasing opportunity is created for potential biases to be prevented. According to King (1996), the socially situated researcher enters a potentially endless cycle of perceptions, interactions, and spiralling dynamics. This is also a necessary part of the process of the successful "explanation building" style of analysis which refers to a specific kind of pattern building where the idea is to generate explanations about the case, particularly as reflexivity can be used as a source of insight (King, 1996). Reflexivity is integral within the paradigm of social constructionism, interpretivism, and social epistemology. Researchers are increasingly encouraged to become aware of their feelings, biases and "personal peccadilloes" and to scrutinise these closely (King, 1996:176).

Since extraneous variables are often not controlled and several factors or "treatments" may be applied or influenced, researchers are not always able to make valid causal inferences using this method, and thus "deception" becomes possible (Shaughnessy et al., 2000). For example, it may be difficult to ascertain exactly which factor or combination of factors enabled the employment experiences. However, according to Kratochwill (1992), numerous tactics can be used to advance understanding of contributions of case studies and draw more valid inferences from the investigation (Kratochwill, 1992). Fortunately, within this study the causal factors

relating to the adult with Down syndrome's employment experiences are not the main aim of the research.

With regard to the first consideration of authenticity (Burgess, 1984 cited in Babbie & Mouton, 2001), it is important to recognise that the participants may lie by presenting a false front or trying to impress the researcher in some way. Working on the assumption that a true reality exists, yet is elusive due to natural human bias, the interpretivist researcher strives to more accurately construct the life world by using varieties of data, and methods of analysis, and different sources or different viewpoints (Henning, 2007). In this study, information on the employment experience of an adult with Down syndrome's was gained from three different sources, namely family members, and work colleagues, and not only the adult himself.

Case study as a methodology reflects the interpretive approach in that it requires multiple data production techniques. A variety of techniques were used in order to strengthen the validity of the study, and eliminate deception, in order to capture the full case in some depth, the aim of the research (Henning, 2007).

3.10 SUMMARY

In this chapter the interpretivist research paradigm in which this study is situated and its impact on the research design and methodology of this study, including the ethical considerations in social research, were discussed. A full description of the way in which the research data were produced, approached, analysed was also given. This included issues of reliability and validity. The intricate working relationship between these research sections and its relevance to the quality of the study was also briefly explored.

In the next chapter a detailed discussion on the results of the study will be presented.

CHAPTER 4

IMPLEMENTATION OF THE CASE STUDY

4.1 INTRODUCTION

In this chapter the implementation and procedure of the study are presented. The physical setting and the nature of the case are contextualised and then the adult with Down syndrome is introduced and contextualised within the study, through a description of relevant background information, mainly from the information of parental interviews, questionnaires and documentation, as recommended by Stake (2000 cited in Mertens, 2005). The implementation procedure and process of the study are discussed in comparison to the literature, with ongoing attention to the process of reflexivity as well as careful analysis of the data (Patton, 2002; Henning, 2007). Findings are then discussed, summarised and presented with diagrammatic representation of several emerging themes.

4.2 CONTEXTUALISATION OF THE CASE STUDY

The study was conducted at an industrial factory warehouse that packages imported food. The packaging factory unit forms part of one of South Africa's large national food companies, and the unit warehouse pertaining to this study is situated near a large shipping port. The food company is listed on the stockmarket. It forms part of the formal economic sector, and permanent employees receive the employment benefit of being made shareholders in the company, amongst others.

The factory unit currently employs about 85 factory workers per 12 hour shift, up to two shifts per day on most days. Day shift times are from 6:00 to 18:00, and night shift is from 18:00 to 6:00. All workers are employed on a full time basis, but not all of them have permanent jobs. The management and supervision structure comprises a floor supervisor, a manager for that shift section, and a general manager for the entire unit as a whole. The main factory floor is divided into various packaging sections and there are also two different packaging departments. There are various

smaller sections and departments involved in the overall functioning of the factory, but they do not necessarily have a direct connection with the factory floor.

Trucks bring the imported foodstuff from the docks, where it is offloaded from ships, to the factory warehouse. Employees are then responsible for checking the quality of the foodstuff as well as packaging and packing orders of foodstuffs for national distribution.

Employment is subject to a selection process, during which candidates are interviewed according to set criteria. The company follows employment policies and labour laws which require it to observe certain employment guidelines. It also contracts outside consultants to put in place structures and implement operational strategies to improve communication between the company and the workers, thus protecting the rights of both the company and the workers. The company has also made efforts to create a culture of understanding, and acceptance amongst its employees by co-operating with and welcoming the support of the Down syndrome Association and their outreach spokesperson.

4.3 CONTEXTUALISATION OF THE ADULT WITH DOWN SYNDROME

4.3.1 Context of family

Chinton is a 27 year old adult with Down syndrome. He is the middle child of three children. He has an older sister who is two-and-a-half years his senior, and a younger who is about two years his junior. His father was 23 and his mother was 22 years old when he was born, and his maternal grandmother was well under the age of 30 when his mother was born. Both his parents are from large families and there are no other known relatives with Down syndrome. Both his siblings have subsequently married and have each started their own families. Chinton lives with his father and mother in a suburban area of average socio-economic status. His sister and her son were also staying temporarily in the family home during the time of the study while she was looking for a new change of career. His mother is a house wife and both Chinton and his father work full time in the factory. Chinton works on the factory floor doing shift work, while his father works in a separate and different

department, doing more senior office management work and working more regular office hours.

Chinton's family are English speaking but his father is also fluent in Tamil, which is also spoken in the community. He learned this from his father, the only one of Chinton's grandparent who came directly from India. The family are practising Hindus. They belong to what is considered in South Africa as a previously disadvantaged cultural group. Opportunities for education and upliftment, particularly for Chinton's parents, were limited as a result. While Chinton was growing up, the family lived in lower socio-economic areas. At that time, his father was slowly developing his career in the factory, having started in a job very much like Chinton's, a worker on the factory floor.

4.3.2 Type of Down syndrome

Chinton's mother took him to the local clinic when he was eight months old, as she noted that he was not turning around or holding his bottle as his sister had done. The sister in the clinic noticed his hands and referred his parents to the child specialist who did several blood tests and informed them at the time that he was a Mongol baby. It was only later that his parents began to discover that this meant that he had what is known as Down syndrome. Only when they began to learn more about what that meant, did they find out that Chinton had the uncommon Mosaic sub-type of Down syndrome.

4.3.3 Developmental Details

4.3.3.1 Physical

Chinton's mother had a normal pregnancy and birth with Chinton, carrying him to full term, and there were no complications. He was quite sickly until he was about two-and-a-half years of, frequently getting colds and ear infections, and then he seemed to grow out of them. His mother noticed some developmental delays at eight months (see 4.3.2). His motor development was delayed, as he sat for the first time, at 10 months (two months late), crawled at 14 months (four months late), and took his first steps at 18 months (four months late).

4.3.3.2 *Schooling*

Chinton went to a mainstream pre-school with his younger brother. At the age of five, he went to a mainstream primary school for a few months. Shortly after he began at the primary school, he was seen and assessed by the school psychologist. He strongly recommended that Chinton be placed in a special school. Arrangements were then made for Chinton to be placed in a training centre for the physically and mentally challenged in a town, where the family were living at the time. He stayed in the trade-school until he was 16 years old. Shortly after that, the family returned to their previous nearby home city. He then had a gap year, living at home before his father found him employment at the factory, where he has been working ever since.

4.3.3.3 *Language and speech development*

Chinton's speech can be relatively difficult to understand. He struggles to say certain sounds, and often leaves out certain linking words from his sentences. At times, with the help of a trained ear to interpret what he is trying to say, he can be far more easily understood. He is able to communicate the main point of what he is trying to say almost all of the time, and is able to seek help from his support structures if and when he is struggling. He does sometimes find it difficult to express himself clearly in work meetings when there are many people talking already. Chinton's speech was the most significantly delayed of his development, and he could not speak fluently until well after he turned six. Before that, he used to have to mime his words. His parents arranged extensive speech therapy through his school, which greatly assisted his speech development.

4.3.3.4 *Emotional and social development*

Chinton is known by family, colleagues and supervisors as someone who makes friends easily. Although he went to a special school, he was included and involved in local neighbourhood and mainstream community events at the time, including sports, balls, and fundraising events. He made new friends with others in the neighbourhood, who had attended a mainstream school, with relative ease. They do a variety of activities together. Chinton says that he does not really have friends at work. Yet, his floor supervisor says that he has lots of friends, as he jokes and socialises with his colleagues during work breaks.

Chinton has had to overcome emotional challenges, brought about during transition periods in his life. His father has previously sought professional assistance during these transitions, which has helped in dealing with emotions of defiance and being easily emotionally influenced and affected by others, and understanding them better. On very rare occasions, Chinton sometimes used to struggle to find appropriate ways of managing emotions of anger when provoked. This led to one notable incident, in the nine years that he has been with the company, where he was suspended from work as a result. Chinton subsequently attended a hearing where he was then reinstated. Chinton's father sought professional medical assistance, but no specific medical reason was found, that could explain the behaviour leading to the incident other than a diagnosis of Down syndrome and intellectual disability. Chinton was placed on daily medications of 1mg of Respirdal and 50mg of Serlife to assist him to control his emotions. No side effects have been noted subsequently. The Down Syndrome Association outreach spokesperson went into the company to help educate colleagues about how to better understand and accommodate intellectual disability, and Down syndrome and suggested practical ways to them and Chinton in which to avoid incidents that could lead to suspension. No further problematic incidents have since been reported.

4.3.4 Quality of life

Chinton has a relatively high quality of life across several areas. On the personal wellbeing index developed by R.A. Cummins & A.L.D. Lau (2005), he rated generally very happy overall. Good general quality of life was also indicated, with a relatively high self-reliance, despite living at home with his parents. He has a high degree of independence, especially evident in his being able to drive himself to work or wherever he wants to go in his own car. His work and regular outings with and visits to friends give him a sense of belonging. Chinton also shows he is capable of having good relationships with others, including having a girlfriend.

4.4 RESEARCH FINDINGS AND PROCEDURES OF STUDY IMPLEMENTATION

4.4.1 Interviews

Doing the interviews was somewhat challenging. Originally I had planned to interview Chinton, his parents and his work supervisor using an interview guide based on the research questions and aims (The planned interview guide is attached in Addendum C). However, after arriving at the factory, and observing the set-up, it became apparent that Chinton had more than one work supervisor. In fact there was a line function of supervision and management. Each person in the line was found to play an important role in affecting his employment experiences.

Chinton's floor supervisor was the person who had the most experience in directly observing his general functioning in his employment, as well as his interaction with colleagues and peers on the factory floor. Chinton's floor manager was the person who had the most knowledge about aspects such as his training, general performance, future potential and general management of his abilities and skills within the factory. It was also found that the general manager of the unit had a vital role to play in that he had made accommodations for Chinton to be successfully employed, including encouraging support. It was then further discovered that the Down syndrome association outreach co-ordinator had also played an important role in supporting Chinton's employment through giving support to him, colleagues, managers, and supervisors within the company. All of Chinton's managers were found to be directly involved in his selection to become employed, and in assisting with managing and overcoming various work challenges as they arose. They were also found to be working to foster a culture of acceptance and belonging in the work place, through adopting attitudes of acceptance, and working to encourage outside support, education and communication. In order to meet the aims of the study, timely adaptations had to be made to accommodate and invite each new relevant person to participate in the study. As a result, interviews were frequently done at short notice. They had to be fitted in between work duties, and with several interruptions taking place in the form of background factory noise and other general factory disturbances. Interviews started off with a "scene setting phase" as described by Henning (2007) in which the research topic and aim as well as the role of each specific role of the interview in the research was clarified. Interviewees frequently had their own unique

information, which they felt was relevant to share, so the interview guide often had to be abandoned in order to adapt to new relevant information. Summarising, clarifying, and reflecting were used as tools to check that my understanding corresponded with each interviewee (Henning, 2007). Fortunately each additionally relevant person to the study was willing to participate at short notice, and was equally accommodating.

Chinton and his parents were interviewed during visits to their family home. Chinton's parents, particularly his father, were very forthcoming and provided useful and relevant information for the study. They could frequently give additional relevant information. In a short space of time I felt that I had succeeded in establishing a strong rapport and deeper trust relationship; Chinton's family were very hospitable and accommodating. According to Johnson (2002 cited in Henning, 2007), this is the kind of relationship needed for in-depth interviewing. This was an advantage in that not only did my experience as a researcher become more meaningful, worthwhile and special to me in my own personal capacity as an individual, but it also meant that the conversations with Chinton's father developed far more naturally than with some of the other participants, and he allowed me the privileged access to a rich variety of relevant information. The only disadvantage was that the in-depth nature of the interviews with Chinton's father generated over two hours of recordings, and over a hundred pages of transcriptions. Although this was initially rather daunting, it did make richer description possible.

Chinton made several efforts to be very accommodating during the interviews. However, the first interview with Chinton was particularly challenging as I did not have much experience of interviewing individuals with intellectual disability. I sometimes struggled to formulate some of the questions clearly and simply, and so I found that he occasionally battled to understand me properly, and would then give me answers that were not relevant to the study. I also did not know what answers to expect from Chinton. As a result, I did not always know how to formulate the questions in a way that would successfully prompt him to talk about the topics that were relevant to the study. The second interview was a little easier, as I had received some tips from his father as to how to appropriately adjust my questions, as well as the manner in which to deliver the questions. I had also had more practice in how to understand his speech a little better.

A summary of the interviews reads as follows:**a) *Floor manager***

The interview with Chinton's floor manager revealed that Chinton has been working with him on his shift for about three years, when a management decision was taken to move him there after there were some problems on another shift. Chinton had kept reporting these to the previous manager, but no response was taken. Extra support was subsequently enjoyed from the Down syndrome Association. Since he has been on the new shift there have been no problems. The floor manager has an understanding and supportive attitude toward Chinton. He respects Chinton's work ethic and good housekeeping, and says that Chinton does pretty well. Chinton has good support from his colleagues, who include him socially. He is treated as an equal as he even went through a selection panel like everyone else. He works on a shift with 84 other workers. Chinton's quality of life and general functioning was seen by the floor manager as above average and excellent, especially due to his strong parental support.

b) *Unit general manager*

Chinton is seen by the unit manager as an asset to the company; he has a good attitude to his work, and is a responsible employee. Although there have been conflicts these are seen to be minimal. His colleagues have been very supportive. The company has arranged meetings with the help of the Down Syndrome Association to help educate his colleagues and create better understanding of Down syndrome. Encouraging the awareness and acceptance of colleagues has been seen as the biggest factor in his successful employment. The manager is aware that the Association wishes to bring in more people with intellectual disability for employment opportunities and is willing to accept them.

c) *Down Syndrome outreach co-ordinator*

The Unit manager is seen by the outreach co-ordinator as having been very involved in the success of Chinton's employment, including his assisting him to overcome various challenges in the workplace. Management has generally treated Chinton like any other employee, and he has to meet the demands of his job. The combination of

Chinton's ability to reach for support through his ability to communicate and his colleagues' willingness to support him has been important. Chinton was not employed just to meet the equity act, although it was a benefit to the company. An incident leading to Chinton's suspension created a welcome opportunity for the association to lend assistance: both Chinton and his colleagues were given skills to deal with conflict situations, and his colleagues were better able to understand and manage working with intellectually disabled colleagues. The incident, where Chinton resorted to physically hitting a colleague was seen as resulting from difficulties with verbal expression in conflict situations, common in individuals with intellectual disability.

d) *Floor supervisor*

The floor supervisor said that he enjoys working with Chinton because he is very responsible; he has no hassles with him. Chinton also does not need extra supervision. Chinton has received a lot of support and acceptance and gets on well with his colleagues. The Down Syndrome Association have sent people in, who have helped to give advice. The floor supervisor has tried to facilitate the way both his colleagues and Chinton treat each other through careful management of their expectations, as he observes their interactions. When Chinton was suspended from work, due to an incident, the union spokesperson did not want to represent him for racial and cultural reasons. He considers that Chinton leads a normal life.

e) *Chinton's parents*

Chinton's parents gave valuable information on his development, health and schooling which has been discussed and outlined in the sections above.

