

THE QUALITY OF LIFE OF THREE MEN WITH AUTISM SPECTRUM DISORDERS LIVING IN A GROUP HOME: A CASE STUDY

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DECLARATION

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



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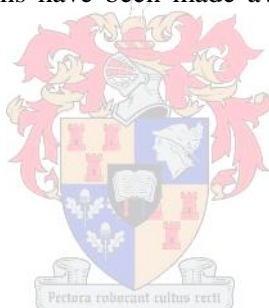


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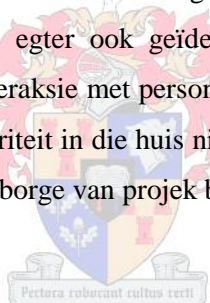
SUMMARY

This thesis focused on three adults with Autistic Spectrum Disorder (ASD) who are living in a group home in Cape Town. The purpose of this exploratory study was to explore and describe the three occupants' perceived quality of life and their experiences of living in the group home. The group home was established in 2005 as a pioneering project by Autism Western Cape, a regional non-profit organisation (NGO). It is designed for adults with high-functioning ASD who require low care. In this interpretative study, a multiple case study method of enquiry was used. The Personal Wellbeing Index – Intellectual Disability (PWI-ID), as developed by Cummins and Lau (2005), was used as the primary subjective outcome measure of quality of life. In addition, the study made use of participant observations undertaken during two semi-structured interviews with each participant and two focus group interviews. All three participants felt that they had enjoyed a higher level of quality of life, especially in the domain of 'personal relationships', since their arrival at the group home. However, they expressed a desire for more independence; a higher income; female companionship and better security at the home. These suggestions have been made available to the relevant sponsors of the housing project.



OPSOMMING

Die studie handel oor die belewenisse van drie volwassenes met outistiese-spektrum-stoornisse. Die volwassenes woon saam in 'n groepshuis in Kaapstad. Hierdie huis is opgerig deur die Wes-Kaapse Outistiese Vereniging, 'n nie-winsgewende organisasie wat dit as hulle pioniersprojek beskou: 'n poging om hierdie volwassenes se lewenskwaliteit te verbeter deur die beskikbaarstelling van so 'n huis waarin hoogs funksionele volwassenes met outisme kan woon. Die navorsingsmetodologie bestaan uit veelvoudige gevallestudies. Vraelyste is onder andere gebruik om inligting in te win. 'n Persoonlike Welstandsindeks "*Personal Wellbeing Index – Intellectual Disability (PWI-ID)*" wat deur Cummins an Lau (2005) ontwikkel is, is gebruik om 'n primêre subjektiewe meting van die drie volwassenes se lewenskwaliteit te verkry. Daar is ook twee semi-gestruktureerde individuele onderhoude met elkeen van die drie deelnemers gevoer, asook twee gestruktureerde onderhoude met die hele groep. Sowel die observasies as die inligting wat tydens die onderhoude bekom is, het verdere inligting verskaf. Die oorwegende gevoel van die drie deelnemers was dat hulle lewenskwaliteit, veral wat hulle persoonlike verhoudings betref, verbeter het sedert hulle in die groepshuis woon. Bepaalde behoeftes is egter ook geïdentifiseer. Dit het geblyk dat hulle meer onafhanklik wil wees, dat hulle, meer interaksie met persone van die teenoorgestelde geslag soek, dat hulle meer geld nodig het en dat die sekuriteit in die huis nie voldoende is nie. Hierdie behoeftes is as aanbevelings geformuleer en ook aan die borge van projek beskikbaar gestel.



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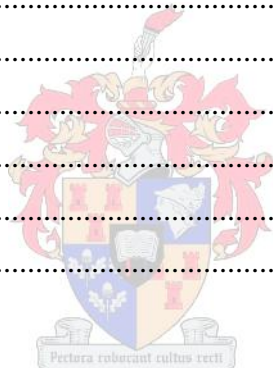
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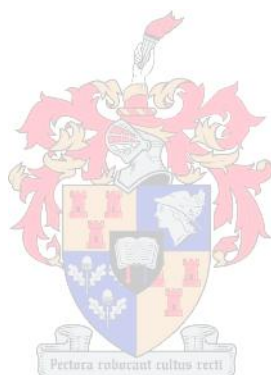
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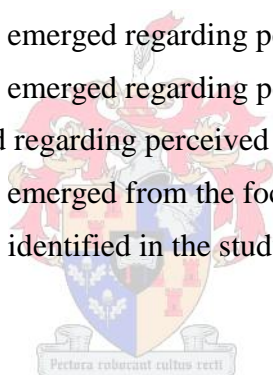
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LIST OF ACRONYMS

AD	Asperger's Disorder
APA	American Psychiatric Association
ASD	Autistic Spectrum Disorder
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders
HFA	High-functioning autism
ICD-10	International Classification of Diseases
QOL	Quality of Life
PDD	Pervasive Developmental Disorders
PWI	Personal Wellbeing Index
PWI-ID	Personal Wellbeing Index for Intellectual Disability
SWB	Subjective Wellbeing



CHAPTER ONE

CONTEXTUALISATION AND ORIENTATION OF THE STUDY

1.1 INTRODUCTION

In this chapter, I describe the context of the study and familiarise the reader with the concepts of Autistic Spectrum Disorder (ASD) and quality of life (QOL). I also provide information on group homes in general as well as a brief description of the housing project where the study was conducted. Next, I outline the relevance of the study, the research problem, the aims of the study and the research design and methodology used in the study. I conclude the chapter by providing a brief summary of the structure of this thesis.

1.2 AUTISTIC SPECTRUM DISORDERS (ASD)

Autism forms part of the family of neurodevelopmental disorders which disrupt the fundamental processes of socialisation, communication and learning, collectively known as Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder (ASD) (Klin, 2006).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), Autism is characterised by widespread impairments in social interaction and communication skills, and by stereotyped patterns of behaviours, interests and activities (American Psychiatric Association (APA), 2000). However, the symptoms, abilities and characteristics of this disorder are expressed in different combinations and in different degrees of severity (Lord, Cook, Leventhal & Amaral, 2000). Thus, Autism is believed to be a spectrum disorder which falls on a continuum of social-communication disability (Leekham, Libby, Wing, Gould & Gillberg, 2000). Many researchers believe that Asperger's Disorder (AD) falls at the high-functioning end of this continuum, between Autism and normality (Howlin, 2003; Klin & Volkmar, 2003).

There is increasing interest in Autistic Spectrum Disorder (ASD). However, most of the research that has been conducted thus far has focused on the educational needs of children with ASD (Hurlbutt & Chalmers, 2002). Thus, little is known about the needs and outcomes of adults with ASD – especially high-functioning adults – and how their **quality of life** can be

enhanced (Howlin, 1997). Professionals and advocates in the field of ASD are only now beginning to acknowledge the importance of understanding the enjoyment and benefit people with ASD obtain from experiences in their homes and communities (Garcia-Villamizar, Wehman & Navarro, 2002).

The limited research that has been conducted on the outcome of adults with ASD has mainly concentrated on two dimensions: descriptive information regarding objective (unidimensional) outcome domains i.e. living and working circumstances (Howlin, Goode, Hutton & Rutter, 2004; Ruble & Dalrymple, 1996), psychiatric functioning (Berney, 2000), academic achievements (Myles & Simpson, 2002); or on the predictive value of variables related to outcome i.e. language skills and communication (Paul, 2003), social functioning (Travis & Sigman, 1998) and IQ (Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001). Very few studies have taken into account subjective variables such as satisfaction and subjective wellbeing (Renty & Roeyers, 2006). Ruble and Dalrymple (1996), who argue that the happiness of people with ASD should be considered as one of the most important aspects in outcome studies, highlight the importance of doing such research.

The construct of QOL is believed to be a more comprehensive, multidimensional outcome measure, which can be used to explore subjective variables such as subjective wellbeing and life satisfaction in adults with disabilities (Cummins & Lau, 2005). It is also believed to be an important measure in monitoring and understanding individual outcomes in adulthood (Halpern, 1993). Furthermore, Dennis, Williams, Giangreco and Cloninger (1993) have suggested that QOL should be the guiding framework in planning and evaluating services for people with disabilities. Moreover, there is increasing awareness that the emerging concept of QOL should also inform policies and services for people with ASD (Garcia-Vallamizar et al., 2002; Jennes-Coussens, Magill-Evans & Koning, 2006; Renty & Roeyers, 2006; Ruble & Dalrymple, 1996).

1.3 QUALITY OF LIFE AND ASD

Quality of Life (QOL) is a broad concept incorporating an individual's physical health, psychological state, level of independence, social relationships, personal beliefs, and his or her relationships with salient features of the environment (The World Health Organisation Quality of Life Group [WHOQOL Group], 1995). QOL is experienced when a person's needs are met and when he or she has the same opportunity as anyone else to pursue and achieve personal goals in the major settings of home, community and work (Schalock, 2000). Over

the past two decades the concept of QOL has increasingly become a focus for research and application in the fields of intellectual and developmental disabilities (Schalock et al., 2005). However, despite growing awareness of the need to use the concept in planning, delivering and evaluating services and support more generally, the factors contributing to the QOL of people with ASD have received relatively little attention (Jennes-Coussens et al., 2006).

During the 1980s and 1990s, the majority of initiatives that were developed for people with ASD were related to learning new skills or increasing adaptive behaviours (Garcia-Villamizar et al., 2002). However, this limited focus often ignored such subjective variables as satisfaction in lifestyle, community involvement, personal control, and social relationships. As mentioned earlier, there is an increasing awareness that the emerging concept of QOL should be used to inform the provision of services for people with ASD and give the people who have previously been ignored a voice.

People with ASD see the world differently from neuro-typical¹ individuals. Jim Sinclair (1993 as cited in Björne, 2006), who has Autism, provides powerful evidence of this:

Autism is a way of being. It is pervasive; it colours every experience, every sensation, perception, thought, emotion, and encounter; every aspect of existence.

It would seem that one of the best ways to learn more about the factors that influence the subjective QOL of adults with ASD is to talk to them and observe them. As a way of increasing the knowledge base about this population's unique needs, perceptions and behaviours, I aim to explore the perceived QOL of three adults with ASD who are currently living in a group home in Cape Town. The name of the housing project has not been included in this study in an attempt to protect the anonymity of the participants.

1.4 RELEVANCE OF STUDY

Internationally, and in South Africa, there appears to be a limited number of housing options for adults with ASD and people with disabilities in general. According to Gutstein (2006), president of the Foundation for Autism Research and Remediation, only about 3% of individuals considered to be high-functioning (meaning that they have at least normal IQ and language capabilities) live independently in Great Britain.

¹ **Neurotypical** (or **NT**) people have neurological development which is consistent with what most people would perceive as normal in their ability to process linguistic information and social cues (Cashin & Sci, 2006).

There do not seem to be any accurate statistics in South Africa for adults with ASD who live independently. However, it seems that there are only a limited number of residential housing programmes which are available for adults with ASD at present. In a recent investigation, Scott (2006) found that, in many instances, people with ASD are excluded from the few residential facilities for learning disabled adults because of their specific needs. The nature of ASD as a disability imposes major demands on the way a group home is set up in terms of routines, communication processes, physical structures and access to expertise.

In the Western Cape, there are only two group homes which cater specifically for adults with ASD. Both are sponsored by Autism Western Cape. The first group home, which was established in 2001 by concerned parents, provides specific services to adults with ASD who are low-functioning and who require high care. This housing project, on the other hand, was established in 2005 to provide independent living within the community for young adults who are high-functioning. To date, it appears that this group home is the only registered facility in South Africa which has been designed specifically for high-functioning adults with ASD who require low care. An evaluation of the effectiveness of this housing initiative on the perceived QOL of its occupants is therefore important and may prove useful to Autism Western Cape. It may make it possible to effect any improvements within the group home. The findings of this study could also contribute towards the establishment of more group homes based on this model.

Conroy and Feinstein (1990 as cited in Garcia-Villamizar et al., 2002:309) argue that evaluations of the quality of services for individuals with developmental disabilities should be focused on the level and type of experiences lived by the consumers. He explains that is not enough to deliver a service and assume the needs of people with ASD will be met simply by providing that service. There is a need to hear the experiences of the consumers themselves, in this case the occupants of the group home, and to evaluate their QOL according to their own perceptions.

The number of individuals with ASD needing community-based services and residential support in South Africa appears to be increasing. There is, therefore, an even greater need to define, assess, implement, and measure an individual's perception of their QOL in order to enhance and provide better support services for them. This study represents an attempt to reflect the voices of the three men with ASD who live in a group home and to share their experiences and perceptions of their QOL.

1.5 GROUP HOMES

1.5.1 Definition

Group homes are small, residential facilities located within a community, designed to serve children or adults with disabilities. Most group homes are standard, single-family houses, often purchased by NGO's or private organisations and adapted to meet the needs of the residents. These homes usually have six or fewer occupants and are staffed 24 hours a day by trained caregivers (Friedrich, 2007).

1.5.2 History and mission

The development of group homes occurred in response to the deinstitutionalisation movement of the 1960s and 1970s (Friedrich, 2007). This development was also driven by the normalisation principle which emphasised the fact that people with disabilities should be given access to living conditions and everyday routines that are as similar as possible to those of ordinary citizens (Grunewald, 2003).

Group homes were designed to provide care in the least restrictive environment and to integrate individuals with disabilities into the community, reducing stigma and improving quality of life. Thus, group homes were developed to provide individuals with disabilities the opportunity to experience 'inclusive living' (Grunewald, 2003). Inclusive living offers people with disabilities the opportunity to live in an environment where they can fulfil their potential and live and participate as equal members of society.

1.5.3 Objectives of a group home

The environment of a group home is intended to simulate typical family life as much as possible. Another major goal is to increase the independence of its residents. To accomplish this, staff members or caregivers often need to teach residents daily living and self-care skills. Daily living skills include meal preparation, laundry, housecleaning, home maintenance, money management, and appropriate social interactions (Friedrich, 2007).

According to the Department of Aging, Disability and Home Care (DADHC, 2007) the aim of any group home should be to provide an individual with the following outcomes:

- Privacy – the client's own room
- Respect
- Access to meaningful activities/community participation

- Development of social networks and relationships and maintenance of familial and cultural networks
- The right to retain personal possessions
- A healthy diet
- Personal hygiene
- A safe, secure and stable environment
- Proper selection and maintenance of clothing
- Accessibility to medical services
- Assistance to live safely in a group
- Development of appropriate interpersonal behaviours
- Improvement and maintenance of communication skills
- Development and maintenance of money and budgeting skills
- Access to a range of generic services
- Planning and assisted access to recreation programs
- Planning for leisure activities and holidays

For this study, a particular group home designed for people with high-functioning ASD was investigated. This housing project was established in 2005 by Autism Western Cape, a regional NGO for Autism. The objective of this specific project was to establish a home within the community setting to provide services and residential care for adults with ASD who are capable of a high level of independent living. This project formed part of the Government's 2010 vision incorporated under the Mental Health Care Act of 2002, in conjunction with the Constitution of the Republic of South Africa of 1996, and the National Integrated Disability Strategy of 1997.

In the next section, a brief description of the home as well as its goals and objectives will be discussed. As I mentioned earlier, the name of the project has been omitted and will be referred to as The Group Home in this paper.

1.5.4 The Group Home

The Group Home is situated next to a School² in the Western Cape which caters for learners with Autism Spectrum Disorder. The aim of project was to supply residential care as well sheltered employment at the School for three to four people with ASD who are high-functioning. At the time of the study, there were only three men residing at the group home and one female caregiver who oversees their every-day living in the home. She also works as a teacher at the School.

The Operational Policy, as quoted below, outlines the objectives, philosophy and service style of Autism Western Cape and describes how this has been developed into a working model of service. This information has been extracted from the original Operational Policy document that was given to me by the Executive Director of Autism Western Cape in November 2007 (Autism Western Cape, 2004).

The establishment of (The Group Home) came about as a result of parent advocacy, dedication, hard work, and the determination to create an adult residential home where the welfare of people with Autism will always be the primary concern.

Table 1.1: Objectives, philosophy and service style of The Group Home

<p><u>OBJECTIVES</u></p> <p><i>The principal objectives of the service are:</i></p>	<ul style="list-style-type: none"> <i>The provision of a life-long residential, caring and developmental service for people with Autism Spectrum Disorder, and related disorders, within a community setting.</i> <i>The provision of a model for future development which will be seen to be particularly appropriate to people with Autism and which will demonstrate their capacity to develop and grow in a service which recognises their human dignity and individual needs.</i>
<p><u>PHILOSOPHY</u></p>	<p><i>The essential philosophy of the service is the recognition of the individuality of people with Autism, their capacity to benefit from education, training, and care and their entitlement to participate in the development of society in accordance with their individual capacity and dignity as human beings.</i></p>
<p><u>SERVICE STYLE - Development of Physical Environment</u></p> <p><i>Autism Western Cape's Model of Service Provision can be identified by the following characteristics:</i></p>	<ul style="list-style-type: none"> <i>A positive functional analysis approach to managing challenging behavior of people with Autism.</i> <i>Minimal use of psychotropic medication for managing behavior.</i> <i>The creation of a socio-developmental model of service rather than a clinical medical model. People with Autism Spectrum Disorder are regarded as persons and not patients.</i>

² The name of the school has also been omitted as a means of protecting the anonymity of the participants.

	<ul style="list-style-type: none"> • <i>Provision of an environment where Autism Spectrum Disorder is understood and people with Autism Spectrum Disorder are accommodated to reach their optimum development.</i> • <i>The development of a homely personal living and working environment is pivotal.</i> • <i>Specialist clinical services of any discipline will be provided on an individual need basis as determined by Autism Western Cape and the Managing Committee.</i> • <i>Provision of such services may be governed by the availability of Primary Health Care as stated in the Constitution of South Africa, assisted by The Departments of Social Development and Health.</i>
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1.6 QUALITY OF LIFE

According to Schalock (2000), there are more than 100 definitions of QOL in the literature today. In this thesis, I use the World Health Organisation's definition of QOL (WHO, 1996:5): Quality of Life is defined as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". This definition reflects the view that QOL should reflect one's subjective experience.

The concept of quality of life (QOL) is increasingly being used internationally in the field of intellectual disabilities in planning, delivering, and evaluating individualised services and supports (Schalock et al., 2005). At an individual level, the QOL construct is being used as a basis for self-advocacy, person-centered planning, and a valued person-referenced outcome measure (Schalock et al., 2002). The concept and application of QOL will be discussed in more detail in Chapter Two.

1.6.1 Quality of Life Assessment

The QOL construct is complex (Cummins & Lau, 2005). As mentioned above, there is neither an agreed-upon definition nor a standard form of measurement. This is not due to a lack of ideas, measurement tools, or research on the subject. A list of about 800 instruments which purport to measure life quality in some form is available on the Australian Centre on Quality of Life website (ACQOL, 2005). This list is provided in Annexure A.

It is also important to note that many QOL instruments have been developed for specific groups in the population, particularly in regard to scales devised to monitor medical conditions or disability types (Cummins & Lau, 2005). Such scales are unsuitable for use with the general population. Similarly, most scales devised for use with general population

samples cannot be used with all sectors of the population, such as people with intellectual impairments and children. These are important limitations since it means that the QOL experienced by minority groups cannot be norm-referenced back to the general population.

In this study, the Personal Well-Being Index for Intellectually Disabled (PWI-ID) population groups was selected. The fundamental component of this scale (PWI) was developed by Cummins and Lau (2005) in response to the criticism of their previous measurement tool, the Comprehensive Quality of Life Scale (ComQol) (Cummins, 1997b; 1997c). These criticisms have been explored in Cummins (2002).

The PWI is a domain-based scale used to evaluate a universal measure of subjective well-being (SWB). Subjective wellbeing, as defined by Diener, Suh and Oishi, (1997), refers to how people evaluate their lives. A person's evaluation of his or her life may be in the form of cognitions (e.g., when a person gives conscious evaluative judgments about his or her satisfaction with life as a whole), or evaluative judgments about specific aspects of his or life such as recreation or standard of living. Thus, a person is said to have a high SWB if she or he experiences life satisfaction and frequent joy, and only infrequently experiences unpleasant emotions such as sadness and anger. On the other hand, a person is said to have a low SWB if he or she is dissatisfied with life, experiences little joy and affection, and frequently feels negative emotions such as anger or anxiety. In this paper, the words subjective wellbeing, subjective QOL, and satisfaction are used interchangeably.

The main reason the PWI was chosen for this study was that it focuses primarily on the *subjective* factors contributing to a person's QOL. This was the primary objective of the current study – to explore the *perceived* QOL of the occupants of the group home.

The Intellectual Disability version of the PWI scale was chosen as the questions were less abstract and it was felt that it would be more suitable to use with participants with ASD (Cummins, Lau, Davey & McGillivray, 2009). Individuals with ASD generally have difficulties in comprehending abstract materials (e.g. metaphors, idioms), understanding inferential based materials, and applying skills and knowledge to solve problems (Myles & Simpson, 2002; Ropar & Peebles, 2007). A unique feature of the PWI-ID is its pre-testing protocol. This protocol includes an initial test for acquiescent responding³. If participants are found to display this characteristic, testing is terminated. Testing for acquiescent responding and Scale competence is important because people with an intellectual disability are likely to

³ Acquiescent responding refers is a tendency of a person to agree with the viewpoint of others (Reber, 1995).

answer in ways they perceive are desired by the interviewer (Cummin & Lau, 2005). More information about the test procedure methodology is provided in Annexure B.

1.6.2 The Personal Wellbeing Index (PWI) Scale – Intellectual Disability

The Personal Wellbeing Index Scale – Intellectual Disability (PWI-ID) is a parallel version of the regular PWI used for general population samples. Both scales have well-developed manuals, normative data, and acceptable psychometric properties (Cummins et al., 2009).

The PWI-ID asks respondents to rate their satisfaction within seven life domains that collectively represent satisfaction with life as a whole. The domains are: standard of living; health; achievement in life; relationships; personal safety; community-connectedness; and future security. These domains are empirically determined to represent the first-level of deconstruction of the concept of QOL, based on a global, abstract question – "How satisfied are you with your life as a whole?" (Cummins & Lau, 2005:5). Evidence for the current domain structure of the PWI has been presented by Cummins (1996), Cummins (1997a) and the International Wellbeing Group (2006).

The personal appraisal strategy addresses the *subjective* nature of QOL – the perceived QOL of the participants. This involves asking the person how satisfied he or she is with the various facets of his or her life. The participant's responses can be interpreted and analysed qualitatively and/or be measured in psychometrically acceptable ways. An 11-point Likert scale is often used to indicate the person's level of expressed satisfaction. In this study, responses will be interpreted both qualitatively and quantitatively.

The advantages of this measurement tool are that it encompasses the most common dependent measure (satisfaction) used in current QOL assessment research (Cummings & Lau, 2005). This instrument will be briefly discussed in the data collection section but will be discussed in more detail in Chapter Three.

1.7 STATEMENT OF THE PROBLEM

As far as I could establish, no research has yet been conducted in South Africa on the subjective experiences of individuals with ASD who live in a group home. In attempting to do such research, the main problem statement was: **What is the perceived quality of life of each of the three men with Autism Spectrum Disorder who are living in the group home?**

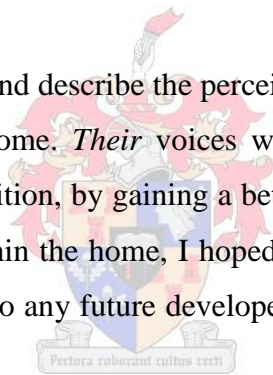
In addition to the main problem statement, there were three sub-research questions. These were:

- Which of the 7 core domains in the PWI-ID scale represent the highest and lowest levels of subjective wellbeing for each participant?
- Do the participants think that their residence at The Group Home has enhanced their overall QOL?
- Are there any aspects of The Group Home that the participants think could be altered to enhance their perceived QOL?

The knowledge produced from this study and the recommendations given to the sponsors of the project could be of value if and when other community homes like this group home are established.

1.8 RESEARCH AIM

The aim of this study was explore and describe the perceived QOL and the experiences of the three men living in The Group Home. *Their* voices were used, therefore, to evaluate the effectiveness of this project. In addition, by gaining a better understanding of the factors that influence their perceived QOL within the home, I hoped to provide recommendations to the sponsors of The Group Home and to any future developers of other group homes to improve their QOL.



1.9 RESEARCH DESIGN

1.9.1 Introduction

This paper is written in first-person as is encouraged by Mouton (2001:130) who explains that, "nowadays it is perfectly acceptable, and even encouraged to let the author speak!" Richardson (1998:346) explains that writing from 'our Selves' strengthen individual voices and we, as writers, are demystified, more fully present, more honest, and more engaged in the writing of our work. Furthermore, research is never truly neutral, and it is important for researchers to take into account the impact they have on the context of the study and on the development of the interpretive account (Kelly, 1999).

According to Mertens (1998:2), research is a process of inquiry that is designed to collect, analyse, and interpret data. This data is then used to understand, describe, predict, or control phenomenon or to empower individuals.

Firstly, research originates from a question. A researcher seeks out information related to that question and tries to make sense of it so that the question can be answered. Following this, a researcher must make a series of decisions along four dimensions: 1) the purpose of the research; 2) the theoretical paradigm informing the research; 3) the context or situation within which the research should be carried out; and 4) the research techniques to be employed to collect and analyse the data (Durrheim, 1999). The considerations that derive from these four dimensions need to form a coherent strategic research design that will guide the entire research process. The research design therefore provides the plan that specifies how the research is going to be executed in order to maximise valid conclusions.

In this study, the research question was identified. It was then necessary to make a series of decisions about how the research question could best be answered by an investigation. In this study, the following research design was chosen to ensure design validity and coherence, and to maximise the validity of the findings:

Research Question	What is the perceived QOL of each of the three men with ASD who are living in the group home?
The theoretical paradigm	Interpretivist paradigm
Purpose of the study	To explore the perceived QOL of the three occupants in the group home
Context or situation	The research takes place at the home
Research design	Qualitative design
Research method	Multiple case study
Data production	<ul style="list-style-type: none"> • Two structured interviews (based on the PWI-ID Scale); • Two semi-structured interviews; • Two focus group interviews; and • Observations

1.9.2 Theoretical paradigm

According to Terre Blanche and Durrheim (1999:6), paradigms are ways of thinking and interrelated practices that guide the researchers along three dimensions:

- Ontology: specifies the nature of reality that is to be studied, and what can be known about it;
- Epistemology: specifies the nature of the relationship between the researcher and what can be known; and
- Methodology: specifies how the researcher goes about practically studying whatever he or she believes can be known.

Paradigms provide a rationale for the research and guide the researcher towards the particular methods of data collection, observation and interpretation that need to be executed. A paradigm is therefore pivotal to the research design because it has a bearing on the nature of the research question (what is to be studied), as well as on the manner in which the question is to be studied (Durrheim, 1999:36).

This study will be located in the interpretivist paradigm. Within this paradigm, "researchers assume that people's subjective experiences are real and should be taken seriously (ontology), that we can understand others' experiences by interacting with them and listening to what they tell us (epistemology), and that qualitative research techniques are best suited to this task (methodology)" (Terre Blanche & Kelly, 1999:123).

Within this paradigm, the ontological belief is that there is no objective reality, rather an internal reality that lies within an individual's subjective experience (Merriam, 1998). Hence, the researcher will need to take on an intersubjective or interactional epistemological stance towards the reality of each participant, which will allow him or her to see the reality from the point of view of that participant (Terre Blanche & Durrheim, 1999:6). By doing this the researcher may bring in an interpretation of reality to the research context which interacts with the participant's interpretations of the phenomenon being studied. It is therefore of vital importance in this type of research that researchers remain mindful of their own subjective perceptions and biases within the context of their study.

In this study, I wanted to explore the subjective world of each participant – *their* internal reality – the way *they* perceive their QOL. I was also interested in using a more personal, interactive mode of data production. This study is, therefore, best located in the interpretivist

paradigm as it attempts to understand the way human beings (the men at the home) understand and experience their lives from *their* perspective.

1.9.3 Purpose of study

By specifying the nature of reality that can be known, paradigms provide broad frameworks for research purpose (Terre Blanche & Durrheim, 1999). In addition, the theoretical paradigm guides what units of analysis are going to be investigated and what type of conclusions can be drawn from these analyses.

The *units of analysis* have an impact on sample selection, data production and the types of conclusions that can be drawn from the research (Durrheim, 1999). In this study, all three participants who live at the home will be the units of analysis.

The *type of study* is driven by what researchers wish to attain through their study (Durrheim, 1999). The purpose of this study was to *explore* the perceived QOL of the three men living in the home. Therefore, this study was exploratory in nature. Exploratory studies are generally used to make preliminary investigations into relatively unknown areas of research and are often open, flexible and inductive (Durrheim, 1999). As mentioned earlier, no previous research had been conducted on the effectiveness of the project on the perceived QOL of its occupants. As a result, an exploratory study was the most appropriate design in order to explore and investigate this phenomenon.

The findings of this research could be used to contribute to any potential improvements to the home and to provide guidance for future developers of other community-based group homes. The study may thus be said to have a practical application.

1.9.4 Research design

The distinction between qualitative and quantitative research marks a series of differences in approaches to data production, analysis and interpretation (Mouton, 2001). The distinction is made on the grounds that qualitative and quantitative researchers base their conclusions on different kinds of information and employ different techniques of data production and analysis. Quantitative researchers collect data in the form of numbers and use statistical types of data analysis; whereas qualitative researchers produce data in the form of spoken and written language or in the form of observations that are recorded in language. They then analyse the data by identifying and categorising themes (Durrheim, 1999:42).

In this study, a primarily qualitative approach was used. Quantitative approaches have traditionally been used for QOL research, but there has been a recent increase in the use of qualitative approaches in QOL research (Brown & Brown, 2005; Verdugo, Schalock, Keith & Stancliffe, 2005). I adopted a more qualitative approach so I could explore the experiences of these three men from their subjective perspective. This allowed me to gain a better understanding of the complexities, richness and diversity in their lives. Essentially, the frame of reference had to be *theirs*.

1.9.5 Research method

In this qualitative study, a multiple case study method of enquiry was used. According to Stake (1994), case study research should not be defined by a specific methodology, but rather by the object of study. He suggests that the more the object of study is a specific, unique bounded system, the greater the rationale for calling it a case study. Merriam (1998:27) describes a case as a thing, a single entity, a unit which can be 'fenced in'. A case could therefore be one person; a programme; a group of people; or a specific policy, for instance.

In this study, a multiple case study method was employed. A multiple case study involves collecting and analysing data from several cases. A set of three cases of the same research entity was examined in this study. The group home acted as the bounded system and each participant was a unique case for investigation.

1.9.6 Participants

I selected all three participants that were living at the home at the time using purposive sampling, also known as judgment sampling. This technique helps to select samples of exceptional or atypical populations or populations that are difficult to reach. Thus, participants were selected with a specific purpose in mind (van Vuuren & Maree, 1999). There were only three men living at the home at the time of the study and it was in the best interest of the study to invite all three occupants of the house to participate in the study. This would allow me to gain a better understanding of the dynamics within the home. The participants were informed about the purpose of the study and the voluntary nature of their participation in the study. The demographics and background information of the participants will be provided in greater depth in Chapter Four.

