

Perceptions of quality of life in people with mild or borderline learning disability and the autism diagnostic process

SUZANNE JANE SMITH

A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Doctorate of Health and Social Care

Sponsored by SEQOL (Care and Support Partnership), Swindon

Faculty of Health and Applied Sciences, University of the West of England, Bristol March 2015

Word Count: 59,067 (Excluding Index, References and Appendices)

Acknowledgments

My thanks go firstly to the people that motivated this study, who are the participants. This is a group of people for whom direct engagement is not always easy and I very much appreciate the time that they and their supporters gave to enable this study to happen.

I have hugely appreciated the support, knowledge, time and focus given by my supervision team: Professor Jane Powell, Professor Sue Roulstone and Dr Neil Summers. They have all been generous in their time and have motivated me to continue to learn and improve on everything I have been trying to do.

Without the support of my husband Gary, and children Tom and Joe this would not have been possible. They have been a part of this process and have contributed to it in numerous ways, some of them they may not have fully realised.

My employer, SEQOL, have been key to ensuring that I was able to complete this doctorate and allowing some time and space to achieve it within a demanding job. Particular thanks go to Graham Walker who helped me to begin the process and believed that it was possible.

Many friends have helped practically and emotionally. I am very grateful to Mark Lever and Richard Mills for their time, support and expertise.

Finally thanks to both my parents and parents-in-law for just being willing to do whatever they could without asking any questions.

This thesis is dedicated to the memory of my brother John, my greatest motivation to continue when times were tough.

Abstract

This study used mixed methods to gather multidimensional quality of life perceptions from a small group of adults (n = 20) who had mild or borderline learning disabilities and had been referred to a local diagnostic process. The methods were developed through a contextual literature search and a focus group. Quantitative methods involved the administration of quantitative tools, which were the Comprehensive Quality of Life Scale - Intellectual/Cognitive Disability (COMQOL-I5) (Cummins et al 1997) and the Personal Wellbeing Index - Intellectual Disability (PWI-ID) (Cummins and Lau 2005) as well as a visual ranking exercise of dimension importance. An in-depth qualitative interview, using some adapted ethnographic approaches was carried out with a purposively selected group of eight of the participants. Quantitative analysis was carried out using selected statistical analysis and qualitative data analysed using thematic analysis (Braun and Clarke 2013).

The findings indicated that the study group had a generally low level of objective quality of life with the exception of the dimensions of health and emotional wellbeing. The study group had a lower level of subjective quality of life than was expected, with the exceptions of the dimensions of social interaction and safety. Themes were identified in the data. These included: people are difficult, people have value, life is

not fair, emotions are a problem, communication is key, control is key,
I want to feel worthwhile and it all boils down to the moneywise.

This study identified some differences in quantitative indicators of subjective and objective quality of life for this participant group from studies of people with a learning disability and the ordinary population. It raised issues in relation to the specific impact of autism characteristics on quality of life perceptions, particularly in the areas of social interaction, health and material wellbeing. It highlighted the importance of combining clinical and research roles and demonstrated that this participant group's quality of life perceptions could be accessed directly with skilled support.

INDEX

Acknowledgments	2
Abstract	4
INDEX	6
Chapter One: Introduction	14
1.1 Overview of study	14
1.2 National and local background.....	18
1.3 Diagnostic process.....	19
1.3.1 <i>Economic factors related to diagnostic services</i>	21
1.3.2 <i>Diagnostic terms</i>	21
1.3.3 <i>Alternative diagnostic outcomes</i>	23
1.3.4 <i>Changes in diagnostic categories</i>	24
1.3.5 <i>Diagnostic labels</i>	27
1.4 Neurodevelopmental difference in Autism Spectrum Disorder .	29
1.4.1 <i>Theory of mind</i>	29
1.4.2 <i>Executive functioning</i>	30
1.4.3 <i>Central coherence</i>	30
1.4.4 <i>Neurotypicality</i>	31
1.5 Relationship between autism and learning disability	31
1.6 Quality of life	34
1.7 Motivation for study of people with a mild or borderline learning disability and possible autism	35
1.8 Aims and objectives of study	38
1.8.1 <i>Primary question</i>	39
1.8.2 <i>Secondary questions</i>	39
1.8.3 <i>Outline of thesis</i>	39
Chapter Two: Contextual literature background to the study	41
2.1 Introduction	41
2.2 Published literature	41
2.2.1 <i>Summary of key points from published literature</i>	57
2.3 Unpublished contextual literature.....	59
2.3.1 <i>Summary of key points from unpublished literature</i>	63

Chapter Three: Theoretical concepts of quality of life in people with a mild or borderline learning disability and possible autism	65
3.1 Introduction	65
3.2 History of quality of life concept in learning disability literature	66
3.3 Current understanding of the term quality of life in learning disability literature	69
3.4 Objective indicators of quality of life	71
3.5 Subjective indicators of quality of life	72
3.6 Relationship between subjective and objective indicators	73
3.7 Subjective wellbeing and happiness	76
3.8 Subjective and objective quality of life for the population of people who do not have a learning disability	77
3.9 Quality of life as a measurement in this present study	79
3.9.1 <i>Measuring quality of life in people with a learning disability</i>	81
3.9.2 <i>Rationale for selection of quantitative quality of life tools</i>	82
3.10 Gathering qualitative quality of life data from people with a learning disability and autism	89
Chapter Four: Methodology and methods	91
4.1 Introduction	91
4.2 Methodological position	91
4.2.1 <i>Relationship between nature of enquiry and methodology</i>	91
4.2.2 <i>Relationship between participant group and methodology</i>	92
4.2.3 <i>Influence of ethnographic approach on methodology</i>	93
4.3 Mixed methods approach	99
4.4 Summary of methodology	100
4.5 Methods overview	101
4.6 Ethical approval	101
4.7 Phase One: the developmental phase	102
4.7.1 <i>Contextual literature approach</i>	102
4.7.2 <i>Focus group</i>	105
4.7.3 <i>Sample selection</i>	106
4.7.4 <i>Advantages and disadvantages of using a focus group</i>	107
4.7.5 <i>Engaging the participants</i>	108

4.7.6	<i>Invitation and venue</i>	110
4.7.7	<i>Approach and structure to focus group</i>	110
4.7.8	<i>Participant characteristics and learning from focus group</i>	113
4.7.9	<i>Learning from focus group</i>	116
4.8	Phase Two: the pilot study.....	120
4.8.1	<i>Purpose of pilot phase</i>	120
4.8.2	<i>Sample selection</i>	120
4.8.3	<i>Engagement in research</i>	121
4.8.4	<i>Pre-testing procedures</i>	122
4.8.5	<i>COMQOL-I5 and PWI-ID</i>	124
4.8.6	<i>Visual ranking exercise</i>	124
4.8.7	<i>Qualitative interview</i>	125
4.8.8	<i>Data gathering and appraisal in the pilot stage</i>	128
4.8.9	<i>Learning from pilot interviews</i>	133
4.9	Phase Three: the research phase.....	137
4.9.1	<i>Justification for quantitative analysis</i>	137
4.9.2	<i>Justification for sample size</i>	139
4.9.3	<i>Justification for sample size for qualitative analysis</i>	141
4.10	Quantitative analysis.....	142
4.10.1	<i>Descriptive quantitative analysis PWI-ID and COMQOL-I5</i>	142
4.10.2	<i>Analysis of observable change in the data</i>	142
4.10.3	<i>Analysis of visual ranking exercise</i>	143
4.11	Qualitative analysis.....	144
4.11.1	<i>Aim of analysis</i>	144
4.11.2	<i>Analytical method</i>	145
4.12	Summary of methodology and methods	146
Chapter Five: Results	148
5.1	Introduction.....	148
5.2	Results from pilot and research phase.....	149
5.2.1	<i>Participant characteristics</i>	149
5.3	Findings related to methods and engagement with the participant group.....	152
5.3.1	<i>Accessing the participants</i>	152
5.3.2	<i>Gatekeepers</i>	153
5.3.3	<i>Location for engagement</i>	154
5.3.4	<i>Response to the quantitative tools</i>	155
5.3.5	<i>Response to visual hierarchy task</i>	156
5.3.6	<i>Response to pictorial supports in the qualitative interview</i>	156
5.3.7	<i>Summary of learning from research engagement</i>	157
5.4	Quantitative results.....	158
5.4.1	<i>Descriptive statistics for mean COMQOL-I5 scores</i>	159
5.4.2	<i>Analysis of significance of observable change in COMQOL-I5 scores</i>	162
5.4.3	<i>Descriptive COMQOL-I5 results at an individual level</i>	169

5.4.4	<i>Descriptive statistics for PWI-ID mean scores</i>	172
5.4.5	<i>Analysis of significance of observable change in PWI-ID scores across whole sample group</i>	175
5.4.6	<i>Comparison of this study with a published study using PWI-ID with people with a learning disability</i>	178
5.4.7	<i>Changes in PWI-ID scores</i>	180
5.4.8	<i>Descriptive statistics for visual hierarchy exercise</i>	186
5.4.9	<i>Summary of quantitative results</i>	188
5.5	Qualitative results	190
5.5.1	<i>Introduction</i>	190
5.5.2	<i>Central themes related to quality of life perceptions across whole data set</i>	191
5.5.3	<i>Changes in central theme patterns throughout the diagnostic process</i>	221
5.5.4	<i>Subtheme patterns</i>	224
5.5.5	<i>Summary of qualitative results</i>	229
5.6	Illustrative cases combining detail of quantitative and qualitative results	232
5.6.1	<i>Mark – an adaptive case</i>	233
	<i>Themes for Mark</i>	235
5.6.2	<i>John – an adaptor moving to deprivation</i>	239
	<i>Themes for John</i>	241
5.6.3	<i>Jane – In wellbeing and remaining there</i>	246
	<i>Themes for Jane</i>	248
5.6.4	<i>David – In wellbeing and life improving</i>	253
	<i>Themes for David</i>	255
5.6.5	<i>Summary of results of illustrative cases</i>	259
Chapter Six:	Discussion	263
6.1	Introduction	263
6.2	Engagement and access	264
6.3	Issues arising from methods employed	273
6.4	Quality of life perceptions across whole study group.....	279
6.4.1	<i>Overall objective quality of life</i>	280
6.4.2	<i>Changes to objective quality of life</i>	284
6.4.3	<i>Overall subjective quality of life</i>	286
6.4.4	<i>Changes in subjective wellbeing</i>	287
6.4.5	<i>Balance of subjective and objective quality of life</i>	291
6.5	Social interaction.....	293
6.6	Health.....	299
6.7	Sensory issues and health.....	302
6.8	Material wellbeing	304

6.9 Safety and community participation	306
6.10 Future security	311
6.11 Limitations of study	314
6.12 Implications for future research and clinical practice	317
Chapter Seven: Conclusions.....	321
7.1 Overview	321
7.2 Contribution to new learning and clinical practice.....	323
References	325
Bibliography.....	343
List of Appendices.....	346
Appendix A.....	348
Appendix B.....	350
Appendix C	351
Appendix D	357
Appendix E.....	359
Appendix F	361
Appendix G	362
Appendix H	368
Appendix I	372
Appendix J	374
Appendix K.....	376

Index of illustrations

Table 3.1: Relationship between indicators and quality of life dimensions	88
Table 4.1: Method phases in the study	101
Table 4.2: Pattern of participant uptake in focus group.....	114
Table 4.3: Focus of questions in pilot phase.....	131
Figure 4.1: Calculation of power curve for this study	139
Table 5.1: Characteristics of participants engaged in research phase of study ..	150
Table 5.2: Background of potential participants who were not engaged in research phase of study	151
Table 5.3: Descriptive analysis of pre and post-diagnostic mean scores in dimensions and total COMQOL-I5 scores for the sample.....	160
Chart 5.1: Patterns of mean COMQOL-I5 scores across dimensions (pre and post-diagnostic process)	161
Table 5.4: Analysis of differences in mean COMQOL-I5 dimensions and in total	163
Table 5.5: Binomial test of distribution of patterns of change of COMQOL-I5 scores in sample	164
Chart 5.2: Changes of mean in specific indicators that make up the COMQOL dimension of emotional wellbeing	165
Table 5.6: Analysis of significance of difference in scores in indicators that make up the COMQOL-I5 dimension of emotional wellbeing using the Wilcoxon signed rank test	166
Chart 5.3 and Chart 5.4: A side-by-side comparison showing mean scores in COMQOL-I5 dimensions from Verri's Australian population (1999) and this researcher's study group.....	167
Graph 5.1: A scattergraph showing individual participant changes in COMQOL-I5 scores across the diagnostic process	169
Table 5.7: Descriptive statistics for PWI-ID scores across all dimensions.....	173
Chart 5.5: PWI-ID scores across all dimensions and scores pre and post-diagnostic process	174
Table 5.8: Analysis of observable change in mean PWI-ID across sample group	175
Table 5.9: Binomial test of distribution of patterns of score change for PWI-ID in the sample.....	177

Chart 5.6 and Chart 5.7: A side-by-side comparison showing mean PWI-ID scores across dimensions in McGillivray’s 2009 study and this researcher’s study	178
Graph 5.2: Individual changes in mean PWI-ID scores across the diagnostic process.....	180
Figure 5.1 Participants overall scores, pre and post-diagnosis, related to Zapft’s dimensions of objective and subjective wellbeing (1984)	183
Table 5.10: Descriptive statistics for visual ranking exercise ratings for participants in study	186
Chart 5.8: Mean ranking scores for each dimension across study group	187
Figure 5.2: Central themes identified from data set	192
Figure 5.3: Subthemes that were linked by the central theme of ‘People have value’	193
Figure 5.4: Subthemes that were linked by the central theme of ‘Other people are the problem’	197
Figure 5.5: Subthemes that were linked to central theme ‘My emotions are the problem’	200
Figure 5.6: Subthemes that were linked by the central theme of ‘Life is not fair’	203
Figure 5.7: Subthemes that were linked by the central theme of ‘Communication is the problem’	207
Figure 5.8: Subthemes that were linked by the central theme of ‘Control is important’	210
Figure 5.9: Subthemes that were linked by the central theme of ‘It all boils down to the moneywise’	214
Figure 5.10: Subthemes that were linked by the central theme of ‘I need to feel worthwhile’	217
Table 5.11: Central theme patterns throughout diagnostic process.....	221
Figure 5.11: Distribution of positive and neutral quality of life perceptions across all qualitative interviews (number of references to code across interview in brackets)	227
Figure 5.12: Distribution of negative quality of life perceptions across all qualitative interviews (number of references to themes shown in brackets)	228
Chart 5.9: PWI-ID scores for Mark	233
Chart 5.10: COMQOL-I5 scores for Mark	234
Table 5.12: Order of dimension importance for Mark before and after diagnosis	235

Chart 5.11: PWI-ID scores for John	239
Chart 5.12: COMQOL-I5 scores for John.....	240
Table 5.13: Order of dimension importance for John before and after diagnosis	240
Chart 5.13: PWI-ID scores for Jane	246
Chart 5.14: COMQOL-I5 dimensions for Jane	247
Table 5.14: Order of dimension importance for Jane before and after diagnosis	248
Chart 5.15: PWI-ID scores for David	253
Chart 5.16: COMQOL scores for David	254
Table 5.15: Order of dimension importance for David before and after diagnosis	254

Chapter One: Introduction

This section will begin by providing a brief overview of the study. Detail will then be provided on the local and national context for the study and an explanation will be given of key terms that will be used throughout. The nature and method of gathering contextual literature to support the study will be described and explained, alongside a review of relevant literature. The introduction will conclude with the questions that this study set out to explore.

1.1 Overview of study

People with a mild or borderline learning disability, who may also have autism, have limited representation in research literature. This group were primarily identified in studies exploring the criminal justice system, substance abuse and mental health issues (Ellem et al 2013; van Duijvenbode et al 2012; Vinkers 2013; Ellem et al 2008). They were most likely to become visible within clinical services supporting people with a mild or borderline learning disability with these additional challenges. As a result, this was a group that had a presence in clinical practice when they experienced difficulties, but little was understood about their lives and perceptions. In general, studies of individuals with a more significant learning disability focused on measurement of objective quality of life, using quantitative tools (Billstedt et al 2011; Gerber et al 2011). The lack of exploration of subjective wellbeing

appeared to reflect the communication challenges for individuals with a moderate or severe learning disability who were generally chosen as participants. These participants were more likely to have difficulties with their own expression and others' ability to interpret their perceptions of quality of life.

Individuals with a mild or borderline learning disability may have subtle speech and language difficulties that could add complexity to understanding their perspective on their lives. Clinical experience has suggested that this group should have adequate verbal ability to express views on their own lives, with skilled support. The existence of an Autism Diagnostic Service in one local area, with a specialism in learning disability, provided an opportunity to access participants with a mild or borderline learning disability and possible autism. The investigator in this study was a Speech and Language Therapist with specific skills and experience in supporting individuals with autism and learning disabilities. The main objective of this study was to explore and describe the quality of life perceptions for this group. This study also set out to describe any change in these perceptions following the diagnostic process and to understand the issues and approaches needed to engage this group in a research process.

This was a small-scale study (n=20), but it represented 77% of the total population of individuals with a mild or borderline learning disability who were referred to the local Autism Diagnostic Service in a

period of one year. A focus group was used to assist in the development of methods for the main study. The main study used mixed methods and incorporated quantitative questionnaires (Cummins and Lau 1997, 2005), a visual hierarchy exercise and in-depth qualitative interviews. These methods measured and described the participants' subjective and objective perceptions across multiple dimensions of quality of life. These measurements were carried out before individuals began the diagnostic process and were then repeated after the diagnostic process had been completed. Statistical analysis was carried out on the quantitative data gathered and thematic analysis was used to identify and explore themes in the qualitative data (Braun and Clarke 2013).

The results showed that this group had lower subjective perceptions of quality of life than demonstrated in other studies of individuals with a more significant learning disability and in the ordinary population (McGillivray et al 2009; Hensel et al 2002). The exceptions to this were the domains of social interaction and material wellbeing, where this group showed the same level of positive subjective wellbeing found in other groups. In general, subjective wellbeing remained relatively stable throughout the diagnostic process. A small subgroup showed an observable decrease in their subjective wellbeing at the end of the diagnostic process.

The objective indicators were similarly low to those found in studies of individuals with a more significant learning disability (Verri et al 1999; Hensel et al 2002), with the exception of the domains of health and safety, which were relatively high. Positive score change was observed, following the diagnostic process, in the overall objective quality of life of the group and also in the dimension of emotional wellbeing. Analysis indicated that this change was close to a level of statistical significance, but was not statistically significant and was of clinical interest. The dimension of community participation was generally perceived to be of low importance across the group.

Qualitative analysis identified some key themes. These were: people have value; people are difficult; control is key; communication is key; emotions can be a problem; life is not fair and needing to feel valued. Key areas for discussion were: The importance of quality rather than quantity for this group in relation to social interaction and material wellbeing; the importance of having a balance of time alone and time with others; the value of family for this group; the relationship between sensory issues and health as well as the links between wellbeing and productivity.

This study demonstrated that this group could participate in research, and that their subjective and objective quality of life perceptions could be effectively gathered. It highlighted the methodological value and ethical challenges of a clinician also taking on a research role. It

suggested that some aspects of quality of life might be perceived differently for people with a mild or borderline learning disability and possible autism, than for other people with a more significant learning disability and the ordinary population. This highlights the need to consider the tools currently used for the measurement of quality of life and their adequacy as a measure of quality of life for people with autism. This area warrants some further investigation, particularly in relation to social interaction, health and material wellbeing. This study raised the possibility of changes in quality of life following the diagnostic process. Further study is required to consider this in a wider population of people with a mild or borderline learning disability and autism. The long-term stability of observed changes also requires further investigation.

1.2 National and local background

Over the past six years there has been a growing national interest in the availability and impact of Autism Spectrum Disorder diagnosis for adults. Three major studies identified a failure to diagnose adults with autism (Eaves and Ho 2008; Matson and Shoemaker 2009; Mackenzie and Watts 2009) and these, in combination with pressure from adults with autism and their families, led to government-level investigation (National Audit Office 2009). This resulted in legislation and new strategic guidance (Department of Health 2010a). These guidelines required all areas to have an accessible autism diagnostic service for

adults, and current learning disability legislation requires the inclusion of people with a learning disability in these services (Department of Health 2007). As a result of these legislative pressures a diagnostic team was commissioned, in this researcher's local area, to provide autism diagnosis for all adults, including adults with a mild or borderline learning disability.

1.3 Diagnostic process

The participants in this study had all been referred to undertake an autism diagnostic process, which was available to them in their local area, if agreed by their general practitioner. The local diagnostic process (see Appendix A) was developed in line with national guidance (National Institute for Health and Care Excellence 2012). This process was not one intervention, but instead a series of interventions, which had some set elements and others which could vary slightly in relation to individual need and presentation.

A core aspect of this process was the identification of whether an individual presented with signs and symptoms that conformed to the medical diagnostic criteria of Autism Spectrum Disorder (American Psychiatric Association 2013). The process also involved an evaluation of the strengths and needs of the individual in relation to his/her social and communication skills and daily functioning. A final session included solution-focused working, appropriate signposting

and linking with local services that were tailored to that individual's needs. Examples of solution-focused working were: the development of an employment disclosure document, a session supporting a partner or parent of a child to understand autism or attendance at a more individualised therapy session. Individuals could be signposted to specialist employment, advice or psychology services and encouraged to access local support groups. The whole diagnostic process generally took place over three sessions and usually took between eight and 12 weeks to complete.

The local service had been in existence for four years. It was run from within the learning disability service, but had a remit to provide diagnostic assessments for individuals both with and without a learning disability across three counties. The team was relatively unusual nationally in having several Speech and Language Therapists, as well as psychologists, trained as diagnosticians above and beyond their usual professional role. This increased skill base, and a strong link with learning disability services, increased the likelihood of people with a borderline learning disability with possible autism, who were not eligible for the learning disability service, being referred to the Autism Diagnostic Service. As a result, the service in which this study was carried out had a greater awareness of and experience with adults who had a borderline learning disability and autism than was conventionally found in other similar services.

1.3.1 Economic factors related to diagnostic services

At a national level, the public sector review demanded that services were provided in an effective, value for money way (Department of Health 2010b) and local commissioners required evidence and assurance that the autism diagnostic service being provided was economically efficient and that the perceptions of the service users were being carefully evaluated and considered within planning and development of these services (Department of Health 1997). Knapp et al (2009) had identified national costs of around £25 billion per year linked to both costs and lost opportunities for adults described as having Autism Spectrum Disorder.

1.3.2 Diagnostic terms

The individuals included in this study have been described as having a mild or borderline learning disability. The term learning disability, also described as an intellectual disability outside of the United Kingdom, is defined as a neurodevelopmental disorder, which results in intellectual and adaptive functioning difficulty in conceptual, social and practical domains. To be considered as having a learning disability an individual must have discernible and measurable difficulties in his/her cognitive functioning that affect him/her in his/her everyday life, and have

occurred in early development (American Psychiatric Association 2013).

Presence and level of learning disability can be measured through cognitive testing or professional evaluation of an individual's intellectual quotient (IQ). A person with an average IQ would score at around 100 on a standard IQ test, and an individual with a mild learning disability would score between 55 and 70 and would be expected to have some mild difficulties in adaptive functioning, meaning that he/she might have more difficulty with more complex daily tasks and activities (Royal College of Psychiatrists 2013).

Emerson et al (2011) estimated that around 2% of the general population were likely to have a degree of learning disability, with the greatest proportion of these likely to be in the mild end of the range. Emerson stated that 0.47% of the adult population accessed support and services designed for people with a learning disability, with the largest proportion of these being people with difficulties in the severe learning disability range.

The term borderline learning disability describes individuals who have an IQ that is at the lower end of the normal range of 70-85, who may present with some difficulties in their adaptive functioning depending on their patterns of ability, levels of natural support and life demand (Ferrari 2009). In clinical practice this group is less likely to be eligible for specialist support and services.

Autism Spectrum Disorder is understood as a neurodevelopmental condition which, historically, has been described in terms of three particular areas of impairment: social communication, social interaction difficulties and restricted or repetitive patterns of behaviour, interests or activities. All of these need to have been demonstrated over a range of contexts and to have been present in the early years of life (American Psychiatric Association 2013). Current estimates suggest that approximately 1% of the adult population fulfils the diagnostic criteria for Autism Spectrum Disorder (Baird et al 2006). The degree to which this actually affects individuals is less well understood, with poor recording of diagnoses and no clear picture of how many people actively need or seek services (National Audit Office 2009).

1.3.3 Alternative diagnostic outcomes

As this was a diagnostic process, some of those who were referred to the service would not have received a diagnosis of autism, and this was the case for some of the subjects in this study (see Appendix K). In this local area, around 60% of referrals were likely to result in a diagnosis of Autism Spectrum Disorder. Another possible outcome was a diagnosis of a Social Communication Disorder, which suggested that underlying speech and language difficulties were the fundamental cause of the difficulties being experienced. Personality Disorders were not formally diagnosed by this service, but if the

process had identified features suggesting this was possible then a referral was made to the local complex needs team. Other possible suspected diagnoses that needed ongoing referrals were: developmental dyspraxia, severe anxiety, depression, or thought disorders such as schizophrenia. It was also possible that an individual's level of learning disability adequately explained the autism features with which he/she presented.

In all these cases, individuals were likely to have been referred because they were presenting with some features of autism and the job of the diagnostician was to decide whether these were best explained as an Autism Spectrum Disorder or whether there was an alternative explanation that matched their presentation more effectively. Occasionally no specific diagnosis was appropriate and that individual was described as having some autistic features but not fulfilling the diagnostic criteria for autism.

1.3.4 Changes in diagnostic categories

Currently, an area of considerable academic and clinical discussion centres on changes in diagnostic criteria for Autism Spectrum Disorder, which have been published in the Diagnostic and Statistical Manual of Psychiatric Disorders V (DSM V) (American Psychiatric Association 2013). Studies have been carried out into the face validity of diagnostic descriptors such as Asperger Syndrome and High

Functioning Autism (Wing et al 2011). These terms were used in previous diagnostic manuals (DSM IV American Psychiatric Association 2000) and these studies have suggested inconsistent use of these terms in clinical practice. As a result, the DSM V has chosen to exclude these descriptive terms and has proposed that diagnosticians use one umbrella term, 'Autism Spectrum Disorder', and have the potential to rate severity of the disorder. Studies have also indicated minimal evidence that individuals present with social communication and social interaction difficulties in isolation (Wing et al 2011) and as a result the DSM V has reduced the 'Triad of Impairments' to a dyad, combining the two communication descriptors. This has resulted in one overall diagnostic term and a severity rating that becomes the primary medical differentiator of case presentation. Guidance in the manual leans towards this rating being related to language skills, issues with adaptive functioning and degree of autistic symptoms, such as repetitive behaviours.

The term Asperger Syndrome is widely used and is a descriptive label in support groups and services as well as increasingly in public and media discourse. The loss of this term as a formal medical diagnosis has caused concern amongst the autistic community (Giles 2014).

Atypical Autism was a term often used to encompass individuals who were felt likely to benefit from autism specific support and services but because of other complexities, such as difficult early life experiences,

limited developmental data, or lack of evidence in one dimension were challenging to match to the full diagnostic criteria. These complexities are commonly experienced during a diagnostic process with people with a mild or borderline learning disability and this presents the possibility of 'missed' diagnosis (Worley and Matson 2012).

Decision-making and policy in public services reflect the overall economic climate in the United Kingdom, resulting in greater scrutiny of resources for those deemed to be in the most need. Adult social care services in the United Kingdom are charged with assessing any adult who presents with social care needs using the Fair Access to Care (FACS) tool (Social Care Institute for Excellence 2013) which uses factors such as severity of disability to assign level of need.

Feedback from clinicians in other parts of the United Kingdom has indicated that individuals have often needed to reach a 'critical' or 'substantial' level of need on these assessments in order to be able to access any financial support. Medical assessments and diagnosis are a core part of local area benefits allocation decisions or access to employment support or reasonable adaptations, with a heavy emphasis on formal medical diagnosis and severity ratings.

Clinical experience assessing people with milder levels of learning disability suggests that they present with more subtle language difficulties and less obvious symptoms of autism. The impact of these

difficulties on their lives and functioning may, nonetheless, be very significant, and there is a risk that a severity rating could minimise this and result in less effective support.

Despite these concerns, there are some aspects of the revisions that may be beneficial in supporting diagnosis. The DSM V no longer requires that problems must have been noted before the age of three years and recognises that children might not show significant problems until they become older or social demands increase. This is particularly helpful in the case of adults where very early history has been difficult to obtain. In the case of adults with borderline and above levels of cognitive skill, there is more possibility that these individuals function well within the structure of primary school and struggle at secondary school (Attwood 2001; Humphrey and Lewis 2008). Additionally, the new criteria include sensory differences, such as tactile or auditory hypersensitivity, as a diagnostic indicator. This is a helpful addition for individuals who have tended to not conform to typical presentations of autism, such as in the case of women with autism, who may have less easily identified restricted and repetitive behaviours (Wing et al 2011).

1.3.5 Diagnostic labels

A key part of a diagnostician's role is to provide referred individuals, if appropriate, with a diagnostic label. The impact of choosing to allocate a specific diagnostic description to an individual is a significant one,

and merits brief discussion in relation to a study exploring the perception of a group of individuals actively involved with a diagnostic service.

There are reasonable concerns that could be raised in relation to providing a label of Autism Spectrum Disorder for an individual. These concerns may be related to the possibility of limiting his/her own or societal expectations or stigmatising him/her and reducing his/her agency. An alternative view would be that a label is explanatory and empowering and enables society to understand difference in a way that prevents alternative and pejorative labels being attached to that individual's difference (Qureshi 2012).

Historically, autism was a categorical and narrow diagnosis that generally described individuals with very visible symptoms, significant learning disability and a perceived poor prognosis. However, the work of Lorna Wing (1996) helped to identify the wider spectrum of autism as a group of heterogeneous individuals with some shared characteristics, but a diversity of life chances and opportunities.

In spite of this change in thinking, there are undoubtedly risks of wider societal misunderstanding of the term autism, and resulting stigmatisation or negative framing. However, as highlighted by Peeters (1997) and Attwood (2007), there are risks of failure to correctly diagnose, which can be both practical in terms of gaining appropriate

treatment and support and also have emotional impact for an individual experiencing difference and distress with no explanation other than his/her own failure (Qureshi 2012; Murray 2006; Mandell et al 2005; Mcleod 1999).

1.4 Neurodevelopmental difference in Autism Spectrum Disorder

There are a number of areas of neurodevelopmental difference, which underpin many of the social, communication and flexibility of thinking differences that people with a formal diagnosis of Autism Spectrum Disorder have. These vary from individual to individual and contribute both to individual strengths and needs.

1.4.1 Theory of mind

This describes the individual's ability to understand a full range of states in others from their observable behaviour, in effect to be able to anticipate why others may be behaving in a particular way without having to ask them (Baron-Cohen 1997). This skill is developmental, and allows children to begin to read signals such as facial expression, gesture, intonation and context and predict what others might be thinking, thus allowing them to show skills such as empathy. Whilst this skill is not necessarily absent in adults with autism, it is felt to have more potential to be impaired, resulting in apparent difficulties with empathy, inference and literal interpretation of language and situations (Peeters 1997). This also means that people with autism are more

likely to say what they are thinking and avoid manipulating information to please others, thereby being perceived as more honest, which can be both problematic and advantageous.

1.4.2 Executive functioning

This term describes skills in an adult which allow him/her to 'project manage' life on a day-to-day basis. These skills incorporate organisation and planning; inhibition and impulse control; self-reflection and self-management; time management and prioritising; understanding complex and abstract concepts and using new strategies. There is a body of research to support the idea that these skills are commonly affected in some way for people with an Autism Spectrum Disorder (Attwood 2007). This can result in a person with autism appearing poorly organised and chaotic.

1.4.3 Central coherence

Central coherence describes a person's ability to rapidly take in an overview of a situation or object and understand its overall meaning. If an individual has weak central coherence he/she will tend to focus with more intensity on a detail of a situation, or consider each detail individually and may struggle to link them up. Weak central coherence has been found to occur in people with Autism Spectrum Disorder (Attwood 2007). This results in difficulties in being able to formulate

and understand whole situations, but also means that people with autism could be far superior to neurotypical (non-autistic) individuals in tasks that require an attention to detail.

1.4.4 Neurotypicality

In order to have a descriptive term to help provide a label for those people who do not have autism, the term neurotypical has been developed and is widely used in many communities of adults who have an Autism Spectrum Disorder diagnosis (Attwood 2007) and also amongst diagnosticians. This term does not indicate that all people without autism are identical in their presentation, but that, like people with autism, they can vary, but do not fulfil the diagnostic criteria for an Autism Spectrum Disorder.

1.5 Relationship between autism and learning disability

Clinically and in research literature there is no available data describing the prevalence and presentation of individuals with a mild or borderline learning disability. It is generally accepted that around 2% of the population of the United Kingdom have a degree of learning disability (Emerson et al 2011). It is believed that about 0.3% of the population have a severe learning disability and this group is easier to identify as they often need high support from an early age and are known to services. Emerson's paper also identifies that up to 30% of people with a learning disability could fulfil the formal criteria for

autism. Brugha (2012) argues that people with autism and a learning disability are generally a hidden group and that large proportions of these are likely to have a mild or borderline learning disability.

Local clinical experience suggests that people with a mild or borderline learning disability were commonly not diagnosed specifically with either a learning disability or autism until later in life. They were often described in childhood as developmentally delayed, slow learners or emotionally immature with a focus on their learning difficulties (reading and writing challenges) rather than learning disabilities (wider cognitive challenges). In the local service many individuals who are referred with a mild or borderline learning disability come from complex backgrounds characterised by unsettled family situations, other medical diagnosis, specific learning difficulty and behavioural difficulties at school. All of these have the potential to mask or distract from a mild or borderline learning disability or autism.

Autism and learning disability are both neurodevelopmental conditions that can impact on communication, behaviour and adaptive functioning. As a result there are risks of autism being overlooked where there is learning disability (Levitas and Hurley 2007). There is evidence that the needs of people with a sole diagnosis of a learning disability are different from those with the dual diagnosis (Gilchrist 2001). Bradley et al (2004) found that people with additional autism were more likely to have anxiety, mood and sleep disorders and life-

long comorbid conditions such as depression and anxiety (Bradley and Bolton 2006).

Individuals with more subtle levels of learning disability may also present with more subtle signs of autism at an early age. As a clinician looking at past history of referred individuals, it is common for a child's skills in social development to be explained by lower intellectual ability. Rigid and repetitive behaviours can occur in children without being an obvious cause for concern and if children are experiencing other disruptions in their early lives, these may be considered explanatory.

This group has a reasonable likelihood of having the capacity to engage in research, as their cognitive difficulties can be relatively mild and they are more likely to have stronger communication skills. Many studies setting out to understand the lives of people with a learning disability and autism are based on convenience samples of groups of people who are in some type of residential care or need high levels of support from services (Billstedt et al 2011; Gerber et al 2011; Alvarez and Crabtree 2008). People with a mild or borderline learning disability and possible autism are more likely to live independently or with family and may be less aware of their difficulties. Difficulties in literacy and social skills, which may be shared by families, may generally make this group less likely to easily engage with services and support.

Other possible indicators of autism may be interpreted in alternative ways with people with mild or borderline learning difficulties. It is recognised that people with autism can have highly variable patterns of skills, sometimes referred to as 'a spiky profile' (Happé 1994). This is often easier to identify in an individual with a higher IQ, where that person might struggle with some everyday tasks but has a very specific area of high ability (Attwood 2007). In an individual with an average to high IQ, this kind of profile is likely to result in some skills that are viewed as exceptional in relation to most people.

In an individual with a mild or borderline learning disability this spiky profile might result in skills that are 'average' or 'good' and some skills that are very poor indeed. Clinical experience suggests that these individuals are often framed by others as 'not trying', 'only putting effort in when interested'; and other negative interpretations, with the 'average' skill being seen as what that person can do when he/she tries.

1.6 Quality of life

The complexity of this term warrants in-depth consideration and this will be presented in chapter three, with particular focus on this term in relation to people with a learning disability. For the purpose of this study it encapsulates a number of other concepts. Firstly, subjective wellbeing, which refers to an individual's perception of his/her own

levels of satisfaction within different dimensions of his/her life.

Secondly, objective wellbeing, which refers to measurable factors in an individual's life, which may be assumed to impact on his/her overall quality of life in a number of dimensions, such as income or level of access to health services. These then need to be considered in terms of that individual's perceptions of the importance of these dimensions and in relation to other people or his/her own hopes and expectations.

1.7 Motivation for study of people with a mild or borderline learning disability and possible autism

The development of a local autism diagnostic pathway and service, hosted within a Learning Disability Service, has resulted in the development of specialist skills and an increase in referrals for people with a mild or borderline learning disability. Discussion with other services (Nylander 2013 personal correspondence) indicated that this group of individuals had a clinical presence in other caseloads and improving understanding of their lives and perceptions was considered of clinical interest and value.

Tacit knowledge and clinical experience suggested that this group's perspective on themselves and their world might be different from other groups and that understanding this would be important to effectively engage with them. In the clinical world of autism, the concept of neurodiversity is an important one for guiding clinical

practice in the support of people with a diagnosis of autism (Kappett et al 2013; Krcek et al 2013; Mackenzie et al 2012). This approach recognises people with autism and people without autism as potentially having different but equally valid ways of viewing and processing the world. This leads to the thinking that it is possible that people with autism may perceive the world in a different but valid way to people who are more neurotypical and that this may apply to their perceptions of quality of life (Robertson 2010).

An important factor in the local autism diagnostic process was developing an understanding of an individual's best hopes for the process and the impact he/she wanted it to have in his/her life. This facilitated the most effective planning of the solution-focused session and consideration of signposting and recommendations that were most likely to be of value to them and make the most positive difference to their lives. All of the individuals referred to this service were likely to present with some autistic features but might not fulfil the criteria for Autism Spectrum Disorder. The perceptions of all the individuals referred were of clinical interest and for this reason people who did not receive a diagnosis of autism (Carl, Mike, and David: see Appendix J) were not excluded from this study, but any differences for these individuals were highlighted and discussed.

A clinician in a diagnostic team is required to consider a very wide range of dimensions of an individual's life. The diagnostic process

involves exploration of relationships, physical and emotional wellbeing, hopes for the future, material and financial understanding, links to the wider community, feelings of safety and security, daily living skills, occupation and fulfilment. These become key areas to consider in terms of strength and needs analysis and solution-focused support. These dimensions map well onto the dimension of quality of life, suggesting that exploring these quality of life perceptions in a multidimensional way was likely to benefit clinical understanding and practice with this group of individuals.

Enhancing clinical knowledge and understanding, with the intention of providing better diagnostic services, lay at the heart of this enquiry. In a small specialist service, that meant that the clinician most motivated and skilled to carry out the study was also the clinician who had the greatest level of clinical skill with people with a mild or borderline learning disability, and was, therefore, most likely to be involved with those individuals clinically.

Whilst this dual role presented considerable ethical challenges, it also highlighted the benefit of clinical skills and experience in designing appropriate methods and facilitating engagement with this group.

Initially, this study had a greater focus on looking at the ways in which participants' perceptions of the quality of their lives changed throughout the diagnostic process. Early in the research process, it became clear that a study that focused on understanding the quality of

life perceptions of this group in general would be challenging and would make a significant contribution to professional practice.

Alongside this, improving understanding of effective ways to engage in research with participants with a mild or borderline learning disability and possible autism would contribute to both clinical and research practice. Change in perceptions across the diagnostic process, therefore, became an area of secondary interest.

1.8 Aims and objectives of study

This study aimed to effectively engage in research with individuals who had a mild or borderline learning disability and possible autism and had been referred to their local diagnostic service. It set out to gather these individuals' perceptions of the quality of their lives in a way that reflected their perceptions of both subjective and objective aspects. This included consideration of the ways in which these perceptions might change or remain stable throughout the diagnostic process.

Objectives of this study were to effectively present and describe the quality of life perceptions of people with a mild or borderline learning disability who were going through the diagnostic process and present learning on tools that had been used or developed to gather this data. A further objective was to be able to summarise engagement approaches that facilitated research involvement with this group of individuals and highlight challenges. A final objective was to evaluate

the challenges and benefits of a clinician taking on the joint role of researcher and diagnostician in this study.

1.8.1 Primary question

What is the perceived quality of life for people with a mild or borderline learning disability who are referred to a local diagnostic process?

1.8.2 Secondary questions

What approaches facilitate research engagement for participants with a mild or borderline learning disability and possible autism?

What are the patterns of change or stability in quality of life perceptions for individuals from beginning to the end of a local diagnostic process?

What are the challenges and benefits of a clinician having a joint role of researcher and diagnostician in this specific study?

1.8.3 Outline of thesis

This thesis will go on to provide an exploration of the contextual literature that relates to these questions and will then move on to a detailed exploration of the construct of quality of life in the field of learning disability. It will link this to the tools and specific approach that were taken in gathering quality of life perceptions from participants. It

will then describe the methodology that underpinned the methods employed and engagement approach that was used.

The results section will begin by presenting learning about research engagement with this particular participant group. This will be followed by a quantitative overview, with a focus on descriptive presentation, comparison to other studies and some consideration of the significance of any observable changes of participant scores.

A qualitative overview will be given looking at central and subthemes and illustrated with participant data. Selected case examples will then be used to present the interaction between quantitative and qualitative data and to consider the interaction between quality of life dimensions. Discussion will then bring together thinking about the ways in which results relate to existing studies and quality of life theory and will go on to consider the ways in which learning disability, autism and other factors impacting on this group may be affecting their quality of life perceptions.

Chapter Two: Contextual literature background to the study

2.1 Introduction

This section will describe the sources of literature and knowledge that were accessed to provide context to this study. There was minimal current literature that specifically examined quality of life perceptions in people with a mild or borderline learning disability or any work suggesting how this group might be approached or specific tools for this purpose. A number of sources of contextual information were accessed, some of which were drawn from published literature. A vital, additional source of contextual literature came from unpublished sources such as correspondence with centres of excellence; contact with other diagnostic services; information from research organisations and attendance or presentation at conferences. These links provided access to studies, thinking and viewpoints that were not formally available from conventional literature databases.

2.2 Published literature

There were a small number of published studies in the area of learning disabilities and autism, which explored quality of life for individuals with learning disabilities, with only a few of these specifically related to adults. Whilst these did not specifically exclude people with a mild or borderline learning disability, this section will appraise some of these

studies and consider the methodological issues that led to these studies being more likely to focus on individuals with more significant levels of learning disability or focus on the carers' perspectives. These studies have value in offering some suggestion of the patterns of quality of life that may occur for people with a learning disability, and an opportunity in some cases to consider whether the results in this researcher's study might differ in any way from published studies.

Plimley's 2007 appraisal of papers, related to the topic of quality of life and autism in adults, highlighted limitation in the data gathered outside of populations with significant learning disabilities and a tendency to rely on quantitative, proxy contact. Large-scale studies favoured measurement of objective quality of life indicators (Billstedt et al 2011; Saldaña et al 2009; Nydén et al 2008; (García-Villamissar et al 2013). Billstedt's study approached a Swedish population of 120 adults diagnosed with autism in childhood, 108 of whom ultimately participated. The majority of this group had a significant learning disability, but 12 were identified as having a mild or borderline learning disability.

This study used specifically developed tools to evaluate the quality of life of individuals in relation to objective indicators, such as identifying whether a care plan was in place or whether staff had autism-specific training. These involved the judgement of experienced clinicians and the views of carers, but did not seek the opinions of participants

themselves. This study appeared to work on the underlying assumption that if concrete objective indicators had occurred, then the quality of life for the individual would be enhanced. Whilst there might have been value in ensuring that objective and measurable indicators were in place it was not clear whether this represented a measurement of quality of life, which by its nature involved the subjective views of the individual. There was no specific reason given in this study for the lack of more direct involvement of those individuals with a mild or borderline learning disability. Billstedt's team suggested that objective quality of life was generally higher for people with higher IQ levels and that poor residential and occupational engagement was associated with poor objective quality of life.

Saldaña et al (2009) used questionnaires to gather objective data for 74 Spanish people with a learning disability and autism. The level of learning disability in this group was unclear. 10% of the participants had received a diagnosis of Asperger Syndrome, which suggested normal or higher IQs. However, in all cases family members, on a proxy basis, completed the questionnaires. Objective indicators in this study were poor compared to the ordinary population, with a lack of community-orientated resources and challenges for proxy reporters in judging subjective wellbeing in individuals with significant communication problems.

Objective indicators can be relatively easy to gather as they can often be obtained without having to get information directly from a learning disabled individual with possible communication challenges. This is likely to be a considerable factor behind the predominance of these measurements particularly in larger scale quality of life studies with people with a learning disability (Gerber et al 2008; Beadle-Brown et al 2009; Baird et al 2006). Gerber's team carried out a smaller scale study involving 30 adults based in two residential units where all participants had moderate or severe learning disabilities, but it was identified that 20 of the group could communicate with signs or verbally. This study was primarily an evaluation of treatment approaches that used objective quality of life measurements. Additionally, staff and family views were sought, but no attempt was made to obtain views from the participants. This study indicated that objective quality of life scores were improved when a specific treatment approach was used but that, generally, objective quality of life measurements were low.