Chinton has exceeded his parents' expectations, in that they never anticipated that he would be able to drive or become employed with such success. Although Chinton's father in particular played a large role in Chinton's employment, he is still deeply appreciative of the company's efforts to accommodate him. Chinton's parents are very proud of their son's employment and financial achievements. They are especially proud of his level of responsibility, level of independence, and attitudes of respect for and empathy with others. Chinton's parents believe that he has greater potential, capabilities and leadership skills than what the company is currently able to

recognise, yet believes that he will still be given opportunities for development, with improvement in technology, which would then lead to a greater job satisfaction. They are proud of his dreams and goals of having his own company and assisting other individuals with disability, and would like to see Chinton married one day to someone who can assist him in his weaker areas and have a family of his own. Chinton's parents have been supportive in helping Chinton to overcome challenges. There has only been one really major stressful challenge at work, where he was suspended due to an incident which occurred shortly after he had been made a permanent employee. That was when he had been working for the company for 5 years. Chinton was seen as being provoked by colleagues, who resented him for being made a permanent employee over them, especially as he had a disability and they did not. His parents also took the view that if the manager in charge of Chinton at the time had responded more effectively to these dynamics of resentment at the time, then the conflict situation could have been avoided. However the manager at the time was seen as ill-equipped to handle the situation, due to an unsupportive attitude and a lack of empathy and understanding of individuals with intellectual disability. They are pleased that he was moved to a work under a more understanding manager.

f) Chinton

Chinton feels a sense of belonging and pride in his employment, and achievements. He does not seem to find his ability to drive surprising, and is most pleased that he made the selection as a permanent employee. He is also proud of his knowledge and skills, adaptability to different kinds of work, and ability to work hard. He is relatively happy in his job yet would like to move to a more challenging and rewarding job, with greater responsibility and job satisfaction; he takes his work very seriously. He does not find the long working hours a strain, but occasionally he has had physical pain, such as back pain from the physical labour. He gets frustrated when people do not treat other people fairly, including himself, and has felt discriminated against, at work, when his previous manager allowed colleagues to mock him, by calling him stupid and saying that he could not get paid like them because they had heard he had Down syndrome. Chinton says that was when he was suspended. Colleagues had physically provoked him, saying it was horse play,

while they teased him, and he had retaliated in order to defend himself. Chinton was proud that he was able to defend himself at the hearing, and was most pleased to be reinstated and to have a new floor manager that he feels understands him. Chinton enjoys hanging out with his friends on weekends. He especially enjoys conversations with his girlfriend, and would like to get married one day. Chinton scored very high on the quality of life personal wellbeing index (Cummings, 2005)

4.4.2 Observations, videos and recordings

Chinton, his parents, sister and nephew, work colleagues, supervisors, managers, and the Down Syndrome Association spokesperson, were visited between Chinton's home and his work, over the course of two full days. The largest amount of time was spent with Chinton's dad who acted as my main host. He introduced me to each relevant and willing participant and assisted with arrangements. After interviewing Chinton and his parents at his home, I accompanied Chinton to the factory where he was going to do the night shift. Chinton ensures that he arrives at work early, which meant that he had time to show me around the factory before he officially started his work. This information was verified by his managers, and his father. I observed that Chinton looked very proud to show me his place of work. He also looked proud to show me his knowledge of company policies, and safety equipment, as well as showing me the clock-in station, and his pay slip, as a permanent employee. After showing me the packaging machine, and the set-up at his work station, Chinton then introduced his colleagues and floor supervisor on duty. Once the employees had settled into work, and the machine operator in charge, had received the job card, the machine was switched on, and the work for the shift began. I observed that Chinton worked with eight other colleagues at his work station. Each of them was responsible for a particular task to ensure that the machine would run smoothly and manage the packing properly. This team of nine worked on a machine in a smaller section of the factory, which is involved with in packaging smaller amounts of foodstuffs than in other sections of the factory. Chinton is the final person in the machine operating line, and he places stickers of production stock numbers on to each 20kg food package, and then he uses his physical strength to strategically load the packages so they fit on a palette. The floor supervisor, showed me the larger sections of the factory floor, and I observed that the packing in those sections was a great deal

faster, and there were up to five times as many people working together on the floor in those sections at any one time. I also observed that once the machines were switched on, all of the factory workers were busy with their specific tasks. The only person who was not working on the machines was the floor supervisor, as it was his responsibility to walk around and oversee everything, and to deal with challenges as they occurred. This made it easier for me to observe these general work tasks as a complete observer, as most individuals in the factory were focused on their set task, and not on me.

I also observed that Chinton's father often acts as the dominant spokesperson, even speaking on behalf of his wife, and is an involved member of his family, and community. His father also frequently expressed many of his strong family values, and gratitude to the grace of God as an active presence in his life.

Video recordings of Chinton's employment experiences in the factory were allowed, subject to the approval of the general unit manager. All the participants gave their permission for their interviews to be both video-taped and recorded. Some of the participants found that they felt a little uneasy in front of the camera at first, yet I observed that they felt increasingly more comfortable as they got more used to it. Most of the time the participants verified the information that others had given. Only on a few occasions did participant give responses that appeared to contradict what others had said. I found it a challenge to move the camera around and set it up at short notice. Sometimes the voice of the participant was muffled by the background factory noise. Fortunately, I was able to access a quality digital voice recorder, for the study. This instrument was extremely mobile. It was small enough to be relatively unobtrusive, and could make very good quality voice recordings despite the background factory noise, allowing more flexibility and adaptability when recording the interviews spontaneously.

4.4.3 Additional relevant documentation

Chinton's parents provided me with copies of his learner's license, and his driver's licence for verification. Documentation was provided of some of his employment benefits as a permanent employee including medical aid card and documents of his shares in the company. His parents also supplied documents based on

developmental amnesia questions that they had completed when he was still very young. They supplied photographs depicting his overall physical development, as well as social development with friends and activities, for further verification. Chinton's parents also showed me his current medications. Chinton's floor manager made a copy of his skills matrix available. This shows the training Chinton received at work and the skills he gained as a result of that training:

Employee Surname	Employee Name	Position	SHEQ / CORE																
			Safety Refresher	Safety Induction (Safety Consultant)	Fire Fighting	Fire Fighting Course	HACCP	Hygiene / Housekeeping Training (Jeeva)	First Aiders	First Aid Course (Paul)	Basic Quality	Basic Quality Course (Jeeva)	Literacy - Std 7	Literacy ABET Level 3	Numeracy - Std 7	Numeracy ABET Level 3	Forklift Licence	Forklift Drivers Course	Forklift Refresher
Smith	(B3) Andrew B	Systems Operator	2	2	1	4	2	2	1	4	2	2	1	2	1	2	1	4	
Smith	(B2) George M	Systems Operator	2	2	1	4	2	2	2	2	2	2						1	4
Smith	(A2) Stephen Chinton	Process Hand	2	2	1	2	2	2	1	2	1	2	1	2	1	2	1	4	4
	Skills	Cannot Perform	0		3		0		2		1		2		2		2		2
		Need Supervision	3		0		3		1		2		0		0		0		0
		Complies To Standard	0		0		0		0		0		0		0		0		0
		Master	0		0		0		0		0		0		0		0		0
		Currently Doing		0		0		0		0		0		0		0		0	1
	Training Intervention	Planned - next 12 months		3		1		3		2		3		2		2		2	0
		Next Plan		0		0		0		0		0		0		0		0	0
		Not Required		0		2		0		1		0		0		0		2	2

Points		
1		= CANNOT Perform (CAN ASSIST)
2		= Can Perform BUT NEEDS SUPERVISION
3		= Can Perform TO STANDARD
4		= MASTER AND TEACHERS

Points		
1		= Essential - Currently Doing
2		= Essential - Must do within next 12 months
3		= Plan for next year
4		= Not Required

FIGURE 4.1: SKILLS MATRIX

4.4.4 Field notes and reflections

Everywhere I went, I was warmly received and I felt that my presence was welcomed. Each participant seemed pleased to accommodate me, and seemed happy to informally 'slot me in' amongst their busy working schedule. I felt as though part of welcoming my presence reflected the sense of pride in the development of a culture and attitude of acceptance that both Chinton's company and his family feel that they have succeeded in bringing about. I felt as though my presence was a very minimal disruption to the working activities, especially as Chinton spoke to me in and around his daily routine. He went about his usual activities, including a casual 'pop-in' to the shop to buy airtime for his cell phone on his way in to work. I felt that most participants relaxed when they were with me in spite of the camera. They seemed only too happy to give what appeared to be a sincere account of their knowledge and their role in Chinton's employment experiences out of a dedicated support for Chinton. I also spoke very informally to some of Chinton's colleagues, who described working night shift as a struggle. They said that they did it because they needed the money. Each expressed the desire to be made permanent employees since this would bring job and financial security. I found the experience of visiting the factory, the family home, Down syndrome Association, as well as observing the employment experiences within the cultural, community and economic context, enlightening and enriching.

4.5 ANALYSIS OF DATA

Data is analysed according to Babbie and Mouton (2001) and Patton (2002:450) who describes the data analysis in a simple three step process (see Chapter 3). These three main steps took place during the production of this chapter, and will be referred to in sections to follow:

- 1) Assemble the raw data.
- 2) Construct a case record, whereby data is organised, classified and edited into a manageable file. (This step is optional, depending on the complexity of the case.)

- 3) Write a final case study narrative in a readable descriptive picture or story about a person or organization making all the information needed to understand the case in all its uniqueness accessible.

4.5.1 Issues in data analysis

As mentioned in Chapter 3, Data analysis should begin during data production, so that researchers do not miss the many valuable opportunities that can be made use of only at that time (Ezzy, 2002). Opportunities that came up during data production to develop relevant information through further verification and the use of multiple sources were explored through interviewing each relevant supervisor, manager and support person, as they were each introduced, and through the process of triangulation as discussed in the section below (Creswell, 1994 cited by Hill, 2002). An example of an unanticipated issue arose early in the data production. When the incident of Chinton being suspended from work arose, it was not anticipated that it would be mentioned by each interviewee. In pursuing the issue, it was discovered that this problematic incident happened shortly after Chinton had been made a permanent employee.

Mauthner and Doucet (1998) cited in Bleazard (2003) describe data analysis as critical in terms of having the potential to decrease or amplify the volume of the respondent's voices, and as such it can be a deeply disempowering part of the research since respondents have little or no control. I found this part of the research challenging, especially with regard to interpreting more complex issues such as the incident leading to Chinton's suspension, as there are many contributing factors to consider, as well as many perspectives on the situation. While the incident is an example of how challenges in the work environment were overcome, it was also only one incident. In analysing it and presenting a possible detailed understanding of it, one runs the risk of over-emphasising its relevance within the context of the employment experiences.

Since the overall goal of the data analysis is to gain an understanding of the adult with Down syndrome's experiences of employment, it is important to sustain the delicate subjective and objective balancing act of analysis of the data.

4.5.1.1 Substantive significance

Patton (2002) emphasises this important responsibility (see Chapter 3) and advocates that it can best be managed through responsible efforts at uncovering patterns, and themes, and determining what is significant and meaningful in the data, across three main questions. In answer to the first question of how solid, coherent and consistent the evidence is, in support of the employment experiences, I relied on my own judgement and what I had been able to observe about the employment experiences in deciding on the predominant themes (Patton, 2002:467). In answer to the second question as to the ways the findings deepen the understanding of the employment experiences, the responses of those who were studied were taken seriously, especially with regard to meaningful relationships developed collectively between individual participants, and in the depth of relationship which I equally experienced with Chinton's father in the short duration of the study. In answer to the third question as to the extent to which the findings are useful to the purpose of the study and are consistent with other knowledge, I took careful account of those who may read the results and of the literature review in my discussion of the findings in Chapter 5. Patton (2002) contends that there is rarely substantive significance through consensual validation of the substantive significance of the findings whereby the analyst, those studied, and reviewers can all agree. Perhaps with naïve optimism, I felt it would be possible to accomplish this in this study.

Within the perspective of reflexivity, I remained aware that readers and users of the analysis will ultimately make their own value judgments about their significance (Patton, 2002). However, in attempting to address the three kinds of questions highlighted by Patton (2002:467), it seemed worthwhile to strive for substantive significance.

4.5.1.2 Triangulation

The use of triangulation is assumed to neutralise any bias in different aspects of the research, including the data sources, investigator and methods (Creswell, 1994 cited in Hill, 2002). In my study, the use of triangulation was applied to the data sources as data were produced from the variety of respondents used, allowing for further

investigation of topics which were repeated, and allowing for greater opportunities to avoid bias, particularly parental.

4.5.2 Transcription

A total of thirteen audio recordings were used to record the interviews. One recording of the interview with the general unit manager, one with the floor supervisor, one of the floor manager, and one of the Down syndrome association outreach co-ordinator. Three recordings were made of the three interviews with Chinton. Three recordings were made of the three interviews with both of Chinton's parents, and three recordings were made of the three interviews with Chinton's father. Each interview was between five and fifty-five minutes in duration. The 13 interviews were then transcribed. This involved careful and repeated listening to recordings. Transcribing some of Chinton's more indistinct speech was especially challenging. However, after repeated listening, it usually became possible to comprehend what had been said as I became more familiar with certain sounds and words. Poland (2002) cited in Henning (2007) warns that despite the need for accurate transcription, the researcher should not see the script itself in isolation as a solitary text, but rather the interview should be viewed as an event, part of a process of contextual data. This is a particularly useful warning when transcribing more difficult text. Since almost all of the interviews were video-recorded, these interviews were also easier to interpret as all the cues were captured.

Chinton's experiences and responses as well as those of the other participants will be dealt with in separate sections in the themes that emerged from the data produced. I attempted to organize the interviews and observations around a list of start codes of employment context, work demands, supervision and support, treatment in the workplace, overcoming challenges, quality of life, meaning of employment, parental expectations, and schooling, training and development.

4.5.3 Process and procedures of analysis

Patton's (2002) simple three step process approach to data analysis, as outlined above and in Chapter 3, was followed. The first step was assembling the raw data. In this step I was careful to begin the research without a fixed initial set of themes and codes as I wanted the interviews to flow as naturally as possible. This reduced the

possibility of my subjectively influencing the responses through my questions, and expectations as a researcher. Instead I had an open-ended idea of which themes to be looking out for based on the research questions. I therefore had relatively open-ended expectations when approaching each interview. The advantage of this approach was that I was able to work inductively in accessing a variety of relevant data, which I may not otherwise have been able to uncover (Patton, 2002). The added advantage is that relevant data was also naturally verified by each interviewee. The disadvantage of this approach was that I also ended up with such a large amount of irrelevant and sometimes repetitive data that was time consuming to organize and interpret.

It was only in the second step of constructing a case record that an initial set of start codes was formulated. This second step was difficult to do as a written exercise; given that once the data were transcribed I had over two hundred pages of transcriptions. Instead I condensed the video file to make it more manageable. This involved careful listening to, watching and thorough editing of the video recordings of interviews and the employment experiences in the factory. The start codes were roughly drafted as main themes or headings in a printed version of a power point presentation. This printed version then served as a guideline for a brief and summarised video documentary of the case data (see Addendum D). Each heading on the printed page served to represent a scene or chapter within the video case record. At the time of compiling the case record of the video material, the aim was to skip this step two, of constructing a case record, due to time and resource constraints and go straight into the step three of a final case study narrative. The final case study narrative provides a readable descriptive picture or story about a person or organization, making all the information to understand the case in all its uniqueness accessible (Patton, 2002). Although, this may have been achieved to a certain extent, it was only after conducting further analysis that the initial codes were built upon, and the data presented, taking further considerations into account. Thus, the initial basic topics or start codes were developed from the research questions, research aims and the conceptual framework of the literature review (Miles & Huberman; 1994 cited in Bleazard, 2003), as follows:

TABLE 4.1: INITIAL START CODES

1)	EMPLOYMENT CONTEXT	EC
2)	WORK DEMANDS	WD
3)	SUPERVISION AND SUPPORT	SS
4)	TREATMENT IN THE WORKPLACE	TW
5)	OVERCOMING CHALLENGES	OC
6)	QUALITY OF LIFE	QL
7)	MEANING OF EMPLOYMENT	ME
	- For Parents	MEP
	- For Employer	MEE
	- For Chinton	MEC
	- For DS Association	MED
8)	PARENTAL EXPECTATIONS	PE
9)	SCHOOLING, TRAINING AND DEVELOPMENT	STD

Once the first step of assembling the raw data was completed and each interview was transcribed, the phrases or sentences that represented or illustrated a conceptual category were then coded.