Participant	Age	Arrival at The Group Home
Participant 1	26 years	April 2005
Participant 2	35 years	September 2005
Participant 3	24 years	April 2005

1.9.7 Data production

I decided to make use of the term 'data production' rather than the term 'data collection' in light of the interpretive approach which provides the framework for this study. This term reflects the notion that one ultimate reality does not exist, but instead it is constructed according to one's own unique perceptions and experiences (Hollway & Jefferson, 2000). As a researcher, my own subjective reality shaped the way I interpreted, collected and then produced the data. Thus, the word 'production' implies that information was gathered and produced in a social process of giving meaning to the social world, as opposed to 'data collection' which implies that 'facts' were available out there ready for collection. The intention within this study was the production of knowledge and understanding into the perceived QOL of the three men living in a group home.

This study relied primarily on the findings of two structured interviews with each participant. These interviews were based on the Personal Wellbeing Index for Intellectual Disability (PWI-ID). In addition, the study made use of participant observations undertaken during two semi-structured interviews with each participant and two focus group interviews. A preliminary literature review was also conducted to provide a context for the study. This allowed me to gain an understanding into previous research done in the field of ASD and QOL.

1.9.7.1 The Personal Wellbeing Index – Intellectual Disability (PWI-ID)

The PWI-ID scale was used to assess each participant's subjective QOL in seven domain areas. Below is a table containing the questions included in the PWI-ID as well as the life domains they represent. The domains as well as the administration of the scale will be discussed in more detail in Chapter Three.

Table 1.2: The PWI-ID questions and the life domains they represent

Life domains	PWI-ID questions
	How happy do you feel about ...?
Standard of living	<ul style="list-style-type: none"> the things you have, like the money you have or the things you own?
Personal health	<ul style="list-style-type: none"> how healthy you are?
Life achievement	<ul style="list-style-type: none"> the things you make and the things you learn?
Personal relationships	<ul style="list-style-type: none"> getting on with the people you know?
Personal safety	<ul style="list-style-type: none"> how safe you feel?
Community connectedness	<ul style="list-style-type: none"> doing things outside your home?
Future Security	<ul style="list-style-type: none"> how things will be later on in your life?

Strategies employed to reduce response bias effects in this study included use of one-on-one interviews when administering the battery, explicitly stating that information would be confidential, checking the understanding of words and concepts and the optional use of visual aids to assist in the understanding of Likert scale response formats. According to Cummins and Gullone (2000), the Likert scale format is a reliable, valid and sensitive measurement tool to assess subjective QOL.

1.9.7.2 Semi-structured interview

According to Kvale (1996), an interview requires that a researcher listen to what people say and what meaning they give to their lives. A qualitative research interview therefore attempts to understand the world from the participant's point of view. In this study, the semi-structured interviews allowed the participants an opportunity to express their opinions about their QOL in the home from their own perspective. It also gave me an opportunity to gather some background information from the participants.

1.9.7.3 Focus group interview

'Focus group' is a general term given to a research interview conducted with a number of participants (Mertens, 1998). According to Kelly (1999:388), when interviewing an individual, one develops an understanding of subjective experience, whereas when one works

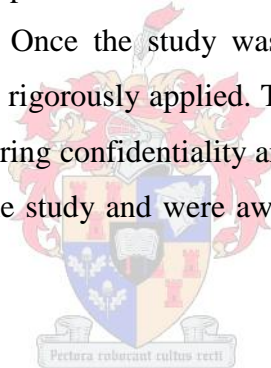
with groups, one can gain access to 'intersubjective experience'. Intersubjective experience is experience shared by a community of people. In this study, all participants were asked to take part in the focus group interviews.

1.9.7.4 Participant observation

Observation is believed to be the second most popular form of data production in interpretive research (Terre Blanche & Kelly, 1999). In participant observation, the researcher interacts with the participants while collecting data and becomes fully involved in the setting being studied (Mertens, 1998). Observations in this study were not a primary method of data production, but were used to verify my interpretations of the interviews and in gaining insight into the interaction styles of the participants.

1.10 ETHICAL CONSIDERATIONS

Prior to conducting the interviews, permission to undertake the study was sought from the Executive Director of the project. Once the study was underway, the ethical criteria for research in the social sciences were rigorously applied. This included obtaining the informed consent of the participants and ensuring confidentiality and anonymity. The participants were aware of the voluntary nature of the study and were aware that they could withdraw at any stage during the process.



1.11 DATA ANALYSIS

According to Mouton (2001), the aim of analysis is to understand the various components of one's data through a thorough investigation of the relationships between concepts, constructs or variables, and to see whether there are any patterns or themes that can be established in the data. The purpose is therefore not merely to collect pieces of 'real-life' information, but to place real-life events and phenomena into some kind of perspective (Durrheim, 1999).

In order to explore the subjective experiences and perceptions of life quality of three participants in this study, a detailed analysis of what the participants said in their interviews and did during the observation was needed.

In order to do this, all the interview data were recorded and transcribed verbatim. This data were then analysed using thematic content analysis in the way described by Braun and Clarke (2006). This involved the following 6 steps: 1) Familiarising yourself with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and

naming themes; and 6) Producing the report. These steps will be discussed in more detail in Chapter Three.

The data collected from the PWI-ID structured interviews were also evaluated quantitatively using the quantitative scoring method outlined in the instrument guidelines which are discussed in Chapter Three (Cummins & Lau, 2005). This information was thereafter integrated and interpreted into the results section in a more qualitative manner.

In an attempt to increase the validity of information in this study, a research strategy known as triangulation was implemented in the research process. Methodological triangulation entails collecting material in as many different ways and from as many diverse sources as possible, to increase confidence in the interpretation (Tellis, 1997; Terre Blanche & Kelly, 1999).

1.12 CLARIFICATION OF KEY CONCEPTS

A brief description of the key concepts used in this study is provided below:

Asperger's Disorder is a pervasive developmental disorder characterised by impairments in social relationships and unusual patterns of interest and behaviour with relatively intact cognitive skills, but without the language delays seen in Autism.

Autism is a pervasive developmental disorder characterised by widespread impairments in social interaction and communication skills, and by stereotyped patterns of behaviours, interests and activities.

The term **Autistic Spectrum Disorder** and the term **Pervasive Developmental Disorder** are used interchangeably to describe a spectrum of disorders which are all characterised by significant impairments in social and communication skills and stereotypes patterns of interests and behaviours. There are five disorders believed to fall on this spectrum of social-communication disability. These include: Rett's Disorder; Childhood Disintegrative Disorder, Autism, Asperger's Disorder and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS).

The term **disability** from a social perspective is seen as an internal condition which is not necessarily undesirable or in need of remediation. From this perspective, disability is viewed as the incapacity to function in a disability-hostile environment in which barriers clash with individual choice. A social model of disability therefore aims to remove societal or

environmental barriers in order to facilitate the full development of the individual's social, physical, vocational and belief systems (Uys, 2005).

The term **intellectual disability** refers to individuals who experience an intellectual barrier to learning and often experience difficulties in adjusting to the conventional social norms of society (Jooste & Jooste, 2005).

A **group home** provides accommodation and (usually) 24 hour support to people with disabilities in group setting for between four to six people. In the group home, clients are supported in their daily living. The location of the home is usually accessible to services in order to meet client's needs, including family or social support, transport, commercial services, education, medical, employment and recreational facilities (DADHC, 2007).

A person's **perception** gives them knowledge of the world around them, how they see, perceive and understand their world. This knowledge of the world is therefore based on their beliefs, desires and experiences of the world and is completely unique (Pollock, 2008).

Quality of life is the degree of well-being felt by an individual or group of people. Unlike standard of living, quality of life is not a tangible concept, and therefore cannot be measured directly. Over the past two decades, quality of life (QOL) has increasingly become an important means for understanding the needs and lives of people with disabilities, and as an outcome indicator for interventions or services. Subjective quality of life, also known as subjective wellbeing (SWB) refers to how people feel about their lives.

The term **subjective** in this sense refers to the fact that the fundamental nature of any experience can only be experienced and known internally and privately by an individual and that this experience can never be publicly known but only inferred by others. By asking an individual about their subjective experiences however can provide one with a deeper understanding into a person's own unique internal world.

1.13 STRUCTURE OF PRESENTATION

In **Chapter One**, I outlined the aims and context of the study as well as the research questions, approach and methods used in the study in order to orientate the reader to the purpose and direction of the study.

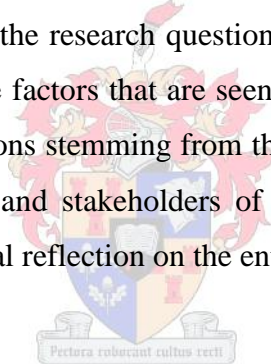
In **Chapter Two** I provide the reader with a review of the most authoritative scholarship and available knowledge on the subject of QOL and Autism Spectrum Disorder (ASD).

Chapter Three presents a detailed account of the method of inquiry. I discuss how I used a predominantly qualitative approach to investigate the perceived QOL of the three participants. I also describe the different techniques which were used to produce the data. Lastly I discuss how I met the demands of ethical research.

In **Chapter Four**, the implementation of the study is discussed. The participants are introduced and the interview and analysis process are described. My interpretations of the data, as well as the main themes as they emerge from the different sources, are provided in table form. Dominant themes in the data set are then identified as a precursor to interpretation.

In **Chapter Five**, I provide a detailed discussion of the dominant themes in relation to the literature and the research questions. In this chapter, the voices of the three participants are explored and described.

Finally, in **Chapter Six** I briefly summarise the previous chapters before discussing the main findings of the study in relation to the research questions and my own interpretations of the research process. I also indicate the factors that are seen as limiting to the study and discuss the implications and recommendations stemming from this research. These recommendations will be presented to the sponsors and stakeholders of the home for their consideration. I conclude this chapter with a personal reflection on the entire research process.



CHAPTER TWO

REVIEW OF THE LITERATURE

2.1 INTRODUCTION

The purpose of this study is not to focus on what Autistic Spectrum Disorders (ASD) are but rather on how they influence an individual's quality of life (QOL). For that reason, I give a brief description of ASD and the impairments associated with ASD in adulthood in this chapter. My focus is primarily on individuals on the higher end of the continuum – individuals with high-functioning Autism (HFA) and Asperger's Disorder (AD), as the participants in my study fall at this end of the spectrum. I also include a comprehensive description of the concept and use of quality of life (QOL) in the evaluation of services for people with disabilities.

2.2 DESCRIPTION OF AUTISTIC SPECTRUM DISORDER

2.2.1 Autism

Autism is defined as a complex, variable, biologically-based, pervasive developmental disorder which influences both the development as well as the functioning of the brain (Koudstaal, 2006). Autism does not only consist of one primary impairment, but rather several impairments that affect an individual's social-emotional, language and cognitive development (Mash & Wolfe, 2005).

Autism is a broad-spectrum neurological disorder which means that its symptoms, range of abilities and characteristics are expressed in different combinations (Hardman, Drew & Egan, 2002). Regardless of the manifestations of Autism, all people on the spectrum are affected to varying degrees by the "triad of impairments" (Wing, 2005, as cited in Moore, 2005:61). To be on the Autism spectrum, an individual should present with an: 1) impairment of reciprocal social interaction, 2) impairment of language and 3) impairment in reciprocal communication, imagination and social understanding (flexible thinking) (Szatmari, 2000).

Although Autism has historically been associated with a seriously reduced level of functioning, a broad range of capacity and severity can be seen, ranging from individuals with severe impairments – who may be silent and locked into a world of hand-flapping and

rocking – to less impaired individuals who may have active but distinctly peculiar social approaches, narrowly focused interests, and verbose, pedantic communication (Klin, 2006). Acknowledgement of this has led to the use of the concept 'Autistic Spectrum Disorders' to cover the range of Pervasive Developmental Disorders (PDDs) which are characterised by widespread abnormalities of social interactions and communication, severely restricted interests and highly repetitive behaviour (Szatmari, 2000).

Many researchers believe that Autism falls at the one end of the spectrum and Asperger's Disorder (AD) on the other milder, high-functioning end of the spectrum (Howlin, 2003; Klin & Volkmar, 2003). If an individual has symptoms of either Autism or Asperger's Disorder, but does not meet the specific diagnostic criteria for either, a diagnosis is given called Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Other rare, very severe disorders that are included on the spectrum are Rett's Disorder and Childhood Disintegrative Disorder (National Institute of Mental Health (NIMH, 2007). A summary of the characteristics and diagnostic criteria for all five PDDs as described by Lord et al. (2000) is provided in Annexure C.

Autism was first described in 1943 by a psychiatrist named Leo Kanner who identified 11 children who, in their first few years of life, "withdrew into their shells, disregarded people for objects, avoided eye contact, lacked social awareness, had limited or no language, and displayed stereotyped social behaviours" (Mash & Wolfe, 2005:284). Kanner's original descriptions of Autism in 1943 are still evident in our current diagnostic guidelines (Tantam, 2003). Hence, Autism is often still referred to as 'Kanner's Autism', 'Classic Autism' or 'Childhood Autism'. In this thesis, the term 'Autistic Disorder' and 'Autism' will be used interchangeably. The current diagnostic criteria for Autism according to the DSM-IV-TR (APA, 2000) are included below:

Table 2.1: DSM-IV-TR Diagnostic criteria for Autism

<p>DSM-IV-TR Diagnostic criteria for 299.00 Autistic Disorder</p> <p>A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):</p> <ol style="list-style-type: none"> 1) Qualitative impairment in social interaction, as manifested by at least two of the following: <ul style="list-style-type: none"> • marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction • failure to develop peer relationships appropriate to developmental level • a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) • lack of social or emotional reciprocity. 2) Qualitative impairments in communication as manifested by at least one of the following: <ul style="list-style-type: none"> • delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime) • in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others • stereotyped and repetitive use of language or idiosyncratic language • lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level. 3) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following: <ul style="list-style-type: none"> • encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus • apparently inflexible adherence to specific, non-functional routines or rituals • stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements) • persistent preoccupation with parts of objects <p>Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.</p> <p>The disturbance is not better accounted for by Rhett's Disorder or Childhood Disintegrative Disorder.</p>

Autism is often divided into *low-functioning* Autism (LFA) and *high-functioning* Autism (HFA) based on IQ thresholds, or on how much support the individual requires in daily life (Baron-Cohen et al., 2001). These labels are generally used to divide the Autism spectrum

into two divisions based on how close the subject's behaviour is to that of non-autistics or neurotypical individuals. Those whose behaviour tends toward the more Autistic side of the spectrum are seen to be 'low-functioning' and the other group whose behaviour resembles that of the non-Autistic is referred to as 'high-functioning' or having 'Asperger's Disorder'. These subdivisions are however, not standardised and are controversial (Fitzgerald & Corvin, 2001; Klin, 2006; Szatmari, 2006).

Much debate has risen regarding what represents functional variations within Autism and what constitutes separate disorders (Klin & Volkmar, 2003). Asperger Disorder has been one such condition. Some researchers still argue that Asperger Disorder is a distinct disorder (Fitzgerald & Corvin, 2001) whereas others contend that it is a higher-functioning version of Autism (Howlin, 2003).

2.2.2 Asperger's Disorder

In the field of Autism research, Asperger's Disorder is a relatively late arrival (Baron-Cohen & Klin, 2006). Although the disorder was first described by Hans Asperger in 1944, few were aware of this autism-related condition until it was brought to the attention of the clinical community by Lorna Wing in 1981 (Wilkinson, 2007).

Asperger's Disorder is characterised by severe and sustained impairment in social interaction combined with restricted, repetitive and stereotyped patterns of behaviour, interests and activities (APA, 2000). It differs from Autism in that few clinically significant delays in language and cognitive development are apparent (Howlin, 2003). Individuals with Asperger's Disorder commonly share characteristics such as a tendency to focus intensely on areas of interest, hyposensitivity or hypersensitivity to certain stimuli, sensory integration problems, self-stimulating behaviours such as rocking back and forth (Myles & Simpson, 2002), and difficulty interpreting facial expressions and other social cues (Tantam, 2003). The current diagnostic criteria for Asperger's Disorder according to the DSM-IV-TR (APA, 2000) are included below:

Table 2.2: DSM-IV-TR Diagnostic criteria for Asperger's Disorder**DSM-IV-TR Diagnostic criteria for 299.00 Asperger's Disorder**

- A) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - 1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - 2) failure to develop peer relationships appropriate to developmental level
 - 3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - 4) lack of social or emotional reciprocity
- B) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
 - 1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - 2) apparently inflexible adherence to specific, non-functional routines or rituals
 - 3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - 4) persistent preoccupation with parts of objects
- C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.
- F) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

As mentioned earlier, there is significant controversy over the difference between Asperger's Disorder and the broader category of high-functioning Autism (HFA). While neither Asperger's Disorder nor HFA have universally accepted definitions (Howlin, 2003), most diagnostic manuals distinguish the two according to speech development i.e. DSM-IV-TR; ICD-10. Delayed speech and normal IQ indicates HFA and the normal onset of speech indicates Asperger's Disorder (Woodbury-Smith, Robinson, Wheelwright & Baron-Cohen, 2005). A language delay is defined as not having used single words by 2 years of age and/or phrase speech by 3 years of age (Baron-Cohen et al., 2001). Besides this variation, the exact relationship between Asperger's Disorder and HFA is unclear, and, in view of the many

similarities in clinical presentation between Asperger's Disorder and HFA, the term Asperger's Disorder will loosely applied to individuals on the higher end of the spectrum.

In this study, the participants lie on the higher-functioning end of the continuum. For this reason, I will mainly focus on the key characteristics associated with Asperger's Disorder. In the next section, I will briefly discuss the prevalence of ASD.

2.2.3 Prevalence

The prevalence of ASD has been a difficult figure to formulate as is evident by the array of varying figures in the research (Bryson & Smith, 1998; Fombonne, 1996; Fombonne & Tidmarsh, 2003). This may be due to changes in diagnostic criteria over time as well as the general heightened awareness of the variability in the expression of ASD (Hardman et al., 2002).

Until fairly recently, ASD was considered rare and thought to occur in only about 4 - 5 per 10 000 (Bryson & Smith, 1998). This estimate was derived from prevalence studies conducted prior to 1985 which relied heavily on Kanner's (1943) description of the 'Classic Autistic' phenotype. More recent studies have yielded rates more than twice as high, which has led to considerable controversy about whether or not there has been a real increase in prevalence (Bryson, 1996; Fombonne, 1996; Volkmar, Lord, Bailey, Schultz & Klin, 2004). Central to the controversy is whether the apparent increase is due to definitional changes and the increased awareness of the heterogeneity of the spectrum or to a genuine increase in incidence (Hardman et al., 2002).

The prevalence of Asperger's Disorder has also not been firmly established (Fombonne & Tidmarsh, 2003), but conservative estimates using the DSM-IV criteria indicate that 2 to 3 of every 10 000 people have the condition. However, the DSM-IV and ICD-10 criteria for Asperger's Disorder have been largely criticised for being too restrictive and often deemed unworkable in clinical practice (Attwood, 2007; Fitzgerald & Corvin, 2001; Szatmari, 2000). The diagnostic criteria of choice by many clinicians, especially in Europe, the U.K. and Australia, are those of Gillberg (1989, as cited in Brink, 2008:5), as they represent more accurately the original descriptions of Hans Asperger. In a recent study by Ehlers and Gillberg (1993), in which the Gillberg criteria were used, findings showed that Asperger's Disorder may be more common than originally thought and more common than 'Classic Autism' (at 36 per 10 000 children for Asperger's Disorder and 5 per 10 000 for Autism).

As mentioned earlier, the prevalence of ASD internationally has been difficult to capture. According to Autism South Africa (2008), the incidence of ASD seems to be on the increase with the latest research implying that this disability now affects approximately 1 per 168 births and is found to occur in 4 times as many boys as girls (Autism South Africa, 2008). Other studies have also made reference to the disproportionate number of males being diagnosed with ASD (Berney, 2000; Bryson & Smith, 1998; Wilkinson, 2007).

2.2.4 Diagnosis of Asperger's Disorder

As discussed, the diagnosis of Asperger's Disorder can be a daunting task, especially in the adult population. Firstly, Asperger's Disorder is often harder to diagnose than Autism as it presents with more subtle impairments in the core clinical phenotype domains (Woodbury-Smith et al., 2005). Secondly, the differentiation of Autism from Asperger's Disorder according to DSM-IV and ICD-10 criteria depends on the time of onset of language and cognitive functions, and this information is often lacking, especially in adults. Finally, there is a great deal of disagreement about the validity of the diagnostic criteria used in the DSM-IV-TR (APA, 2000) and the ICD-10 (WHO, 1992) to distinguish between these two disorders (Fitzgerald & Corvin, 2001; Szatmari, 2000). Indeed, several studies now suggest that if the DSM-IV-TR/ICD-10 criteria are applied, a diagnosis of Asperger's Disorder becomes unlikely (Howlin, 2003). Hence, Gillberg's criteria (1991 as cited in Autism South Africa, 2008) are often used in clinical practice for the diagnosis of Asperger's Disorder. An example of Gillberg's diagnostic criteria is provided below.

Table 2.3: Gillberg's (1991) Diagnostic criteria for Asperger's Disorder (Autism South Africa, 2008)

The Gillberg Diagnostic Criteria for Asperger's syndrome

Severe Impairment in Reciprocal Social Interaction (At least two of the following):

- a) inability to interact with peers;
- b) lack of desire to interact with peers;
- c) lack of appreciation of social cues;
- d) socially and emotionally inappropriate behaviour.

All-absorbing narrow interests (At least one of the following)

- a) exclusion of other activities;
- b) repetitive adherence;
- c) more rote than meaning.

Imposition of routines and interests (At least one of the following)

- a) which affect on self, in aspects of life;
- b) on others.

Speech and language problems (At least 3 of the following)

- a) delayed development of speech;
- b) superficially, perfect expressive language;
- c) formal, pedantic language;
- d) odd prosody, peculiar voice characteristics;
- e) impairment of comprehension, including misinterpretations of literal/implied meanings;

Non-verbal communication problems (At least one of the following)

- a) limited use of gestures;
- b) clumsy/gauche body language;
- c) limited facial expression;
- d) inappropriate expression;
- e) peculiar, stiff gaze.

Motor Clumsiness

Poor performance on neuro-developmental examination

All six criteria must be met for confirmation of diagnosis

There are also a few phenotypic instruments which are helpful for screening adults who may have Asperger's Disorder. These include:

- The *Autism Spectrum Disorder in Adults Screening Questionnaire* (ASDASQ) (Nylander & Gillberg, 2001);
- The *Autism Spectrum Quotient* (AQ) (Baron-Cohen et al., 2001);
- The *Empathy Quotient* (EQ) (Baron-Cohen & Wheelwright, 2004);
- The *Friendship Questionnaire* (FQ) (Baron-Cohen & Wheelwright, 2003);

In this study however, the aim was not to diagnose the three participants, but rather to explore their perceptions of their quality of life. In the next section, I will briefly discuss some of the characteristics commonly found in individuals with Asperger's Disorder.

2.2.5 Key characteristics

The characteristics of Asperger's Disorder vary from one person to another but are generally divided into three main groups: 1) difficulty with social communication; 2) difficulty with social interaction; and 3) difficulty with social imagination. The following information has been provided by the British National Autistic Society (NAS, 2008).

Table 2.4: Dominant characteristics of Asperger's Disorder (NAS, 2008)

<p>Difficulty with social communication</p>	<p><i>People with Asperger's Disorder sometimes find it difficult to express themselves emotionally and socially. For example, they may:</i></p> <ul style="list-style-type: none"> <i>• have difficulty understanding gestures, facial expressions or tone of voice;</i> <i>• have difficulty knowing when to start or end a conversation and choosing topics to talk about;</i> <i>• use complex words and phrases but may not fully understand what they mean;</i> <i>• be very literal in what they say; and</i> <i>• may have difficulty understanding jokes, metaphors and sarcasm.</i>
<p>Difficulty with social interaction</p>	<p><i>Unlike a person with 'Classic Autism', who often appears withdrawn and uninterested in the world around them, many people with Asperger's Disorder want to be sociable and enjoy human contact. Many find it difficult to understand non-verbal signals, including facial expressions which make it more difficult for them to form and maintain social relationships with people unaware of their needs. For example, they may:</i></p> <ul style="list-style-type: none"> <i>• not understand the unwritten 'social rules' that most of us pick up without thinking, e.g. they may stand too close to another person, or start an inappropriate topic of conversation;</i> <i>• find other people unpredictable and confusing;</i> <i>• become withdrawn and seem uninterested in other people, appearing almost aloof; and</i> <i>• may behave in ways that seem inappropriate.</i>
<p>Difficulty with social imagination</p>	<p><i>People with Asperger's Disorder can be imaginative in the conventional use of the word, e.g. many are accomplished writers, artists and musicians. But people with Asperger's Disorder can have difficulty with social imagination. This can include:</i></p> <ul style="list-style-type: none"> <i>• imagining alternative outcomes to situations and finding it hard to predict what will happen next;</i> <i>• understanding or interpreting other peoples thoughts, feelings or actions; and</i> <i>• having a limited range of imaginative activities, which can be pursued rigidly and repetitively i.e. lining up toys or collecting and organising things related to his or her interest.</i>

The above characteristics are the three dominant characteristics associated with Asperger's Disorder; however there are some other related features. These are briefly discussed below.

Table 2.5: Related features of Asperger's Disorder (NAS, 2008)

<i>Routine</i>	<i>To try and make the world less confusing, people with Asperger's Disorder may have rules and rituals (ways of doing things) which they insist upon. People with Asperger's Disorder often prefer to order and plan their day in a specific routine, e.g. if they work set hours, an unexpected delay to their journey to or from work can make them anxious or upset.</i>
<i>Special interests</i>	<i>People with Asperger's Disorder may develop an intense, sometimes obsessive, interest e.g. a person with Asperger's Disorder may focus on learning all there is to know about trains or computers. Some are exceptionally knowledgeable in their chosen field of interest. With encouragement, interests and skills can be developed so that people with Asperger's Disorder can study or work in their favourite subjects.</i>
<i>Sensory difficulties</i>	<i>People with Asperger's Disorder may have sensory difficulties. These can occur in one or all of the senses (sight, sound, smell, touch, or taste). The degree of difficulty varies from one individual to another. Most commonly, an individual's senses are intensified (over-sensitive) or underdeveloped (under-sensitive) e.g. bright lights, loud noises, overpowering smells, particular food textures and the feeling of certain materials can be a cause of anxiety and pain for people with Asperger's Disorder.</i>

Of all these characteristics, the impairment in social reasoning or perspective-taking, also known as *theory of mind* (Baron-Cohen, Leslie & Frith, 1985; Bowler, 1992), is believed to be the most prominent and defining feature of the condition (Attwood, 2007). Consequently, people with Asperger's Disorder have difficulty understanding and appreciating the feelings and thoughts of others. These challenges include: a) difficulty inferring the intentions of others, b) a lack of understanding of how their own behaviour affects others, and c) difficulty with turn-taking and other reciprocal skills (Myles & Simpson, 2002). Thus, most people with Asperger's Disorder are often unable to put themselves into the 'mind' of another person, which is a prerequisite for empathy.

It is most often the secondary problems associated with their social impairments that bring the person with Asperger's Disorder to the clinician for treatment (Wilkinson, 2007). Many are chronically frustrated by their feelings of social isolation, rejection, and their difficulty establishing friendships (Orsmond, Krauss & Seltzer, 2004). Consequently, many adults with Asperger's Disorder also suffer from other mental health problems that require treatment (Klin, Pauls, Schultz & Volkmar, 2005). In fact, comorbidity appears to be the rule rather

than the exception (Wilkinson, 2007). Depression and anxiety are the most common co-morbid psychiatric conditions reported for individuals with Asperger's Disorder (Ghazuiddin, 2002).

2.2.6 Outcome in adulthood

As mentioned in Chapter One, there have been very few studies that have focused on the outcome of high-functioning adults with ASD (Howlin et al., 2004). In a review of the available literature, it was found that the majority of these studies had focused on objective unidimensional domains related to outcome (Howlin, 2000; Howlin et al., 2004; Myles & Simpson, 2002; Ruble & Dalrymple, 1996). In these studies, it was found that only a minority of adults with ASD had received college or university education, lived semi-independently, had close, spontaneous friendships, were married, or had a paid job. Of these studies, very few had taken into account subjective variables such as life satisfaction and subjective wellbeing (SWB) in their evaluation of outcome (Ruble & Dalrymple, 1996).

The construct of QOL is believed to be a more comprehensive, multidimensional outcome measure which can assess subjective variables such as subjective wellbeing (SWB) (Cummins & Lau, 2005). In addition, it is also believed to be an important measure in monitoring and understanding individual outcomes in adults with disabilities (Halpern, 1993). There appear to be only a few available studies to date that have incorporated QOL into ASD research (e.g. Garcia-Vallamisar et al., 2002; Jennes-Coussens et al., 2006; and Renty & Roeyers, 2006).

Jennes-Coussens et al. (2006) found many similarities between young men with and without Asperger's Disorder in areas such as living arrangements, education, social support, number of close friends, and overall QOL. However, their findings showed that the young adults with Asperger's Disorder were less satisfied with their physical health and they reported a different kind of social QOL. Only half the Asperger participants in the study had dated. The study reported that 'a lack of necessary skills was the most common reason for not dating'. In the study by Garcia-Vallamisar et al. (2006), a positive relationship between supported employment (as opposed to sheltered employment) and improved QOL was found. The findings in Renty and Roeyers's (2006) study showed that perceived social support⁴ was more

⁴ "Perceived social support was conceptualized as a perception that one's network is ready to provide support and aid if needed rather than received social support which was measured by the actual transfer of advice, aid, and affect through interpersonal networks" (Wethington & Kessler, 1986 as cited in Renty & Roeyers, 2006: 519).

strongly linked with a higher QOL than received social support. In contrast, a lower level of QOL was associated with unmet formal support needs especially in the areas of accommodation, interpersonal relationships, daytime activities and ASD-specific information. The study also found that QOL was not significantly influenced by severity of disability or number of autism-specific traits. The conclusions drawn from this study were that there should be a greater emphasis on the assessment of met and unmet needs from the 'individual's viewpoint' (Renty & Roeyers, 2006:521). This study identified the importance of incorporating subjective variables in outcome research.

QOL is an elusive concept to study and research (Cummins, 1997a) – especially within intellectually-disabled populations as it relies on normative ideas of quality, and it may be particularly problematic to assess this in individuals presenting with ASD, who experience meaningfulness in atypical ways (Morgan, 1996 as cited in Bennett, Wood & Hare, 2005:58). However, despite the complexity of ASD, there is growing consensus that the emerging concept of QOL should dominate the evaluation of services for people with ASD (Garcia-Vallamisar et al., 2002; Jennes-Coussens et al., 2006; Renty & Roeyers, 2006; Ruble & Dalrymple, 1996).

2.3 QUALITY OF LIFE

According to Felce and Emerson (2001:73), *"the way we live, our relationship with others, our productivity and contribution to society, our sense of self, and our success in determining a fulfilling course through life are integral to what may be termed our quality of life"*.

In the past decade, QOL has emerged as an important theme in planning and evaluating services for people with disabilities (Schalock, 2004; Verdugo et al., 2005). For individuals with disabilities, living an ordinary life requires support beyond that normally needed by others at a similar age and stage of life. Such support may include a variety of forms such as specialised training, guidance, structured and supported opportunities, or specially designed environmental or social arrangements. Providing this support should be a major function of education, health and human service programmes (Halpern, 1993).