Verri's (1999) study looked at a group of 151 adults with a learning disability in Australia and 125 people with a learning disability in Italy, alongside a group of 100 adults in Australia without a learning disability and 92 in the Italian sample. This study used the COMQOL-15 as a measurement tool that will be described in more detail in section 3.9.3. The participants in Verri's study included people with a

mild learning disability, but the majority had a more significant learning disability and, therefore, required a higher level of direct care. A similar study was carried out by Hensel et al (2002) looking at 31 people with a learning disability, drawn from a community setting, who were either in a specialist programme or residential care. Verri's study was completed on a postal basis, which reduced certainty that it had been understood and completed by the participants at whom it was targeted. Both studies showed that, in general, subjective perceptions of people with learning disabilities were similar to the ordinary population, and in the case of the Italian study appeared inflated. Objective quality of life in both countries was generally lower in the learning disabled group.

Baird et al (2006) carried out a longitudinal study based on a cohort of children in Camberwell who had been identified as having an Autism Spectrum Disorder. This study recruited 72 adult participants from an original cohort of 92. Whilst the majority of the study group were evaluated using objective measurements a small sample of nine participants were interviewed using the Quality of Life Questionnaire (QOL-Q), which was a quantitative tool for gathering subjective wellbeing data, in an attempt to get the participants' views on their quality of life. It was not clear from the data the precise level of learning disability for this small sample group. These individuals had been identified as having communication skill levels which could allow them to consent and respond to the questionnaires, but the authors felt

that this sample size was too small to warrant inclusion in analysis.

The authors reported that overall satisfaction levels with life and with employment were lower than identified in the proxy reports.

Other studies have explored specific areas of life for children with autism, primarily looking at proxy reports. Kuhithau et al (2010) identified generally lower levels of objective quality of life in children with autism, compared with children with chronic conditions. Tavernor et al (2013) explored the direct use of a quality of life tool (Paediatric Quality of Life tool) with 10 children with autism and their parents that also suggested a lower quality of life than that found within the ordinary population.

There is little published work that describes or explains changes in perceptions of any kind throughout the diagnostic process. A small number of qualitative studies and papers have presented the perceptions of individuals, usually described as having Asperger Syndrome, after they have received a diagnosis (Punshon et al 2009; James et al 2006). This group's higher level of cognitive skills results in less severe communication challenges. This is, therefore, a group whose subjective perceptions are potentially more straightforward to gather. These studies have been limited in the dimensions of quality of life that have been considered and have focused on psychological changes or medical management considered to have occurred in direct relation to an autism diagnosis.

Punshon's (2009) psychological perspective used an interpretive phenomenological analysis with an opportunistic case sample and a clear focus on the views of the participants. This resulted in person-centred thematic data and an approach that could consider an individual's perspective. This study identified feelings of relief and reduction in guilt following diagnosis.

James et al (2006) used an opportunistic case selection strategy to analyse instances of late autism diagnosis from the perspective of psychiatric medical management and related changes. This study did not consider individual perception of these changes, but indicated the author's perception that the diagnosis of autism might result in positive changes in the individual's quality of life. In both studies, the opportunistic nature of selection and analysis limited the potential to explore the data in a more structured and thoughtful way and to consider the possibility of changes during the diagnostic process.

Shrubb (2010) presented a personal perspective of life perceptions post diagnosis, highlighting primarily feelings of relief mixed with some concerns about possible stigma.

Robertson (2010), an autistic researcher, presented an analysis of the ways in which an autistic perspective of the domain of quality of life could be considered and particularly highlighted the tendency for current research to ignore issues such as social stigma and

marginalisation and focus on consideration of outcome-based treatments when discussing quality of life.

There have been studies using qualitative approaches with subjects with Asperger Syndrome or using proxy models. Jennes-Coussens et al (2006) used a mixed methods approach to explore the quality of life of 12 young men with Asperger Syndrome. This used a matched group of participants without autism. In this design, a qualitative interview was used to probe for greater depth to add to the data gathered through a quantitative interview and highlighted lower levels of satisfaction in areas such as productivity and social interaction for people with Asperger Syndrome who also scored lower for positive employment and higher for solitary activity.

Van Heijst and Geurts (2014) carried out a meta-analysis of ten studies carried out over the previous eight years, looking at quality of life in autism over the life span of people with autism. The majority of these studies were in the area of paediatrics, four involved some adults and only one involved direct engagement with affected individuals to obtain data. This study (Kamio et al 2013) was limited to the domains of psychological and social wellbeing, focused on objective measurements of quality of life and was completed by postal questionnaire. This made it harder to be certain that data came directly from the participants themselves.

The results of this meta-analysis suggested that the most affected domain was social functioning and that participants generally had fewer friends and relationships, fewer leisure and sexual relationships and poorer physical health. There was also a suggestion that this group placed greater emphasis on family than on friendship. Overall, this study suggested that quality of life was lower for people with autism but that a greater level of learning disability did not correlate to a lower quality of life. Persson (2000) similarly focused on outcomes in people with a dual diagnosis, and particularly linked to a teaching programme that he argued was linked to a better quality of life.

Shipman et al (2011) gathered perceptions of young people with Asperger Syndrome and found lower scores in all domains for this group, with quality of life being higher for young people with higher self-esteem and lower for those reporting high anxiety. Jones et al (2001) explored web-based blog pages of five individuals with Asperger Syndrome to look at emotional themes that arose and found that alienation was an overriding theme along with frustration, depression and a pervasive sense of fear. Burgess and Gutstein (2007) highlighted the degree of social support as a predictor of quality of life and Bauminger and Kasari (2000) highlighted the importance of considering the difference between quality and quantity of friendship for people with autism, but also identified loneliness as a serious issue for children with autism. Bauminger and Kasari (2000) in their study of

22 children with autism without learning disabilities found that, compared with 19 matched typically developing children, the children with autism showed difficulties with quality of friendship, increased loneliness and often a poor awareness that lack of friendship could be the cause of their loneliness. This study asked children to complete scaled questionnaires in relation to sets of statements such as 'I don't have any friends in class', and 'I feel alone at school'. It also asked children to define friendship, finding that children with autism gave more limited definitions of friendship and also found that parental estimates of numbers of friends were greater than those of children with autism. One potential predictive factor in quality of life, highlighted by Brown and Brown (2005) and Cummins and Lau (2005) was self-determination, as this allowed choice, autonomy and independence.

There are a number of studies that explore quality of life perceptions for people with a learning disability and no specified Autism Spectrum Disorder. These tend to focus on people with a significant learning disability with the prime purpose of validating tools for measurement with this group. As such, they frequently use proxy respondents rather than direct report, with the notable exception of McGillivray et al (2009) and Hensel et al (2002). The literature is divided on the likelihood of correlation between the subjective perceptions of people with a learning disability and those who know them well. McVilly et al (2000) sampled a small group of people with a learning disability and their

carers, using questionnaires rather than direct interviews and concluded that there was good concurrence in quality of life perceptions between people with a learning disability and their carers. Larger samples carried out by Schwartz and Rabinovitz (2003) found some areas of concordance but noted that the higher the level of cognitive ability the less concordance occurred and that concordance was greater with staff than with family. Sheldrick et al (2012) found that concordance was generally poor, but could be improved if proxy reporters were explicitly asked to say 'what they thought the individual would say if asked'.

The concerns raised in these studies were that carers who had different life experiences due to factors such as lack of disability, age and lifestyle would inevitably judge another person's level of satisfaction in relation to their own. The people they cared for might not choose to tell them things about their thoughts and views that they thought might upset their carers or contradict them. A carer might also fail to accept that a person's views had changed. Studies relating to subjective wellbeing for people with a learning disability are varied in outcome and this might reflect the relative paucity of truly subjective, direct work, which is absent from larger scale studies. Several studies, however, appear to suggest that people with a learning disability have the same patterns of stable and high subjective wellbeing as other

groups (Lucas-Carrasco & Salvador-Carulia 2012; McGillivray et al 2009; Hensel et al 2002 Verri et al 1999).

McGillivray et al (2009) recruited 114 Australian subjects, 82 of whom were reported to have a mild learning disability and 32 a moderate learning disability. These were recruited from a variety of agencies and settings supporting people with a learning disability. This study specifically excluded people with an autism diagnosis. The majority of the sample lived with their parents or siblings and a small number (4%) lived independently. The Personal Wellbeing Index, a quantitative tool designed to measure subjective wellbeing, which will be discussed in depth in section 3.9.3, was used to gather data directly from all the participants. The purpose of this paper was to introduce this as a reliable and valid tool for the measurement of subjective wellbeing of people with a mild or moderate learning disability.

McGillivray's study was limited to individuals who were relatively dependent and who might, therefore, be expected to have more significant levels of learning disability. The authors also noted that they took the decision to remove from the data any respondents with skewed high data sets, which they acknowledged might lower the overall scores, which was a decision that the tool allowed them to make, but that assumed that especially high scores were not valid. They also highlighted that subtle differences that were made between 'satisfaction' and 'happiness' in the wording of the scales for people

with and without a learning disability could have an impact on scores. Overall, the participants in this study produced very similar results to studies involving people with no identified learning disability with relatively high levels of subjective wellbeing that seemed to be unaffected by factors such as age or gender.

Hensel and colleagues used the subjective scales of the COMQOL-15 (prior to the development of the PWI-ID) with 31 people with a learning disability and matched controls. Whilst the level of learning disability of the subject group was not specified, they were recruited from day centres and group homes. This increased the likelihood of these participants having more significant levels of learning disability that required this level of support. This study identified that, in general, participants with a learning disability showed the same high levels of subjective satisfaction (>75%) with their lives that were shown in the control group. The exception to this was in the dimension of health, where the group with a learning disability expressed lower satisfaction levels (52.5%). In objective terms, the group with a learning disability showed generally lower levels of objective wellbeing than matched controls. The exceptions to this were material wellbeing, which showed higher scores, and the productivity, community and emotional domains that showed lower scores than the controls. The authors felt that the higher material wellbeing scores reflected property rights, which did not fully reflect full autonomy and control.

One perspective is that this suggests that people with a learning disability appear to be as genuinely satisfied with their lives as other non-disabled individuals. Another perspective is that other complex factors relating to the lives of people with a learning difficulty might impact on the way they view and express their lives. A number of writers have expressed concerns that this reduces the validity of these subjective views. Hughes et al (1995) identified the tendency of people with a learning disability to report favourable quality of life conditions in the face of abject decay and poverty. Antaki (1999) also shared concerns about the ways in which subjective quality of life data was gathered from people with a learning disability. His work explored the specific style of questions used in research with people with a learning disability. This highlighted the risks linked to the researcher attempting to gather subjective quality of life data 'sensitively', potentially steering subjects towards the positive and failing to hear concerns and negatives. His study observed a tendency to try and 'look on the positive side' to ensure that the person with a learning disability had a positive experience throughout the research process. In doing this, researchers avoided asking subjects to give any further details of any negative comments that they began to make.

In general, there was evidence of worse objective circumstances (Gerber et al 2011; Howlin et al 2004) as participants' level of learning disability increased. Howlin et al (2004) followed up 68 participants

who met the criteria for autism and measured their progress in objective terms. These included areas such as employment and independence. The team concluded that objective measurements were poor for all participants, but that this was particularly the case for people with a greater degree of learning disability. A significant limitation with studies that focused on very specific measurements was that they could then fail to consider other areas that might have been important. It was unsurprising, for instance, that a greater degree of learning disability could reduce the possibility of paid employment, but this failed to consider unpaid meaningful engagement for some people, which might have been considered just as beneficial in terms of quality of life.

White and Roberson-Nay (2009) studied 20 young people with autism who did not have a learning disability and particularly looked at levels of anxiety and levels of social interaction in this group. They reported that a milder level of learning disability had the potential to lead to a greater capacity for anxiety and lower quality of life perception. In effect, they suggested that a more significant cognitive difficulty might have a protective function, allowing the individuals to have less awareness of their difficulties and, therefore, less distress. Reports such as 'Death by Indifference' (Mencap 2007) clearly highlight significant inequalities having direct and catastrophic impacts on individuals with a learning disability. Most studies in adults focus on

individuals in some kind of organised care and this is not reflective of the largest proportion of people with a learning disability, who will have less significant levels of learning disability and are likely to be living independently or with families.

Studies with individuals with autism and carers of people with a more significant learning disability or people with Asperger Syndrome

(Morisse et al 2013; Petry et al 2005) have suggested that overall quality of life might be lower than average, with lower perceptions of emotional wellbeing, social isolation and alienation being indicated.

Petry et al (2005) used qualitative interviews to explore the quality of life perceptions of people with profound and multiple disabilities through proxy views of parents and support staff. They used a semi-structured approach that used open questions to encourage participants to discuss the topics of quality of life for the individual that they supported, as well as providing some structure to ensure that all domains were given opportunity for consideration.

Morisse et al (2013) used focus groups designed to gather data about quality of life perceptions in people with a learning disability, autism and mental health problems. These perceptions were gathered on a proxy basis from 22 professionals and family members using content analysis to analyse the transcripts, with a focus on measuring frequency of mention of specific quality of life areas within transcripts and linking this with perceived importance. Morisse's study identified

that professionals most frequently raised emotional wellbeing, social inclusion and interpersonal relations whilst families focused more on social inclusion. Rights and physical wellbeing received the least attention.

It was not possible to locate any specific literature referring to quality of life and people with a borderline learning disability. Published literature in this area tended to relate to subjects who could be viewed as troubled or marginalised in areas such as psychiatric care, alcoholism and the criminal justice system (Ellem et al 2013; van Duijvenbode 2013; Vinkers 2013; Ellem et al 2012; van Duijvenbode et al 2012; Cocking and Astill 2004).

2.2.1 Summary of key points from published literature

Current larger scale studies exploring quality of life perceptions for people with autism and a learning disability predominantly used objective indicators and made use of proxy reports. In some cases (Beadle-Brown et al 2009) small adaptations were made to approach participants more directly. There were very mixed results in terms of concordance of proxy and direct reports, which suggested that it could not be assumed that proxy reporting was a reliable way of gathering data from people with a learning disability.

Studies with people who had a more significant learning disability generally reported lower objective quality of life outcomes for this

group. Current studies suggested that this was expected to increase as an individual's level of learning disability became greater.

Subjective quality of life outcomes generally reflected the positive scores (75% satisfaction) that were usually found in the general population. Whilst the literature was very limited, the possibility was raised of both positive and negative changes in self and societal perception for individuals post-diagnostically, which could theoretically have an impact on quality of life perceptions.

Based on the existing, limited literature it would be reasonable to predict that people with a mild or borderline learning disability and possible autism might have a low objective quality of life, but with a likelihood of these being higher with higher cognitive levels. It would also be reasonable to predict that subjective wellbeing could be in the same positive range as that reported for people with more significant learning disabilities and the ordinary population. The existing literature, primarily based on proxy views, does suggest that for someone with a milder learning disability and autism that some reduction in subjective measurements might occur and might be more likely to occur in areas such as social interaction, emotional wellbeing and social inclusion.

There is a relatively large body of literature exploring the ways in which people with a learning disability could be engaged in research, and this was clearly of value in planning and development of the methodology.

This literature is appraised and described throughout chapter four, with

the learning from this literature being integrated with method choices and development. There is a paucity of literature describing the ways in which people with autism could be engaged in research with one guidance document, which gives recommendations incorporating a range of communication challenges (Nind 2008), which will be further discussed in chapter four.

2.3 Unpublished contextual literature

The limitations in the literature, relating to this subject group, meant that a more flexible approach had to be taken in order to gain some contextual knowledge for the study question. This involved considering clinical routes to knowledge and exploring the unpublished or grey literature around this study group. The sources for this literature were centres of excellence for autism and also quality of life, which in this case included Research Autism (Bristol), Sheffield Hallam University, The Lorna Wing Centre, The Autism Research Centre at Cambridge, The National Autistic Society and Deakin University, Australia. The results of these approaches were regular meetings with Research Autism and with a National Autistic Society research group.

These links then led to the opportunity to present this researcher's study at national and international conferences (Meeting of Minds 2013, National Autistic Society Professionals Conference 2013 and European Autism Congress 2013), which allowed discussion with both

clinicians and researchers who had knowledge and experience of supporting the individuals in the study group.

Another approach was to enter into direct correspondence with experts in the field of autism, borderline learning disability and quality of life.

This resulted in advice and support that was key to the development of methodology (Nylander 2013, Cummins 2012), opportunities to access unpublished works and also invitations to peer review relevant articles.

A significant element of contextual knowledge was the tacit and experiential knowledge gained from direct clinical experience with this participant group and learning from local colleagues and other diagnostic services also involved with providing direct clinical care.

This knowledge and experience was key at all stages of the study and was gained both by direct experience of working as a diagnostician with people with a mild or borderline learning disability and also through supervision, peer discussion and presentation and feedback within the local and neighbouring diagnostic services.

Direct contact with centres of excellence resulted in a number of concrete areas of knowledge acquisition. Permission to view and make use of an as yet unpublished thesis was one of these gains. In the case of Daves (2011), she had carried out a phenomenological exploration into the lived experience of autism. This had involved working with seven co-researchers, who had autism and no learning

disability, and had completed a semi-structured interview exploring their day-to-day perceptions of the lived experience of autism.

Qureshi (2012) in an unpublished thesis explored a tool designed to measure the utility of diagnosis for the parents of 120 children who had a diagnosis of autism. She reported parents expressing a sense of relief, explanation and empowerment in relation to a positive diagnosis.

Thematic analysis identified a number of themes. These were divided across the diagnostic process. Pre-diagnostically there were themes of 'not fitting in' and 'difference' as well as 'confusion' and 'depression'. There was a theme related to a 'sense of relief and reassurance' as well as 'sadness and regret', 'self-understanding and empowerment' associated with the diagnosis. Other themes post-diagnostically were a sense of anger, injustice and rejection and misunderstanding from others. Other objective areas were identified, such as accessibility of specialist services, employment and day services and also the need for access to counselling and psychological therapies. This study was small in size and there was limited information about recruitment strategies within the thesis. It did, however, highlight the same potential for positive and negative changes to perceptions post-diagnostically that were highlighted in the published literature (Qureshi 2012, Punshon et al 2009; James et al 2006).

A further aspect of evaluation of the grey literature was consideration of clinical knowledge and tacit experience gained from the local diagnostic service and other services. Feedback from outcome questionnaires and verbal feedback locally and elsewhere from individuals going through the diagnostic process described positive experiences such as relief and self-understanding. There was also potential for individuals to feel confused and disappointed if no concrete changes occurred in their lives as well as negative feelings associated with a diagnosis of a life-long disability, and in some cases disappointment in relation to a 'not autistic' diagnosis.

More specific reflections from diagnosticians working with individuals with a mild or borderline learning disability were that often these individuals came to the service at a time of crisis, such as court appearance or parenting issues, with the primary hope that a diagnosis would be of assistance. The sense was that they appeared less likely to communicate changes to their overall wellbeing and more focused on specific issues. Their level of life satisfaction might, therefore, have been related to the impact of the diagnostic process on that particular issue. Clinical discussion with diagnosticians had suggested that objective factors, such as employment, benefits and signposting to increased support, were the most likely changes that could be facilitated within the local diagnostic process.

Sharing of this research at national and international conferences gained some helpful learning in both the clinical and research interest in this specific subject group. Clinical colleagues in the fields of psychology and psychiatry in both the United Kingdom and Sweden confirmed that this group of individuals represented a considerable proportion of their clinical caseloads (Nylander 2013). Inclusion of this study in the oral presentation programme for the 'Quality of life' section of the European Congress for Autism (September 2013) indicated the scientific value of gaining a better understanding of this group.

Another important area of discussion with centres of excellence and clinical and research colleagues concerned the most appropriate tools to gather quality of life perceptions. In general, available tools focused on outcomes and primarily objective measures rather than individual perceptions. Discussion with Deakin University (Cummins 2012) and also Research Autism and the Lorna Wing Centre helped to identify published quality of life tools that were currently being considered for as yet unpublished work with people with Asperger Syndrome.

2.3.1 Summary of key points from unpublished literature

In spite of a limited presence in the literature, the quality of life perceptions of people with a mild or borderline learning disability and possible autism were of clinical and research interest and this was a group that appeared to have clear clinical needs and presence in

clinical practice. It also appeared more likely that a local diagnostic process would impact on objective quality of life indicators in this group than on subjective quality of life indicators. Unpublished contextual literature also highlighted the importance of considering negative as well as positive changes for people following the diagnostic process. It also identified the importance of having a method that supported the gathering of data that reflected emotional perceptions and explored areas such as marginalisation, stigma and loneliness for this participant group.

Chapter Three: Theoretical concepts of quality of life in people with a mild or borderline learning disability and possible autism

3.1 Introduction

This chapter sets out to describe concepts that underpin quality of life in this subject group and explore the history of quality of life research and practice in the field of learning disability and autism. This will provide the justification for the methodological choices made in this study and this chapter will go on to focus on the specific tools selected for this study with an exploration of the rationale for selection.

Quality of life has been described as the 'slipperiest creature in the human zoo' (Compton 1997 p 120) and this phrase captures the challenge of understanding and explaining a complex but frequently articulated concept. Exploring the literature highlighted quality of life as an exciting concept within learning disability generally, but one which was limited in its evidence of direct engagement of people with a learning disability and highly limited in relation to the participants in this researcher's study group.

In clinical practice, a frequently, informally articulated aim is to improve quality of life for individuals receiving care. National statutory documents guiding health-based services frequently describe aspirations relating to enhancing quality of life as an overarching

theme (Department of Health 2010a; Department of Health 2010b; Department of Health 2001).

3.2 History of quality of life concept in learning disability literature

Cummins (1996), in his review of quality of life literature, focusing on people with a learning disability, described the early understanding of quality of life as a unidimensional means of conceptualising failings in the care of people with a learning disability in institutionalised living (Verdugo et al 2009). This meant that there was a desire to improve the quality of life for people with a learning disability, which was perceived as poor overall, without any particular exploration of what this meant in more precise terms. This focus prevailed with the intense paradigm shift of institutionalised care to community living for people with a learning disability in the 1980s and 1990s. There was then a gradual progression to quality of life being viewed as a complex and useful concept with multiple domains, which might differ from and influence each other (Cummins and Lau 2003).

At the same time, others saw challenges in the use of quality of life as a measurement arguing that quality of life was a term of little value in the study of life for people with a learning disability (Wolfensburger 1995). The idea that there was any value at all in gathering subjective quality of life data from people with a learning disability was questioned. At the heart of the debate in the literature lay the issue of

meaningful communication. The question raised was whether researchers were truly able to capture and genuinely understand the subjective views of an individual who might have significant challenges in the area of verbal understanding and expression. Wolfensburger (1995) argued that some people with learning disabilities were unable to assess subjectively and, therefore, their subjective quality of life was not measurable. Becker (1963) suggested that behaviour and views could be shaped by the expectations of others who might be supporting them. Wolfensburger (1995) concurred with the idea that people's behaviour was 'affected profoundly by the role expectations placed upon them'. These theories clearly gave rise to the possibility that people with a learning disability might be limited in their perceptions of self-governance by the discourse of those supporting them. Bourdieu (Maton 2008) described the complex concept of 'habitas' in which practice and structure impacted on individuals' agency in a given situation, and Williams (1973) described the idea of hegemony which allowed the power and privilege of one group to appear natural and reasonable to the subjugated group.

These views created the theoretical possibility of people with a learning disability understanding themselves as satisfied when they were in extreme states of deprivation or seeing the need for others to speak for them as natural and unquestionable. Hughes et al (1995) emphasised the importance of combining subjective and objective

measurements of quality of life for this group to ensure that these wider issues were fully understood.

Cummins (2005), however, countered this with the view that the primary issue was about supporting people with a learning disability to communicate their quality of life perceptions, rather than challenge their capacity to assess. This view suggested that energy should be focused on better interpretation of the communications of people with a learning disability, with Tetzchner and Jensen (1999) arguing that the most ethical view was to take the individual seriously as an authentic communicator of his/her own perspective, no matter what his/her limitations. This emphasised that the responsibility lay with the non-learning disabled researcher to make the effort to understand any communicative attempts. The non-learning disabled researcher then needed to make sense of these perceptions, and attribute them some value.

Whilst this view is put forward passionately, the existing literature suggests a different reality, with the predominance of objective measurements in larger scale studies into quality of life with people with a dual diagnosis of autism and a learning disability (Endermann 2013; Beadle-Brown et al 2009; Alvarez and Crabtree 2008; Gerber et al 2008). These studies have made the methodological decision to manage the communication challenges of the study group by avoiding direct engagement and gaining proxy views from carers or family

members. This results in data that may not reflect the perceptions of the individuals themselves, with current studies varying in their assessment of concurrence in proxy and individual quality of life perceptions (Sheldrick et al 2012; Schwartz and Rabinovitz 2003; Mcvilly et al 2000).

3.3 Current understanding of the term quality of life in learning disability literature

The complex and at times controversial nature of the concept has meant that it has had varied interpretations in the literature. Hughes et al (1995) identified 44 different definitions of quality of life in the learning disability literature. In spite of the variations, there are currently some key areas of agreement (Kober 2010) in the literature relating to people with a learning disability. Firstly, that quality of life is viewed as a global, overarching concept, not a unidimensional one that can only be applied to a narrow area of human functioning (Brown et al 2009). This indicates an acceptance of a multidimensional model, which includes a number of dimensions of quality of life (also sometimes referred to as domains). Secondly, that quality of life is a fundamentally subjective concept in nature (Cummins 2005a) with Claes et al (2010) also arguing that, in the field of learning disability, it has moved from being an abstract concept to a measurable and socially valid construct.

There are three key areas in which the term quality of life is used in the literature: economics, where satisfaction and happiness are more closely linked to income; medicine, which focuses heavily on health and use of treatments and, thirdly, social sciences which view quality of life as an overarching concept (Cummins et al 2010). The focus in relation to learning disability is in this final area. In his 2006 paper, Cummins presents an empirical and theoretical argument for seven dimensions of quality of life, with international consensus of eight core dimensions (Keith 2001). Kober's appraisal of the learning disability literature (2010) identifies (in order of frequency of mention): interpersonal relations, social inclusion, personal development, physical wellbeing, self-determination, material wellbeing, emotional wellbeing, rights, family, recreation and leisure and safety and security. These domains can then be further subdivided into the areas of human functioning that can be measured and these subdivisions are described as quality of life indicators. A further demarcation of these indicators is that they can be described as objective or subjective in nature.

3.4 Objective indicators of quality of life

Given the inherent subjectivity of quality of life perceptions, it may seem contradictory to use the term objective to describe a quality of life measurement. These, however, have predominance in larger scale quality of life studies in learning disability literature and their use raises issues that warrant clarification and discussion.

Objective quality of life indicators are generally understood as using measurements that can be observed or viewed externally as well as described by the participants themselves. The idea that anything can be entirely objective is a controversial one and there is no doubt that the degree of objectivity in all of these indicators can be questioned. Some can be more easily verified totally externally, without consulting with the individual. Indicators such as the amount people earn, the type of house that they live in or how often they visit their medical practitioner are good examples. Objective indicators can also be more of an interaction between objective and subjective concepts, producing answers that can be verified externally but still be dependent on the subjective opinion e.g. 'How many personal possessions do you feel you have in comparison to other people?' 'How often do people from outside your home ask you for help or support?' These reflect the indicators used more frequently in Australian studies (Cummins 1996). This type of indicator is likely to be measured using some kind of Likert scale, so that any answer can be quantified.

Tools that use and score objective indicators often appear to be based on a set of assumptions such as in the COMQOL-I5 (Cummins 1997) with examples, such as, 'people who watch ten hours or more television per day will have a poorer quality of life' or 'people who are unemployed will have a poorer quality of life' underpinning some of the scoring on particular indicators. These tools then measure individuals or populations in relation to these assumptions and resulting standards. Objective indicators have been criticised for being too ethnocentric (Kober 2010) and failing to recognise that one set of standards may not be applicable to all individuals and groups.

3.5 Subjective indicators of quality of life

A subjective indicator, on the other hand, is an assessment of life satisfaction or wellbeing for an individual that cannot be viewed externally and reflects a personal evaluation. This, therefore, may be more time consuming and complex to obtain with any degree of validity from a person with a neurodevelopmental difference. At times, subjective wellbeing has been viewed as a unidimensional concept, e.g. 'What is your satisfaction with life as a whole' (Veenhoven 1991), but in many other models continues to be seen as multidimensional.

In a multidimensional model of subjective quality of life an individual is seen as having the potential for differing levels of satisfaction with quality of life across a number of domains, such as health, productivity

and social relationships, for example. Micalos (1985) describes subjective quality of life as being based on an individual's perception of the discrepancies in one of three areas: between what one has and what one needs or wants (aspiration); between what one has and what others have (social comparison) and between what one has and what one deserves (equity).

A question that seeks a subjective indicator will tend to ask for information that only that individual can give, such as: 'How satisfied are you with life as a whole/your health/your standard of living?' A proxy can give a view on what he/she thinks an individual's view might be, but that will cease to be a measurement of that individual's perspective and therefore, arguably, cease to measure that individual's perceived level of satisfaction.

3.6 Relationship between subjective and objective indicators

It might be anticipated that objective indicators of quality of life will be good predictors of subjective wellbeing and, therefore, reduce the need for gathering subjective information. However, there is strong evidence in the literature to suggest that the opposite is true, with a very poor positive correlation between the two (Cummins 2005; Claes et al 2010). Zapft (1984) presented a helpful model of potential patterns of subjective and objective wellbeing in individuals. Rapley (2006) provided some application of Zapft's (1984) paper to current

thinking and he described a person with positive objective and subjective indicators as being in a state of 'wellbeing'. This model suggested that poor objective indicators combined with positive subjective indicators reflected an individual 'adapting' to his/her difficult situation. Positive objective indicators and poor subjective indicators reflected a 'dissonant' state and poor responses across both indicated a perceived 'deprived' state. Zapft suggested that the majority of people would be in a state of wellbeing or adaptation and that these would be the states in which people were able to function and develop. The dissonant and deprived states were more likely to have a disruptive impact in daily functioning.

The potential for these differing states reflect the 'surface' nature of objective indicators, where an outward appearance might not reflect an individual's perceived reality. A person, for example, might show on an objective indicator that he/she has interactions of a number of types every day and this will result in a higher objective quality of life rating around the domain of social interaction. An expectation could be that the subjective quality of life for this person in relation to the domain of social interaction would be good. Others, in a proxy role, may be able to verify that the individual has multiple and varied social interaction, which would seem to confirm that expectation.

However, the individual, when asked how satisfied he/she is with his/her interactions, might indicate that he/she has not enjoyed them

and this will result in a lower subjective quality of life score for social interaction. Equally, someone may only rarely have a brief social interaction and this can result in a low objective quality of life score, which others, who know him/her well, can verify. However, that person might perceive that those rare interactions are deeply satisfying and that time spent alone is highly desired, in which case his/her subjective social interaction satisfaction score will be high. It is well documented that beyond the extremes of, for example, wealth or abject poverty, that individuals have a remarkable stability in the subjective satisfaction levels in key domains and life in general (Cummins et al 2010). Individuals generally report a level of 70-80% satisfaction with life in spite of a number of life circumstances that would be assumed to impact upon it.

One theory put forward by Cummins et al (2010) and described by Schalock et al (2010) to explain this apparent paradox is that of homeostatic theory. This involves various mechanisms such as disposition, adaptation, selective attention and cognitive restructuring. It suggests a basic human survival mechanism which allows aspects of specific dimensions, such as money or close relationships, to act as shields against adversity allowing people to rate their perceptions of their lives more highly at times when other aspects appear more negative. So, for example, if a person's health were compromised he/she might feel that this has given him/her an opportunity to develop

closer relationships or different skills. Therefore, the dimensions of social interaction and productivity would gain a higher rating than it would have done before, resulting in overall stability. This stability may be affected by severe adverse events or stress, which cause the mechanism to break down, which Schalock suggests may be a factor in depressive illness (Schalock 2010).

3.7 Subjective wellbeing and happiness

It is necessary to give some context to the theoretical overlaps of the concepts of subjective wellbeing and satisfaction. In quality of life tools designed for people with a learning disability, words like 'happy' and 'happiness' are used in place of the words satisfaction or wellbeing. This is done to recognise the complexity of vocabulary and pragmatically to ensure that those for whom it is designed can understand the tool. This decision brings with it some theoretical challenges. Whilst subjective wellbeing is felt to be a relatively stable concept, with in-built mechanisms to achieve this, happiness as a construct is viewed as more prone to change within a situation or a moment (Rapley 2006)

In qualitative terms, happiness as a term has the potential to represent an emotional extreme, whereas satisfaction suggests a level at which an individual can function comfortably. Inevitably the two terms are complex to separate and in the Personal Wellbeing Index (PWI-ID)

(Cummins and Lau 2005) the term 'happiness' is used with simplicity of language being a greater driver than theoretical correctness.

Cummins et al (2010) note the theoretical challenge that the use of this term brings but cites the study of McGillivray et al (2009) in which no substantial difference is noted between the scores of individuals tested with the PWI-ID, using the word 'happiness' and those without a learning disability who were tested using the PWI-A (Cummins and Lau 2005) using the word 'satisfaction'.

3.8 Subjective and objective quality of life for the population of people who do not have a learning disability

Subjective wellbeing is generally viewed as a fairly stable concept but there is evidence to suggest that within populations there can be variance within dimensions and that it can change across time (Phillips 2006). Statistics for the United Kingdom identify the majority of the population identifying themselves as having satisfaction levels in the range of 70-80% (Office for National Statistics 2013). A small overall increase in satisfaction was noted for 2012/2013. Some factors such as lower satisfaction for those who are unemployed, not being in a long-term relationship and some age groups being consistently lower appear to occur year on year.

Objective indicators are far more likely to change and vary at an individual level. Cummins et al in their 1994 validity study explored the use of COMQOL-I5 with a university population, which included both

staff and students. A good example of these predictable variations was a clearly lower level of objective material wellbeing, which included wages, in students when compared with university staff.

COMQOL-15 has been used in studies outside the field of learning disability and appraisal of these has suggested that whilst objective quality of life scores are more subject to change the majority of dimensions score above 50% (Jau-Hong et al 2009; Butler and Ciarrochi 2007). Studies, then, tend to identify dimensions, which are lower or higher for specific populations. Material wellbeing was found to be lower in a study of the elderly, who reported high levels of community participation (Butler and Ciarrochi 2007). This study was carried out with a group of 187 elderly participants recruited from both community nursing caseloads and community groups in Australia using a mix of postal and direct contact. This different approach resulted in a much lower level of response from those receiving nursing care than those living in the community, which resulted in a less effective representation of the perceptions of those with more complex needs.

Material wellbeing and health were found to be lower in a physically disabled population in Taiwan (Jau-Hong et al 2009). This study surveyed 157 adolescents with a physical disability through contact with specialist schools in the country and this was compared with matched students from mainstream schools. Material wellbeing was

found to be lower in a population of people with brain injury in Hong Kong (Man et al 2004); it was, however, unclear from the study whether these schools were exclusively residential or whether the participants came from home environments, which could have been a key factor in material wellbeing. In his Australian study of university staff and students, Cummins (1994) sampled 243 students and 63 staff on the university campus, with a predominance of females in the sample. He found that staff generally had a higher material wellbeing, poorer health and safety and better emotional wellbeing/future security. Whilst this population was selected as one that had not been identified as having any specific disability it was not considered to be representative of an average individual, as factors such as employment with or attendance at university increased the likelihood of variables such as higher intelligence levels.

3.9 Quality of life as a measurement in this present study

This leads towards the definition and model of quality of life used as the basis for this present study. Schalock (2000) presents the simple definition of quality of life as a concept that reflects an individual's desired conditions of living, which are then related to the core dimensions of that individual's life. This definition is helpful in that the consideration of a person's desired conditions emphasises that the very personal and subjective nature of quality of life does not restrict the multidimensional nature of the concept but allows some

consideration of more concrete conditions of living. This present study focused entirely on individual rather than proxy report whilst acknowledging the concerns and limitations that might exist for subjective approaches alone. For this reason the approach in this researcher's study combined both objective and subjective indicators with the intention of gaining a better depth of understanding of participants' quality of life.

As has previously been discussed, the diagnostic process is not one intervention and involves a range of processes which can vary slightly in nature depending on individual needs. The group of individuals coming to the diagnostic process were heterogeneous, united by degrees of challenge in cognition, social communication and flexibility of thinking. As a result, there was potential for a wide range of perceptions across multiple dimensions and it was reasonable to consider that change could occur across any of those dimensions through the process.

A significant advantage of using quality of life as a measurement was its multidimensional nature, which permitted exploration of a wide range of everyday life experiences and considered the possibility of change over a broad range of areas. The potential to explore objective and subjective indicators gave both structure and depth to the exploration. Recognition of individual subjectivity in the concept ensured that the enquiry maintained a focus on the perceptions of the

participant. Approaching the enquiry with a measurement that incorporated subjective and objective indicators recognised that perceptions of an individual's life included concrete factors such as being employed, living in specific accommodation or the number of visits to a health professional, as well as more abstract concepts, such as satisfaction with those concrete factors.

3.9.1 Measuring quality of life in people with a learning disability

In the field of learning disability, quality of life has been viewed as a macro-concept that can be measured for service evaluation, to gain a broader picture of the quality of life of a wider population (Kober 2010) or for a micro-level individual evaluation. Sometimes study has focused on particular dimensions such as health (Endermann 2013) or across multiple domains (Kamio et al 2013), with Townsend-White et al (2012) describing quality of life as a 'key individual outcome domain', emphasising the importance of looking at effective ways to measure it.

As a result there has been interest in the literature in developing tools that have the potential to gather data and provide some measurement of quality of life and potential changes in quality of life for people with a learning disability. This section will describe some of these tools and in doing so justify the use of the tools selected for this study, as well as acknowledge their limitations.

3.9.2 Rationale for selection of quantitative quality of life tools

It is recognised that the lives of people with a learning disability, regardless of issues such as human rights and economy, differ significantly from those who are not learning disabled (Cummins 2005). It is, therefore, reasonable to consider more specific approaches to measuring perceptions of the life experiences of people with a learning disability. A study by Townsend-White et al (2012) systematically reviewed the quality of life measurement tools referred to in the literature, but also pointed to a significant lack of information about the actual value of the tools. They focused on the population of individuals with a learning disability and challenging behaviour and included papers published between 1980 and 2008, which reflected a period of considerable activity in this field. They initially identified 24 instruments, considered to measure the quality of life of people with a learning disability. They then considered which of these matched four criteria: included the eight established quality of life domains; possible to administer in two hours or less; having available psychometric data and used internationally (translated into a language other than English).

Six tools were identified through this process that were then subjected to a more detailed evaluation using a further four criteria: having both objective and subjective domains measured to gain a whole construct;

having acceptable psychometric properties and being easy to score; having a pre-test to reduce risk of acquiescence of client group and being centred on gaining views from people with a learning disability and promoting dialogue between researcher and participant.

Two tools in particular ranked well in relation to these criteria. QOL-Q (Schalock and Keith 1993) was widely used in literature and its main weaknesses were that it did not measure subjective and objective domains separately and did not have any kind of acquiescence pre-test. COMQOL-I5 (Cummins 2007) had acceptable psychometric properties and measured objective and subjective indicators separately and had a pre-test which then allowed adaptation of scales used to support people with more complex communication difficulties to respond. In addition to this, it had validated versions for use with individuals who did not have a learning disability, which then supported comparison of data with other studies involving people without learning disabilities.

Cummins and his team had identified some challenges in aspects of scoring of the subjective element of the COMQOL-I5, which led to the development of a new tool, the Personal Wellbeing Index, which specifically focused on subjective wellbeing. Townsend's review and discussion with the author of COMQOL-I5 (Cummins 2012) personal correspondence) identified that a suitable combination of tools for this study was the COMQOL-I5 (Cummins 1997) to measure objective

quality of life and the Personal Wellbeing Index (Cummins and Lau 2005) to measure subjective perceptions of wellbeing. The two tools together were both psychometrically tested, would gather separate objective and subjective data across an accepted range of domains and provided data that could be considered in relation to other studies using this tool with people both with and without learning disabilities.

3.9.3 Comprehensive Quality of Life Scale – Intellectual/cognitive disability (Cummins 1997) (COMQOL-I5) and Personal Wellbeing Index (PWI-ID) (Cummins and Lau 2005)

A significant driver behind the development of this particular scale was the absence of a tool, which could be used with a wide range of populations, allowing comparisons of quality of life perceptions and related discussions. Historically, these tools had been developed for very specific populations (Cummins 1997) and could not be used, for example, in both children and adults or across learning and non-learning disabled populations. The COMQOL-I5 was designed to have adaptations within the same tool framework allowing for comparable scoring systems across different groups. COMQOL-I5 had also been validated using generally accepted indicators (Schalock 2010).

Cummins (2002) described a key point in the understanding of this tool when a careful evaluation of its strengths and limitations needed to take place and some technical challenges with the subjective element

of the tool were identified. Firstly, related to the length of the measurement scales used, the tool originally used only five and seven-point scales. Cummins and Gullone (2000) described the inadequacy of these scales for the gathering of quality of life data. He acknowledged that shorter scales were felt to be more reliable, but with a concept such as quality of life a small change in perception could be critical and shorter scales were not sensitive enough to pick this up. This suggested that for individuals with milder levels of learning disability the more sensitive 11-point scale might be the most useful way to gather data. He acknowledged, however, that for a person with a more significant level of learning disability a shorter scale might be the only one he/she could accurately understand and use. These considerations led Cummins and his team to develop the Personal Wellbeing Index (PWI-ID) to gather subjective indicators (Cummins and Lau 2005).

The PWI-ID used the same principles as the COMQOL-I5 tool but was solely focused on gathering subjective data. This tool used the same acquiescence and pre-test as the COMQOL-I5 with a further test to identify which of the available Likert scales (three-point, five-point or 11-point) would be most appropriate for the participant with a calculation then being made to adjust the scores so that they were comparable to each other between participants who had completed different scales.

PWI-ID incorporated the same seven dimensions of quality of life with the addition of measurement of the participants' construct of 'life as a whole'. This concept was described by Cummins et al (2010 p 37) as being collectively representative of the seven dimensions. McGillivray et al (2009) argued that the seven domains of the scale formed a single stable factor that predicted over 50% of the variance in life as a whole. The measurement of 'life as a whole' had some support and some critique as a global concept in the literature. Some authors in the 1990s (Lyons 2010) argued that this was a valid measurement of individual quality of life in its own right, citing that studies had shown remarkable consistency and reliability of a measurement of life as a whole. This had been countered with criticism of the lack of a clearly explained relationship between the global scores and the specific domain scores. The populations that were used in these studies were felt to be limited and excluded those not in formal employment and the final concern was that the global 'life as a whole' measurement lacked the potential to explore differences in domains and, therefore, lacked value in actual application to people's lives. For this reason in this study, whilst subjective 'life as a whole' will be measured and patterns in this domain reported and discussed, the broad range of domains scores and their relationship to overall scores will have a focus.

There were some adaptations to the development of the PWI-ID in terms of descriptive labels for dimensions, which meant slight

differences between the PWI-ID and the COMQOL-I5. COMQOL-I5 had a domain labelled as emotional wellbeing, which incorporated future security, control and anxiety. PWI-ID described this domain as future security and used the domain of health to cover both physical and emotional wellbeing. The domain of intimacy in the COMQOL-I5 was described as social interaction in the PWI-ID. The potential limitations relating to these differences will be discussed later in section 6.11 of this thesis.

The ways in which the details of quality of life indicators map across into COMQOL-I5 are described in Table 3.1.

Table 3.1: Relationship between indicators and quality of life dimensions

Schalock's dimensions	Cummins' dimensions	Indicators within these dimensions
Interpersonal relationships	Personal relationships	Intimacy, affection, family, interaction, friendships, support
Emotional and physical wellbeing	Health	Health care, safety, spirituality, happiness, freedom from stress, self-concept, contentment
Material wellbeing	Standard of living	Ownership, financial, security, shelter, socio-economic status, possessions, food
Personal development	Life achievement	Education, skills, fulfilment, advancement, purposeful activity, personal competence
Social inclusion	Community connectedness	Acceptance, status, supports, work, community activities, roles, volunteering, residential environment
Rights	Personal safety	Privacy, civic responsibility, law, due process
Self-determination	Future security	Autonomy, choice, personal control, self-direction, personal goals

3.10 Gathering qualitative quality of life data from people with a learning disability and autism

This section will describe the thinking behind the development of the qualitative interview component in this study. The quantitative tools previously described naturally isolate dimensions, considering and scoring them on an individual basis. Homeostatic theory (Cummins et al 2010) suggests a dynamic interaction between dimensions which allows people to perceive one area more positively in relation to another area that may be perceived less positively. Tacit knowledge from clinical experience also suggests that individuals do not tend to talk about their lives in a compartmentalised way. It would be reasonable to consider that perceptions of future security, emotional wellbeing and safety, for instance, may interrelate for participants. Exploration of perceived interaction of dimensions was, therefore, limited using objective tools, but the design and development of a qualitative interview was planned to alleviate this limitation.