4.5.4 Emergence of themes and areas

Whilst I had predicted some of the themes and areas applicable to the employment experiences, there were several themes that emerged in addition to the ones I had anticipated. The final set of areas, themes and codes that I used were as follows:

TABLE 4.2.1: CONCEPTUALISED AREAS OF EMPLOYMENT EXPERIENCES AND ASPECTS OF EXPERIENCES

A	B	C	D
AREAS OF EMPLOYMENT EXPERIENCES	CODE	ASPECTS OF AREAS	CODE
10) EMPLOYMENT CONTEXT	EC		
11) WORK DEMANDS	WD		
12) SUPERVISION AND SUPPORT	SS	<ul style="list-style-type: none"> • Parents • Colleagues • Supervisors • Management • Community • Self 	SSP SSCOL SSS SSM SSCOM
13) TREATMENT	TW		
14) CHALLENGES	CH	<ul style="list-style-type: none"> • What Challenges • Overcoming Challenges 	CHW CHO
15) QUALITY OF LIFE	QL	<ul style="list-style-type: none"> • General functioning • Independence • Payment, and benefits • Limitations • Social life • Relationships 	QLGF QLIND QLPB QLLI QLSOC QLREL
16) MEANING OF EMPLOYMENT	ME	<ul style="list-style-type: none"> • For parents • For employer • For Chinton • For DS Association 	MEP MEE MEC MED
17) EXPECTATIONS AND ACHIEVEMENTS	E	<ul style="list-style-type: none"> • For parents • For employer • For Chinton 	EP EE EC
18) SCHOOLING, TRAINING AND 19) DEVELOPMENT	STD		

DISCUSSION OF AREAS

The area of the employment context was important in providing background information on the employment experiences, observations, and physical setting, as required by Stake (2000 cited in Mertens, 2005). It was also important to the description of Chinton's employment context, in giving concrete explanations of his actual work experiences.

The area of the work demands was relevant to Chinton's supervisor's and parents, who provided background information on how well Chinton was doing in his work. This made it possible to build an understanding and appreciation of what he has accomplished in spite of the challenges of Down syndrome.

Supervision and support was an area that came up on numerous occasions. It was important to Chinton that he be understood. He received a variety of forms of support. There was supervision as part of general company structure, hence the reason for interviewing his supervising managers and floor supervisors. Chinton and his parents felt that the support was important to the success of his employment. These two terms have been grouped together as they were frequently used interchangeably in referring to his employment success.

Treatment came up as an area as it was important to Chinton that he be treated with respect. There were also times when he was discriminated against. Each of his supervisors noted that the supportive manner in which he was treated by his colleagues contributed further to the success of his employment experiences.

The area of challenges within the workplace was identified, particularly as Chinton, his parents, his managers and his supervisors noted that there were various challenges that had to be overcome in order to succeed in remaining employed. Two examples are an incident in the workplace and adapting to accommodate him.

The area of quality of life came up, as a result of several areas of independence and functioning as noted but almost all of the participants including Chinton himself.

The fact that Chinton had succeeded in being permanently employed held a lot of meaning for each participant, which therefore contributed to a worthwhile employment area in terms of the experience of meaningfulness and fulfilment.

Chinton exceeded many expectations through accomplishing many achievements. This area came up as each participant made mention of an expectation that Chinton exceeded or an achievement that they were proud to mention.

The area of schooling, training and development, was relevant in terms of how Chinton prepared for the employment context. Work managers and supervisors had information on his training and skills, and Chinton and his parents had background information on his overall schooling and development, which related to his employment performance.

TABLE 4.2.2: THEMES GENERATED IN AREAS OF EMPLOYMENT

A	B	C	
THEMES IN AREAS OF EMPLOYMENT	CODES	THEMES IN AREAS OF EMPLOYMENT	CODES
Independence	INDP	Asset	ASSE
Self-esteem	SEST	Opportunity	OP
Help	HELP	Lack opportunity	LOP
Self-reliance	SREL	Resentment	RENT
Health	HEAL	Problems	PROB
Friendships	FRIE	Expression	EXP
Fulfilment	FULF	Behaviour	BEH
Safety	SAFE	Dreams and goals	DG
Meaningfulness	MEAN	Abilities	ABIL
Financial wellbeing	FWEL	Self protection	SPRO
Driving	DRIV	Lack satisfaction	LSAS
Attitude	ATTI	Pride	PRID
Housekeeping	HOUK	Family	FAM
Capabilities	CAPA	Equality	EQUAL

A	B	C	
THEMES IN AREAS OF EMPLOYMENT	CODES	THEMES IN AREAS OF EMPLOYMENT	CODES
Skills	SKIL	Frustration	FRUS
Leadership	LEAD	Self-belief	SBEL
Belonging	BELO	Disability	DIS
Discrimination	DISC	Moving	MOV
Future planning	FPLA	Strength	STRE
Understanding	UND	Lack of Understanding	LUND
Structure	STRU	Dangers and Risks	DANR
Acceptance	ACCP	Respect	REST
Technology	TECH	Responsibility	RESP
Communication	COM	Accommodating	ACO
Support	SUP	Parental fear	PFE
Conflict	CON	Emotions	EMO
Success	SUC	Education	EDU
Moving	MOV		

The above themes were identified as occurring frequently across several of the areas. Each of the themes came from the content of the interviews. Independence, self esteem and self-reliance arose from the employment context, and across several achievements such as learning to drive, various skills, abilities and capabilities, as well as self-protection. Themes such as discrimination, lack of understanding, conflict, parental fear, and dangers and risks, were also generated out of areas such as challenges, across several of the interviews. Each of the themes originated as occurring frequently out of each of the interviews. For example, the way in which these challenges were overcome also generated further themes including responsibility, education, communication, technology, acceptance leadership and moving. These themes overlapped across several of the areas including treatment in the workplace, quality of life, and meaning of employment. A

further understanding of the themes and employment areas emerges from a discussion of the findings.

4.6 DATA DISPLAY



DIAGRAM 4.1: CONCEPTUALISED AREAS OF EMPLOYMENT EXPERIENCES

A diagrammatic representation of the themes and areas of the employment experiences is presented below. The areas of the employment experiences are presented in the boxes on the left with the arrows and the development of each of the themes is presented in the window boxes on the right.

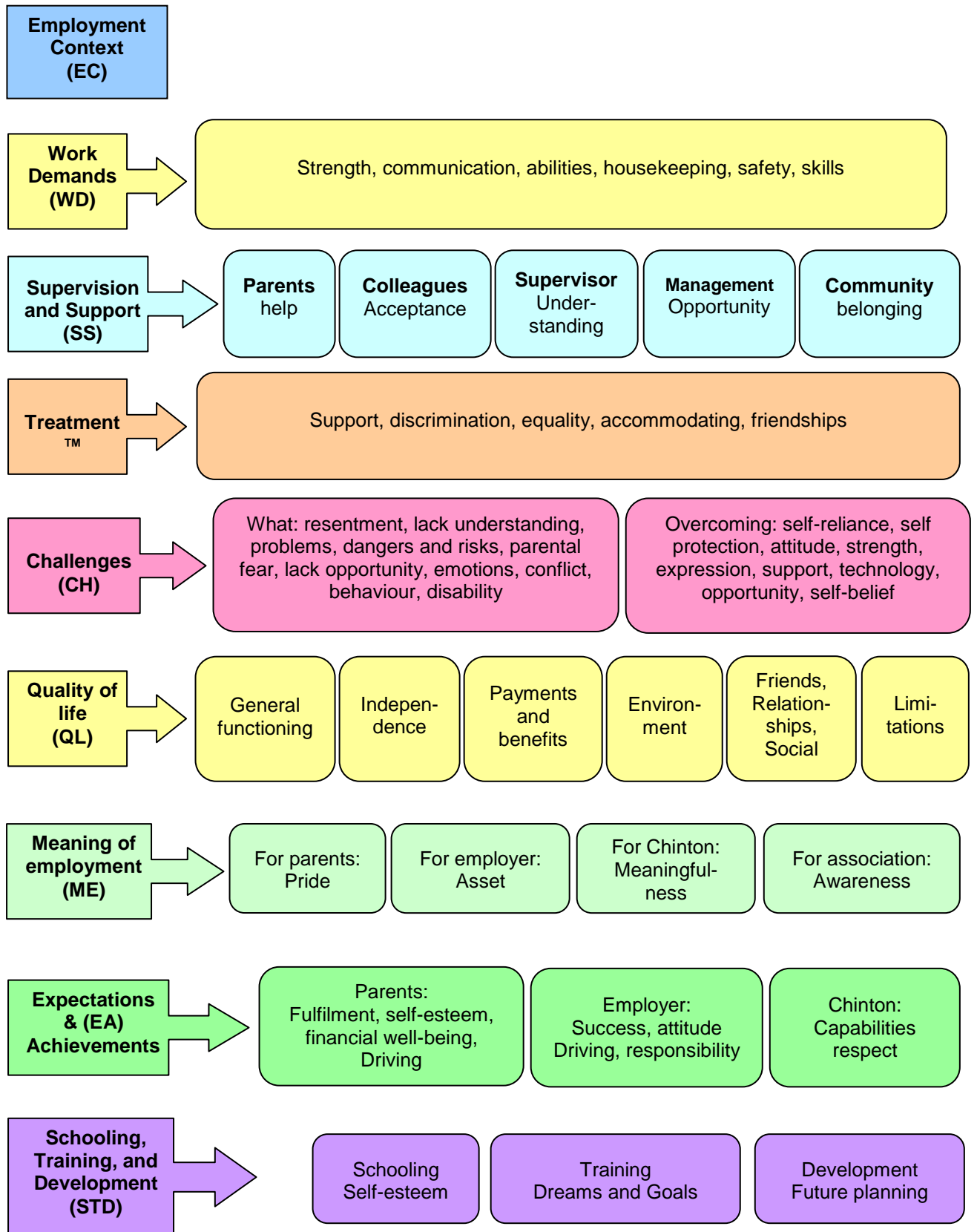


DIAGRAM 4.2: THEMES GENERATED WITHIN ASPECTS OF EXPERIENCE AREAS

These dominant themes were the themes which occurred most frequently in the information produced during the interviews relating to Chinton's employment experiences. Chinton, as well as his supervisors, parents and employers spoke frequently about values of responsibility, understanding and respect. There was a strong sense of pride amongst many of the participants, including Chinton, relating to the employment experiences and various achievements in and around the workplace. Chinton's self-protection skills were a common theme across participants, especially pertaining to examples of discrimination. Thus dominant themes across the employment areas were outlined as follows.

FIGURE 4.2: DOMINANT THEMES IN CHINTON'S EMPLOYMENT EXPERIENCES



4.7 DISCUSSION OF THE FINDINGS

Chinton's parents were first informed of his being a Mongol baby, when Chinton was eight months old, which would have been in 1981. In the literature review it was noted that the term 'Mongolism' was used interchangeably with Down syndrome as recently as 1978 (Newton, 1997; Wingate, 1972; Thomson, 1971). The findings differ from the literature in this regard as they indicate that the term was practically used by medical specialists in South Africa, in informing parents as recently as 1981.

R	<i>What did the specialist tell you? Can you tell me more about that?</i>
S2	<i>Mom: At that time many years back when we went back for the reading and the blood sample he told us that it was a Mongrol baby that we didn't know at the time.</i>

Since, the literature reveals that use of the term 'Mongolism' as first named by Down in 1866, who had noted that this group of people was a sub-species of the human race (Newton, 1997; Pueschel, 1999). The literature has established that the use of the term is indicative of the paradigm of older traditional medical models that are not always culturally sensitive, or humanitarian by nature (Newton, 1997; Swart & Pettipher, 2005). These findings are therefore consistent with Chinton's parents' experiences of a lack of support or a culture of understanding, in the area at the time.

S1	<i>Dad: We had no prior knowledge or members of the family who had similar features that we could differentiate to us he was just a normal baby and only after Dr Naidoo the child specialist looked at him and said to us that he's a Mongrol and even then he still didn't trigger off as what specifically that meant or show me what to expect – just in simple terms that he is a Mongrol baby and so then onward from there we tried to find our way around it.</i>
R	<i>Okay.</i>
S1	<i>And we took it upon ourselves to get more involved and find out exactly what is the meaning of this and what to expect from now onwards to set our path open for him and find more information and support group. At that point in time there were no support groups that we came off from that and we had to find our own way around gathering information at the time.</i>

The literature indicates that there is scientific evidence in support of the incidence of Down syndrome as increasing significantly in children born to mothers aged 35 and older (Kirk, Gallagher & Anastasiouw, 2000; Newton, 1997; Malini & Ramachandra, 2006; Christianson, 2004; Thomson, 1971; Molteno et. al., 1997). However, Chinton was born to his mother when she was 22 years old. Maternal age was, therefore, not

a factor in Chinton's case. Although, the literature indicates that the age of the father does not seem to be as significant as the age of the mother (Newton, 1997; Christianson, 2006). Once again this finding was also not a factor in Chinton's case, as his father was 23 years old when he was born. There is some literature in support of the age of the maternal grandmother as being a factor in the incidence Down syndrome (Malini & Ramachandra, 2006). However, since Chinton's maternal Grandmother was under the age of 30 when his mother was born, the age of Chinton's maternal grandmother was also not found to be a factor in Chinton's case.

S1	<i>Dad: ... And at that time we were ignorant and I was 23 years old and my wife was 22. And we just had a baby ...</i>
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Chinton was found to have the sub-type of Mosaic Down syndrome, which according to the literature most likely means that he received all the correct number chromosomes from both of his parents, at the time of fertilization, unlike the most common standard trisomy 21. However, shortly afterwards the chromosomes failed to disjoin or split-up in a process of non-disjunction (Kirk, Gallagher & Anastasoiv, 2000).

As a result Chinton has a considerably milder form of Down syndrome, as he has some but not all of the characteristics of Down syndrome caused by the lowered percentage of cells carrying the extra chromosome.

P1	<i>Dad: Because he was one of the fortunate ones with Mosaic DS that he was always first choice in school when they were plays or concerts or in the choir. And he was always – they would always look upon him even in the school activities he did cross country sports and so on. He brought a lot of honours to the school even swimming as well.</i>
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Chinton does not have nearly as many medical complications, including sensory defects, motor problems, heart defects, or immune system defects, which are common as a result of Down syndrome (Kaplan & Saddock, 1998; Rasore-Quartino, 1999). Chinton, however, experienced many colds and flu as a baby and suffered ear problems which needed regular medical attention.

P2	<i>Mom: Yes, as a child. Ja, frequently getting colds, his nose was always cloggy and eyes watery. There was something wrong with his tear ducts – ja. His eyes was sort of matching and he had ear infection all the time – we had to syringe his ears all the time.</i>
----	---

He suffered oral-motor function difficulties common to infants with Down syndrome, where he had initial difficulty with feeding. He also has speech and language difficulties common to individuals with Down syndrome (Fowler, 1999).

P2	<i>Mom: At that age he couldn't even speak fluently at that age and they had a little show a concert and he had to mime his words he was a poor boy.</i>
----	--

Along with academic and intellectual difficulties, he had higher social and adaptive skills than expected given his speech and intellectual difficulties, all of which are characteristic of Down syndrome (Kirk et al., 2000).

P2	<i>Mom: I don't think he felt any different because at this school he wasn't given any extra attention though he couldn't cope like the other children – at least in this school here he could and the learning was not as high as ...</i>
P1	<i>Dad: Academically it was more of a low nature like show and tell and work stewardation it was more what he needed.</i>

Chinton is able to write and to read, but is not proficient. A diagnosis of mental retardation or more appropriately worded cognitive impairment is characterised by deficits or impairments in adaptive functioning (Kaplan & Saddock, 1998). Despite several marked characteristics of intellectual disability, Chinton is currently almost completely independent in his general functioning; this is especially noticeable in his ability to drive.

I	<i>On a scale of 1 to 10 how would you rate his independence at the moment?</i>
P1	<i>Dad: I would say an 8 out of 10 because he has got his own room and he is all neat and tidy with his things and he doesn't like people touching his things like his car – he wouldn't like his brother or sister driving his car and he is totally independent he would choose things like what he wants to wear.</i>
P1	<i>Dad: You know I can leave the entire house with him and he can get up – there were instances where we had to go and while he's sleeping he would get up and get something to eat and he could lock up he'll arm the house, lock up and go – he will just phone me and tell me.</i>
P2	<i>Mom: There's nothing that he likes – he just fries easy thing egg, Vienna's cheese. He will make his own meal He's self sufficient.</i>
P1	<i>His strengths are that he is very very independent in a sense and he could create a conversation and if I say to him now to go to the airport and come back, he can find his way to the airport and he will come back.</i>

Due to his higher general functioning, his intellectual disability can be noted as mild, as indicative of what the DSM-IV terms as mild mental retardation IQ between 50 and 70. This is also consistent with median findings discussed in the literature whereby most people with Down syndrome have IQ's that fall in the mild to moderate range of retardation and the remaining few fall into the severe to profound range of retardation (Hardman, Drew & Egan, 2005).