Historically, the concept of QOL has come from several sources (Schalock et al., 2002 as cited in Schalock, 2004:204):

- A shift in focus away from the belief that scientific, medical and technological advances alone would result in improved life; towards an understanding that personal, family,

community and societal well-being emerge from complex combinations of these advances plus values, perceptions, and environmental conditions;

- The rise of consumer empowerment and client rights movements and their emphasis on person-centered planning, personal outcomes, and self-determination (Wehmeyer & Schalock, 2001);
- The next step from the deinstitutionalisation and normalisation movement that stressed community-based services; and
- The emergence of sociological changes that introduced the subjective or perceptual aspects of QOL.

Since the latter part of the 20th century, the concept of *disability* has also been changing. This is reflected in the social-ecological perspective, the personal empowerment and self-determination movement, a stronger emphasis on personal rights and desired personal outcomes, and an awareness of the effects of discrimination and marginalisation on persons with disabilities (Block, Balcazar & Keys, 2001 as cited in Schalock, 2004:204).

Research has shown that people with disabilities are increasingly viewed as reliable informants on issues that affect their lives (Lefort & Fraser, 2002). This transformed vision of what constitutes the life possibilities of people with disabilities is reflected in the following emerging concepts: self-determination, inclusion, strengths and capabilities, the importance of normalised and typical environments, the provision of individualised support systems, equity, and enhanced adaptive behaviour and role status (Wehmeyer & Schalock, 2001). As a term and as a concept, QOL captures this changing vision.

2.3.1 Current use of the QOL construct

The utility of the QOL concept is currently being reinforced by "society's increasing concern for the social and psychological dynamics of subjective well-being, including factors related to social support, social integration, interpersonal trust, internal control, autonomy/independence, self-confidence, aspirations/expectations, and values having to do with family, job, and life in general" (Schalock, 2004:204).

According to Schalock (2000:116), the concept of QOL is currently reflected in the following ways:

- As a *social construct* that is used as an overarching theme for planning, delivering, and evaluating individualised services and supports to enhance an individual's well-being in

the areas of transition (Halpern, 1993; Kraemer, McIntyre & Blacher, 2003); health-care; education, and intellectual disability (Halpern, 1993);

- As a *criterion* for assessing the effectiveness of services to people with disabilities;
- As a *sensitizing notion* that gives a sense of reference and guidance from the individual's perspective, focusing on the person and the person's environment; and
- As a *unifying theme* that provides a framework for conceptualizing, measuring, and applying the QOL construct.

Despite its attractiveness, there seems to be very little applied QOL research which has been documented. The few studies available demonstrate the application of this work to practice in the field of assessment and evaluation (Brown & Brown, 2005).

Cummins (2005) believes that the field of QOL is still young and that there is still much to be learnt. As a concept, however, there are emerging areas of agreement and a more coherent framework for understanding the QOL construct is emerging. The latest iteration from The Special Interest Quality of Life Group defines four QOL conceptualisation principles (Cummins, 2005:700). These principles conceptualise QOL as a construct that: 1) is multidimensional and influenced by personal and environmental factors and their interactions; 2) has the same components for all people, 3) has both subjective and objective components; and 4) is enhanced by self-determination, resources, purpose in life and a sense of belonging. In the next section, these principles will be briefly discussed.

2.3.2 QOL is multidimensional

There is increasing agreement that QOL is a multidimensional concept. This precludes reducing it to a single 'thing' of which the individual may have a considerable amount of, some of, or none of (Wehmeyer & Schalock, 2001). Instead, QOL can be described by its component parts. These are commonly referred to as 'life domains'. According to Schalock (2004), the exact number of domains is not as important as the need for any proposed QOL model to have a multi-element framework. Furthermore, any set of domains represent in aggregate the complete QOL construct.

Current and ongoing research in this area has identified eight core QOL dimensions (Schalock, 2000): emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Although the number and configuration of these core dimensions vary slightly among

investigators, there is a great deal of common ground. These core dimensions are based on the work of several researchers (e.g. Cummins, 1997a; Felce, 1997). In respect of these core dimensions, the emerging consensus is that each person values them differently, and the value attached to each varies across one's life (Brown & Brown, 2005; Schalock, 2000).

In this study, Cummins's (1996; 1997a) core domains are used. These include: standard of living; health; life achievement; personal relationships; personal safety; community-connectiveness; and future security.

2.3.3 Same for everyone

It has been recognised for a number of years that the QOL concept is understood at a general level in similar ways by most people (Felce & Emerson, 2001). There will however, be variation in the extent to which components are valued because of cultural context and socio-economic differences. But the crucial idea is that there is "an identifiable set of core, essential, and fundamental building-blocks of life quality that are common to us all" (Cummins, 2005:700). It has to do with the 'goodness' of life, and being able to live successfully and happily within our environments (Brown & Brown, 2005). Many researchers embrace the idea that the essential meaning of QOL in general can be universally understood, but when the concept is applied to individual people or groups of people, different aspects of QOL may dominate and be valued in different ways (Cummins, 2005).

Brown and Brown (2005) give a good example of these individual differences. They explain that a close social connection with others is an aspect of life that is important to most people's QOL; however, to some people this may mean having many friends; to others it may mean having only a few close friends, and to others it may mean very being close to one person or having a close family support. QOL research has therefore come to realise that there are no arbitrary 'rights' or 'wrongs', but rather it is important that the form of expression supports a more universal fundamental need (e.g. social connection) in ways that reflect personal and social values that guide the individual's life (Cummins, 2005).

It is, therefore, important to consider the cultural context of an individual in QOL research as it allows the elements within an individual's environment that influence personal and social values to be acknowledged. In turn, these values serve as the guidelines for assessing the degree of 'quality' in people's lives (Brown & Brown, 2005; Schalock et al., 2005).

In this study, QOL is understood as "as individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals,

expectations, standards and concerns" (WHO, 1996:5). This definition reflects the view that QOL refers to the evaluation of one's subjective experience.

2.3.4 Subjective and objective components

Measuring QOL can focus on either: a) the level of satisfaction experienced by an individual using personal appraisal (i.e. the subjective component of QOL measurement, known as subjective wellbeing [SWB]); or b) objective indicators of life experience using functional assessment (i.e. the objective component of QOL measurement) (Schalock, 2000; Wehmeyer & Schalock, 2001).

Objective measures of QOL assess personal experiences and circumstances in the public domain and typically use dependent variables such as physical quantities or frequencies. Subjective QOL measures on the other hand, assess perceptual issues and typically use dependent variables such as importance and satisfaction (Schalock, 2005). Subjective QOL only exists within the private consciousness of each individual and is verified only through repeated responses provided by the person concerned (Cummins, 2005).

The personal appraisal strategy addresses the subjective nature of QOL, typically asking the person how satisfied he or she is with his or her 'life as a whole' (Cummins, 2001). Satisfaction is the most commonly used dependent measure in evaluating perceived QOL. It has been found that the measurement of each domain of satisfaction and the total global score based on these domains provide more refined information about the components of QOL than the single question regarding life as a whole (Schwartz & Rabinovitz, 2003). The major advantages of using satisfaction as an indicator of one's perceived QOL are its usefulness in: a) comparing population samples; b) providing a common language that can be shared by consumers, providers, policy-makers, regulators, and researches; c) assessing consumer needs; and d) evaluating organisational outputs (Schalock, 2000:118). It also allows one to assess the relative importance of individual QOL domains.

There has been a considerable debate about whether the concept of QOL is best regarded as an essentially subjective construct or whether it is more usefully defined as a combination of subjective and objective elements (Cummins, 1997a). The major disadvantages of using only satisfaction as a dependent QOL measure include: 1) the reported low correlation between subjective and objective measures of QOL; 2) its tendency to provide only a global measure of perceived well-being; 3) the lack of demonstration to date that it is a sensitive measure of

good environmental design and service programmes; and 4) its trait-like nature (i.e. stability over time) known as homeostasis (Cummins, 2001; Mellor, Cummins & Loquet, 1999).

Cummins (2001) has described this homeostatic model for subjective QOL, in which personality, an internal regulatory mechanism, and environmental experience interact to determine expressed satisfaction. The purpose is to maintain a positive psychological well-being even under adverse circumstances. This is believed to be an attribute which may have become part of the human condition because of its survival value (Cummins, 2005). The model is compatible with empirical observations that life satisfaction is maintained on average at about 75 % of the scale maximum and held within a narrow range.

There is a widespread belief that people with intellectual disabilities experience restricted lifestyles (Emerson & Hatton, 1996 as cited in Perry & Felce, 2005:279). According to homeostatic theory, one may assume that, despite restricted lifestyles, the expressed satisfaction of people with intellectual disabilities would be the same as in the general population. Research on adults with moderate or mild intellectual disability living relatively independently has found this to be the case (Cummins, 2001; Hensel, Rose, Stenfort Kroese & Banks-Smith, 2002; Perry & Felce, 2005). Likewise, Cummins et al. (2009) reported that in Australia, the PWI-ID population means scores were 77.08% and in Hong Kong the mean scores were 63.99%. A table of these scores is provided as Annexure E. Thus, the view that people with intellectual impairment necessarily have a level of subjective wellbeing (SWB) that is lower than the normative range has not been shown. However, the research is limited: more studies are needed to test the homeostasis assumption with people with intellectual disabilities.

Despite the evidence of the remarkable stability of satisfaction scores across time and individuals, the literature still shows that life satisfaction, also referred to as subjective wellbeing (SWB), is still the most commonly used dependent measure in evaluating perceived QOL (Cummins, 2001).

2.3.5 The enhancement of QOL

Subjective wellbeing is believed to be enhanced by self-determination, resources, purpose in life and a sense of belonging (Cummins, 2005). According to Nota, Soresi and Perry (2006:372), when looking at one's SWB "it is important to consider issues such as how at ease one feels at home, work or school; the degree of satisfaction with one's interpersonal relationships, and the ability to participate in the range of activities and to perform the tasks

appropriate to one's age and culture". It has been suggested that satisfaction in these areas is a consequence of the interplay between a number of psychological dimensions such as recognising the existence of aims (self-determination), feeling a sense of belonging, and realising that one can control one's own destiny and have an impact on that of significant others (Schedler et al., 1993 as cited in Nota et al., 2006:372). In addition, QOL is believed to be optimal when the individual's needs and wants can be met by society and the individual has adequate resources to meet the demands of the environment (Dennis et al., 1993). The implication is that enhancement techniques should be based on these principles and tailored to the needs, values, culture and context of the individual.

2.3.6 Measurement of QOL

2.3.6.1 *Who should be involved?*

Traditionally, the QOL of people with intellectual disabilities has been evaluated by others on the basis of objective, unidimensional indicators (such as health, social welfare, education, housing etc.) (Verdugo et al., 2005). However, the quality and subjective wellbeing revolution has changed the way people think about who should be involved in the measurement of one's QOL (Schalock, 2004). According to Verdugo et al. (2005), the emerging consensus is that individuals with intellectual disabilities should be involved directly in the measurement of their subjective QOL, and that proxies should be used only if absolutely necessary because of significant communication impairments.

2.3.6.2 *Why measure QOL?*

According to Verdugo et al. (2005:714), the measurement of QOL in intellectual disability research is useful for two reasons. Firstly, the concept of QOL is useful for the reorientation of the activities carried about by professionals and service providers, giving the person with intellectual disabilities an essential role as a service consumer whose perception and experience is important to take into account. Second, QOL displays an integral and multidimensional view of the person's life that allows one to identify and plan his or her support needs without reductionism (i.e. only focusing on one dimension such as physical health, work productivity or academic needs). The decisions made about a person's life cannot be restricted to a limited understanding of his or her needs. Neither can they be based merely on the services, organisation or programme objectives. Thus, QOL is believed to be more useful as a comprehensive, multidimensional outcome measure which can assess

satisfaction and subjective wellbeing from the person's perspective (Cummins & Lau, 2005). This idea is reinforced in the following statement:

"At its core, the concept of QOL gives one a sense of reference and guidance from the individual's perspective, an over-riding principle to enhance an individual's wellbeing and collaborate for change, and a common language and systematic framework to guide our current and future endeavours" (Schalock, 2004:214).

2.4 CONCLUSION

It appears that very few studies have thus far been carried out that have incorporated QOL into ASD research. In the light of the lack of available research on QOL and ASD and the need for feedback on the effectiveness of this housing project, I decided to conduct an exploratory study to explore and describe these phenomena. In the next chapter, I discuss how I used a predominantly qualitative approach to investigate the perceived QOL of the three participants at the group home. I also describe the different techniques which were used to gather and produce the data. Finally, I discuss how I met the ethical requirements of research.



CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

According to Durrheim (1999) the research design forms the strategic framework for action and serves as the bridge between the research questions and the execution of the research. A research design also provides the plan that specifies how the research is going to be executed in order to maximise valid conclusions. The choice of a research design is guided along four main dimensions (Durrheim, 1999:33):

- 1) The theoretical paradigm informing the research;
- 2) The purpose of the study;
- 3) The context or situation within which the research is carried out; and
- 4) The research techniques employed to collect and analyse data.

In this chapter I shall be discussing these four main dimensions as they present themselves in this study. I begin by acquainting the reader with the problem statement and the sub-research questions posed in this study. I then discuss the research design, the research process and the methodology followed in this study. I shall also discuss ethical considerations. In the final section, I outline the data analysis process.

3.2 PROBLEM STATEMENT AND RESEARCH AIM

As mentioned earlier, the housing project was established in 2005 to explore the merits of independent living within the community for young adults with ASD who are high-functioning. No research had yet been conducted to evaluate the effectiveness of a pioneering housing initiative on the perceived QOL of its occupants. The findings of a study of this nature could make a strong case for more group homes based on this model. It could also make it possible to effect potential improvements in the home. From this point of reference, the problem statement and research questions were borne.

3.2.1 Problem statement

This study represents an attempt to explore and reflect the voices of the three men who live in the group home and to hear their experiences and perceptions of their QOL within the home. In attempting to do such research, the main problem statement was: **What is the perceived QOL of each of the three men with Autism Spectrum Disorder who are living in the group home?**

3.2.2 Sub-research questions

In addition to the main problem statement, there were three sub-research questions:

- Which of the 7 core domains in the PWI-ID scale represent the highest and lowest levels of subjective wellbeing for each participant?
- Do the participants think that their residence at The Group Home has enhanced their overall QOL?
- Are there any aspects of The Group Home that the participant's think could be altered to enhance their perceived QOL?

3.2.3 Research aim

As discussed in Chapter One, the aim of this study was to explore and describe the perceived QOL and the experiences of the three men living in the group home. In this way, their voices could be used as the point of reference for the evaluation of the project. In addition, I intended to make any potential recommendations available to the sponsors of the group house and to other interested parties for further research.

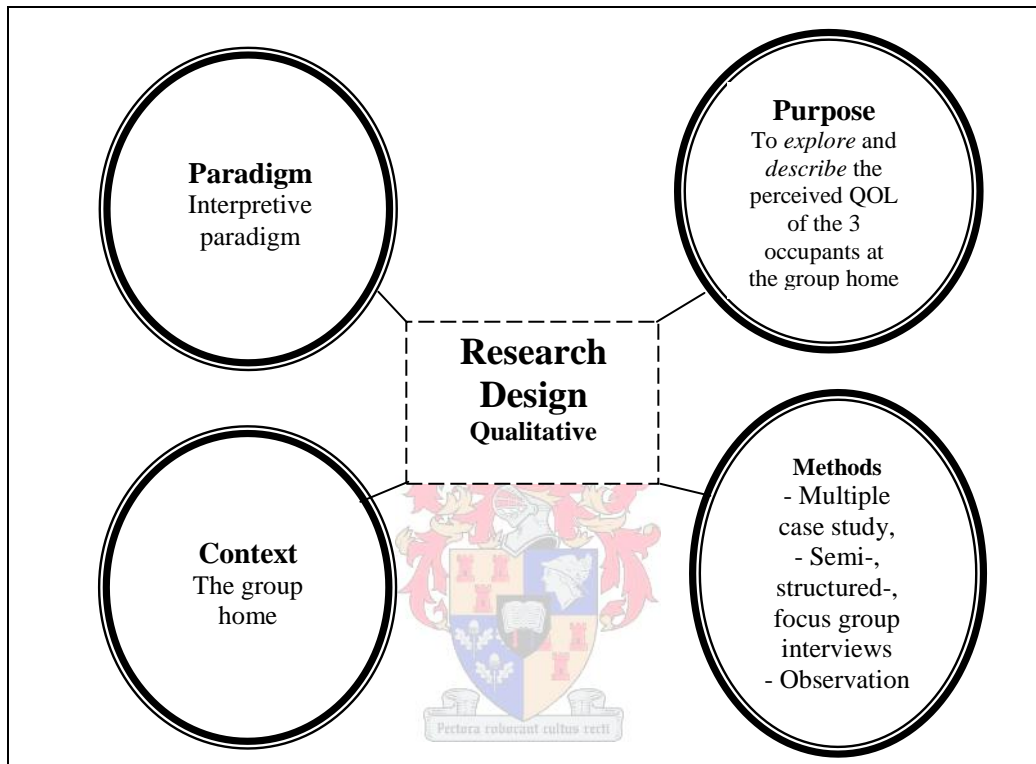
3.3 THE RESEARCH DESIGN

According to Mouton (2001:55), a research design refers to the overall plan or blueprint according to which information (data) will be assembled, organised and integrated. Thus, when planning an investigation, the researcher must make a series of decisions about how the research questions can best be answered by the investigation. According to Durrheim (1999:36), "the researcher must find a compromise between the ideals of good research and the numerous practical constraints that present themselves in real-life research settings". The researcher therefore needs to develop a research design which is coherent. This requires that the techniques of sampling, data production, and interpretation as well the context of the

study 'fit' within the logic of the interpretative paradigm and are consistent with the purpose of the research (Durrheim, 1999:35).

In order to explore the research questions posed in the study, I chose to make use of a primarily qualitative research design. Below is a diagrammatic representation of the four dimensions that have guided this qualitative study.

Figure 3.1: Research Design Dimensions



One of the major distinguishing characteristics of qualitative research is the fact that the researcher is interested in understanding the meaning people have constructed for themselves about their world (Merriam, 1998:6). I used a more qualitative approach in an attempt to understand and explore the experiences of the three participants from their subjective perspective. This allowed me to gain a better understanding of the complexities, richness and diversity in their lives. This can only be captured by describing what is really going on in their everyday lives in the context in which they operate.

3.3.1 Paradigm

The selection of an appropriate theoretical paradigm is central to the planning of an investigation as it has an influence on the research problem and the manner in which the research can be conducted (Durrheim, 1999). Paradigms therefore, act as perspectives that

provide the rationale for the research and commit the researcher to particular methods of data collection, observation and interpretation.

As mentioned in Chapter One, this study made use of an interpretivist design as this paradigm allows for an in-depth portrayal of human endeavours, interactions, situations, and perceptions. The two basic assumptions that guide this paradigm of inquiry are that: 1) knowledge is socially constructed by the people who are actively involved in the research process; and 2) researchers should attempt to understand the meanings people attach to their lived experiences of their world (Schwandt, 1994).

Within the interpretivist framework, the underlying assumption is that reality is not an objective entity; rather that there are multiple interpretations of reality. Thus, the researcher brings a construction of reality to the research context which interacts with other people's constructions or interpretations of the phenomenon being studied (Merriam, 1998). This meant that I had to be aware of my own subjective perceptions and biases within the context of this study.

3.3.2 Purpose of the design

In this study, both exploratory and descriptive questions were posed. Firstly, the aim was to *explore* the occupant's perceived quality of life within the group home. The design was therefore open, flexible and inductive in nature. This provided the participants with an opportunity to talk openly about their feelings and thoughts about the home – e.g. what they like; what they would like to change; what effect has the home had on their lives; which areas of their lives are they the most satisfied with and what is their perceived quality of life in the home etc. They were also given an opportunity to rate their perceived QOL using the PWI-ID.

Secondly, the aim was to *describe* the participant's thoughts and feelings about the house in such a way as to provide feedback to Autism Western Cape. The findings of the study, therefore, also have a practical application and may contribute towards any improvements to the group home or may provide guidance for future developers of other community-based group homes.

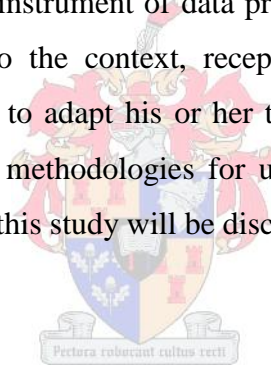
3.3.3 Context of the study

This study was shaped by the interpretivist perspective and is exploratory and descriptive in nature. The value of this type of qualitative research is that it takes place in the real world in which the phenomenon takes place. It strives to understand situations in their uniqueness as

part of a particular context. A study within this orientation is therefore interested in understanding the nature of a setting – "what it means for participants to be in that setting, what their lives are like, what's going on for them, what their meanings are, what the world looks like in that particular setting – and in the analysis to be able to communicate that faithfully to others who are interested in that setting" (Patton, 1985 as cited in Merriam, 1998:6). In this way, interpretative researchers want to make sense of feelings, experiences, social situations or phenomena as they occur in the real world, and therefore want to study them in their natural and unique setting (Terre Blanche & Kelly, 1990). In this study, the unique context was The Group Home.

It was also important to acknowledge the role of the researcher in context. In qualitative research the researcher takes on a more personal, empathetic and interactive mode of inquiry. This allows the researcher to become immersed in the social setting and it facilitates intersubjective understanding between the researcher and the participants (Mertens, 1998). The researcher is also the primary instrument of data production and analysis. It also allows the researcher to be responsive to the context, receptive to the non-verbal cues of the participants and allows him or her to adapt his or her techniques to the particular situation (Merriam, 1998). There are many methodologies for understanding human phenomena 'in context' and the techniques used in this study will be discussed below.

3.4 METHODOLOGY



Research methodology focuses on the research process and the kinds of tools and procedures to be used. It is the interpretative framework that guides the research process and ensures the systematic, methodical and accurate execution of the research design (Mouton, 2001).

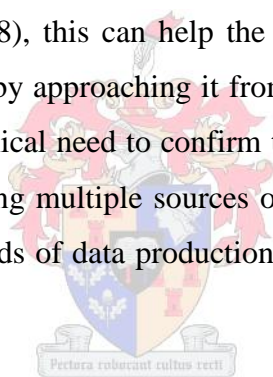
3.4.1 Method – multiple case study

In broad terms, a case study is an empirical inquiry that 'investigates' a contemporary phenomenon within its real-life context (Yin, 1989 as cited in Merriam, 1998:27). A case study focuses on the holistic description and explanation of phenomena within a bounded context. In this study, a multiple case study approach was used. A multiple case study can be distinguished from the single case in that it involves collecting and analysing data from several cases (Merriam, 1998). The more cases included in the study, the more compelling an interpretation is likely to be. In this study, a set of three cases of the same research entity were examined. The Group Home acted as the bounded system and each participant a unique

case for investigation. The inclusion of multiple cases is a common strategy for enhancing the external validity or generalisability of the findings (Merriam, 1998).

Case studies are widely used and have an esteemed history in education and social research (Yin, 1984 as cited in Tellis, 1997). Case studies are often defined as ideographic research methods as they study individuals as individuals rather than members of a population (Lindegger, 1999). This method of research has the advantage of allowing new ideas and hypotheses to emerge from careful and detailed observation. But case studies also have limitations: there may be problems with the validity of information; causal links are difficult to test; and generalisations cannot be made from single-case studies (Lindegger, 1999).

In an attempt to increase the validity of information in this type of study, a research strategy known as triangulation was implemented in the research process. Methodological triangulation entails collecting material in as many different ways and from as many diverse sources as possible, to increase confidence in the interpretation (Tellis, 1997). According to Terre Blanche and Kelly (1999:128), this can help the researcher to 'hone in' on a correct understanding of the phenomenon by approaching it from several different angles. The need for triangulation arises from the ethical need to confirm the validity of the processes. In case studies, this is usually done by using multiple sources of data (Yin, 1984 as cited in Tellis, 1997). In this study, various methods of data production were used. These will be discussed in the data production section.



3.4.2 Participants

Purposive sampling is based on the assumption that the researcher wants to understand a phenomenon and must therefore purposefully select a sample from which the most can be learnt (Merriam, 1998). In addition, studies working in the interpretivist paradigm particularly select their participants with the goal of identifying information-rich cases that will allow for in-depth study. The participants in this study were selected with a specific purpose in mind. They were the only available participants who had had the experience of living in the group home. The group of participants in this study was therefore homogenous to the extent that they shared the experience of living in the group home. These participants will be introduced in Chapter Four.

3.4.3 Data Production

According to Yin (1984 as cited in Tellis, 1997), the unique strength of using a case-study method is its ability to deal with a full variety of evidence. There are many different

production techniques to produce data according to the research question. Below I have included a description of the data production techniques that were followed in this study.

3.4.4.1 Literature review

According to Mouton (2001), the aim of the literature review is to find out what has been done in the field of enquiry. A review should therefore describe, summarise, evaluate and clarify the literature. It should also provide a theoretical basis for the research and help determine the nature of the research. It should illustrate how the subject has been studied previously and should outline gaps in previous research. The reasons for doing a literature review for this study were to provide a context for QOL research and to demonstrate the dearth of research on the QOL of people with ASD.

3.4.4.2 Structured Interview – Personal Wellbeing Index-Intellectual Disability (PWI-ID)

As discussed in Chapter One, the PWI-ID was used in this study as the primary outcome measure of subjective QOL also known as subjective wellbeing (SWB). It was administered in the form of a structured interview. The aim was to interview each participant twice using this scale. In the following section, I aim to familiarise the reader with the history of the PWI as well as information regarding the psychometric properties and application of the PWI-ID. The following information was extracted directly from the PWI-A Manual (International Wellbeing Group (IWB), 2006) and the PWI-ID manual (Cummins & Lau, 2005).

Historical Development of the Personal Wellbeing Index (IWB, 2006)

The PWI scale was created from Cummins' (1997b; 1997c) original Comprehensive Quality of Life scale (ComQol) (Cummins, McCabe, Romeo & Gullone, 1994). The ComQol comprised both an objective and subjective measure of life quality. In 2001, the ComQol was abandoned due to two major flaws. One was that, despite repeated modification, the objective scale did not factor in seven non-complex domains. The other flaw was that domain importance and domain satisfaction were multiplied. A detailed rationale for the abandonment of the ComQol is available in Cummins (2002).

A major difference between the PWI and ComQol is the change in the response scale format. This involved the replacement of the original 7-point Likert scale with an 11-point Likert Scale. There were several reasons for this decision, the details of which have been described in Cummins and Gullone (2000). The 11-point (0-10) choice is preferred as it optimises respondent discriminative capacity and is simple to understand.

The Personal Wellbeing Index (Cummins & Lau, 2005)

The PWI was developed to measure the subjective dimension of QOL also known as subjective wellbeing (SWB). It is generally agreed that SWB can be measured through questions of satisfaction directed to people's feelings about themselves. The PWI is designed as the first level of deconstruction of the concept of QOL. It is based on a global, abstract question – "How satisfied are you with your life as a whole?"

This scale can be used with many sections of the population. Three parallel versions of the adult PWI (PWI-A) have been developed. PWI-PS is for use with children and adolescents attending school, PWI-PS is for pre-school age children, while PWI-ID is designed for people who have an intellectual disability or another form of cognitive impairment. In this study, the PWI-ID version was used.

The Personal Wellbeing Index – Intellectual Disability

The PWI-ID scale differs from the PWI-A in that it incorporates a pre-testing protocol to determine whether, and to what level of complexity, respondents are able to use the scale. Questions on 'satisfaction' from the PWI-A are substituted by the term 'happiness' in the PWI-ID scale. While these two terms are not equivalent, they yield very similar data (Lau, Cummins & McPherson, 2005). The ID version also uses more simple and concrete wording. An additional question which asks how happy or sad the respondent is with life as a whole is included. A reduced choice format, illustrated as a series of faces, from very sad to happy, can also be used if participants cannot cope with the Likert scale format.

In addition, the sixth question of the PWI-A which taps into SWB of 'community-connectedness' was altered in the PWI-ID. Compared with the other items of the PWI-A, this item carries high abstractness and complexity. In the current PWI-ID scale, the question "How happy do you feel about doing things outside your home?" replaces "How satisfied are you with feeling part of your community?" in the PWI-A version. The aim of this item is to tap the extent to which a person is happy or satisfied with his or her sense of 'connectedness' or 'belonging' with their community.

Measuring Quality of Life using the PWI-ID

This approach to QOL measurement adopts a domain-level representation of global life satisfaction. A Likert scale response format is then used to indicate the person's level of expressed satisfaction. Here, questions refer to specific life domains (life aspects) and the scores are averaged to produce a global measure of SWB. There are 7 items in the scale.

These include: standard of living; health; life achievement; personal relationships; personal safety; community-connectiveness; and future security. Evidence for the adoption of these seven domains has been presented by Cummins (1996); Cummins (1997); Cummins (2005); Cummins, McCabe, Romeo, Reid and Waters (1997).

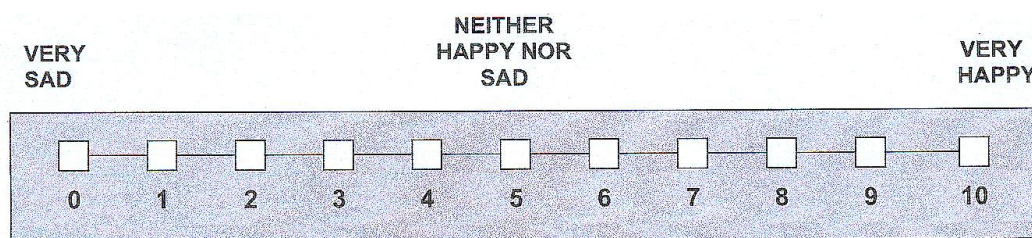
In this study, responses from the PWI-ID will be interpreted qualitatively and quantitatively. However, the final analysis will be done qualitatively. The responses will be analysed quantitatively using the guidelines in Cummins and Lau (2005) and qualitatively using thematic analysis by Braun and Clarke (2006). These techniques will be discussed in the data analysis section.

Psychometric Properties

The PWI-ID appears to be the most reliable, valid, and sensitive instrument for use with intellectual disabilities that current international research has been able to generate to date (Cummins & Lau, 2005). Only a limited number of studies have made use of the PWI-ID instrument, although studies are beginning to emerge, and the results are promising (Cummins et al., 2009). In Australia and Hong Kong, the scale has yielded a Cronbach α of 0.76 and 0.68 respectively, and the domains form a single stable factor that predicts over 50% of the variance in "satisfaction with life as a whole" (Lau, Cummins, Chan, Kwan & Davey as cited in Cummins et al., 2009). These values mirror those obtained previously in the general population with the PWI-A (Cummins & Lau, 2005).

From these findings, it appears that the PWI-ID fulfils the statistical requirements of being reliable and valid (Cummins et al., 2009). The particular strengths of this scale are that its construction is theoretically embedded and that its output can be compared with normative values. It is also unique among scales of this type in having a pre-testing protocol that attempts to ensure that the people who complete the questions of satisfaction have the intellectual capacity to do so reliably. According to Cummins et al. (2009:13), the "*PWI-ID represents the state of the art for the measurement of SWB for people with an intellectual disability*". Below is an example of the PWI-ID structured interview rating scale taken directly from the PWI-ID manual (Cummins & Lau, 2005).

Figure 3.2: The PWI-ID structured interview rating scale



Respondent's Rating

11-pt

(0-10)

Part I: Happy with Life as a Whole [optional]

"How happy do you feel about your life as a whole?"