Quantitative questionnaires were narrow in the nature of data recording and so did not allow the participant to expand on or explain individual meaning. It was reasonable to consider that an individual's perception of what satisfying social communication actually was might perhaps be different for a person with specific challenges in that area. The use of a qualitative interview provided an opportunity to explore

the participants' responses in more depth, and in relation to their everyday lives to provide some context to the quantitative data.

Whilst the structure of dimensions and indicators that made up the quantitative tools were helpful in providing a basis for data gathering, this was an area of enquiry with a limited existing research base and this study, therefore, needed to be able to capture novel and unexpected responses if they occurred. Developing a more open qualitative interview allowed this to happen and it also allowed some flexibility with indicators, which were important to an individual, but were not considered to make a significant difference to overall population studies, such as spirituality (Cummins 2002).

Chapter Four: Methodology and methods

4.1 Introduction

This section will explain the methodological position of the study and describe the methods, along with adaptations made in the developmental and pilot stages. This section will include references to relevant literature that was identified to develop these methods and describe the ways in which the researcher's role as a clinician, for some participants, formed a part of method development and delivery.

4.2 Methodological position

There were a number of factors that contributed to the methodological position underpinning this study. These factors related to the study question and the limitations in existing research in relation to the group being studied; the complex nature of the subject group; gathering quality of life data from subject group and the researcher's own position in relation to the subject group.

4.2.1 Relationship between nature of enquiry and methodology

This area of enquiry does not have extensive literature or well-established theory. Existing studies had made some suggestions about the nature of quality of life for people with a learning disability, but these suggestions were not consistent and were not particularly clear on the way a milder learning disability or an additional diagnosis

of autism might impact on quality of life perceptions. For this reason this study required an inductive, exploratory approach. The intention was to describe the range of quality of life perceptions that participants might experience and also consider whether any of those perceptions were subject to changes of note during the diagnostic process.

4.2.2 Relationship between participant group and methodology

The participant group were heterogeneous individuals who were united by cognitive and social interaction challenges to a degree that resulted in their referral to an autism diagnostic process. The complex nature and lack of studies in relation to this group required a flexible, reflexive approach with a capacity to adapt to individual and cognitive differences. In particular, data gathering needed to acknowledge the relatively subtle communication challenges of this group and related difficulties in gathering more abstract verbal data (Nind 2008).

This group had specific challenges identified by Booth and Booth (1996) which related to their ability to express themselves (both physically and emotionally); difficulties with open question styles; problems with abstract thinking; trust; difficulties around understanding and expression and understanding of time concepts. This group were also likely to be relatively independent due to their high level of cognitive level compared to the wider population of people with a learning disability. Methods employed in other studies for people with a

more significant learning disability (via carers) or people with high functioning autism (via internet, self-referral as in Jones et al 2001) were less likely to be successful.

4.2.3 Influence of ethnographic approach on methodology

Exploring quality of life perceptions for people with a mild or borderline learning disability required consideration of the ways in which participants could be supported to provide data that most effectively expressed those perceptions. As this group were heterogeneous in their presentation but were more likely to be experiencing some social communication difficulties it was reasonable to consider that finding a context and approach that facilitated this might be complex.

A number of studies have highlighted the value of making use of an ethnographic approach in exploring the lives of adults and children with autism (Ochs et al 2004; Savage 2000; Solomon et al 2008).

Ochs et al (2004) set out to take an anthropological perspective on autism and viewed people with autism as key participating members of society and communities, identifying a number of the social and communication challenges that having an Autism Spectrum Disorder might present for an individual attempting to participate in society and in communities. They focused on 16 children between the ages of eight and 12 who had a diagnosis of Asperger Syndrome and analysed extensive periods of video and audio recording of the

children in a range of activities both at home and at school. Their focus was on understanding the ways in which those children's social functioning impacted on their social cultural position.

Solomon et al (2008) reviewed a number of studies including several led by Ochs that took place using the group of children and their families described in Ochs' 2004 study. These looked at child directed communication, children's 'everyday talk' and the ways in which children with autism were socialised. Other studies explored areas such as theory of mind, bilingualism, accountability and morality, politeness and narrative. A key component in all these studies behind the choice to use ethnographic approaches was the sense that people with autism should be understood as part of society and in relation to it, rather than separated from it. Solomon suggested that the use of methods that aimed to allow the researcher to gain a naturalistic view into a range of daily life experiences allowed researchers a more nuanced view and reduced the risk of stereotypical assumptions.

Savage (2000) presented a nursing perspective on the use of ethnography in health care settings. This article highlighted the value of the context that ethnographic approaches could bring to data being gathered in a study. In particular Savage described an approach that captured a wide range of evidence in a clinical setting. Savage used an intensive approach which video recorded participants over lengthy periods, in both their home and nursery environments. Potentially, this

was a very effective way to gather data about a group of individuals with complex needs and to understand their lives and functioning. However, it was time and analysis intense with over 300 hours of video to analyse. Also, whilst the researcher had used video to try and minimise direct intrusion into people's lives the presence of a camera might still have had an impact and fail to gather naturalistic data.

One possible decision for this researcher, in this present study, could have been to approach the study of quality of life in this participant group with a greater focus on actively observing the group, for an extended period, in a naturalistic environment to faithfully gain the perspectives of the participants (Green and Thorogood 2014).

However, the social interaction difficulties that this group were known to experience could have made the presence of an observer in their daily lives intense and ethically challenging. For many of the participants, cognitive difficulties and lack of support at home might have limited the practicality of using video as a technique. The lack of existing research in the specific area of enquiry could have made identifying specific case study work more challenging and completion of lengthy observations and analysis on a larger number of participants was considered to exceed the realistic time frame of doctoral study.

Whilst this present study was not formally ethnographic, elements of the methodology were developed using techniques and approaches, which formed a part of ethnographic methods. Spradley's (1979)

description of ethnographic question styles inspired an approach to developing a topic guide for the qualitative interview that set out to assist participants to 'paint a picture' of their world (see Appendix I). As participants described their perceptions, probe questions were used to gain a richer picture. Ethnographic theory also assisted in thinking about the essential role of gatekeepers in accessing the participants in this study, reflecting the challenges in access to the participants (Hammersley and Atkinson 2007) and informed thinking about the challenges and impacts of the researcher's relationship with the participants, their environment and impact on their daily life experiences.

The initial motivation for this study was driven by questions raised in clinical practice. This resulted in the combined role of researcher, Speech and Language Therapist and Autism Diagnostic Clinician. These concurring roles and the everyday experience of working as a clinician with people who had a degree of learning disability and possible autism influenced the ontological and epistemological position driving the study. At the beginning of the research process, reflective notes indicated a greater focus on the word 'outcome' in relation to this enquiry. A professional doctorate is likely to contain clinically based enquiry and there is a requirement to contribute to professional knowledge and practice. In the early stages of this study, the focus of enquiry was on understanding the perceptions of individuals

experiencing the intervention of a diagnostic process and considering whether the intervention had any positive or negative impact on individuals referred to the clinical service. The study developed to have a greater focus on an in-depth understanding of quality of life perceptions.

A further ontological reflection was the impact on research methodology of the predominant paradigms within the clinical field of autism. The role of an autism diagnostician involved being firmly grounded in a world where neurodevelopmental differences in individuals were seen as an external reality, which could be measured and described against agreed criteria. The role of a diagnostician, however, also involved viewing people within the social model of disability where complex, contextual factors within the individuals, their immediate environment and within the culture in which they operated might also have an influence on their behaviour and perspectives. A diagnostic perspective was that a particular neurodevelopmental difference might provide a theoretical explanation for a difference in behaviour or perceptions, within the context of the complexity of the individuals' own life experience.

This clinical perspective maps well onto a realist approach to research design, which recognises the phenomenon as an external reality that might not be possible to fully understand. Importantly, a realist approach recognises the complex and multiple layers of the real world,

allowing individuals to be understood in context and takes note of the perspective of participants (Robson 2002). A realist perspective is based on having a thorough knowledge and understanding of the phenomenon being explored, which allows for thoughtful consideration of explanatory theories and reasons for observations (Robson 2002). This approach is, therefore, one well suited to a researcher exploring an area of clinical interest.

The ways in which the dual role of clinician and researcher contributed to this enquiry will be presented later in the results section. At the outset, it was recognised that this could present some challenges and the justification for maintaining this joint role with some of the participants was in part a pragmatic one. In a small specialist service it was essential that the person carrying out the diagnostic intervention had a high degree of expertise in supporting people with a mild or borderline learning disability. This was also a factor both in research interest and in the skill required to engage with participants. This meant that it was not possible for the researcher to be removed from the clinical service for the participants, without potentially compromising the quality of their care or delaying their access to the service.

It was recognised that there was potential for the dual role of researcher and diagnostician to have an impact on both the participants' decisions in terms of participation and also the

perceptions they chose to share in the study. For this reason, all communications to participants were overt in clarifying that the participation decisions in the study would have no impact on the nature of the clinical service they received. It was possible for an additional, suitably experienced clinician to see a small number of participants for their diagnostic process without resulting in a delay in their appointment. The engagement and results with these participants were then considered to appraise whether there were any obvious differences for those participants who had been seen for research and diagnosis by the same person.

4.3 Mixed methods approach

At the early stages of this study the intention was to use a relatively fixed approach, which equally balanced the use of qualitative and quantitative methods. This reflected early thinking where a greater focus on measurement of change appeared to lend itself well to quantitative methodology. In terms of typology, the intention was to use mixed methods as a way of triangulating the data (Greene et al 1989), checking to see if there was corroboration between the two methods and 'completeness' gaining a richer and more comprehensive account (Bryman 2007). The qualitative and quantitative phases were, therefore, concurrent, being mixed at the data gathering stage and set up as a convergent parallel design where both types of data were gathered at the same time (Cresswell & Clarke 2011). However,

emergent elements occurred in relation to this balance as the study developed. The depth of data required in order to understand the quality of life perceptions for participants became greater, with a need for an increased focus on the qualitative element becoming apparent. Another unexpected research turn was that objective data became more of a vehicle for the gathering of subjective data, helping to provide structure and concrete information that was used as a tool for gathering subjective perceptions

4.4 Summary of methodology

A number of factors relating to the nature of the question, the joint role of researcher and professional diagnostician, the nature of the subject group and also the theoretical underpinnings of the concept of quality of life influenced the ontological roots of the methodology behind this study. The focus of the study developed over time, moving away from a study seeking outcome data to a study of an exploratory and inductive nature. The study required a mixed methods approach from an underpinning theoretical perspective and specifically for triangulation and providing completeness of data. The ontological position was best framed as realism and the complexities of engagement with this subject group meant that approaches used in ethnographic methodologies were appropriate

4.5 Methods overview

This study had three key phases:

Table 4.1: Method phases in the study

Phase of study	Description	Method
Phase one	Developmental	Literature review and focus group of five individuals leading to development of final methods
Phase two	Pilot Study	Pilot of methods (n = 2)
Phase three	Research	Use of methods (n = 20)

The methods and the processes involved in these from a participant perspective are described in a method flow diagram (see Appendix B) and Table 4.1 presents the key phases of the study and the overall method involved.

4.6 Ethical approval

Prior to the commencement of this study approval was obtained from the local organisation providing autism diagnosis to contact and involve their patients. Ethical approval was obtained from the local Research Ethics Committee (REC), the study was approved by the University of the West of England (UWE) Ethics Committee and

gained local research and development approval (Bath Research and Development).

4.7 Phase One: the developmental phase

Phase One consisted, firstly, of a detailed review of relevant literature and the development of links with centres of excellence in the fields of autism and learning disability to extend knowledge of the unpublished literature and knowledge in the field. Secondly, two meetings were held with a focus group made up of individuals who had a mild or borderline learning disability and had completed the local autism diagnostic process. The purpose of this phase was the development of effective methods for use in the later phases of the study.

4.7.1 Contextual literature approach

The study of adults with autism was a relatively new field. The majority of available literature focused on paediatric studies, with a tendency for available studies to explore treatment approaches, aetiology and neuropsychological characteristics of autism. The approach to literature searching, therefore, had to be broad enough to consider studies of children as well as other related areas, such as mental health.

Quality of life was used broadly in the literature and was sometimes identified as one component in a range of measures of interest. This

meant a flexible approach to the consideration of which literature was pertinent in search terms had to be used. Studies or papers were identified from a range of areas: quality of life or outcome measurement for adults or children with Autism Spectrum Disorder and those describing aspects of quality of life or outcome measurement for adults or children with a learning disability. Other areas explored were papers related to engagement of people with autism and a learning disability in research. This literature linked to specific approaches, such as interview, observational techniques and focus groups.

There was a very broad set of guidelines and papers specifically exploring different models and techniques of research engagement with people with a learning disability (Booth 2002; Garbutt et al 2010; Cleaver et al 2010; Boxall and Ralph 2009; Björnsdóttir and Svendsdóttir 2008; Ellem et al 2008; Nind 2008; Cameron & Murphy 2007; Barr 2007; Department of Health 2006; Brown & Thompson 1997; Booth & Booth 1996; Clare & Gudjonsson 1993), for example. When the focus was moved to specific models and techniques that could be helpful in engaging people who might have autism effectively in research, then the literature base was minimal. There was a far greater focus on the value of improving knowledge about people with autism than exploring the best ways to engage with this group in research. There were examples of people with autism as

accomplished researchers, such as Michelle Dawson at the University of Montreal (Dawson et al 2007; Gernsbacher et al 2006). Robertson (2010) was an autistic researcher who highlighted the lack of research into everyday experiences of people on the autism spectrum. Loyd (2013) explored methods of gaining consent for research with young people with autism, with the majority having significant learning and communication challenges.

Nind (2008), in setting out research methodology advice for the Economic and Social Research Council, made recommendations focused on learning disabilities and included people with autism, but did not specifically highlight issues for people with autism. This demonstrated that a further strand to this study was going to involve taking some of the recommendations of learning disability literature and integrating clinical experience in working with people with autism and a mild or borderline learning disability to develop an effective approach.

The original nature of this enquiry meant that, in addition to database searching, contact with specialist centres, clinicians and sources of unpublished work was required. This allowed access to projects, studies and individual clinical perspectives, which had not or might never have developed to a level of formal publication. This was further facilitated through the dual role of clinician and researcher and exploiting established clinical links within academic and clinical

institutions specialising in learning disability and Autism Spectrum Disorder.

This process was dynamic throughout the study and included making new links and developing opportunities to gain further unpublished work by presentation at international conferences (Meeting of Minds, January 2013; National Autistic Society Professionals Conference, April 2013 and Autism Europe, September 2013) as well as presentation to fellow researchers at the University of the West of England (June 2014).

4.7.2 Focus group

A focus group was carried out for a number of reasons. Firstly, piloting question styles to identify approaches that were more likely to effectively gather quality of life perceptions from this group of individuals. The focus group allowed for practice, reflection and adaptation of both the question format and also critique and adaptation of personal style in areas such as pace of delivery and dominance of interaction. It was also possible to trial using visual prompts and explicitly gain feedback from the group (Robson 2009).

It also provided the opportunity to reflect on environmental and practical considerations, such as sensory factors in the room and issues for individuals in coping with the practicalities of attending the session. It allowed for practice setting up and collecting data

concurrently with supporting and interacting with the group. It also provided the opportunity to pilot a visual ranking exercise intended to explore participants' perceptions of the importance of different quality of life dimensions for them. When the focus group stage was developed there was no intention to subject any data to formal analysis. The aim was to consider whether the tools and approaches piloted had produced data that could be subjected to the analytical processes proposed for the next phase.

4.7.3 Sample selection

Participant selection for the focus group was made from referrals received in the previous year to the local diagnostic service. This was a list kept to facilitate clinical allocation of cases and it contained basic contact information, age, referrer and an indication of cognitive level. Potential participants were initially selected if they had a mild or borderline learning disability. Seventeen individuals fulfilled the sample group criteria and it was decided that if a large number of individuals then consented to participate, selection decisions would be made on the basis of having a range of characteristics in the group such as age, gender and level of learning disability to try and reflect some of the diversity that might be present in the final research sample.

4.7.4 Advantages and disadvantages of using a focus group

A focus group was judged to be an efficient way to get some very broad-based feedback about the suitability of the materials and approach planned for the research phase (Robson 2009). Kaehne and O'Connell (2010) and Gates and Waight (2007) support the view that focus groups can be an effective way of enabling people with learning disabilities to tell 'their story'. In a client group with communication issues the support of others and the reduction of pressure in a group situation may result in greater participant contribution. A considerable advantage for this group was that, compared with approaches such as questionnaires, literacy requirements were minimal and this was a group with high rates of difficulties with reading and writing (Frith and Happé 1998).

Participants with autistic traits may find group situations difficult, some individuals with autism describe fear and anxiety in situations involving new people and situations (Attwood 2001). Boyden et al (2009) highlight that a well-planned and paced group can help to dilute the anxiety and communicative pressure experienced in a one-to-one situation. In order to plan to reduce pressure, the group size was kept relatively small and facilitation was carried out directly by the researcher making use of her own skills and experience as a Speech

and Language Therapist in supporting groups of people with autism and a learning disability.

4.7.5 Engaging the participants

All potential group participants were sent an explanatory letter, using easy words and pictures (see Appendix C) asking them to contact the service if they were willing to be involved and indicating to them that they would receive a telephone contact. Clinical experience with this group had suggested that issues such as literacy and organisation could reduce response rates to a letter. It was judged to be beneficial to provide an alert to a phone call to minimise the stress for an individual with autism of an unpredictable and possibly stressful social interaction. All letters and information sent to service users were reviewed by individuals with a learning disability and autism who worked with staff at the University of the West of England and their advice and feedback informed the final letters

A phone call was then made to the participants to confirm whether they wished to be involved. The Mental Capacity Act (Department of Constitutional Affairs 2005) clearly directs that people over the age of 18 must be assumed to have capacity until otherwise demonstrated, and that factors such as a learning disability or autism would be reasonable grounds to check that the capacity that is being assumed is correct. The FACE framework (Department of Constitutional Affairs

2005) was used to assess the individual's capacity to consent for research using FACE criteria (see Appendix D). This involved establishing whether the individual was able to understand the concept of being involved with research; could weigh up and consider any possible benefits or harm that could occur from research involvement and was able to retain this information and express his/her willingness to participate or decline. If some concerns were raised during this process then a plan could be made to meet the individual face-to-face or ask the participants' permission to liaise with carers or other professionals to try to make a capacity decision.

Involving people with any degree of learning disability in research can be challenging and ethically complex, to an extent that may sometimes result in their exclusion (van Teljlingen et al 2008) with Waltz (2007) raising this as a particular case for research in the area of autism.

Ethical process suggests that if it is possible to answer a question and involve people who have capacity, this is preferable to involvement of those who do not (Department for Constitutional Affairs 2005). In this case, tacit knowledge and clinical experience with this group suggested that there were likely to be individuals who fitted the criteria who had capacity; therefore, the decision was made to exclude participants who did not have capacity.

4.7.6 Invitation and venue

The selected group participants were then sent a letter of invitation to a first group meeting, using accessible words and pictures. To accommodate the needs of a diverse group it was important to have a space where a flexible approach could be taken by the facilitator. The venue chosen was a meeting space used for focus groups by the local learning disability advocacy service. Clinical experience suggested that people with autism might find it easier to participate in groups, if they had an additional quiet space to move into, which was provided in this venue.

The room was carpeted and uncluttered with minimal external noise and no discernible mechanical or electrical noise, which might have been irritating to a person with autism (Attwood 2001). The room was based in the town centre with an easy bus route for participants.

4.7.7 Approach and structure to focus group

Participants were able to travel to the venue with a supporter, but were asked to attend the focus group on their own. The intention was to pilot methods that could be carried out without a supporter being present, who might have had an impact on the expression of quality of life perceptions. People with autism were generally understood to benefit from structure and clear information (National Autistic Society 2014a).

Clear ground rules were set up with the group at the beginning and visual tactics such as colour coded cards stating 'I wish to speak' and 'I don't understand' were introduced to help facilitate communication with a group who might find some aspects of social communication rules challenging (Kaehne and O'Connell 2010; Boyden et al 2009; Attwood 2007). Participants were given access to paper and pens and encouraged to write or draw their thoughts if spoken communication was uncomfortable. This was based on the thinking that a person with autism might struggle to use the verbal form even if he/she had verbal ability (Wing 1996).

A flip chart was available to allow the facilitator to use simple drawings to help support understanding of any concepts being discussed.

Pictorial information was given both directly to focus group participants and also projected on a screen so that all participants had a range of ways to cope with the information they were being asked to process and comment on. Additional visual support was felt to be helpful in verbal comprehension for people with autism, even if they appeared to have higher levels of verbal understanding (Nind 2008; Attwood 2007).

The participants were asked to come to two meetings, and these were planned to be no more than two weeks apart. The first meeting was structured as explanatory and an opportunity for the group to get to know each other. It also allowed the facilitator the opportunity to understand the group dynamics and communication skills of the

participants and any additional support that might be required for the second session.

Whilst a flexible approach to a focus group was beneficial, an unstructured approach could have been highly stressful for people on the autism spectrum (Baron-Cohen 2007). For this reason, a timetable for this session was planned and structured and this was shared with the group in written and pictorial form. The facilitator's skills as a Speech and Language Therapist allowed her to respond in a flexible way to individual need within this structure.

The first session was planned to introduce the concept of quality of life and to gauge the level at which this could be discussed when presenting the pictorial information in the next session. This also allowed participants to ask questions and seek explanations about the next session. Individuals with autism and a learning disability may have more difficulty with language processing (Nind 2008; Attwood 2007) and this is likely to be aided by preparation and repetition.

The second session was planned as a facilitated group discussion in relation to the seven core dimensions of quality of life (Cummins 2002) to be used in the main phase of the study. The group were shown a range of pictorial supports that had been considered for use in the research phase (see Appendix C). These included photographs, symbols, line drawings and scales. This session was also used to

support participants to trial the visual ranking exercise devised to gather data on their perceptions of the importance of dimensions of their quality of life (see Appendix F).

Each session was two hours long with two 45-minute group discussions and a 30-minute break. These sessions were directly facilitated and moderated by the researcher using video and audio recording as well as field notes taken by a member of staff from the Autism Diagnostic Service. This use of multiple recording methods was done in order to assess what was required to capture free flowing data and also to ensure that multiple voices, which could vary considerably in volume, could be recorded well enough for data from this session to be later transcribed.

4.7.8 Participant characteristics and learning from focus group

Table 4.2 presents the characteristics of all those participants who were approached in relation to the focus group. This shows that a range of participants were initially approached but that only one person with a borderline learning disability, who lived independently, was actually able to be included. The majority of the final group were people with a mild learning disability in some form of supported living arrangement. Other factors, such as age and gender, were fairly balanced in the focus group

Table 4.2: Pattern of participant uptake in focus group

Name	Participation agreed	Reason for decline	Level of LD	Age	Living arrangement	Capacity
Ella	N	Currently sectioned	MLD	25-40	Residential	Not assessed
Andrew	N	N/R	BLD	25-40	Independent	Not assessed
Kim	Y		MLD	18-25	Residential	Y
Kathy	Y		BLD	25-40	With family	Y
Alan	N	Made contact after group finished	BLD	25-40	Independent	Not assessed
Neil	Y		MLD	40-55	Residential	Y
Gemma	N	Made contact after group finished	BLD	18-25	Independent	Not assessed
Liam	N	N/R	BLD	18-25	With family	Not assessed
Dom	Y		MLD IQ 55	25-40	Residential	Y

Sue	N	N/R	BLD	18- 25	With family	
Adrian	N	Capacity	MLD	18- 25	With family	N
Pete	Y	Unable to fit in with morning group	BLD	25- 40	With family	Y
Lionel	N	Did not want to participate	MLD	18- 25	With family	Y
Stuart	Y	Did not attend group after agreement	BLD	25- 40	With family	Y
Tom	N	Capacity	MLD	18- 25	With family	N
Paul	N	N/R	BLD	40- 55	Independently	Not assessed
Sarah	Y		MLD	40- 55	Residential	Y

Key MLD= Mild learning disability

BLD= Borderline learning disability

N/R= No response

Y= Yes

N= No

Several potential participants had experienced changes in circumstances since diagnosis. Gemma and Alan had changed contact details and Ella was in secure care due to mental health issues. Andrew and Paul who lived independently did not respond at all, nor did Sue and Liam who lived at home with parents who also had a learning disability.

Adrian and Tom's parents contacted to say that they did not feel that their sons would understand the research process and that they would not support them in taking part. In these cases, a decision was not made by the individual, but by people who would be needed to support that individual to attend. Lionel was the only participant who had capacity but then indicated that he did not wish to attend a group. Stuart indicated that he wished to attend and then did not attend the sessions, but did not give a specific reason. The final group attendees, Kim, Kathy, Neil, Dom and Sarah, were predominantly in more supported situations and, with the exception of Kathy, were supported by someone else to come to the group.

4.7.9 Learning from focus group

This experience indicated that recruitment was going to have to be a dynamic process where people were more actively supported to engage, particularly if they were living independently. The planned adaptations to the next phase were follow-up phone calls; checking to

make sure addresses had not changed and carefully considering the context of participants and those who might support them.

The role of gatekeepers, who provided support to enable engagement, had been demonstrated in the focus group and this was actively used in the next phases of the study. Nind (2008) and Tuffrey-Wijne et al (2008) talk about gatekeeper organisations, such as advocacy services, and highlight their role in both bridging and blocking access to research. In the case of this participant group, the gatekeeper was often an individual, such as a parent or a support worker. This gatekeeper could read research letters and support the participant to respond, as well as actually facilitate his/her effective arrival at a research session.

Evaluation of the data produced in the focus group clearly demonstrated that the facilitator was the dominant voice in the room. This could be explained if a technique such as summarising was being used or a structured explanation of a task or activity was being given. However, what appeared to be happening was a need for the researcher to fill silences with no such clear rationale. Booth and Booth (1996) discuss the importance of listening to people who have limited verbal communication and valuing silence as part of communication.

One aim of the focus group was to provide the opportunity to pilot some question styles to see what was likely to be effective in eliciting quality of life perceptions in the qualitative interview. It was clear from existing literature that open questions were understood to be good in terms of gathering richer data, but potentially poor for use with people with a learning disability (Nind 2008). This was because open questions made greater linguistic and cognitive demands, and also because people with a learning disability were more likely to have had experiences of oppression and dependence and might feel more anxious and uncertain about questions without a clearly defined response (Nind 2008).

There was opportunity to trial using an ethnographic question style, described later in this chapter. An example of this approach was with Dom, who struggled at times to move on from his areas of special interest and respond to the topic. Dom was initially supported to talk about his work life, which triggered him to share with the group a difficulty that he had experienced in social relationships in an occupational environment.

Facilitator: *'You mentioned work as a place where people might have relationships. Any other places where you might have relationships?'*

Dom: *'Don't say 'haha' to other people.'*

Facilitator: *'Don't say haha to people.... so don't tease them?'*

Dom: *'Ah.'*

The focus group also explored some of the pictures that were being considered for the qualitative interview and were encouraged to give some direct feedback.

Facilitator: *'What about the picture of the calendar?'*

Sarah: *'That's quite clear.'*

Kim: *'The money's good, I can't understand what the calendar means.'*

One particular area that was raised by the group was in relation to the pictures of people on their own, who they felt tended to look sad, whilst some of them wanted a person on their own to look positive to express the perception that being on your own could be a good thing. A suitable picture was identified for the next phase of the study.

The focus group provided an opportunity to trial the visual hierarchy exercise and assess whether those in the group with more significant cognitive challenges would be able to cope with it. Most of the participants were able to complete the task with minimal support and were then able to discuss their hierarchy. Dom required several repetitions and some support, and needed some time away from the group to be able to focus, but was able to complete and then discuss his hierarchy.

4.8 Phase Two: the pilot study

4.8.1 Purpose of pilot phase

This phase provided an opportunity to pilot administration of the quantitative and qualitative tools selected and developed following the literature search and the focus group. This phase permitted changes to methods prior to beginning the main study and allowed the opportunity to include the pilot participants in the main study if no significant changes were made.

4.8.2 Sample selection

The same inclusion criteria of having a mild or borderline learning disability and capacity to consent to research were used, as described for the focus group, with a process of a letter of invitation and a follow-up phone call. In this case, however, participants were identified from the waiting list for the service, so had not experienced a diagnostic process and whilst they had characteristics that had led them to be referred for diagnosis they did not at this stage have a diagnosis of autism.

4.8.3 Engagement in research

The location for the pilot study was a key consideration and, initially, the intention was to try and see participants in their natural environment to allow the use of environmental prompts to talk about their everyday lives as well as reduce the possible anxiety of a new situation. An important additional consideration was also safety of location being in keeping with a local lone worker risk assessment. If required, alternative options were for the participants to be seen in the Autism Service clinic or at the local advocacy services offices.

Similar considerations applied to those made for the research environment in the focus group (see sections 4.7.6. and 4.7.7.) The difference in this case was that where people were seen within their own homes, factors such as noise and clutter could not be managed before the session began, but this was balanced by the participants' decision that this was the most comfortable environment for them.

Participants were asked in writing to attend two meetings with the researcher. One meeting was arranged before their diagnostic assessment (no more than one month before); and one was at the end of the diagnostic process (no more than one month afterwards).

4.8.4 Pre-testing procedures

Each participant completed two questionnaires: The Comprehensive Quality of Life Scale (COMQOL-I5) (Cummins 1997) (see Appendix G) and the Personal Wellbeing Index (PWI-ID) (Cummins and Lau 2005) (see Appendix H). These processes were preceded by a test of acquiescence and then a cognitive pre-test to ensure that the participant was able to reliably use the Likert scales that were going to be used in these tools

Acquiescence was considered to be a particular concern with people with a learning disability (Cummins 1996), with participants potentially answering, as they felt was expected by an examiner or others who might be present (Nind 2008). This could, arguably, have been a particular risk with an examiner who also had a clinical relationship with them, which was the case for several of the participants in this study.

The acquiescence questions were designed to be ones that included an obviously untrue statement, which should be disputed by the participant. The authors suggested confirming the participants' name or gender, to which they should agree and then asking 'Did you make your clothes yourself?' or 'Can you choose who your neighbours are?' which they should dispute. Some discussion was held with the tool author (Cummins 2012 personal correspondence) as some feedback

from the initial focus group had suggested that the clothes question could have a sense of insult attached to it. It was agreed that the acquiescence questions could be changed to a question about the weather, which was obviously untrue e.g. 'Is it snowing outside?' or about the day of the week: 'Is it Saturday today?'

There was then a pre-test designed to determine which Likert scales the participant could accurately use (Cummins 2005). This involved explaining the 11-point scale, and asking the participants to show what they would do if their answer to a question was 'quite happy', which was a point that was not explicitly labelled on the scale. If they struggled to do this then the pre-test moved to a gradual process of identifying the point at which they could successfully show an understanding. If the participant could not cope with any level of scale or appeared completely acquiescent then the tool's author suggested that they should be excluded from the study.

The expectation, based on clinical experience of this participant group, was that majority of people who had been referred to the Autism Diagnostic Service with a mild or borderline learning disability would be able to complete this test. This was confirmed by the literature supporting the use of this test (Cummins 1996). It was, however, possible for a participant to have more significant learning challenges in some areas than had been described, because of a 'spiky profile' linked to their autism (Happé 1994) or a life pattern and history

impacting on acquiescence (Clare and Gudjonsson 1993) and, therefore, a careful approach was justified.

4.8.5 COMQOL-I5 and PWI-ID

In the pilot sessions, once the pre-test was completed each participant completed the COMQOL-I5. This involved answering 21 objective quality of life questions, with wording specifically adapted for people with a learning disability. These 21 questions covered seven dimensions of quality of life and had three more detailed indicator questions identified in each one. Questions varied from simple facts, such as, 'How much do you earn?' to questions involving Likert scales and a greater sense of individual perception e.g. 'How many possessions do you have compared with other people?'

This was then followed by the complementary Personal Wellbeing Index (Cummings and Lau 2005), which gathered subjective quality of life data. Participants were asked to rate their perception of their level of satisfaction in the seven dimensions of quality of life using the appropriate Likert scale for them.

4.8.6 Visual ranking exercise

An important component of quality of life was considered to be the relative importance of a particular dimension to an individual. The balance between how satisfied people are with a dimension of their

lives and the importance in which they hold it is central to gathering a rounded understanding of their perceptions (Cummins 1996).

However, Cummins also highlighted the inherent difficulties of trying to incorporate this into one tool (Cummins 2002). For this reason, a stand-alone visual hierarchy was developed which could provide a simple way of participants describing the relative importance of specific quality of life dimensions to them at that point in time.

Participants were asked to rank cards with words and pictures representing the seven quality of life parameters used in the Personal Wellbeing Index (see Appendix F). These were presented on colour-coded laminated strips for ease of manipulation and the ranking was facilitated using a simple pictorial scale.

4.8.7 Qualitative interview

The developmental phase facilitated the production of a topic guide for a semi-structured interview (see Appendix G) that was used in the pilot phase. Once the topic guide for the qualitative interview had been developed this was shared with individuals with autism and a learning disability, linked to the University of the West of England, who gave their thoughts and feedback. The purpose of this interview in the pilot phase was to enable the participants to describe their everyday life experiences and for the researcher to have prompt questions and

pictorial supports to facilitate the participants in describing areas linked to their quality of life perceptions.

A topic guide (see Appendix I) was used to ask some 'grand tour questions' (adapted from Spradley 1979) such as, 'if I was with you on an ordinary day, what would I see you do?' These were designed to get a visual picture of the participants' daily life, to then support more specific probe questions. The quantitative tools acted as a facilitator in this process by identifying that the participants were involved in particular activities, described themselves in a particular way in relation to others, or had specific health issues. These factual leads facilitated mini-tour questions, such as 'I can see that a lot of your time is taken up with education and childcare, tell me about that', with the qualitative interview then seeking more depth, such as, 'how do you feel about your level of activity?' 'You said you visit your doctor a lot, is that a good or bad thing for you?' This kind of approach allowed for extension and triangulation of the previously gathered quantitative data.

Westby et al (2003) were Speech and Language Therapists who advocated an ethnographic style of questioning as a way of seeing the world through the eyes of the participants. Touring questions were descriptive and allowed an overview of how the participants saw their world and what was important to them. Westby described the use of

visual language: 'what would I see if ...' to facilitate a person's viewpoint in a very concrete way.

Tacit knowledge from clinical experience in Speech and Language Therapy indicated that the use of summary and confirmation e.g. 'What I have understood is...' would be an important tool. Interviews with people with autism and a learning disability ran a risk of participants losing track of what they had said, repeating because they were unsure they had been understood or forgetting where they were going with their narrative.

Westby advocated always using an open question style that avoided closing down the responses of the participant, but her focus was not specifically on people with a learning disability. Nind (2008) described the dilemma of balancing the benefits that people with a learning disability derived from more structured, closed approaches with the desire to avoid constraint. The qualitative interview was planned to take no more than 45 minutes and the pilot stage gave an opportunity to consider whether this gathered data was rich enough to contribute to answering the research enquiry.

The use of visual supports alongside language was strongly indicated in research literature (Nind 2008; Barr 2007; Lewis and Porter 2004; Booth and Booth 1996). Lewis et al (2008) advocated the use of pictorial cueing systems to help facilitate a flowing narrative from

children with a learning disability. The pilot stage of this study therefore trialled a set of pictorial supports that were being considered to support the topic guide for the qualitative interview. One challenge with effectively using both verbal and pictorial supports was striking a balance between providing enough supports and prompts and avoiding leading potentially vulnerable individuals to respond in a particular way (Clare & Gudjonsson 1993). In an attempt to reduce the risk of pictorial support excessively leading the participants, these were not brought out immediately but were offered if an individual struggled to respond to a particular question.

4.8.8 Data gathering and appraisal in the pilot stage

Data from the COMQOL-I5 and the Personal Wellbeing Index was recorded directly onto forms provided with the tool. This data was then stored in line with local ethical guidance and transferred onto a secure laptop for analytical purposes. Clinical experience suggested that participants might have communication challenges which could increase the importance of gathering non-verbal data. For this reason, each qualitative interview was recorded using both a video and an audio device. This resulted in a high quality audio recording and video recording to support transcription of less clear speech and capture details such as gesture, facial expression and other non-verbal communication techniques. This robust recording method allowed the

researcher to focus more fully on the participants and adapting approach rather than having to transcribe in detail as interviews took place.

A 'Live Scribe' digital pen was used for audio recording, which gave the facility to audio record speech but also note other data such as non-verbal behaviour, feelings or environmental issues unobtrusively. This approach was used both for the qualitative interview and for the hierarchy exercises.

Reflective notes were made immediately after each interaction with participants and field notes were recorded throughout the study period. All data was transcribed from the audio and video recordings as soon as possible after it had been gathered and further reflective notes were then made immediately after transcription. The areas considered in reflections were: practical aspects of methods and environment; engagement with the participant; the researcher's thoughts and feelings throughout the process; themes and any other observations in the interview.

Data from the pilot stage was not subjected to any major analytical process, such as thematic analysis or statistical evaluation at the pilot stage. The relative value of this with two cases was felt to be limited. Instead a number of questions were considered in relation to the

objectives that were set at the outset of the pilot phase; these questions are described in Table 4.3.

Table 4.3: Focus of questions in pilot phase

Focus	Question
Interview organisation	How well did the order of activities and interviews work for the participants?
Interview organisation	Was the timing of interviews reasonable?
Participant support	Did participants appear to be able to understand what was being asked of them?
Data gathering	Did the qualitative interview allow participants to generate data, which appeared to describe daily life experiences in relation to the chosen quality of life dimensions?
Evaluating tools	Did any of the pictorial materials seem more or less helpful in facilitating descriptions of daily life experiences?
Evaluating tools	Were all of the dimensions possible to gain data for in the interviews?
Evaluating tools	Were the quality of life tools easy

	to administer, did the participants appear to understand them?
Understanding dynamics	Did the researcher's knowledge or relationship with the participants as a diagnostician feel as if it impacted on the data gathered during the study?
Evaluating research environment	Did the environments selected for the interview facilitate the interviewer in feeling that the participants could provide a rich description of their daily-lived experience?

4.8.9 Learning from pilot interviews

This section will focus on learning from the pilot interviews with Mark and Adam and the ways in which this was then applied to the research phase.

Mark in particular responded less well to small talk and responded well to the initial factual style of the quantitative interviews. In both Mark and Adam's interviews, it was possible to make use of the initially gathered objective, quantitative data and build into qualitative questions. In Mark's case, his quantitative data highlighted his hours spent in a voluntary job at the radio station as a significant proportion of his week. He was able to answer factual questions about this job at length but could be monosyllabic on less factual questions. This suggested that to carry out the quantitative questionnaires initially in the research interview had some advantages.

M: *'At the radio station?'*

S: *'What happens there?'*

M: *'I just help out the manager and other volunteers.'*

S: *'What sort of things do you do?'*

M: *'Take programmes that they have recorded and take the beginnings and the end of the recording and make sure the news is taken out.'*

Mark and Adam both managed to complete all tasks. Mark did not want a break during the interview, and there was a sense for him that he wanted the session to be over as quickly as possible as he was finding the situation difficult. Adam needed several breaks, and he was happy to request these with both participants completing the whole process in an hour and a half or less.

Both participants appeared to understand the purpose of the sessions and were able to respond to the questions that were asked without needing any more language adaptations than had been planned.

Evaluation of the transcripts indicated that Mark and Adam were both able to describe some perceptions of their lives in relation to all seven dimensions being explored.

Both Mark and Adam used available pictorial materials and in Mark's case, in particular, these seemed essential where he was struggling with language around emotion.

S: *'(Passes pictures) These might or might not help. A few things to do with safe or safety.'*

M: *'That one is... I don't know what that is on there.'*

S: *'Mark do you want a break for a minute?'*

M: *'No... I am not sure what that one is.'*

S: *'I think it's meant to be someone not feeling very safe, bit insecure, little bit frightened.'*

M: *'I think that is what I get.'*

Mark and Adam both completed the pre-tests for the COMQOL-I5 and the PWI-ID, all sections of these tools and were able to use the 11-point Likert scales. The tests were easy to explain and to administer. Mark and Adam both completed these visual hierarchy tasks easily and in Mark's case the non-verbal nature of the task seemed to be more enjoyable for him than verbal interaction. Both participants put the dimensions in their preferred order and then made some subtle alterations, suggesting a reflective process.

An alternative diagnostician saw Adam for his diagnostic process whilst the same person saw Mark for the research session and diagnosis. Reflections do not suggest that any particular issues were raised at this stage. Adam chose to be seen at home and an immediate advantage to this approach was being able to use this environment to generate questions about his everyday life.

S: *'and...well obviously I've just seen...what's the name of your beardie?'*

A: *'Mr Red.'*

S: *'Mr Red...does he take up any of your time?'*

A: *'Ah.'*

Reflective notes indicated that an early challenge as an interviewer remained a tendency to dominate the interviews verbally, and to do this by asking long questions, being overly repetitive and not allowing the interviewees space to reflect and respond. Booth and Booth (1996) provide a detailed account of working with one young man, Daniel, whom they include in a group of people they describe as 'inarticulate'. This was reflective of early interviews, particularly in the case of Mark, who was a young man with considerable social anxiety. Mark was able to understand a great deal, but, like Daniel, would often answer in monosyllables or with 'don't know'.

An initial tendency was to ask longer questions and try and recap on 'what was known so far'. Whilst this was a reasonable strategy in some cases, this was less effective for Mark who talked less as others talked more. An adaptation in further interviews was to use more non-verbal strategies, such as pictures, and use silence or 'encouragement' words such as 'right', 'ah' and 'Ok'.

4.9 Phase Three: the research phase

The process for recruitment and engagement with participants in the research phase reflected that already described in the pilot phase, with no significant changes in the way in which tools and approaches were carried out in this phase (see sections 4.7.6 and 4.7.7). This phase involved the recruitment of a further 18 participants who were again seen both before and after their diagnostic process had been completed. Adaptations were generally related to areas such as reflections on interviewer technique including pace and balance and these will be described in more detail in the results section of this thesis. A development in the research phase of the study was the use of analytical processes in relation to the data and these will be described below.

4.9.1 Justification for quantitative analysis

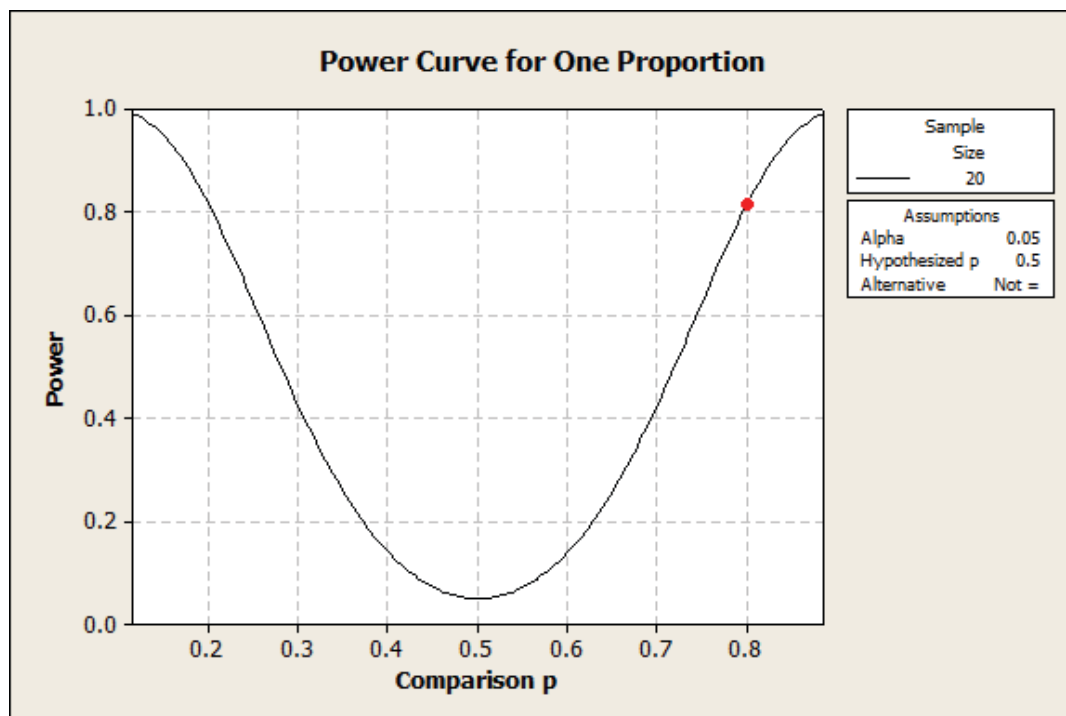
The quantitative analytical approach had two dimensions. Firstly and primarily, the statistical analysis was descriptive. This meant that data was used to describe the quantitative 'appearance' of the sample, allowing presentation of patterns of quality of life perceptions in data such as range, mean scores and variations across the diagnostic process. This was planned to be at both a group and an individual level and to explore this graphically. Secondly, a more specific

inferential statistical analysis was carried out in order to establish whether any observable changes were statistically significant.