Chinton developed friendships and social relationships during his time at his special school, yet had also developed friendships and social relationships in their mainstream community environment, assisted by his family. The literature suggests that having both groups of friends increases independent living and a wider range of more independent relationships, which is consistent in the case of Chinton. Each of the respondents acknowledged that he was very social, and that his quality of life, independence, and self-reliance was above average in comparison to other individuals, with intellectual disability.

R	<i>And the socialization that he had at school because he is at school with a lot of other physically and mentally disabled children – so how was that socialization?</i>
P1	<i>He got on quite well with the kids there and he had a lot of empathy for the kids as well – he understood and they understood him because they came from the same disadvantage.</i>
P1	<i>What we found is that in PM the neighbourhood was very supportive and those ages he grew up with the children and he wasn't isolated – they played bicycles and he played with his skateboard.</i>
I	<i>Even though in special school he still had community around him.</i>
P1	<i>Exactly! He used to go down to the cricket with the boys play all those.</i>

At work he has been able to adapt easily to new social relationships

R	<i>And does he have friends at work?</i>
P	<i>Supervisor: Oh he has plenty. Plenty of friends!</i>
R	<i>Okay.</i>
P	<i>Because he just speaks with everybody. He jokes with them too. But as I told him he must be careful also, because if you joke with somebody also and those people don't like it, and they joke with him he might get offended because of his disability. So I explained it to him.</i>

Interestingly Chinton did not necessarily feel that he had friends at work. Nor did he feel that friends were all that necessary at work. Chinton clearly has a different definition of the term 'friend' than his supervisor.

R	<i>My next question is do you have friends at work?</i>
P1	<i>Chinton: Not too much.</i>
P1	<i>Chinton: My friends are more the old people. One guy in packing and One African guy old man – the young people they get up to nonsense.</i>

Down syndrome is also associated with behavioural problems, as the literature indicates that adolescents who have impaired speech and language have behaviour problems out of what may stem from the emotion of frustration (Cuskelly & Gunn, 1997). In Chinton's case he never had noticeable behaviour problems while he was at school; this was only a factor in the case of the incident resulting in his suspension from work.

P1	<i>Dad: In the early days of schooling is that he went to school so that he was normal as in not that different that he would show behaviourally. He was still calm and collected so no bad behaviour or sort of ill disciplined no no no.</i>
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Chinton had felt discriminated against by the manager on duty, and therefore felt unable to report harassment from his colleagues. His frustrations grew, as he received no support or assistance. He finally acted out in defence against his colleagues. According to the WHO definition of 'handicap' as outlined by Barbotte et al. 2001 in Chapter 2, this incident can be subjectively viewed as an example of how Chinton's intellectual disability became a handicap in the workplace.

P	<i>Chinton: As I told you about this guy Sheldon (Manager on duty) – He didn't know firsthand about the Down syndrome – someone was telling him I got a Down syndrome but when the new man or girl comes in the workshop he lets them mock. He say I've got Down syndrome I can't get paid like them number one. Number two – he says – I am stupid! – he says on me that I must deserve to do the dirty work for them.</i>
P	<i>I was working night shift 6 to 6 till the Sunday morning. I told the operator, I said you know what he was a-told to come back. I'm relaxed. You want to tease with me – I'll go – It was tense – they started with ... but I didn't know ... they had a broom, two kind broom, and they take the broom – and they hit me on the head.</i>
I	<i>Wow!</i>
P	<i>The said it was just horse play.</i>
I	<i>So they were playing and they hit you?</i>
P	<i>They wasn't playing.</i>
I	<i>Okay, Shoo. So was that the time when you hit him back and you were dismissed and then you were suspended?</i>
P	<i>Yes.</i>

Several interviewees have mentioned emotions as being a difficulty for Chinton, including Chinton himself.

P	<i>Chinton: Ja, you see and I defend myself. He first time he caught me by my neck he picked me up and tried to throw me down – second time, he caught me out I tried to kick him. But with the anger now and the mood it's now my weak spot – I kill wonky and he left me on the floor.</i>
I	<i>Gee, so the broom incident was that also Sheldon?</i>
P	<i>No that was the African people.</i>
I	<i>Okay and then Sheldon got you around the neck?</i>
P	<i>No that was still the African people.</i>
I	<i>But Sheldon was the manager on duty at the time?</i>
P	<i>Yes, you know he saw what happened and never one step forward.</i>

His father has noted within this study that Chinton has been further helped by calming medications. Behavioural problems stemming from emotional frustration are one factor in the challenges to Chinton's employment as they once contributed to him nearly losing his job. This may be one example of how in a special school, the school support staff were more equipped to deal with, as well as prevent, such behavioural difficulties through better understanding, than his more mainstream supports in his employment.

As the Outreach co-ordinator at the Down Syndrome Association says that:

... colleagues are only going to be able to assist if they understand some limitations that the person faces."

However, a conclusion of behavioural difficulties seems hardly logical from one single example. A more appropriate conclusion might instead focus on Chinton's ability to express himself at the hearing. It would seem that this is a skill which is required frequently in his employment experiences, as a result of the incident, this skill can be appreciated, and not taken for granted, in light of his disability, the other majority of the time.

Down syndrome Association spokesperson: *"But what impresses me about Chinton is that he can speak his mind. He is really a young man, and he can express himself, he can say what he likes, and can actually also tell you, you know the things he is actually really unhappy about."*

His ability to express himself has been acknowledged.

P	<i>Current floor manager: ... in the previous shift. He would keep on reporting things but that manager didn't do anything about it and he get a little aggressive now saying I cannot work in this shift because people don't listen to me.</i>
R	<i>How does he feel listened to in the work now, and do his colleagues listen to him?</i>
P	<i>I explained to him the line of communication: if he have a problem you must speak to the operator first. I have an open door policy but you must speak to your supervisor first. So he knows the line. If you fail in that you can see me. And I think he understand – you got to give clear direction as to the communication is working upwards and downwards.</i>
R	<i>So that's how it is working now?</i>
P	<i>Ja and it's working; it's working.</i>

The above extracts, reflecting Chinton's achievements in his ability to express himself are no doubt a reflection of how challenges have been overcome in the employment context, in spite of disability.

In this context I experienced the finding that Chinton who was currently in inclusive employment, and had in fact attended a special school, quite unexpected, and rather surprising in light of the literature on inclusion.

Within the context of inclusion, the finding suggests that it is perhaps not necessarily the type of schooling that reflects an inclusive society, but rather the inclusive attitude of the society in including the school, and acknowledging that each of its individual school members are equal members who each belong to that society. However, the limitations of a single case study do not essentially allow such a generalisation.

In Chinton's case, he benefited from his specific type of schooling.

R	<i>So he went from a special needs school into mainstream employment?</i>
P1	<i>That's correct yes, it was a huge step but as he worked through and learnt how to conduct himself – but as the special needs school was actually a trade school ... as he grew older he moved up his classes from a junior level to a senior level and through that he was taken through the various workshops where he understood woodwork and working with art and creativity.</i>
R	<i>So they did a lot of training?</i>
P1	<i>At the trades school yes, where he was introduced to the trade where he could handle machinery and furniture and creating things gardening and ja</i>

Chinton also did not receive any formal training after his schooling that prepared him or qualified him for his later employment. All his current skills needed for his job were learnt either on the job, or through in-house training, which is reflected through the example of his skills matrix as seen in Chapter 4. Training and support were found to have benefited this adult in a number of areas and he has a general pattern of skill development not too far different from that of his colleagues. It was also established that he had found innovative ways of re-enforcing the specific training needed, such as continuous and persistent observation. This is consistent with the suggestion made by Botroff et al. (2002) that additional training could be experienced within the work context.

There are perhaps many unique and surprising aspects to note about Chinton, as within the competitive job market in South Africa, where employment is currently under further threat as we face economic decline as a result of rising fuel costs, increase in food prices, and the energy crisis. Within this context, Chinton has not only secured himself employment in the competitive open labour market, which is the least protected, and most mainstream type of employment as discussed in the literature review (WWW.NDSS.ORG). He has also managed to secure himself a permanent position where he is less likely to risk retrenchment. This finding is a notable achievement, especially as the employment equity act does not specify a disability quota specific to intellectual disability. According to the Down syndrome outreach spokesperson, intellectual disability is frequently overlooked in most competitive employment.

"So we wanted to go in there to ... create awareness about intellectual disability so that if they meet their equity act, you know the 2% that they have got, so they have already started with intellectual disability. So we thought we wanted to go and say to them, this is intellectual disability, you know it already working with Chinton so therefore in future if you are going to employ people with disabilities just make sure the other people employed also have intellectual disability. Because most of the companies mainly employ people mainly with physical disabilities or that are deaf you know and intellectually they are okay. But they ... as an organization have actually like broken the rule if you call it so."

This achievement has been made possible by Chinton's strong family support base, supportive attitude of senior management, and accepting colleagues.

P	<i>Down syndrome outreach spokesperson: "Ben, the manager, he is really sold on getting people with disabilities within the workplace and I think his support was very creating in Chinton's case, because I mean he accommodated him even though maybe he could of actually used the rules by the book, if he wasn't committed to assisting people with intellectual disabilities. But also what I like about him he's not like saying 'Oh, because you have got an intellectual disability you can do as you please and we will always like accommodate you'. You know the sort of things he says is because you are working a job like everybody else you are going to be treated like everybody else – with support. Because that is what is important with people with intellectual disabilities, is supported work."</i>
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Chinton is able to get to work independently, which according to a London study by Carr (1995 in Jobling & Cuskelly, 2002) is most uncommon, since most of the employed adults studied were unable to get to work independently.

Chinton was found to be engaged in packing and collating type of work which was similar to the main type of work found with adults with Down syndrome in urban Australia (Jobling & Cuskelly, 2002). However, unlike either of the studies who found that most of the young adults with Down syndrome worked between 12 and 40 hours a week, Chinton works an average of 60 hours a week.

Similar to findings mentioned in the literature, Chinton reason for wanting to work was to have the opportunity to perform specific tasks and valued roles in employment, and to a lesser extent to establish friendships and improving personal wellbeing (Jobling & Cuskelly 2002; Botroff, 2002; Brown, 1996).

R	<i>And tell me out of all the work that you have been doing which is the work that you like the best?</i>
P1	<i>Chinton: "I like to do the operating job."</i>
R	<i>So that's the work you're doing now?</i>
P1	<i>No.</i>
R	<i>You're doing the packing now?</i>
P1	<i>Ja.</i>
R	<i>And so the operating work you did before?</i>
P1	<i>Ja – with the machine and the packing work – he was standing there and saying show me.</i>
R	<i>The machine?</i>
P1	<i>Ja.</i>
R	<i>The operating machine?</i>

P1	<i>Ja and then he showed me he go sit down and he watched me after he showed me.</i>
R	<i>Okay. And can I ask this machine that you are working and that you want to operate?</i>
P1	<i>Yes.</i>
R	<i>Why did you like that the best? What is it about that that you really like?</i>
P1	<i>I achieved a lot.</i>
R	<i>You achieved a lot?</i>
P1	<i>Yes because people like me a lot.</i>
R	<i>So you get more respect?</i>
P1	<i>Yes.</i>
R	<i>And is there more?</i>
P1	<i>Yes and I've done lots of things like the time I go to work and people like to joke and play with me. Sometimes I get seriously.</i>

Consistent with findings in the literature, Chinton's parents were more concerned about Chinton and his level of satisfaction, whereas Chinton was more concerned about the type of work that he would like to perform, showing that his thinking is more concrete.

I	<i>Okay. And you were saying about it being not necessarily the most suitable job because its quite challenging you said.</i>
P	<i>(Dad) Mmmnn (Nods).</i>
I	<i>Can I ask about why, because its challenging is it not the most suitable? Can you tell me more about that?</i>
P	<i>(Dad) Okay you see Chinton is put on – he is given employment and the position that he is – even I know he feels unhappy with the position because he knows he can do something much higher than that.</i>
I	<i>Oh.</i>
I	<i>So he's not getting job satisfaction.</i>
P	<i>He's not.</i>
P	<i>No, So he knows that he's capable of being an operator but because his company... has given him employment he will do that</i>

Despite improvements that could be made on overall work satisfaction, it was found that there was still a real possibility that Chinton's work satisfaction could potentially be improved within the future.

P	<i>Chinton: At the moment you know I told you last night the company they going to send me for training for the operator.</i>
I	<i>Okay so that's going to come.</i>
P	<i>Ya.</i>
I	<i>So they've told you?</i>

P	<i>Yes they have told me, and I wait now.</i>
I	<i>So that's the training that you are going to get in the future so you can do the operator job that I know you really want to do.</i>
P	<i>Ja</i>

Chinton the adult with Down syndrome, was found to be benefiting economically from the employment experiences, to the extent that he was able to assist with buying the family home, as well as enabling to cover all his own individual expenses and additional savings, however not without the overall financial management skills of his father.

According to Botroff et al's view of the employment experiences within the quality of life model, Chinton has overcome one of the main challenges to quality of life, through being helped by his father in understanding some of the more complex reasons for work.

P	<i>Chinton: Then after that my dad he spoke to the company he said I got Down syndrome and I can work.</i>
I	<i>Okay.</i>
P	<i>I am not lazy like other people.</i>
I	<i>So there's other people you know that are quite lazy?</i>
P	<i>Yes.</i>
I	<i>So you didn't want to be like that?</i>
P	<i>Na-ah.</i>
I	<i>So you wanted a job and you were ready to work hard?</i>
P	<i>Yes.</i>
I	<i>Okay, and now you happy with what you are doing?</i>
P	<i>Yes</i>

Further findings revealed that Chinton keeps up with work demands with ease. Almost all of the respondents naturally verified that he was found to be generally happy in his employment and was found to be seen as an asset to the company as well as having a responsible work ethic.

Chinton's experience of inclusion within the workplace was noticeable in most of his work experiences, except for his description of 'the incident' and his resulting suspension, which was subsequently addressed and he was re-instated. It can only be speculated that the incident represented the tip of the iceberg regarding a build up of on-going tension within the workplace. In which case, although it is merely a

single event, its relevance could be more significant to the employment experiences than initially realised. Furthermore, the fact that the union spokesperson did not want to represent Chinton for cultural reasons is indicative that the notion of inclusion does not apply to the inclusion of disabled people alone, but also of the inclusion of each and every cultural group.

P	<i>Supervisor: "And the union didn't want to represent him although he was in the union I am not sure why. Because I think they are looking at an African guy was involved and then an Indian guy and then because most of shops stewards there were African and maybe they didn't want to represent him against the members."</i>
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This is particularly relevant in a South African context, especially within the context of the recent xenophobic violence, as reflected in the media in May of 2008, occurring shortly after the study was conducted at the end of March of 2008. This current context may be politically reflective of a build up of underlying tensions that spread throughout South Africa. While on the surface, the case study provides an illustrative example of inclusive employment, representing inclusion into society, within a culture of acceptance and support. However, within the South African context of a variety of sensitive underlying factors including employment rivalry, cultural tensions, and disability, amongst others, it is difficult to know how vulnerable attitudes of inclusion really can be, when placed under pressure.

There have been several protective factors, which were discovered in Chinton's case, in addition to his own self-reliance. Chinton's self-reliance is particularly evident in the quote below regarding how he learnt to drive. Since obtaining his driver's licence, he has bought his own car and so provides his own transport to work.

I	<i>Did you ever believe that you would drive?</i>
P	<i>Chinton: Yes</i>
I	<i>You did. And what do you think helped you?</i>
P	<i>Okay. I helped myself a lot to drive. People think I can't drive. I would do down the lane and then I watched people driving the car</i>
I	<i>So in a way you watched people how to do it and worked it out like that?</i>
P	<i>Yes.</i>

Further protective factors were found to lie within his developed sense of independence that the employment experiences had generally allowed, giving him a

sense of belonging and a feeling of respect, as well as financial independence. His own determination, and persistence together with his remarkable family, community and work support have allowed him many remarkable achievements outside the workplace including a group of mainstream friends that he sees regularly and whom he later met after leaving his school for special needs learners.

A high level of family involvement was also found to be a protective factor within Chinton's case to a certain extent. Chinton's father actively sought support and assistance when it was needed, silently assisting his son, in overcoming a variety of challenges. This high level of family involvement is clearly reflected in the manner in which Chinton's father sought employment for Chinton, and the way his company responded reflects the degree to which the needs of Chinton, the adult with Down syndrome were recognized, and the degree to which the demands on Chinton's parents lessened as a result (Carr, 1995; Fujiura & Smith, 1997 in Jobling & Cuskelly, 2002).