Part II: Personal Wellbeing Index – Intellectual Disability

"How happy do you feel about...?"

1. the things you have? Like the money you have and the things you own?
2. how healthy you are?
3. the things you make or the things you learn?
4. getting on with the people you know?
5. how safe you feel?
6. doing things outside your home?
7. how things will be later on in your life?

3.4.4.3 Semi-structured interview

In the attempt to construct knowledge about the perceived quality of life of three men, two semi-structured conversations were used in conjunction with the structured interview described above. This allowed the participants an opportunity to express their opinions from their own perspective (Kvale, 1996). The first interview allowed me to create a rapport with each of participants as well as to collect background information from them. The second interview gave the participant's an opportunity to speak about aspects of the home that they thought were important. The questions were guided along the following lines: what aspects of living in the house did they like or enjoy; what aspects of living in the house didn't they like or enjoy; and how would they like to change these aspects. These questions were broad in

nature in order to allow the participants to select what they felt was important aspects to discuss.

Each interview was approximately 20 minutes long. The interviews were recorded using a tape recorder and then transcribed verbatim. In the interviews, I generally tried to maintain a sequence of themes and follow general questions mentioned above, but at the same time remain open to changes in the sequence and flow as determined and indicated by the direction the participants steered the conversations.

3.4.4.4 Focus group interview

A focus group interview is defined by MacMillan and Schumacher (1993) as a strategy for obtaining a better understanding of a problem by interviewing a purposefully sampled group of people rather than each person separately. Focus groups are often selected so as to reflect a heterogeneous cross section of interests and attitudes within the parameters of whatever main criterion qualifies them for membership in the study (Kelly, 1999). A topic guideline was used as a framework to investigate the participant's views on the various components of living in a group home. The questions were open-ended. The participants were asked how they felt about various aspects in the home such as the routines in the house, their chores and the structure and layout of the house. They were also given the opportunity to discuss any other aspects that they felt were important about living in The Group Home.

3.4.4.5 Participant observation

A crucial aspect in the process of observation is looking, taking in as much as you can without influencing what it is that you are looking at (Kelly, 1999). According to Darlington and Scott (2002), combining interviews and observation is a common approach to research with children and with people with learning disabilities. Observations in this study were not a primary method of data production, rather they aided in the verification of my interpretations of the interviews and in gaining insight into the interaction styles of the participants.

3.5 ETHICAL CONSIDERATIONS

Mertens (1998) states that ethical considerations should be an integral component of the research planning and implementation process. Merriam (1998:212) notes that ethical dilemmas are more likely to occur in qualitative research at two points, namely during the production of the data and in the disseminating of findings.

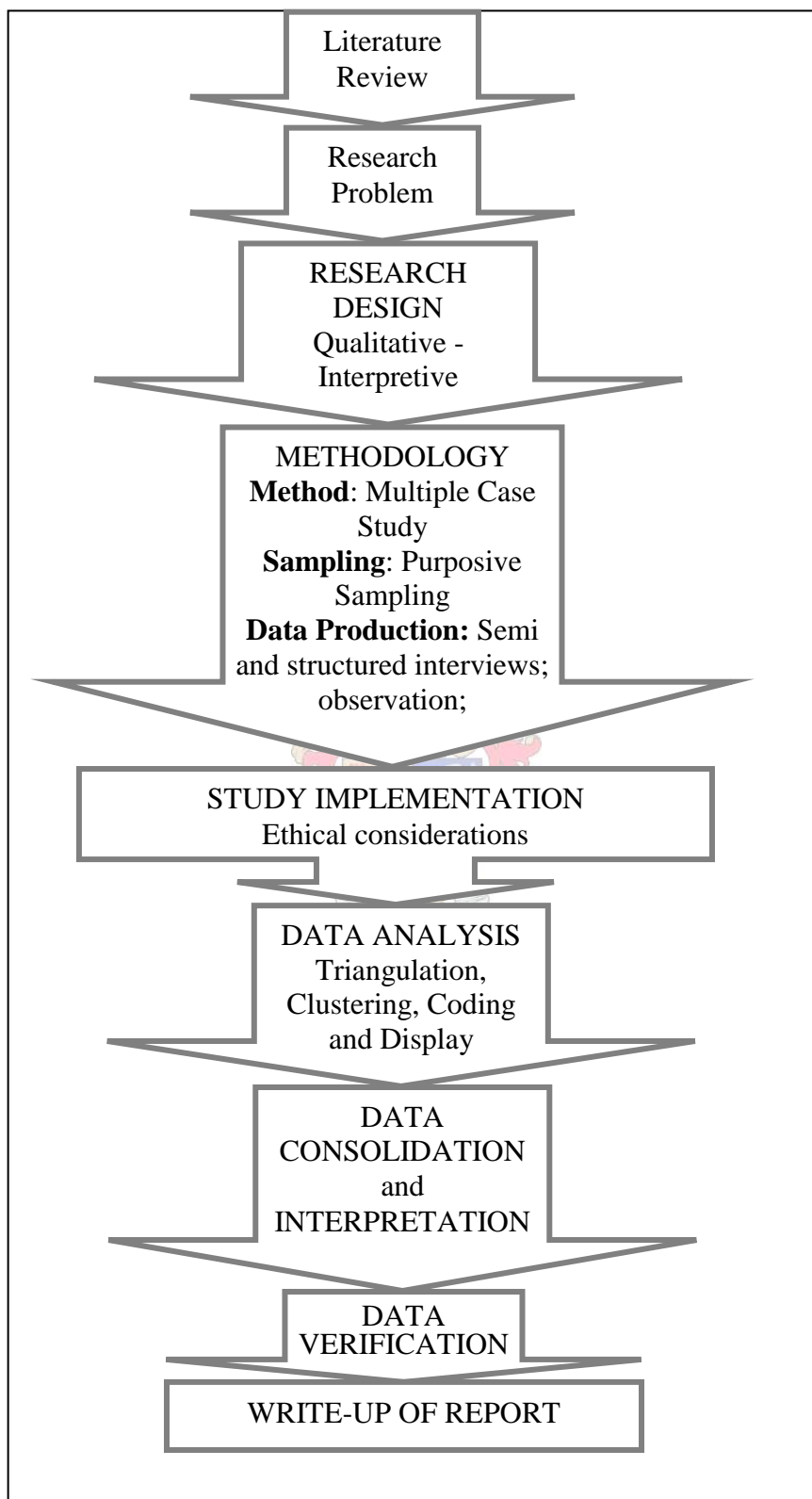
According to Stake (1994), qualitative researchers are guests in the personal spaces of others and that this feeling of privilege should ensure that participants are treated with courtesy and respect. The following methods were employed to control ethical concerns in this study:

- Prior to commencing the study, approval for the study was secured from the Executive Director of the project.
- Informed consent was given by the participants as well as a parent or guardian of each participant. Their consent was given in writing. An example of the letter of consent is provided in Annexure E. The participants in the research were informed of the purpose of the study.
- Permission was given by the participants to tape all interviews.
- The participants were informed that the study was voluntary and that they could withdraw at any stage during the process.
- The participants were encouraged to select a pseudonym to replace their name and identity. This was to ensure confidentiality and anonymity.

3.6 RESEARCH PROCESS AND IMPLEMENTATION

Figure 3.3 presents a visual representation of the research process I went through. The research process began with the literature review and ended with the completion of the written report (thesis).

Figure 3.3: A diagrammatic representation of the research process adapted from Mouton (2001:47)



3.7 DATA ANALYSIS

The methods of data production have been discussed above. All interviews were audio recorded and transcribed verbatim to facilitate the interpretation and reduction of the data into themes using thematic content analysis. The data produced from the PWI-ID interviews was first analysed using the quantitative scoring method described below and then analysed qualitatively using content analysis.

3.7.1 Data analysis for the PWI-ID data

The scores obtained from the 11-point (0-10) Likert Scale format were standardised into percentage scores (%SM) on a 0 to 100 distribution. This was achieved by converting the score derived from the 0 to 10 point Likert scale to a percentage by shifting the decimal point one step to the right, e.g. a value of 6.0 on the Likert scale becomes 60%. A final score for each domain was calculated by averaging the two scores from both PWI-ID interviews for each participant.

The 7 domain scores were then aggregated and averaged to form an overall score of subjective wellbeing (SWB). The first question "how happy are you with your life as a whole" was not a domain component and should be seen as an additional variable providing verification for the overall score of SWB. Thus, this score was not included in the average subjective wellbeing score (Cummins & Lau, 2005). These quantitative findings were then integrated and interpreted in the results section in a qualitative manner.

3.7.2 Thematic content analysis

In this study, thematic content analysis as described by Braun and Clarke (2006) was used. A start list of codes was selected prior to the analysis based on the research questions and the aims of the study. The following phases were then followed:

Table 3.1: Phases of thematic analysis (Braun & Clarke, 2006:87)

<i>Phase</i>	<i>Description of the process</i>
1. <i>Familiarising yourself with the data</i>	<i>Transcribing data (if necessary), reading and re-reading the data</i>
2. <i>Generating initial codes</i>	<i>Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code</i>
3. <i>Searching for themes</i>	<i>Collating codes into potential themes, gathering all data relevant to each potential theme</i>
4. <i>Reviewing themes</i>	<i>Checking if the themes work in relation to the coded extracts and the entire data set</i>
5. <i>Defining and naming themes</i>	<i>Ongoing analysis to redefine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme</i>
6. <i>Producing the report</i>	<i>The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis, to the research question and literature, producing a scholarly report of the analysis</i>

At this stage, the integration of all the sources of data should then be combined to re-assess the main themes. The other sources of data can then be used to either highlight consistencies or identify difference in the themes.

The main themes identified across all sources should capture the 'story' you are telling about your data (Braun & Clarke, 2006:92). These over-arching themes and sub-themes then form the written account of the phenomenon being studied and form the bulk of the findings section. Chapter Four includes a discussion of the interview process as well as a description of the main themes identified in the participant and focus groups interviews. Chapter Five then presents a more detailed discussion of the dominant themes in relation to the literature and the research questions.

3.8 DATA VERIFICATION

Merriam (1998) refers to the importance of research being trustworthy to other professionals in the applied field. Thus, validity and reliability are important concerns that can be addressed through a careful consideration of the conceptualisation of the study as well as the research process.

There are no single commonly accepted standards for judging or ensuring validity and reliability of qualitative research (Merriam, 1998). According to Mertens (1998:181) there are a variety of criteria against which data can be verified. The criteria for credibility, transferability, dependability and confirmability were found to be appropriate constructs for testing the trustworthiness of this qualitative study. These criteria will be briefly discussed below.

3.8.1 Credibility

The concept of credibility parallels the concept of internal validity in quantitative research. Credibility poses the question as to whether there is a "correspondence in the way the respondents perceived the social constructs and the way the researcher portrays their viewpoints" (Mertens, 1998:181). Several methods were used to ensure credibility in this study and these will be mentioned below.

- **Triangulation:** According to Mertens (1998) triangulation involves checking information that has been collected from different sources for consistency of evidence across sources. As discussed earlier, multiple methods of data production were used in this study. By means of analysing the data and looking for recurrent themes, the themes from the different sources were cross-checked for consistency of interpretations.
- **Prolonged and substantial engagement:** A great deal of time was spent getting to know the participants. I was involved in this process for a period of 11 months.
- **Peer examination and debriefing:** The data production was discussed with fellow educationalists from my institution of study as well as with a psychologist from the School next to The Group Home.

3.8.2 Transferability

The concept of transferability parallels the concept of external validity in quantitative research. In this context, transferability refers to the applicability of the study to other contexts and settings. Merriam (1998:211) suggests that through a 'rich, thick description' this criterion can be met. This requires an extensive and careful description of time, context, place and culture.

3.8.3 Dependability

Dependability of a qualitative study is the equivalent of reliability in a quantitative study. Reliability refers to the degree to which the same results would be obtained if the study were

to be repeated. Merriam (1998) suggests that reliability in social sciences is problematic as human behaviour is never static. Therefore, in qualitative research, the focus should rather be on dependability, or the consistency of the results obtained from the data. Merriam (1998) recommends the use of an audit trail to describe in detail how the data was produced, decisions were made and how the data was analysed. In this study, a detailed description of the processes of data production and analysis will be provided in Chapter Four. In addition, transcripts, tapes, notes, records and documents will be retained if the original data needs to be consulted.

3.8.4 Confirmability

Confirmability is the qualitative parallel of objectivity. This occurs when the influence of the researcher's judgment is minimised. This is to ensure that the data is factual and not merely a 'figment of the researcher's imagination' (Mertens, 1998:184). To strengthen the confirmability of the data, I shared observation notes, transcripts and reviews of documentation with peers and my supervisor.

3.9 CONCLUSION

In this chapter, a qualitative (interpretivist) research design was described and illustrated. This design served as the framework for this study and directed the entire research process. The problem statement and the research questions were initially mentioned in order to familiarise the reader with the intention and purpose of the study. The theoretical paradigm, purpose and context of the study were then discussed. Next, the reader was introduced to the methodology that was followed in the study. This included information about the method of sampling, data production and data analysis. Ethical considerations were also discussed. The chapter concluded with a discussion on reliability and validity and the procedures that were used to enhance these aspects.

In Chapter Four, I describe the implementation of the study. This includes the presentation of the data produced, the analysis of the data and a discussion of the themes found in the study.

CHAPTER FOUR

IMPLEMENTATION OF THE STUDY

4.1 INTRODUCTION

In this chapter, I contextualise the study in terms of the background of the three participants, the setting, the procedures leading up to the interviews and the interviews themselves. I also discuss the main themes that emerged from the interviews.

4.2 PARTICIPANTS

I selected the participants in the study using purposive sampling in that they were selected with a specific purpose in mind. There were the only three men with ASD living in the group home at the time of the study. Before the study could be implemented, I made sure that the necessary ethical requirements were met:

- I began by obtaining approval for the study from the Executive Director of the project in September 2007.
- I obtained approval from the principal of School next to The Group Home in a meeting with him in September 2007.
- I met with all three potential participants at the group home and invited them to take part in the study. I informed them about the purpose of the study and the voluntary nature of their participation in the study. I also requested their permission to audio tape all the interviews. All three participants agreed to participate in the study and their informed consent was given in writing. Informed consent was also obtained from a parent or guardian of each of the participants during one of the project meetings.
- I invited participants to select a pseudonym. This was to ensure their anonymity.

Participant 1 chose the name **Seth Diablo Voldemort** from Harry Potter. Participant two chose the name **Ladybug**. Participant 3 selected the name **Y2J Chris Jericho** after his favourite WWF wrestler.

In the next section, I shall briefly introduce the three participants. This information was collected during my first three visits to The Group Home. All visits were organised over the

phone. The main purpose of these sessions was to meet the participants individually in order to get to know them better using a semi-structured interview format. This helped me to create a rapport with each of them as well as to collect background information from them. The information that is provided below is the background information that was provided by each participant in response to the following questions: *Tell me about ...?*

- *yourself?*
- *your background?*
- *the schools you went to?*
- *where you used to live?*
- *your interests?*

Unfortunately, the introductory interviews with the first two participants were not tape-recorded due to unforeseen problems with the tape recorder. However, detailed notes were made during the interviews and will be discussed below. It is important to emphasise that this information is what the participants deemed important to share regarding their background and interests. All three participants were learners at some stage at the School they are now working at. As mentioned earlier, this School is situated next to The Group Home.

4.2.1 Participant 1 – Seth Diablo Voldemort

Seth was born in Cape Town. His parents were divorced when he was in Sub A (Grade 0). He attended the same school he now works at from Grade 0 till he was 15 years old. He then moved to Gauteng in 2002 with his mother and went to another school which was a technical school. He didn't enjoy the school very much and he had no friends. He then stopped school and helped his mother in the garden as she had a big plot of land at the Vaal. He was very unhappy and lonely there. He then decided to move back to Cape Town in 2004 and began to work at the same school he was at before he left. At this stage, he was adopted by the principal of this School. He lived with him in Somerset West for the rest of 2004 and the beginning of 2005. In April 2005, he moved into The Group Home. Seth enjoys flight simulation, flying jets and he wants to be a pilot one day. In 2002, his biological father moved to Harrysmith and he died in 2007. Seth said that he did not have a close relationship with his biological family.

Seth was still working at the same School in the accounts department.

4.2.2 Participant 2 – LadyBird

Ladybug was born in Cape Town in 1972. He is the oldest member of the house. He explained that his mouth was very sensitive to food when he was growing up and he had lots of allergies. He completed his schooling at this School and then moved to another special school in 1989. Here he worked in the bakery and made all sorts of breads and biscuits and things. He said that he enjoyed that school but there were a few people there that made problems for him. In 2004, he left there as he said it was too difficult for his parents to keep him there. In addition, his grandfather had died and his mother was very sad. He spent the rest of 2004 living with his parents. In September 2005, he moved into The Group Home. He said that he felt *greatly contented and settled here* and that his doctor *recognises how well he is looking*. When asking Ladybug about his interests he said that he liked *to keep things clean; the beaches at Kommetjie, Fishhoek and Pringle Bay; reading about astrology, numerology* and that he was *interested in learning more about the psychic realm*. Ladybug also told me that the psychologist that diagnosed him with Autism when he was younger had said that he only had 7% of Autism.

Ladybug was working in the kitchen at the School. He helped to make lunch for the learners and tea for the staff. He also delivered tea to the staff during the day. He said that he thoroughly enjoyed his job.

4.2.3 Participant 3 – Chris Jericho

This is the only introductory interview that was recorded on tape, thus, quotes have been included.

Chris was born in Cape Town and lived with his parents in Goodwood for about 21 years. When asking Chris about his school background he explained: *I went to three different pre-schools because I was different and shy, I couldn't communicate well with others and I just wanted to always be alone. I was a very quiet and shy person and that's why I got moved to different pre-schools and eventually I went to, it's now a technikon, but it was a preparatory school and I was there for two years, and they put me in a special class because of my personality, my shyness and my inabilities to communicate*. After that he went to another school for about 4-5 years. He then left that school to help his parents in their carpeting and upholstery business. He explained that he got a bit frustrated with the job and *they eventually decided to just leave me, and eventually in 1999, I was alone and not doing much besides staying around the house, sitting around watching TV and I was very much alone, I didn't*

have any friends. At this stage, his parents took him to a psychologist where he was diagnosed with Asperger's Disorder. He explains that after that they decided to put me into a school and they recommended this School would be the school for me and eventually I settled down here and I was a pupil here for two years from 2000 to 2001.

A year after finishing school, he was appointed as a groundsman at this School. However, he left in 2002 and went to help his dad in his business. He explained his reasons for leaving as, I felt like there was too much pressure on me and people were rushing me too quickly. And I felt because I was so happy being a pupil at school, I felt that my days were short numbered, my pride and my joy were short-lived. Eventually I couldn't cope with the fact that I was an adult and I even, I even hated admitting that I was an adult; I didn't even want to be known as an adult. I decided to go home and the rest of 2002 I was at home and in the following year, 2003, I did the same and then eventually, well, until I got bored and frustrated. I then went to (another special school) in Bellville, which is also a working place, factories and that with odd jobs and I tried my best to get along with the people and I tried my best to be happy, but it just didn't work out there and I constantly felt like I was over-worked and I didn't have much freedom to do what I like to do. They didn't let me help myself in anyway; I always had to wait until they had prepared teatime or lunch for me. And eventually I said to my dad that I wasn't happy there and I wanted to get out of there.

So my dad phoned (this School) and they decided to take me on again, and they said that this time would be easier with less pressure and I had a meeting with John and Peter* and my parents and they decided that this School was the best place for me, the best place you'll ever be at. So, eventually I decided to give it another shot, another try. So, then to this very day, I've settled in and the work isn't so pressuring, everything is easy now and plain sailing and I am friends with everybody and it's great. I'm much, much happier. Chris says that he really enjoys listening to music and watching rugby.*

Chris was again working as a groundsman at the School. He said that he enjoyed his job. He said: I like what I do now, and I must say that I'm quite fortunate because I don't do the same jobs everyday or the whole day. I'm very, well, I do all types of jobs and I'm happy.

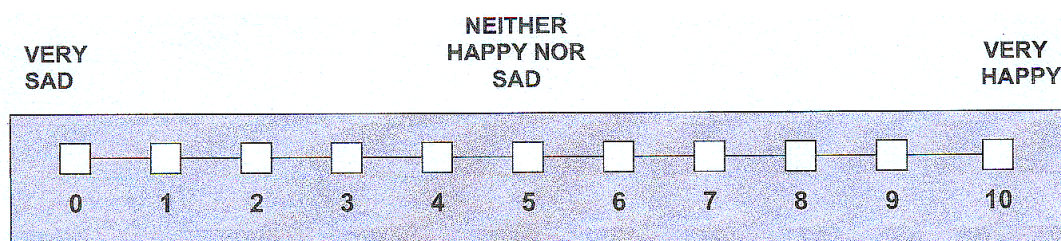
* Not their real names

4.3 THE INTERVIEW PROCESS

4.3.1 Preparation

After the introductory semi-structured interviews were completed with each participant, the structured interviews began. A time was set up with each participant and the pre-testing protocol was conducted. All three participants were able to respond to the pre-testing questions in an appropriate manner with no obvious acquiescent responding. They were also able to understand the 11-point Likert scale format. At this time, I felt that the participants were able to continue with the PWI-ID structured interview. The same 11-point Likert scale visual format that was used during the pre-testing phase was used in the subsequent interviews. Below is an example of the 11-point Likert format used in the structured interviews:

Figure 4.1: PWI-ID 11-Point Likert Scale



4.3.2 Structured interviews



The structured interview consisted of the PWI-ID scale. The contents and the administration of the PWI-ID were discussed in Chapter Three.

Two of the participants were interviewed twice using the PWI-ID scale. Unfortunately, Ladybug was only interviewed once due to unforeseen circumstances. The PWI-ID interview took approximately 20 minutes to complete with each participant. The first PWI-ID interview phase took place during November and December 2007 and the second interview phase took place in April 2008. The same administration procedure was used for all interviews however the pre-testing phase was only administered before the first interview with each participant.

4.3.3 Semi-structured interview

An introductory semi-structured interview was carried out at the beginning of the study to collect background information from the participants. This information has been discussed above. Between the first phase and the second phase of structured interviews, another semi-

structured interview was carried out in December and January. This interview consisted of the following broad questions:

- What aspects of living in the group home do you like or enjoy?
- What aspects of living in the group home do you not like or enjoy?
- What recommendations could you make to improve these areas?
- Do you think living at the group home has increased your QOL?

These questions were broad in nature in order to allow the participants to select what they felt were important issues to discuss.

4.3.4 Focus group

After the second semi-structured interview, two focus group interviews were conducted in April and July. Unfortunately, the same two participants were present during both these interviews since the third participant (Ladybug) was on holiday on both occasions. The participants were asked how they felt about various aspects in the home such as the routines in the house, their chores and the structure and layout of the house. They were also given the opportunity to discuss any other aspects that they felt were important about living in the group home.

4.3.5 Impressions and observation of the participants

All interviews took place within the house, in the lounge. For each interview, I was offered the same couch to sit on and each participant appeared to have a couch that he preferred. On my first visit to the house, the participants showed me around the kitchen and the lounge. The participants did not offer to show me their bedrooms. The psychologist at the School had mentioned to me beforehand that the men do not generally like to show people their bedrooms as they feel that it is their private space. I was aware of this and did not ask to see the rest of the house. My impressions of the participants during the interview process are briefly mentioned below:

Participant 1: Seth appeared to be a very confident and talkative young man. He was able to make good eye contact and engaged enthusiastically in the interview conversations. However, there were many instances where he changed the conversation to things he wanted to talk about e.g. flying jets and being a pilot. He seemed calm and relaxed during the interviews. He appeared to have a close relationship with Chris.

Participant 2: Ladybug was fidgety and did not volunteer information during our conversations and it was generally difficult to get information from him. When he did volunteer information, it was generally off the topic and he needed to be re-orientated to the questions in the interview. He was verbose and his speech was often difficult to hear or understand. I unfortunately was only able to interview Ladybug twice due to unforeseen circumstances. He was on holiday on both occasions when I was in Cape Town to conduct interviews.

Participant 3: Chris seemed very relaxed during the interview process. He appeared to be a lot more focused on the interview process than the other two participants, and he was able to articulate his experiences in a more coherent manner. He would thank me frequently for being his friend and he said that he really enjoyed talking to me. He was also very interested in knowing more about me and frequently asked me questions about my family, my religion, what music I liked etc.

All three participants were welcoming and friendly. On each visit to the house, each participant greeted me with a hug.

4.4 DATA ANALYSIS

Ramazanoğlu and Holland (2002) state that just as data are not simply lying around to be collected, so meaning is not simply lying around in the data, waiting to be found. It is the work of the researcher to submerge herself in the data and decide on meanings, codes and themes.

4.4.1 Preparation for analysis

A start list of codes was identified prior to the analysis phase. These preliminary codes were drawn from the research questions in the study and included the different life domains in the current QOL framework. The initial start list consisted of the following codes:

Table 4.1: Initial Codes

Initial Codes	
QOL Domains	Code
Happy with life as a whole	LW
Standard of Living	SL
Health	H
Achievement in Life	AL
Relationships	R
Personal Safety	PS
Community-Connectiveness	CC
Future Security	FS
Highest QOL domain	H QOL
Lowest QOL domain	L QOL

General	Code
Suggestions/wishes re: house	Sug/wish
Aspects they like re: house	Li
Aspects they dislike re: house	Dis
Other	O

4.4.2 Analysis

I began the analysis process by personally transcribing all the interviews. I then read each transcription many times in order to familiarise myself with the data. I read the interviews of the three participants separately in order to get a feel of their unique perceptions of QOL. I aimed to identify emerging themes for each participant independently and then to explore over-arching themes or similarities between them.

4.4.2.1 Generating codes

Words, phrases or sentences that illustrated or represented a conceptual category were identified and coded together with the initial codes mentioned above. An example of a coded interview is provided as Annexure F.

I initially coded the different segments of data using abbreviated codes. I then highlighted the codes using different colours. This made it easier to visually identify similar categories of data. Below is an example of an extract from a PWI-ID interview that was coded and beneath that is the list of the identified codes.

Table 4.2: Extract with Initial Coding

Okay, how satisfied are you with feeling part of the community?	Codes
<p>I'm very satisfied, well this time I have a lot more things than I used to have before I moved to Cape Town.</p> <p>I have friends, I have people. That side I didn't have anyone, I had myself and beers and my demonic music. But now I have a lot more than when I was living in the Vaal area. I didn't have friends there, I was mostly on my own. This side it is the total opposite, a turn-around. From that day on I was much more on the 1 or a 0. and there were some days when I was 3 to 4 to 5. But from here it is from 9 to 10, mostly 10. With the kind of people I have now, I would say 9, 10, mostly 10.</p>	<p>CC sat</p> <p>CC more</p> <p>CC frie/ppl</p> <p>CC alone</p> <p>CC more</p> <p>CC alone</p> <p>CC low QOL</p> <p>CC higher QOL</p> <p>CC frie/ppl</p>

Second PWI-ID interview with participant 1 – Seth Diablo Voldemort

Table 4.3: List of Initial Codes

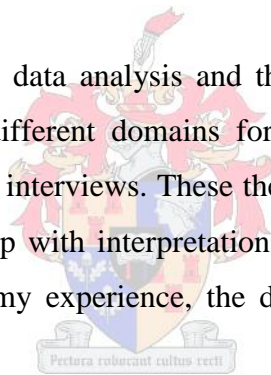
Second PWI-ID interview with Seth Diablo Voldemort.			
Initial code		Identified Code	
QOL Domain	Code	Emerging Category	Emerging Code
Community-connectedness	CC	Very satisfied with current situation	CC sat
		Have a lot more than used to have	CC more
		Now have friends and people	CC frie/ppl
		Was alone	CC alone
		Was a low QOL	CC low QOL
		Increase in QOL	CC higher QOL

After the initial coding phase, I was able to collate all the codes from the interviews into a list for each participant. An example of a full list of identified codes for one participant is provided as Annexure G.

According to Braun and Clarke (2006:89), the next phase in the analysis process involves sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes. This process was facilitated by using the copy and paste function on my computer. I created separate files in order to consolidate the words, phrases and sentences under the various emerging themes. This stage involved thinking about the relationship between codes, between themes, and between different levels of themes (i.e. main themes and dominant themes). After I had devised a set of preliminary themes for each participant, I needed to review and refine the themes I had selected and also explore similarities in themes across participants.

4.4.2.2 Identifying themes

Moving between the raw data, the data analysis and the aims of the study, I was able to identify potential themes in the different domains for each participant. I also identified potential themes in the focus group interviews. These themes were then reduced to a smaller number of dominant themes to help with interpretation. This was done by clustering them into broader categories based on my experience, the data, the research questions and the literature.



In the next section, I will present a table of the potential themes that emerged for each participant and in the focus group interviews. I have also included the quantitative scores from the PWI-ID interviews for each participant in these tables. These scores were averaged across the two PWI-ID interviews. After each table, I included a data display of the dominant themes which were identified for each participant. These dominant themes will be discussed in more detail in Chapter Five.