For the purpose of carrying out inferential analysis, the experimental hypothesis was that mean quality of life scores for this sample would show an observable change by the end of the autism diagnostic process, with the greatest likelihood being a change in objective scores. The lack of research in this area meant that analysis had to allow for both negative and positive changes. The null hypothesis would be that there was relative stability and that any observable change at the end of the diagnostic process was a chance occurrence.

4.9.2 Justification for sample size

Figure 4.1: Calculation of power curve for this study



Statistical power in this study described the probability that a significance calculation on a sample would avoid error and produce a result, which correctly proved or disproved the experimental hypothesis and potentially allowed inferences to be drawn for the whole population being studied. In the case of this study, the whole population were people who had a mild or borderline learning disability and had been referred to the local diagnostic process. For an inferential analysis to have value, the sample size in the study had to have a sufficient predictive power, one that would result in a 0.8 (80%) chance of avoiding error.

To complete this calculation the probability (α) of a type two error, where the null hypothesis was incorrectly rejected, was set at 0.05. Figure 4.1 illustrates that, in order to reach a power of 0.8, a medium to large effect size would be needed. As will be described in more detail in sections 5.4.2 and 5.4.5, it was planned to use a binomial test on the data. This had the advantage that it would be able to identify the proportion of the sample that had experienced the observed change and could confirm whether a medium to large effect size had occurred.

Figure 4.1 illustrates that a sample size of 20 had an acceptable power to detect a medium to large change across the sample, but not a small effect, which would require a much larger sample size than was likely to be obtained. Clinical experience suggested that in such a heterogeneous group, a medium to large effect size was likely to have the most clinical relevance and was, therefore, appropriate in this case, justifying a sample size of 20 for quantitative analysis.

Based on previous records, it was predicted that no more than 35 people would be referred to the Autism Diagnostic Service who fulfilled the selection criteria for the study in a period of a year, and could, therefore, be included in the sample frame. Limited research with this specific group meant that participant uptake had to be approximated. The prediction was that it would be possible to recruit 60-80% of this population and that approximately 20 of these participants would be

willing to be involved and would have capacity to participate and successfully complete relevant pre-tests. Twenty participants was also a realistic number of individuals to be seen both by the diagnostic service and for research purposes in a period of one year.

4.9.3 Justification for sample size for qualitative analysis

An initial plan had been that all participants would be involved in both the qualitative and quantitative aspects in this study. However, following the pilot it was clear that a purposive selection strategy with the qualitative interviews would be required, to ensure that the volume of data was manageable whilst effectively answering the research questions. Consideration was given to the factors that could reasonably be thought, from existing literature, to have a potential impact on quality of life perceptions. The main consistent factor in the learning disability literature was level of learning disability of participants (Howlin 2003, 2004). It was judged reasonable and feasible to consider age and gender as factors.

Participants were selected for qualitative interview who presented with a characteristic of age, gender or level of learning disability that had not previously appeared, with participants who matched existing profiles only being seen for the quantitative element of the study. The result of this strategy was of a total of 20 participants being seen for quantitative interviews, eight participants were also seen for qualitative

interviews. Two additional subjects, Ralph and Kathy, were not included as Ralph had to postpone his diagnosis due to his wife's ill health and Cathy did not attend her second research session (see Appendix J for details of participants).

4.10 Quantitative analysis

4.10.1 Descriptive quantitative analysis PWI-ID and COMQOL-I5

The COMQOL-I5 and the PWI-ID both produced data on a quasi-interval level, which was converted into percentage scores. This data was initially entered on an Excel spreadsheet to be prepared and transferred onto IBM SPSS predictive analytic solutions software. The data was then analysed descriptively and graphically to look at range and mean scores across dimensions, and as a whole or on average for subjective and objective scores as well as observable changes. Individual participants' data was explored and presented graphically using Excel.

4.10.2 Analysis of observable change in the data

It was not appropriate to assume normal distribution in the sample because of the complex and heterogeneous nature of the group. This meant that a non-parametric, paired-sample Wilcoxon Signed Ranks for significance of any observable changes in mean scores was the

most appropriate statistical test to be applied. As this test focused on pairs of scores that changed and some of the scores may have remained stable, a binomial test was carried out to look at the probability of the pattern of scores in this data having occurred.

4.10.3 Analysis of visual ranking exercise

The visual ranking exercise was self-designed and involved participants assigning a rank denoting importance to specific dimensions of quality of life. These ranks were then recorded numerically so that the results could be explored graphically and descriptively to look at patterns of importance across the whole group and considered in relation to other qualitative and quantitative data at an individual participant level.

4.11 Qualitative analysis

4.11.1 Aim of analysis

The aim of the qualitative analysis in this study was to identify and describe themes relating to participants' perceived quality of life.

These were then explored in relation to their occurrence, patterns and relationship to each other, across the group and in individuals. The intention was to also explore the relationship between identified themes and the seven quality of life dimensions measured and the balance of positive and negative themes that were identified. This data was then considered in its own right as well as being used to triangulate and add depth to quantitative results. Braun and Clarke's (2013) Thematic Analysis (TA) provided a structured approach to thematic analysis, which they argued was suited to explorative studies. The application of this analytical approach to this study was planned as follows.

4.11.2 Analytical method

Immediately following each interview, a reflective record was kept of the researcher's thoughts and feelings and also initial themes, which had been noticed during the interview. This process was then repeated following verbatim transcription of audio and visual to written form, which was carried out as soon as possible after the actual interview. After the eight pre-diagnostic interviews had been completed, the transcripts were re-read and then the data from the transcripts was reduced to data judged to relate to participants' quality of life perceptions (Braun and Clarke 2013). This data was then re-read whilst actively searching for codes and producing a code and sub-code list, which was shared with this researcher's supervision team, along with an example interview for discussion.

The full interviews were then transferred onto NVIVO 9 and the code list that had been developed was used for re-coding all the full interviews. Throughout this process, codes were added and some codes were subsumed into existing codes and overarching themes were noted and gradually these became central contextualising themes, which were used throughout the pre-diagnostic data set. This process was then repeated with the eight post-diagnostic interviews with any new codes then being reconsidered within the pre-diagnostic data set.

4.12 Summary of methodology and methods

This study was designed to explore the perceptions of a group of people for whom previous research knowledge was limited and who formed part of an active clinical caseload. The methodology behind the study reflected a realist perspective, using an inductive and exploratory approach, seeking to gain knowledge into the perceptions of a group of participants with potential communication challenges and making use of tacit knowledge and clinical experience in the development of specific approaches and to facilitate engagement.

A mixed methods approach was used and throughout the study the significance of the qualitative element of the study increased, with the qualitative component providing structure and also directly supporting the administration of the qualitative components. A novel approach was needed and this was facilitated by a developmental stage that involved service users in a focus group and a broad based analysis of contextual literature, which included access to unpublished, grey literature.

Quality of life tools, which had been developed for people with learning disabilities, were incorporated into the design along with self-developed interviews and pictorially supported tools. The self-developed qualitative approach made use of ethnographic interviewing techniques and used self-reflection, tacit knowledge and experience and existing literature in the field of learning disability and autism. This

enabled the development of an approach designed to gather in-depth quality of life perceptions to complement and add to the data gathered using quantitative methods.

Analysis reflected both the quantitative and qualitative components. Quantitative design and analysis aimed to effectively visually describe objective and subjective indicators across the group and at an individual level. A sample size and analytical approach was used that created an adequate power to calculations of statistical significance and also used an approach suitable for the nature of the participant group. Braun and Clarke's Thematic Analysis (TA) model provided an adaptable but structured method to analyse data and to identify and describe themes within the data.

Chapter Five: Results

5.1 Introduction

The results of this study will be presented in several sections. Firstly, learning in relation to research engagement with the participant group will be considered. This will include the data and learning relating to the characteristics and engagement of the participants in the research phase.

Quantitative and qualitative findings will initially be presented separately for clarity. Specific cases will then be presented which have been selected to represent a range of possible balances of objective and subjective quality of life perceptions using Zapft's (1984) descriptive groups. These cases will be presented to illustrate the ways in which subjective and objective indicators, data from the qualitative interview and importance ranking interact in individual presentations. Throughout this section the participants will be presented using alternative names and any data that might increase the risk of identification has been removed.

5.2 Results from pilot and research phase

5.2.1 Participant characteristics

This section will present data on participant characteristics gathered from the initial referral sheet, quantitative questionnaires and qualitative interview or from field notes kept during the research process. This data will be presented in two ways. Firstly, Table 5.1 presents a summary of key characteristics of the participants who took part in the study. This will be followed by a summary of the key characteristics of the participants approached who did not participate in the study and the reasons for non-participation, which are shown by Table 5.2.

Secondly, in Appendix K, more detailed descriptive information about the study participants will be presented on a case-by-case basis. This data will provide more specific details of participant characteristics, some details of the participants' clinical relationship with the researcher in this study, and some more detailed descriptive data of specific engagement issues with particular participants.

Table 5.1: Characteristics of participants engaged in research phase of study

Name	Gender	Age	LD and diagnosis	Occupation	Carer for others	Mental health issues	Level of support in daily life
Mark	Male	18-25	Mild LD/ autism	Part-time voluntary	No	No	Mother
Adam	Male	26-40	Mild LD/autism	Unemployed	Yes – children	Yes	Partner
David	Male	18-25	Borderline LD/Language Disorder	Part-time voluntary	No	No	Mother
Don	Male	26-40	Borderline LD/autism	Part-time student	No	Yes	Mother
John	Male	50-60	Mild LD/autism	Unemployed	No	Yes	None
Valerie	Female	18-25	Mild LD/autism	Unemployed	No	No	Supported living
Pat	Male	26-40	Mild LD/autism	Part-time voluntary	No	No	Supported living
Teresa	Female	40-50	Mild LD/autism	Unemployed	Yes – children with disability	No	None
Jane	Female	18-25	Borderline LD/autism	Student	No	No	Father
Jim	Male	50-60	Mild LD/autism	Part-time employment	No – two children nearby	No	Mother
Laura	Female	18-25	LD/autism	Unemployed	No	Yes	Father
Chris	Female	40-50	Borderline LD/autism	Unemployed	Yes – child with disability	Yes	None
Nick	Male	50-60	Borderline LD/autism	Unemployed	No	Yes	None
Mo	Female	25-40	Borderline LD/autism	Unemployed	Yes – child with disability	Yes	None
Michelle	Female	25-40	Borderline LD/autism	Unemployed	Yes – two children with autism	Yes	None

Cathy	Female	50-60	Borderline LD/autism	Part-time employment	Yes – child with disability	No	None
Ralph	Male	25-40	Borderline LD/autism	Unemployed	Yes – wife and child	No	None
Joanna	Female	18-25	Borderline LD/autism	Full-time student	No	Yes	Mother
Mike	Male	25-40	Mild LD	Unemployed	No	No	Parents
Carl	Male	50-60	Borderline LD and anxiety	Unemployed	No	Yes	Supported living
Luke	Male	18-25	Borderline LD and autism	Full-time student	No	No	Mother
Liam	Male	18-25	Borderline LD and autism	Unemployed	No	Yes	Mother

Table 5.2: Background of potential participants who were not engaged in research phase of study

Name	Gender	Level of LD	Occupation	Carer	Mental health	Level of support	Reason for decline
Jake	Male	Mild	Unemployed	D/K	D/K	Residential care	Capacity
Julie	Female	Mild	Unemployed	D/K	D/K	Family	Capacity
Nancy	Female	Borderline LD	Unemployed	D/K	D/K	Family	Family declined
Mary	Female	Borderline LD	Full-time student	D/K	D/K	Family	Family declined

Key for Tables 5.1 and 5.2

LD- Learning disability

D/K- Do not know

Twenty-six people were approached to participate in the research phase of the study. The adaptations made to the recruitment approach following the focus group appeared effective, as only four could not be engaged in the study at the outset. Table 5.2 shows that of these four, two could not be engaged because their capacity assessment indicated that they did not have capacity to consent to research (Jake and Julie). In the case of Nancy and Mary their parents were their gatekeepers and whilst their parents did not question their capacity, they felt that they would not cope and that they 'would not like that sort of thing'.

5.3 Findings related to methods and engagement with the participant group

This section will present the learning about engagement with the participant group by the end of the research phase.

5.3.1 Accessing the participants

John's case provided a good example of the types of challenges experienced in accessing participants once they had been engaged. He regularly moved house, as he seemed to have difficulty both financially and socially. This meant that he did not receive notification of appointments and he failed to attend a number of times and was then difficult to contact. These factors resulted in some specific approaches with John. Advice was sought from his referrer and it was

established that he could be located on a daily basis in the café of a local shopping centre, which he had also mentioned in his first interview.

The decision was taken to informally contact him by visiting this café to let him know that his new address was not known. The researcher's lack of knowledge of his new address surprised him and he was keen to emphasise that he wanted to carry on with the research. This happened on two occasions and this approach resulted in John's attendance at both interviews.

5.3.2 Gatekeepers

The use of gatekeepers as a key part of engagement arose in the pilot and became increasingly important in the research phase. One ethical challenge was ensuring that interactions with gatekeepers were not covert, as the intention was to engage participants as adults consenting to research, who could understand the process.

Adam selected his wife as a gatekeeper as he found any new communication stressful and she linked with a community nurse on the Learning Disability Team with whom Adam had already met. Mo's mother acted as a gatekeeper, although she lived a distance away, and she helped her daughter with tasks involving written correspondence.

Liam did not, at the outset, attend appointments, although he had agreed by telephone. Eventually, his support worker provided a contact email and this link established that his mother's mental health difficulties meant that she did not open post or consistently answers the phone and that Liam needed the support worker to engage with visits. The support worker was able to explain that Liam's social anxiety meant that he might need to be seen at home to be certain of engagement. Chris and Teresa both asked their child's support worker to make contact when they received their research letter. It became apparent that they were both being informally supported by their child's support worker, as they had no support of their own. In both cases, this person helped them understand the paperwork, made the phone calls and also supported them to attend the research sessions.

5.3.3 Location for engagement

At the outset of the research, an assumption had been that, unless a risk was identified, a person's home would be the best, natural environment to support an interview process for him/her. In ten cases the home environment was preferred, and this facilitated conversation related to that environment, e.g. Adam about his bearded dragon, parrot and children, who were all present; Pat about his flat mates and home environment and certificates of achievement. In Pat's case, he requested a break to go and change into a suit as he felt this was what

'should happen' at an interview. He appeared to be trying to create a context that allowed him to feel comfortable to engage in research in his home environment.

In 12 cases participants did not wish the researcher to come into their environment. There were a number of reasons given for this, some because they had negative feelings about their home environments and said they felt uncomfortable with others seeing them (Nick, Cathy, John, Jim); because they were noisy and distracting to meet in (Carl, Valerie); because the clinic environment was where a researcher *should* be seen (Mark, David); because strangers could not be trusted to come into the home (Teresa, Chris); because coming to another venue was an interesting experience (Luke).

5.3.4 Response to the quantitative tools

The majority of participants were able to use a full 11-point scale with only three participants requiring an adapted five-point scale in order to complete the PWI-ID. These three, Pat, Valerie and Laura, all had a mild learning disability. The scores of these three participants were converted so that they could be compared to the other scores, but would lack the sensitivity of the 11-point scale.

5.3.5 Response to visual hierarchy task

Reflective notes indicated that the participants in general managed the visual hierarchy task well. Several participants verbally commented that all the dimensions were important and the majority reorganised their order a few times before being satisfied with them, suggesting that they were giving some depth of thought to their answers.

5.3.6 Response to pictorial supports in the qualitative interview

During the qualitative interview, several of the participants made active use of the pictorial support (Mark, Adam, John, Valerie and Pat.)

Mark's interview transcript indicated that he used the pictures actively for expression, where he found it difficult and it appeared stressful to speak.

S: 'So is there anything that helps you feel more part of your neighbourhood makes you feel like you know the people round you?'

M: (Sigh)

S: (Passes pictures) 'some of these could be about people in your local area or you in your daily life.'

M: (looks intently at pictures) 'that one' (points at picture of man on his own with people around but no links between him and the people).

Other participants appeared to use them more as a prompt to then allow them to talk around the subject in a particular dimension.

P: *'um um... I was never very good with this one... this relationship'*
(points at male/female relationship picture).

S: *'Is that with... with women?'*

P: *'um um with... with women ah.'*

5.3.7 Summary of learning from research engagement

During the focus group stage of this study, an engagement approach was taken which put clear boundaries between the researcher and the participants. These approaches relied on participants being able to process adapted written communication, manage phone calls and to be able to attend an appointment or manage a home visit relatively independently. This resulted in engagement with participants who had some degree of natural support in their immediate environment, such as family or staff who shared their home. These participants were more likely to be individuals with more significant learning disabilities. In order to access people with a borderline learning disability, who lived more independently, and for whom their natural support systems might be more remote or lacking, a different approach was needed to ensure that they had an opportunity to make an informed decision about research engagement.

A flexible and dynamic approach was developed with a greater degree of persistence and support from the researcher. This involved more tactics, such as regular reminder phone calls and engagement with gatekeepers, who took on a bridging role to overcome issues such as literacy, memory and social anxiety. This persistence was focused on ensuring a full understanding of the process and overcoming obstacles, rather than a pressure to participate. Context for the participation was also an important area of learning, with participant-led flexibility and careful consideration required of sensory issues, safety, privacy, trust and the benefits of context in supporting communication.

Structured quantitative tools, designed for people with learning disabilities, were accessible and useable for people with additional autism characteristics and appeared to provide a good basis from which to move on to use qualitative methods. Structure and predictability were facilitated by clear visual planning and the use of visually based tools, such as the visual hierarchy and pictorial support to the qualitative interview, which facilitated more depth of communication than a verbal approach alone.

5.4 Quantitative results

This section will present the quantitative results of this study. This will begin by looking at the objective quality of life data gathered using the

COMQOL-I5 tool. It will then present the subjective wellbeing data gathered with the PWI-ID. It will go on to present the ways in which these results theoretically translate into an individual participant's balance of subjective and objective wellbeing. It will then present a descriptive analysis of the visual ranking exercise of importance of quality of life dimensions to the participants.

5.4.1 Descriptive statistics for mean COMQOL-I5 scores

To gain an objective measure of their quality of life perceptions, participants were asked 21 questions with the COMQOL-I5. This tool explored objective indicators of quality of life across seven dimensions. Each dimension contained three questions asking about specific indicators, such as current income or number of visits to the GP (see Appendix G). Each dimension could score between zero and 15, with 15 being the highest score. This meant that across the whole COMQOL-I5 a participant could *score* a minimum of zero and a maximum of 105.

Table 5.3: Descriptive analysis of pre and post-diagnostic mean scores in dimensions and total COMQOL-15 scores for the sample

	N	Minimum	Maximum	Mean	Std. Deviation
PRE Material wellbeing	20	4.00	10.00	6.6500	1.59852
POST Material wellbeing	20	4.00	9.00	6.9000	1.48324
PRE Health	20	6.00	15.00	10.9500	3.10305
POST Health	20	6.00	15.00	11.0500	3.28433
PRE Productivity	20	3.00	12.00	8.2250	2.13045
POST Productivity	20	3.00	15.00	8.3000	3.21346
PRE Social interaction	20	3.00	13.00	7.8500	3.42245
POST Social interaction	20	3.00	14.00	7.9000	3.74025
PRE Safety	20	4.60	14.00	9.7300	3.00615
POST Safety	20	6.00	14.00	10.1500	2.34577
PRE Community connectedness	20	3.00	10.00	5.9875	2.21162
POST Community connectedness	20	3.00	13.00	5.9625	2.42963
PRE Emotional/future security	20	5.00	15.00	8.9500	2.64525
POST Emotional/ future security	20	5.00	15.00	9.9250	2.74473
PRE Total COMQOL	20	38.00	72.00	54.9000	9.49460
POST Total COMQOL	20	40.00	74.00	56.9500	9.83402
Valid N (listwise)	20				

Table 5.3 shows that across all the interviews, the range of scores from all 20 participants, in their pre and post-diagnostic interviews, varied from three to 15 in each dimension and 38 to 74 in total. The range of scores in each dimension stayed relatively stable across the diagnostic process. In the dimensions of community connectedness and productivity there was a small increase in the upper end range after the diagnostic process.

Chart 5.1: Patterns of mean COMQOL-I5 scores across dimensions (pre and post-diagnostic process)

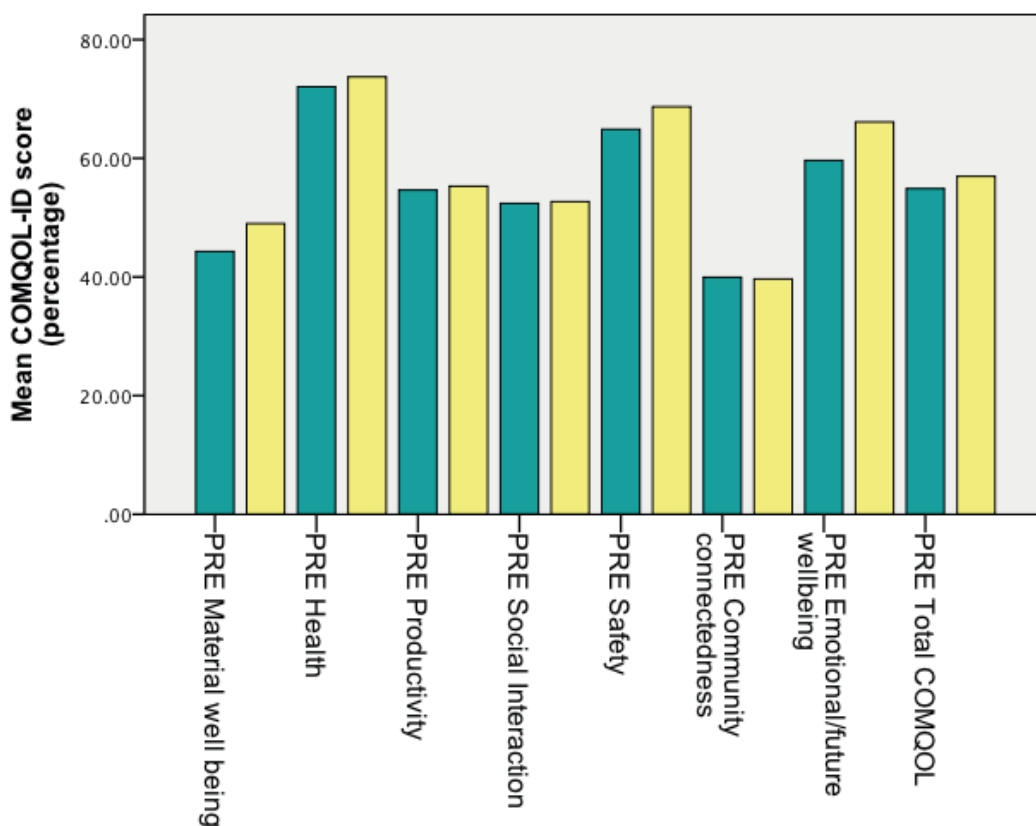


Chart 5.1 shows that objective scores were generally lowest in the dimensions of material wellbeing, productivity, social interaction and, most markedly, community connectedness. Scores were highest in the dimensions of emotional wellbeing, safety and particularly in the dimension of health. Chart 5.1 also shows relative stability in scores before and after the diagnostic process in the dimensions of productivity, social interaction and community connectedness. There were small visible increases in the mean scores of material wellbeing, health, safety and emotional wellbeing/future after the diagnostic process. There was a small visible increase in the mean overall

COMQOL-I5 score from 54.9 to 56.95 out of a possible 105 after the diagnostic process had been completed.

5.4.2 Analysis of significance of observable change in COMQOL-I5 scores

To test the statistical significance of these differences in means, a non-parametric Wilcoxon's signed rank test was used. Table 5.4 gives the results from this analysis and shows that for the dimension of emotional/future wellbeing and for the total COMQOL-I5 scores the resulting p value was equal to 0.05. In order for the outcome of a statistical analysis of difference to be considered statistically significant, it should result in a p value that is less than 0.05. A p value of less than 0.05 would suggest an acceptable likelihood that any difference observed was not a result of chance factors. Whilst the p value in this case was very close to a significant outcome, the differences in total COMQOL-I5 and emotional wellbeing dimension scores cannot be described as statistically significant. This difference warrants further discussion in terms of clinical application and importance.

Table 5.4 shows that in all other COMQOL-I5 dimensions the analysis of statistical significance of the difference in the pre and post-diagnostic scores resulted in a p value that was greater than 0.05. This

indicated that these differences could not be described as statistically significant.

Table 5.4: Analysis of differences in mean COMQOL-I5 dimensions and in total

	POST Material well being - PRE Material well being	POST Health - PRE Health	POST Productivity - PRE Productivity	POST Social interaction - PRE Social interaction	POST Safety - PRE Safety	POST Community connectedness - PRE Community connectedness	POST Emotional/future wellbeing - PRE Emotional future wellbeing	POST Total COMQOL score - PRE Total COMQOL score
Z	-1.311 ^b	-.229 ^b	-.183 ^b	-.095 ^c	-1.05 ^b	-.114 ^c	-1.959 ^b	-1.964 ^b
Asymp. Sig. (2-tailed)	.190	.819	.855	.924	.294	.909	.050	.050

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

c. Based on positive ranks.

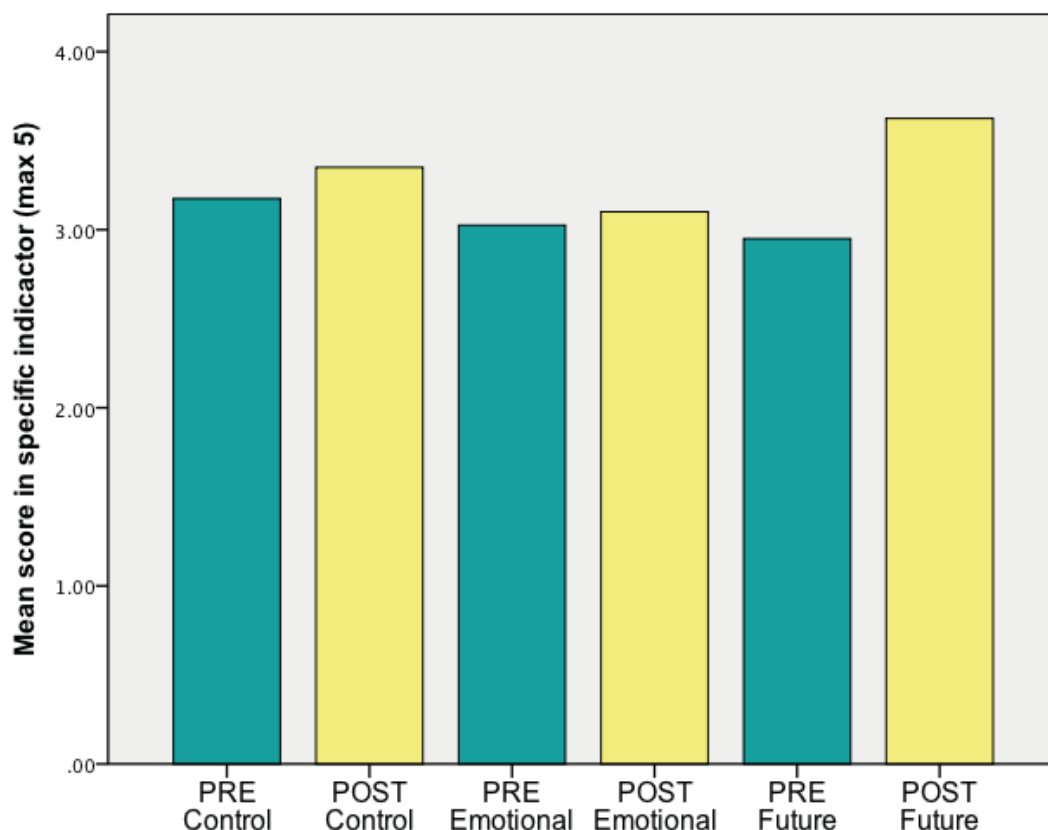
The Wilcoxon test focused on data from the sample where differences occurred and the analysis excluded data from the calculation where the pre and post-diagnostic scores did not change. It was, therefore, important to test the probability of the overall pattern of stability and change in the group occurring by chance. This was done using the binomial test, as illustrated in Table 5.5.

Table 5.5: Binomial test of distribution of patterns of change of COMQOL-I5 scores in sample

		Category	N	Observed Prop.	Test Prop.	Exact Sig. (2-tailed)
COMQOL Scores	Group 1 Positive change in scores	1.00	16	.80	.50	.012
	Group 2 Stable or negative change in scores	.00	4	.20		
	Total		20	1.00		

Table 5.5 shows that in the case of the COMQOL-I5 scores, the binomial test indicated a relatively small chance (0.012/1.2%) of the pattern of stability and positive change in the sample occurring by chance. This provides strength to the results of the Wilcoxon test and adds to the clinical interest of these results.

Chart 5.2: Changes of mean in specific indicators that make up the COMQOL dimension of emotional wellbeing



The calculation of a p value that was equal to 0.05 for the dimension of emotional wellbeing/future warranted some deeper evaluation of this dimension. This dimension was composed of three indicator questions; the first indicator question asked about control, the second was about emotional wellbeing and the third about hopes for the future. Chart 5.2 illustrates the pattern of mean scores in each of these specific indicators showing some visible increase after the diagnostic process, with the greatest visible change in the area of hopes for the future. Table 5.6 shows that whilst this was an observable difference, the

Wilcoxon signed rank test of this difference resulted in a p value that was greater than 0.05 and, therefore, these differences were not statistically significant. Whilst acknowledging the greater potential for chance in these results, these patterns will be considered and discussed later in section 6.4.2.

Table 5.6: Analysis of significance of difference in scores in indicators that make up the COMQOL-15 dimension of emotional wellbeing using the Wilcoxon signed rank test

	POST Control - PRE Control	POST Emotional - PRE Emotional	POST Future - PRE Future
Z	-.778 ^b	-.260 ^b	-1.752 ^b
Asymp. Sig. (2-tailed)	.437	.795	.080

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

Chart 5.3 and Chart 5.4: A side-by-side comparison showing mean scores in COMQOL-I5 dimensions from Verri's Australian population (1999) and this researcher's study group

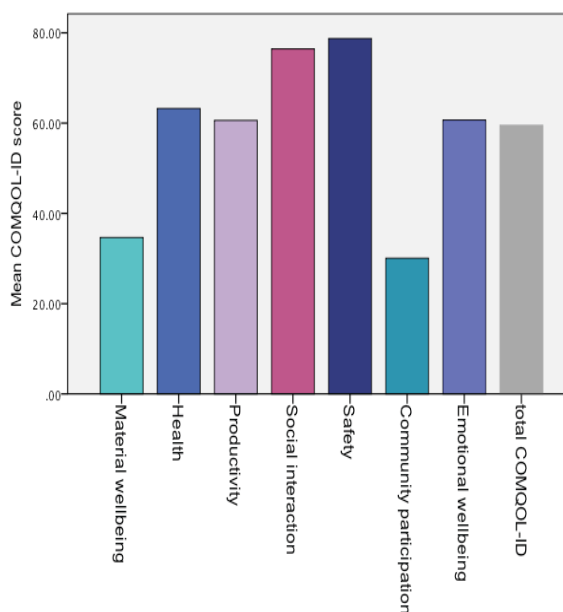


Chart 5.3

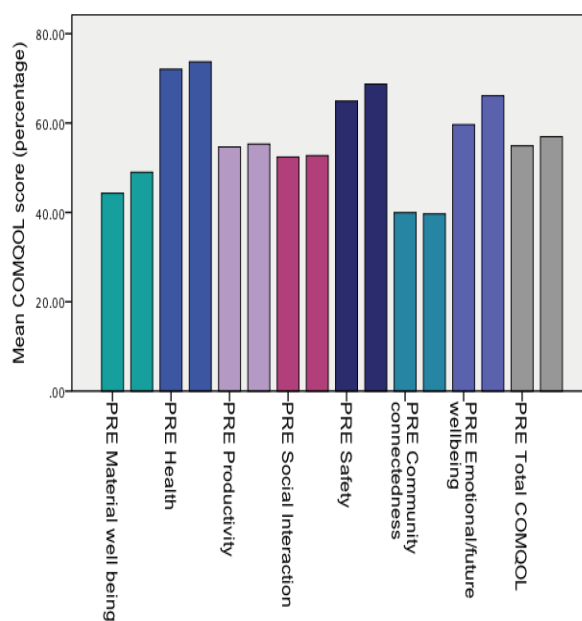


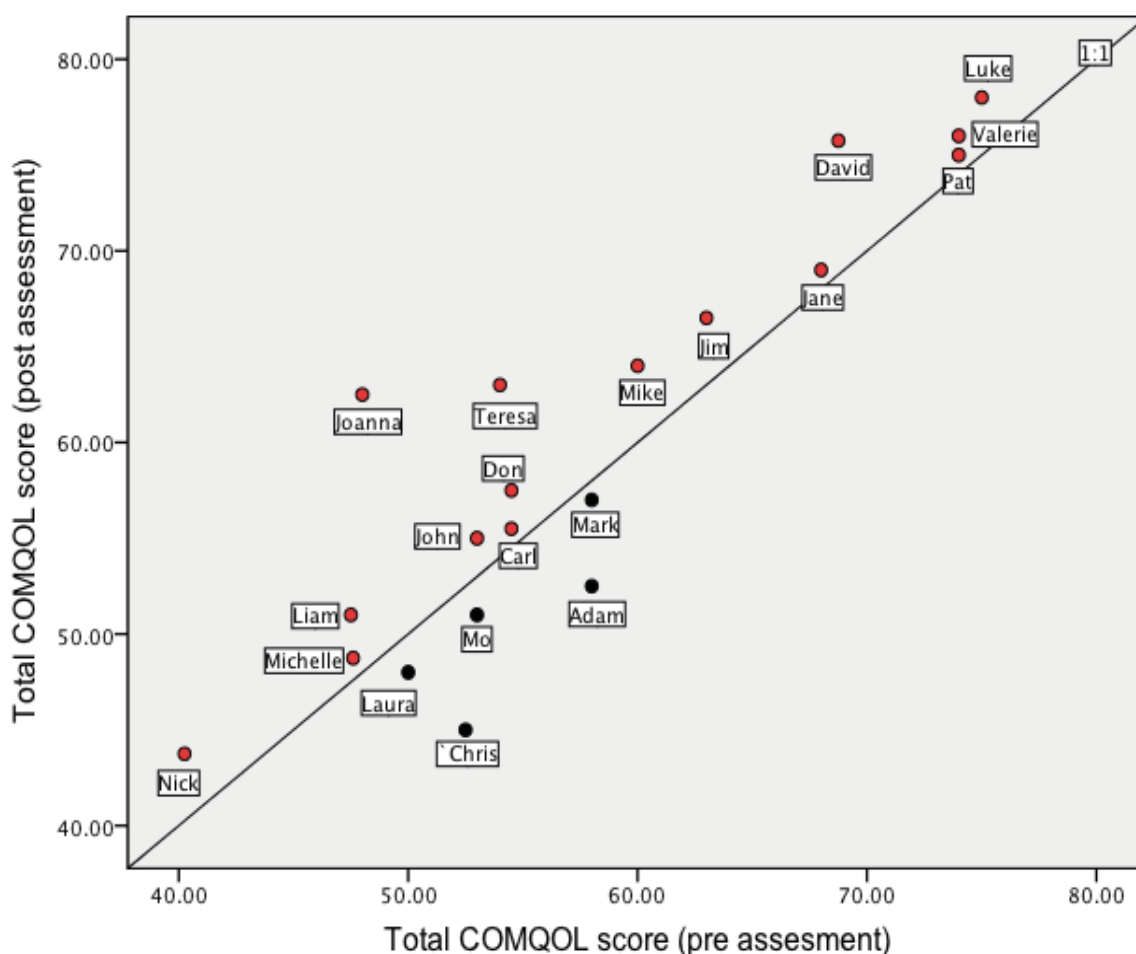
Chart 5.4

At the outset of this study, one factor in the selection of the COMQOL-I5 was that it was a tool that had been used in other studies and this allowed consideration of the ways in which scores in this study compared to other findings. Chart 5.3 shows the COMQOL-I5 scores for a sample of 150 Australian people with a learning disability from a study by Verri et al in 1999. Chart 5.4 shows the COMQOL-I5 scores for this researcher's study group. There are some observable similarities in the pattern of data gathered in both the samples as well as some differences.

In both sample groups there are relatively low mean scores for material wellbeing and community participation. In Verri's study, the health, safety and emotional dimensions had similar mean scores to each other at around 60%. In this researcher's sample, these same dimensions scored between 60 and 70 so were slightly higher. Social interaction showed one of the highest scores in the Australian sample but this was not the case for this researcher's group, where mean scores were around 50%.

5.4.3 Descriptive COMQOL-15 results at an individual level

Graph 5.1: A scattergraph showing individual participant changes in COMQOL-15 scores across the diagnostic process



Graph 5.1 is a scattergraph that shows the change in total COMQOL-15 scores from before to after the diagnostic process at an individual level. The centre, diagonal 1:1 line represents the point where a score remained unchanged between the two interviews. Those participants who are shown above this diagonal line showed an increase in their

total COMQOL-I5 score after the diagnostic process. Those shown below the diagonal line showed a decrease in their COMQOL-I5 score after the diagnostic process. Participants who are marked on the lower left side of the graph will have begun the diagnostic process with a lower COMQOL-I5 score whilst those marked on the higher right hand side of the graph will have begun the diagnostic process with a higher score.

Graph 5.1 shows that scores were spread across a wide range with participants such as Luke, Valerie, Pat and David beginning the process with scores over 70 (out of a possible 105). The majority of the participants began the process with middle to lower end scores and Nick, Michelle and Liam all began the process with scores below 50.

Graph 5.1 shows that the majority of the participants had only small movement away from the central diagonal line before and after their diagnostic process. For the majority of participants, any changes that occurred were in a positive direction with a cluster of five participants, Laura, Mo, Mark, Adam and Chris, who showed a reduction in their objective quality of life score after their diagnostic process.

One outlier was Joanna who showed the greatest positive change in her mean objective score with David and Teresa also showing more positive objective score change than the majority of participants.

These three participants did not have any specific factors in common.

Joanne had moved back to university and was getting specific support in relation to her autism after having failed the year before; Teresa had been reassessed following her diagnosis and had moved house and had the possibility of getting some support worker time. David had begun a voluntary job and his employment support had changed their approach following his specific language difficulty diagnosis and he had the possibility of future paid work. In considering the five participants showing negative changes, Laura showed the greatest of these. New factors for her post-diagnostically were an additional diagnosis of a learning disability and a formal diagnosis of depression.

5.4.4 Descriptive statistics for PWI-ID mean scores

To gain a subjective score of quality of life, participants were asked standard questions using the PWI-ID. This involved asking the participants for their satisfaction levels with their life as a whole and the seven quality of life dimensions making up the PWI-ID. Participants then selected a score on an 11-point Likert scale. If they were assessed as requiring it, then this was reduced to a two, three or five-point scale and the resulting raw score was then converted to a percentage.

Table 5.7 shows the mean scores across all the PWI-ID dimensions and shows the range of scores that contributed to these means.

Across all the dimensions these scores ranged from zero at the lowest end to 100 at the highest. In the dimensions of material wellbeing, productivity and social interaction, participants' lowest scores were greater than zero. In other dimensions participants sometimes chose to represent their perception of their subjective wellbeing with a rating of zero.

Table 5.7: Descriptive statistics for PWI-ID scores across all dimensions

	N	Minimum	Maximum	Mean	Std. Deviation
PRE Life as a whole	20	.00	100.00	49.5000	29.59819
POST Life as a whole	20	.00	100.00	55.7500	25.25007
PRE Material wellbeing	20	25.00	100.00	71.7500	27.30312
POST Material wellbeing	20	20.00	100.00	64.7500	25.72501
PRE Health	20	10.00	100.00	57.7500	28.07298
POST Health	20	.00	100.00	50.0000	23.61980
PRE Productivity	20	10.00	100.00	64.5000	27.23678
POST Productivity	20	20.00	100.00	57.0000	21.78846
PRE Social interaction	20	10.00	100.00	73.0000	28.62645
POST Social interaction	20	10.00	100.00	64.5000	25.28261
PRE Safety	20	.00	100.00	58.5000	30.74085
POST Safety	20	.00	100.00	61.7500	29.12202
PRE Community participation	20	.00	100.00	53.6250	30.90174
POST Community participation	20	.00	100.00	59.2500	28.11045
PRE Future	20	20.00	100.00	60.0000	23.39591
POST Future	20	.00	100.00	60.0000	26.45751
PRE Average PWI	20	26.00	100.00	62.5250	18.64874
POST Average PWI	20	29.00	100.00	60.1500	19.31259
Valid N (listwise)	20				

Chart 5.5: PWI-ID scores across all dimensions and scores pre and post-diagnostic process

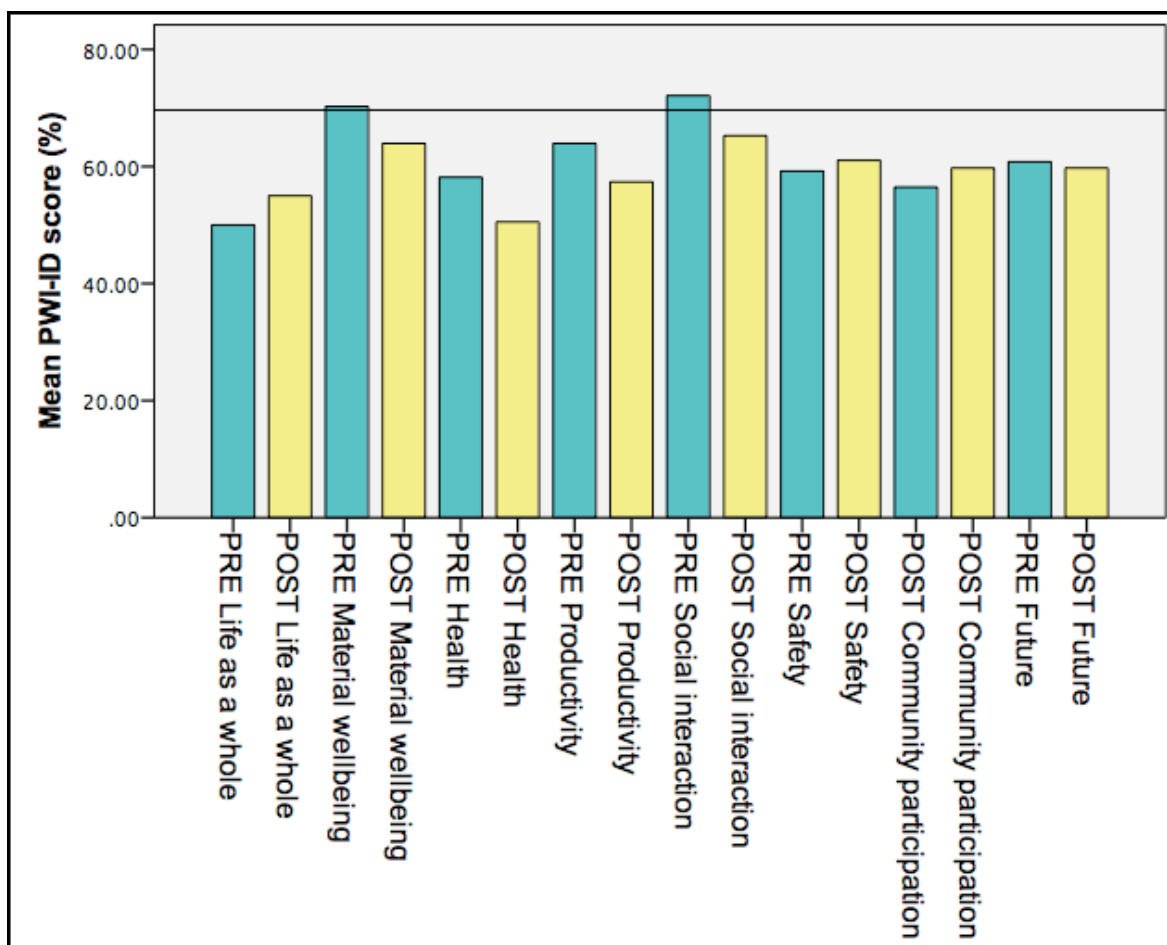


Chart 5.5 shows the change in mean scores in each dimension between the pre and post-diagnostic process interview. In the majority of dimensions the mean scores changed by a relatively small amount (< 5%). In the dimensions of material wellbeing, productivity and social interaction Chart 5.5 shows a more visible negative change in mean scores.

Chart 5.5 shows the line indicating a 70% score in the PWI-ID above which most studies (McGillivray et al 2009; Hensel et al 2002) suggest a 'normal' level of subjective wellbeing. This shows that in this study the only mean subjective scores that reached expected levels were in

material wellbeing and social interaction prior to the diagnostic process. This will be considered in more depth in relation to a larger scale study later in section 5.4.6.

5.4.5 Analysis of significance of observable change in PWI-ID scores across whole sample group

In order to analyse whether the observable changes to pre and post-diagnostic means were statistically significant a non-parametric Wilcoxon Signed Ranks test was carried out.