P1	<i>Dad: ... That was when I approached management and I said "I have a son who is staying at home now, and it is detrimental" - Its going to effect my wife cos if I am at home I can control him, with him now he can take advantage of me so therefore I said "I need help" because my mind is at home and my body is at work! So – and she is uneasy as well – because she doesn't know what is going to happen next whether he is going to arrive or whether he is going to get up to mischief or what he is going to do?! I mean you don't know! So therefore I said to him: "You now listen – I need him employed!" – "You know I need employment for him because he is going to distract my work. I am going to have to leave my work and run back home just to get him away from the mischief making".</i>
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The company's efforts to support Chinton were appreciated by his father, as reflected in his quote below.

<i>Dad: "... I applaud Ben for giving Chinton a job! "... looking at the company I am very grateful to Ben in particular is that he is the man who has been instrumental in giving Chinton a job and I must thank him from the bottom of my heart- with his support as well."</i>

4.7 SUMMARY OF FINDINGS

The data reveals that the adult with Down syndrome was reported to have Mosaic Down syndrome, to be in good general health and have relatively good general functioning and have intellectual disability. He has been employed full time in the

open labour market by a large company as a factory worker, where he has worked all his adult life. He keeps up with work demands with ease. According to each of the respondents, he was found to be happy in his employment and was found to be seen as an asset to the company as well as having a responsible work ethic. Senior management and his parents have been very supportive in creating the opportunity for his employment, and he has been made a permanent employee by the company. The Down Syndrome Association is very happy about their support of him. Management have found that his colleagues are generally very supportive.

It was found that there was one major challenge, mentioned by all the interviewees. After an incident, he was suspended from work. After the hearing, he was moved to work under a different floor manager. There have been no further reported problems.

Each of the respondents acknowledged that he was very social, and that his quality of life, independence, and self-reliance were above average in comparison to other individuals with intellectual disability. The adult with Down syndrome was found to be benefiting economically from the employment experiences to the extent that he was able to assist with buying the family home, as well as to cover all his own individual expenses and accrue savings. However, he relied on the financial management skills of his father.

Training and support were found to have benefited the adult in a number of areas with a general pattern of skill development not too far different to that of his colleagues. It was also established that the adult found innovative ways to re-enforce the specific training needed through continuous and persistent observation.

While it was found that the employment experiences allowed more independence through a sense of belonging, and a feeling of being respected, as well as financial independence, The individual with Down syndrome's own determination, and persistence together with his remarkable family, community and work support have made possible many remarkable achievements outside the workplace. These include having a group of mainstream friends, whom he met after leaving his school for special needs learners, that he sees regularly, obtaining a driver's licence, and getting to work in his own in a car that he was able to buy. The results show that there are a number of contributing factors which have assisted him to attain an

improved quality of life and a relatively high degree of self-reliance. These findings, along with further conclusions and interpretations will be discussed in more detail in the chapter to follow.

4.9 REFLECTIONS

It is interesting to note that it was felt that the research aims, and purpose of the study would be best achieved if the adult with Down syndrome were employed in the competitive labour market. Furthermore, given the complex nature of our combined first and third world nature of South Africa, placing us into the category of a middle income country (Christianson et al., 2006), and given the relevance noted within the literature of marked differences in quality of life, and other findings in developed and developing countries, it was felt that an adult from a disadvantaged background, would be more relevant to the context of this study. It may be interesting to note that in searching for such an adult for this study, I was told many times that he or she could not possibly exist. After searching for such an adult through networking with various Down syndrome associations across South Africa, I eventually found him on the opposite side of the country, in a completely different province altogether. I think it is important to note that I know of no other individuals who even remotely match the employment characteristics and accomplishments of Chinton, and that also have Down syndrome. Should any readers know of any other such remarkable individuals, I would very much appreciate it if they would contact me. Kindly note that as mentioned, all names of participants within this study have been changed to protect their anonymity.

CHAPTER 5

SUMMARY, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the qualitative analysis of the findings presented in Chapter 4 will be discussed and explained, according to themes and patterns, which emerged within the data, with reference to the literature review. This is followed by a summary of the chapters. The limitations of the study are then explored, followed by recommendations for various role players affecting the case study. Implications of the study and conclusions are discussed. The chapter concludes with reflections on the part of the researcher.

5.2 SUMMARY OF THE CHAPTERS

Chapter 1 provides a general introduction to the study, with a discussion of the background to the study, the purpose of the study, the context of the study, the research problem, a definition of concepts, and a brief outline of the research design, research paradigm, method of research, and research methodology is provided. It also identified the knowledge gap about the employment experiences of the adult with Down syndrome. This provided the rationale for investigating the employment experiences of an adult with Down syndrome in South Africa, including exploring to what extent the employment experience led to an improved quality of life for the adult with Down syndrome across several areas of functioning and the factors which influenced these experiences on various levels.

Chapter 2 provided a literature review which explored the context of Down syndrome in terms of its historical and scientific research developments. It explored the known and the unknown etiological factors of Down syndrome, as well as the incidence, life expectancy, prevalence, outcome, diagnosis, associated features, and management of Down syndrome. It also explored the main identifiable features of Down syndrome. The employment context for adults with Down syndrome and intellectual disability was briefly explored familiarising the reader with the contextual theoretical

background and scientific research that informs the goals of the study and guides the exploration of the research problem, through various criteria of quality of life.

Chapter 3 situated the research design and methodology in the interpretivist research paradigm, and described the research problem and the aims of the study. The detailed description of the design and methodology included the various qualitative research techniques and data analysis used. Ethical considerations and potential limitations of the study were discussed.

Chapter 4 described the implementation and procedure of the study and discussed the findings. The physical setting and the nature of the case was contextualized. Next, the adult with Down syndrome was introduced and contextualized within the study through a description of relevant background information, mainly drawn from parental interviews, questionnaires and documentation. The implementation procedure and process of the study were discussed, with ongoing attention to the process of reflexivity, as well as careful analysis of the data (Patton, 2002; Henning, 2007). Findings were then discussed, summarised and presented with diagrammatic representation to illustrate several emerging themes. These findings were then compared to the literature, whereby the assumption of the study is central to his employment experiences, because the study is based in the interpretive approach. These were then verified through a process of triangulation to his parents, supervisors and managers (Hill, 2002).

5.3 FINDINGS

As already stated, this is a descriptive case study situated in the interpretive research paradigm. The nature of the study is reflected through descriptions of the life world of the adult with Down syndrome according to his employment experiences, and the way in which meaning is constructed concerning these experiences. The purpose of the study is met through sharing the employment experiences of an adult with Down syndrome, in order to make this information known to other parents, supporters, carers and individuals with Down syndrome and intellectual disability. In answering the questions, care has been taken in order to provide detailed information across several contexts of the employment experiences.

The aim is to provide a rich description of these experiences, whilst bearing in mind the situation of the study within a dynamic and complex South African context.

The findings of the study revealed that Chinton's employment has broken new barriers, in creating opportunities for colleagues and employers around him to express new and supportive attitudes of inclusion and acceptance of individuals with intellectual disability. Whether Chinton, his employers, or his parents, had the intention of breaking new ground within the fields of inclusion, inclusive employment and intellectual disability, or not, they have paved the way for others by providing an example of what can be achieved in spite of disability. The implications of breaking this new ground, are further highlighted when one considers Chinton's situation according to career theory discussed earlier, Chinton was found not only to be working, but also to be formally employed. Furthermore, Chinton was found to be in an unusual type of work considered for a person with Down syndrome, namely that of manual labour. The influence of his father's work on Chinton's chosen work profession, was also found to be an important factor, which is consistent with career theorists such as Super (Stead and Watson, 2006).

The findings reveal that we can assume from Chinton's account of his quality life across several areas according to the criteria of Cummins (2005) and Cummins (1997), that central to his experiences was relatively high degree of quality of life for him. Cummins (1997), Personal Wellbeing Index, and Cummins (2005) comprehensive quality of life scale manual for intellectual disability, explore criteria applicable to his employment experiences, across areas of material wellbeing, productivity, importance and satisfaction. Achievements outside of the employment context, including social functioning and independence in being able to drive, make it difficult to ascertain the exact impact of his employment experiences on his quality of life since his quality of life extends beyond his employment experiences.

Perhaps the most remarkable finding of Chinton's employment experiences for other adults with Intellectual disability and Down syndrome is that as a result of his employment experiences, Chinton's employer is willing to create more opportunities for employment for more individuals with intellectual disability. In this way, the case study has shown ways in which it has challenged some of the stereotypes of individuals with intellectual disability such as the view of individuals with disability as

being individuals who are "not able". The narrative of Chinton's employment experiences also reflect the degree to which attitudes of inclusion can also be extremely vulnerable, under the stress of basic economic survival, and the degree to which these attitudes can be affected by a lack of understanding.

The case study is an example of the challenges that can be overcome and the support that can be offered. It is an example of the degree to which inclusive attitudes and models of human rights are being reflected in mainstream society within the employment context. It is an example of self-determination, and self-belief in one's own ability to learn, and to accomplish. Sometimes you never know until you try.

5.4 CONCLUSIONS

The detailed findings of this study, as discussed in detail in Chapter 4, reveal the extent of which the research questions and aims were achieved, through a thorough in depth description of the employment experiences, relating them to the literature as well as the research questions, completing the final case study narrative step 3 of Patton (2002). The main research problem was addressed in answering the primary research question mentioned in Chapter 1: *What are the employment experiences of an adult with Down syndrome?* The employment experiences of an adult with Down syndrome have been described and discussed in the final case narrative, above. The research aims of investigating the various aspects of the employment experiences pertaining to quality of life were addressed through answering the secondary research questions outlined in Chapter 1 and 3. Thus, the aim of investigating the employment experiences of an adult with Down syndrome in his place of work in South Africa was addressed to see whether they affect quality of life, according to the criteria provided by Cummins (2005), and how the experiences were able to come about. Working from the interpretive approach, it was assumed from the account of the main participant, the adult with Down syndrome, that he indeed had a relatively high quality of life across the areas of material wellbeing, productivity, importance and satisfaction, applicable to employment.

The aim of investigating what the emotional experiences of employment are for the adult with Down syndrome was addressed in terms of reactions to treatment in the

workplace, and the effects of the employment experiences on self-esteem, and reaching potential, such as job satisfaction. The employment experiences were interpreted as enhancing emotional wellbeing to a large extent, according to one of the criteria for quality of life (Cummins, 2005).

The aim of investigating the cultural employment experiences in terms of integration into the community and a feeling of cultural belonging for the adult with Down syndrome in order to gain insight into the adult with Down's syndrome's experience of inclusion were addressed through a description of both a culture of acceptance within the workplace, as well as cultural tensions within the workplace, and social dynamics. Thus, although several challenges were discovered, a strong sense of belonging, as well as of complete inclusion, was clearly indicated.

The aim of investigating the economic experience of employment, with regard to gaining a degree of self-reliance, and basic means for the adult with Down syndrome was addressed according to the criteria for quality of life, as noted by Cummins (2005). The economic experiences were described through, economic independence, and financially assisting family members, whilst still relying on family support for financial skills. Thus, a relatively high degree of self-reliance was interpreted from the findings, as well as of economic sustainability and independence, except in financial management skills such as counting.

Identifying the possible types of training and support implemented in preparing the adult with Down syndrome for the employment experiences was aimed at offering useful insights for parents and carers. Training was found not to be necessarily implemented in preparing the adult with Down's syndrome for employment, although his schooling allowed for general training in basic trade skills. As is revealed in the skills matrix in 4.4.3, on the job training occurred. Support was not implemented in the form of supported employment as discussed in Chapter 2, but was rather fostered by several role players within the working environment, creating a culture of support and understanding, with the help of teamwork, and outside support from the association at times. Thus, the adult that did not have any formal training in preparation for work received training on the job. He was found to have benefited from the special needs trade school he attended, and was found to be surrounded by

a culture of support. Each support person was interviewed for the study, resulting in a total of six additional interviews.

The criteria for quality of life noted by Cummins (2005) were applied to explore generally to what extent the employment experiences led to an overall improved quality of life for the adult with Down syndrome. It was difficult to ascertain the degree to which the employment experiences affected quality of life outside his employment context, according to criteria such as social functioning and independence such as being able to drive. However, the adult with Down syndrome reported feeling very happy about several factors which indicated high quality of life outside of his employment context according to Cummins (2005) criteria. These included a group of mainstream friends, whom he sees on a regular basis, the ability to drive, and a marked sense of autonomy. While he did feel a sense of respect, responsibility, belonging and accomplishment as a result of his employment experiences, it seems that many outside factors also impacted on his higher level of quality of life. The extent to which his employment experiences assisted in the development of an improved quality of life was therefore not clear. However, it was evident from the findings, that he did have a comparatively high quality of life, according to areas of functioning as outlined by Cummins (2005) and discussed in Chapter 2. It is evident that his employment experiences contributed to this quality of life in terms of material wellbeing life quality, a sense of satisfaction, productivity and importance. Furthermore, his employment experiences contributed to a sense of normalcy, noted within the literature as relevant to increased independence, quality of life, and life expectancy.

Thus although the exact impact of the employment experiences on his overall quality of life cannot be determined, according to the main approach of this study, this finding provides a reminder that when relating this finding to systems perspective, the employment experiences cannot be considered in isolation, as an inter-relatedness exists between each of the life worlds of the individual.

5.5 LIMITATIONS

The limitations need to be taken into consideration, when interpreting the results. Since this is a single case study, only limited generalization can be made. There are

a number of rare factors making this case especially unique, including the most uncommon type of Down syndrome experienced by the adult with Down syndrome. The case study can be used as an example, in an idiographic manner as mentioned in 3.3 to identify what it unique, through its depth of detail of the case studied, rather than establishing generalisations that apply to a wider population. While to some degree generalisations may be possible, in the field of intellectual disability, these must be discussed with great caution and care.

Consideration has been made of potential challenges to validity, through a lack of authenticity on the part of the participant, and distortion and deception on the part of the researcher, as discussed in Chapter 3. A great deal of care has been taken to overcome these, through interviewing a variety of participants, and careful attention to reflexivity, and verification with participants where possible. However, it is also important to remain humble and open to the reality of these limitations, in order to remain equipped to overcome them.

The question of whether generalisation is appropriate to case study data, has already been briefly discussed in 3.3 where it was noted that it is not likely to be appropriate to the case study data, giving the limitations of a single case study.

5.6 IMPLICATIONS AND RECOMMENDATIONS OF THE STUDY

5.6.1 For educators and educational psychologists

Within the field of educational psychology, we should be careful to bear such examples in mind when facilitating and fostering support for our clients within wider contexts. We should take special care not to limit our own expectations as to what potential can be reached for persons with disability.

5.6.2 For the wider academic community

This study can serve to alert our larger academic community, as carefully defined by Botroff et al. (2002) (see Chapter 2), to the danger of the misuse of the term 'disability' and the extent to which it frequently does not serve us, or the individuals that it represents, through frequently misguiding our expectations, and curbing potential opportunities.

5.6.3 For employers and human resource personnel

The case also has implications for employers and human resource personnel, in terms of what value, individuals with intellectual disability are able to bring to their employment context, and in shifting attitudes toward government policies of equity, and equal opportunity.

5.6.4 For future research

In conducting this study, the awareness of the dire need for continued research on employment experiences has deepened. There is currently little information on this topic. As discussed in Chapter 3, valuable substantiation of the findings presented in this study could be obtained through feedback and verification of the findings discussed here, by each participant.

5.6.5 For public awareness campaigns

Public awareness campaigns, with the aim of educating employers and community members of their role in assisting adults with Down syndrome into employment, through attitudes of support and understanding, could assist further with the creation of employment opportunities for adults with Down syndrome. Each Down Syndrome Association can continue to play a role in this.

5.6.6. For Chinton

Quality of life could be improved by fulfilling his dream of getting married to a life partner who could assist him with general financial transactions, and having his own family one day. Quality of life could also be improved through being promoted to more challenging and stimulating work, where he would enjoy a greater sense of control and job satisfaction.

5.7 REFLECTIONS

While this study originated out of concerns raised by parents for the future wellbeing and planning, particularly in making the transition from school into employment, within the process of developing and conducting this study, this study goes further than that. It also addresses deeper or unconscious questions that lie in the heart of

any person involved in the field of disability, and in truth affect everyone in our society. Questions such as how realistic is it for us to think that that the person with intellectual disability or Down syndrome that we know, or love, or have just met, could find a place in mainstream employment? How realistic is it that they will be able to cope or to become an asset to the employment context? Will the employment just be tokenism or something to keep them busy? The literature albeit limited has hinted that the abilities of individuals with Down syndrome are frequently underestimated by the society around them. The findings from this study is consistent with this, and through its example, holds the potential to open the minds of society and change expectations and attitudes towards individuals with disability, and, in doing so, create more opportunities for a greater quality of life for each one of us.