4.5 IDENTIFIED THEMES

4.5.1 Seth Diablo Voldemort

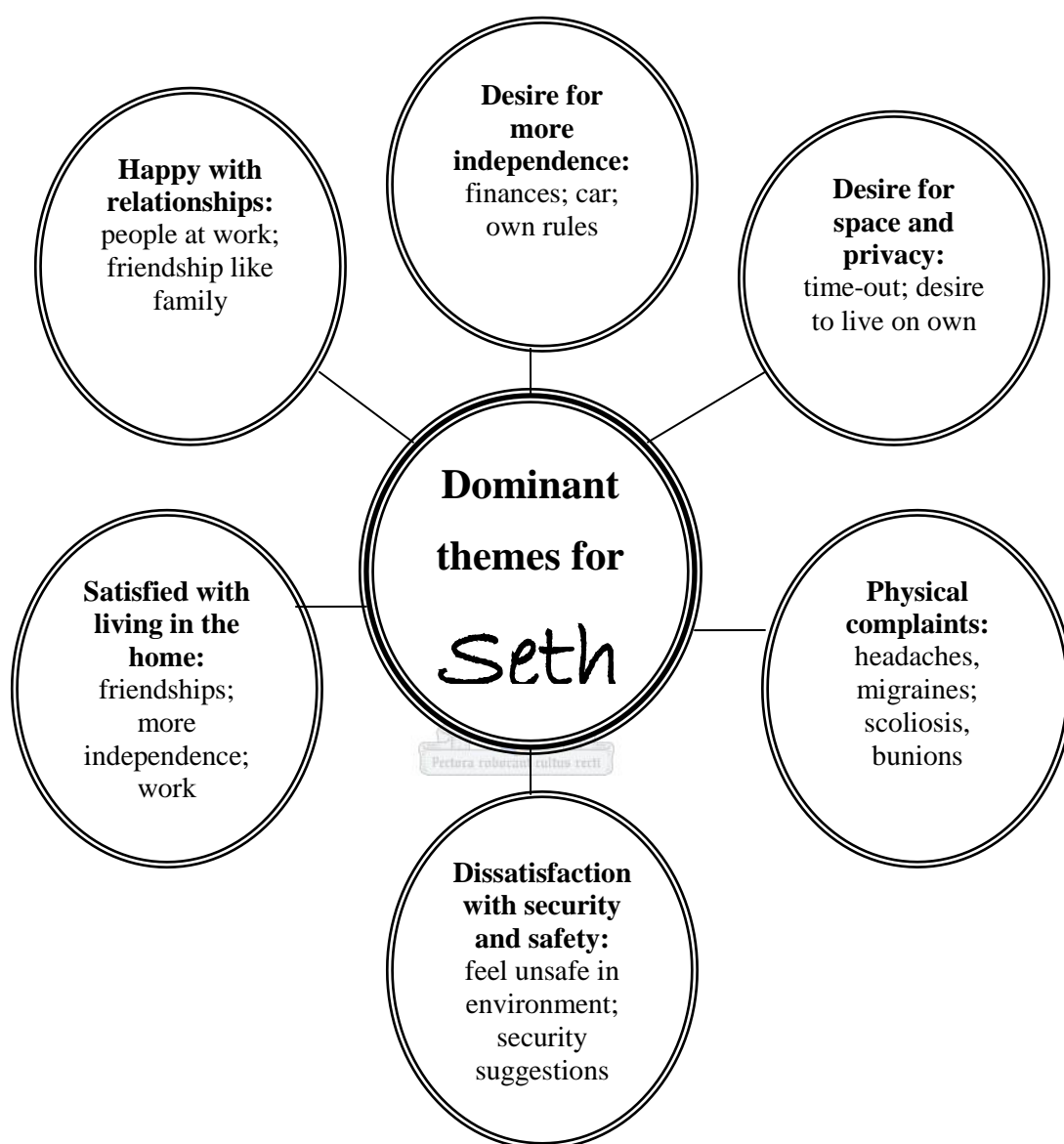
4.5.1.1 List of potential themes identified for Seth

Table 4.4: Potential themes that emerged regarding perceived QOL for Seth

QOL Domains	Potential Themes
Happy with life as a whole (SWB = 9) HIGH	<ul style="list-style-type: none"> - QOL variates - Increase in QOL living in the home - Would prefer to live alone - Happy with working environment
Standard of Living (SWB = 6.5%)	<ul style="list-style-type: none"> - Content but desire for more freedom/space - Desire for more money - Realistic about financial limitations - Happy with possessions - Frustrated – no car
Health (SWB = 5)	<ul style="list-style-type: none"> - Can be more healthy - Many physical complaints - No car (walking)
Achievement in Life (SWB = 9) HIGH	<ul style="list-style-type: none"> - Can do more with life (want to be a pilot) - Dependent on other people (no car)
Relationships (SWB = 10) HIGH	<ul style="list-style-type: none"> - Friendship like family - Little support from own family
Personal Safety (SWB = 2) LOW	<ul style="list-style-type: none"> - More security needed - No car (safety)
Community-Connectiveness (7.5)	<ul style="list-style-type: none"> - Limited free time - Desire for more independence/ no car - Desire more independence at home - Prefer to live on own - Frustrated with rules
Future Security (SWB = 7)	<ul style="list-style-type: none"> - Optimistic about future - Future unpredictable
Other themes that emerged regarding living at the group home	
Suggestions/wishes	<ul style="list-style-type: none"> - Additional appliances (tumble dryer, washing machine) - Need a car (quicker/safer) - Domestic help - More security – alarm, safety gate, burglar bars
Other	<ul style="list-style-type: none"> - Increased QOL in group home - Frustrated with income - Frustrated – no car - Grateful for home - Don't want to be dependent on people - frustrated with rules
Quantitative analysis of PWI-ID scores	
PWI-ID Total Score:	47
Average Subjective Wellbeing (SWB)	67% SWB
Highest Domain of SWB:	Relationships (Average 100% SWB)
Lowest Domain of SWB:	Personal Security (Average 20% SWB)

4.5.1.2 Dominant themes that emerged for Seth

Figure 4.2: Data display of dominant themes for Seth



4.5.2 Ladybug

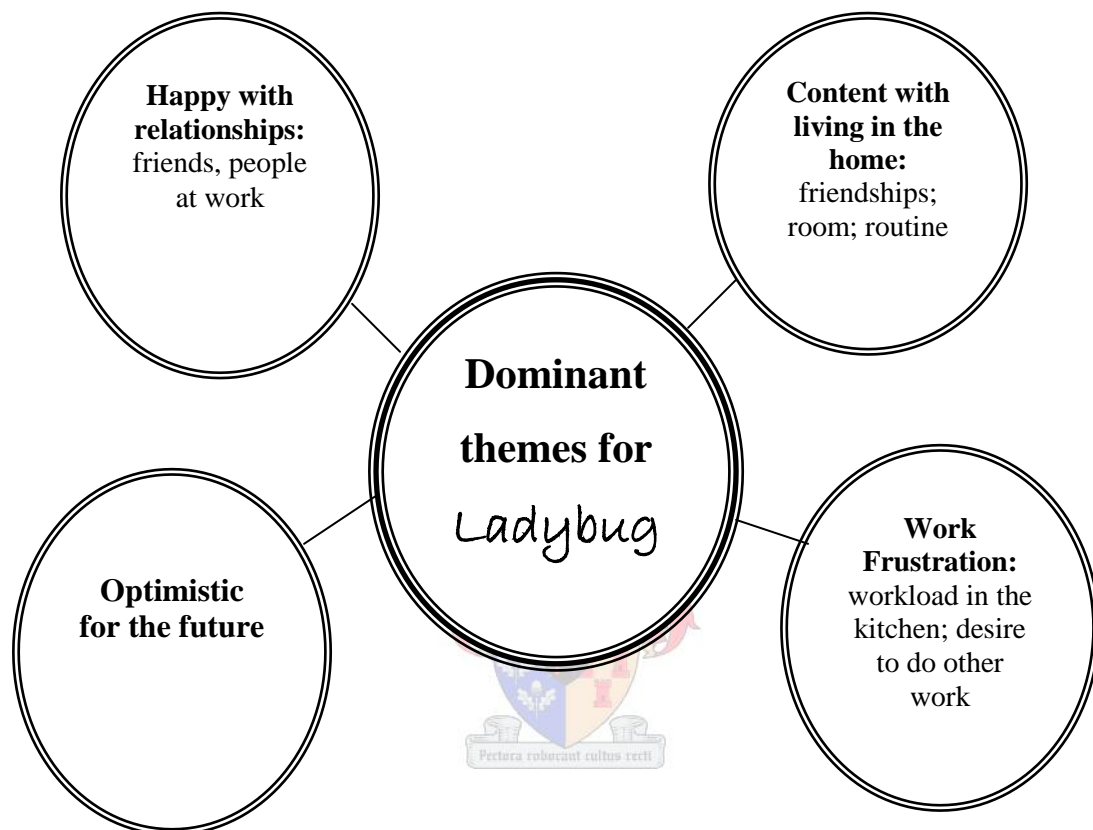
4.5.2.1 List of potential themes identified for Ladybug

Table 4.5: Potential themes that emerged regarding perceived QOL for Ladybug

QOL Domains	Potential Themes
Happy with life as a whole (SWB = 7)	- Content with life
Standard of Living (SWB = 5) LOW	- Ambivalent/ doesn't bother him - Content with what he owns
Health (SWB = 7)	- An improvement in the home
Achievement in Life (SWB = 5)	- Happy with opportunities - Desire to work in garden and in 'spirituality' sphere - Workload/ stressful in kitchen
Relationships (SWB = 9) HIGH	- Happy with friendships - Happy with people at work
Personal Safety (SWB = 7)	- Content
Community-Connectiveness (SWB = 7)	- Satisfied with community - Desire for more entertaining
Future Security (SWB = 9) HIGH	- Optimistic about future
Other themes that emerged regarding living at the group home	
Suggestions/wishes	- Practical appliances (blinds, jet master) - More entertainment at the home - More security – better lighting
Aspects they like	- location of home - routine at home - own room
Quantitative analysis of PWI-ID scores	
PWI-ID Total Score:	49
Average Subjective Wellbeing (SWB):	70% SWB
Highest Domain of SWB:	Relationships (Average 90% SWB) Future Security (Average 90% SWB)
Lowest Domain of SWB:	Standard of Living (Average 50% SWB) Achievement in Life (Average 50% SWB)

4.5.2.2 Dominant themes that emerged for Ladybug

Figure 4.3: Data display of dominant themes for Ladybug



4.5.3 Chris Jericho

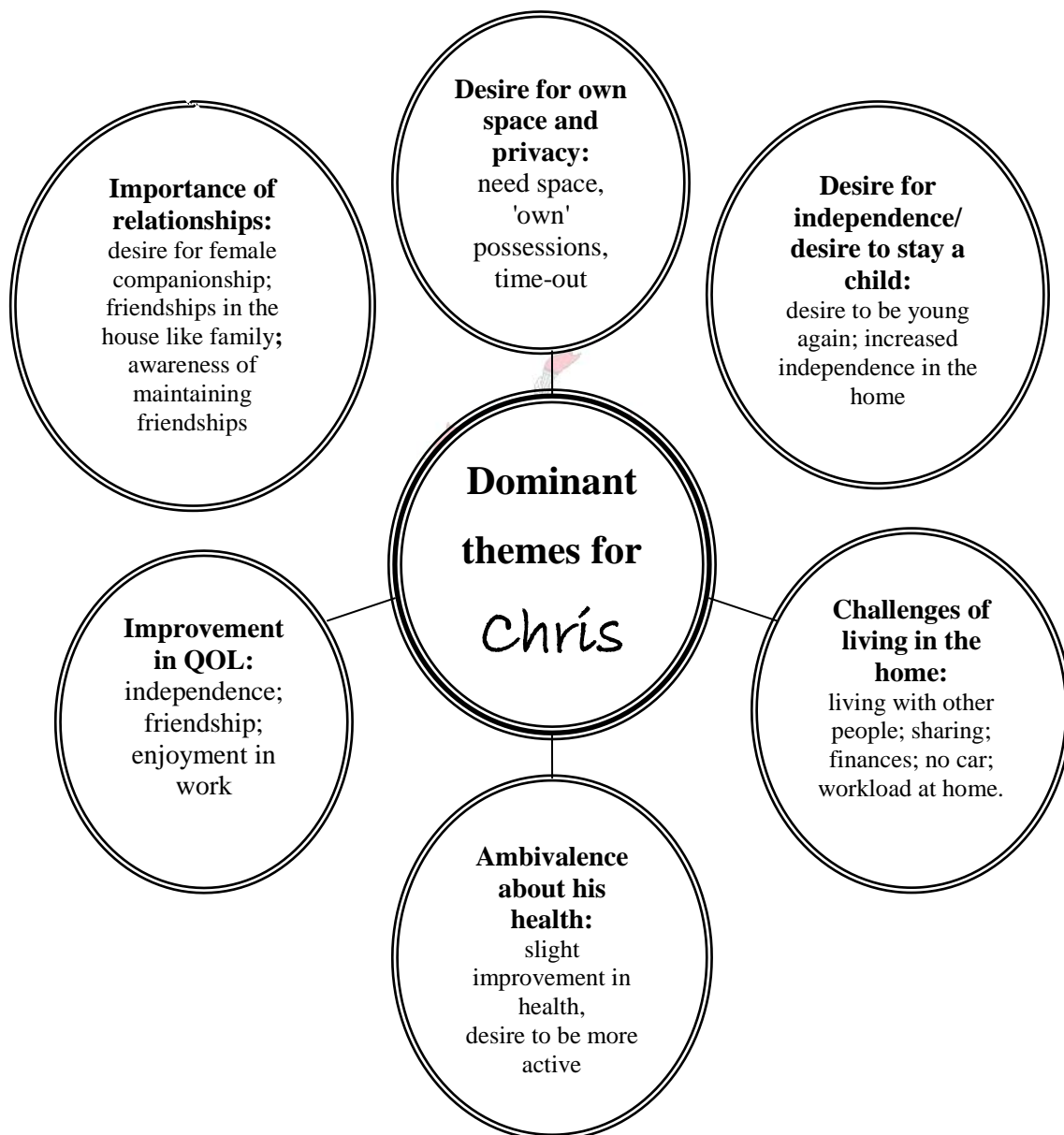
4.5.3.1 List of potential themes identified for Chris

Table 4.6: Themes that emerged regarding perceived QOL for Chris

QOL Domains	Potential Themes
Happy with life as a whole (SWB = 7)	<ul style="list-style-type: none"> • Higher QOL with girlfriend in past • Desire for a relationship with a women now • Desire to be young/ back at school
Standard of Living (SWB = 9) HIGH	<ul style="list-style-type: none"> • Happy with own possessions • Have gained independence • Friendship like family
Health (SWB = 5.5) LOW	<ul style="list-style-type: none"> • Ambivalent/ slight improvement in health
Achievement in Life (SWB = 8.5)	<ul style="list-style-type: none"> • Happy with opportunities at work • Dislike work • Frustrated with income/ desire for more pay • Feelings of accomplishments/ competence
Relationships (SWB = 10) HIGH	<ul style="list-style-type: none"> • Very content with friendships • Tries to be friendly/ aware of others
Personal Safety (SWB = 7)	<ul style="list-style-type: none"> • Protect each other (closeness) • Frustrated – no car (dependent on other people) • Better security needed
Community-Connectiveness (SWB = 9) HIGH	<ul style="list-style-type: none"> • Active in community / possibilities to do things • Nice neighbours • Frustration – No car (walking/safety)
Future Security (SWB = 7)	<ul style="list-style-type: none"> • Optimistic
Other themes that emerged regarding living at the group home	
Suggestions/wishes	<ul style="list-style-type: none"> • Additional appliances • More entertainment • More security
Other	<ul style="list-style-type: none"> • Challenges living with people • Need for other group homes to be built • Need for space/privacy • Mixed feelings about the house • Egocentricity
Quantitative analysis of PWI-ID scores	
PWI-ID Total Score:	56
Average Subjective Wellbeing (SWB):	80% SWB
Highest Domain of SWB:	Relationships (Average 100% SWB)
Lowest Domain of SWB:	Health (Average 55% SWB)

4.5.3.2 Dominant themes that emerged for Chris

Figure 4.4: Data display of dominant themes for Chris



4.5.4 Focus Group

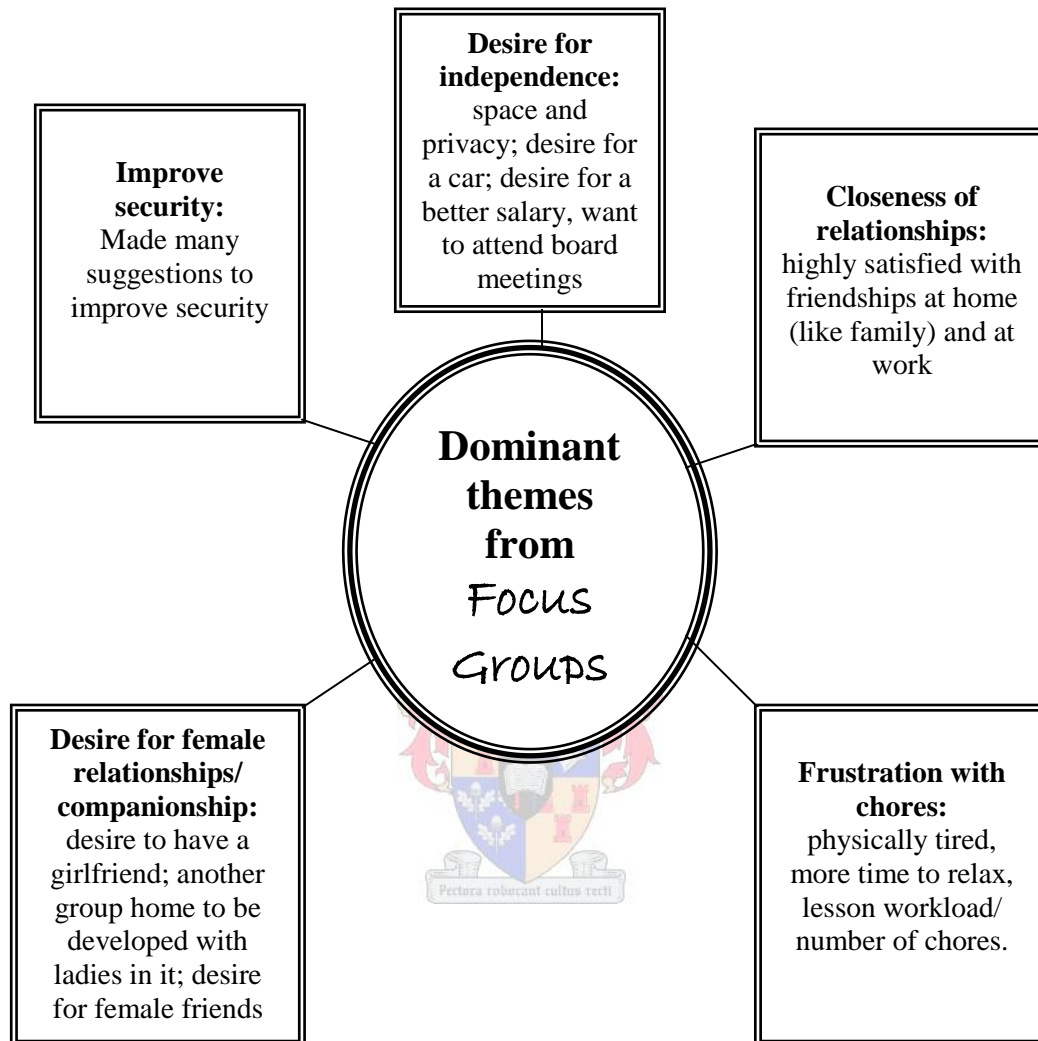
4.5.4.1 List of potential themes identified in the focus groups

Table 4.7: Potential themes that emerged from the focus group interviews

Suggestions	<ul style="list-style-type: none"> • Appliances (tumble dryer, washing machine) • Lesson workload/chores • More socialising in the home • Need a car • Improve security • Find ladies to live with
Aspects they like about the group home	<ul style="list-style-type: none"> • Increased independence • Space/privacy • Own rules • Freedom • Friendships
Aspects they dislike about the group home	<ul style="list-style-type: none"> • Chores/workload • Dependence on people • No car • Rules • Limited income
Desires	<ul style="list-style-type: none"> • To meet more ladies • Privacy • To be involved in the meetings • To have their own rules • More time to relax
Other	<ul style="list-style-type: none"> • The desire of companionship/ friendship with a woman • Another group home with ladies to be developed • Aloneness • Don't want to live with more men in the home • Desire to live on their own • Physically tired from chores • Realistic about circumstances • Friendship like family • Advantages of the Asperger's support group • Identity/ group membership in the house

4.5.4.2 Dominant themes that emerged in the focus groups

Figure 4.5: Data display of dominant themes for the focus group



4.6 SUMMARY OF THE ANALYSIS PROCESS

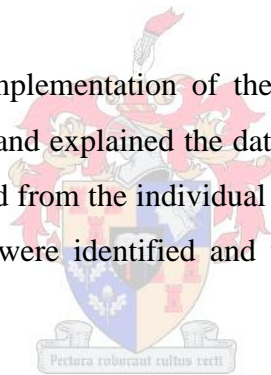
Thematic analysis involves the searching across a data set to find repeated patterns of meaning. In this study, the dominant themes were identified using the guidelines described by Braun and Clark (2006). Firstly, I coded and collated the data and then created a long list of codes for each participant and for the focus group interviews. The next step involved me sorting the different codes into potential themes within the different domains, and collating all the relevant coded data extracts within the identified themes. The potential themes that

were identified were then presented in a table format. This list of potential themes was comprehensive and lengthy. These themes then needed to be reviewed and refined into a smaller number of dominant themes. This was done by identifying over-arching patterns in the data. I was mindful at this stage that the data within the themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes. This involved identifying the 'essence' of what each dominant theme was about (as well as the themes overall), and determining what aspect of the data each theme captured (Braun & Clarke, 2006:92).

According to Braun and Clark (2006), by the time you have identified your dominant themes, you should have a fairly good idea of how they fit together, and the overall story they tell about the data. In the next chapter, I will be discussing the dominant themes in detail and 'identifying the story' that each theme tells.

4.7 CONCLUSION

In this chapter, I discussed the implementation of the study, introduced the participants, reflected on the interview process, and explained the data analysis process. I then provided a list of potential themes that emerged from the individual interviews and from the focus group interviews. The dominant themes were identified and will be discussed in more detail in Chapter Five.



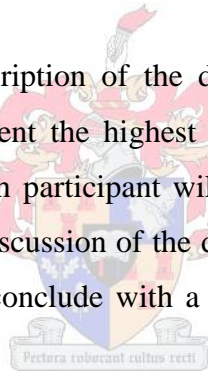
CHAPTER FIVE

DISCUSSION OF THE FINDINGS

5.1 INTRODUCTION

According to Braun and Clarke (2006:92), it is important that the analysis (the write-up of it, including data extracts) provides a concise, coherent, logical, non-repetitive and interesting account of the story the data tell within and across the themes. In this chapter, my detailed discussion of the dominant themes is related to the research questions, literature and my own interpretations of the data. This process of interpretation and discussion is one in which I found myself being confronted with choices about the meanings I attributed to the participant's words. Throughout the process I was conscious of my own subjective biases and expectations of the study.

This section will begin with a description of the dominant themes identified from each participant. The domains that represent the highest and lowest levels of subjective QOL, subjective wellbeing (SWB), for each participant will also be identified within the various themes. This will be followed by a discussion of the dominant themes identified in the focus group interviews. This section will conclude with a discussion of the over-arching themes identified across the entire data set.



5.2 THEMES IDENTIFIED FROM THE PARTICIPANTS

In the analysis process I attempted to capture the essence of the experiences and perceptions of QOL of each of the participants in the following dominant themes. I will discuss each of these themes in more detail using extracts from the data to support these findings.

5.2.1 Dominant themes that emerged for Seth Diablo Voldemort

I categorised Seth's words into six dominant themes. These were: **happy with relationships; satisfied with living in the home; desire for more independence; desire for space and privacy; physical complaints** and **dissatisfaction with security and safety**. These themes will be described in more detail below:

5.2.1.1 *Happy with relationships*

Seth appeared to be very satisfied with the friendships that he had made since he moved into the group home. This appears to be an aspect that has had a positive affect on his life and has enhanced his overall QOL. He described this improvement as: *I'm very satisfied, well this time I have a lot more things than I use to have before I moved to Cape Town. I have friends, I have people. That side I didn't have anyone ... But now I have a lot more than when I was living in the Vaal area. I didn't have friends there, I was mostly on my own. This side it is the total opposite, a turn-around.*

He also explained that the friendships he had made at the home and at work were very close. For example, he states: *Here we live like family. Like better family than I had. Since I moved to Cape Town and the school, I'd say the people I have now became much better than my own family.* The importance of this theme is reinforced by the high score that Seth attached to it on the PWI-ID rating scale. On both occasions, Seth gave the life domain of 'personal relationships' a score of 10 which represents the highest level of subjective wellbeing. Thus, the 'personal relationship' domain represented the highest level of subjective QOL for Seth.

This finding contradicts previous research which reported that many people with Asperger's Disorder find it difficult to establish close friendships and do not seem to be satisfied with the friendships they make (Orsmond et al., 2004; Travis & Sigman, 1998). However, it may have been easier for Seth to establish stable friendships with the people around him as he was living and working in an environment where people are understanding and knowledgeable about the intricacies of Asperger's Disorder.

5.2.1.2 *Satisfied with living in the home*

On many occasions, Seth expressed his satisfaction with living in the group home: e.g. *I don't think I would be very satisfied if it wasn't for this house. I would have shot myself already because if it wasn't for this house.*

Seth also commented that he was much happier in certain areas of his life since he moved into the group home. As mentioned above, Seth was experiencing an increased sense of belonging in the home. This is reflected by the high level of satisfaction he was experiencing in his personal relationships. He also mentioned that he was happy in his working environment and he felt satisfied with what he was achieving in life. He explained: *I love working at this place, this business, I don't think you could get a better place than that.* This

statement is reinforced by the high satisfaction score he attaches to the domain 'Achievement in Life'.

Seth also said that he was satisfied with what he owned - his possessions: e.g. *Ja, but I am actually quite satisfied with the things I own.* However, he said that he still desired to have more. He went on to list certain aspects that he would like to add to the house or change about the house. These suggestions included: an improvement in security; the addition of some practical appliances such as a tumble dryer and a washing machine; the assistance of a domestic worker for cleaning; and a splitter for the DSTV. These suggestions will be discussed in Chapter Six.

He also shared the fact that he was grateful to be living in the home. He explained: *I'm lucky I've got people sponsoring me for my stay, if it wasn't for that, where would I be. Maybe doing drugs, selling drugs or joining the mobs and being a terrorist, a human bomb for money, maybe I would have joined Bin Laden and his people. This house has definitely helped me a lot from the background I came from.* This statement, along others, supports the notion that Seth felt that the group home had enhanced his overall QOL. This impression is reinforced by the fact that he gave a high satisfaction score to the domain 'happy with life as a whole' despite the few frustrations that are described below.

5.2.1.3 Desire for more independence

The importance of independence resonated in many different areas in Seth's stories. On a few occasions he mentioned that he was satisfied with the amount of independence he was experiencing at the home: *but, for this house, I feel very happy, because um, you know, it's more independent.* But, for the majority of the time, he expressed his feelings of frustration with being so dependent on other people – dependent on others for money (financial limitations), for lifts (no car) and for decisions/permission to do things (listening to other people's rules). His two main areas of frustration, however, seemed to be: not having a car and lack of available money (income). He described his satisfaction within these areas as 'zero'. These frustrations are demonstrated in the following statements:

- *You see only if I have my car, now that's the only things I'm very unhappy about, now that would be a zero. That would make a big difference, it would go sky high. If I could achieve that it would be big pressure off my shoulders.*
- *And I'm not happy with the income. I'm sorry. Zero with the income. We don't mind the job only the money, if the money was there, I wouldn't mind if there had rules here and to*

abide by the rules, but for the money we get, we might as well only come in for one day for an hour.

- *We don't want to be dependent on other people and telling you what to do or please go there, do this and let's do this, you know, according to rules, we'll have our own rules because I feel like I could rather have my own rules and go according to my rules and then you have to go and obey those rules.*
- *Ja, I would like to do a lot more things, unfortunately I'm always depending on other people and now that's a pity.*
- *The thing is I have to rely on my friend and that's unfair towards him all the time. I'd prefer to rely on myself and all that.*

However, between these statements, Seth made mention of the fact that he understood the constraints of the situation, especially regarding the financial constraints of living in a sponsored home: e.g. *There can be more done, much more, but the other thing you have to think about, you have to think about the finances. But, I feel that it can be more, even if it's finance wise, financial possible, then wishful things can be done.*

Seth also frequently voiced his desire and need for space, freedom and privacy.

5.2.1.4 Desire for space, freedom and privacy

As discussed in the literature, people with Asperger's Disorder tend to have difficulty with social interaction and social communication and may find other people unpredictable and confusing (NAS, 2008; Orsmond et al., 2004). Thus, social interaction with other people may be difficult, overwhelming and at times tiring. According to the Autism South Africa website (2007), people with Asperger's Disorder often need 'space' and 'time' on their own – "sometimes the onslaught of people around them and the demand for the correct social interaction may cause them a great deal of stress" (Autism South Africa, 2007).

Seth voiced his desire to live on his own as well as his desire for privacy and space. This theme is reflected in the following statements: e.g. *I want more freedom, I want more freedom, space, more freedom and space.* The need for space and privacy appeared to be a common theme for all the participants.

5.2.1.5 Physical complaints

In the study by Jennes-Coussens et al. (2006) it was shown that the young adults with Asperger's Disorder were less satisfied with their physical health. This seemed to be the case

with Seth. He spent a great deal of time talking about his physical ailments. He complained about his migraines, scoliosis, and the bunions on his feet. However, he also mentioned that his health had improved slightly since moving into the home despite his still having many physical complaints e.g.: *I feel that I'm being more healthy, but I get back problems in all areas in my back, pains in my hips and legs and that. And I have bunions as well that bother me now, especially this left one.* Seth's desire to have a car seemed to be influenced by these physical complaints as he said it was difficult to walk because of his bunions and because he was 'unfit'.

5.2.1.6 Dissatisfaction with security and safety

This seemed to be an area of great concern for Seth and came up frequently in our conversations. The domain 'personal safety' was also his lowest satisfaction score (SWB = 2). He expressed his concern with the security in and around the house and voiced his concerns about the 'neighbourhood'. He also said that he felt unsafe walking around in the neighbourhood. He gave a few suggestions which he believed could improve the security of the house: e.g. *Ja, you know there could be more done here, if we could belong to a security company as I said more safety doors, more burglar-proofings and a alarm system, they have to fix the gate, we have to use a lock on that, and I'm not happy about that.* These suggestions will be discussed in Chapter Six.

5.2.2 Dominant themes that emerged for Ladybug

Ladybug's words were categorised into four dominant themes. These were: **happy with relationships; content with living in the home; work frustration** and **optimistic for the future**. These themes will be described in more detail below:

5.2.2.1 Happy with relationships

Ladybug often reflected on the friendships he had made in the home and at work. He said that he *likes being around the people here*. When asked the question about 'How happy are you in the domain of "personal relationships"?', he responded: *Ja, with the people on the school grounds. Practically, pretty happy.* Ladybug also reported the highest level of life satisfaction for this domain (SWB = 9).

5.2.2.2 Content with living in the home

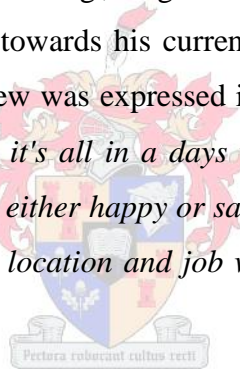
Ladybug appeared to be content with many aspects of living in the group home. *It certainly has improved my life*, he explained. The areas which he mentioned he was content with

include: the location of the home, his health; the security, his bedroom; and the organisation of the home. For example, he stated:

- *The house is very well organised and we have a special roster and we have to attend to our duties;*
- *I like my room very much because of the position, it gets warm during winter;*
- *Health: I feel satisfied. Not completely. About 7. Not completely;*
- *Security: Ja, I'm very happy with the standard. I'd give it a 7.*

In these responses, along others, Ladybug's referred to being 'content', 'happy' or 'satisfied' with living in the home. However, only when referring to his 'personal relationships', did I get the feeling that he was completely satisfied. This was also reflected in his high PWI-ID score he gave for that domain and the lower satisfaction scores he gave in the other domains.

With regard to the domain 'standard of living', he gave it a low satisfaction score (SBW = 5). However, he expressed ambivalence towards his current situation – he said he was content but could be more contented. This view was expressed in the following statement: *It doesn't actually bother me, circumstantially; it's all in a days work at the end of the day. I guess, where I am right now, I guess I'm not either happy or sad, about 5. In that sense, like for me, you know, of course, concerning this location and job wise, I am content with what I have, but I could be a lot more contented.*



The fact that he was content with living in the home but not fully satisfied in some areas was reflected in his score he gave to the question, 'How happy are you with you life as a whole?'. He responded: *I feel happy. About a 7 I think.* This score implies that he was content but not completely satisfied with his current situation in the group home. He provided a few suggestions which he believed could improve his QOL. These suggestions include: more appealing blinds; a jet master for winter, better security lighting outside and more entertainment. These suggestions will be discussed in Chapter Six.