Table 5.8: Analysis of observable change in mean PWI-ID across sample group

	POST Life as a whole - PRE Life as a whole	POST Material wellbeing - PRE Material wellbeing	POST Health - PRE Health	POST Productivity - PRE Productivity	POST Social interaction - PRE Social interaction	POST Safety - PRE Safety	POST Community participation - PRE Community participation	POST Future - PRE Future	POST Average PWI - PRE Average PWI
Z	-1.222 ^b	-.999 ^c	-1.092 ^c	-1.093 ^c	-.627 ^b	-1.395 ^c	-.642 ^b	-.104 ^b	-.503 ^b
Asymp. Sig. (2-tailed)	.222	.318	.275	.274	.530	.163	.521	.917	.615

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks

c. Based on positive ranks

Table 5.8 shows this calculation, which indicated that in all dimensions the resulting p value was greater than 0.05. A p value of less than 0.05 would be required for an analysis to indicate that any differences were statistically significant. For this reason any changes observed in subjective mean scores were not considered to be statistically

significant. Wilcoxon's test only uses differing scores in its calculation and excludes pre and post-diagnostic scores that had remained the same. It was, therefore, important to consider how likely the pattern of scores within the sample is to have occurred by chance. For this purpose a binomial test was carried out and this is illustrated in Table 5.9.

Table 5.9: Binomial test of distribution of patterns of score change for PWI-ID in the sample

		Category	N	Observed Prop.	Test Prop.	Exact Sig. (2-tailed)
PWI Scores	Group 1 Stable of negative change in scores	.00	8	.40	.50	.503
	Group 2 Positive change in scores	1.00	12	.60		
	Total		20	1.00		

This calculation indicated that there was a 50.3% chance of this balance of scores occurring in this sample by chance. This level of chance would have needed to be considered carefully if any claims of significance had been made in relation to the outcome of the Wilcoxon's test on this data.

5.4.6 Comparison of this study with a published study using PWI-ID with people with a learning disability

Chart 5.6 and Chart 5.7: A side-by-side comparison showing mean PWI-ID scores across dimensions in McGillivray's 2009 study and this researcher's study

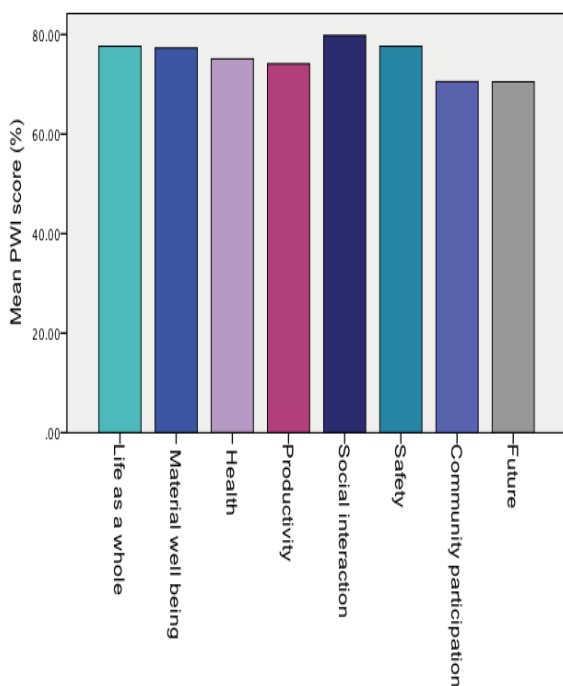


Chart 5.6

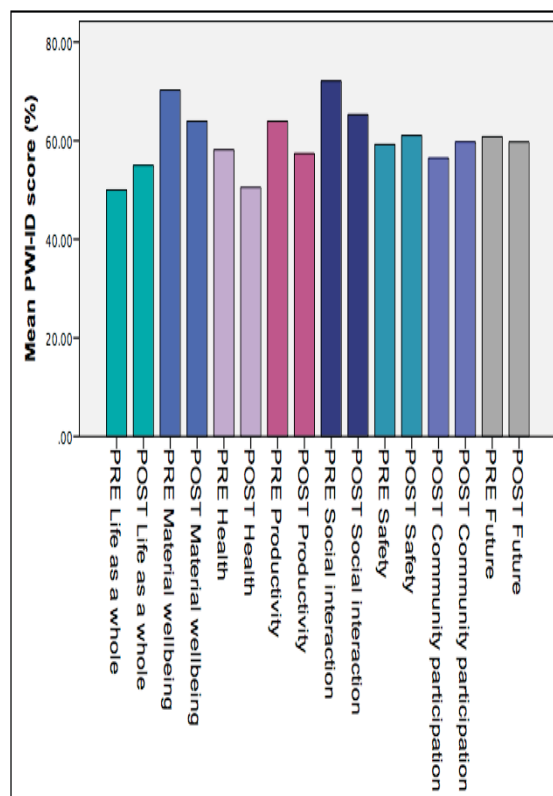


Chart 5.7

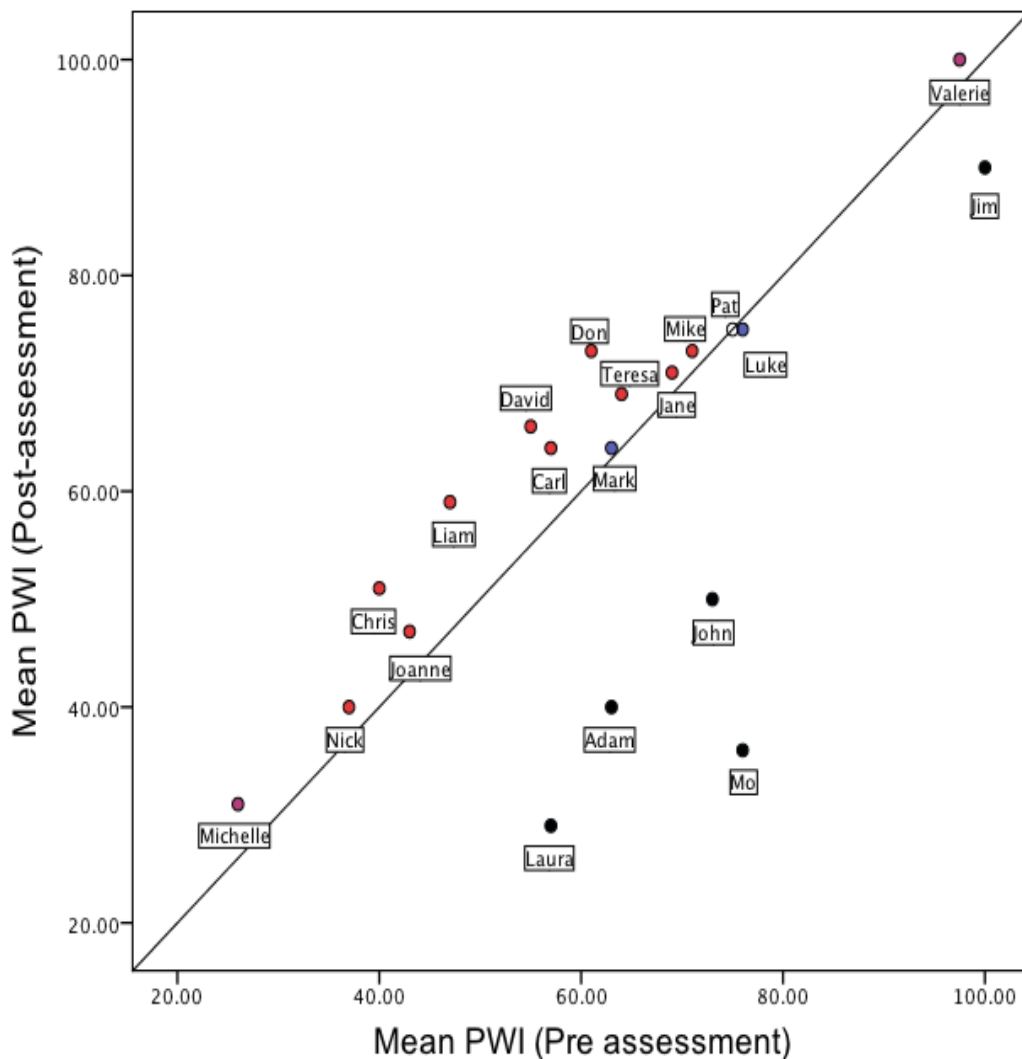
Chart 5.6 shows the PWI-ID scores for a group of 112 people with a learning disability from a study by McGillivray et al (2008) carried out in the United Kingdom. This study demonstrated that the mean level of satisfaction with 'life as a whole' and across all dimensions was 75% or more in their sample. This concurs with the theory that most individuals maintained high levels of life satisfaction and suggested

that this might be the same for people with a learning disability, although people with autism were excluded from this study. Chart 5.7 shows the pattern of PWI-ID scores from this researcher's sample group.

There are some similarities and some differences between these two sets of data shown by a side-by-side comparison of Chart 5.6 and Chart 5.7. In very broad terms, McGillivray's sample had very similar high scores in all dimensions (75-80%). This researcher's sample had a less even pattern of scores and at a somewhat lower level (50-65%). It is notable that 'life as a whole' and post-diagnostic 'health' were visibly lower in the researcher's group in Chart 5.7. The most similar dimensions between the two studies were material wellbeing and social interaction with Chart 5.6 showing that pre-diagnostically these dimensions in this researcher's study were at the more expected levels of satisfaction, with a slight drop after the diagnostic process.

5.4.7 Changes in PWI-ID scores

Graph 5.2: Individual changes in mean PWI-ID scores across the diagnostic process



Graph 5.2 is a scattergraph, which shows the change that occurred to participants' mean PWI-ID scores at an individual level. The central diagonal line represents the points where the mean PWI-ID scores before and after the diagnostic process remained the same, which appears to be the case for Pat shown on this graph. Participants who

were marked above the diagonal line had a mean PWI-ID score that increased after their diagnostic process, whilst those who are marked below the line had a reduced mean PWI-ID score after the diagnostic process. Those participants marked in the lower left end of the graph had a lower mean PWI-ID score before the diagnostic process began, such as Michelle. Those who are marked in the upper right hand end of the graph began the diagnostic process with a score in the higher range, such as Valerie and Jim. In general, it shows that the greatest negative change occurred for those participants who had started the process with lower scores. Jim who began the process with higher scores, showed a drop, but maintained scores within a range that was considered to represent a high level of life satisfaction.

In general, Graph 5.2 shows that the majority of participants had relatively stable mean scores, with the majority staying neutral or making small positive changes but staying close to the diagonal line on the graph. A more substantial negative change was noticeable for a small group. Adam, John, Laura and Mo all appear to have shown visible negative changes in their subjective mean scores. These four had some things in common, but they were not factors that were exclusive to them in the sample. They all had noted additional mental health difficulties, which were described on their quantitative questionnaires as depression that was being treated by their GPs (see Table 5.1). They were all unemployed and all except Laura felt that

they had additional carer responsibilities and lived in socially deprived areas (see Appendix J). It should be noted that Laura used a five-point scale and this meant that her scores were more likely to be extreme. Graph 5.2 shows that Don and David had the most positive change in subjective scores in the group with some post-diagnostic changes recorded for them as David had obtained a job and Don had achieved some educational success. These patterns overall will be considered in more depth in the discussion section of this thesis with the cases of John and David being highlighted for more detailed presentation later in this section.

Figure 5.1 Participants overall scores, pre and post-diagnosis, related to Zapff's dimensions of objective and subjective wellbeing (1984)

Adaptation (Objective Negative/Subjective Positive)	Wellbeing (Objective Positive/Subjective Positive)
Don Post	Jim Pre/ Jim Post
Mark Pre/ Mark Post	Jane Pre /Jane post
Carl Pre /Carl Post	David Pre /David Post
Teresa Pre /Teresa Post	Valerie Pre/ Valerie Post
Mo Pre	Luke Pre/ Luke Post
Adam Pre	Pat Pre/ Pat Post
John Pre	Ralph Pre
Laura Pre	Mike Post
Cathy Post	Joanne Post
Mike Pre	
Nick Pre /Nick Post	
Michelle Pre /Michelle Post	
Joanne Pre	
Cathy Pre	
Don Pre	
John Post	
Laura Post	
Mo Post	
Adam Post	
Liam Pre	
Deprivation (Objective Negative/Subjective Negative)	Dissonance (Objective Positive/Subjective Negative)

Figure 5.1 illustrates the balance of subjective and objective scores for specific individuals using Zapft's (1984) descriptive criteria. Zapft identified people in four states according to the balance of their objective and subjective quality of life indicators. He described people with positive objective and subjective indicators as being in a state of wellbeing. He described people as being in a state of adaptation where they had negative objective indicators but positive subjective wellbeing. He identified those with negative subjective and objective indicators as being in a state of deprivation and the final state was dissonance where people had positive objective circumstances but negative subjective perceptions. For presentation purposes Figure 5.1 describes people with scores of 50% or higher as more positive and 49% or lower as more negative. This table identifies participants both at pre and post-diagnostic points and allows consideration of those participants who remained in the same descriptive state throughout the process and those who changed their state.

Figure 5.1 shows that Mark, Carl and Teresa remained in an adaptive state with positive subjective and negative objective perceptions. Jim, Jane, David, Valerie, Luke and Pat all remained in a state of 'wellbeing' with positive objective and subjective perceptions. It is noticeable that if a participant began the process in a state of wellbeing, this was the state that he/she maintained throughout the diagnostic process, whilst change occurred from the starting point of

adaptation or deprivation. Nick and Michelle remained in a state of deprivation with low subjective and objective perceptions.

Mo, Adam, John and Laura moved from a state of adaptation into a state of deprivation. Cathy and Don moved from a state of deprivation to a state of adaptation and Mike moved from adaptation to a state of wellbeing. Joanna made the most substantial shift, moving from a state of deprivation to a state of wellbeing. It should be noted that for her the greatest change was in her objective circumstances, with her subjective perceptions only just reaching positive levels. Zapft's theory suggests that the states of wellbeing and adaptation represent states in which people can function, whilst deprivation and dissonance are states in which people struggle to function and Cummins et al (2010) suggests that individuals in these groups have experienced a failure in their homeostatic mechanism which could be related in some way to internal or external stress and individual capacity to manage this.

There were no participants who presented with a dissonant state and no single factor such as age, gender or IQ linked those in any specific group. Factors that may have contributed to these results will be discussed throughout chapter 6 of this thesis and the participants' position in relation to these groups was used as a factor in selecting cases for a more detailed evaluation later in sections 5.6.1 to 5.6.4.

5.4.8 Descriptive statistics for visual hierarchy exercise

Participants were asked to rank the seven dimensions of quality of life. They did this using a visual hierarchy that allocated a number to each dimension. For the purposes of clear graphical presentation and analysis this was transposed so that a participant's ranking of one (most important) was given a score of seven and a participant's ranking of seven was given a score of one.

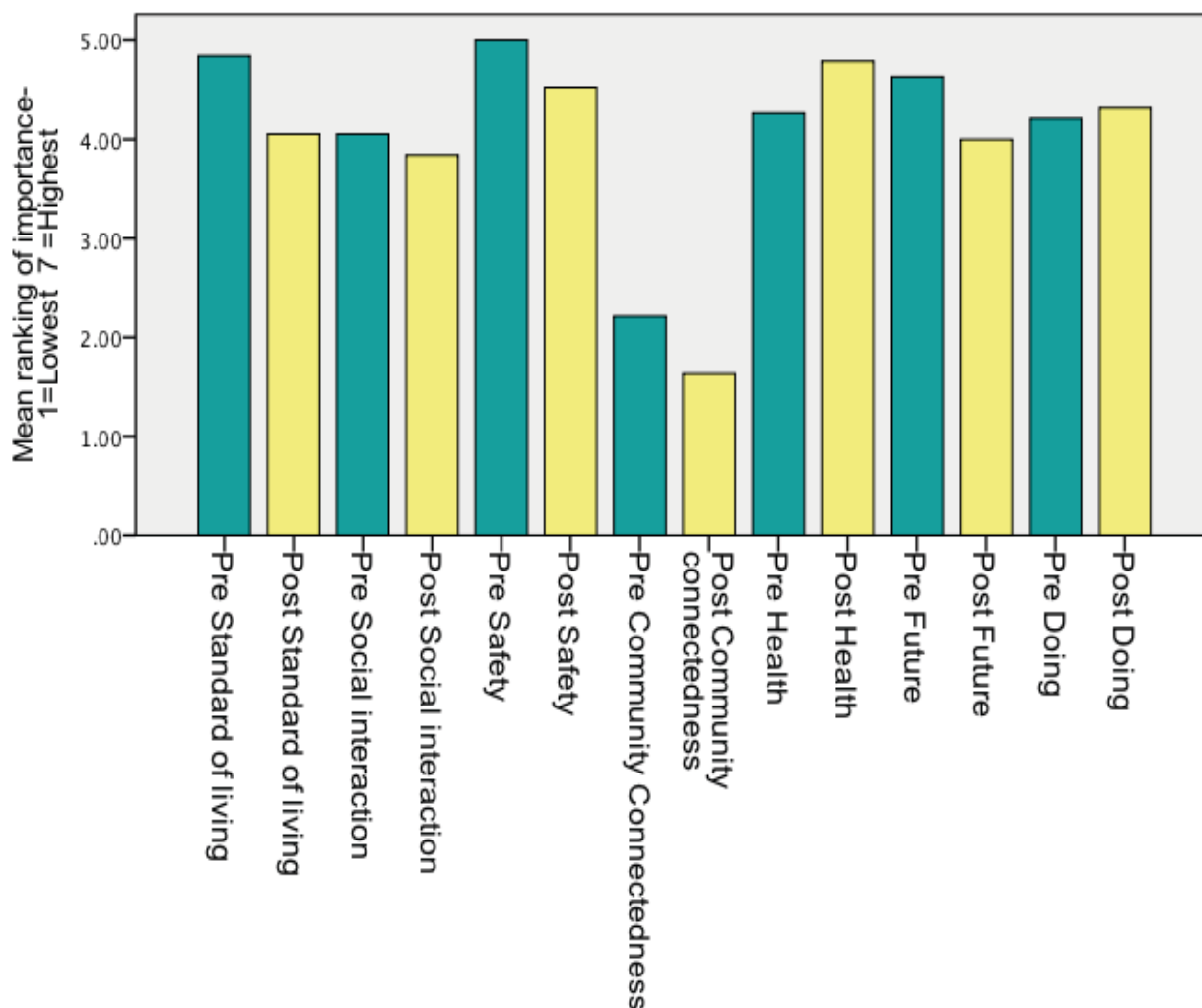
Table 5.10: Descriptive statistics for visual ranking exercise ratings for participants in study

	N	Minimum	Maximum	Mean	Std. Deviation
PRE Standard of Living	20	2.00	7.00	4.8500	1.59852
POST Standard of Living	20	1.00	7.00	4.1500	1.84320
PRE Social interaction	20	1.00	6.00	4.0500	1.50350
POST Social interaction	20	1.00	7.00	4.1000	2.14966
PRE Safety	20	1.00	7.00	4.9500	2.13923
POST Safety	20	1.00	7.00	4.4500	2.06410
PRE Community connectedness	20	1.00	6.00	2.3500	1.75544
POST Community connectedness	20	1.00	6.00	1.9500	1.53811
PRE Health	20	1.00	7.00	4.4000	1.72901
POST Health	20	2.00	7.00	4.5500	1.90498
PRE Future	20	1.00	7.00	4.2500	2.14905
Post Future	20	1.00	7.00	3.9500	2.08945
PRE Doing	20	1.00	7.00	4.5500	1.90498
POST Doing	20	2.00	7.00	4.2500	1.48235
Valid N (listwise)	20				

Table 5.10 shows the range, mean and standard deviation of the ranked order choices of specific dimensions across the group. This shows that in most dimensions a full range of ranks was selected. In most dimensions the mean score was around three or four, which

suggested an even spread of decisions within most dimensions about dimensions importance between participants.

Chart 5.8: Mean ranking scores for each dimension across study group



The notable exception to this was the dimension of community connectedness. Chart 5.8 indicates that the mean ranking score for this dimension was between one and two, which suggests that a larger number of participants chose to rank this dimension as of lower importance. Chart 5.8 shows differences in mean ranking scores

across dimensions before and after the diagnostic process. In broad terms, mean rankings remained relatively stable before and after diagnosis. There was some observable change shown by Chart 5.8 with a reduction in the importance ranking of material wellbeing, community connectedness and the future after the diagnostic process. Individual decisions will be explored later in sections 5.6.1 to 5.6.4 through the use of case examples and the strengths and limitations of this exercise will be considered in the discussion element of this thesis (section 6.11).

5.4.9 Summary of quantitative results

Participants in this study generally presented with objective indicators, which had some similarities to other studies of people with learning disabilities, with low scores in material wellbeing and community connectedness. This study group showed lower objective scores for social interaction and higher scores for health, safety and emotional wellbeing. Overall, objective scores were relatively stable throughout the process with the majority showing small positive changes and this being particularly noted in overall COMQOL-I5 scores and in the area of emotional wellbeing, this was close to but not at a statistically significant level of difference. At an individual level, it was noted that where objective scores worsened this was generally where they had been low at the outset of the study and this was reflected in a small

cluster of participants who demonstrated a negative change in their objective indicators.

In general, subjective wellbeing scores were lower than might have been expected and this tended to remain relatively stable throughout the diagnostic process. The most positively perceived subjective dimensions were in material wellbeing and social interaction and the least positive were health and community connectedness. In individual terms the majority of participants showed stability or small positive changes were noted, with a small subgroup that had notable decreases in their subjective perceptions by the end of the study. Whilst participants varied in their starting score, if they began with very positive perceptions these were likely to remain high.

This links to the pattern that participants who began the process in a state of wellbeing seemed to maintain that balance, whilst those who were in an adaptive or deprived state showed changes by the end of the diagnostic process.

Relative importance of dimensions of quality of life appeared to vary considerably between participants with the exception of community participation, which was more consistently rated as lower in importance than the other dimensions.

5.5 Qualitative results

5.5.1 Introduction

This section will present the qualitative results from this study. All the qualitative data was subjected to a thematic analysis (TA) using the methods described by Braun and Clarke (2013). This process resulted in the identification of coded data judged to link to the quality of life perceptions of the participants. These codes were then appraised to identify candidate-overarching themes, which linked these codes (Braun and Clarke 2013). These were evaluated in relation to the whole data set until centralising overarching themes had been decided upon.

The results of the analysis of qualitative interviews will be presented, initially describing and explaining the identified central themes (see Figure 5.2) across the entire data set. Giving examples of data from specific participants from the whole data set support this. The relationship between central themes and subthemes will be visually represented and described. This description will include some illustrative examples from the interviews and brief comment on the balance of these codes within the data or for individuals. The balance of negative and positive subthemes and the relationship between these and the dimensions of quality of life that have been at the basis

of the tools used for this research will be presented diagrammatically (see Figures 5.11 and 5.12).

Finally, the pattern of data being gathered that related to central themes, before and after the diagnostic process, will be presented in tabulated form (Table 5.11).

5.5.2 Central themes related to quality of life perceptions across whole data set

This section will present the qualitative results from the analysis of data generated by the qualitative interviews carried out in this study.

Figure 5.2: Central themes identified from data set

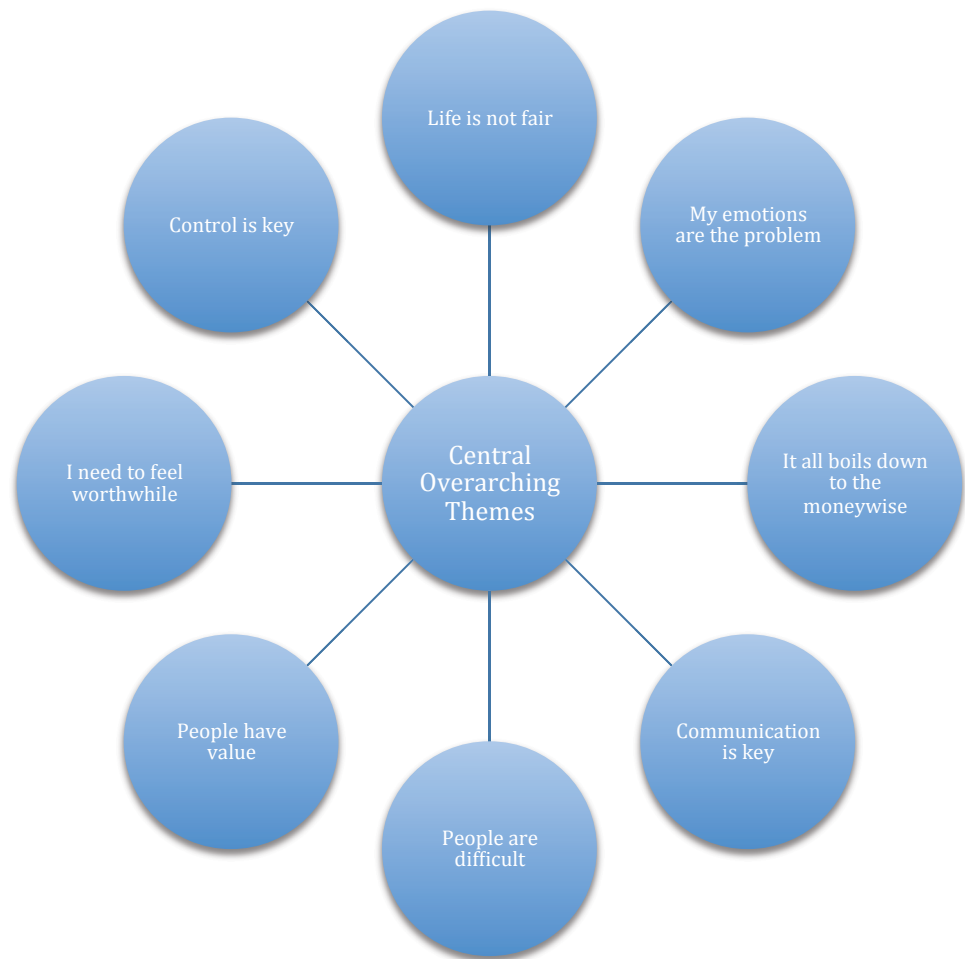
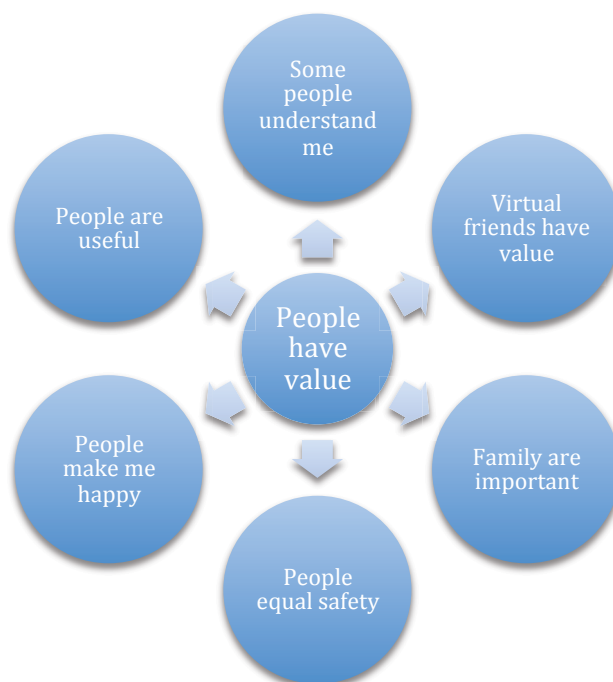


Figure 5.2 shows the central overarching themes that were selected because they most effectively linked the subthemes, which had been developed through coding of the data in the qualitative interviews. These central themes will now be presented in more specific detail with illustration of their subthemes and some examples from across the entire data set.

5.5.2.1 People have value

Figure 5.3: Subthemes that were linked by the central theme of 'People have value'



This was a central theme, which encapsulated a sense that the participants perceived an inherent value in people in relation to their lives and the quality of that life. A number of subthemes were identified for which this was an overarching theme and this is illustrated in figure 5.3 above.

Adam expressed the value of his partner and the importance of family:

'... or when she is out... I panic and get nervous.'

Jane referred to the positive role of others when she accessed the community:

'... but I feel better when x was there because I had someone with me.'

John described his mother's role in improving interaction with services:

'If my Mum's not happy with it she'll be on the phone and say "look you're not helping my son out."'

John also referred to the happiness he gained from his relationship with a shopkeeper with whom he interacted on a daily basis:

'It's basically because he cheers me up more and we have a laugh.'

Valerie highlighted the feelings of safety her carers gave her, and the importance of this feeling when she said:

'You know that no matter what I need to be safe so that I know... oh and that the most important thing to keep me safe is that they never walk off without me.'

For others, such as Pat, this was about a more general perception of the importance of people for safety in their lives:

S: *'So is there anything else that helps you feel safe?'*

P: *'um um um I feel safer with people.'*

Adam, Jane, John, Pat, Teresa and Valerie all described a sense that particular people understood them. John, for example, when referring to his wife:

'People don't have to trigger me off... my missus always said to me... she knows when I am not very happy.'

Valerie explained the benefits of her carers understanding her. She used the term 'real carers' to describe those who knew her and 'strangers' for paid carers who were new to her:

'Like this new lady in here. It's only because they're strangers... that's when I need help from my real carers.'

Family were frequently referred to as useful and important in a number of ways. In the case of Jane she shared an especially intense interest the Eurovision song contest with her father, which meant his presence could have a positive impact on her:

'I ...I don't. I would say if my Dad's here it's a lot more fun because we have...end up talking through it and everything.'

Teresa viewed her family as an important part of life's routine, which she described in a positive way:

'Then on a Sunday the boys come up for their Sunday lunch and basically spend the day with the boys and once the boys have gone home we sit down and watch the TV.'

Jane, David and Adam described the importance of and ascribed value to some virtual social relationships, raising feelings of a sense of belonging and self-esteem. Adam was a keen user of 'Call of Duty'.

A: *'There is a group of us and we are a clan...we go against each other clans and that.'*

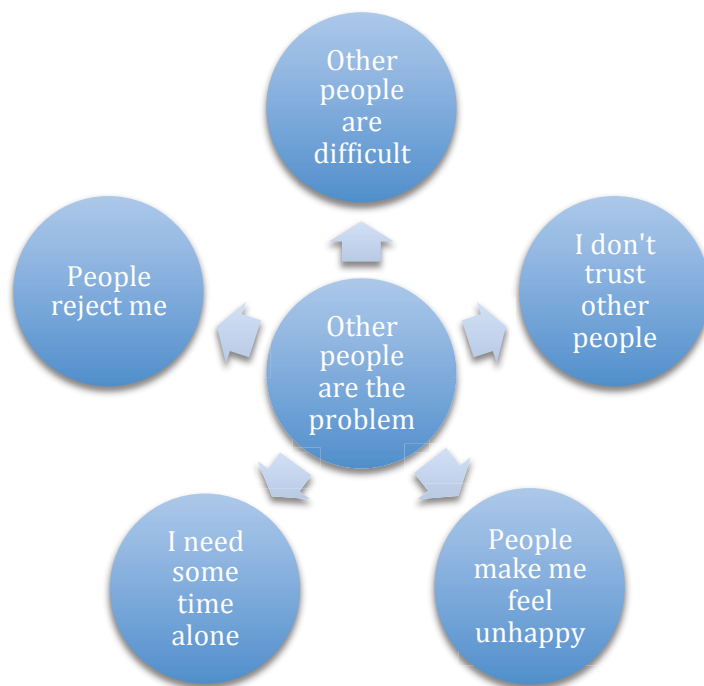
A: *'We are Elite.'*

S: *'Is that quite important?'*

A: *'Well yeah (shakes head laughing) to us.'*

5.5.2.2 Other people are the problem

Figure 5.4: Subthemes that were linked by the central theme of 'Other people are the problem'



This was a central theme illustrated by Figure 5.4, which linked together data that expressed the perception that responsibility for difficulties and dissatisfaction that the participants were experiencing in their daily lives lay with other people.

Valerie described her feelings if people were unhappy with her behaviour:

'Well... well that like if I was to been told off that would make me upset and a bit sad.'

A common theme for all of the participants was the need to be able to get away from people and a frustration that this was not always possible or acceptable to others. Pat described the challenges for him of living with others in shared supported living:

P: *'Sometimes, sometimes they burst in.'*

S: *'They burst in?'*

P: *'No not burst in sometimes they... sometimes they... need a bit of time to yourself.'*

Teresa described her reaction to attempts from neighbours to interact with her and her daughter when she was asked whether she ever interacted with her neighbours:

'I don't, I only say "good morning" and "good afternoon" to 'em and that is it (emphatic) I get in the flat and we shut the door and that is it.'

In response to questions about what made him feel safe, Mark responded:

'Like to have time alone.'

David described a sense of rejection from wider society in his lack of interaction with his neighbours in the local area:

'No very much an outsider looking in. Trying to look in but the curtains are drawn.'

John described a feeling of rejection from his father, who had dementia, and his reaction when John tried to go and see him:

'He doesn't like me spending time with my mum... like the other night I went round her house and she's in there and tell me to get out.'

All the participants described a feeling that other people were being difficult in some way. Mark, for example, described the reasons that he found it difficult to make relationships with people:

'That'd be a bit hard (sigh) difficult for me to engage with them.'

David described the way in which the behaviour of others limited him in terms of where he could go in his home:

'I'll stand there in the door but I don't want to be in that room where those people are gonna be yelling and shouting. I'd rather stick where people keep their feelings to themselves.'

All participants, except for Mark and David, described a perception that other people could not be trusted. This code appeared especially important for Teresa who described a range of difficulties with trust, including her perception of her relationship with a neighbour who had been a friend:

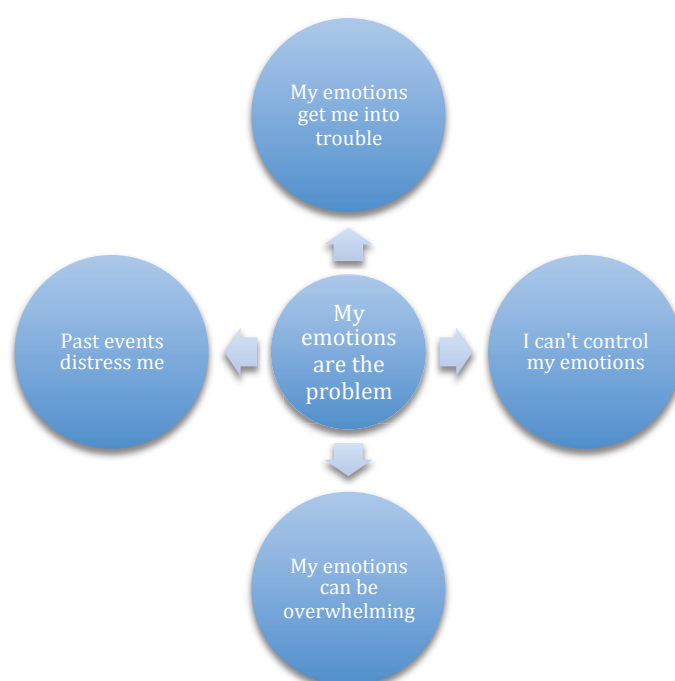
T: *'Cos the other one just messes me and M about and uses us.'*

S: *'The other one?'*

T: *'Ah the other girl well you could call her a... she a p... she used to be a friend of me and M but now she just uses me and M basically.'*

5.5.2.3 My emotions are the problem

Figure 5.5: Subthemes that were linked to central theme 'My emotions are the problem'



This was a central theme, illustrated by Figure 5.5, which was linked to the participants perceiving that their emotions and lack of emotional control affected their quality of life.

Adam, John, Pat, Teresa and Valerie described getting into trouble because of their emotions. John described his tendency to get into

fights and arguments and he focused on the impact that this had on him:

'Cos at the end of the day it's not a person it's going to hurt it's me.'

Pat described breakdowns with his family caused by emotional upsets:

'Yeah upset I wanna play my guitar but Mum told me not to and sometimes I call nasty words sometimes.'

All participants, except David and Jane, talked about difficulties with emotional control affecting their lives. Teresa, for example, described the effect other people had on her:

'As just everything at the moment is really getting worse with me down. It just getting the weight of anger at the moment it is about to explode... I'm to exploding point.'

John described lack of emotional control and unpredictability:

J: *'It could strike anytime.'*

S: *'So sometimes you get crossfired.'* (John's word)

J: *(nodding)*

All participants, except for David, described a sense of being overwhelmed by emotion. Jane, for example, described overwhelming panic on going into a new environment.

'Like I found it really hard when we went to D that day I found it really hard to get in the door cos I felt really uncomfortable.'

Jane, John, Pat, Teresa and Valerie expressed a perception that their current life was negatively affected by past distressing events. John, for example, in describing his current concerns explained this in the context of a distressing historical experience:

'My health over Christmas time deteriorates. 1982 I was in hospital before I came down here.'

Pat experienced acute emotion during the interview in relation to historical events:

P: *(crying) 'Because I mucked up my Dad's computer.'*

S: *'Oh when did that happen?'*

P: *'Couple of years ago back he was shouting at me (angry).'*

5.5.2.4 Life is not fair

Figure 5.6: Subthemes that were linked by the central theme of 'Life is not fair'



This central theme, illustrated by Figure 5.6, included data linked to participants' perception that their life experience was not fair compared to others or society in general. Adam and John expressed the view that they had missed out because they were not disabled enough:

A: 'I just didn't have the right school... the right school help. I was always the one who got like left. Get on and do things by yourself and that.'

John expressed the perception that others saw him as more able than he was:

'I get pushed around get told "you can stand on your own two feet" "deal with your own health" "you can deal with everything". I ask for help from the doctors I ask for help from anywhere ok.'

Adam, David, Jane and John described the ways in which they felt their disabilities impacted negatively on their lives. All of these participants had additional disabilities beyond an autism and learning disability diagnosis. Adam expressed the view that his level of disability did not match his level of financial benefits:

'Sorry my disability should be more than what I'm getting with all the problems that I've got.'

Adam, David, John and Pat all expressed a perception that their local community had rejected them. Adam described a sense of humiliation and rejection in his local area, as he had had to moderate his behaviour to fit in:

'I got to be more like "don't say nothing". Makes me, you know, makes me look like I'm nothing. They can take the mickey out of me.'

David described a sense of rejection in the world of employment:

'If a company had two of them it is the disabled person that gets fired first. It just feels like really I just it makes me want to cry sometimes the way people seem to react to a disabled person (voice trembling with emotion).'

John, Adam, David and Teresa all expressed the perception that their lives were less good than others. This was a strong theme for John, especially post-diagnostically, who felt others didn't understand or appreciate how difficult his life was compared to theirs, describing his life as:

'Just the same every day. I take the same all the time. None of you round here have any idea what it is like for me but I take one step at a time.'

David, Jane, John, Teresa and Valerie all expressed the view that their life was negatively affected by other people's judgments of them.

Teresa felt that others reported her to the authorities and unfairly judged the way she chose to live:

'But still go back to the housing officer and say "that house stinks".'

David described feeling judged by the system:

'I have to have the paperwork to show what I have been doing. I feel like I am being judged on how... to other people's standards... I haven't done enough.'

John, pre-diagnostically, had directly expressed hopes that his situation would be changed in some way and his post-diagnostic perceptions appeared to reflect disappointment at a lack of change:

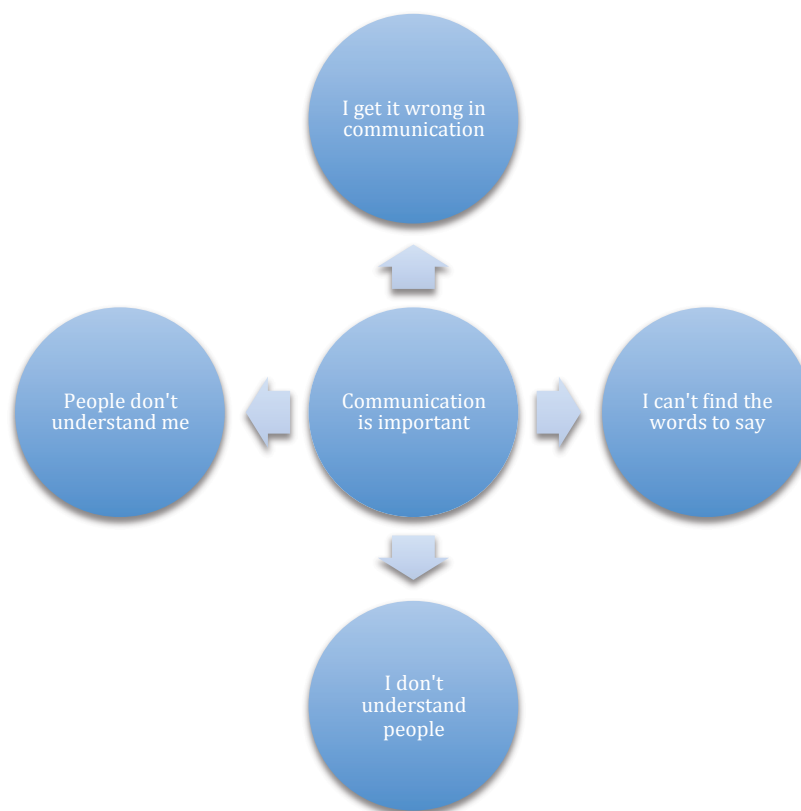
'You wouldn't see much change I'm the same person I am.'

'Nothing's changed (unhappy voice) where we are.'

'The future's only going to be like it is now.'

5.5.2.5 Communication is important

Figure 5.7: Subthemes that were linked by the central theme of 'Communication is the problem'



This was a central theme, illustrated by Figure 5.7, which brought together perceptions related to either the participants' communication or how others communicated with them. All these represented negative perceptions. John, Teresa and Valerie, who all had a mild learning disability, commented on the difficulties that they had with understanding other people:

J: *'Sometimes I get confused with what you're talking about or I get confused with what I am saying.'*

Adam, John and Valerie, who all had a mild learning disability described difficulties with expressing themselves on a day-to-day basis. Adam described:

'Well where I can't get my own words out like normal.'

Valerie described the difficulty of expressing herself when in groups:

'If a lot of people are asking that (what's wrong?) and they are all surrounding me in a big circle it is hard to explain when a lot of people gather around me.'

Jane, along with the other participants with mild learning disabilities, expressed frustration at other people's inability to understand what she was trying to convey:

'It's like people are trying to understand me but they are going about it in the wrong way if you know what I mean.'

Valerie described frustrations trying to explain things to her carers.

'I'm trying to be gentle with them but it's hard to be gentle with them when you don't understand what I am doing.'

Jane, John, Pat and Valerie all described situations where they struggled to follow the social rules of communication and this created a day-to-day challenge for them. Pat identified that he *'just interrupts, interrupts people's conversations'*. Valerie suggested that she could

'make things worse when I'm trying to speak to them (carers) softly'.

Jane said *'I can get annoyed I'll end up saying things I regret'.*

5.5.2.6 Control is important

Figure 5.8: Subthemes that were linked by the central theme of 'Control is important'



Control is important was a central theme, illustrated by Figure 5.8, bringing together a range of perceptions in the interviews that related to the participants' need to control themselves, others or their environments in order to maintain their wellbeing in their everyday lives.

Adam, Jane, John, Pat and Teresa all expressed the need to control and to some extent succeed in controlling their behaviour to maintain a positive quality of life. Pat described his struggle to control behaviour that was less helpful to him ('cheap') saying he hoped to go on to do:

'new better things and activities to learn my mistakes to trust my instincts and to learn how things is so good not so cheap.'

Jane, Mark and Valerie highlighted the importance of others behaving in the way they wanted them to. This was a particularly strong theme in both of Valerie's interviews and in this pre-diagnostic example she talked about her difficulties with new carers.

'and also, and also it's very important that someone reminds me about these people and that my carers remind these people about me so that they don't you know get the wrong idea because it scares me a bit. Is very important as well is for them to try and understand me they have to try and understand my conditions of my, of the way I can react.'

Control of environment occurred as an important theme for all participants, often in relation to the need to control the sensory environment, as in this example for Pat, which had resulted in a serious relationship breakdown:

'Yes um I hear my Mum's coughing and my brother's coughing. Really wound me up... it's annoying... annoyed me.'

Teresa similarly described the impact of sensory irritation on her mood and relationships when talking about her sons who also have autism:

'but A is very talkative and C he is a bit of dark horse. He just sits there and messes about with his ringtones on his phone and I... with that going on and I'm in the kitchen but my anger starts building up again.'

Other participants described the need to maintain sameness in their environment. Mark, for example, described his need to remain in the same location in order to maintain safety:

S: *'Anything about the place you live that's important?'*

M: *'Upstairs in my room is a safe place.'*

Valerie also emphasised the need for environmental control when describing her room:

'um it feels alright but I would have to organise things just the way I like it.'

This also linked to the theme of needing to control the environment to prevent changes. Jane, for example, described difficulties with coping with changes to her routine:

'Then again I'm still a bit "eeeuu" when things get disrupted and I know it's disrupted and I'm annoyed.'