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ADDENDUM A

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Research Title: The employment experiences of an adult with Down syndrome

You are asked to participate in a research study conducted by Julia McAllister (B.Soc.Sci, B.A (Hons), M.Ed. Psych), a student in the Educational Psychology department at Stellenbosch University. The results of the study will contribute to both a research paper, as well as a thesis. The ... family together with ..., and his employment supervisor have been selected as possible participants in this study, because ... is known by the Down Syndrome Association of South Africa, to be an adult with Down syndrome, who is currently employed in the open labour market.

1. PURPOSE OF THE STUDY

This research study attempts to address the need for further research into the transition to employment, by examining the employment experiences of a young South African adult with Down syndrome. It is anticipated that the findings from the study may make a valuable contribution to the knowledge base of individuals with Down 's syndrome.

2. PROCEDURES

Participation in the study will involve the following:

- An interview with the researcher.
The interview questions will be on background information, quality of life, as well as work experiences.
- Completion of a form and/or a questionnaire regarding background information, quality of life, and work experiences.
- Allow the researcher to make copies of documents which are relevant to the study in terms of background information, quality of life, and work experiences.
- Allow the researcher to visit the place of work for between 2- 3 hours.
- Allow the interviews to be recorded by the interviewer, so that the data can be captured accurately for the research.

Role of Participants:

Parents: The researcher would like the parents to complete about five short questionnaire's, which should not also take longer than one hour. The researcher would like to complete one interview with the parents together, which should take less than one hour. The parents are welcome to ask about any questions that they may feel unsure of. The researcher would also like to be able to ask any clarifying questions with regard to the questionnaire's within the interview. The researcher would like have a copy of any documents that the parents are aware may be relevant to the study.

Adult with Down syndrome: The researcher would like the adult with Down syndrome to complete two short questionnaire's, with assistance, which should take less than an hour. The researcher would like to complete one interview with the adult with Down syndrome, which should take less than one hour. The adult is welcome to ask about any questions that they he may feel unsure of. The researcher would also like to be able to ask any clarifying questions with regard to the questionnaire's within the interview. The researcher would like to visit the adult at his work for between 2-3 hours, so that the researcher can get a physical idea of his work experiences. Should the presence of the researcher at the place of work become obtrusive in anyway, or have a noticeably negative influence on the adult's employment experiences and the working environment, then the amount of time spent at the place of work will be reduced or terminated

Work Supervisor:

The researcher would like to conduct one interview with the work supervisor which should not take longer than an hour.

Location:

Interviews can take place, in a place, where there will be little disturbances or interruptions. An appropriate location can be chosen by the hosting participants, either at home or at work, and agreed upon by the visiting researcher.

3. POTENTIAL RISKS AND DISCOMFORTS:

It is not the intention of this research to cause any harm of any kind to participants whatsoever. Participants are encouraged to discuss any concerns they may have, so that these can be addressed by the researcher, and so that any potential harm can be avoided.

In order to protect the adult with Down syndrome from any unforeseeable risks and discomforts, anonymity within the written presentation of the thesis research, as well as the paper will be assured through the changing of names as well as any identifiers. The participants will be contacted and first asked for permission should the researcher wish to present or discuss the data in any other way, or to present the video tape data.

The adult with Down syndrome may be contacted later and invited in the opportunity to assist in presenting some of his employment experiences, at a later conference, at his own cost.

4. POTENTIAL BENEFITS TO SUBJECTS AND SOCIETY

The study aims to be allow the adult with Down syndrome the opportunity of sharing his employment experiences to the benefit of other adults with Down syndrome as well as their parents. It aims to be a positive and meaningful experience for the adult, his work supervisor and parents. The purpose is to benefit other parents and adults with Down syndrome.

The study aims to benefit Down syndrome societies around the world in showing an example of what employment experiences are possible for an adult with Down syndrome in a developing country, and in making an example of what employment potential is possible to achieve.

5. PAYMENT FOR PARTICIPATION

While there is no payment for participation in the study, each participant will receive a small gift of thanks for their contribution. Should a participant for any reason decide to withdraw from the research, they will still receive a small gift.

6. ANONYMITY

Any information that is obtained in connection with this study and that can be identified with you will remain anonymous and will be disclosed only with your permission or as required by law. Anonymity will be maintained by a means of content and thematic analysis, whereby the content of the information and themes within the employment experiences will be described, rather than the identifying information. Any personal identifying information that is relevant to the content will be changed, such as names, and places amongst others.

Recorded interview data, and copies of transcripts, copies of documents, and/or videotapes will be kept with the researcher and the supervisor at the Educational Psychology department at the University of Stellenbosch. While, the researcher and team of professional psychologists at the university will have access to the raw data, the data will be used anonymously, and the video will only be used at a conference if specific permission is granted. Participants also have the right to review and edit the videotapes

If the information will be released to any other party for any other reason, participants will first be contacted for permission before hand.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF RESEARCHERS

If you have any questions or concerns about the research, please feel free to contact: Julia McAllister on 0832380064 email: juliamcallister@yahoo.co.uk and Professor Rona Newmark on 021 8082229 and email: rnew@sun.ac.za

9. RIGHT OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue without penalty. You are not waiving any legal claims, rights or remedies because of your participation in

this research study. If you have any questions, regarding your rights as a participant, you may contact Professor Rona Newmark at the Unit for Educational Psychology, as mentioned above.

I hereby give my consent to participate in the above mentioned research, and I give my consent for my interview data to be videotaped and recorded as mentioned above. I therefore agree that I understand the terms outlined above, and that they are to my satisfaction.

Name: _____ Signature: _____

Signed on: _____

Name: _____ Signature: _____

Signed on: _____

Name: _____ Signature: _____

Signed on: _____

Name: _____ Signature: _____

Signed on: _____

Name: _____ Signature: _____

Signed on: _____

**STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH**

Research Title: The employment experiences of an adult with Down syndrome

You are asked to participate in a research study. The researcher is Julia McAllister (B.Soc.Sci, B.A (Hons), M.Ed. Psych). Julia McAllister is a University student. Her University is Stellenbosch University. She is studying the subject of Educational Psychology, so that she can work as an Educational Psychologist. The employment experiences of an adult with Down syndrome, will be written in a research article. They will also help her thesis, where she will write them there too. Your parents as well as you and your employment supervisor have been selected as possible participants. This is because, you are known by the Down Syndrome Association of South Africa, to be an adult with Down syndrome, who is currently employed.

1. PURPOSE OF THE STUDY

This research study attempts to help other people with Down syndrome, their parents, and their teachers. They need to learn about what it is like for a Down syndrome adult to be employed. And they need to learn how it was made possible for you (as the adult with Down syndrome) to become employed. In writing about your employment experiences, other people around the world can learn from them, and it can help them to understand better. They can learn about what is possible.

2. PROCEDURES

Participation in the study will involve the following:

- An interview with the researcher.
The interview questions will be on background information, quality of life, as well as work experiences.
- Allow the researcher to make copies of documents which are relevant to the study in terms of background information, quality of life, and work experiences.
- Allow the researcher to visit the place of work for between 2- 3 hours.
- Allow the interviews to be recorded by the interviewer, so that the data can be captured accurately for the research.

Role of Participants:

Parents: The researcher would like your parents to complete about five short questionnaire's, which should not also take longer than one hour. The researcher would like to complete one interview with your parents together, which should also take less than one hour and a half. Your parents are welcome to ask about any questions that they may feel unsure of. The researcher would also like to be able to ask any clarifying questions with regard to the questionnaire's within the interview. The researcher would like have a copy of any documents that your parents are aware may be relevant to the study.

Adult with Down syndrome: The researcher would like to complete one interview with you, which should take less than one hour. You are welcome to ask about any questions that you may feel unsure of. The researcher would like to visit you at your work for between 2-3 hours. This is so that the researcher can get a physical idea of your work experiences. The researcher will also be happy to leave the work place early, if this would be better you, and your work.

Work Supervisor:

The researcher would like to conduct one interview with your work supervisor which should not take longer than an hour.

Location:

Interviews can be in a place, where there will not be many noises or interruptions. The right location can be chosen by you and your parents, either at home or at work, and agreed by the visiting researcher.

3. POTENTIAL RISKS AND DISCOMFORTS:

The researcher does not wish to cause any harm or discomfort to you or your parents, or work supervisor. The researcher will do her best to make you feel comfortable with the research. The researcher would prefer if you can please tell her or someone else, if you are in anyway uncomfortable, or if it feels like there are too many questions, and you are getting tired.

The researcher wants to protect the you from any risks that she may not have thought of. The way she will do this, is to keep the information anonymous. This way, when she writes about your employment experiences, people will learn about them, but they will not know who's experiences they are. They will not know, because she will change your name. They will also not know any details which can make them recognize that these are your experiences. If the researcher thinks it would be a good idea to tell someone it is about you, then she will make contact with you and your parents, and first ask if it is alright if she can. If the researcher thinks it is a good idea to present the video data, then she

will also first make contact, explain what it would be for, and ask if it would be alright.

You may be contacted later. You might be invited to a conference to talk about your employment experiences. You also might not. If you are, you will have to pay for your transport to the conference.

4. POTENTIAL BENEFITS TO SUBJECTS AND SOCIETY

The study aims to allow you the opportunity of sharing your employment experiences to benefit of other adults with Down syndrome as well as their parents. It aims to be a positive and meaningful experience for you, your work supervisor and parents. The purpose is to benefit other parents and adults with Down syndrome.

The study aims to benefit Down syndrome societies around the world in showing an example of what employment experiences have been possible for you.

5. PAYMENT FOR PARTICIPATION

There is no payment for participation in the study. You will receive a small gift of thanks for your contribution. Should you for any reason decide to withdraw from the research, you will still receive a small gift.

6. ANONYMITY

Recorded interview data, and copies of transcripts, copies of documents, and/or videotapes will be kept with the researcher and the supervisor at the Educational Psychology department at the University of Stellenbosch. The researcher and team of professional psychologists at the university will have access to the raw data, and the data will be used anonymously. The video will only be used at a conference if specific permission is granted. You will also have the right to review and edit the videotapes

If the information will be released to any other party for any other reason, participants will first be contacted for permission before hand.

7. PARTICIPATION AND WITHDRAWAL

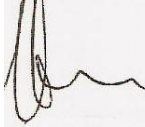
You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise which warrant doing so.

30 April 2008

Att Julia McAllister

I give my consent for you to use the video material during our interview regards you research on employment experience of an adult with Downs syndrome.

Kind Regards



Rice Unit Manager

Registration No. 1944/017881/06

Directors
Non Executive: R A Williams (Chairman), B H Adams, D D B Bend, S L Botha, B P Connellan, U P T Johnson, A C Nissen, G N Padayachee, B L Sibiba, J L van den Berg,
L C van Vught
Executive: N Dennis (Managing Director) (British), M H Franklin, M C Norris, R V Smither, C F H Vaux

Company Secretary: I W M Isdale

ADDENDUM B

EXAMPLES OF INTERVIEW TRANSCRIPTS WITH CODING

FIRST INTERVIEW WITH CHINTON

R	Ok so Chinton if you can tell me how old are you at the moment?		
P1	27	EAC	
R	And can you tell me a bit about what you do? What do you do, what work do you do?		
P1	Woodwork	EAC	SKIL
R	Woodwork?		
P1	Yes, and Art	EAC	SKIL
R	Art?		
P1	Yes, and I used to carve the table	EAC	SKIL
R	I didn't know that, so that is something you do when you are not in your job. Something you do in your spare time, that you like the woodwork and things?		
P1	Yes		
R	Ok and if someone says to you what do you do in your job?		
P1	What do you mean?		
R	Like if I said to you what is your job? What employment do you do?		
P1	At work?		
R	At work yes.		
P1	Ok, I am a qualified packer, and cleaner we clean the floor do things around the other people and the operators,	EC WD	SKIL
R	Yes, Please tell me more?		
P1	We do the fast machine and the back-up machine and around.	WD	
R	Oh the back-up machines?		
P1	Ja		
R	Ok		
P1	Then No 1 is the housekeeping, then timekeeping	WD	HOUS
R	Housekeeping is also part of your work in the factory and that involves like cleaning ecetera?		
P1	Yes		

R	Tell me more?		
P1	Then there's a PPE the ear plugs and hats.	WD	SAFE
R	What does the PPE stand for?		
P2	Dad: Personal protective equipment		
R	And so you have ear plugs?		
P1	Yes		
R	Really I didn't know that- is that cos it gets very loud there?		
P1	Yes		
R	And you have hats?		
P1	Yes		
R	Ok, what are the hats for?		
P1	Ok, the hair might fall in the rice		
R	Ok so they are so that hair doesn't fall in the rice?		
P1	Ja.		
R	Good so you said Housekeeping, you said the PPE- Are there more things you can tell me about your job?		
P1	The 20 keys we go intercoms then I tell him must I just check my own thing- I tell him why doesn't he do it the first time- the people don't respect the operators sometimes the operators don't also respect the workers too. Each too is part of the team and do it.	WD TM	COM LRES
R	So the team work and the respect is important to you, and not only respect for the people but respect for the space as well. That's important.		
P1	Yes. So if the operator tell me Chinton I'm going to the toilet now watch the machine I must guard the machine- no problem- when the reject goes out take the trolley put it on the trolley when you come back I can go, just put the reject on the floor there.	EAC EC	REST SKIL
R	So even just going to the toilet needs to be something that's managed?		
P1	Yes		
R	And that's not always easy or is it always easy or is it fine?		
P1	Its easy		
R	Ok Good. And can I ask Chinton can you say a little bit about your working hours from what time to what time do you work?		
P1	I work from 6 in the morning and we do the change overs...	ECC	
R	So if you start at six in the morning you finish at what		

	time?		
P1	We finish at 6 in the evening	EC	
R	So you are working for 12 hours. And you don't get tired in the 12 hours? No? You fine?		
P1	No, I come home and I have supper bath change relax and then -	EC	SREL
R	And then you go to sleep? It's a long time for anyone to work. Maybe a person with Down syndrome would also find that long- you want to tell me a bit about that about the hours for you?		
P1	Ok, ja for many hours we work and we work many hours then next and we have breaks 9.15. and so on a fifteen minute break	EC	CAPA
R	15 minute break		
P1	Yes		
R	And the breaks make easier to carry on with the work?		
P1	Yes		
R	And do you always work the day shift	EC	
P1	No, night shift, 6 to 6- 12 hours		
R	Which do you prefer the day shift or the night shift	EC	ATTI
P1	Night shift		
R	Really- why?		
P1	There's more job to be done		
R	Can you tell me more? like what?		
P1	There's all the more bailers bailing sheets like a roll that can go-	EAC	SKIL
R	that's that plastic sheet that goes around?		
P1	Yes		
R	So there's more of that at night?		
P1	Yes		
R	I am going to see that later you can maybe show me- And you like that?		
P1	Yes I've been working as an operator in the warehouse before	EAC	DG SKIL

INTERVIEW WITH CHINTON ON QUALITY OF LIFE

I	This first question is can you show me how happy are you with your life as a whole on a scale of 1 -10?		
P	10	QLGF	
I	How happy are you about the things that you have like the money that you earn?		

P	Ok I feel happy	QLPB	FWELL
I	And the things that you earn how happy are you?		
P	Very happy	QLPB	FWELL
I	How happy are you with your health?		
P	Very happy	QL	HEAL
I	How happy are you with the things you want to be good at?		
P	Ok, uh very happy	QL	CAPAS SES
I	How happy are you about getting on with people you know?		
P	Very happy	QLREL	
I	How happy are you about how safe you feel?		
P	Ok, I very safety person,	QL	SAFE
I	So you feeling safe?		
P	Yes		
I	How safe you feeling on the scale?		
P	Very safe		
I	How happy are you about doing things away from home	QL	SREL
P	Very happy		
I	How happy are you about what will happen to you later on in life as you get older?	QL	FPLA
P	When I marry I will feel happy	QLREL	
I	So you would like to get married?		
P	Yes		
I	So that's one thing extra that you would like to do before you can say that you very happy. So you would like to get married in the future and look after yourself?	QL	FULF
P	Yes		
I	Do you feel confident that you can do this?	QL	SES
P	Very		
I	Ok great thank you		

INTERVIEW WITH MOM ON HEALTH

I	So you were saying that he was actually a sick baby as a child.		
P2	Yes, as a child. ja, frequently getting colds, his nose was always cloggy and eyes watery. There was something wrong with his tear ducts- ja. His eyes was sort of matching and he had ear infection all the time we had to syringe his ears all the time.	STDD	HEAL
I	Oh really?		
P2	Ya.		
I	So those were some common symptoms of having Down syndrome -if you can call it- symptoms really- or rather effects of having down syndrome?		
P2	Ja.		
I	And that was when he was about how old?	STDD	
P2	It was when he was a baby until about 2 and a half.		
P1	Dad: Ya		
I	How did you manage that?		
P2	We went frequently to the doctor.	STDD	SUP
I	Ok.		