5.2.2.3 Work frustration

An area of frustration for Ladybug appeared to be around his work environment. He appeared to have a desire to do more with his life. His frustration in this area is reflected in the fact that he places a low level of satisfaction in the domain 'Achievement in Life' (SWB = 5). He appeared to be finding the current workload in the kitchen stressful, especially during functions. Firstly, he mentioned that he would prefer to work in the garden. He explained: *I*

like my job but I'd prefer, well, I don't thoroughly enjoy it. I guess I like it medium. I'm pleased with it, but I would be thoroughly more enjoyable if I worked in the garden. I have told them that I'm not too comfortable in the kitchen. The problem in the kitchen, there's not enough hands-on availability, helping hands. There are times when there are too much work like with functions. More people need to be available to help me out. He did not elaborate on why he would prefer to work in the garden however this desire came up twice in our conversations.

He also expressed a desire to work in the field of 'spirituality'. He described this desire as follows: *I could be a lot more contented if I had, well, if I was working in the field of spirituality, like in research. I feel that I've got higher intelligence, gifted, intellectual virtues, and I can hone in to things concerning in the field or area of spirituality of psychic situations and I'm really interested in subjects such as astrology, numerology. I'm very interested in an activity concerning like people that have died but they have died before their actual time, so their spirit is stuck in the earthly realm.*

Ladybug expressed his desire to work in these different areas very vaguely and I found it sometimes difficult to understand why these activities were appealing to him.

5.2.2.4 *Optimistic for the future*

In addition to the domain 'personal relationships' Ladybug also rated a high level of satisfaction with the domain 'future security'. He explained: *Yes, I'm completely satisfied with what the future will bring. I feel very positive about the future. I would give it about a 9.* This is an encouraging reflection as it implies that Ladybug feels safe in his current situation. This in turn allowed him to feel positive and secure about what the future could bring.

5.2.3 **Dominant themes that emerged for Chris Jericho**

Chris's words were categorised into six dominant themes. These were: **importance of relationships; desire for own space and privacy; desire for independence/ desire to stay a child; improvement in QOL; ambivalence about health; and challenges of living in the home.** These themes will be described in more detail below:

5.2.3.1 *Importance of relationships*

All three participants have given the domain 'personal relationships' a high satisfaction score. Thus, the ability to establish and maintain friendships in their current environment appears to

be having a positive effect on each participant's overall QOL. Chris also reported the highest level of life satisfaction for this domain (SWB = 9).

When I asked Chris about the friendships he had made, he responded: *Ja, I think very well, I couldn't ask for anything better. The people around me are very special. You know I get along with everyone in the house. Ja, the relationships are strong.* Chris, like Seth, compared these relationships to a family: e.g. *we like real brothers*". In addition, Chris reinforced this idea by referring to the fact that they protect each other: *You know we protect each other, look after each other. If anyone tries to interfere with is, tries to put their nose where it doesn't belong, or tries to get into our faces, we just tell them to go away or ignore them.*

Throughout his stories, Chris appeared to be overtly aware of the attributes needed to maintain these friendships. For example, he explained that he tried to be *tolerant, patient, kind towards them and caring towards them* and to do his *best to be patient and help them and care about them and love them as much as [he] can*. He spoke about these attributes in a rather prescribed manner. According to Autism South Africa (2008), many people with Asperger's Disorder have to be "taught specific social skills" in order to establish and maintain friendships. Chris referred to these traits several times during our conversations as if he was trying to remind himself or reinforce these behaviours in the house.

Another common theme that emerged in Chris's stories was his desire to have a girlfriend or a female companion. As was reflected in his list of attributes needed to maintain friendships, Chris appeared to have a set idea about what a girlfriend was and why he felt that he would like one. Many of the reasons were centred on what the girlfriend could do for him. According to Attwood (2007 as cited in Brink, 2008) many people with Asperger's Disorder do not have empathy due to their problems with Theory of Mind (Baron-Cohen, Leslie & Frith, 1985; Bowler, 1992). "This does not mean that they do not care about other people. They can form very strong attachments to people who accept them as they are and who are prepared to help them. However, their caring is mostly based on their needs" (Brink, 2008:39). This notion was reflected in Chris's stories.

Chris's desire to have a girlfriend was expressed rather from an individual needs perspective than from a reciprocal joint relationship perspective. It was also very romanticised. He explained: *I am ready for it, maybe not entirely ready, to have another relationship with a young lady, who hopefully if I meet up with the right kind of person and we go on a date, and then I hope it will last forever this time ..., somebody that can really love me for who I am*

and take good care of me and somebody who's got a lovely friendly attitude that's kind and caring, and can make me laugh to. A special some one. The kind of person I'm looking for should be very smart, very intelligent someone that can make me happy and also to help me make myself happy, and some one to teach me new things.

5.2.3.2 Desire for own space and privacy

Like Seth, Chris also expressed his need for space and privacy. In one of our conversations, Chris reinforced the notion that people with Asperger's Disorder need space and time on their own. He explained this by saying: *Ja, I like to be alone a lot of times, because I like my own privacy because I am a very private person. And sometimes I feel that people are in the way a bit if you want to do things. Otherwise I'm happy. Life is looking up for me.*

In one of the questions I asked him how many people he would like to live in the group home. He responded: *I wouldn't encourage homes to be enormous, huge, because otherwise people might just suffer, find it too difficult to live with certain people, privacy, enough space, their space to think and relax might very well be invaded, can't relax, because that is how I would feel; Ja, people who are Asperger's, such as myself and others who are high functioning autists, they need space and they need time on their own for a while, and it would be good for us, but in the same sentence it is also good if we do have friends, and we do have enough friends in our lives, a lot of friends is good, it's just good to mix with people, to get to know them better, to chat to them, to enjoy their company, because that's what I like to do; and I encourage that most asperger and autistic people will hopefully have the same, enjoy it as well, be friends with the rest of the world. In the current situation, I think for me three is enough I would say.*

5.2.3.3 Desire for independence/desire to stay a child

There seemed to be a major contradiction in Chris's stories. On the one hand, he expressed his desire to be a learner again and to be back at school, and on the other hand he described how satisfied he was with the growing independence he was experiencing in the group home.

He appears to have had a happy experience as a learner at school and so desired to be young and carefree again. He explained: *I was very happy as a pupil to be honest and I don't think I could have asked for a better life and I was such a happy child, I never used to let things get me down, and I didn't used to fret so much and let things worry me, spend my whole life worrying like I do now. A lot of people miss their childhood.*

Despite this, he appeared to be experiencing high levels of satisfaction with his growing feelings of independence in the group home. This is demonstrated in the following extract and in the fact that he gave the domain 'standard of living' and 'achievement in life' a high satisfaction score based on his satisfaction with his independence e.g. *I've accomplished quite a lot over the last year or so now...I am making rapid improvement over the last few years now, and the longer I've lived here the more independence I've gained, the more satisfied I am, I am more cheerful each and every day and Every day I live here and I gain independence more by the day. I am good at cleaning up after myself, and looking after myself and dressing myself.*

5.2.3.4 Improvement in QOL

Chris's residence in the home appears to have had a positive effect on his overall level of QOL. He appeared to be very satisfied with his personal relationships, his standard of living and what he was achieving in life.

Chris also appeared to be content within the following domains:

- Community involvement (*I have nice neighbours; there's quite a lot to choose from out there. There are a lot of places out there that I find very interesting*);
- Standard of living (*I'm pretty happy about my possessions in my own life, my own television, my own magazines, my own bedroom, and clothes and that, I'm very happy about that*);
- Security, (*I think it is also very good*) however, he says that he starting to think that the neighbourhood is becoming less safe;
- His working environment (*I would say, every day I learn something new, and every day is a challenge for me, my jobs is also a challenge and depending on what I do, I would say, I often look forward to it*); and
- Future security (*I'd say I'm pretty excited actually, a touch nervous too in a way, but I must say I'm mostly excited, looking forward to the new year, the future and what my future is*).

As in the case of Ladybug, the fact that Chris was content with living in the home but not fully satisfied in all the domains was reflected in the score he gave to the question, 'How happy are you with your life as a whole?'. He gave a satisfaction score of 7 for this domain. This score implied that he was content but not completely satisfied with his current situation

at the home. He provided a few suggestions which he believed could improve his overall QOL. These suggestions include: a pool table; a splitter for the DSTV; more parties with friends; freedom to talk about anything; and better security. These suggestions will be discussed in Chapter Six. Despite the fact the Chris's overall QOL appeared to have been enhanced by living in the group home, there were a few aspects that he was not satisfied with. These frustrations will be covered in the next two themes.

5.2.3.5 Ambivalent about his health

Chris appeared to feel ambivalent about his current health status, however he attached a low satisfaction score to the domain 'health' (SWB = 5.5). As mentioned above, this appeared to be a common finding in people with Asperger's Disorder (Jennes-Coussens et al., 2006). However, in our conversations, he reported that he felt a bit healthier than he used to feel. He referred to the fact that he would like to be healthier and fitter: e.g. *I'm not too convinced that it's as good as it can be. It's not bad but I believe it can be better. I can be more physically active and work on my fitness levels especially and maybe cut down on certain food like the fast food, if you can call it junk food and all that.*

5.2.3.6 Challenges of living in the home

Like Seth, Chris's main areas of frustration seemed to be: not having a car (having to walk places) and lack of available money (financial limitations). With regard to income, Chris stated that his satisfaction with the money he earned was zero. He explained: *I just try be as positive as I can and just do what I can and work hard because I suppose my main worry is lack of pay. Money wise I would have to say zero.* This is similar to the response given by Seth.

Chris also discussed his frustrations with not having a car. His frustration appeared to be less about independence (as in the case of Seth) than the fact that he had to walk to places. He complained that walking is tiring and unsafe. Again, he expresses the fact that he is dissatisfied with his overall physical health: e.g. *what gets me down sometimes, because I get so tired because you see, your feet get very tired when you walk on the hard road, on the hard tar road. You see it tires you out and there's been a lot of times when I'm out of breathe, I've always had to sit down, every ten minutes or so, because it's so constantly tiring. That's the only thing that let's me down. It gets me down a bit is I wish we had a car for this house then I would have been ten times more satisfied if we had a car because it would be easier for us.* He also explains that he thinks walking is dangerous: e.g. *if we had a car to go with, it*

would be far safer and far easier because some times its dangerous walking as well. You never know what could happen. You know it makes you very tired and exhausted but you could be in danger too ... That's why it's best to have a car to get you places far easier and far quicker and if only that could get sorted out.

In addition, Chris mentioned the fact that he sometimes found it challenging to live with people. This again reinforces the notion that people with Asperger's Disorder often find social interactions difficult and tiring because they don't know what people expect from them (NAS, 2008). This extract from Chris really emphasises this difficulty: *for me it's quite a challenge living with people, I find it quite difficult actually living with people because living with people in general in a group home can be very frustrating and very difficult at times because you never sure what people want from you or what will make them happy, or what will make them sad, and just sometimes you get that impression you just don't know where you stand with them.*

In addition, Chris explained that he sometimes found it difficult to share things with the other members of the house, especially the T.V.: e.g. *Although, we are doing our best to share, everyone's doing pretty well. But we'd just find it a lot easier if we had our own TVs, own decoders.* This seems to be a common theme. Seth also voiced his desire to have a splitter for the DSTV so that they could all watch their 'own' programs.

Chris expressed his dissatisfaction with the fact that there were sometimes arguments and disagreements in the house and he wished that people could just talk openly about things they wanted to: e.g. *I just wish there weren't any arguments or fights, just peace-making instead of war-making, and because I think there should be more love and more peace and harmony and I wish people are able to be free to talk about absolutely everything.* These statements reinforce the assumption that many people with Asperger's Disorder have a difficulty with Theory of Mind (Baron-Cohen, Leslie & Frith, 1985; Bowler, 1992) and find it difficult to adjust their conversations to accommodate another person's views. I found this aspect quite challenging during the interviews as the participants often changed the topic to talk about their interests.

On several occasions, Chris expressed his desire to live alone with his 'own' things. This was also expressed by Seth. For example, Chris stated: *I wish I was living on my own one day in a special house somewhere close to the sea, close to the beach, if I were in that environment and I had everything for myself like a DSTV full pack decoder, hi-fi system, a DVD player,*

video machine, whatever, then I feel as though if I were well off like that living on my own with no one interfering with me or bothering me, then yes I would say life would be perfect. This is another example which illustrates the apparent 'egocentricity' that often accommodates people with Asperger's Disorder.

As indicated above, some common themes were identified between the three participants. Many of these themes were also common to those identified in the focus group interviews. The dominant themes that emerged from the focus group interviews will be discussed below.

5.3 THEMES IDENTIFIED IN THE FOCUS GROUP INTERVIEWS

As mentioned earlier, Chris and Seth were only present for the focus group interviews as Ladybug was away on both occasions. The words of these two participants were categorised into 4 dominant themes. These dominant themes were: **desire for independence; closeness of relationships; desire for female relationships/ companionship** and **frustration with chores**. There are many similarities between these themes and the themes identified for the participants. These similarities or over-arching themes will be mentioned below and discussed in Chapter Six.

5.3.1 Desire for independence

The theme of independence arose frequently in our conversations. It seems that both participants experience more independence and freedom since living on their own away from their parents. This was reflected in the following comments: *You feel a lot more mature being on your own than being with your parents and usually with your parents you have to obey their rules and live under their roof. But here you've got your own.*

5.3.1.1 Space and privacy

The theme of independence was also reflected in the fact that they could enjoy their own space and privacy to do their own things in the home: e.g. *you can do your own things at your own time, and you can chill down whenever you want to, and listen to your music with no one interfering.* Their desire for independence and space was also reflected in their wish to live on their own. This was a common theme that emerged in the individual interviews as well. In the focus group interviews, however, both participants acknowledged the financial constraints which they believed were preventing them from living on their own. One participant explained: *If I could I would have moved and lived on my own, but unfortunately it won't happen that quick. Live on my own and do my own things at your own time, even he agrees.*

But unfortunately it's not that time yet, not at the moment. If I could afford it I wouldn't mind, but if you can't, then you have to be satisfied with what you have.

5.3.1.2 Desire for a car

The participant's desire for independence was also linked with their desire for a car. Their feelings of increased independence seemed to be contradicted by the fact that they didn't have a car and they had to rely on other people to drive them around. This was a theme that also emerged frequently in the individual interviews: e.g. *hopefully one day, they can get a car. I really want to drive. I don't want other people to drive me around.*

5.3.1.3 Desire for a better salary

Another common theme that arose, which also contradicted their feelings of increased independence and freedom, was their frustration with their income. Both participants voiced their frustrations with their salary saying that they couldn't buy anything they wanted to buy: e.g. *That is what gets us down too is the lack of pay. We don't get, not that we want a lot and a lot and a lot, but we want just about enough amount of money, pocket money to supply ourselves with certain things we want to buy, things that we need. We want freedom too, we want more things.*

5.3.1.4 They want to attend meetings with the board

A desire for more independence was also highlighted by the fact that they wanted to attend the board meetings about the group home. They strongly expressed their desire to be involved in the decisions about the house. They both stated that they were the ones that lived in the home, they were the pioneers of the project and they had a right to be included in the decision-making process. This notion was expressed in the following statements:

- *But I don't know why they don't tell us as well. The thing is we want to have our rights as well, we are the residents. We are the pioneers.*
- *Ja, we want to be involved in the meetings as well, because we only hear about it after the meetings have happened and what they want and all of that. And I feel that it would be fair if we could attend the meetings too, then they can see us face-to-face and communicate with us.*
- *Yes, we stay here and they talk about us behind our backs. We the individuals in the house, and they chattering behind our backs and we don't know what's going on. I would feel better if we could attend the meetings and we can be face-to-face with them.*

- *You see the thing is the committee doesn't actually know what's going on because they don't live here but we do. So, we actually know more than they know. But sometimes they don't seem to want to realise that. We also have to do what they say all the time and go according to their rules. I don't know quite how it works really.*

These statements highlight the participant's feelings of frustration about being excluded in the decision-making process.

5.3.2 Closeness of relationships

Similar to the themes identified in the individual interviews, both participants expressed a high level of satisfaction with their personal relationships in the home and in their work environment. Likewise, they spoke about the fact that they felt that the relationships in the house were as close as family i.e. *Ja, we happy ... We like a family. Everyone's like a hellova family. Everyone is one, crazy happy family.*

5.3.3 Desire for female relationships/companionship

Chris was the only participant to mention his desire for a relationship with a woman during the individual interviews. However, in the focus group interview there appeared to be a strong desire from both participants to meet and befriend some 'ladies'. They suggested that either two ladies could move in with them or a group home especially for 'high-functioning' ladies could be developed close to their home. Seth suggested that the board should advertise to find these ladies and that he and Chris should be involved in the selection process in order to 'study' them. The manner in which he described this selection process was rather prescriptive and clinical and reflected his apparent difficulty to relate to another person on a more personal and emotional level. He explained: *It would be great if they could advertise it. Then we should attend the meetings and if they have ladies in the house we should go and see and study them, like when you join the army or join NASA space station or any kind of forces. The doctor goes to you and searches you and says if you fine, you physically and mentally stabled. Or if he sees something he is not happy with, he says sorry you physically and mentally not stabled so sorry, you're not okay. Like a check-up. We can check if they are ok or not ok.*

The two participants also emphasised the fact that they both felt the 'need' for a special woman in their lives. This apparent 'need' was expressed in a way that related this to feeling incomplete and unbalanced without a woman. Again, their explanations for this sounded very

concrete and restrictive and lacked the concept of mutual companionship and interrelatedness. Their need was reflected in the following statements:

- *Now, when we get the opposite, we will be the full package;*
- *It's something you have to have, like electricity to survive. It's important.*
- *And what makes it easier for us is that we do need the opposite sex because we can't just be around guys all the time and have no girls...I mean with girls you can also have great conversations. You can do things and you can have heart-to hearts. Women generally are more understanding than men and have more patience than men;*
- *It's like balanced you see, two ladies and two men, you can say like a group. It's like partners, real partners. Else it's like wearing an army boot on one side and a tackie on another. That's how I feel at the moment. It should be like my socks, they match.*
- *Because you need the best of both worlds, you can't just have one world all the time. Otherwise you'll die with a broken, sore heart and you don't know where to go to, where life's gonna take you. You gonna feel lost if you just with the same sex-gender.*

The notion of a platonic friendship with woman also appeared to be a strong desire for them. However, it did not appear to be as strong as their desire to have a romantic relationship with a woman. They appeared to desire female friends to talk to in order to feel *less lonely and left out*. When I asked them why they would like some female companionship, one participant said: *To become good friends with them I would say mainly. To be friendly with them, love them and appreciate them as they are. And to have some good company, some female company. And we can chat to and share our thoughts with and share our ideas with and all that. That would be wonderful I think. We wouldn't feel so left out and so alone. I think it would be great.*

The fact that they had no female friends was mentioned on numerous occasions. On one occasion, both participants thanked me for being their only female friend: e.g. *you see we don't actually have any girl pals, except for you, but we only see you occasionally and I'm glad at least I have a girl who is a friend of mine.*

5.3.4 Frustration with chores

A theme which emerged only briefly in the individual interview's but was a prominent and central theme in the focus group interviews was their frustration with their current workload, mainly their chores in the home. Both participants complained that the manual chores such as

sweeping, gardening, cleaning were tiring and boring e.g. *I mean I don't mind cooking, I like to do it, but it's the cleaning up afterwards, sometimes I'm so tired and worn out through all my days of work and I don't feel like it, I just want to take it easy and I know the chores that tire me out the most are mopping, dusting and sweeping the floor. I hate to sweep floors because that is very tiring.*

In addition, they both complained that they have to do too many chores too often and they don't have enough free time to themselves: e.g. *I would say we do it too much, we over do it. We always have to cook food and wash dishes every single day, every single hour of the day and you know it's a daily basis from Monday to Thursday. I think the only time we have for ourselves is over the weekend and sometimes we do it too much; and ... because a lot of cleaning and working and gardening gets in the way of relaxing.*

Both participants acknowledged the need for chores in the home, however they expressed their desire to lesson the number of times they had to do their chores: e.g. *I know you have to have chores because otherwise you'll have an army of cockroaches and rats and well, unfortunately there has to be chores, otherwise who would do them, but sometimes I feel we should maybe lesson that, maybe do it occasionally, every month maybe. Not every single week exactly because otherwise it gets boring, it becomes too dull and it comes too much.*

They suggested that they do gardening only once a week instead of twice a week. They appeared to be happy with the current cooking roster – they cooked on their own on Mondays and Fridays and *'it's only Tuesday's, Wednesday's and Thursday's that everybody cooks together'*. It was only the cleaning up afterwards that they appeared to be unhappy about. One of them suggested that Board buy a washing machine or hire a domestic worker to help with the cleaning and gardening. These suggestions will be discussed in Chapter Six.

5.4 OVER-ARCHING THEMES

As I have mentioned above, there were certain common themes that resonated across the entire data set. These over-arching themes are listed below and will be discussed in Chapter Six in relation to the research questions.

Table 5.1: Over-arching themes identified in the study

Over-arching themes identified in the study
An enhanced overall level of quality of life in the group home
A high level of satisfaction with personal relationships
Need for space and privacy
A desire to have a car to increase independence/ safety
A desire for an increase in salary/money

5.5 CONCLUSION

According to Braun and Clarke (2006:93) a discussion of the findings needs to do more than just provide data: "Extracts need to be embedded within an analytic narrative that compellingly illustrate the story which you are telling about your data, and these narratives needs to go beyond description of the data, and make an argument in relation to your research questions". In this chapter, I discussed the dominant themes in detail using extracts which I believed captured the essence of each theme. Then, from within these themes, commonalities in the voices were heard and trends were identified.

In the final chapter, I shall discuss these over-arching themes in relation to the three research questions. A list of tentative suggestions for the home will also be included. In addition, I shall provide a summary of the preceding chapters, identify the limitations of the study and suggest recommendations for future research. I conclude the thesis with some reflections on the research process.

CHAPTER SIX

SUMMARY OF THE FINDINGS, LIMITATIONS, RECOMMENDATIONS AND REFLECTIONS

6.1 INTRODUCTION

This chapter begins with a brief summary of the previous chapters. I then discuss the findings in relation to the main research questions and also make as a list of tentative suggestions for the home. In the last section of this chapter, I shall explore the limitations of this study and recommendations for further research before reflecting on the research process.

6.2 SUMMARY OF CHAPTER 1, 2, 3 AND 4

Chapter One provided an orientation to the study. The research problem, research aims, theoretical approach of the study, the research design and methodology as well as the way the thesis is structured were described. In addition, the concepts of ASD and QOL were introduced and the relevance of the study in the current South African context was discussed. There appears to be a growing need to define, assess, implement, and measure an individual's perception of their QOL in order to enhance and provide better support services for them, especially individuals with disabilities. This study represented an attempt to reflect the voices of three men with ASD who live in a group home and to share their experiences and perceptions of their QOL.

Chapter Two provided the reader with a review of the most authoritative scholarship and available knowledge on the subject of QOL and Autism Spectrum Disorder (ASD). The literature review revealed that very few studies had incorporated QOL into ASD research. In the light of this as well as the need to evaluate the services offered by the group home, there was a clear need for an exploratory study.

In **Chapter 3**, the qualitative (interpretivist) research design of the study was described. This included dimensions such as purpose, paradigm, context and techniques. The various data production techniques used in this study, namely structured and semi-structured interviews, focus group interviews and observations were also described. Ethical considerations were outlined and the various steps in the data analysis process were shown in the form of a table.

The chapter concluded with a discussion on aspects of reliability and validity and the procedures that were used to enhance these aspects.

In **Chapter 4**, the implementation of the study was discussed. Here the participants were introduced and the study site was delineated. Next, some reflective comments on the interview process were provided and the data analysis and verification process were clarified. The chapter concluded with a list of identified themes from each participant and from the focus group interviews. These themes were then reduced to a smaller number of dominant themes to make interpretation more manageable.

In **Chapter Five**, these dominant themes were discussed in detail in relation to the research questions, the literature and my own interpretations of the research process. Over-arching themes from across the data set were also identified. These over-arching themes were:

- A high level of satisfaction with personal relationships;
- An enhanced overall level of quality of life in the group home;
- Need for space and privacy;
- A desire to have a car to increase independence/ safety;
- A desire for an increase in salary/money

Throughout the research process, I was mindful of my own position as the researcher and was conscious of my own subjective biases and expectations of the study. The aim of this study was to explore the subjective worlds of each participant – *their* internal reality – the way *they* perceive their QOL in the group home. Working within the interpretivist paradigm allowed me the opportunity to do just that – I was able to listen to the meanings the participants gave to their world and make sense of their own unique experiences of living in the group home from *their* perspective. Their perception of their QOL within the group home could therefore be explored using more personal and interactive modes of data production – interviews and observations. The data were analysed to detect patterns and contradictions in what participants had voiced. The themes that emerged were then explored in relation to my research questions. These themes were then discussed with the participants. The participants agreed with the themes identified and gave me permission to include all of them in this paper. A summary of these findings is provided below.

6.3 SUMMARY OF THE FINDINGS

It has been argued that an evaluation of services for individuals with disabilities should focus on the level and type of experiences lived by the consumers (Garcia-Villamizar et al., 2002). This means one needs to listen to the experiences of the consumers themselves. This case study was an attempt to allow the three men with ASD to voice their perception of their quality of life in the group home. By acknowledging that these men have important views and knowledge to share about their experiences of living in a group home placed me in a privileged position to share their invaluable insights and stories with others.

As I showed in Chapter Five, clear patterns emerged in the conversations with the three participants. In the next section I shall explore the over-arching themes in relation to the three main research questions that were posed.

6.3.1 Areas that represent the highest and lowest levels of subjective QOL

Which of the 7 core domains in the PWI-ID scale represent the highest and lowest levels of subjective wellbeing for each participant?

6.3.1.1 Highest level of QOL

The highest level of satisfaction for all three participants was in the domain 'personal relationships'. These high satisfaction scores were reinforced throughout the interviews with stories of friendship, companionship, support and brotherhood. The notion that people with Asperger's Disorder are generally unsuccessful in establishing and maintaining friendships (Myles & Simpson, 2002) did not appear to hold true from these participants' perspective. The fact that this domain was collectively viewed as holding the most life satisfaction implies that the environment in the home and at work was conducive to the men's forming and maintaining friendships and feeling a sense of belonging. This may have been enhanced by the fact that the participants lived and worked in an environment where the people understand and are knowledgeable about the intricacies of Asperger's Disorder. In addition, the group home was designed specifically to meet the unique needs of high-functioning adults with ASD. The men received ongoing professional support and Seth and Chris attend an Asperger's Disorder support group. This might have made it easier for them to function optimally within the home.

Ladybug also expressed a high level of satisfaction in the domain 'future security'. This is encouraging as it implies that Ladybug feels safe in his current situation and is able to look

forward to the future positively. The other two participants also expressed optimism about the future.

6.3.1.2 Lowest level of QOL

The domains which represented the lowest level of QOL varied for each participant.

Seth was the most dissatisfied with the domain 'personal security' and suggested how he thought the security could be improved. These suggestions will be discussed later in this chapter. He expressed the fact that he felt unsafe in the current environment which resulted in him reporting a low level of subjective wellbeing in this domain. Chris also voiced his concerns about the security in and around the house and suggested some ways of improving the security.

Ladybug voiced his frustration with his current work situation and subsequently gave the domain 'Achievement in Life' a low satisfaction score. He expressed his desire to work in the garden or work in the realm of 'spirituality'. Ladybug's low score in this domain stood in contrast to the other two participant's scores in this domain, which were relatively higher. The other two participants expressed their enjoyment in their work environments and appeared satisfied with what they were achieving in life. Ladybug also expressed his dissatisfaction in the domain 'standard of living'. However he seemed ambivalent in his response and was unable to give a reason for his low level of satisfaction within this domain.

Chris gave the domain 'health' the lowest satisfaction score. He expressed his desire to be more physically active and fit. He also complained frequently about getting tired when doing things i.e. he got 'tired' walking places as he didn't have a car and he got 'tired' doing his chores around the house e.g. cleaning and gardening. He also expressed the fact that he has never liked 'work' because it made him 'tired'. However, he said that he was currently enjoying his job as a groundsman. Seth was also not very satisfied with his health and had many physical complaints i.e. migraines, headaches, scoliosis and bunions on his feet.

6.3.2 Overall level of QOL

Do the participants think that their residence at the group home has enhanced their overall QOL?

All three participants made reference in their interviews to the fact that they think the group home has enhanced their overall QOL. In addition, each participant's average subjective wellbeing (SWB) score reflected an overall high level of satisfaction. These scores were

obtained by adding each participant's seven domain scores, averaging it and converting it into a percentage score (%SM). This process was explained in Chapter Three and the PWI-ID scores were provided in Chapter Four.

A high average subjective wellbeing score implies that a person is satisfied with his or her perceived QOL over many life domains (Cummins & Lau, 2005). In this study, each participant showed varying degrees of satisfaction within the different domains. The domain 'personal relationships', however, showed a collective high satisfaction score. It can therefore be deduced from the themes in the data, as well as from the high average SWB scores, that each participant perceived himself as experiencing a high level of QOL in the group home. For example:

- Seth explained that he 'wouldn't be as satisfied if it wasn't for this home'. He also expressed his gratitude for the group home and explained that his life has done a 'turn-around' since he left the Gauteng. He explains that he now has 'friends and people in Cape Town'; 'he is satisfied with his own possessions' and 'he enjoys his working environment'. Seth's average subjective wellbeing score was 67%.
- Ladybug explained that the home had 'certainly improved his life'. He expressed his satisfaction with the location of the house, his room and the organisation of the home. He also expressed his optimism for the future. Ladybug's average subjective wellbeing score was 70%.
- Chris expressed his satisfaction with many aspects of the home. He explained that he felt more independent since he moved into the home. In addition, he enjoyed his job as a groundsman and was happy with the possessions he owned. He was happy in the community and optimistic about the future. Chris's average subjective wellbeing score was 80%.

From the findings, it was clear that the group home had played a significant role in enhancing the participant's perceived QOL. However, there were some aspects in the home that the participant's indicated had a negative effect on their perceived QOL. Their common complaints or frustrations were related to: not having a car and being dependent on people for lifts; poor salary and lack of money to do things they wanted to do; poor security in and around the house; the need for space and privacy; not being involved in the board meetings; and not having any female friends. Many of these frustrations appear to be linked to the participants' desire for more independence in the home. The participants offered some

suggestions that they felt could improve their perceived QOL further. These suggestions are listed in the section below:

6.3.3 Suggestions

Are there any aspects of the housing programme that the participant's think could be altered to enhance their perceived QOL?

As mentioned in Chapter Five, the participants offered several practical suggestions. These were:

6.3.3.1 Suggestions to improve security

- The installation of a burglar alarm
- Joining a security company like ADT
- The installation of a safety gate on the front door
- The installation of a safety gate on the kitchen door
- Better security lighting outside
- Burglar bars on all the windows, especially the two big windows in the lounge.

6.3.3.2 Appliances and decoration

- A dishwashing machine to help with cleaning and to minimise the number of chores
- A tumble dryer to dry the clothes especially in winter
- A jet master to keep the house warm in winter
- More appealing blinds for the windows
- A splitter for DSTV so that they didn't have to share programmes
- A pool table for entertainment.

There was also a suggestion to hire a domestic worker to help with the cleaning and gardening. This would reduce their number of chores and would allow them to have more free time to relax.

A suggestion was also made to have more parties at the home, especially dress-up parties. The participant's agreed that it would be a nice way to meet new people.