David, Jane, Teresa and Valerie also indicated a sense of increased control over their lives. Jane described how she had achieved better overall health by reducing some control:

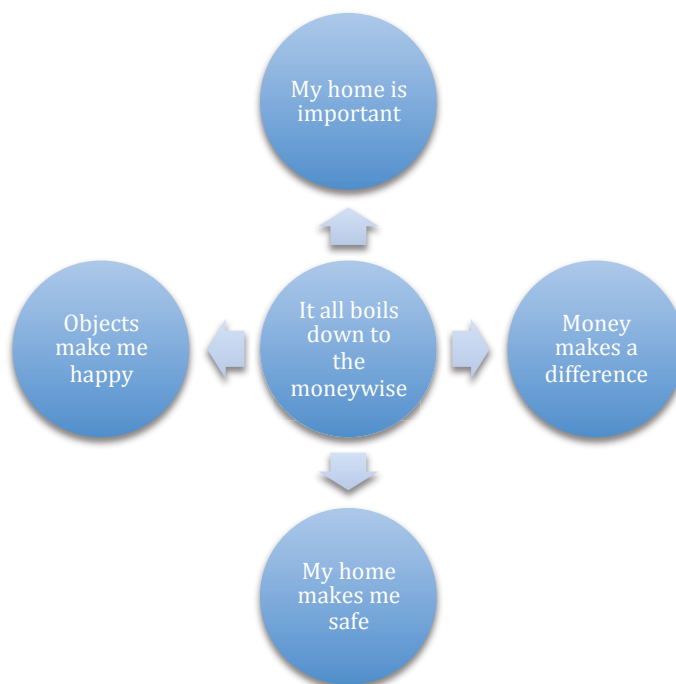
'I think it's because I have learnt to sort of try and relax a bit more.'

Valerie described the way that she had learnt to manage the people around her better:

'or they just come to my room and I'll talk about it to help with the problem.'

5.5.2.7 It all boils down to the moneywise

Figure 5.9: Subthemes that were linked by the central theme of 'It all boils down to the moneywise'



This was a central theme that brought together codes related to money and material ownership or interest. Several participants highlighted the direct difference that money made to their day-to-day lives. Adam, for example, described difficulties managing his weight and his view that this was linked to lack of money:

A: *'I's trying to lose this weight at the moment or someone to train me.'*

S: *'Right.'*

A: *'It's just having the money.'*

John described his sense that money was the factor that made the most difference in his life and the lives of others:

'It's the money, what it boils down too. I am not having a go at anybody. It just boils down to the moneywise and that makes me sick 'cos I've been to the job centre and I've seen people queuing up and they're all "I haven't received this, I haven't received that".'

All participants, except John and David, described the importance of objects or animals to their quality of life. Mark, for example, described the pleasure he gained from looking at a desired object:

S: *'Ah right anything special on Ebay?'*

M: *(Pause) 'The Oncor 1000 American CD player and mixer, that's what I keep looking at.'*

Included in this code were animals, primarily because of Valerie who focused on the pleasure that being able to see and touch animals gave her and a strong sense that they were pleasurable objects:

'I just love to look at the animals' (big smile and exaggerated happy intonation).

'Yeah looking at them and touching them.'

Adam, Mark, Pat, Teresa and Valerie, who all had a mild learning disability but came from a variety of home situations, all very specifically described the importance and value of their home for them:

P: *'I like living here, yeah, this house is my house.'*

When Valerie was asked what could cause her to have concerns for the future, she gave the example of being removed from her home:

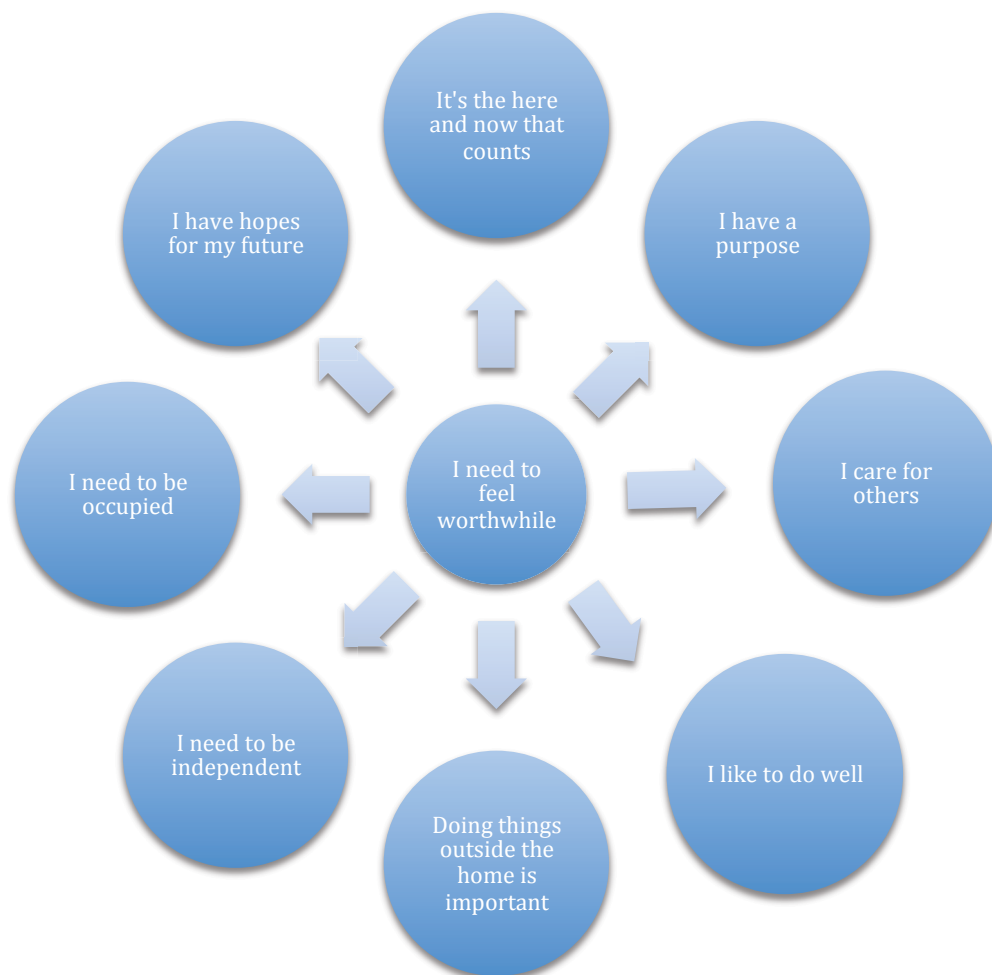
'Well you might say that I might be dragged all the way back from W (home) that would be a very bad future.'

David, Mark, Pat, Teresa and Valerie all linked their home to feelings of safety in some way. Pat described the value for him of knowing the door to his home was secure:

'Makes me feel safe is locking the... checking the... being secure of the doors. I don't want any burglars, burglars or arsonists or being attacked or assaulted or on the roads I don't want to get runned over or knocked over.'

5.5.2.8 I need to feel worthwhile

Figure 5.10: Subthemes that were linked by the central theme of 'I need to feel worthwhile'



This was a central theme uniting codes that expressed the importance for that participant of being engaged in a purposeful way, being occupied, autonomous and valued by others. Figure 5.10 illustrates the subthemes making up this central theme. All participants, at some stage, expressed a need to be occupied. John described his overall approach to life:

'I'm always trying to do summat to keep my hands busy.'

David described the way in which he occupied himself with video games, with a strong sense that this was a way of coping and avoiding the boredom that would go with stopping playing them:

'Usually it's I know it's playing. Usually I think the reason why I play like video games is it burns the hours away.'

Jane, Pat, John and Valerie expressed the need for independence.

Pat described the more independent behaviour of another person that he knew and his view that he should be allowed to do the same and frustration that he was not:

'X goes on a train on his own' (shout and unhappy expression)

'Like to do all sorts of things. I like to visit places on my own... on a coach.'

Adam, Jane, Pat, Teresa and Valerie expressed some sense that they had hopes for the future for their lives. Adam described this when he referred to his ambition to *'be the best'* at 'Call of Duty'.

Teresa described the activities she hoped to do in the future:

'There are things I'd like to do. Dancing and singing and going to the gym.'

The importance of making the best of the here and now was also present for Adam, David, John, Teresa and Jane. Teresa talked about it as a way of managing the difficult nature of life:

'It... I know it seems really hard sometimes but I just take every day as it comes basically.'

David described his perception of being unable to look to the future:

'It's like being on a ladder. I can't see where I'll be in a few days' time let alone a few years' time.'

Many of the participants expressed their own sense of purpose and value in life; sometimes these were in highly practical terms. Valerie and Jane described their feelings of self-esteem in relation to completion of tasks:

V: 'Well if I done the chores well I feel a lot more of myself.'

J: 'I feel really wow feel really good because I can actually cook hash browns' (smiling).'

Several participants had identified caring for others as an important part of the way they saw their lives. Teresa and Adam cared for their children; John felt that he cared for his parents and Jane for her family after her mother left. John expressed the perception that his time was dedicated to his parents' care as his father had dementia:

'My mum can see that I can see it, but at the end of the day I'm still coming to terms. I have some concern about my mum and dad at the moment and that mostly my time is spent on them. As well as what I want to do I have to put my time to them.'

The motivation to succeed and do well was expressed by David, Mark, Jane, Pat and Valerie. David and Adam both talked about this in relation to Internet games. When asked what made him feel good or successful David said:

'Probably this will sound daft when I am playing my on line games with friends is the progression.'

Pat expressed his frustration at not being able to achieve in some areas and his sense that others might judge his need for help:

'I can learn things... really said... I'm not talking about people waving a magic wand and disappear. I'm not really. I don't want I don't want other people playing some magic.'

David, Jane, John, Teresa and Valerie were the only participants who clearly referred to the value for them of doing things outside of their homes. Jane described the challenge that going out had been but the benefits when she had achieved it:

'I think I've gotten better I've gone out more... Cos I've been to the shops on my own. Whereas normally I'd like to sit and wait to go up and look at the bargains... I've done it as much, like sort of worked myself up to going out.'

5.5.3 Changes in central theme patterns throughout the diagnostic process

Table 5.11: Central theme patterns throughout diagnostic process

Themes	Present pre and post-diagnostic process	Present pre-diagnostic process only	Present post-diagnostic process only	Not present for participant
People have value	Adam, Jane, John, Pat, Teresa, Valerie	No participants	Mark	Teresa
People are the problem	Adam, David, Jane, John, Mark, Pat, Teresa, Valerie	No participants	No participants	No participants
Emotions are the problem	Adam, Jane, John, Pat, Teresa	Valerie	Mark	David
Life is not fair	Adam, David, Jane, John, Teresa	Pat	Valerie	Teresa
Communication is important	Adam, John, Teresa	Jane, Valerie	No participants	David, Mark, Pat
All boils down to the moneywise	Adam, David, Jane, John, Mark, Pat, Teresa, Valerie	No participants	No participants	No participants
I want to be worthwhile	Adam, Jane, David, John, Pat, Teresa, Valerie	Mark	No participants	No participants
Control is important	Adam, Jane, Pat, Valerie	David, John, Mark, Teresa	No participants	No participants

Table 5.11 illustrates an analysis of central theme patterns and the ways in which these were observed to occur and change throughout the diagnostic process. Data linked to 'People are the problem' and 'It all boils down to the moneywise' were widely present in interviews for all participants before and after the diagnostic process. The themes of 'People have value' and 'Life is not fair' were present at some point for all participants with the exception of Teresa.

Table 5.11 shows that if a participant began the research process with 'People have value' as a theme in their interview then they also expressed it in their post-diagnostic interview. Data coded as 'People have value' was not seen for Mark until his post-diagnostic interview. 'Life is not fair' was not found in Valerie's post-diagnostic interview whilst Pat began to express this theme in his post-diagnostic interview.

The theme of 'Emotions are the problem' was present at some stage for all participants, with the exception of David. Valerie did not express this theme in her post-diagnostic interview and it was a new theme for Mark in his post-diagnostic interview. 'Communication is important' was present across the process in a smaller number of individuals (Adam, John and Teresa). It did not appear in the post-diagnostic interviews for Jane and Valerie and was not present at any point for David, Mark and Pat.

'I want to be worthwhile' appeared for the majority of participants as a theme in both pre and post-diagnostic interviews, with the exception of Mark for whom it did not appear until after his diagnostic process had been completed. 'Control is important' appeared to be the theme that showed the most change throughout the process. It was not a new theme for any participants post-diagnostically but for David, John, Mark and Teresa it was the theme that did not appear in the post-diagnostic interviews.

Table 5.11 summarises the theme patterns that were expressed during the interviews. A number of factors may have influenced which topics were discussed during both interviews and these results cannot claim that participants' perceptions actively changed during the process, as they might simply have chosen to share specific perceptions on each occasion. The focus of the interviews and the topics participants wished to talk about varied in some cases and this was of interest to report and discuss. It is interesting to note that David and Teresa were participants who did not seem to provide any data at all on particular areas in either of their interviews. For David, this was in the area of emotions and communication and for Teresa the areas of people having value and life not being fair.

5.5.4 Subtheme patterns

Qualitative subthemes were evaluated to consider which ones could be described as positive (appeared to relate to positive quality of life perceptions) and neutral (related to quality of life perceptions but with no indications of positivity or negativity) and then mapped on the seven quality of life dimensions outlined by Cummins (1996) to facilitate understanding them as quality of life perceptions.

Figure 5.11 shows that positive and neutral subthemes were well spread across all seven dimensions, and that the themes with the greatest range were in the dimensions of social interaction and material wellbeing. A number of theme patterns were found that might not have been captured through quantitative data alone. For example, in the area of social interaction many of the themes were related to behaviour and value of other people rather than the more concrete area of the skills or abilities of the participants. This group also regularly referred to their families in positive terms when talking about social interaction and support. There was a sense that for some participants social interaction with family was the interaction they valued the most. The qualitative data highlighted that home was important for safety and security, whilst COMQOL-15 focused on describing the size and type of a person's accommodation. The qualitative data also highlighted the importance of objects and animals

as a source of satisfaction beyond their number, variety and financial value.

Figure 5.12 shows the themes relating to negative quality of life perceptions for the participants. These were mapped onto Cummins' seven quality of life dimensions. What this showed was that whilst all dimensions mapped to at least one theme, social interaction was the dominant area for negative themes. Community participation and physical and emotional health also had a larger number of themes.

Some of these subthemes were not highlighted by the quantitative data or added depth to this data. COMQOL-I5 was able to identify mental health diagnosis or broad measures about levels of anxiety and PWI-ID was able to gather data about satisfaction levels with emotional and physical wellbeing. The qualitative data added depth, for example, by showing perceptions of distress related to past events and problems arising from emotional outbursts and identifying subtle negative perceptions, such as not being disabled enough, not supported or understood by others.

In the area of social interaction, quantitative data had suggested relatively positive perceptions of social interaction. However, the large number of negative perceptions related to social interaction suggests that this area warrants more in-depth consideration. It is interesting to note that the largest number of negative perceptions related to the role

of others creating difficulties in social interaction, rather than difficulties relating to the participants' own skills or ability

Figure 5.11: Distribution of positive and neutral quality of life perceptions across all qualitative interviews (number of references to code across interview in brackets)

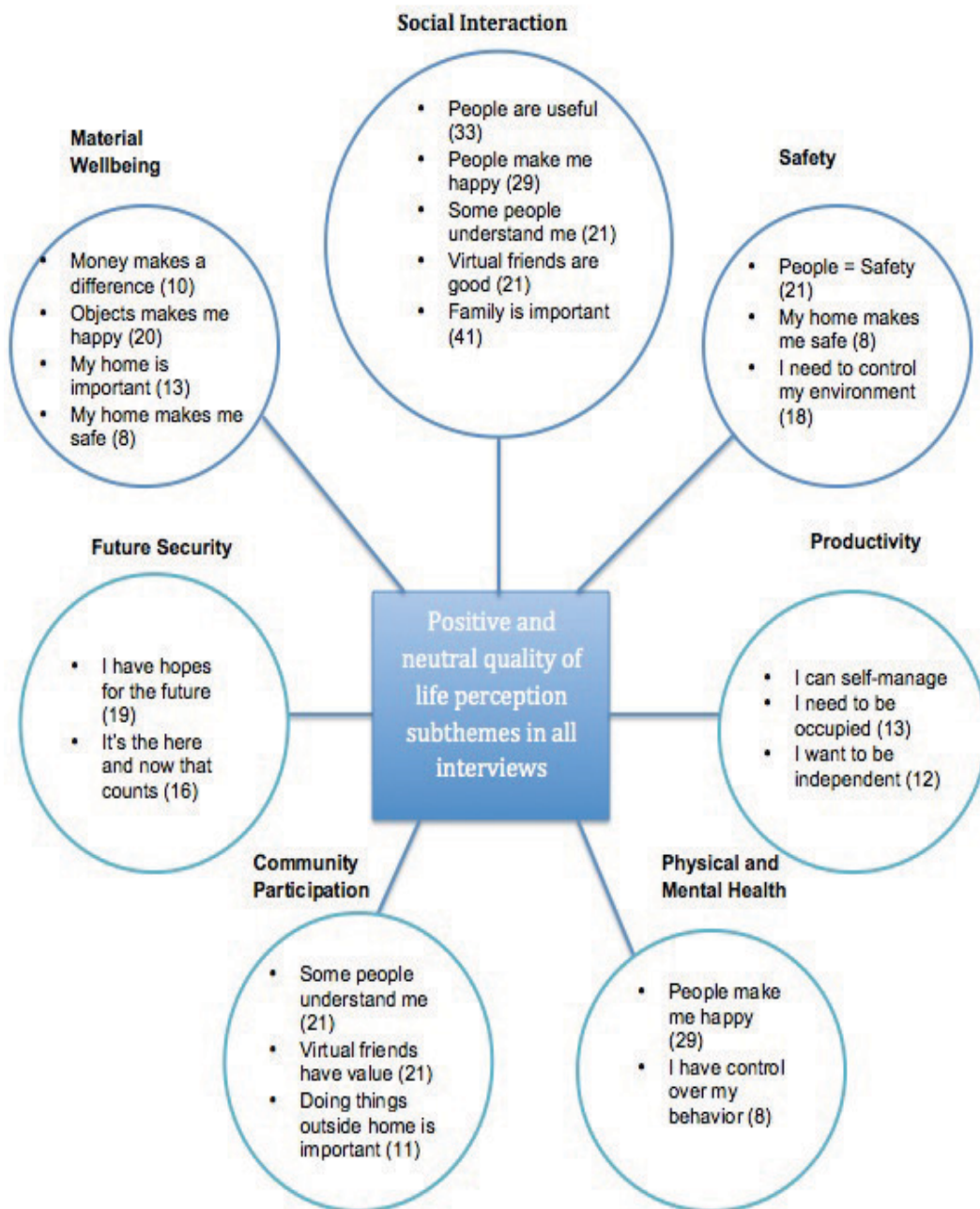
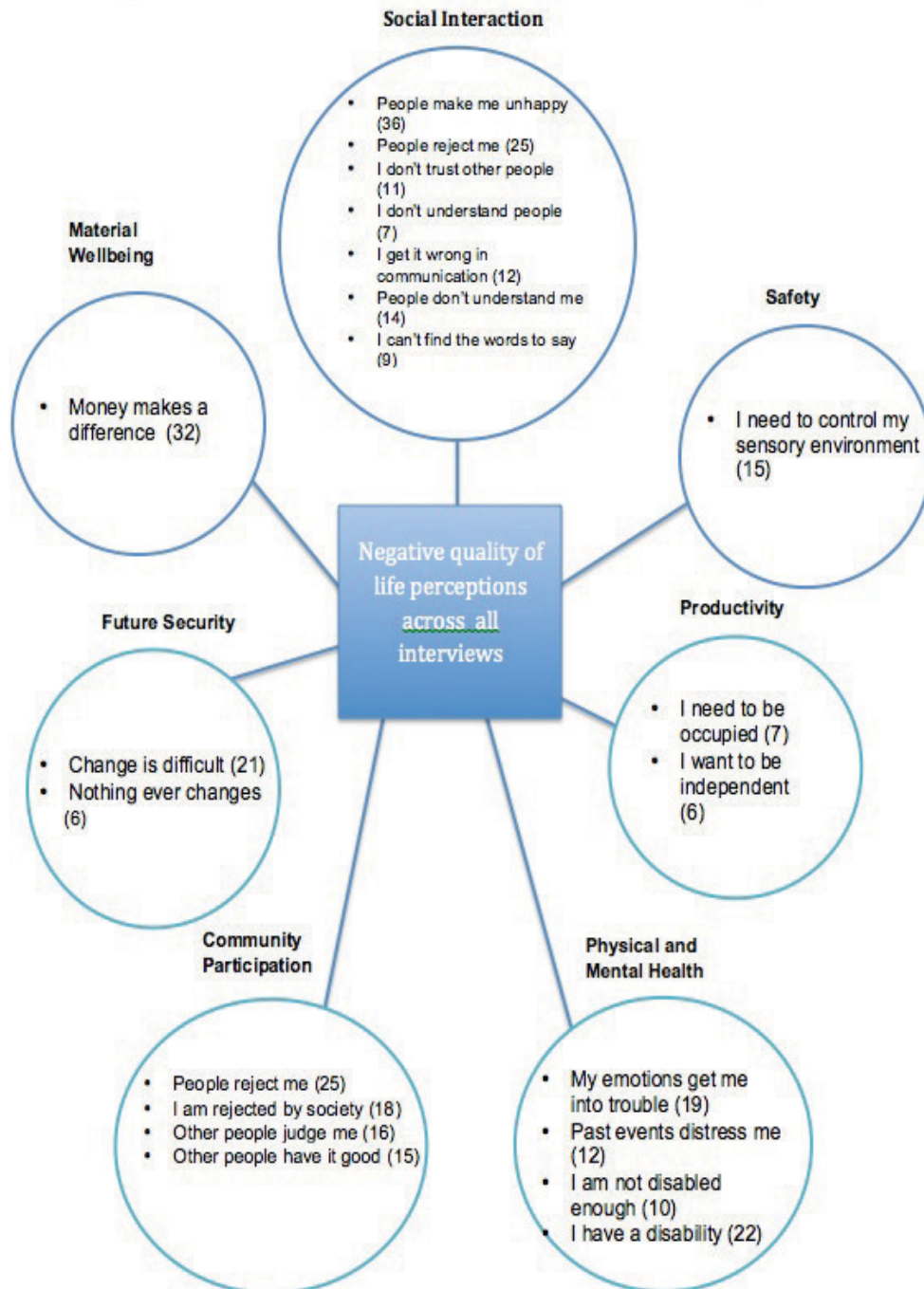


Figure 5.12: Distribution of negative quality of life perceptions across all qualitative interviews (number of references to themes shown in brackets)



5.5.5 Summary of qualitative results

Thematic analysis of the qualitative data in this study identified a number of codes relating to the quality of life perceptions of the participant group. These codes were captured by the overarching themes of people have value, people are difficult, my emotions are the problem, life is not fair, it all boils down to the moneywise, communication is important, control is important and I want to feel worthwhile. Many of these themes were judged to be important in terms of quality of life perception because of the regularity of their occurrence or their shared presence in the data for the group (people are the problem and it all boils down to the moneywise). Others were identified as important to a number of the participants (control is important and communication is important).

The subthemes in these overarching themes reflected the seven quality of life dimensions that underpinned this study and described both positive and negative perceptions of quality of life. There was a noticeable presence in the data of perceptions related to social interaction which expressed the difficulty of dealing with and interacting with other people, as well as the value of people in participants' lives and the need for some kind of relationship. Whilst the majority of themes were found across the diagnostic process, some participants showed some pattern differences before and after

diagnosis. This was most noticeable in the areas of control and communication.

The qualitative analysis provided depth to understanding the perceptions of participants across the seven quality of life areas. In social interaction, the concept of people having a value but a need for time away from other people and some control of the interaction was raised. The participants' perception of valuable communication included virtual communication, interaction with family and special interests. In terms of barriers to social interaction, the participants primarily described barriers created by others, making some references in specific cases to their own communication difficulties. The attitude and behaviour of others were also an issue that dominated perceptions of barriers to community participation with important individuals and virtual communities being described as facilitators of community participation.

Some participants linked past events and overwhelming emotions to current difficulties they were experiencing, but it was less common for these to be directly attributed to participants' current moods and emotions. Physical wellbeing lacked significant mention in the data but the issue of having a mild disability and the way this was understood or ignored in society was raised. An important area for several participants was the perception that their sensory environment was

having an impact on their wellbeing and that this affected their health, emotions and feelings of safety and security.

Positive perceptions of material wellbeing focused on home and possessions but there was recognition that participants generally did not have access to money and that this could be a barrier. Some participants referred to others having more than them, but in general the focus was on having the things that were personally important to them, rather than wanting the things that others had. In the area of productivity, many participants did raise, to some extent, the need for occupation and productivity but also the challenges of this. In several cases this related directly to difficulties in employment and challenges in the areas of social communication and community access. When asked to consider the future, several participants voiced that this was not something they were able or wanted to do. The concept that change was difficult was raised along with a sense that positive changes weren't happening. In the case of John this was specifically voiced in relation to the diagnostic process and a perception that nothing good had resulted from it.

The qualitative data helped to map the perceptions of the participants, showing the complex ways in which dimensions interacted and the way in which one thing, e.g. a person in your life, could be both positive and negative. This data also highlighted wider themes that went across all the dimensions, such as the balance of quality and

quantity of something in the participants' life and the way in which this was reflected in a quality of life perception. These areas will be discussed further later in this thesis.

5.6 Illustrative cases combining detail of quantitative and qualitative results

Whilst this thesis initially presented quantitative and qualitative results separately, the complex and multifaceted nature of quality of life meant that it was logical to consider a way in which the multiple methods of data gathering could be brought together. The intention was to help present any interactions between different aspects of quality of life perceptions to give the fullest picture of what these perceptions might be and the ways in which participants might perceive connections between dimensions.

Illustrative cases were selected from the eight individuals who had completed both the quantitative and qualitative aspects of the study. The aim was that cases would reflect Zapft's descriptive states, would show both stability and change and would show some balance in terms of age, gender, diagnosis and level of IQ. This resulted in the selection of Mark, John, Jane and David. In this section, qualitative data will be linked in brackets to the theme onto which it was coded.

5.6.1 Mark – an adaptive case

Case One was Mark who maintained an ‘adaptive’ pattern of subjective and objective quality of life throughout the diagnostic process (Negative Objective/Positive Subjective). Mark was diagnosed with autism and had a mild learning disability.

Chart 5.9: PWI-ID scores for Mark

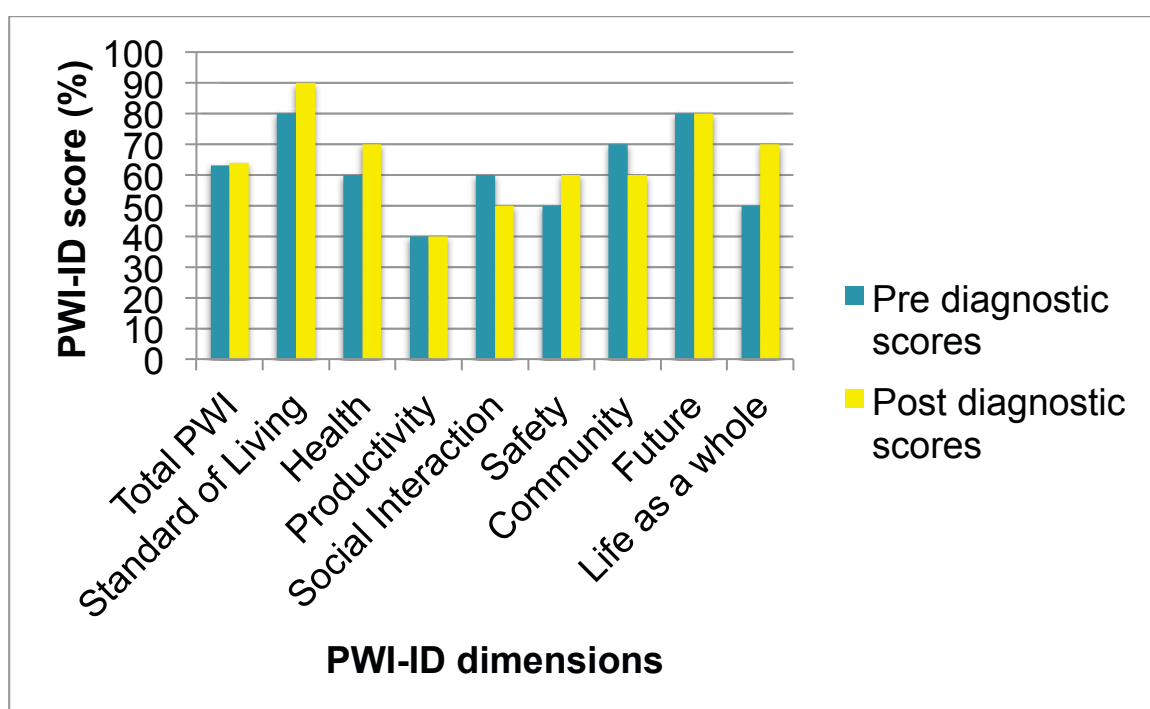
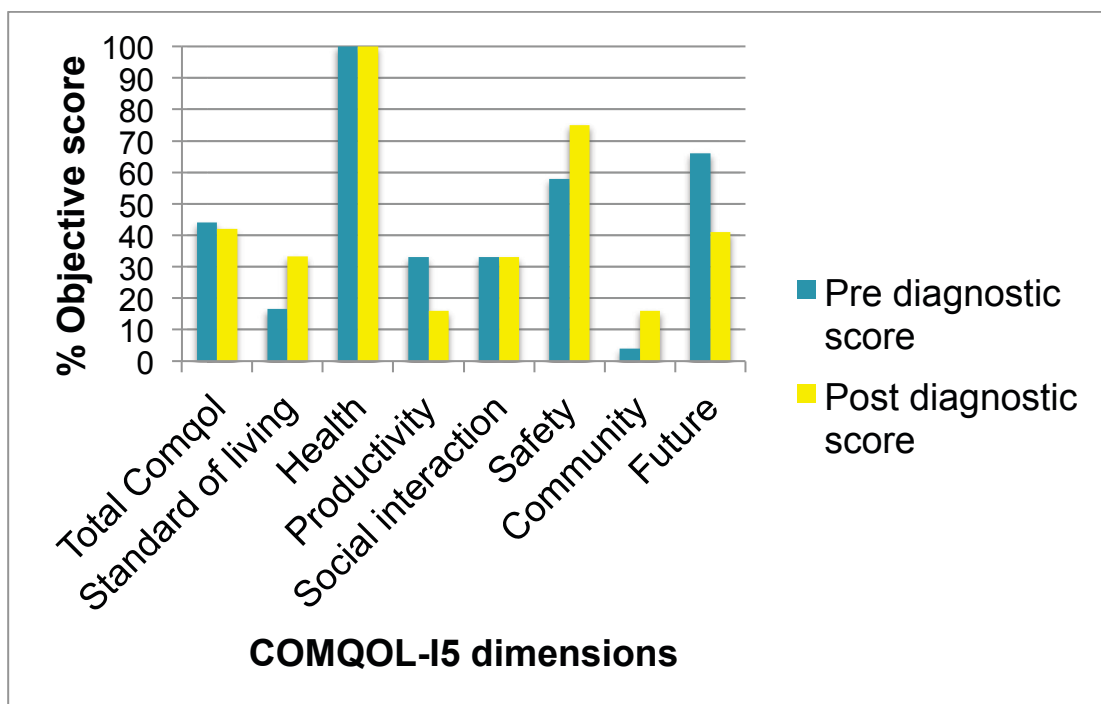


Chart 5.10: COMQOL-I5 scores for Mark



Mark was an adaptive individual and Chart 5.10 shows that in measurable, objective terms, his quality of life was low overall. Chart 5.10 illustrates that with the exception of health, safety and the future, Mark had very low scores in most dimensions for his objective quality of life. Chart 5.9 shows that Mark, however, had the adaptive pattern of reporting relatively positive subjective wellbeing in all areas apart from productivity. Table 5.12 shows that the relative importance of dimensions was quite variable for Mark across the diagnostic process with the importance of safety remaining high and social interaction remaining low.

Table 5.12: Order of dimension importance for Mark before and after diagnosis

Hierarchy	Pre-diagnosis	Post-diagnosis
1	Future	Safe
2	Safe	Standard of living
3	Community	Health
4	Doing	Community
5	Standard of Living	Future
6	Social	Doing
7	Health	Social

Themes for Mark

In his qualitative interview, Mark placed a lot of value on his house, and this reflected the importance of his room for escape from people and to carry out gaming activity. He did not indicate significance of size, location or type of ownership of his house, but instead focused on possession of a house as key to safety and future security, referring multiple times to the importance of having his own safe space.

‘Upstairs in my room is a safe place.’ (My home makes me safe)

He also referred to his attitude to his possessions and the value he ascribed to them. He described pleasure in being able to own specific items and being able to have them for a length of time.

'Possessions I like to buy and keep forever.' (Objects make me happy)

He identified a link between a positive future and having enough money:

S: *'What helps you to think that the future will be Ok?'*

M: (Sigh) *'that' (pointing at the money picture). (Money makes a difference)*

Mark's concept of satisfaction with material wellbeing was focused on specific items and having a bedroom of his own. His qualitative data did suggest, however, that his view of a happy future involved safely 'staying in his bedroom'. The future was initially the most important dimension for Mark, with this decreasing after the diagnostic process.

Mark's visual hierarchy indicated that social interaction was one of the least important dimensions to him and this was reflected in the consistent themes in his interview that his preference was for being on his own in his room. In his pre-diagnostic interview, Mark linked being on his own to greater productivity, safety, happiness and feeling well.

S: *'What in your everyday life helps you to do things well and be successful?'*

M: *'Just doing it on my own with no-one around me.'* (I need some time alone)

In contrast to the other dimensions, health was something that Mark was satisfied with and that objectively was given a positive score (100%). Initially, Mark identified health as the least important dimension to him, with this increasing throughout the process. Post-diagnostically, Mark referred to his emotional health in his interviews.

S: *'What about if things are harder to do, how does that feel?'*

M: *'Bad'* (stressed voice) (My emotions can be overwhelming)

Mark's objective community participation score was very low but his adaptive pattern was illustrated in that he gave it a middle ranking in terms of importance and appeared relatively satisfied with it (60/70%). The only area outside of his home, which provided the sense of being part of his community, was his voluntary job at a local radio station.

S: *'If I was at the Radio Station watching you, what sort of thing would I see you doing?'*

M: (leans back in chair – sighs) *'Well (pause tapping table, sighing, hands touching head and face) just surfing the Internet on the personal computers that they have in the corner.'* (I need to be occupied)

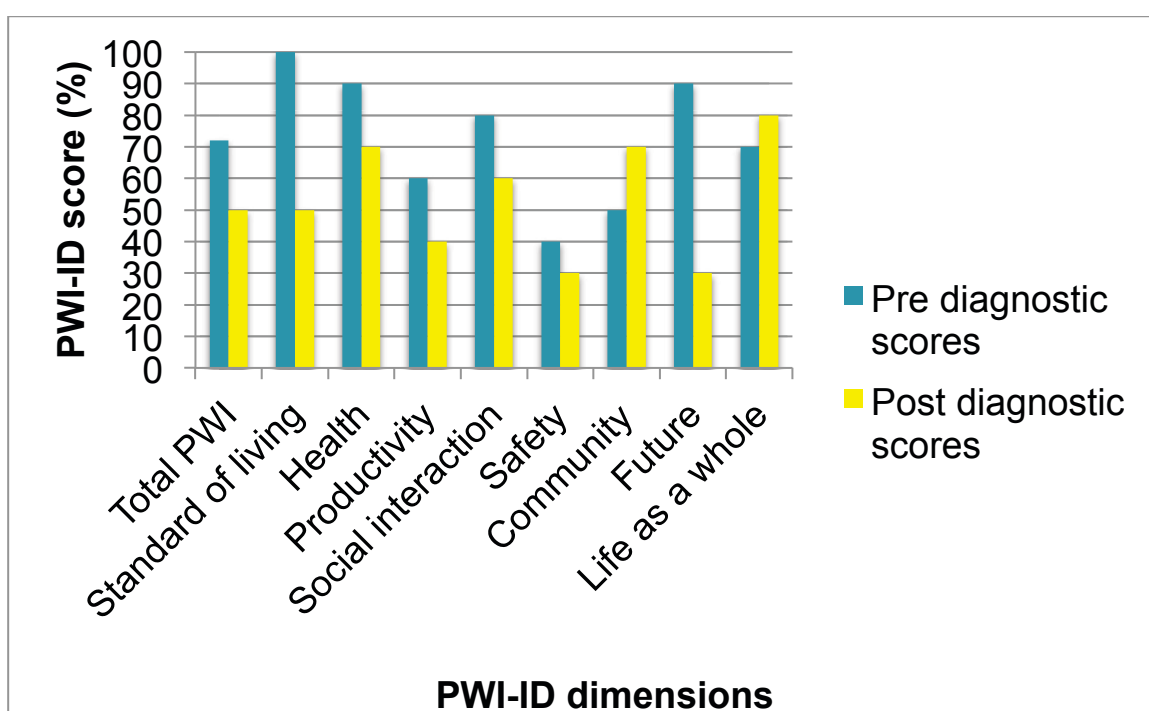
These results suggested that Mark had a genuine satisfaction with life circumstances that others might perceive as poor. The picture that

emerged was one of someone for whom life outside of his room was anxiety provoking and that his current aspirations were to have the means to be able to minimise contact with people and ensure access to objects and items that gave him pleasure and security whilst maintaining the support of his mother.

5.6.2 John – an adaptor moving to deprivation

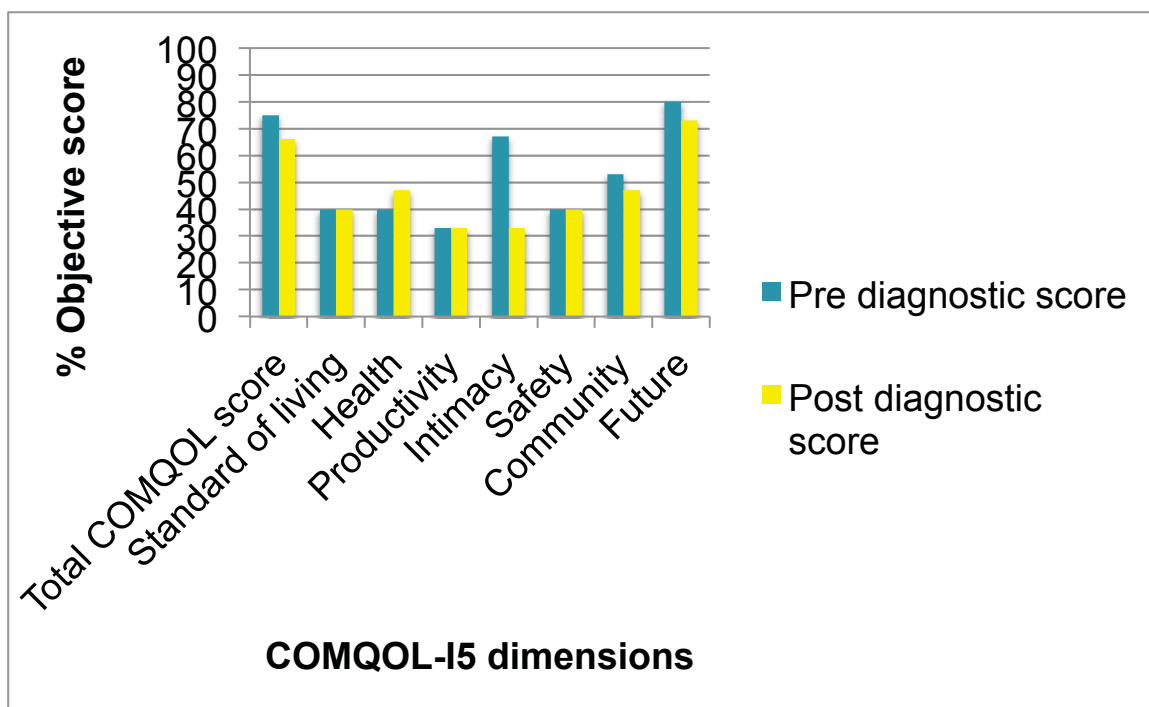
Case Two is John who presented pre-diagnostically in a state of ‘adaptation’ and moved post-diagnostically to ‘deprivation’ (Negative Subjective/Negative Objective). He had a mild learning disability and a diagnosis of autism.

Chart 5.11: PWI-ID scores for John



John began the diagnostic process as an adaptive individual who overall tended to have lower objective quality of life scores but described relatively high subjective quality of life as illustrated by Chart 5.11 and Chart 5.12. However, post-diagnostically, John moved to a state of deprivation where he had an overall subjective view of his quality of life which had been lowered to reflect a generally low objective quality of life.

Chart 5.12: COMQOL-I5 scores for John



In all areas, apart from community participation, John showed a reduction in his subjective wellbeing. Objectively his health had improved and his social communication had dramatically decreased.

Table 5.13: Order of dimension importance for John before and after diagnosis

Hierarchy	Pre-diagnosis	Post-diagnosis
1	Health	Health
2	Doing	Safe
3	Safe	Standard of living
4	Social	Community
5	Community	Doing
6	Standard of living	Future
7	Future	Social

Table 5.13 shows John's perceptions of the importance of the dimensions to him across the diagnostic process showed considerable variation. Health, however, remained the most important to him, and the future was consistently something which he rated as being of low importance.

Themes for John

In his post-diagnostic qualitative interview, John described a sense of being satisfied with what he had, but also knowing that he found life financially difficult. He made sense of this because he felt everybody was the same:

J: *'(Pause) I have money and belongings but I find it difficult.'*

S: *'Right.'*

J: *'At the end of the day everyone is struggling... right?' (I can self-manage)*

John also linked his lack of activity and productivity to a lack of financial resources:

'That's what I do mostly, plan, plan it and if I can't afford it I just leave it 'til the following month. That is what I mostly do. So plan what I want to do. There's hardly anything to do.' (I need to be occupied) (Money makes a difference)

John often referred to emotional state in his qualitative interviews and problems with managing his emotions, his emotions overwhelming him, lack of control and emotions of past events upsetting him. This was the case before and after diagnosis and John felt that he was trying to control these:

'I'm trying to stop I am trying to say to myself, don't get worked up.' (I can't control my emotions)

John also referred both before and after diagnosis to a physical health disability and the impact this could have, particularly an impact on his productivity:

'I can't even use a computer because my coordination won't let me do it right.' (I have a disability) (Other people have it good)

John perceived his physical disability as an unfair barrier in his life that others were not willing to help him with, forcing him to struggle on by himself:

'I get to a certain level and I say "can I do this on my own or do I turn around and see if I can get help on"... see... that's where I get stuck on... and that's about my opinion.' (People reject me)(I am not disabled enough)

John pre-diagnostically described enjoying talking to people but also finding them difficult. He felt this caused him to react badly and then feel isolated:

'I'll speak to anyone as long as they don't turn round and upset me about all the rumours that are going round. 'Cos that's what will trigger me off.' (People make me unhappy) (I can't control my emotions)

Post-diagnostically, he made fewer references to interaction with other people and his focus had become supporting his family. This support was not well received and he described becoming more isolated:

'He's pushing me away... it's like I said to my Mum, I said like my Mum's been away, he's pushing me away.' (People reject me) (Family are important)

John was a participant who also referred regularly to his perceived communication challenges in his qualitative interview, particularly post-diagnostically:

'Sometimes I get confused with what you're talking about or I get confused with what I'm saying.' (I don't understand people) (I can't find the words to say)

John talked about his frustration with lack of occupation before his diagnosis:

'Ah... nothing for me for meeting... there's nothing for me to do in S that's why I prefer to go out and about once a month.' (I need to be occupied)

John's interviews suggest that post-diagnostically he saw his purpose as linked to his support to his family, but also felt he was failing at this:

'At the end of the day, the worst happens I can't come to their rescue. At the end of the day what do I do? I'm stuck in the middle and they're asking the family to come to the rescue.' (I care for others) (Other people have it good)

He described a fish and chip shop owner whom he had known all his life, who appeared to be an important part of his community participation and social interaction:

'It's basically because he cheers me up more and we have a bit of a laugh – there are certain days when it looks at me and says "oh there is something wrong in't there eh?".' (Some people understand me) (Other people make me happy)

Whilst this relationship involved short interactions in a functional setting, it was clearly one that had considerable importance to John and was referred to regularly after his diagnosis. A strong theme for John in his pre-diagnostic interview was that it was the here and now that was the most important thing and that he didn't think about the future:

'Ah, I live every day as it comes.' (It's the here and now that counts)

This theme was less prevalent in John's post-diagnostic interview and he began to refer more to his perception that nothing had changed since his autism diagnosis:

'The future's only going to be the same as it is now.' (Nothing ever changes)

Overall, John's data created a picture of someone who very much 'lived in the moment'. For John, his health impacted on his productivity and this limited his material wellbeing. It made sense in this case that health was very important to John as he saw it impacting on other things. John's reduction in social interaction seemed to have had a significant impact on him. His focus was on his family, who he felt were rejecting him and this also appeared to be isolating him and having an effect on his wellbeing.