P2	And that time it helped me to frequently get it syringed		
I	Ok - And now he doesn't have the problem anymore since he was 2 and a half?		
P2	Ya		
I	So that's been really quite fortunate in a sense that it didn't carry on after that age.	STDD	HEAL
P2	Yes, MMmmm		
I	So as he has grown and developed is there anything special maybe that you did that you can think of?		
P2	Not really		
P1	Dad: We worked hard with his speech and we had to take him to a speech therapist for 3 months and she spent a lot of time talking to him flash words and so on.	STDD	HELP
P2	Mom: Because I used to take him after school and he used to get very tired and couldn't understand really why he was going. It was rather better at the school rather than going out. So we arranged it during school.	STDS	HELP
P1	Dad: They fitted in to the school curriculum as part of a subject that speech therapy.		
I	So that was another advantage of him being at that school?		
P1	Dad; Ja		
P2	Mom; Mmmnn, yes		

INTERVIEW WITH UNIT MANAGER BEN HOLMAN

P	My name is Ben Holman I'm the rice Unit manager here at the company in Durban. As far as Chinton goes, besides Chinton being quite strong and wanting to work, and excited about working, I believe that the people of the company, the workers, the people on the shop floor have made a difference as well. I've never actually told them that. We've had meetings where we try and educate the people that he works with, through the Down Syndrome Association in Durban. And when there's been conflict I've made them have, what we call an SGA, which is a Small Group Activity, and then they deal with their issues with Chinton, and he goes back to work. We've moved him once or twice from different departments but what I've tried to do is make him, or not necessarily him, but rather make the people that he is working with, more aware of his situation and the way he is, and that's how I believe has made it work.	EAE SSCOL SSM SSCOM CHW CHO CHO CHO	STRE/ ATTI SUP SUP EDU CON COM MOV AWA
---	--	--	--

		EAE	SUCC
R	So that's the difference.		
P	That's the difference that the people have made. He is keen and he does his work. The only thing is, he is different to the other guys, and they have accepted him and taken him in and that for me is so great.	EAE SSCOL	ATTI ACCP
R	So that's to you, been the credit to them, that's made it work for him,		
P	I believe so:		
R	That acceptance and that support in that sense.		
P	Yes, they have definitely made a difference besides himself I mean he has wanted to work, he enjoys working and I think he is pretty responsible, I mean you see him driving his car.	EAE EAE EAE	ATTI RESP DRIV
R	It also sounds to me that there has been a role of management in helping the workers to help him, and in him using the situation just in terms of educating people in terms of what you were saying and also through building the conflict space to air any conflicts.		
P	Yes, you know the conflict is not major, its small stuff ,but maybe they don't understand the way he thinks and the way he behaves, and I think (I don't know if you've interviewed anybody there down on the floor), but maybe you might pick that up, that the little bit of education that we've given them on down syndrome, because for everyone of us, I mean none of us are used to that you know, type of person, but he's an asset I see him as an asset.	CHW SSM MEE	LUND EDE ASET
R	Can I ask this education that you are talking		

	about, how did it work? Could you tell me a little bit more about it?		

INTERVIEW WITH DOWN SYNDROME ASSOCIATION OUTREACH CO-ORDINATOR- DEE KUZWAYO.

P	Hi I'm Dee Kuzwayo, and I'm the outreach co-ordinator for the Down syndrome association Kwazulu Natal. My job is actually giving information to parents so that they understand that Down syndrome is just a child with a disability, and is going to have some challenges in life, but the most important thing is that the child can achieve quite a lot given the opportunity. The only reason that people with Down syndrome haven't achieved a lot up to now is because we the society have never given them an opportunity.	SSCOM	LOPT-
P	I am involved with young children and also with adults as well, and I have been involved in Chinton's life and in his work situation. The thing that we went to do there as an organization was to create awareness about Down syndrome for his colleagues, because Chinton just went to work and nobody knew what having Down syndrome actually will do in his life. So therefore like all the employees had some problems at work, and we just felt, because we hadn't been able to go earlier on, and educate people about intellectual disability. So now that there was a problem, we had to get in and help them understand as to why he had reacted the way that he did, because for people with intellectual disability, especially Down syndrome, they don't have enough vocabulary to actually express their feelings. So if they are happy they will like maybe say a word or two and then get physical like almost carry off the floor to show you how excited they are and it also goes for when they are angry, and that you know they can't tell you in a thousand words to go to hell, so they usually maybe would get physical. So this is what we tried to get the people to understand, that if they tease Chinton he is going to get angry. This belief that they are so nice they are always loving and cuddling and whatever, there is no such. People with Down syndrome are very individual. They are going to express their feelings very individually according to how they are, so that is actually why we went and you know their company is very perceptive. And the other thing that I love so much about the company is	SSCOM CHW SSCOM SSCOM SSCOM SSM	AWA LUND PROB EDU EMO COMM AWA

	that they have actually given a different disability, a person with intellectual disability, an opportunity to do a job like every body else.		EQUA
P	Ben, the manager he is really sold on getting people with disabilities within the workplace and I think his support was very creating in Chinton's case, because I mean he accommodated him even though maybe he could of actually used the rules by the book if he wasn't committed to assisting people with intellectual disabilities. But also what I like about him he's not like saying "Oh, because you have got an intellectual disability you can do as you please and we will always like accommodate you". You know the sort of things he says is because you are working a job like everybody else you are going to be treated like everybody else- with support. Because that is what is important with people with intellectual disabilities, is supported work. Mainly support by colleagues because you can always get somebody from outside to come and support, but then you need, colleagues are only going to be able to assist if they understand some limitations that the person face. But what impresses me about Chinton is that he can speak his mind. He is really a young man, and he can express himself, he can say what he likes, and can actually also tell you, you know the things he is actually really unhappy about.	SSM SSM TM EAD	EQUA SUP SUP EXP
R	Mmmn, that makes a difference		
P	Ya, Ya, and he is also able to say why. You know this incident we were talking about at his workplace, we were all expecting him to say: "Ok, now its fine, and I've forgiven everyone." and he looked and he said there was this one person. He looked- he says- we gonna talk to him he says "Uh Uh"-,which actually shows that he behaves like all of us, you cant just decide ok, cos we had a tiff, now people say its over, its actually over, cos its not. And the other thing which I have found to be an eye opener for me is the brutal honesty of people with Down syndrome. They cant say "Hmm I like it", they will say if its ok its ok, if its not ok its not ok, so once they give you exactly how they feel they tell it how it is.	EAD EAD	EXP EXP
R	Dee, can I ask that when you said about that he was employed by default as you explained earlier can you say a little bit more about that and then the aims that you had before now?		
P	You know Chinton was employed at The company well before my time, When I joined Down syndrome he was already working there but I understand that he went to work there and at The company (and I	EC	

	<p>stand to be corrected) but they didn't know that he had a disability. They just employed him to work. That is why I say he was employed by default because he just happened to go look for work and they actually employed him. So the real reason we went in later was when there was a problem. But we have been trying for months to get in there to do disability awareness. Because, since the company is the only company I know that has employed a person with intellectual disability on a full time basis, not just not just deciding "Oh what can we give him to do today"- just to keep him employed. So he is doing an ordinary job, a job that he goes to work every day to do and it is his job so we wanted to go in there to the company and create awareness about intellectual disability so that if they meet their equity act, you know the 2% that they have got, so they have already started with intellectual disability. So we thought we wanted to go and say to them, this is intellectual disability -you know it already working with Chinton- so therefore in future if you are going to employ people with disabilities just make sure the other people employed also have intellectual disability. Because most of the companies mainly employ people mainly with physical disabilities or that are deaf you know and intellectually they are ok. But the company as an organization have actually like broken the rule if you call it so. Because Chinton is not like given a two hour shift just so that he does something he actually works shifts. If his shift goes on night shift he works night shift, and if his shift does day shift he does day shift. And he is expected he got to score- He has got to achieve the same thing that other people are achieving at work.</p>	<p>EC</p> <p>CHW CHO SSM</p> <p>SSCOM</p> <p>EC</p>	<p>PROB AWA EQUA</p> <p>OPOR</p>
--	--	---	--

INTERVIEW WITH THE PALATISING AND WHITE RICE SUPERVISOR

P	Hi I'm the palletizing and white rice supervisor	SSS	
P	What else what else?		
R	Can you tell me about what its like to be working with Chinton? Is there anything for example, any thing that you need to be more lenient for or things you need to explain?		
P	Chinton has been in my department at the white rice plant for two months now. It's a pleasure working with him and he listens to whatever say but at sometimes he gets a bit nervous of certain things and he goes and complains to his father, but other then that it's a pleasure to work with him.	EAS CHW	ASSE DEP
R	So there are times when he doesn't always feel he can come to you and talk directly if he is uncomfortable with		

	something, sometimes he goes to his dad.		
P	Yes.		
R	So that's maybe a disadvantage of the fact that his dad is around?		
P	Yes		
R	And maybe if he was a person without Down syndrome he wouldn't do that is that what you mean?		
P	Maybe		
R	Maybe not?		
P	Yes, I did speak to the local guy that came around not sure of his name think it was Leon from Durban. I have his number here let me get his number and his right name and I'll mention it to you.	SSCOM	COM

ADDENDUM C

INTERVIEW GUIDES

Parents:

BIRTH AND DEVELOPMENT

1. When did you first find out that Chinton had Down syndrome? (*While pregnant, immediately after birth, or much later?*) Can you tell me about it?
2. Did you know at the time what Down syndrome was? How did you first hear about it?
3. How did the news that your son has Down syndrome affect your family? (*nuclear and extended*)
4. What type (if any) support structures were there in place? Did you find the support they offer meet your needs? Are there current support structures in your life that offer you support?
5. Can you tell me what type of challenges you have faced? (*frustration with professionals, anxiety about the future, emotional wellbeing of parents and marriage, social relations in family, lack of moral and social support*)
6. Do you know what type of Down syndrome Chinton has?
7. Could you share with me, what your understanding is of how Down syndrome is caused? Do you think it could have been prevented?
8. Are you expecting Chinton to live a long and happy life? Do you think he is likely to outlive you?
9. What do you think makes Chinton's development unique in comparison to your understanding of other adults with Down syndrome?
10. Can you tell me about Chinton's medical history? (Operations?, regular check-ups?, Affordability and access to healthcare?)

ADOLESCENCE

1. What has your experience been regarding Chinton's schooling?
2. Can you tell me more about your involvement with the school?
3. Tell me more about Chinton's adjustment to the school.
4. What (if any) behavioural changes did you notice.
5. How successful do you think his type of schooling has been for your son, regarding:
 - academic gains
 - socialization
 - independence
 - language
 - self-esteem
 - development of friendships
6. Five word description of your son.
7. Can you tell me about some of your son's abilities and interests?
8. What were your hopes and dreams for your son while he was at school?
9. Did you ever expect that he would be able to do what he is doing today?
10. What about your son makes you proud?

QUALITY OF LIFE

11. How happy are you with Chinton's quality of life as a whole?
12. How happy are you about the things he has like the money he has and the things you he owns?
13. How happy are you about his health?
14. How happy are you about the things you want him to be good at?
15. How happy are you about his getting on with people he knows and his role in the community?
16. How happy do you think he is about doing things away from home?
17. How happy are you about his personal safety?
18. How happy are you about what may happen to him later on in life?

WORK EXPERIENCES

19. What does Chinton do in his work?
20. How did he come to be in his job?
21. Can you tell me about the very first day that he started at his work?
22. What do you think Chinton enjoys most about his job?
23. What do you think he enjoys the least about his job?
24. What does his having this job mean to you? What do you think it means to him?
25. Do you think this is the most suitable job for Chinton? Why? Why not?
26. Is there any other kind of work that you think Chinton would maybe be interested in doing if it was not this work? What do you think it would be?
27. What opportunity does he have, that you are aware of, to increase the number of social interactions he has outside of the work building?
28. What aspects of the work do you think come more easily to Chinton?
29. What aspects of the work do you think are more difficult for Chinton?
30. How do you think he handles these challenges?
31. Who do feel is his main avenue of support at work?, emotionally? Physically?
32. Do you think this support is adequate at the moment? Has it always been this way? How does Chinton respond to support?
33. Did he have any training for this work? What did it involve?
34. What was your role in the training?
35. Do you think further training would be helpful to him?
36. Do you know where you would go to find out about training?
37. How does Chinton manage his payment? What is your understanding? What is your role and his role in the expenditures and money management?
38. Do you ever feel that Chinton is excluded because he has Down syndrome? What things, people or events have made his inclusion easier?
39. What things do you think make Chinton sad/angry at work or at home?
40. Please tell me more about Chinton's learning to drive?

Adult with Down syndrome:

1. Can you tell me about what you do?
 2. Did you always know you wanted to do this job?
 3. What did you want to be when you were younger?
 4. Does it feel good to be employed? Can you tell me why?
 5. How did you come to be in this job?
 6. Are you amazed that you could do this?
 7. Can you tell me how you felt on the very first day that you started here?
 8. If you could choose any job in the world, would it be this one or another one? What other one would it be? Can you tell me why?
 9. Do you have friends at work? Can you tell me what you do together?
 10. Do you have friends at home? Can you tell me what you do together?
 11. Are your friends at home the same as at work or are they different?
 12. Do you feel you have enough friends? Do you sometimes feel you wish you had more friends?
 13. What type of work do you like doing the most when you are at work? Can you tell me why?
 14. What work don't you like? Can you tell me why?
 15. What work do you find the easiest to do?
 16. What work do you find the most difficult to do?
 17. Do you find your work very tiring? How do you cope with that?
 18. How do you look after yourself?
 19. Did you have any training for this work? Can you tell me what training you had?
 20. Did you enjoy the training? Did you find it easy or hard? Do you think it has helped you in your work?
 21. Do you think you would like to have more training?
 22. Do you know where you would go to find out about this type of training?
 23. Where do you spend break times? What do you do at break?
 24. Do you have meetings? What happens there?
 25. Can you tell me how you are paid?
 26. Can you tell me how you usually spend your pay?
 27. Is there anything in particular that you like to buy?
 28. Is there anything especially important that you need to afford?
 29. How does it make you feel to be able to buy those things with your own hard-earned money?
 30. Do you ever feel like you are being excluded because you have Down syndrome?
 31. Where are you when you most often feel this way?
 32. Do you play sport? What sport do you play? Where do you play?
 33. What do you enjoy doing?
 34. What makes you sad / happy / angry at school/home?
 35. Is there anything else about you, you would like me to know?
 36. Was it hard to learn how to drive?
 37. Did you ever believe that you would be able to drive?
 38. What do you think helped you to manage it?
 39. Who do you think helped you to manage it?
 40. How is your experience of driving now?
-

The adult with Down syndrome will be asked a further 8 questions from the personal wellbeing index (Cummins, 2005)

The questions are answered on a scale of 1-10 (10 being very happy):

- 1) How happy are you with your life as a whole?
 - 2) How happy are you about the things you have? Like the money you have and the things you own?
 - 3) How happy are you with your health?
 - 4) How happy are you with the things you want to be good at?
 - 5) How happy are you about getting on with people you know?
 - 6) How happy are you about how safe you feel?
 - 7) How happy are you about doing things away from your home?
 - 8) How happy are you about what may happen to you later on in your life?
-

Work supervisor:

- 1) Can you tell me about Chinton's work experiences? What does he do? What is your role as his supervisor?
- 2) Can you tell me about any challenges which are encountered?
- 3) How do you deal with these challenges?
- 4) What other strategies are in place in order to accommodate Chintons needs within the working environment?
- 5) What other support does Chinton have aside from you at work?
- 6) How is he treated by the staff members?
- 7) Does he have the opportunity to speak when he wishes with the other staff members?
- 8) How much time would you say is devoted to Chinton by other staff members including yourself, in any given week?
- 9) Can you describe the type of social relationships that he has established with the other staff members?
- 10) What degree of privacy is there in discussing the difficulties that he encounters?
- 11) Are you aware of other activities that he likes to do when he is not at work?
- 12) Can you describe to me the type of exceptions or leeway he is given at work?
- 13) Does he have the opportunity to visit new and stimulating new environments? Can you tell me about these?
- 14) What opportunity does he have, that you are aware of, to increase the number of social interactions he has outside of the work building?
- 15) How would you describe his general overall quality of life in terms of (*emotional, social, spiritual and physical aspects*)
- 16) What is your opinion with regard to the hygiene and tidiness of Chinton's working environment, and the places that he visits most often?
- 17) Can you tell me about the training processes that took place in order for Chinton to do this work? Do you think he would benefit from further training? Can you tell me more?