6.3.3.3 Suggestions to provide more independence

As mentioned above, many of the common themes that emerged were related to the participant's desire for more independence. The participant's proposed the following suggestions to increase their sense of independence and freedom:

- The participants would like to attend the board meetings so that they too can be involved in the decision-making process;
- Seth would like to do his drivers licence and they would like to be able to use a car when required;
- The participants would like for another female house to be developed so that they can make friends with ladies; and
- The participants would like their salary to be increased so that they can have more freedom to buy the things that they would like to buy e.g. magazines, food, treats for someone special in their lives.

Despite the fact that the participants made these suggestions, they were also realistic about the improbability of some of them due to the home's financial limitations. This was especially true of the suggestion regarding an increase in salary and the acquisition of a car.

6.4 RECOMMENDATIONS FOR THE BOARD

I felt that many of the participants' frustrations were centred on the fact that they wanted to live more independent lives. They seemed to externalise their frustrations and focus on the aspects of their environment that they perceived as restricting their daily living. As a recommendation to the sponsors of the home ('the Board'), and others like it, I would suggest that the occupants be involved as much as possible in the decision-making process regarding the group home. This could be beneficial for both parties. Firstly, it could increase the occupants' feelings of independence and could provide them with a greater sense of ownership of 'their home'. In addition, the occupants could take more of the responsibility for running the home and be in a better situation to understand the financial limitations of living in a group home. The increased involvement of the occupants could provide the shareholders with invaluable insight into the daily on-goings of the house. It could also help them to identify and implement any necessary improvements to the home.

I would also like to recommend that the number of occupants in the home be kept to a minimum. As the participants mentioned, they find living in the company of other people rather challenging. This is understandable as people with Asperger's Disorder often do have significant difficulties with social interaction and so have a particular need for their own space and time on their own.

In addition, I would like to recommend to the Board that they discuss the possibility of improving the security with the participants. It was obvious that they are concerned about their present security situation in the home and they provided various practical suggestions which they believed could alleviate some of their concerns. According to Maslow's Hierarchy of Needs (Huitt, 2004), 'personal security and safety' is a second level need. In order to satisfy their higher-order needs, such as social and esteem needs, they need to feel a sense of personal safety in their environment. This would allow them to then move on to the next level of needs in their journey to self-fulfilment and self-actualisation.

The aim of this study was to explore the perceived QOL of three adults with ASD who are currently living in a group home in Cape Town. However, the fundamental goal of this study was to hear the voices of three men who present with unique perceptions of the world. *Their* voices were the sole source of data – the evaluation of the group home was made from *their* perspective. From our conversations, it was clear that the group home had played a significant role in enhancing each participant's perceived QOL in many domains. There were, however, some aspects in the group home that the participants indicated had had a negative effect on their perceived QOL. By gaining a better understanding of these factors, I am able to provide some suggestions and recommendations to the sponsors of The Group Home. These suggestions could lead to further enhancement of the participant's subjective QOL. The findings could also provide guidance for future developers of other community-based group homes.

6.5 LIMITATIONS OF THE STUDY

- I relocated to Johannesburg in January 2008 which made it difficult for me to conduct the interviews with the participants. I had to organise the interviews in advance and the participant's were not always available when I was in Cape Town.
- I was only able to interview Ladybug twice which minimised my ability to fully explore his feelings about the home or his perceptions of QOL.

- I would have liked to interview some of the people that were in daily contact with the participants in order to explore their views on the participants' QOL, especially the caregiver that lives with them. However, due to time constraints this was not possible.
- It is possible that other information would have come to light if I had spent more time with the participants.
- Two of the participants started attending an Asperger's Disorder support group in July 2008 and I was only able to conduct one focus group interview with them shortly after that. I wonder if prolonged involvement in this group would have had any affect on their perceived QOL, especially with regards to meeting new people.
- Lastly, my inexperience of working with individuals with Asperger's Disorder left me wondering how much more I could have probed/ extracted if I had had more experience working with people with this unique and fascinating disorder.

6.6 RECOMMENDATIONS FOR FUTURE RESEARCH

There appears to be a growing need to define, assess, implement, and measure an individual's perception of their QOL in order to enhance and provide better support services for them. However, as mentioned in the literature review, very few studies had been carried out that have incorporated QOL into ASD research. Thus, more research is needed to:

- develop appropriate tools to assess subjective QOL in people with developmental disabilities and intellectual disabilities;
- explore the relationship (if any) between the QOL and the severity of ASD;
- explore the misconception that people with intellectual disabilities have a lower level of QOL than people without disabilities;
- investigate the relationship between objective and subjective indicators of QOL; and
- investigate the homeostasis assumption about people with developmental and intellectual disabilities.

6.7 PERSONAL REFLECTIONS

My experience of the research process was positive overall. However, I wish I had been able to spend more time with the participants in order to get to know them better and in order to give more justice to this investigation.

It was a challenging experience for me in many ways. This may have been due to my inexperience as a researcher as well as the uniqueness of the participants. Firstly, I found the literature review process overwhelming as there were many contradicting opinions in the literature, especially regarding terminology. There appears to be an on-going debate in research regarding what represents functional variations within Autism and what constitutes separate disorders (Klin & Volkmar, 2003). For this reason, I chose to use the umbrella term 'Autism Spectrum Disorder' to cover all three participants. As I mentioned earlier, the aim of this study was not to diagnose which participant's had high-functioning Autism or which had Asperger's Disorder (if there is actually any difference in adulthood?), but rather to listen to their experiences. However, in the study, I chose to make use of the term Asperger's Disorder to describe and make sense of their high-functioning 'autistic' behaviour.

Secondly, I found it particularly difficult to conduct some of the interviews. I often had to repeat the questions and keep the participants focused on the questions at hand as they tended to change the topic to things they were interested in talking about e.g. flying, sports, music and religion. Thus, I was not always able to get the information I was asking for and the interviews often took longer than expected. Their apparent difficulty in adjusting their conversations to accommodate the other person has been described as a common characteristic of people with Asperger's Disorder.

Thirdly, I found some parts of the interviews difficult to transcribe as their language was often tangential and repetitive. Lastly, I found it difficult to integrate all the findings. I was able to look at the cases separately. However, I found it challenging to integrate the findings across the whole data set as I felt there were so many variables and I didn't want to privilege some over others. This challenge was definitely related to my inexperience as a researcher.

Regardless of these challenges, I feel that I was able to accomplish the central aim of this study – **I was able to give the three men at the group home a voice in which they were able to share their experiences and perceptions of their QOL in the home.**

Finally, this study taught me a great deal about the intricacies of Asperger's Disorder and I would like to thank the participants for showing me a window into their world which often appeared very different from my own.



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ANNEXURE A

LIST OF QOL INSTRUMENTS (ACQOL, N.D.)

http://acqol.deakin.edu.au/instruments/instrument.php#index_code_Z7

This directory is intended to allow the rapid identification of instruments which may be of interest to researchers into QOL. As such, it is designed to provide only the basic information necessary for this purpose. It does not provide details of psychometric performance. It does, however, provide references to articles that report on the psychometric characteristics for each scale. Typically a maximum of two recent articles will be cited for this purpose.

In order to assist in the rapid identification of scales that are designed for particular groups, each scale description has a tag that can be entered into the search engine to retrieve such groups of scales. The tags are as follows:

- Z1 Normal Population
- Z2 Intellectual/Cognitive Disability
- Z3 Medical
- Z4 Psychiatric
- Z5 Geriatric
- Z6 Children/Adolescents
- Z7 Disability
- Z8 Congenital Disability
- Z9 Adventitious Injury



The description of each reference contains the name and initials of the first author, the name only of a second author, and 'et al' if there are two or more other authors. The full reference is usually available from the Bibliography on the website.

The title of the Journal, Book or Publisher is in a code. This code can be accessed through the Instrument Database Abbreviations Codes. Codes link that appears below each scale description. The codes are as follows:

Journals - These are formed from the first letter of each word making up the Journal title.

Books and Manuals - These are designated by a 'B.' preceding the Book code. The code is formed as before.

Publishers and Universities - These are designated by a 'P.' preceding the Publisher or University code. the code is formed as before.

Bottom of Form

[28-National Indicators of Child Wellbeing \(Z6\)](#) Land, K. et al. (2001)

[42 item Ways of Coping Checklist \(\)](#) Walkey, F.H. & Green, 1999, P.VUW; Boyd-Wilson, B.M, PAID (2000)

[Abbreviated Loneliness Scale \(Z1\)](#) Paloutzian, R.F. & Ellison, B. LASO (1982)

[Aberrant Behavior Checklist \(Z2\)](#) Aman et al (1985)

[Accepting the Past Scale \(Z1\)](#) Santor, D. & Zuroff (1994)

[Acculturative Stress Scale \(Z1\)](#) Cawte, J. et al. (1968)

- [Acculturative Stress Scale for Foreign Students \(Z1\)](#) Sandhu, D.S. & Asrabadi: PR (1994)
- [Acquiescence Scale \(Z1\)](#) Winkler et al (1982)
- [Activation - Deactivation Adjective Checklist \(Z1\)](#) Thayer, R.E. (1989)
- [Activity and Attitude Inventory \(Z5\)](#) Cavan, R.S. et al., B. PAIO (1949)
- [Adaptation to Old Age Questionnaire \(Z5\)](#) Efklides, A. et al. (2003)
- [Adjective Check-list \(Z1\)](#) Gill, W.M., CHS1, 1984a, 8, 288-296; SSAM (1984)
- [Adolescent Coping Orientation for Problem Experiences Questionnaire \(Z6\)](#) McCubbin, H.I. & Patterson, 1983, B. SSAT, 7-37; Patterson, J.M. & McCubbin (1987)
- [Adolescent Coping Scale \(Z6\)](#) Frydenberg, E. & Lewis (1993)
- [Adolescent Coping Strategies Scale \(Z6\)](#) Burnett and Fanshawe (1996)
- [Adolescent Family Life Satisfaction Index \(Z6\)](#) Henry et al (1992)
- [Adolescent Feel-bad scale \(Z6\)](#) Lewis, C.E. et al: AJOPH (1984)
- [Adolescent Psychosocial Seizure Inventory \(Z3\)](#) Batzel, L.W. et al. (1991)
- [Adolescent Quality of Life Scale \(Z6\)](#) Manificat, S. & Dazord (2002)
- [Adolescent Ways of Coping Checklist \(Z6\)](#) Vitaliano, P. et al. (1985)
- [Adolescents' Questionnaire \(Z1, Z2, Z6\)](#) Timmons, V. Quality of Life, Thesis, U.C (1993)
- [Adult Dispositional Hope Scale \(\)](#) see Hope Scale
- [Adult Sources of Self-Esteem Inventory \(Z1\)](#) Watkins et al (1998)
- [Advanced QOL Index \(Z1\)](#) Diener, E. (1995)
- [Affect Balance Scale \(Z1, Z2\)](#) Bradburn, N.M., B.TSOP (1969)
- [Affect Grid \(Z1\)](#) Russell, J.A., (1989)
- [Affect Intensity Measure \(Z1\)](#) Larsen, R.J. & Diener (1987)
- [Affective Quality of Life of University Students \(Z1\)](#) Roberts, L.W. & Clifton: SIR (1992)
- [Affective Well-being Scale \(Z1\)](#) Warr, P. (1990)
- [Affectometer 2 \(Z1\)](#) Kammann, R & Flett: AJOP (1983)
- [Affects Balance Scale \(Z1\)](#) Derogatis (1975)
- [Albert Einstein College of Medicine Coping Styles Questionnaire \(Z1\)](#) Plutchik, R., (1989) B.TMOE, 1-35
- [Allocentrism vs. Idiocentrism \(Z1\)](#) Triandis, H.C. et al.: IJOP (1995)
- [Alzheimer's Disease-Related Quality of Life Scale \(Z4\)](#) Rabins, P.V. et al (1999)
- [American Demographics Index of Well-Being \(Z1\)](#) Kacapyr, E. (AD (1997)
- [Anamnestic Comparative Self-Assessment Scale \(Z3\)](#) Bernheim, J.L. & Buyse (1983)
- [Anxiety and Depression Scale \(Z3\)](#) Goldberg, D. et al., (1988)
- [Anxiety, Depression and Mood Scale \(Z2\)](#) Esbensen, A.J. et al. (2003)

[Apparent Affect Rating Scale \(Z5\)](#) Lawton, M.P. et al., 1999, JOMHAA, 5, 69-82
[Arabic Scale of Optimism and Pessimism \(Z1\)](#) Abdel-Khalek, A. & Lester (2006)
[Arc's Self-Determination Scale \(Z1\)](#) Wehmeyer, M.L. & Kelchner (1995)
[Areas of Satisfaction and dissatisfaction scale \(Z1\)](#) Crabbe, J.L. & Scott: JOCP (1972)
[Arel Spiritual Well-Being Scale \(Z1\)](#) Hungelmann et al (1996)
[Arizoma Social Support Interview Scale \(Z1\)](#) Barrera, M (1983)
[Arizona Social Support Scale \(Z1\)](#) Barrera, M., B.SNAS (1981)
[Arthritis Beliefs Scale \(Z3\)](#) Schiaffino, K.M. et al. (1991)
[Arthritis Impact Measurement Scale \(Z3\)](#) Meenan, R.F. et al.: AAR (1980)
[Ask Kids Inventory for Children/ASK-Q Inventory for Adolescents \(Z6, Z7\)](#) Bornholt, L.J. 2005
www.acer.edu.au/publications/newsletters/psych_livewire/05_plw1/ASKKIDSinfo.html
[Aspiration Index \(Z1\)](#) Kasser, T. & Ryan (1996)
[Assessment for Problem Focused Coping \(Z3\)](#) Nattterlund, B. & Ahlstrom
[Assessment of Daily Experience \(Z1\)](#) Stone & Neale (1982)
[Assessment of Quality of Life Instrument \(Z1, Z3\)](#) Hawthorne, G. et al. (1999)
[Assessment of Residents' Satisfaction and Family Perceptions Index \(Z2\)](#) Bowd (1988)
[Asthma Quality of Life Questionnaire \(Z3\)](#) Juniper, E.F. et al.; ARORD (1993)
[Attitude Questionnaire \(Z1\)](#) Magaletta, P.R. & Oliver (1999)
[Attitudes Index \(Z1\)](#) Stein, M.J. et al. (1988)
[Attributional Dimension Scale \(Z1\)](#) Benson (1989)
[Attributional Style Questionnaire \(Z1\)](#) Peterson, C. et al., CTAR (1982)
[Autonomous Functioning Checklist \(Z2, Z6\)](#) Sigafos, A.D., B.AP) (1988)
[Autonomy Questionnaire \(Z6\)](#) Noom, M.J. et al. (1999)
[Autoquestionnaire Enfant Image Questionnaire \(AUQUEI\) \(Z2, Z6\)](#) Manificat, S. (1995)
[Availability of Social Support Scale \(Z4\)](#) Baker, F. et al.: CMHJ (1992)
[Avoidance Coping Scale \(Z1\)](#) Moos, R.H. et al.: P.SUMC
[Bachman Self-Esteem Scale \(Z1\)](#) Bachman, J.G. & O'Malley (1977)
[Balanced Inventory of Desirable Responding \(Z1\)](#) Paulhus, D.L. (1989)
[Basic QOL Index \(Z1\)](#) Diener, E. (1995)
[Beach Center Family Quality of Life Scale \(Z1\)](#) Summers, J.A. et. al. (2005)
[Beck Depression Inventory \(Z1, Z2, Z4\)](#) Beck, A.T. et al.: AOGP, 1961, 4, 561-571; Beck, A. et al, 1979, B. CTOD; Beck, A.T. et al., 1996, B. MFTBD.
[Bedford Life Events and Difficulties Schedule \(Z1\)](#) Brown & Harris (1978)

[Behavioral Risk Factor Surveillance System - Health Related Quality of Life \(Z1\)](#) Hennessy et al (1994)

[Belief in a Just World Scale \(Z1\)](#) Rubin, Z. & Peplau, JOSI (1975)

[Belief in Good Luck \(BIGL\) Scale \(Z1\)](#) Darke, P.R. & Freedman: PASPB (1997)

[Berkeley Expressivity Questionnaire \(Z1\)](#) Gross & John (1995)

[Berkman Psychological Wellbeing Scale \(Z1\)](#) Berkman, P.: AJOE (1971)

[Berne Questionnaire on Adolescents' Subjective Well-being \(Z1, Z6\)](#) Grob (1995)

[Bernese Questionnaire on Adolescents' Perception of Control \(Z6\)](#) Flammer et al (1994)

[Bipolar Profile of Mood States \(Z1\)](#) Lorr & McNair (1982)

[Birleson Depressive Short form Self-Rating Scale \(Z2, Z6\)](#) Birleson, P. (1981)

[Blood-Wolfe Marital Satisfaction Scale \(Z1\)](#) Blood & Wolfe (1960)

[Brief Leisure Rating Scale \(Z1\)](#) Ellis, G.D. & Niles: TRJ (1985)

[Brief Mood Introspection Scale \(Z1\)](#) Mayer, J.D. & Gaschke: JOPASP (1985)

[Brief Multidimensional Student's Life Satisfaction Scale \(\)](#) see - Multidimensional Students' Life Satisfaction Scale

[Brief Symptom Inventory \(Z1\)](#) Derogatis & Spencer (1982)

[Burden Scale \(Z1\)](#) Pruchno, R.A. (1990)

[Burnout Scale \(Z1\)](#) Pines, A. et al. (1978)

[Calgary Depression Scale for Schizophrenics \(Z4\)](#) Addington, D. et al. (1990)

[Camberwell Family Interview \(Z1\)](#) Brown, G.W. & Rutter (1966)

[Campbell Well-Being Scale \(Z1\)](#) Campbell, A. et al. (1976)

[Cancer Behaviour Inventory \(Z3\)](#) Merluzzi, T.V. et al. (1999)

[Cancer Rehabilitation Evaluation System \(Z3\)](#) Ganz, P.A. et al.: JOCE (1990)

[Caregiver Burden Scale \(Z1\)](#) Macera, C. et al. (1993)

[Caregiver Social Support Scale \(Z1\)](#) Poulshock, S.W. & Deimling, 1984, (1984)

[Caregiver Strain Index \(Z1\)](#) Robinson, B.C. (1984)

[Caregiver Well-being Scale \(Z1\)](#) Tebb, S. (1995)

[Caregiver's Quality of Life Scale \(Z4, Z5\)](#) Thomas, P. et al. (2006)

[Caregiving Difficulty Scale \(Z1\)](#) McCallion, P. et al. (2005)

[Caregiving Gains Scale \(Z2\)](#) Chen, F-P & Greenberg (2004)

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[Quality Of Life Interview Schedule \(Z4\)](#) Holcomb, W.R. et al.: JOCP (1993)
[Quality Of Life Inventory \(Z1\)](#) Frisch (1995)
[Quality Of Life Measure for Children \(Z6\)](#) see C-QOL
[Quality Of Life Measure for Children \(C-QOL\) \(Z6\)](#) Jirojanakul, P. & Skevington (2000)
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[Quality Of Life Profile Adolescent Version \(Z6\)](#) Raphael, D. et al. (1996)
[Quality Of Life Questionnaire \(Z2\)](#) Brown, R.I. & Bayer, 'Rehabilitation...', CUP-T (1992)
[Quality Of Life Questionnaire \(Z3\)](#) Schraub, S. et al., In: B.TQOL (1987)
[Quality Of Life Questionnaire \(Z1\)](#) Shye, S. (1985)
[Quality Of Life Questionnaire \(Z2\)](#) Cragg, R. & Harrison, 1984: B. LIAS (1986)
[Quality Of Life Questionnaire \(Z4\)](#) Greenley, J.R. et al.: SW (1997)
[Quality Of Life Questionnaire \(Z3\)](#) Lim, L.L.Y. et al. (1993)
[Quality Of Life Questionnaire \(Z1\)](#) Evans & Cope (1989)
[Quality Of Life Questionnaire \(Z1, Z4\)](#) Bigelow, D.A., Gareau & Young, P.OHSU (1991)
[Quality Of Life Questionnaire \(Z2\)](#) Schalock, R.L. & Keith P. IDS (1993)
[Quality Of Life Questionnaire for Children \(Z3, Z6\)](#) Bouman et al. (1999)
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[Quality Of Life Scale \(Z1\)](#) Olson, D.H. & Barnes (1992)
[Quality Of Life Scale \(Z3\)](#) Burckhardt, C.S. (1989)
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[Quality Of Life-Linear Analogue Self-Assessment \(Z1, Z3\)](#) Shag et al (1994)
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[Quality Of Well Being Scale \(Z3\)](#) Pyne, J.M. et al.: PS (1997)

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[Relational Self-Concept Scale \(Z6\)](#) Schott, G.R. & Bellin (2001)

[Relationship Assessment Scale \(Z1\)](#) Hendrick, S.S.: JOMATF (1988)

[Relationship Inventory \(Z1\)](#) Barrett-Lennard, 1964 (1978)

[Relationships Scale \(Z1\)](#) Clements, C. et al. (2005)

[Religious Coping Activities Scale \(Z1\)](#) Pargament, K.I. et al. (1994)

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[Residential Loneliness Questionnaire \(Z1\)](#) Lunskey, Y. & Benson (2001)

[Residential Satisfaction Inventory \(Z2\)](#) Burnett, P.C.: ADR (1989)

[Revised Life Orientation Test \(Z1\)](#) Scheier, M.F., et al.

[Revised Version of the Ways of Coping \(Z1\)](#) Folkman et al (1986)

[Role Checklist \(Z1\)](#) Baker et al (1991)

[Role Quality Questionnaire \(Z1\)](#) Baruch, G.K. & Barnett (1986)

[Rolls-Royce Quality-of-Life Scale \(Z3\)](#) Ozyilkan, O., Karaagaoglu, E., Topeli, A.A., Kars,

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[Ryff Psychological Wellbeing Questionnaire \(Z1\)](#) see Psychological Wellbeing Questionnaire

[Satisfaction with Illness Scale \(Z3\)](#) Hyland, M.E. & Kenyon: PR (1992)

[Satisfaction with Life Domains Scale \(Z3, Z4\)](#) Baker, F. & Intagliata: EAPP (1982)

[Satisfaction with Life Scale \(Z1\)](#) Diener, E. et al, JOPA (1985)

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[Scales of Psychological Well-being \(Z1\)](#) Ryff, C.D. (1989)

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[Schedule of Recent Events \(Z1, Z4\)](#) Holmes, T.H. & Rahe: JOPR (1967)

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[Scl-90-R \[SCL-90-R\] \(Z4\)](#) Derogatis L.R., 1975, B. SCL-1; 1983, B.SCL-2

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[Seigol \[SEIQOL\] \(Z3\)](#) see Schedule for the Evaluation of Individual Quality of Life

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- [Self Anchoring Striving Scale \(Z1\)](#) Kilpatrick, F.P. & Cantril (1960)
- [Self Attributes Questionnaire \(Z1\)](#) Pelham, B.W. & Swann: JOPASP (1989)
- [Self Concept Clarity Scale \(Z1\)](#) Campbell, J.D. et al.: JOPASP (1996)
- [Self Concept Questionnaire \(Z1\)](#) Waugh, R.F. (2001)
- [Self Concept Scale \(Z2\)](#) Tymchuk, A.J. (1991)
- [Self Concept Scale \(Z1, Z4\)](#) Roid, G.H. & Fitts, P.WPS (1988)
- [Self Concept Semantic Differential Scale \(Z1\)](#) Morganti et al (1980)
- [Self Control Questionnaire \(Z1\)](#) Brandon, J.E. et al.: HV (1990)
- [Self Control Schedule \(Z1\)](#) Rosenbaum (1980)
- [Self Description Questionnaire I \(Z6\)](#) Marsh (1988)
- [Self Description Questionnaire I \(Z6\)](#) Marsh, 1990; P.UWS
- [Self Determination Scale \(Z1\)](#) Sheldon K.M. & Deci (1996)
- [Self Efficacy Questionnaire \(Z1\)](#) McAvay, G.J. et al. (1996)
- [Self Esteem Questionnaire \(Z2, Z6\)](#) DuBois, D., P.UOMC (1996)
- [Self Esteem Rating Scale \(Z1\)](#) Nugent, W.R. & Thomas (1993)
- [Self Esteem Scale \(Z1, Z2\)](#) Rosenberg, M, 1968, B. SATA, 17-18; 1979, B.CTS, 291-5
- [Self Esteem Scale \(Z1\)](#) Richardson, T.M. & Benbow, C.P.: JOEP (1990)
- [Self Esteem Worksheet \(Z1\)](#) Overholser, J.C.: PAID (1993)
- [Self Evaluation of Life Function Scale \(Z5\)](#) Linn & Linn (1985)
- [Self Handicapping Scale \(Z1\)](#) Jones, E.E. & Rhodewalt (1982)
- [Self Image Questionnaire \(Z6\)](#) Offer et al (1982)
- [Self Liking/Self Competence Scale - Revised \(Z1\)](#) Tafarodi, R.W. & Swann, 1995, JOPA-1, 65, 322-42; Tafarodi, R.W. & Swann, 2001, PAID, 31, 653-73
- [Self Perception Profile for Adolescents \(Z6\)](#) Harter, S. (1988)
- [Self Perception Profile for Adolescents \(Z6\)](#) Harter, S., B.CATT (1988)
- [Self Perception Profile for Children \(Z2, Z6\)](#) Harter, S. (1985)
- [Self Rating Inventory \(Z1\)](#) Brownfain, J.J.: JOAASP (1952)
- [Self Rating Scale \(Z1\)](#) Fleming, J.S. & Courtney: JOPASP (1984)
- [Self Report Depression Questionnaire \(Z2\)](#) Reynolds, W.M. & Baker (1988)
- [Self Scheme Complexity \(Z1\)](#) Stein, K.: CTAR (1994)
- [Semantic Differential Scale \(Z1\)](#) Osgood et al (1967)
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- [Semantic Differential Scale of Self-Evaluation \(Z1\)](#) Singh, I.K (1990)
- [Sense of Belonging Instrument \(Z1\)](#) Hagerty, B.M.K. & Patusky (1995)

[Sense of Coherence Scale](#) ([Z1](#), [Z3](#)) Antonovsky, A., 1987: B. UTMO; 1988; Antonovsky, A. & Sourani: JOMAF (1988)

[Sense of Community Index \(Short form\)](#) ([Z1](#)) Chavis, D.M. et al. (1986)

[Sense of Community Scale](#) ([Z1](#)) Doolittle & MacDonald (1978)

[Sense of Control Scale](#) ([Z1](#)) Ross, C.E. & Mirowsky (1992)

[Sense of Usefulness Scale](#) ([Z5](#)) Stevens, E.S.: IJOAAHD (1993)

[Seriousness of Illness Rating Scale](#) ([Z1](#), [Z3](#)) Wyer et al (1968)

[Shapiro Control Inventory](#) ([Z1](#)) Shapiro (1993)

[Short Form](#) ([Z1](#), [Z2](#)) Boss, M. & Taylor (1987)

[Short Form](#) ([Z1](#)) Reid, D.W. & Zeigler, B.RWTL (1981)

[Short Form Health Survey \(SF-36\)](#) ([Z1](#), [Z3](#)) McHorney, C.A. et al.: MC (1993)

[Short Happiness and Affect Research Protocol](#) ([Z1](#)) Stones, M.J. et al. SIR (1996)

[Sickness Impact Profile](#) ([Z1](#)) Bergner, M., et al., MC (1981)

[Single Item Self-Esteem Scale](#) ([Z1](#)) Robins, R.W. et al. (2000)

[Situational Humor Response Questionnaire](#) ([Z1](#)) Martin, R.A. & Lefcourt: JOPASP (1984)

[Snaith Hamilton Pleasure Scale](#) ([Z1](#)) Snaith, R.P. et al. (1995)

[Social Activity Measure](#) ([Z1](#)) Cooper, H. et al.: PAID (1992)

[Social Activity Scale](#) ([Z1](#)) Argyle & Lu (1990)

[Social Assurance Scale](#) ([Z1](#)) Lee, R.M. & Robbins (1995)

[Social Avoidance and Distress Scale](#) ([Z1](#)) Watson, D. & Friend (1969)

[Social Behaviour Assessment Schedule](#) ([Z1](#), [Z3](#)) Platte, S. et al., 1980, SP, 15, 43-55)

[Social Belonging Scale \(SBS\)](#) ([Z1](#)) Skantze & Malm (1996)

[Social Burden Scale](#) ([Z1](#)) Pai, S. & Kapoor: BJOP (1981)

[Social Capital Scale](#) ([Z1](#)) Sampson, R. et al. (1997)

[Social Capital Scale](#) ([Z1](#)) Narayan, D. & Cassidy (2001)

[Social Connectedness Scale](#) ([Z1](#)) Lee, R.M. & Robbins (1995)

[Social Desirability Response Set](#) ([Z1](#)) Hays, R.D. et al.: EAPM (1989)

[Social Dysfunction Rating Scale](#) ([Z1](#)) Linn, M.W. et al.: JOPR1 (1969)

[Social Functioning Scale](#) ([Z1](#), [Z4](#)) Birchwood, M. et al. (1990)

[Social Goals Value Inventory](#) ([Z1](#)) Braithwaite, V.A. (1982)

[Social Isolation Scale](#) ([Z1](#)) Andrews et al (1977)

[Social Network List](#) ([Z1](#)) Hirsch (1980)

[Social Optimism Scale](#) ([Z1](#)) Schweizer, K. & Schneider (1997)

[Social Provisions Scale](#) ([Z1](#)) Russell and Cutrona, 1984; Cutrona & Russell (1987)

[Social Relationship Scale \(Z1\)](#) Brim, J.A.: TJONAMD (1974)
[Social Resources Rating Scale \(Z5\)](#) M. Powell Lawton (1986)
[Social Responsibility Scale \(Z6\)](#) Berkowitz, L. & Lutterman (1968)
[Social Skills Inventory \(Z1\)](#) Riggio, P. CPP (1996)
[Social Stress Scale \(Z6\)](#) Tolan, P. et al.: JOYAA (1988)
[Social Support Appraisals Scale \(Z1\)](#) Vaux, A. et al. (1986)
[Social Support Interview \(Z1\)](#) Schulz, R. & Decker: JOPASP (1985)
[Social Support Inventory \(Z1\)](#) McCubbin, H.I. et al. . In: B. FIU (1982)
[Social Support Inventory \(Z3\)](#) Renwick et al (1995)
[Social Support Questionnaire \(Z1\)](#) Dalgard, O.S. et al.: BJOP (1995)
[Social Support Questionnaire \(Z1\)](#) Schaefer, C. et al.: JOBM (1981)
[Social Support Questionnaire \(Z1\)](#) Sarason, I.G. et al. (1987)
[Social Support Questionnaire of Transaction \(Z1\)](#) Suurmeijer, T.P., et al. (1995)
[Social Support Scale \(Z3\)](#) Zich, J. & Temoshok (1987)
[Social Support Self-report for Mentally Retarded Adults \(Z2\)](#) Reiss, S. & Benson (1985)
[Social Value-Need Scale \(Z2\)](#) Bolduc (1960)
[Sources of Life Meaning \(Z1\)](#) Prager, E. et al. (1999)
[Southwestern Oncology Group Quality of Life Questionnaire \(Z3\)](#) Moinpour, CM., In: B.QOLAI (1994)
[Spheres of Control Scale \(Z1\)](#) Paulhus (1983)
[Spiritual Meaning Scale \(Z1\)](#) Mascaro, N. et al. (2004)
[Spiritual Well-being Scale \(Z1\)](#) Paloutzian & Ellison, In: B. LASO (1982)
[Spitzer Index \(Z7\)](#) Spitzer, W.O. et al (1981)
[Srole Anomie Scale \(Z1\)](#) Srole, L.: ASR (1956)
[Staff Support and Satisfaction Questionnaire \(Z1\)](#) Harris, P. & Rose (2002)
[Staff Support Questionnaire \(Z1\)](#) Harris, P.E. & Thompson (1993)
[Standard International Occupational Prestige Scale \(Z6\)](#) Treiman (1977)
[Standard of Living Complement \(SOL-I-Comp.\) \(Z4\)](#) Skantze (1996)
[Standard of Living Interview \(SOL-I\) \(Z4\)](#) Skantze (1996)
[Standard of Living Questionnaire \(SOL-I\) \(Z4\)](#) Skantze, K. et al. (1992)
[State Hope Scale \(Z1\)](#) Snyder, C.R. et al.: JOPSAP (1996)
[State Self-Esteem Scale \(Z1\)](#) Heatherton, T.F. & Polivy, JOPASP (1991)
[State-Trait Anxiety Inventory \(Z1\)](#) Spielberger et al (1970)
[State-Trait Personality Inventory \(Z1\)](#) Spielberger (1979)