5.6.3 Jane – In wellbeing and remaining there

Case Three was Jane who maintained an overall state of ‘wellbeing’ during the diagnostic process (Positive Subjective/Positive Objective). Jane had a borderline learning disability and autism.

Chart 5.13: PWI-ID scores for Jane

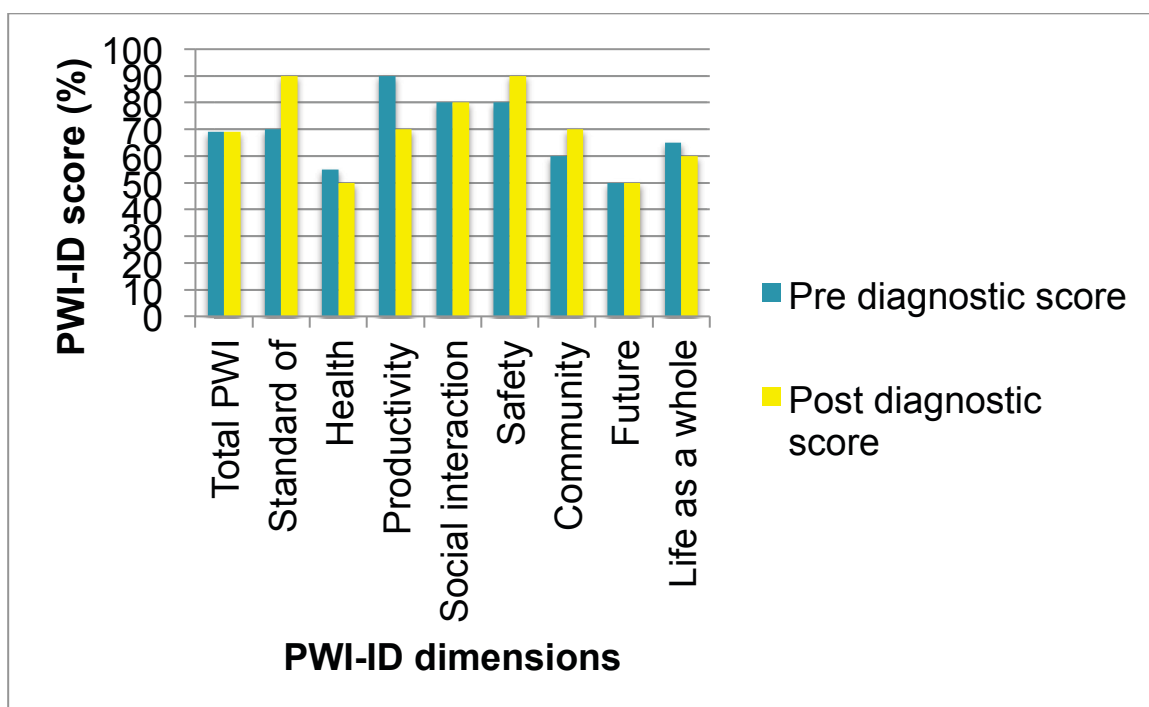
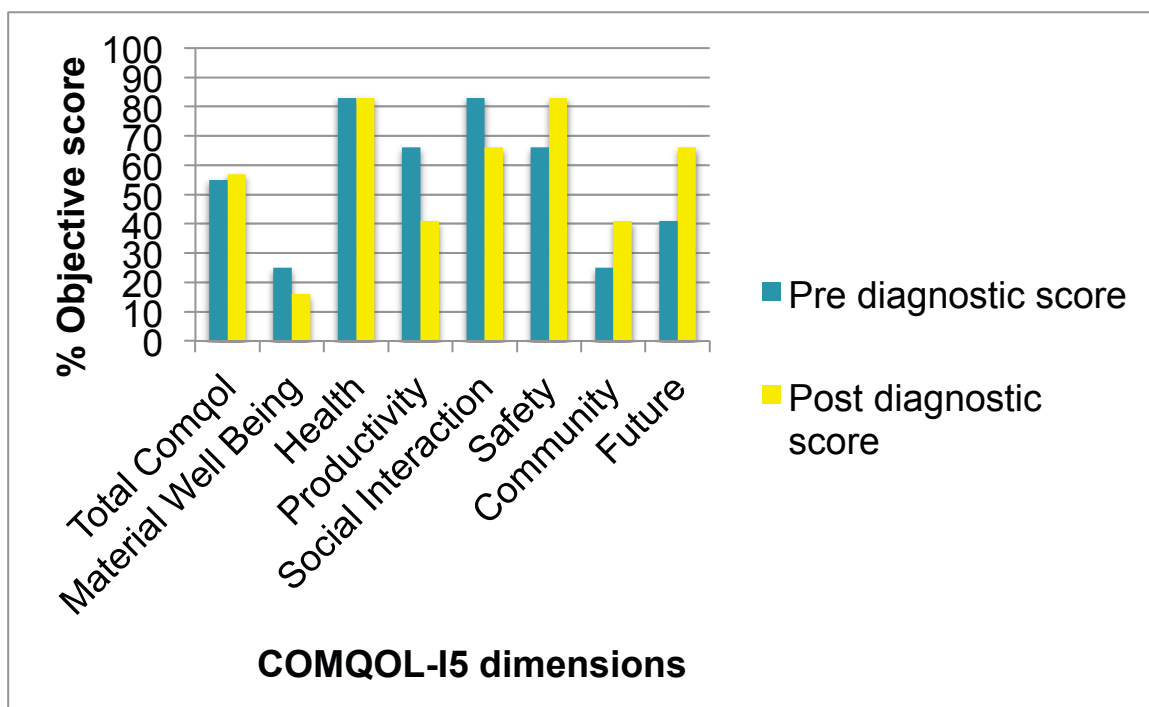


Chart 5.13 shows that overall Jane tended to show positive subjective scores and generally maintained these throughout the diagnostic process. She showed positive changes in subjective material wellbeing, safety and community participation. She showed positive changes in objective safety, community participation and future security and negative changes in objective material wellbeing, productivity and social interaction.

Chart 5.14: COMQOL-I5 dimensions for Jane



Jane provided an example of a participant who maintained a relatively positive overall subjective score throughout the process along with a generally positive objective quality of life score. Chart 5.14 shows lower objective scores in material wellbeing and community participation.

Table 5.14: Order of dimension importance for Jane before and after diagnosis

Hierarchy	Pre-diagnosis	Post-diagnosis
1	Safe	Safe
2	Standard of living	Health
3	Social	Standard of living
4	Health	Social
5	Doing	Doing
6	Community	Future
7	Future	Community

Table 5.14 shows that Jane’s ranking of importance of dimensions remained relatively stable. Safety was very important to her, with community participation and the future remaining consistently less important.

Themes for Jane

In her qualitative interviews, Jane linked people and safety, and their value in getting her out of the house into the community.

‘I think I feel safer when I’m with like er someone else at least. Like I wouldn’t go into town on my own unless I really had to or meeting.’

(People are useful)

Jane talked about challenges in communication pre-diagnostically, both in her communication confidence and in others understanding her:

'I don't know (sad voice) it's like people are trying to understand me, they're trying to understand but they're going the wrong way about it if you know what I mean.' (People are difficult) (People don't understand me)

'and I don't tend to think before I speak, I tend to just say what I am thinking.' (I get things wrong in communication)

The focus of her data about communication post-diagnostically was on improvements in friendships and relationships, as she had been able to access the community more:

'Erm... one of my friendships has gotten better just I go round her house... I see her more.' (Some people understand me) (People make me happy)

Pre-diagnostically, Jane focused on the difficulty she had with money and the way in which this limited her and also upset others:

'I would say I'm really bad with money. I would say I am one of those people who if I have got it spend it.' (Money makes a difference)

In her post-diagnostic interview, she still recognised the importance of money to her but linked it to her own productivity and independence since her mother left the family home:

'So my Mum pays me 'X' amount all week to do some jobs and if I have done them I'll get money and if not I don't er I also sometimes get paid by my aunt if I do erm some jobs for her.' (Money makes a difference) (I like to be occupied)

Post-diagnostically, Jane suggested that her ability to engage in the community had improved:

'I think I've gotten better, I've gone out more... 'cos I've been to the shops on my own... I've done it as much, I've sort of worked myself to going out.' (Doing things outside the home is important) (I need to be independent)

Chart 5.13 shows that Jane's objective productivity and social interaction declined, corresponding to ceasing college and being in a period of uncertainty about the future. Jane also talked about some of her anxieties related to work, which were based on past negative experiences:

'but erm it's the whole erm getting into a job I really don't like and I know if I don't like it I won't do my best and...'(I like to do well)

Jane described improvement in her ability to manage her physical disabilities but Charts 5.12 and 5.13 show that she had a dissonant pattern in relation to her health:

'I'm still prone to falling over and stuff but gotten myself better with keeping myself on two legs.' (I have a disability)

Jane was aware that her emotional health could have an impact on her ability to access some things that previously she would not have attempted:

'Like I found it really hard when we went to D the other day. I found it really hard to get in the door 'cos I felt really uncomfortable.' (My emotions can be overwhelming)

Jane expressed mixed views with some hopes and anxieties about her future in terms of employment:

'I know I need to get a job, but it's just getting there, the whole thing.'
(I have hopes for the future)

She also talked with a similar mixture of emotions about the possibility of future relationships.

'Erm I am not really sure at the moment. I've got... I don't really know. I think there's a bit of everything I'm looking forward to. Meeting someone... to maybe meeting someone who, to do whatever we're going to do... this that and the other.'

Jane had experienced a number of changes across the diagnostic process. Lack of productivity had impacted on her levels of social interaction but her increased independence had resulted in an expression of confidence and willingness to interact in her community. Safety remained important to her, and this limited her emotional confidence. She was tending to invest more time in her family and was less sure about the future.

5.6.4 David – In wellbeing and life improving

Case Four was David who was in a state of wellbeing throughout the diagnostic process whilst showing observable positive change. David had a borderline learning disability and was not diagnosed with autism; instead he was felt to have a social communication difficulty which reflected a childhood diagnosis of specific language disorder.

Charts 5.15 and 5.16 show that David's total scores for subjective and objective quality of life suggested a state of 'wellbeing' prior to diagnosis. His scores either remained stable or improved in most dimensions, giving an observable impression of positive change.

Chart 5.15: PWI-ID scores for David

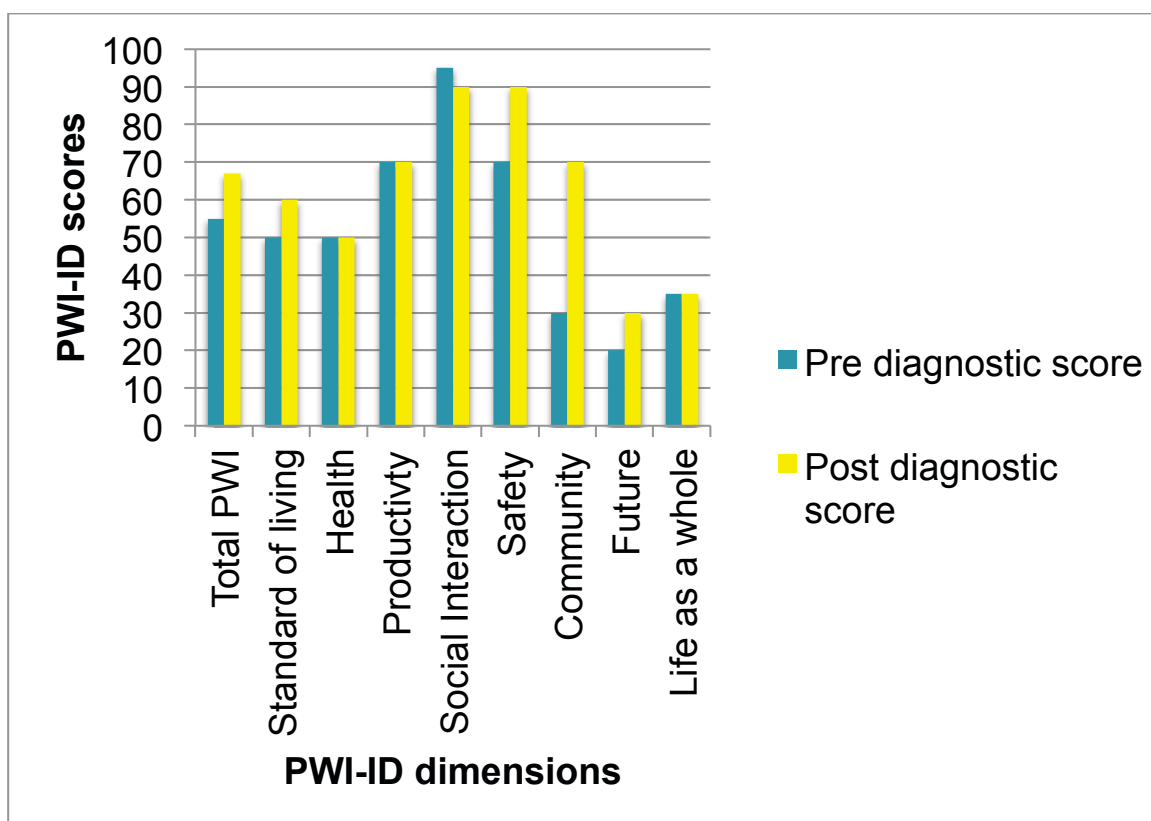


Chart 5.16: COMQOL scores for David

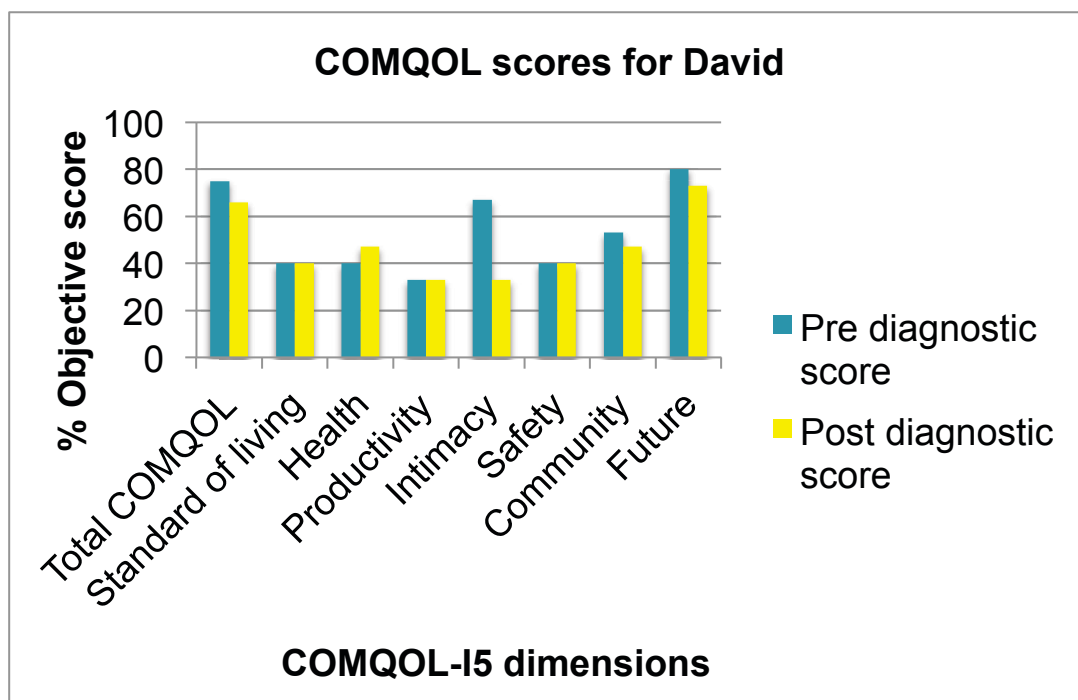


Table 5.15: Order of dimension importance for David before and after diagnosis

Hierarchy	Pre-diagnosis	Post-diagnosis
1	Future	Future
2	Standard of living	Standard of living
3	Safe	Safe
4	Social	Doing
5	Doing	Health
6	Health	Social
7	Community	Community

Evaluation of Chart 5.15 shows that pre-diagnostically David had a high level of pre-diagnostic satisfaction with productivity, social interaction and safety, but lower scores for hopes for the future and

life as a whole. Post-diagnostically, several areas of subjective satisfaction had improved, most noticeably community participation. However, his satisfaction with life as a whole and the future remained low.

Chart 5.16 illustrates that David had high objective scores in the areas of future security/emotional wellbeing and intimacy that were a factor in his overall higher total score. He had some lower scores in productivity, safety, standard of living and health. These reflected his lack of employment and some visits to the GP. Table 5.15 shows that many aspects of David's perceptions of importance of dimension importance remained stable throughout the diagnostic process.

David provides a good example of a participant whose overall scores can mask to some extent very different perceptions in a range of dimensions.

Themes for David

Future security, material wellbeing and safety were all important and his qualitative interview suggested they were strongly related to the concept of home.

David identified the importance of his home in helping him feel safe:

S: *'The roof over your head... how important is that to you?'*

D: *'Very.'* (*Home is important*)

David also described the impact of his sensory environment and the way in which others behaved on his feelings of safety:

'I'll stand here in the door but I don't want to be in that room where people are gonna be yelling and shouting. I'd rather stick to where people keep their feelings to themselves.' (Other people can be difficult) (I need to control my environment)

A very strong theme for David was around the value of employment and his current status as unemployed. He described the challenge of dealing with the lack of occupation and the way this impacted on his mental health:

'... probably just knowing that... I can't keep myself mentally occupied, so I can ignore things and focus on other stuff.' (I need to be occupied)

He also talked about the shame and guilt that he felt in not having a paid job when other people did and the difficulties this created for him in social interaction:

'It's more it feels like a dirty little secret I have.' (Other people judge me) (I am rejected) (I have a disability)

David also talked about the value of success in his online games and how this was important to balance the challenge of not being engaged in productive employment:

'Probably this will sound daft when I am playing my online games with friends... it's the progression.' (Virtual friends are important) (I like to do well)

David regularly referred to the importance for him of his gaming friends, who were a regular part of his life and when asked what a good future would be like he said:

'Mmmm I have a lot of friends that's probably about it.' (Other people are useful)

David described his satisfaction with life as linked to social interaction. He expressed fears about the impact of his long-term unemployment on his friendships and, therefore, his future:

'I don't see... I can't see them being friends even though M (games club) like thing and they're there. It's what happens five-six years down the line. I don't know and in more ways it's a case of what's gonna happen on a year's time not where I am going to be in five or ten.' (I am rejected) (I have a disability) (It's the here and now that counts)

David showed a noticeable decrease in the number of visits he had made to his doctor, pre and post-diagnostically, but did not refer to his physical health and was the only participant who did not appear to directly refer to his emotions in a way that suggested he had difficulties with them. Instead, he described a range of situations (being unemployed/noisy environment/annoying people) that he found

difficult, with a sense that he managed to hold back any emotions of distress, whilst he might 'want' to express them. Often his statements were made with a lot of visible emotion or emotive language:

'If you had a company of fifty people and two of them were disabled it is the disabled person that gets fired first. It feels like really it makes me want to cry sometimes the way people react to a disabled person (voice trembling with emotion).' (I have a disability) (Other people have it good)

He did at times in the interview refer to his fitness and diet and needing to lose a little weight. David had a diagnosis of dyslexia before he came for an assessment and he indicated that he considered himself to be disabled and that this was a disadvantage. He did this without directly referring to himself:

D: *'I feel like it's gone from the bankers are the target to the disabled person.'*

S: *'Mmmm.'*

D: *'and the disabled person without a job.'* (I have a disability) (People judge me)

When David was asked what aspects of life were enjoyable to him at that moment he described:

'Probably getting out the house, not having that, knowing... not tied down to do certain things.' (*Doing things outside the home is important*)

Whilst David did not feel that he had any strong links with his immediate local area he described his volunteer work in the town centre and his meeting with gaming friends as key activities involving others in his local town and these had increased in the post-diagnostic period.

5.6.5 Summary of results of illustrative cases

The results in the illustrative cases present a number of different aspects of the quality of life perceptions of the participants. Firstly, the ways in which individual dimensions varied in one presentation underneath an overall score. In all four cases, individual scores were very variable across dimensions, producing quite a 'spiky' profile, which when converted into an overall score then lost' an interesting result in a particular dimension. This was particularly noticeable in the case of Mark, who had overall scores which were in the 40 to 50% range, but within specific dimensions these varied from zero in the area of community participation, which reflected an absence of specific access to clubs, groups or activities or specific contributions to the local community. In the area of health he had a score of 100%, which indicated an absence of visits to the doctor, no illnesses or medication.

Whilst in general there was a less dramatic variation in subjective scores, David was a participant whose overall profile of positive scores covered a considerable degree of dissatisfaction with the dimensions of future security and life as a whole.

These four cases also illustrated that at an individual participant and specific dimension level, objective indicators did not necessarily reflect subjective perceptions. Jane's objective material wellbeing score was low to begin with and reduced throughout the diagnostic process whilst her subjective perceptions of her material wellbeing were high and increased throughout the process. David's objective indicators of future security were high but his subjective perception of the future was one of his lowest scores.

The importance ranking exercises indicated considerable variation in the decisions made by individuals (with the exception of the lower ranking of community participation which has already been highlighted as a pattern across the whole group). In these illustrative cases, the dimensions of greatest and least importance remained relatively consistent for all participants over the diagnostic process. David and Jane showed the least change in their ranking decisions across the process.

These illustrative cases also showed the ways in which participants in their quantitative interview scored some dimensions and then this was

either added to, or challenged by their data in the qualitative interview. In David's case, his low subjective view of the future was given more depth in his qualitative data, which highlighted his financial, social, and employment fears for what the future could hold for him. In Jane's case her subjective and objective indicators of her social interaction were high, with social interaction rated as being of middle importance to her. However, in her qualitative interview she raised specific examples of her negative perceptions of her own communication skills and the way that these could get in the way of her successful interaction. John was subjectively positive about his health in his quantitative data but raised several issues related to his disability and the negative impact that this had on his daily life. Mark objectively appeared to have had little community participation in his life but rated this as being of middle importance and considered himself satisfied with it. In his qualitative interview, the importance of his voluntary work with a local community radio station became more apparent and this data suggested some value attached to community participation in this way.

These four cases also highlighted some of the interactions that could occur between dimensions and the ways in which participants perceived these interactions occurring. David and Mark both highlighted the link between material wellbeing in the form of home ownership and feelings of safety and future security. Jane's case

highlighted a perceived relationship between her social communication skills and her ability to access the community and gain employment. David linked his disability to difficulties in obtaining employment and perceptions of his future security. For David, his employability also linked his perceived success with social interaction, in terms of what others would think of him.

Another result from these four cases was that the relationship between participants' perceptions of 'life as a whole' did not necessarily relate to their overall subjective scores in the same way in each case. In Jane's case, her mean PWI-ID scores and her perceptions of her 'life as a whole' were broadly the same and positive. In Mark's case, they were broadly similar, but his scores suggested that his 'life as a whole' noticeably improved after his diagnosis, but this is not reflected in his overall scores and John also showed a better score on his view of 'life as a whole' with much lower overall scores. In David's case, his view of his 'life as a whole' was very different to the majority of his dimensions, appearing much lower. This area will be discussed in more detail in section 6.4.3.

Chapter Six: Discussion

6.1 Introduction

This study was designed to answer one primary and several secondary questions. The focus of the primary question was around understanding the perceived quality of life for the participant group. The secondary questions asked what approach facilitated engagement with this group; what patterns of change and stability in quality of life might be observed through the diagnostic process and, finally, what the challenges and benefits were of having a researcher with a joint role as a Speech and Language Therapist and diagnosing clinician. This section will explore some of the findings and additional learning that arose through answering these questions in this study and will identify how this learning has contributed to research knowledge and clinical practice.

This will begin with consideration of the practical and ethical issues encountered in accessing and engaging with the participant group and will move on to a more specific focus on methods, including consideration of the impact of the combined role of researcher and diagnostician on the study. Some attention will then be given to findings from the study with a discussion of the overall quality of life perceptions of the study group. It will then move onto discussion of development of understanding of quality of life perceptions in individual dimensions. This will include the patterns of change in quality of life

that were identified in this study group and factors that may have contributed to these patterns. This discussion will incorporate reflections on the potential impact of the diagnosis of a mild or borderline learning disability and autism on both the gathering of data and the nature of these perceptions. This section will then move on to describe some of the limitations of this study and the implications of this study for further research and clinical practice.

6.2 Engagement and access

Literature evaluation earlier in this thesis suggested that studies in the field of learning disability and autism tended to focus on participants with significant levels of learning disability and that their carers were the primary source of data. At the focus group stage, in this researcher's study, it became clear that there was a possibility of a bias towards engagement with participants with a more significant learning disability and a failure to engage with people with borderline learning disabilities. A number of factors appeared to be contributing to this and might have reflected the bias in the existing literature.

Participants with a less significant learning disability in this researcher's study were more likely to be living independently or receiving very informal support. In the case of this researcher's study group these informal carers were sometimes family members but could also be support staff linked to other family members or a

referring agent providing a link. One factor contributing to easier access to participants with a more significant learning disability was that they were more likely to have paid carers who could assist them to deal with communications and support them to organise and attend appointments. These paid carers could then act, in effect, as professional gatekeepers for the study. Some of the barriers to interaction and community participation, identified through the qualitative data in this researcher's study, were linked to literacy, organisation, trust and social confidence. A paid worker might well be expected to support the participant overcome these difficulties in general interactions with researchers, professionals and other agencies.

In this study group, the unpaid gatekeepers had less clear roles and responsibilities in the participants' lives. In some cases, such as John, there was no clear immediate gatekeeper, with this role potentially being a referring agent or, in the case of Teresa, her child's support worker. This meant that a greater degree of persistence was required from the researcher to gain initial contact, and that once in contact, the gatekeeper became key in maintaining that research relationship.

A challenge for this researcher, at the initial engagement stage, was deciding how to interpret an initial lack of response from the participants. Lack of response to an initial letter and phone call could have been interpreted as a lack of interest in participation and to an

extent this was the approach taken with the focus group in this study. However, there may have been participants who were happy to engage in the process if they had been more effectively supported to understand and engage in the initial contact. The evidence from the focus group was that several potential participants, who were less highly supported, made contact too late to be involved and that others who initially consented did not attend (see Table 4.2). It was not possible to state with certainty that a more dynamic approach would have changed this outcome, but it was a reasonable hypothesis with which to approach the next phase of the study, and the result of a more persistent approach in the next phase was an increase in research engagement patterns (Tables 5.1 and 5.2).

One issue in actively seeking and accepting gatekeepers, as a positive part of engaging with this participant group, was the risk that these individuals would coerce participants into engagement in some way. A further possibility was that status of the researcher would influence the gatekeeper's belief that the individual should participate. There was potential for people who had a degree of learning disability to passively acquiesce to those in their environment who had some control over their lives. Charlton (2000) highlighted the concept of hegemony and the way in which an oppressed group of individuals accepted the power of others in their lives and accepted this power and privilege as natural and their domination as inherently right. Those who provided

support to vulnerable individuals held a position in their lives which engendered gratitude and also fear of what life would be like without them. This then made opposition of this person's views more challenging. The concern in this case was that participants might feel less able to oppose the views of their supporters or for the researcher's position to be viewed as one that should not be opposed.

In addition to this, the power of the researcher in a joint role of diagnostician needed consideration. The gatekeepers' view of the power of the researcher to benefit their own and the participants' lives could have had an impact on the degree of persuasion that the gatekeeper used in supporting that individual to make a choice. A researcher would have been considered powerful in the sense that he/she could take views and make them available to a wider audience or to other powerful individuals. The additional role of diagnostician meant that gatekeepers might have considered that participation or failure to participate could have had an impact on the diagnostic process. These factors could directly and indirectly have had an impact on the agency that the participant had in deciding to engage in this study.

McDermott et al (2014) and Kong and Chau (2013) discussed the challenges of combining research and clinical practice. These authors suggested that the benefits of this combination outweighed the challenges and that joint roles should be pursued in professional

areas. McDermott et al (2014) argued for the fundamental value of involving clinically experienced nurses in the delivery of clinical research studies within the National Health Service in the UK. The view put forward was that clinical staff should be sufficiently skilled and knowledgeable to meet the needs of the research environment. The argument, relevant in the case of this researcher's study, was that a skilled clinician would bring both questions that directly arose in clinical practice and also possess direct skills of engagement with a participant group.

These issues created a complex ethical path to walk in terms of engagement and participation in this researcher's study. Participants needed to feel able to decide for themselves whether they wanted to participate, but appeared less likely to be engaged without the practical support of the gatekeeper to explain and often to support them to attend. The risk of coercion and acquiescence was difficult to completely avoid, but this study was designed to make clear in the correspondence that engagement did not impact on clinical care and that participants could withdraw from the study at any time without giving a reason, and this was repeated verbally both to participants and supporters. There were also clear points where the participants were seen on their own and this provided the opportunity to appraise their willingness to engage without the direct presence of their supporter.

In many ways this challenge reflected the tension between an emic (insider perspective) and an etic (outsider analytic perspective) (Green and Thorogood 2014) in this study. At the outset of this study, the approach to engagement was less flexible and involved a greater distance between the researcher and the participant. Initially, the focus was on trying to separate the two roles, and 'not be a clinician' when carrying out the research function. In this model, the participants were contacted and if no response was received then that participant was not included in the study. This more etic approach was likely to have been a factor in the lower response rate from participants with less formal support in the early stages of the study.

An acceptance of a more emic model involved some acknowledgment of the dual role of researcher and clinician and reflected the tacit skills upon which this joint role could draw. This meant a greater consideration and application of the approach that would be used as a clinician with this client group. This approach was one that accepted that engagement could be difficult and sought flexible methods to engage. It also involved an acceptance that the diagnosing clinician was, for a short time, a part of the participants' social world and had, to some extent, an insider role as a researcher. Whilst this could have presented challenges it may well have increased the likelihood of engagement and participation and thus gained a better representation of participants' perspectives.

An example of the process of ethical considerations related to engagement in this study was with John. John had initially attended his first research appointment and had indicated a desire to continue the process. He had also changed addresses and phone numbers once in the early stage of the process and had been able to give new contact details. John then failed to attend his second research appointment and failed to respond to any contact. One option at this point was to accept that John's failure to respond was a way of ending contact with the researcher. Clinical experience with this participant group suggested that it was possible that John might have changed addresses again or had difficulty accessing the information sent to him. This clinical experience suggested that he might not have been trying to end contact with the study and might need support with access.

In a pure role of a diagnostic clinician trying to engage with a patient, it would have been acceptable to make broad based enquiries with others in the Learning Disability Team about John's whereabouts. However, this would have involved making contact with professionals not listed on the initial referral sheet and this was considered ethically too far outside the agreed research protocol. However, the referrer for John was listed on the initial referral sheet and the researcher was permitted access to this. For this reason, contacting the referrer fell within agreed access to data, and allowed the researcher to learn

where the best place was to locate John, and then to successfully locate him.

Supportive persistence also remained a theme throughout the study. One consideration was that some of the neuropsychological and cognitive difficulties, related to autism, might have had an impact on the participants' ability to engage. These included challenges with central coherence, executive functioning and theory of mind as well as dyslexia and language processing difficulties. No participants spontaneously made contact after receiving their initial letter, although the letter invited them to do so if they wished. When contacted by telephone, several participants quickly elected to hand over to a gatekeeper or suggested waiting until a gatekeeper was available (Adam, Liam, Carl). In terms of planning and organising attendance, the gatekeeper was the person who could prompt about the appointment or could provide transportation or a venue for a meeting (Teresa, Cathy, Jim, Luke, Liam, Mark).

This could have created the impression of a participant who did not wish to engage. Tacit knowledge and clinical experience supported the view that this lack of response could also reflect cognitive and practical barriers and supported the use of a more dynamic approach towards engagement. Experience in the focus groups highlighted the need to contact the participants and their gatekeepers on the meeting day, for example, and ensure that they were clear about what was going to be

happening. Several of the participants expressed the view that they would only feel safe if the gatekeeper accompanied them (Teresa, Chris, Liam, David, Mark) and this meant that research sessions needed to be coordinated to work well for both the participants and their supporters.

From the outset of the study, ethical issues associated with carrying out a research study directly involving people with a degree of learning disability were a regular feature of reflection and challenge. One aspect of this was balancing the involvement of people with complex needs in research, with sensitivity to the potential vulnerabilities of the client group. Cleaver et al (2010) identified, in their systematic review of health intervention research, that there had been no increase in the number of participants with learning disabilities directly involved in research over the past 20 years, and a tendency to involve carers. There was evidence that ethical committees were reluctant to approve research, even when people with learning disabilities had been shown to have capacity. Lai et al (2006), Dye et al (2004) and Wong et al (2000) have highlighted the way in which the ethical principles of benevolence (protection of vulnerable) and justice (need to benefit the wider population) can be in conflict within the ethics of learning disability research and Hammersley (2010) has argued that excessively stringent and inflexible ethical regulation actively restricts potentially valuable research. This highlights the idea that concern

about protecting the vulnerable could override the need to gather information directly from small but important populations. These populations may require a more flexible approach, which may be time consuming, in order to be ethically engaged.

6.3 Issues arising from methods employed

This study explored quality of life perceptions for a specific group that had not previously been directly engaged in research. This meant that tools either had to be adapted from elsewhere or self-designed by the researcher. There were no existing tools for gathering multidimensional subjective and objective data specifically from people with autism (Townsend et al 2012) but there were tools specifically designed for people with learning disabilities. The tools selected for this study (PWI-ID and COMQOL-I5) were well suited to the participants and to the nature of the study as they were accessible and provided a concrete, quantitative basis on which to build further qualitative questions. The style of the quantitative questions was closed, which meant that the participants could only provide a pre-set response as an option or on some kind of numerical scale. Closed questions naturally limited the breadth of data that could be gathered, but as a method of asking questions they were recognised as easier and less stressful for people with a learning disability to respond to (Nind 2008).

In a client group with potential characteristics of autism, other factors may also increase the ease with which participants respond to these types of questions. Theory of mind is a neurodevelopmental skill and involves the ability to be able to take information that has been gathered about a situation, the context and the people in it and work out from that information what others are likely to be thinking and will know (Baron-Cohen 1997). This skill enables participants to infer what a researcher might want to know from the context of the research. The majority of children who have a diagnosis of autism show specific difficulties with these skills (Baron-Cohen 1997). Theoretically, it may be easier for people with autism to cope in a situation where the requirements of that situation are explicit (closed questions) rather than open questions where they have to understand what other people are expecting and guess what additional information might be valuable to share. This was supported by the findings in this researcher's study, which suggested that it was beneficial to incorporate quantitative interviews, using closed questions, particularly as an initial approach with this participant group.

It also became clear as this researcher's study progressed that the structure and concrete approach provided by quantitative tools were effective for many of the participants and provided a framework on which further qualitative questions could then be built. In clinical practice clear, structured approaches are frequently advocated for

people with autism. Several papers have explored and supported the value of structured approaches to learning and interacting for children with autism (Marquez-Caraveo and Albores-Gallo 2011; Hungelmann 2001) and structured pictorial approaches (Ganz et al 2013; Lerna et al 2012, Pasco and Tohill 2011). Lerman et al (2013) in a very small-scale study, using highly structured teaching methods with four adults, found that three of these adults made considerable, measurable clinical progress. He suggested from this that some of the structured teaching approaches used with children might have benefits for adults in terms of learning and engagement.

Theoretically, in this researcher's study, provision of structure reduced the need to imagine or infer what was going to happen next. The reduction of this need helped the participants to understand what was happening, allowed them to carry out tasks and also reduced stress or anxiety. A further area of challenge for people with autism is in the area of executive functioning. This is the skill that allows people to break a task down into a number of subtasks and then control these actions in a flexible way (Baron-Cohen 1997). If a person experiences a breakdown in this skill it can manifest as a repetitive pattern and a lack of ability to move on in that task or action. In this study, a structured approach with clear pictorial support reduced the pressure on the participant to have to break a task down, as that breakdown

was made more transparent by the structure and clear indication of what the next action should be.

The use of closed, quantitative methods alone would have limited the depth of data that could have been gathered in this researcher's study. To remedy this, a qualitative interview was developed using adapted ethnographic approaches and created a method that supported participants to describe their daily lives and express their quality of life perceptions within that daily life experience. This approach was effective in gathering a greater depth of data from these participants and quality of life perceptions that had not been identified through the use of quantitative data alone. There were a number of reasons why this approach was particularly helpful for people with some characteristics of autism.

Barnes and Baron-Cohen (2012) and Craig and Baron-Cohen (2000) have explored the neurodevelopmental skills required for narration and storytelling and have identified a number of challenges for adults with autism. In his small-scale 2012 study, Baron-Cohen explored the storytelling skills of 12 adults with Asperger Syndrome and no additional learning disability. This study highlighted the tendency for participants to focus on smaller localised details rather than linking details to a whole story or relationship. This finding relates to another area of neurodevelopmental functioning called central coherence. This is the skill that enables people to view a situation and understand the

ways in which a number of factors act together to produce a 'bigger picture'. Weak central coherence can be a specific difficulty for people with autism (Attwood 2001). This makes it harder for participants to 'tell their story' without a clear structure to the interview process. It also emphasises the importance of the role of the researcher in noticing where a detail of everyday life might have some significance to the wider picture of participants' quality of life perceptions and prompting further discussion.

Reflections on methods from this study also suggested that pictorial supports added value to the qualitative interview and ranking exercise by acting as prompts and at times providing a helpful alternative to speech. Mark, Adam, Valerie and Teresa all provided examples of rich data gathered using pictorial supports. Without this additional support, their ability to express their views on more abstract concepts, such as loneliness and their future, would have been limited and may have been assumed to be an area in which they had no comments to make. There was some suggestion that people with autism were more likely to think in a visual way (Attwood 2007) rather than a verbal way. This mirrors clinical experience of working with people with Asperger Syndrome who were able to describe complex situations involving a number of people with different views, thoughts and feelings if they were supported to use visual imagery or provided with pictorial support.

All the participants in this study had a mild or borderline learning disability and were primarily verbal communicators. As such, they could have been assumed to not have the language difficulties that would impact on their day-to-day communication. This could also have suggested that this group would require very little in the way of specific communication adaptation. Clinical experience, however, suggested that this group often required skilled linguistic adaptation to support their interaction and this was, therefore, a consideration in the development of the interview approach.

During the developmental stage of this study, it was noted that the participants had potential to have subtle difficulties with language. An ongoing challenge for the researcher was adapting her approach so that she did not dominate the interactions and kept sentence structures simple and accessible. This was a greater challenge because the participants had additional characteristics of autism. Bishop and Seltzer (2012) highlighted the way in which speech and language difficulties in children with specific speech and language disorders could mirror the difficulties of adults with autism. Colle et al (2008) described the mild linguistic difficulties, such as use of pronouns and references to others that could occur in more able people with autism and Slocombe et al (2013) concluded that if clinical tasks involved skilfully structured and goal directed interactions then language difficulties were minimal between people with Asperger

Syndrome and control groups?. This literature and clinical experience indicated that subtle speech and language difficulties were likely to be present for this group and suggested that making adaptations to language reduced these issues and improved engagement in the process. The evidence from this present study was that careful adaptations, regular reflection and consideration of subtle language difficulties improved the depth and quality of the data being gathered. A key example of this was Mark who benefitted from a reduction in verbal pressure from the researcher, acceptance of silence, increased use of single acknowledgement words and use of non-verbal pictorial cues.

6.4 Quality of life perceptions across whole study group

The aim of this study was to gain an understanding of the quality of life perceptions of a very specific group of individuals and these were people who had a mild or borderline learning disability and were referred for autism diagnosis in the local service. The majority of studies exploring objective quality of life perceptions for people who had a learning disability and autism were quantitative and gathered data directly from carers. The only existing studies that engaged in directly gathering subjective data from people with a learning disability were McGillivray et al 2009, which excluded people with autism, and Hensel et al 2002, which primarily focused on people with a more significant learning disability. There were no identified studies, which

specifically explored quality of life perceptions for people with borderline learning disabilities. The findings from this present study add to the literature by directly gathering the perceptions of participants who have a mild or borderline learning disability and autistic characteristics or a diagnosis of autism.

6.4.1 Overall objective quality of life

The pattern in this present study group was for objective scores indicators of quality of life to be low, with the exception of the dimensions of health and safety. This overall tendency reflected some thinking in national documents relating to both people with autism (Department of Health 2010a) and a learning disability (Emerson et al 2011) and existing studies exploring objective quality of life indicators with people with a learning disability (Hensel 2002; Verri 1999).

Emerson and his team suggested that people with autism and learning disabilities might be more likely to experience inequalities in a range of areas and it would be reasonable to consider that this could link to a lower objective quality of life.

The Royal College of Nursing (2013) produced guidance for nurses on meeting the needs of people with learning disabilities, which highlighted that conditions such as epilepsy were more likely to occur alongside greater degrees of learning disability. These illnesses and their implications for medication and GP visits could result in lower

scores on the COMQOL-I5. It is possible that the higher degree of support likely for Verri's group could relate to access to health services, with participants, with milder levels of learning disability, in this researcher's study being primarily self-supporting and potentially less able to access health care and related diagnosis. It is therefore possible that Verri's sample included more individuals with greater health needs but also possible that individuals in this researcher's sample had undiagnosed or untreated conditions, creating a false impression of good health. Factors relating to quality of life scores in the dimension of health will be discussed in more depth later in this section along with learning from the qualitative data.

The objective safety dimension in the COMQOL-I5 was made up of indicators related to feelings of safety and security in the participants' home environment and aspects of emotional wellbeing, such as sleep and level of anxiety. Participants in this present study reported more positively in these areas than in Verri's study. Verri's study did not give enough detail to comment on the specific nature of the participants' home environments but sampled participants who were involved with specialist programmes or who were in residential care. This researcher's clinical experience suggested that a greater degree of learning disability was often linked to greater support needs and a likelihood of some type of residential care or support programme. This meant that participants' in Verri's study were more likely to have been

living in a group arrangement, whilst in this present study participants generally lived in their own residence or a family home, with only a small number in group residential care.

A strong theme in the qualitative data in this study was participants linking their home with safety and security and in some cases avoiding the world outside of home. The qualitative data in this study also described the theme of positively valued time alone. It is possible that the participants in Verri's study had no choice but to live in the company of others and that this contributed to their lower objective levels of quality of life in terms of safety. In this current study, the overall pattern of higher objective safety and positive qualitative themes relating to safety and the home suggested that control over home environment could be an important component of quality of life for this participant group. In this researcher's study, the qualitative data gathered from the majority of the participants contributed to the theme of home creating a safe haven and the importance of having a space where time could be spent away from other people. Pat and Valerie, who lived in residential care and had to share with others, also raised the challenges in their qualitative interviews of having to deal with other people in their space and having to follow the rules and directions of other people.

Social interaction was rated objectively higher in Verri's study group and was low in this present study. This meant that participants in this

researchers' study had less frequent social interactions, fewer times when others showed care for them and less frequency of shared experiences. Pat and Valerie in this study, who lived in a residential care home, referred to other individuals in their home and staff as friends in their COMQOL-I5 interview. The majority of participants did not have these home-based social environments so had more potential to spend larger amounts of time without contact with people other than their families. Verri's study, as already discussed, was likely to have had a higher number of participants with similar living arrangements to Valerie and Pat. Participants in Verri's study might have had higher objective social interaction because their environment created a situation in which social interaction occurred. COMQOL-I5 does not include family and virtual relationships in its scoring for the social interaction dimensions and the qualitative data for this present study highlighted family and virtual relationships as positive and important for several participants such as David, Adam and Jane. This might also in part have contributed to higher satisfaction scores in this researcher's study compared to objective social interaction opportunities.

6.4.2 Changes to objective quality of life

It is relatively straightforward to understand the ways in which objective indicators enable change in a person's life. Change is more likely in an objective measure than in a subjective one as concrete events or actions can create that change. An example would be getting a job and gaining an income and becoming engaged in more hours of work. In this case that person's objective income and productivity scores would increase, as would their overall objective scores. The reverse could occur if a person lost his/her job and both these changes could happen quickly.

The diagnostic process had the potential to contribute to changes in objective quality of life indicators. This could have been through a specific action from a clinician, such as referring to another agency or employment support or a social group. In Nick's case, his route through a court was changed because of his diagnosis and he was supported to acquire new accommodation. In Teresa's case, she was supported to gain additional support hours to help her access the community. Jane and David were referred to specialist employment services and this resulted in either a job or regular attendance at a job club.

The specific objective dimension in which the greatest observable positive change in mean scores was observed was the dimension of

emotional wellbeing. The greatest positive change was observed in relation to the specific questions related to hopes for the future. This indicator was explored by asking participants how often they had experienced wishes or hopes for the future that they did not believe would ever happen. The other questions in this dimension asked how often they felt they could do what they wanted to do (control) and how often they did not want to get out of bed in the morning (emotional wellbeing).