Footnote: Please note that I am taking a copy of the comprehensive quality of life scale (Cummins, 1997) It is aimed specifically for intellectual disability. (It is also in the first article in your file on quality of life)

On his 1997 scale- there are several questions that I would consider using which address the same areas i.e. social, emotional, health etc, they ask more specific details, and are also all on his objective scale, which as I understand implies that even though it is not ideal, they can be answered by someone close to the person under study. Since many of the questions overlap, and since I am already likely to get the answers to these questions from the others which I shall ask as well as the amnesia. I thought I would hold them for back-up. In other words, I may ask the same above 8 questions to his parents and supervisor, and if their answers differ substantially then I shall consider using another scale for 'back-up' so to speak. I thought I would adapt them as outlined above

Cummins, R.A. & Lau, A.L.D (2004) **Personal Wellbeing Index** (2nd Edition). Intellectual Disability Manual (English). Melbourne: School of Psychology, Deakin University.

Cummins, R.A. (1997) **Comprehensive Quality of life scale - Intellectual/cognitive disability (ComQoI-I5): Manual**. Melbourne: School of Psychology, Deakin University.

Morrison, L, 2007. Stellenbosch University Thesis.

Nota, L., Soresi, S., Perry, J., (2006) **Quality of life in adults with intellectual disability: the evaluation of quality of life instrument**. In: Journal of Intellectual Disability research (50) 371-385.

ADDENDUM D

DATA ANALYSIS: STEP 2 ADDENDUM: ROUGH WRITTEN DRAFT PLANNING COPY OF VISUAL CASE RECORD

The employment experiences of an adult with Down syndrome

- Dedicated to individuals with Down syndrome
- Special thanks to Chinton, his family colleagues and management at the company
- Compiled and documented by Julia McAllister
- Produced and mastered by Pete De Jager

Introduction

- Chinton is 27 years old. He has Mosaic Down syndrome and intellectual disability. For the last 8 years Chinton has been employed full time in the open labour market at ...
- the company factory, where he recently joined the company as a permanent employee about 8 years ago
- As a result of being made a permanent employee Chinton is a shareholder// in the company he receives medical aid provident fund and other benefits.
- Chinton works 12 hour shifts at a time tonight he is working the night shift from 6pm until 6am

What the employment involves

- Although Chinton precise job description does change from time to time, at the moment Chinton is working as a packer or process hand.
- His team work together on a job order
- Tonight they are packaging 1 kg old mill brown rice
- Each colleague in the team is part of the process
- Chinton is the last person in line. He has the job of sticking the bar codes and stock numbers onto each pack and then loading them onto the palates, ready for his final colleague to wrap them with plastic so that the rice can then be transported
- The team is headed by an operator who is in charge of the machine

What the work demands

- Chinton 's work is quite labour intensive as he is lifting 20kg's continuously every 20 seconds. He also needs to know not to get the stickers mixed up or they could potentially lose count of of the amount the team produced.
- Chinton also needs to have several skills which he has learnt through on the job training.
- Chinton 's sense of responsibility and accountability as well as his determination is noticed and respected by his supervisors

How Chinton feels about his job

Supervision and support

- Chinton has his team and his team leader
- Chinton has his floor supervisor L
- Chinton has his warehouse manager M
- Chinton also has the support of entire rice unit manager G
- Chinton has the support of the Down syndrome association
- Chinton has the support of his parents, family and friends

Treatment in the workplace

Overcoming challenges

Quality of life

- Health
- Happiness
- Independence and general functioning
- Safety
- Friendships
- Future
- General

What it means that Chinton is employed

- For dad...
- For the company
- For Chinton ...
- For Down syndrome...

Exceeding mom and dad's expectations

- Getting to work
- How Chinton learnt to drive
- How is it that you managed to get the driving come about?
- I said you can do anything you want to do but there are certain things that it takes to get there so you must decide now are you ready for it.
- So in your mind you're thinking he wants to drive but I don't know if he's really going to be able to do it
- Exactly
- But you didn't want to deprive him of the chance so then what did you do because that's quite expensive if you're actually think that he might not make it
- I said to myself, as at that point he had started working already. So I said he earns his money and he wants to drive so I said ok
- God you have lead me so far and now what do I do and he said you are going to assist me in this now so I said ok fine so I made contact with some driving schools and said listen I have a son who is got ok and he is eager to get his license and you know people walked into my life at the right time at the right place like you walked into my life now that's how it progresses so much I think that the good that we sowed out there and god has sent back in two folds I think its through his grace that all this has happened so I did some investigation I said I've got a son and see what you can do for him I didn't want to dampen his dreams so I said see what you can do for him
- So they said they've worked with deaf and dumb people before. I said deaf and dumb is one but here he is intellectually impaired the capacity of reaching there I don't know, so he said just leave it to me
- So in the back of your mind you were still hoping that maybe somewhere he would be able to do it yet exactly because being positive with the enthusiasm he was showing that he wants to get his drivers license I said is maybe he can get it but lets see first wait and see so I said fine so the driving instructor said that I have to take him and train him I said how much is it going to cost me so he said it will cost you around the region of \$5000 for that I said ok he's earning his money and he wants to make sure that he gets his license you know he set his goal on getting his license so at that time I said nothing ventured nothing lost so if he had rather blind and failed then failed to try so I said ok lets go for it and he came back and he was stuck in the room checking the signs out checking his things and he was very determined
- So he was very determined

Exceeding mom and dad's expectations (2)

- You know, Alfie I will be totally honest with you anything that he said his mind on I know he will achieve it. Oh with the car you know he came back with the license I said ok fine all something that he achieved for something tangible now I can see for him to get the license so I said no this is a step something that now has proven me wrong but now its going to happen so I said a piece of paper its just a document that's fine but still back of the head now I said how you gonna drive a car on a public road? The fear of the unknown came over me so he said no fine that means if he gets his license that means that whenever I am in the car I will allow him to drive under my supervision. He's not going to drive alone no definitely not.
- So you were never thinking that he would drive alone. You were always thinking that's fine but at least he's going to be going under my supervision and my supervision only. mine because of a fear of the unknown now because why if I read that I know what I am going to show to you that he can be a driver.
- Oh because I can read understand it? I said fine ok so I said to the driving school I am going to take him and I am going to go and I am going to show to you that he can be a driver.
- So the driving instructor that more confident than you are?
- Exactly and I mean that I said you know you are professional in your job, and I said normal bodice driving on the road and you see them driving fine and that's what I thought on the 1st thing in a public road give me a break in anyway he he go.
- And so he would go for his lessons on a Saturday morning and come back and I didn't get to see him driving the vehicle because my wife sheeps? I spoke and the instructor name was C so he came down with Chinton after the lesson he came back with Chinton he says to me I said are you ready for what he said we are going to the yard to do the other driving. I said ok I will see you later. So I jumped in the car and I see Chinton is getting now, handbrake up, puts the car into drive and puts the handbrake down. I could have died. He drives and goes down, and as we get into France's Highgate drive the car was hitting I was around about 4 o'clock and the speed was on the dot while pulling off vehicle so he passed his car off. I am just in the back seat now thinking you know we're got trouble he puts him off the very good afternoon now why you, he says good afternoon where's your bag so he was every officer I am just the instructor on you can put your bag on top the gear box on the carry on. We drive for about five A's and we were where they do the other driving so he says alright you can get the gear box out of the car off and he got off he said do the speed stand and watch. The new control because my Chinton has been doing a second and wasn't there to see if he says ok right the up boy so there he went in he did the three point turn and then he drove us back and Ch I was so excited.
- And then you let him really can drive. I said you know what I proved myself wrong and I said you know he can drive. You know even then I thought he was with the instructor now.
- So how you let me really with the instructor he can drive.
- He turning control is right his blind spots are fine he gets into the traffic fine at the right time he checks the mirrors and I thought that's fine he can drive under your supervision you understand I will not do the car alone. He came back home got his license came back home with his license he was over the moon he got his license I said fine I am happy but you still not getting the car. So now after time he was having his money, so there was this European body working with us the name was Brenda's file was asking her and the Maggie so I approached her and said my son wants to buy the car, she says I will let you have it for 15 K so I bought the car for Chinton. He used to drive I used to be the passenger.

Training, Schooling, and development

Some of Chinton's dreams and goals

Relevance of the case of Chinton

- This case study contributes to building the much needed information on the employment experiences of adults with ds and intellectual disability
- Although mosaic ds occurs in only about 2-5% of all cases with ds and individuals with mosaic ds tend to show all, some or none of the characteristics of ds. (Newton, 1997). Chinton never-the-less has several ds features including intellectual disability. While his case cannot be generalised to all other adults with ds, it still provides an example of what potential can be achieved when least expected, what challenges can be overcome through understanding, support and determination, and what awareness can be introduced within the employment context which can pave the way forward toward changing attitudes for acceptance and understanding for future adults with intellectual disability.

ADDENDUM E

EXAMPLES OF PERSONAL DOCUMENTS

Telephone Number - 71245 (work)

Home Address - 15 Silvia Place, Northdale.

Father's occupation - Relief clerk

Mother - ^{House wife} H.S. EDDAHIN TRAINING CENTRE

FAMILY HISTORY:

SURNAME: _____

CHRISTIAN NAME: _____

1. Date of Birth: 7/6/80
2. Hospital and District of Birth: _____
3. Was child one of twin or multiple pregnancy? If so how many babies and how many have the defect? No
4. At the time of Birth of the Child, what was Mother's age 22 years
Father's age 23 years
 - 4.1 What was mother's maiden name? _____
5. Do either mother or father have the same defect? No
 - 5.1 Are mother and father related to each other? No

K. E. V. GOUGHEN

8. How many pregnancies did child's mother have altogether? 3

How Many:	Number:
1. Full term	<u>Yes</u>
2. Premature	<u>No</u>
3. Stillborn	<u>No</u>
4. Miscarriages	<u>No</u>
5. Therapeutic miscarriages	<u>No</u>
6. Is mother pregnant now?	<u>No</u>
7. How many children still alive	<u>No</u>
8. If any have died, state age at death	<u>Age 3</u>
	<u>No</u>
9. Did mother have any illnesses during the pregnancy e.g. cold, flu, chicken pox, etc. If so, name condition and at what stage in pregnancy illness occurred e.g. 3 months. No
10. Did mother have any immunisations during the pregnancy? If so, specify (what and when). No
11. Was mother exposed to X-rays during the pregnancy? No
12. Do any of the family members suffer from epilepsy? No

13. Neonatal and Birth History:

1. How far was the pregnancy at the time of delivery?
(e.g. 9 months, 8 months) 7 months
2. How many hours was the labour? 9 weeks
3. What was born first (mark with an X)
 Head Buttocks
 Other (e.g. hand, leg.)
4. Did the mother have (mark with an X)
 Normal Birth Forceps
 Vacuum extraction Caesarian Section
5. Was the baby (mark with an X)
 Pink Blue
6. Did the baby develop jaundice (go yellow)? No
 Was baby put under the lights? No
7. Did mother (mark with an X) during pregnancy?

Yes No Number/day

Drink : Yes No Amount/day

14. Are there any family members who have a similar, or the same condition or congenital defect. (If you can, please name them) No
 1. Muscle conditions No
 2. Hormone or endocrine e.g. thyroid No
 3. Nerve conditions No
 4. Mental retardation No
15. When did you feel that something was wrong with the child - 8 months

MILESTONES:

16. At what age did the child -
 1. Smile - 8 MTS
 2. Sit - 10 MTS
 3. Crawl - 14 MTS
 4. Walk - 18 MTS
 5. Talk - 2 1/2 years
17. Did the child have any illnesses as a baby, if so, name them.
 No
 Was the child ever in hospital. -
 That far - No

-3-

18. Do you feel the child has been like this from birth or has
he/she slowly become like this
SINCE BIRTH.

19. Any other information:

e.g. Chromosome tests ~~yes~~

Metabolic tests

Any other tests > Blood-Test.

20. Initial observations and remarks:

BEGINNING - TO SPEAK, FLUENTLY,
WRITE, UNDERSTANDS

Patricia

ADDENDUM F

**UNIT FOR EDUCATIONAL PSYCHOLOGY
UNIVERSITY OF STELLENBOSCH**

QUESTIONNAIRE 2

NAME: _____

Indicate with ✓

NURSERY SCHOOL

1. If this child attends/has attended nursery school:

SCHOOL

PERIOD

SCHOOL PRINCIPAL

TEACHER

2. Did the teacher identify any problems? YES NO

If YES, describe briefly:

3. Do you judge that your child is / was ready for school?

YES NO UNSURE

DEVELOPMENTAL DETAILS

A. Physical

1. **Pregnancy**

- 1.1 Was it a normal unknown problematic pregnancy?

If problematic, describe briefly: _____

- 1.2 Was infertility a factor in this pregnancy?

YES NO

- 1.3 Was this pregnancy planned?

YES NO

- 1.4 Duration of the pregnancy? normal premature (36 weeks or less) postmature (more than 41 weeks)

If premature, how many weeks?

- 1.5 Age of mother at the birth:

2. **Birth**

- 2.1 Was the birth normal problematic (e.g. forceps or suction delivery); umbilical cord around neck

Caesarean section induction unknown ?

If problematic, describe: _____

If Caesarean section, why? _____

If induction, why? _____

2.2 Duration of normal birth:

normal	long: ____ hrs	short: ____ hrs
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2.3 Appearance of baby after birth:

blue	pink	yellow	marks on head	other:
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2.4 Was oxygen administered after birth?

YES	NO
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If YES, why? _____

2.5 Was the baby placed in an incubator?

YES	NO
-----	----

If YES, why? _____

For how long? _____

2.6 Birth weight:

normal (2,7 – 4 kg)	lighter: ____ kg	heavier: ____ kg
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2.7 Apgar score:

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3. **Feeding**

3.1 Type of feeding after birth:

breast up to ____ months	bottle up to ____ months
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3.2 Any feeding problems during infancy? (e.g. colic, sucking reflex)

YES	NO
-----	----

If YES, describe: _____

3.3 Any feeding problems as toddler or at present?

YES	NO
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If YES, describe: _____

4. **Motor development**

4.1 Sit :

normal stage (6 – 8 months)	sooner	later
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4.2 Crawl :

normal stage (8 – 10 months)	sooner	later
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4.3 Stand :

normal stage (9 – 11 months)	sooner	later
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4.4 Walk :

normal stage (12 – 14 months)	sooner	later
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4.5 Control over big movements, e.g. running:

clumsy	average	quick
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4.6 Control over small movements, e.g. threading beads: clumsy average good

4.7 Toilet training: During the day: under 2 yrs 2 – 3 years after 3 years

During the night: under 2 yrs 2 – 3 years after 3 years

5. General health

5.1 Has your child had all the prescribed immunisations? YES NO

5.2 Specify all **illnesses**, the **ages** at which your child had them, whether accompanied by high **temperature** and whether your child was **hospitalised** for the specific illness:

5.3 Specify all **injuries** and **operations** and **age** at particular time:

5.4 Is this child physically handicapped? YES NO

If YES, describe: _____

5.5 Has this child had convulsions loss of contact (black outs) ? YES NO

If YES, describe (indicate age at time): _____

5.6 Does this child have any allergies? YES NO

If YES, specify: _____

5.7 In your opinion, is your child's general health good average weak ?

5.8 Does your child take any medication AT PRESENT? YES NO

If yes, please provide the information below

Name of medication	Dose	Period used	Reason for prescription

Has your child taken his/her medication before coming to the Unit today? YES NO

- 5.9 Does any other member of your family suffer from a serious or chronic illness? YES NO

If yes, please specify

Which family member?	Kind of illness	Length of time

- 5.10 Please indicate if any member of your family suffers from psychiatric problems (e.g. depression, eating disorder, etc). YES NO

If yes, please specify

Which family member?	Kind of illness	Length of time

6. Sensory Development

- 6.1 Vision: good problematic do not know
- 6.2 Hearing: good problematic do not know

B. Language and Speech

1. Words: normal stage (10 – 14 months) sooner later
2. Interest in stories: great average not at all
3. Ability to repeat a story: good average poor
4. Problems with word building? YES NO
5. In your opinion, is this child's language development good average poor ?
6. Any speech problems? YES NO

If YES, specify and indicate whether your child was examined in this connection:

QUESTIONNAIRE COMPLETED BY:

FATHER / MOTHER / OTHER:	DATE: ___/___/___
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