- [Stockton Geriatric Rating Scale \(Z5\)](#) Meer, B. & Baker: JOG (1966)
- [Strategic Approach to Coping Scale \(Z1\)](#) (Hobfoll, S.E. et al (1993)
- [Strategic Approach to Coping Scale -- Dispositional \(Z1\)](#) Monnier, J. et al (1998)
- [Strategic Approach to Coping Scale -- Situational \(Z1\)](#) Monnier, J. et al (1998)
- [Stress of Life Events Scale \(Z1\)](#) Tennant, C. & Andrews: AANZJOP (1976)
- [Stressor and Coping Response Inventory for Children \(Z6\)](#) Elwood, S.W.: PR (1987)
- [Stroke Impact Scale: Version 2.0 \(Z3\)](#) Duncan, P.W. et al. (1999)
- [Structured and Scaled Interview to Assess Maladjustment \(Z1\)](#) Gurland, B.J. et al.: AOGP, 1972, 27, 259-264; Gurland, B.J.: In: MH (1987)
- [Student Rating Scale \(Z1, Z2, Z6\)](#) Brown, L. & Hammill (1990)
- [Student Worry Scale \(Z1\)](#) Davey et al (1992)
- [Student's Life Satisfaction Scale \(Z6\)](#) Huebner (1991)
- [Student-life Stress Inventory \(Z1\)](#) Gadzella, B.M.: PR (1994)
- [Subjective Burden Scale \(Z1\)](#) Montgomery, R.J.V. et al. (1985)
- [Subjective Domains of Quality of Life \(Z1, Z3\)](#) Bar-on & Amir (1993)
- [Subjective Estimation of Quality of Life \(SQoL\) \(Z1\)](#) Naess, S. (1987)
- [Subjective Exercise Experiences Scale \(Z1\)](#) McAuley, E. & Courneya 1994; JOSAEP, 16, 163-177
- [Subjective Family Burden Scale \(Z1\)](#) Noh, S. & Turner: SSM (1987)
- [Subjective Happiness Scale \(Z1\)](#) Lyubomirsky, S. & Tucker (1998)
- [Subjective Health Rating \(Z5\)](#) Suchman, E.A. et al.: SF (1958)
- [Subjective Quality of Life Profile \(Z3\)](#) Dazord, A. et al., In: B.QOLAI (1994)
- [Subjective Well-Being Inventory \(Z1\)](#) Nagpal, R. & Sell, 1985, P.WHO-I; Sell, H.: IJOMH (1994)
- [Subjective Well-Being Under Neuroleptics \(Z3\)](#) Naber, D. et al. (2001)
- [Survey of Recent Life Experiences \(Z1\)](#) Kohn, P.M. & MacDonald: ASAC (1992)
- [Systems of Belief Inventory \(Z1\)](#) Holland, J.C. et al. (1998)
- [Taylor Manifest Anxiety Scale \(Z4\)](#) Taylor, J.A. (1953)
- [Taylor Manifest Anxiety Scale - Bendig Short Form \(Z4\)](#) Bendig, A.W. (1956)
- [Teaching Satisfaction Scale \(Z1\)](#) Ho, C-L. & Au, W-T. (2006)
- [Temperament Evaluation of Memphis, Pisa, Paris and San Diego - Autoquestionnaire \(Z1, Z4\)](#) TEMPS-A) (Akiskal, H.S. et al. (2005)
- [Temporal Satisfaction with Life Scale \(Z1\)](#) Pavot et al (1997)
- [Tenaciousness of Goal Pursuit and Flexibility of Goal Adjustment \(Z1\)](#) Brandtstadter, J. &

Renner: PAA (1990)

[Tennessee Self-Concept Scale](#) ([Z1](#), [Z6](#)) Fitts, W. 1965, B.TSCS; P. CRAT; Roid, G.H. & Fitts, P.WPS (1988)

[Tennessee Self-Concept Scale - Revised](#) ([Z1](#)) Roid, G.H. & Fitts, P.WPS (1988)

[The 32 Attributes Checklist](#) ([Z6](#)) Falbo, T. et al.: JOCCP (1997)

[Thought Control Questionnaire](#) ([Z1](#)) Wells, A. & Davies (1994)

[Total Perceived Control Scale](#) ([Z1](#)) Pallant, JOPA-I (2000)

[Trait Meta-Mood Scale](#) ([Z1](#)) Salovey, P. et al. (1995)

[Trust in Neighbours Scale](#) ([Z1](#)) Fattore, T. et. al. (2003)

[Twenty Statement Test](#) ([Z1](#)) Kuhn, M.H. & McPartland, ASR (1954)

[Twenty-two Item Screen Scale](#) ([Z4](#)) Langer (1962)

[Two Faces Scale](#) ([Z1](#)) Kunin (1955)

[UCLA Lonliness Scale](#) ([Z6](#)) Russell, D., 1982, B.LASO, 81-104; Russell, D.W., 1996, JOPA-1, 20-40

[Ulm Quality of Life Inventory for Parents of a Chronically Ill Child](#) () Goldbeck, L. (2001)

[United Way/ORC Life Events Scale](#) ([Z1](#)) Smith, T.W.: SSR (1992)

[University of Michigan Composite International Diagnostic Interview](#) ([Z3](#)) see World Health Organisation Composite International Interview

[Unrealistic Optimism Measure](#) ([Z1](#)) Weinstein, N.D. (1980)

[Unrealistic Optimism Measure](#) ([Z1](#)) Weinstein, N.D., JOPASP (1980)

[Urinary Incontinence Quality of Life Questionnaire](#) ([Z3](#)) Marquis, P. (1998)

[Waring Intimacy Questionnaire](#) ([Z1](#)) Waring (1988)

[Way I Feel about Myself](#) ([Z2](#)) Piers, E.V. & Harris (1964)

[Ways of Coping Checklist](#) ([Z1](#), [Z6](#)) Vitaliano, P. et al.: MBR (1985)

[Ways of Coping Questionnaire](#) ([Z1](#)) Folkman & Lazarus (1988)

[Ways of Coping Revised Version](#) ([Z1](#), [Z4](#)) Folkman et al. (1986)

[Wbq12 \[W-BQ12\]](#) ([Z1](#)) Pouwer, F. et al. (1999)

[Welfare Attitude Scale](#) ([Z1](#)) Fattore, T. (2003)

[Well Being Index](#) ([Z1](#)) Headey, B. et al.: SIR (1984)

[Well Being Manifestations Measure Scale/Distress Manifestations Measure Scale](#) ([Z1](#))

Masse, R. et al. (1998)

[Well Being Measure](#) ([Z3](#)) Lundman, B. et al. (1990)

[Well Being Questionnaire](#) ([Z1](#)) Andrews, F. M. & Withey, B.SIOW (1976)

[Well Being Questionnaire](#) ([Z3](#)) Bradley, C., B. HOPA (1994)

[Well Being Scale \(Z1\)](#) Tellegen (1982)
[Wellness Evaluation of Lifestyle \(Z1\)](#) Myers, J.E. (1998)
[Wellness Inventory \(Z1\)](#) Travis (1981)
[Wellsprings Questionnaire \(Z1\)](#) Isaacowitz, D.M. et al. (2003)
[What I Think About Myself Scale \(Z6\)](#) Kosmoski et al (1994)
[Who 10 Well-Being Index \[WHO \(10\)\] \(Z3\)](#) Bech, P. et al., PPI (1996)
[Who 5 Well-Being Index \(WBI-5\) \[WHO \(5\)\] \(Z3\)](#) Bech, P.,B.TBHA (1996)
[Who Composite International Diagnostic Interview \[WHO\] \(Z1\)](#) see World Health Organisation
[Whoqol-100 \[WHOQOL-100\] \(Z1, Z3\)](#) WHOQOL group; IJOMH, 1994a, 23, 24-56; In: B.QULAI, ; P. WHO (1994)
[Whoqol-bref \[WHOQOL-BREF\] \(Z1, Z3\)](#) P. WHO
[Wisconsin Quality of Life Index \(Z4\)](#) Becker, M. & Diamond (1997)
[Work Conditions Questionnaire \(Z1\)](#) Abrams, M.: ST (1973)
[Work Locus of Control Scale \(Z1\)](#) Spector, P.E. (1988)
[Work Related Affective Well-being \(Z1\)](#) Daniels, K. (2000)
[Worker's Loneliness Questionnaire \(Z2\)](#) Chadsey-Rusch, J. et. al. (1992)
[Working Environment Scale-10 \(Z3\)](#) Rossberg, J.I. et al. (2004)
[World Assumptions Scale \(Z1\)](#) Janoff-Bulman, R.: SC (1989)
[World Health Organisation Composite International Diagnostic Interview - Short Form \(CIDI-SF\) \(Z3\)](#) Kessler, R.C. et al. (1998)
[Worry Scale \(Z1\)](#) Abrams, M.: ST (1973)
[Xenophobia Index \(Z1\)](#) Michalos, A. & Zumbo (2001)
[Young Adult Quality of Life Instrument \(Z1\)](#) Chen, H. et al. (2004)
[Youth Quality of Life Instruments \(Z6\)](#) (www.yqol.org) Patrick, D. et al (2002)
[Youth Self Report \(Z6\)](#) Achenbach, T. (1991)
[Zarit Burden Interview \(Z5\)](#) Zarit, S.H. et al.: TG (1980)
[Zubrod Scale \(Z3\)](#) Zubrod, C.G. et al.: JOCD (1960)
[Zung Self-Rating Anxiety Scale \(Z2\)](#) Lindsay, W.R. & Michie: JOMDR (1988)
[Zung Self-Rating Depression Scale \(Z1, Z4\)](#) Zung, W.W.: AOGP (1970)

ANNEXURE B

PWI-ID SCALE ADMINISTRATION

(Cummins & Lau, 2005: 7-8)

2. Scale Administration

2.1. General Information

The scale must be administered on an individual basis to the person with an intellectual disability. It is NOT to be answered 'on behalf of the person' by a caregiver or someone who 'knows the person well'. Such Proxy Responses are invalid in relation to subjective measurement (see Cummins 2002 for a review).

It should be emphasised that there is no time limit. The pre-testing and the full scale administration take from 10 to 20 minutes to complete, depending on the extent of pre-testing required.

2.2. The Testing Environment

When using the scale with people who have a suspected intellectual or cognitive disability it is vital to ensure that the information they supply is valid. This requires great care on the part of the interviewer due to the problem of acquiescent responding.

People with an intellectual or cognitive disability are substantially more likely, than members of the general population, to answer in ways they perceive are desired by the interviewer. This problem is exacerbated by a sense of threat or unease. Such a response bias may be generated through the perception of a power differential or being questioned in an unfamiliar environment.

In an attempt to overcome this problem, the interviewer should take special precautions with the interview process. The interviewer should:

- dress in a manner which does not invoke anxiety;
- they should be prepared to engage in simple social rituals, such as having a cup of tea or meeting other members of the household before testing takes place, and
- should be perceived by the interviewee as friendly, or at least neutral.
- Ideally, the interview should be held on home-ground for the person being interviewed, in a quiet place away from the distractions of other people or television.

2.3. The Role of Caregivers

Caregivers MUST NOT be present during testing. The interviewees should be seen alone or, if absolutely necessary, with one supportive friend of their choice.

2.4. Ethics

Prior to conducting the test, it is the responsibility of the test administrator to ensure that:

- (a) appropriate ethics approval has been obtained from the relevant authority under which they are operating, and also
- (b) that approval for such testing has been obtained from the interviewee or when necessary, the interviewee's parent or legal guardian.

Chapter 4 provides a useful protocol for obtaining informed consent from people who are able to process information at a relatively high level.

2.5. Pre-Testing and Test

Without doubt, the most essential aspect of testing people with an intellectual or cognitive disability is to ensure that they understand the nature of the task they are agreeing to perform. Only then can the test administrator have confidence that the responses being provided are valid. Such assurance requires a carefully constructed pre-testing protocol as follows:

2.5.1. Pre-test Step 1: Initial selection of potential respondents

DO NOT attempt to test anyone who has a severe or profound level of intellectual disability on the PWI-ID. It has now been well established that people who have a severe or profound level of intellectual disability cannot respond validly to this, or any other, scale of subjective wellbeing (e.g. Chadsey-Rusch, DeStefano, O'Reilly, Gonzalez, & Collier-Klingenberg 1992). The only known method of measurement for such people is through behavioral observation. Caveats apply. See Cummins (2004) for further discussion on this topic.

2.5.2. Pre-test Step 2: Testing for acquiescent responding

People with intellectual or cognitive disability are particularly prone to acquiescent responding (see Chapter 3 for discussion). Formal testing for acquiescent responding can take place as follows:

1. After checking that the respondent is comfortable and ready to respond, carefully and slowly proceed as follows:
2. Point to the respondent's watch or some item of clothing. Ask them:
 - a) "Does that (e.g. watch) belong to you?"
 - b) "Do you make all your own clothes and shoes?"
 - c) "Where you live, have you seen the people who live next door?"
 - d) "Where you live, did you choose who lives next door to you?"

Scoring:

If a positive response is provided to items b and d, then it is apparent that the respondent is not sufficiently competent to complete the Index. Hence, no further testing should take place.

2.5.3. Pre-test Step 3: Testing for Likert scale competence using 0-10

If the interviewee passed Pre-test Step 2, formal testing for Likert scale competence can take place. This involves two stages, as establishing the respondent's familiarity with a 0 to 10 distribution, and then testing the person's ability to use a 0 to 10 Likert scale.

The optimal response scale for the interviewee to use is the modified version of the normal 0-10 scale employed with PWI-A, which replaces 'satisfaction' with 'happiness'. This allows maximum discrimination of degrees of happiness and is likely to be within the competence of people with a mild level of intellectual disability.

ANNEXURE C

DSM-IV-TR/ICD 10 DIAGNOSTIC CRITERIA FOR PERVASIVE DEVELOPMENTAL DISORDERS (LORD ET AL., 2000)

	Autistic Disorder	Rett's Disorder	Childhood Disintegrative Disorder	Asperger's Disorder	PDD-NOS
Age of Onset	Delays or abnormal functioning in social interaction, language, or play by age 3.	Apparently normal prenatal development; apparently normal motor development for first 5 months; deceleration of head growth between ages 5 and 48 months.	Apparently normal development for at least the first 2 years of birth; clinically significant loss of previously acquired skills before age 10.	No clinically significant delay in language, cognitive development, or development of age appropriate self-help skills, adaptive behavior, and environment in childhood.	This category is to be used in cases of pervasive impairment in social interaction and communication with presence of stereotyped behaviors of interests when criteria are not met for a specific disorder.
Social Interaction	Qualitative impairment in social interaction, as manifested by at least two of the following: a) marked impairment in the use of multiple nonverbal behaviors, i.e., eye-to-eye gaze; b) failure to develop peer relationships appropriate to developmental level; c) lack of spontaneous seeking to share enjoyment with other people; d) lack of social or emotional reciprocity.	Loss of social engagement early in the course (although often social interaction develops later).	Same as Autistic Disorder along with loss of social skills (previously acquired).	Same as Autistic Disorder.	
Communication	Qualitative impairments of communication as manifested by at least one of the following: a) delay in, or total lack of, the development of spoken language; b) marked impairment in initiating or sustaining a conversation with others, in individuals with adequate speech; c) stereotyped and repetitive use of language or idiosyncratic language; d) lack of varied, spontaneous make-believe or imitative play.	Severely impaired expressive and receptive language development and severe psychomotor retardation	Same as Autistic Disorder, along with loss of expressive or receptive language previously acquired.	No clinically significant delay in language.	
Behavior	Restricted, repetitive, and stereotyped patterns of behavior, as manifested by one of the following: a) preoccupation with one or more stereotyped or restricted patterns of interest; b) adherence to nonfunctional routines or rituals; c) stereotyped and repetitive motor mannerisms; d) persistent preoccupation with parts of objects.	Loss of previously acquired purposeful hand movements; appearance of poorly coordinated gait or trunk movements.	Same as Autistic Disorder, along with loss of bowel or bladder control, play, motor skills previously acquired.	Same as Autistic Disorder.	
Exclusions	Disturbance not better accounted for by Rett's or CDD.		Disturbance not better accounted for by another PDD or schizophrenia.	Criteria are not met for another PDD or Schizophrenia.	

ANNEXURE D

PWI-ID INDIVIDUAL DOMAIN MEAN SCORES (CUMMINS ET AL., 2009)

These domain and PWI-ID scores (measured on a 0-100 scale) are drawn from an Australian and Hong Kong sample (Cummins et al., 2009).

	Australia		Hong Kong	
	M	SD	M	SD
Life domains				
Satisfaction with:				
Standard of living	75.18	26.86	61.52	33.98
Personal health	70.49	26.39	61.05	33.66
Life achievement	79.30	26.05	66.98	31.76
Personal relationships	82.06	24.19	73.69	28.68
Personal safety	79.25	23.12	66.00	30.78
Community connectedness	81.84	23.10	65.40	32.20
Future security	72.41	26.44	52.99	34.05
Personal Wellbeing Index	77.08	16.64	63.99	18.86



ANNEXURE E CONSENT LETTER

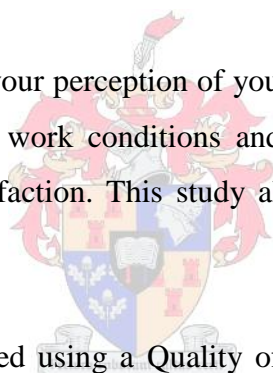
STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

THE QUALITY OF LIFE OF THREE MEN WITH AUTISTIC SPECTRUM DISORDERS LIVING IN A GROUP HOME: A CASE STUDY

This is an invitation to participate in a research study conducted by Kerry Skinner from the Department of Educational Psychology at Stellenbosch University. The results will contribute to a research thesis. You were selected as participants of this study because you are currently living in the group home.

1. PURPOSE OF STUDY

The aim of the study is to explore your perception of your current quality of life. This relates to your living arrangements, your work conditions and your general feelings of personal wellbeing, happiness and life satisfaction. This study also aims to explore the factors that influence your quality of life.



Your quality of life will be assessed using a Quality of Life Questionnaires known as the Personal Wellbeing Index for People with Intellectual Disabilities (PWI-ID).

2. PROCEDURES

If you volunteer to participate in this study, I shall ask you to do the following things:

- Give me permission to interview you about your quality of life. The duration of these interviews will vary according to the purpose of the interview.
- Give me permission to use this information for research purposes.

You may refuse to answer any questions at any stage during the research process.

3. POTENTIAL BENEFITS TO SUBJECTS AND/ OR SOCIETY

Your participation in this study will help us to gain insight into the perceived quality of life of people with Autism Spectrum Disorder that live in group homes.

4. CONFIDENTIALITY

All the information that I gather in my conversations with you will be handled professionally and only used for research purposes. A pseudonym can be selected if you choose to remain anonymous.

Many of the interviews will be recorded on audio tape or video tape. No information will be disclosed in the public domain without your permission. The data of the study, in its original form, will however, be available to the supervisor of the study, for verification purposes.

5. PARTICIPATION AND WITHDRAWAL

Participation in this study is voluntary. Should you decide to take part in the study, you have the right to withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study.

6. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the researcher, Kerry Skinner, on 021 685 6030 or 082 377 0732. You may also contact the supervisor of the study, Rona Newmark, by email at rnew@sun.ac.za.

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at anytime and discontinue participation without penalty. If you have any questions regarding your rights as research participants, please contact Ms M. Hunter-Husselman on 021 808 4623 at the Unit for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information on the previous two pages was described to me, the participant, by KERRY SKINNER in a language that I understand. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Name of Participant

Signature of Legal Representative

SIGNATURE OF RESEARCHER

I declare that I explained the information given in this document to all the participants involved. The participants were encouraged and given ample time to ask me any questions. This conversation was conducted in English.

Name of Researcher

Signature of Researcher

Date

ANNEXURE F
SECOND PWI-ID INTERVIEW
WITH CHRIS JERICHO (9/04/08)

Interview	Generating Codes
<p><u>Part I: Happy with Life as a Whole</u></p> <p>How happy are you with your life as a whole? Thinking about your life and your personal situation at the moment, and where you living and your environment, how satisfied are you with your life as a whole at the moment living in the group home, between 1 and 10?</p> <p>Okay, can I also look at it from the moment as well. Ok well, <u>if I had to feel now, now with just me, Seth and Vinetta, then I would give it a high mark this time.</u> At this time, I think a high mark is deserved. Is it okay if I go for 10?</p> <p>Yes, like I said earlier there is no right or wrong. It's just how you feel.</p> <p>Ok, I think it deserves a 10.</p> <p><u>Part II: Personal Wellbeing Index – Intellectual Disability</u></p> <p>Okay, how satisfied are you with your standard of living?</p> <p>Um, well my standard of living is I think it's very good. <u>Every day I live here and I gain independence more by the day. I am good at cleaning up after myself, and looking after myself and dressing myself. And whether it's preparing food, breakfast, lunch or supper what ever it may be.</u> I think it's also, I would give it a fine mark. I think I would say. Probably just one weakness is that I'm not the best cook in the world or even one of the best in the house. I would probably say 9.</p> <p>Ok. How satisfied are you with your health?</p> <p>Okay well, I think I would have to say, I would probably say at this point in time, I would <u>probably give it a 6, because I'm not too convinced that its as good as it can be. It's not bad but I believe it can be better.</u> I can be more physically active and work on my</p>	<p>LW high - happy living with others</p> <p>SL Indep - good standard of living - gain indep - more responsible - not a good cook</p> <p>H S ≠ C - satisfied but not content - could be better</p> <p>H act</p>

<p>fitness levels especially and maybe cut down on certain food like the fast food, if you can call it junk food and all that. Although I don't eat so much chocolate anymore which is a good thing, a plus. <u>But I think I can work on it a bit harder although it's improving, it's better than it used to be.</u> I think maybe a 6 I would say for my health.</p>	<ul style="list-style-type: none"> - can be more active/fit - less junk food
<p>How satisfied are you with what you are achieving in life at the moment?</p> <p>I think I am very satisfied, I would probably, I would also give it a 9. <u>I've accomplished quite a lot over the last year or so now,</u> so I think 9 would be the best mark. I am <u>making rapid improvement</u> over the last few years now, and <u>the longer I've lived her the more independence I've gained, the more satisfied I am,</u> I am more cheerful each and every day and so I think it deserves another high mark.</p>	<p>H improve</p> <ul style="list-style-type: none"> - slight improvement
<p>Ok, how satisfied are you with your personal relationships?</p> <p>Ja, I <u>think I'm also very satisfied. Ja, I think its going well.</u> You <u>know I get along with everyone in the house, I try my best to be patient and help them and care about them and love them as much as I can.</u> So, I would also say it is doing very well. That's if I consider <i>Seth</i> and Vinetta and that, I would probably give it a 10 as well. Ja, <u>the relationships are strong.</u></p>	<p>AL comp</p> <ul style="list-style-type: none"> - feelings of competence <p>AL improve</p> <ul style="list-style-type: none"> - rapid improvement <p>AL indep</p> <ul style="list-style-type: none"> - more independence - more satisfied
<p>How satisfied are you with how safe you feel, your security?</p> <p>Um, I think I would have to lower the mark a bit, maybe, I <u>am not fairly convinced that it's that safe</u> because you see if you look outside here where the <u>black gate is where I opened up for you,</u> <u>we've had endless trouble with it because the last two years now it hasn't done particularly well because it's, there's a huge problem</u> with it, it's not working the way it should normally work, like when you use a remote or that to close. You always have to use a lock and struggle with it and <u>there's a lot of people, how do I say, look very sceptic looking;</u> they don't look like very nice decent people that hang around in our neighbourhood. They have a bit, they like</p>	<p>R high - very satisfied</p> <p>R get - get along with others</p> <p>R help – helpful, caring, patient</p> <p>R strong</p> <ul style="list-style-type: none"> - Relationships are strong <p>PS more</p> <p>PS gate</p> <ul style="list-style-type: none"> - problem with gate - need to fix it - always need to manually lock it <p>PS ppl</p> <ul style="list-style-type: none"> - sceptical ppl around - unpredictable

<p>gangsters in a way and they look like they can strike at anytime. And we always get people who answer the door, ring the door bell, who always want money or food every single time. <u>So I'm starting to think that it's not very safe. So in general I would give it a 5. the safety's not as good as it can be.</u></p> <p>How do you think it can be improved?</p> <p>Well, maybe if we got the <u>gate sorted out</u>, maybe a <u>safety door</u>, or even a <u>burglar alarm</u>. Ja, that's how I feel about it.</p> <p>How satisfied are you with feeling part of your community?</p> <p>Ja, I would say it's ok. It's alright. I mean I'm very fortunate to <u>have nice neighbours around me who are very friendly, very kind, loving people</u>. I've got nice friendly neighbours so I would say that's pretty good. I would give that a 9.</p> <p>And doing things in the community?</p> <p>Ja, I would also give that a 9.</p> <p>Are there a lot of things to do around here in the community?</p> <p><u>Seth and I normally go to Kenilworth centre and stroll around there like CNA, like go to book stores like CAN and Paperweight and we shop for groceries, get some supplies for ourselves and that. But sometimes when we go to other places it's always far to walk you see. That's what gets me down sometimes because I get so tired and my legs because you see. Your feet get very tired when you walk on the hard road, on the hard tar road. You see it tires you out and there's been a lot of times when I'm out of breathe, I've always had to sit down, every ten minutes or so, because it's so constantly tiring. That's the only thing that let's me down. It gets me down a bit is I wish we had a car for this house then I would have been ten times more satisfied if we had a car because it would be easier for us. It would be much easier for Seth and I to go out somewhere. We could go by, if we had transport, if we had a car to go with, it would be far safer and far easier because some times its dangerous walking as well. You never know what could happen. You know it makes you very tired and exhausted but you could be in danger too.</u></p>	<p>PS unsafe - feeling unsafe</p> <p>PS more</p> <p>- need better security</p> <p>Sug sec</p> <p>- suggestions for security</p> <p>CC neigh</p> <p>- nice neighbours</p> <p>CC do</p> <p>- lots to do in neighbourhood</p> <p>i.e. centres</p> <p>CC car</p> <p>- get tired walking places</p> <p>- unfit</p> <p>- physical complaints</p> <p>CC car</p> <p>- desire for a car</p> <p>- easier to go out</p> <p>- safer</p> <p>- safer and easier with a car</p> <p>- walking makes you tired</p>
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<p><u>Because you get some funny people that walk around in the street areas all that, in the roads, in your neighbourhood wherever. There's full of strange, weird people around. You never know because a lot of them are up to no good so you can't really trust them.</u> That's why it's best to have a car to get you places far easier and far quicker and if only that could get sorted out. If <i>Seth</i> finally for once had his licence then we would be in a far better easier position, a better scenario. <u>So that is the only real thing that I really wish for in this day and time.</u></p> <p>How satisfied are you with your future security? How things will be later in your life?</p> <p>I think it would definitely be better. I think I've got <u>a very positive frame of mind about that.</u> So I think it's gonna get better because I don't think can worsen because I'm very <u>optimistic about the future</u> in a month's time or a year or two's time I think it will be good. Although I'm not to sure about the soccer world cup in 2010 that will be staged here, the world cup that will be staged here. I don't think too highly about that because I'm actually worried about that, because there's gonna be so much traffic everywhere and it's gonna be chaotic everywhere. It's gonna be such madness and I thought, juici, well I might as well not live then (laugh). I am concerned mostly about the future security of the stadiums in Athlone and wherever. I don't know I'm worried about that, two years time about the world cup. I just hope it doesn't become a disaster.</p> <p>And what about your future? How do you feel about that?</p> <p>I would give it a 9 as well.</p>	<p>CC ppl - strange people walking around</p> <p>CC car - expressed need to have a car</p> <p>FS S + P - satisfied and positive for future - can't worsen - optimistic - concern for world cup</p>
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ANNEXURE G

AN EXAMPLE OF THE FULL LIST OF IDENTIFIED CODES FOR CHRIS JERICHO

After the initial coding phase, I was able to collate all the codes from the interviews into a list for each participant. I was also able to get an average subjective wellbeing (SWB) score for each domain. This was done by averaging the two scores collected in the two PWI-ID interviews. Below is the initial list of codes from the PWI-ID interviews and semi-structured interviews with Participant 3, Chris Jericho:

Quality of Life Domains and initial codes for Participant 3			
QOL Domain	Domain Code	Emerging Categories	Emerging Codes
Happy with life as a whole	LW	Overall low QOL Dismal year High QOL when I had a girlfriend Ready for girlfriend function Functions of a girlfriend Enjoyed being at school Desires to be back at school Higher QOL with Vinetta and Seth	LW Low LW Dis LW H Girl LW R Girl LW F Girl LW H school LW Back Sc LW High
PWI-ID for LW = average 7			
Standard of living	SL	Gain independence Friendship like <u>family</u> (with Seth) Has his OWN possessions	SL indep SL Frie/fam SL Possess
PWI-ID for SL = average 9			
Health	H	Satisfied but not completely; not as good as it can be Can be more physically active Improvement, better than it used to be	H S≠C H act H improve
PWI-ID score for H = average 5.5			
Achievement in life	AL	Happy with opportunities – learn something new Hate working Lack of pay – can't do anything Accomplished/ Competence Rapid improvement Increased independence, more satisfied Desire for more <u>money</u> – independence	AL Opp HS+C AL Hate AL Fin AL comp AL improve AL indep AL <u>money</u>
PWI-ID score for AL = average 8.5			
Relationships	R	Satisfied with personal relationships Get along with the people in the house Try hard to be patient, helpful, Relationships are strong People around are very special	R high R get R help R strong R Soc

PWI-ID score for R = average 10			
Personal safety	PS	Very happy – well protected We protect each other No car – gets them down (safety is an issue) Concerns about the gate not working, no remote Not as good as it can be Starting to think that it's not very safe Skeptic looking people around	PS Saf H PS group PS car PS gate PS more PS unsafe PS ppl
PWI-ID score for PS = average 7			
Community-connectedness	CC	Satisfied and content Nice neighbours Lots to do in neighbourhood – shopping centre Strange ppl walking around Get tired walking to places; unsafe, need a car	CC S+C CC neigh CC do CC ppl CC car
PWI-ID score for CC = average 9			
Future security	FS	Completely satisfied and positive about future	FS S+P
PWI-ID score for FS = average 7			
TOTAL Subjective Wellbeing Score = 80%			