This positive reduction in the frequency of times when people did not believe good things could happen to them, could relate to published narratives from individuals with Asperger Syndrome (Shrubb 2010), Qureshi (2012) and to Punshon's (2009) work which explored post-diagnostic feedback from adults with Asperger Syndrome without a learning disability. In these studies, relief and a sense of emotional control were linked to receiving an autism diagnosis.

6.4.3 Overall subjective quality of life

This study has taken a multidimensional perspective and has gathered data from all seven of the dimensions of quality of life identified in the PWI-ID. This meant that whilst the global measure of 'life as a whole' was recorded, the focus of this study was considering participants' perceptions across all dimensions and then overall. The global concept, in the case of this participant group was one of the lower mean scores across the group (40-50%) whilst the mean PWI-ID score was around 50-60%.

This differs from McGillivray's (2008) study where the 'life as a whole' measure was more in keeping with the high scores achieved in all the other dimensions. In the PWI-ID tool, 'life as a whole' was the first area explored. Participants were then asked to consider each dimension one at a time. One possible interpretation of the lower overall 'life as a whole' scores was that as participants were given the opportunity to reflect on each dimension it prompted them to think more specifically and consider some of the positive aspects of their lives in more depth. For people with characteristics of autism, this approach may provide more structure to their thinking process than asking one global question, where they have to imagine, mentally balance and weigh up all the dimensions in order to come up with one global score.

Another possible interpretation of the lower 'life as a whole score' was that particular negative dimensions of life were more influential than others in the case of some of these participants. In the case of David, for example, it could be that his subjective perception of the future was highly influential in his 'life as a whole'. In this case his negative view of the future could have impacted on 'life as a whole'. In his case his qualitative data suggested a heavy focus on a fear that employment would not happen and this 'future' was one that he regularly referred to in very negative terms.

6.4.4 Changes in subjective wellbeing

Subjective wellbeing is generally recognised for its stability Phillips (2006). This means that for most individuals or populations very little change will be observed in overall scores and these scores will generally be reported at a high level of between 70 and 80%. This capacity for stability, in spite of objective changes, has been related to individual internal mechanisms. Cummins et al (2010) described a homeostatic theory, which suggested that people were able to quickly adjust their perspectives to adversity in order to survive. This might involve focusing positively on one dimension of life when another was affected negatively. Cummins argued that a loss in this stability could represent a failure in these mechanisms when the stress levels were too great for the individual.

Whilst subjective wellbeing might be generally stable, there is some evidence that whole populations can experience changes in their subjective wellbeing scores when major large-scale objective changes take place within that population. Some populations, for example, Russia, Hungary and Belgium, have shown fairly dramatic changes in population level subjective wellbeing following major changes in those countries (Phillips 2006). At an individual level, dispositional factors such as personality may have an impact on homeostatic processes and result in some individuals being more likely to remain stable (Denier and Lucas 1999, Chico Librán 2006).

In this present study, subjective scores were relatively stable but were generally lower than in McGillivray's (2008) study. The exceptions to this were the dimensions of social interaction and material wellbeing, where pre-diagnostically the mean satisfaction scores were above 70%. There were a number of factors that could have contributed to the generally lower subjective scores. These same factors might also help to explain why some participants moved to or remained in a deprived state, when other participants were adaptive or able to move into a state of adaptation.

It is important to consider the very specific nature of the group of individuals being explored in this researcher's study. This also relates to the tendency for people with a borderline learning disability to become visible in literature and clinical practice when they are 'in

trouble'. Other people had referred all participants to the diagnostic process, and this referral was likely to have been made because the referrer was concerned about the individual in some way or because he/she was experiencing some additional specific difficulties. Mo had been referred because of concerns about her vulnerability; Teresa's support worker had identified financial and housing risks; Joanne had been referred because she had failed her year at university, Nick was in the process of being seen by a court. The tendency for people to be referred to the diagnostic process when they were 'in trouble' logically increased their likelihood of having a current life experience that might be causing them additional stress, increasing the likelihood of lower subjective wellbeing. The level of stress might have been so high for some individuals that their homeostatic mechanisms failed and they were unable to make that change independently. This could have contributed to the generally lower subjective scores and the failure of some participants to maintain a state of adaptation or wellbeing.

Cummins et al (2010) puts forward the theory that this homeostatic failure may relate to a clinical presentation of depression. Depression being noted on the COMQOL-I5 was not exclusive to those participants with lower subjective scores, but was a feature of all of the subgroup who showed negative changes following the diagnostic process. Whilst there was little published evidence for the emotional outcome of the diagnostic process, Shrubb (2010) and Punshon et al

(2009) suggest generally positive emotional outcomes. It is, however, reasonable to hypothesise that the diagnostic process may be a negative experience for some and could in some way relate to the group of participants who showed a negative change post-diagnostically. This kind of negative impact of diagnosis would be related to a person learning that he/she had a lifelong disability, or receiving a negative response from family or friends. In the case of John, his qualitative data indicated disappointment that his diagnostic process had not resulted in any change in his wellbeing

It is also possible that the homeostatic process maintaining stability was a slower process in some participants than in others, and that the process of moving from one state to another was not effectively picked up in this study because of the limited timescales of doctoral research. In this hypothesis, some of the participants, for reasons perhaps of personality or resilience (Mak et al 2011), would have had a more efficient mechanism for maintenance and others would have eventually moved into an adaptive state if the length of time over which they were monitored had been longer. Joanne, for example, made a very substantial positive change in her objective quality of life measures, and some change in her subjective wellbeing. These more dramatic objective changes may have eventually been reflected for her in her subjective scores.

A further theoretical consideration was that the neurodevelopmental difficulties that could affect this group were impacting on their homeostatic processes. It is worth considering that being able to adjust to difficulties in one area of life by focusing on the benefits in another, in the face of adversity, requires a degree of self-deception or at least some capacity to use imagination and flexible thinking. One theory could be that some of those participants, who were objectively badly off and also felt subjectively dissatisfied, were actually seeing things as they really were and lacked the skills required to survive difficult times. Theoretically, it might be harder for people with autism to activate the homeostatic processes required to maintain a state of wellbeing in the face of a less positive reality. This is particularly likely if that homeostatic process requires neurodevelopmental skills that may be an area of difficulty for someone with the characteristics of autism.

6.4.5 Balance of subjective and objective quality of life

This study viewed the participants' balance of objective and subjective quality of life using Zapft's model (1984). The participants were effectively described using these states and the ways in which they operated within these states were of theoretical and clinical interest. Many of the participants began the diagnostic process in a state of 'wellbeing' (positive subjective wellbeing/positive objective quality of life). All of these participants maintained this state of wellbeing

throughout the process. Several participants were in a state of 'deprivation' at the beginning of the diagnostic process (negative subjective wellbeing and negative objective quality of life). Joanne had moved into a state of wellbeing but most either remained or moved to a state of adaptation at the end of the diagnostic process. Participants in an adaptive state, at the beginning of the process, showed considerable variation. Some moved to a state of wellbeing, some to deprivation and some remained in adaptation.

Theoretically this was important, as the suggestion could have been made that people who were in a state of adaptation or of wellbeing were able to function, even if adverse circumstances occurred. Those participants who moved into deprivation by the end of the diagnostic process were less likely to be able to cope with adversity unless major changes occurred to their objective indicators (as in the case of Joanne). It was not possible within the constraints of this study to identify any linking factors for this group, other than the observation that they were more likely to report depression. It would be of value to further explore the factors that might impact on any change or stability in state in this group, such as resilience or personality type. Clinically it was also important to consider that whilst there was some evidence of positive changes for this participant group, there were also a small group for whom changes were negative and visible and they may

represent a group for whom embarking on the diagnostic process should be approached with great care.

6.5 Social interaction

One feature identified in this researcher's study was that, compared with Verri's (1999) study, the objective social interaction scores were low which, in terms of COMQOL-I5, related to number and frequency of interactions and shared activity. This suggested that at an individual level social isolation and loneliness could have been an issue for this group. A number of papers have indicated that this might be the case for people with autism, primarily in relation to young people with Asperger Syndrome. Bauminger and Kasari (2000) studied 22 children with Asperger Syndrome and matched controls and found that the children with autism showed difficulties with quality of friendship, increased loneliness and often a poor awareness that lack of friendship was the cause of their loneliness.

Bauminger and Kasari's study raised the issue that autistic children might have had different perceptions of friendship and, although this was not discussed in depth, it should be considered that their participants might have had different perceptions of what loneliness was and the related positive or negative perceptions that went with this. In Bauminger's study, it was noted that the children with autism reported a higher feeling of closeness to those people who were their

friends than the children without autism. This has potential to link to the qualitative data in this present study, which suggested that quality of interaction was of greater importance to some of the participants than quantity and that quality could be quite individually defined.

In the cases of Mark, Adam, Pat and Teresa, their qualitative interview indicated that they placed high value on time away from others and indicated that the presence of others in their home environment was important but that this did not have to relate to direct interaction. They described situations where direct interaction was difficult and caused them specific behavioural and emotional issues. Bauminger's study assumed that lack of friendship was directly related to loneliness and this present study suggests that a greater focus could be placed on the quality and nature of interaction that provides positive wellbeing for a person with autism, rather than assuming that a lack of typical friendships is a cause of difficulty in itself.

Chamberlain et al (2007) observed the challenges for 398 children with Asperger Syndrome in a mainstream classroom environment and their tendency to be isolated and marginalised by others. In spite of these indicators, the children did not actually report feelings of isolation.

Ellem et al (2013) and Ferrari (2009) suggest that this kind of marginalisation can occur for people with a mild or borderline learning disability. Some data that relates to a sense of marginalisation was gathered in the qualitative interviews in this researcher's study. John

and David expressed the idea that other people had a better life than theirs and David in particular talked about a sense of being excluded from a world in which others were able to operate. Pat also talked about others being able to do things that he could not do and Teresa and Adam talked about being distanced from a community that they felt had negative opinions of them.

The participants in this researcher's study showed an adaptive response to social interaction, giving it a subjectively higher rating than any other area, which differed from patterns in other studies of people with a learning disability (McGillivray et al 2009; Hensel et al 2002).

This could be interpreted in a number of ways. It could be that the factors that made social communication feel positive to individuals in this study were different in some way to participants in other studies. In this researcher's study, the qualitative data suggested that having a communicative partner who understood, having family to communicate with, being able to have time alone and having access to virtual communications or social interaction related to special interests were all important to the participants. These appeared more important for this group of participants than volume of interaction.

This interpretation needs to be balanced with Bauminger and Kasari's and Chamberlain's suggestion that someone with autism might not make the link between the effects of loneliness and a lack of friends. This raises the possibility that a person with autism may spend time

alone and experience negative emotions and not connect these with the feelings of loneliness he/she has. The qualitative interviews in this present study created a strong picture of unhappiness with others and the way they behaved and interacted but it was noted that this was often not directly linked to feelings of negative mental wellbeing. The participants in this group reported general satisfaction with social interaction, but frustration with the responses of others, which participants might not have connected together. It was also conceivable that they might have ceased trying to engage in new interactions because of the challenge they presented. Family appeared to have been the constant source of social support and interaction for many of the participants and for some, in the short term, the safest and therefore the most satisfying.

Some specific types of social interaction were not effectively captured by the quantitative interview but were highlighted in the qualitative data as important to some participants. Virtual relationships, for example, were not explored specifically in the COMQOL-I5 and time spent engaged with a computer screen was only measured as a negative quality of life factor in terms of productivity. The qualitative data in this researcher's study identified in the cases of Jane, David and Adam that time spent involved in computer-based games was perceived by them as a positive aspect of productivity and social interaction. Jane

also identified television as a positive shared basis for social interaction with her father.

There were concerns raised in the literature about links between problematic behaviour and ungoverned usage of video games, particularly in relation to sleep and behaviour patterns in young autistic boys (Mazurek 2013; Engelhardt et al 2013). Engelhardt's team carried out a study of 56 boys with autism, 44 boys with Attention Deficit Hyperactivity Disorder (ADHD) and 41 boys with typical development. This study used questionnaires to gather data about the number of hours children spent on video games and on problematic behaviour. The study was limited to parents' reports and was only carried out with boys. It suggested that participants with autism were more likely to engage for long periods with video games and also more likely to have what was framed as problematic behaviour.

There has, however, been interest in the potential benefits for adults and young people with autism of virtual social interaction. Mitchell et al (2007) explored the use of virtual environments with six teenagers with autism. This study explored the impact on these participants of experiencing a virtual reality recreation of everyday situations and considered the impact on their learning in real situations. The reasoning and performance of these students was then independently rated. This produced mixed results with some students performing at a better level with virtual reality support and others at the same level.

Kandalaft et al (2013) carried out a similar study with eight young adults and, more specifically, found improvements in areas such as theory of mind tasks as well as actual improvement in real task social functioning.

Lorence (2007) used grounded theory to explore the ways in which individuals with Asperger Syndrome used online chat rooms. This was done with a focus on Asperger Syndrome-specific online bulletin boards. The study did not make clear the number and breadth of sites accessed, but described accessing the largest and most active. The study identified a value in providing autism-specific information and guidance online for social interaction. Lorence also identified that the postings online had the quality of 'cyber therapy'.

This is a complex area that warrants future study in its own right.

Current studies with positive indications for virtual social communication tend to be small scale and studies exploring the negative effects of virtual technology are more focused on children and teenagers than on adults. There was a strong suggestion from existing literature, and from this present study, that it would not be appropriate to assume that virtual communication represented an inferior level of quality of life in the area of social communication for people with autism and that for some individuals these might have an important role in contributing to positive quality of life.

6.6 Health

Physical and emotional health PWI-ID scores were considered together under the umbrella term of health in this present study, the limitations of this will be discussed later in section 6.11. The objective health score in this study group indicated that participants generally reported fewer additional illnesses or disabilities than were reported in Verri's 1999 study. Potvin et al 2013, in their small-scale study of 30 children with autism without a learning disability, identified a lower level of health compared to matched controls without autism.

Endermann (2013) in his study of 142 young adults with epilepsy and a learning disability identified psychological distress as the only predictive factor for lower objective quality of life and concluded that support to manage psychological aspects of health were an important factor in improving quality of life in this group. Vannucchi et al (2014) evaluated a range of literature looking at the relationships between psychiatric disorder and adults with an Autism Spectrum Disorder. They highlighted increased diagnostic rates for depression, anxiety and obsessive-compulsive disorder in these groups, with unipolar depression and anxiety having the most common co-occurrence in the literature (Ghaziuddin et al 2002).

The subjective scores for this group suggested that health was an area in which, overall, participants felt less satisfied, but, interestingly, direct

references to physical and mental health did not constitute a large proportion of the data in the qualitative interviews. Some individuals referred to their own specific medical diagnosis and the way in which it affected their lives (John, Adam, Jane). There was some direct reference to emotional control and challenges with emotions but a greater focus on the concrete difficulties created by other people and environment and less on emotional impact on individuals. The group of participants with the greatest decrease in their overall subjective scores all identified themselves as actively being treated for depression. The qualitative interview was able to identify themes related to distress associated with sensory environment. This was particularly highlighted in the cases of Pat, David and Teresa.

It could be considered that this relatively unsupported group, with milder learning disabilities, may be less likely to access medical treatments, visit their GP and be aware of their physical issues and, therefore, less likely to articulate issues with health. Muskat et al (2014) described experiences for young people with autism in hospital and identified some of the barriers, such as sensory challenge, lack of structure and communication breakdown that might reduce trust and willingness to access health care. Strunk et al (2014) interviewed parents of children with autism and found concerns that autism was often used as an explanation for other symptoms, creating the risk of diagnostic overshadowing.

Clinical experience has suggested that this group of participants can have negative experiences in GP surgeries and hospitals that can be framed as challenging behaviour on their part and result in an unwillingness to engage in future. Difficulties with social interaction or sensory environment might be misinterpreted as rude or threatening behaviour, and without any clear diagnosis an individual is unlikely to have reasonable adaptations made for them by a service. Those who live independently run the risk that they could struggle to support their own health needs, and may focus on supporting their children's health needs, for example, Adam and Teresa; or may live with parents who also have a learning disability, such as Mike, and may need support themselves to access care.

In considering data gathered relating to perceptions of emotional wellbeing, emotional expression for people with autism warranted some consideration. There can be a stereotypical perception that people with autism lack emotional feeling or response and clinical experience with people with autism has often indicated quite the opposite, with patients reporting intense feelings of emotion and a desperate need to express them. Baron-Cohen (1997) explored the impact of difficulties that people with autism had in anticipating perception of emotions in others and Attwood (2001) described the difficulty that children with autism had in expressing the emotions they were experiencing and the related challenge in learning to effectively

link and label those emotions. Begeer et al (2007) observed that children with autism might find it more difficult to express and discuss mood than neurotypical children.

In terms of health, this researcher's study group were less likely to describe specific health issues than in other studies of people with learning disabilities. This might have reflected lower occurrence of physical and mental health difficulties in this group than in people with more a significant learning disability, but might also have reflected wider issues in their engagement with health services. This group were also more likely to describe situations and individuals that were impacting on their emotional wellbeing than to provide details of the state of their emotional wellbeing.

6.7 Sensory issues and health

Sensory differences can mean that people with autism are less able to identify pain and discomfort (Moore 2014). Whilst there is some research to suggest that there has been an increase in the use of medication to manage autistic symptoms in children (Spencer et al 2013), there is less information regarding adults. Several comments in the qualitative data in this study suggested sensory challenges, and were related in some way to anxiety; some of these did not fit the conventional view of an anxiety-provoking event. Pat, for instance, talked about the distress caused by his mother's cough, and Teresa by

her children talking. Jane talked about noise on the bus and in the street and Vanessa about being frightened by too many people talking to her at once.

It was recognised that many people with Autism Spectrum Disorder experienced significant enough sensory challenges to result in sensory difficulties being included as part of the diagnostic criteria (American Psychiatric Association 2013; Kern et al 2007). Sensory integration literature links sensory overload to the natural 'fight or flight' associated with fear in people with this disorder (Attwood 2007). The theory is that for people with autism this reaction occurs at a lower threshold and can result in behaviour that is then understood as aggressive or excessively anxious for the situation.

People with autism may, therefore, be experiencing health issues that are difficult for them to describe and report or may be framed as unreasonable, challenging behaviour. Their autism in itself may be considered explanatory of symptoms or difficulties such as anxiety and this may not be treated. This researcher's study would suggest that in order to understand quality of life perceptions in the areas of health, for people in this study group, careful consideration should be given to the impact that sensory differences might have both on perceptions and the ways in which these perceptions could be articulated.

6.8 Material wellbeing

This group's perceptions of material wellbeing warrant some careful consideration. In this researcher's study group, overall, their objective quality of life scores were low. This meant that participants had a low income, were less likely to own their own property, have a job or have many possessions. Overall, participants' view of their subjective wellbeing was positive, suggesting that this group felt satisfied with their material wellbeing. There was literature that suggested that people who had autism or a learning disability were more likely to have poor outcomes in relation to employment (Roux et al 2013; Ross et al 2013). Burgess and Cimeria (2014) identified that where people with autism were employed it tended to be for fewer hours and at lower wages. This present study group had extremely poor rates of employment, with only Jim and Cathy having low paid part-time work, and Cathy then being made redundant.

The quantitative tools used in this study tended to focus on money and ownership, rather than personal value for particular objects or home.

The qualitative interviews identified awareness in the group that they were limited by their incomes and that money was important in a number of ways, but there was also a greater depth in perceptions in this area. Valerie ascribed strong value to being able to experience, own and discuss animals. Mark was more forthcoming on the details of items he liked to view and purchase on Ebay, than on people. Teresa

needed prompts to discuss her family but was able to talk at length about her collections and her house. Adam and David were comfortable discussing their virtual games and the importance of this world to them. Jane generally discussed her relationships with people in the context of object related shared interests such as the Eurovision song contest and virtual technology.

The qualitative interview did gather some data, which suggested that the participants might prefer to live in a different house or alternative location. Lack of money was linked in several cases to challenges with purchasing cared for objects or activities. However, for the majority the focus in this area was on factors such as having a room or a space in which they could be private (Mark, Jane, Valerie, Teresa, David) and this seemed to link to manageable social interactions in the cases of Mark, Pat, Teresa and Adam. Home had a value for many participants that did not appear to be related to its size or cost, but instead to its safety and the way it also linked to future security.

This indicated that this study group had perceptions regarding their material wellbeing and these were effectively captured through a qualitative research process. Specific areas such as ownership of special objects and collections, animals and safe individual space warrant further consideration in relation to understanding what positive quality of life might mean to this group.

6.9 Safety and community participation

Community participation was an area with a low overall objective score, which suggested that this group had less interaction with local people and organisations and did not feel valued or active in their neighbourhoods. It was the only area, which was ranked as consistently of low importance for participants across the group. Subjectively, participants expressed overall satisfaction within this dimension. This subjective finding reflects other studies for people with a learning disability (McGillivray et al 2009).

In general, the objective tools tended to frame community as referring to an individual's local neighbourhood or to clubs and groups. An important consideration was what the participants' own sense of their 'local community' was for them. Local community could hold different meanings for specific individuals and for some people their community did not, for example, relate to the neighbourhood around them, but to something else. The qualitative interview data helped to clarify some of these differing perceptions. David and Adam were relatively negative about their geographical local community, but talked positively about their virtual gaming community. Pat, John and Teresa talked about their families, who lived away from them, with a sense of connection and importance. These extended family structures appeared to make up a community that they wished to be involved in,

but expressed a sense of frustration that they could not always successfully feel part of.

One consideration at the outset of this study was the possible role of church or spiritual activity in the quality of lives of the individuals in the study. This was seen as an area that warranted specific consideration in the ordinary population (Sawatsky et al 2005) with some studies suggesting that this domain might relate to increased wellbeing for some individuals (Frame 2005). Cummins et al (2010) did not include this domain in the PWI-ID as he argued that there was no evidence that it made any significant contributions to overall scores.

COMQOL-15 did ask a specific question about church attendance and in this study the qualitative interview was supported with pictures designed to support discussion about spiritual components. The only person to make any reference to this area was David, who described a decline in his regular church attendance but made positive comments about some members of that church and described them as significant individuals in his life.

Feelings of marginalisation and exclusion from communities were commonly reported in the learning disability literature, which were linked to historical institutionalisation; visible differences (Beart et al 2005); life-long nature of the condition (Gillman et al 2000; Harris 1995); hegemonic acceptance or poor situations and lack of power to

change situations (Burns 2000, Walmsley 2001). White and Roberson-Nay (2009) studied 14 teenagers with autism who did not have a learning disability, but in some cases were described as having a low IQ. This study found a correlation between degree of anxiety and social isolation, suggesting that this kind of wider societal isolation could be related to issues with mental wellbeing. The suggestion that levels of anxiety contributed to social isolation also naturally linked to perceptions of safety, and the extent to which this could be a barrier to participants.

Previous discussion in this chapter about the concept of loneliness suggested that it was a complex area. The qualitative data in this researcher's study suggested that for some participants, such as Mark, Pat, Adam and Teresa, rather than a desire to be more included in the community they had a desire to be supported to spend more time on their own or with very specific people or activities. David in his qualitative interviews regularly referred to a sense that society was rejecting him because of his disability and employment status and appeared to want to be 'allowed in'. At the same time, his preferences were for very specific community groups that related to his specific interests and for contact that led to employment. Jane was probably the participant with the most positive comments regarding her engagement with her local community, particularly post-diagnostically where she changed location and was making active efforts to engage.

Bolick (2008) described the potential gains in social capital for people with autism if they could be more involved with their local community, but also highlighted the social and sensory challenges of this. The qualitative interview, in this present study raised some specific issues in relation to trust and in the cases of Pat, Teresa and Adam that lack of trust of others in the local community, such as, neighbours and people in town could have prevented them from connecting with the local community. References in interviews in this study to threats of difficulty in the world outside of home were generally related to the difficult and complicated nature of others, rather than directly to feeling unsafe. Mark, John and Teresa felt safer keeping themselves in their home space and minimising their contact with people who they perceived as problematic and dangerous. This resulted in less presence in the community and a reduced volume of social interaction. For others, key people provided their protection from danger. Pat and Valerie felt their support staff fulfilled this role whilst Adam felt safer if his wife was present when he was in the community, as she enabled him to keep his own behaviour in check.

Müller et al (2008) explored the views of 18 people with Asperger Syndrome in relation to their social world and the kind of social support that assisted them. The majority of participants were male and represented a range of academic backgrounds with data gathered using semi-structured interviews and then subjected to a thematic

analytical process. Themes included feelings of intense isolation and a desire to contribute, with a major barrier to contribution being the heavy social communication focus of most community-based activities and events. Müller advocated that more interest-specific activities would be of value in supporting people with autism to access community-based activities. In this present study, David was positive about groups in his local area that related to his interest in trading cards and it was also notable for Mark that in the environment of the local radio station, where he was allowed to focus on his special interests, he described being comfortable outside of his room and being part of his local community.

Another factor, described in the qualitative interviews in this study, was the role of trusted supporters in facilitating community engagement. Throughout this study, a key factor in engagement in research was the role of gatekeepers. Participants also described the role of gatekeepers in accessing the community. Valerie and Teresa expressed that they could not go into the community without their supporting person. Adam talked about the role of his wife and children in enabling him to take on a more positive approach in his community and cope better with those people who annoyed him. Jane described the role of her mother and a friend in accessing a local community support group and going for the first time to college.

Community participation, in the context of involvement with a local geographical community, was an area that this group consistently rated as low in importance and were rarely actively involved with their local community. In broad terms they reported being satisfied with this situation. The qualitative data in this study highlighted the relationship with feelings of safety and security being greatest when at home and with the individuals who were perceived as safe. As a dimension, safety was objectively and subjectively relatively highly rated and one way this was achieved for this group was by minimising their contact with a wider community that they described struggling to engage with or relying on a supporter to make that access possible. This study has raised the importance of considering a wide range of contexts for community participation as of importance to this participant group and considering the role of supportive individuals in accessing those opportunities. The finding that perceptions of positive community participation involve virtual communities, special interest groups and extended family is an important one for future research and clinical practice.

6.10 Future security

Consideration of the future was a concept that had the potential to be a complex area for an individual with a degree of learning disability and possible autism for a number of reasons. It required the capacity to imagine events that had not yet happened and this required abstract

and flexible thinking. Terrett et al (2013), in their study of 30 children with autism and no learning disability, asked participants to complete an adapted autobiographical interview. In completing this task the children had to describe past events that had actually happened to them and future events that could possibly happen. Their responses were then compared with a control group of typically developing children. This study identified that children with autism found it harder to describe past and future events, and that episodic memory might play a part for both groups in predicting future events. This study focused only on children and it is difficult to be certain of the impact of an adult life experience on the skill of imagining future events, but it was suggestive of some specific difficulties related to autism.

In objective terms, participants in this study had positive indicators overall in this dimension and showed the greatest positive change across the diagnosis process in the indicator of future security. This indicator asked them how often they believed that their hopes and dreams for the future would come true. The measure of subjective future security was, however, relatively low and did not change throughout the process. A number of participants in this study were resistant to the idea of thinking beyond the 'here and now', and when they did describe the future it had a magical and unreal quality. This was noticeable in the case of Teresa who talked of being taken away by a handsome prince, Adam talked about moving the whole family to

somewhere by the coast and Valerie described transporting pets on the plane for an exotic holiday, because she would not like to leave them.

Several participants expressed fears for the future and referred to their reliance on informal support that they were aware was going to change in the future. John, Mark, David, Jim and Jane, for example, were all reliant on parental support; Teresa was relying on her daughter's support worker, with the likelihood that at some stage her daughter would move away from home. Teresa and John both referred to the idea that they only focused on the 'here and now' and indicated that this stopped them worrying about a difficult future. A connecting factor for many of the participants was the unofficial nature of their support, which added to the fragility and uncertainty of that support. Several of the participants, including Adam, John and David referred to the idea of not being disabled enough to be eligible for any formal support. This data reflects the relatively mild nature of the participants' learning disabilities and the concern that this would mean the degree of support that was needed was not being fully understood. A future without informal social support was one that participants were fearful of and this uncertainty might have contributed to the low subjective scores.

6.11 Limitations of study

This study was designed to explore a small and very specific population. This population were individuals who had been referred to the local Autism Diagnostic Service and who also had a mild or borderline learning disability. It has already been considered that individuals who were referred to the diagnostic service could share factors such as concern about their current situation. It is possible that the factors that stop someone being considered for an autism diagnosis can have a significant impact on his/her quality of life perceptions. This limits the ways in which the result of this study could be applied to people with similar characteristics but who have not been referred to the diagnostic process.

The research process identified a number of limitations in the tools that were used in this study. The quantitative tools by their nature risked ethnocentric assumptions. An example of this was the assumption that greater lengths of time spent watching 'screens' would equate to reduced quality of life in the dimensions of productivity and social interaction. As has already been discussed, this was not a well-founded assumption in a population of people with additional autism. A further limitation of the PWI-ID tool was that a number of dimensions were combined that may have been valuable to explore separately. A specific example of this was in the area of health where subjective perceptions of physical and emotional health had to be rated as one

measure and could well have been very different from each other. This was possible to address to some extent through exploration of the qualitative data.

The limitations identified with the quantitative tools for people with autism and a degree of learning disability were in many ways useful findings as they were informative of development needs for quantitative tools specifically designed for this group. These included the need to reflect sensory issues, the importance of quality as well as quantity in terms of material wellbeing and social interaction and some reflection of the value of time spent alone in social interaction. These issues will be additionally reflected on when considering future research.

The benefits of the joint role of researcher and clinician have already been discussed and there were potential limitations that this brought to the study. Participants might have chosen to reveal or conceal information because of their own perceptions of this joint role. They could, for example, have chosen to emphasise negative aspects of their lives, believing the researcher as a diagnostician had power to remedy these. Equally, they might have felt that they needed to please a perceived powerful figure and been more inclined to share positive information. In the case of Chris, her decision not to attend her final session might have been related to dissatisfaction with 'services' of which this researcher, in her joint role, could have been viewed as

being a part. Equally, she might have chosen to come to the research sessions because she believed the researcher, having a clinical role, could influence change in her life.

Mark was a participant who appeared to find the interview process stressful and was a key provider of data that suggested that he did not wish to generally be engaged in activity outside of his special interests and home environment. It could be argued that an ethical limitation of this study was that it required direct interaction with a group of people who found this stressful and difficult. It has already been discussed that this group was a difficult group to engage and it seems likely that in order to gain a true perspective on this group's lives then some participants who found engagement stressful needed to be engaged. If participants who found engagement stressful had been excluded from this group then there would have been a risk of failure to understand and include the perspective of someone like Mark.

This study had the natural time limitations that accompany doctoral research, which prevented a more longitudinal study. It could have been beneficial to have had the opportunity to evaluate changes in quality of life dimensions over a greater length of time to thoroughly assess the stability and change within the participant group. A greater length of time might have also allowed the opportunity to use the quantitative data to assess and select a larger number of individual cases for qualitative evaluation. Laura and Cathy, for example, were

participants who showed changes in their quality of life perceptions that might have warranted qualitative analysis, but this only became apparent when all the quantitative data had been evaluated.

The area of sexual relationships and sexuality was not specifically explored and no data, with the exception of some mention of partners and boyfriends and some allusion in the case of Pat to difficulties in relationships with women, was gathered in this specific area. McCabe and Cummins (1998) identified this as an important area for people with no additional learning disability, in terms of their quality of life, and it would be reasonable to consider that it would have been a helpful area to explore with this study group. The materials used in this study did include pictorial prompts regarding a range of different types of relationships, but in order to gather more detail about a potentially complex and sensitive area a specific and skilled approach which asks more direct questions in this area is likely to be needed.

6.12 Implications for future research and clinical practice

Learning from this study has the potential to be informative for clinicians and researchers interested in engaging with people with a mild or borderline learning disability and possible autism. The first area in which the study contributed to new knowledge and practice was in terms of achieving engagement and involvement of a group of

individuals whose perceptions have not been understood in current literature.

This group were effectively engaged when they were naturally being drawn into a clinical service and this makes clinical practice an effective place to consider as a point of access to this group. This close link to clinical practice extends to advocating for the direct involvement of clinicians in research who can then bring their expertise to engagement, design and delivery of research methods. In the case of such a small and specialised caseload this may mean a joint role in relation to some participants. Whilst this may initially seem problematic this study highlights that, with a participant group for whom engagement and trust can be such a significant barrier, this joint role may enable engagement that would otherwise not occur.

It was also essential both as a clinician and a researcher to carefully consider the role of gatekeepers who might have a relatively informal role in individual's lives. Identifying an appropriate and ethical way of engaging with these key people would be an important aspect of setting up any research study that aims to directly engage with this group. This study demonstrated that a proactive approach was required to gain access to this group and clinicians and researchers would need to plan an approach which allowed time and a process for reminders and follow-up communication with both the individuals and their supporters.

This study has also helped to identify the importance of considering the impact of the neurodevelopmental and linguistics characteristics of autism when engaging this participant group. Key areas of consideration would be use of structured approaches, pictorial supports and Likert scales. Additionally, this study identified the value of using a closed quantitative style to gather data that can then be used as a prompt or probe to extend for more narrative. This can be effectively supported using approaches that draw on ethnographic questions.

This study highlighted a number of dimensions of quality of life, which warrant both future study and also consideration in relation to clinical support and management. The area of social interaction was complex and was extensively discussed by participants in their qualitative interviews. A deeper understanding of the balance of perceived distress related to social isolation and the need for time alone for wellbeing would be beneficial in terms of clinical practice and also in planning care and support for this group.

This study would suggest that simply trying to develop social communication skills and social environments for this group may be too simplistic and more careful consideration of the need for a balance of time alone and social time related to special interests would benefit from further consideration and investigation, as well as the importance of trusted supporters in bridging into local community. Additionally, this

study identified some positive perceptions of virtual communication and technology for people within this participant group, which could be considered contrary to some concerns that have been raised about excessive 'screen time'. This research study suggested that for some individuals virtual communication was perceived as a positive aspect of their social communication and as such the value of this for this group of individuals warrants clinical and service level consideration. Other areas warranting further investigation would be links between perceived quality of life and sensory issues. This would include specific consideration of the dimensions of health, social interaction and community participation.

Chapter Seven: Conclusions

7.1 Overview

This study set out to describe the perceived quality of life for people with mild or borderline learning disabilities, who were referred to the local Autism Diagnostic Service. It did this using a mixed methods approach to gather data in the form of objective and subjective indicators, ratings of importance and an in-depth qualitative interview. Initially, the study had a greater focus on identifying change in quality of life perceptions across the diagnostic process, which resulted in the quantitative and qualitative components of the study having a more equal balance. Whilst changes in perceptions patterns remained of interest, it became apparent that the quantitative methods had a more significant role to play in producing data that then supported the development of a qualitative approach and the focus became more clearly one of developing a thorough, multidimensional understanding of quality of life for this participant group. This increased the value, importance and focus on the qualitative methods within the study.

The local diagnostic process provided a point at which this group could be accessed and provided an opportunity for engagement and also linked this study to the expertise and interest in the participant group within the diagnostic service. The use of a focus group helped to identify the initial challenge of engagement with this group and to

develop a change of approach that improved engagement in the later phases. This pilot and research phase of this study highlighted the degree of persistence needed to engage with this group, the importance of actively using gatekeepers and the value of combining the knowledge, experience and role of a clinician with that of a researcher of a complex and marginalised group.

This study found that quantitative data showed generally low levels of objective quality of life, with the exception of areas such as health and emotional wellbeing. Subjectively this group had lower levels of life satisfaction than might have been expected, with the exception of material wellbeing and social interaction. Overall importance of dimensions to participants was varied but one area of consistency was that community participation was ranked as of lower importance than other dimensions of quality of life.

People with mild or borderline learning disabilities and possible autism are an under-researched group. This study indicates that in general their objective quality of life is lower than the ordinary population, but that what constitutes a positive quality of life for this group may be different and warrants further investigation. This study suggests that their additional autism characteristics may have an impact on their quality of life perceptions and their milder learning disabilities may result in less support, higher expectations and greater awareness of their difficulties. All these factors could be related to their overall lower

sense of subjective wellbeing by comparison with other studies of people with a learning disability.

7.2 Contribution to new learning and clinical practice

This study contributes to new knowledge in how to visually present multidimensional data relating to the quality of life perceptions of people with mild or borderline learning disabilities and possible autism. It has developed new methods to approach and engage this group in research that can be applied in the future by other researchers. It has identified areas of potential future quality of life research that may be of clinical interest and have relevance for how people are supported once the diagnostic process has been completed.

This study demonstrates that people with a mild or borderline learning disability and possible autism are able to express their quality of life perceptions and that quantitative tools for gathering objective quality of life data, have value, but may require some adaptations in areas such as social communication, material wellbeing and community participation to be more pertinent to this participant group.

This study has demonstrated that qualitative methods were essential to gain depth and to ensure that the participants were effectively supported to provide some narrative in expressing their perceptions. A qualitative approach allowed for wider and unplanned areas of quality

of life perception to be explored and was a helpful counterbalance for the ethnocentricity of the quantitative tools.

This study has contributed to understanding of the value of a joint role of clinician and researcher. This emerged naturally from the clinical location that was a point for engagement with a participant group that has rarely appeared in other research studies. This joint role was fundamental to the flexible methods, which needed to be accessible to the participants, and required clinical skill to administer. Ethical issues linked to this joint role can be managed with regular reflection and clear communication to participants and gatekeepers.

This study has identified that the perceptions of quality of life in this specific study group are different in several key ways to those identified in other studies of participants with more significant learning disabilities or without autism. This key finding needs to be considered within clinical practice, to ensure that those differences are reflected in engagement with and planning care and support for this group of individuals.

References

Alvarez, J., and Crabtree, J. (2008) The effect of a residential setting on quality of life for adults with an autism spectrum condition. *Good Autism Practice*. 9 (2), pp.3-8.

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders. 5th edition*. Washington, DC. London, England: American Psychiatric Publishing.

American Psychiatric Association (2000) *Diagnostic and Statistical Manual of Mental Disorders. 4th Edition, Text Revision (DSM-IV-TR)*. 4th ed. Washington: American Psychiatric Association.

Antaki, C. (1999) Interviewing persons with a learning disability: How setting lower standards may inflate well-being scores. *Qualitative Health Research* [online]. 9 (4), pp.437-454. [Accessed 4/09/2011].

Attwood, T. (2007) *The complete guide to Asperger's Syndrome*. London, Jessica Kingsley Publishers.

Attwood, T. (2001) *Asperger's Syndrome: A guide for Parent and Professionals*. London: Jessica Kingsley Publishers.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet* [online]. 368 (9531), pp.210-215. [Accessed 20/05/2010].

Barnes, J.L. and Baron-Cohen, S. (2012) The big picture: storytelling ability in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders* [online]. 42 (8), pp.1557-1565. [Accessed 21/04/14].

Baron-Cohen, S. (1997) *Mindblindness. An Essay on Autism and Theory of Mind*. Cambridge: The MIT press.

Barr, O. (2007) Research in learning disability nursing: importance and relevance to all areas of nursing. *Journal of Research in Nursing* [online]. 12 (2), pp.107-109. [Accessed 23/05/2010].

Bauminger, N. and Kasari, C. (2000) Loneliness and Friendship in High-Functioning Children with Autism. *Child Development* [online]. 71 (2), pp.447-456. [Accessed 21/04/2014].

Beadle-Brown, J., Murphy, G. and DiTerlizzi, M. (2009) Quality of Life for the Camberwell Cohort. *Journal of Applied Research in Intellectual Disabilities* [online]. 22 (4), pp.380-390. [Accessed 23/05/2010].

Beart, S., Hardy, G. and Buchan, L. (2005) How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities* [online]. 18 (1), pp.47-56. [Accessed 25/06/2011].

Becker, H.S. (1963) *Outsiders: Studies in the sociology of deviance*. New York Free Press of Glencoe.

Begeer, S., Terwogt, M.M., Rieffe, C., Stegge, H. and Koot, H.M. (2007) Do children with autism acknowledge the influence of mood on behavior? *Autism: The International Journal of Research & Practice* [online]. 11 (6), pp.503-521. [Accessed 21/04/14].

Billstedt, E., Gillberg, I.C. and Gillberg, C. (2011) Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study. *Autism: The International Journal of Research and Practice* [online]. 15 (1), pp.7-20.

Bishop, S.L. and Seltzer, M.M. (2012) Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders* [online]. 42 (11), pp.2354-2363. [Accessed 28/04/2013].

Björnsdóttir, K. and Svendsdóttir, A.S. (2008) Gambling for capital: learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities* [online]. 36 (4), pp.263-270. [Accessed 04/05/2014].

Bolick, T. (2008) "It Takes a Community": Social capital, Autism Spectrum Disorders, and the real world. *Topics in Language Disorders* [online]. 28 (4), pp.375-387. [Accessed 22/06/2014].

Booth, S. (2002) A philosophical analysis of informed consent. *Nursing Standard*. 16 (39), pp.43-46.

Booth, T. and Booth, W. (1996) Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society* [online]. 11 (1), pp.55-70. [Accessed 05/04/2012].

Boxall, K. and Ralph, S. (2009) Research ethics and the use of visual images in research with people with intellectual disability. *Journal of Intellectual and Developmental Disability* [online]. 34 (1), pp.45-54. [Accessed 21/04/2014].

Boyden, P., Esscopri, N., Brennan, A. and Kalsy-Lillico, S. (2009) Service users leading the way: Focus group methodology in developing accessible information DVDs with people with learning disabilities. *Journal of Intellectual Disabilities*. 13 pp.183-194.

Bradley, E.A., Summers, J.A., Wood, H.L. and Bryson, S.E. (2004) Comparing rates of psychiatric and behavior disorders in adolescents and young adults with severe intellectual disability with and without autism. *Journal of Autism & Developmental Disorders* [online]. 34 (2), pp.151-161. [Accessed 08/05/2014].

- Braun, V. and Clarke, V. (2013) *Successful Quantitative Research*. London: SAGE Publication Ltd.
- Brown, H. and Thompson, D. (1997) The ethics of research with men who have learning disabilities and abusive sexual behaviour: A minefield in a vacuum. *Disability & Society* [online]. 12 (5), pp.695-708. [Accessed 02/04/2011].
- Brown, R.I. and Brown, I. (2005) The application of quality of life. *Journal of Intellectual Disability Research* [online]. 49 (10), pp.718-727. [Accessed 27/04/2014].
- Brown, R.I., Schalock, R.L. and Brown, I. (2009) Quality of life: Its application to persons with intellectual disabilities and their families—Introduction and overview. *Journal of Policy & Practice in Intellectual Disabilities* [online]. 6 (1), pp.2-6. [Accessed 02/05/2013].
- Brugha, T. (2012) Adults with severe learning disability are 'invisible' group more likely to have autism. *British Journal of Hospital Medicine (17508460)* [online]. 73 (3), pp.128-128. [Accessed 02/03/2013].
- Bryman, A. (2007) Barriers to integrating qualitative and quantitative research. *Journal of Mixed Methods*. 1 pp.8-22.
- Burgess, A.F. and Gutstein, S.E. (2007) Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health* [online]. 12 (2), pp.80-86. [Accessed 11/09/2011].
- Burgess, S. and Cimera, R.E. (2014) Employment outcomes of transition-aged adults with autism Spectrum Disorders: A state of the states report. *American Journal on Intellectual & Developmental Disabilities* [online]. 119 (1), pp.64-83. [Accessed 27/06/2014].
- Burns, R.B. (2000) *Introduction to research methods*. London Sage Publishing.
- Butler, J. and Ciarrochi, J. (2007) Psychological acceptance and quality of life in the elderly. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation* [online]. 16 (4), pp.607-615. [Accessed 12/13/12]
- Cameron, L. and Murphy, J. (2007) Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities* [online]. 35 (2), pp.113-120. [Accessed 01/04/2011].
- Chamberlain, B., Kasari, C. and Rotheram-Fuller, E. (2007) Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of Autism & Developmental Disorders* [online]. 37 (2), pp.230-242. [Accessed 04/12/2012].

- Charlton, J.I. (2000) *Nothing About Us Without Us: Disability, Empowerment and Oppression*. University of California Press.
- Chico Librán, E. (2006) Personality Dimensions and Subjective Well-Being. *The Spanish Journal of Psychology* [online]. 9 (1), [Accessed 04/12/2012].
- Claes, C., Van Hove, G., van Loon, J., Vandeveld, S. and Schalock, R.L. (2010) Quality of life measurement in the field of intellectual disabilities: Eight principals for assessing quality of life related outcomes. *Social Indicators Research*. 98 (1), pp.61-72.
- Clare, I.C.H. and Gudjonsson, G.H. (1993) Interrogative suggestibility, confabulation, and acquiescence in people with mild learning disabilities (mental handicap): Implications for reliability during police interrogations. *British Journal of Clinical Psychology* [online]. 32 (3), pp.295-301. [Accessed 12/02/2012].
- Cleaver, S., Ouellette-Kuntz, H. and Sakar, A. (2010) Participation in intellectual disability research: A review of 20 years of studies. *Journal of Intellectual Disability Research* [online]. 54 (3), pp.187-193. [Accessed 06/09/2011].
- Cocking, A. and Astill, J. (2004) Using literature as a therapeutic tool with people with moderate and borderline learning disabilities in a forensic setting. *British Journal of Learning Disabilities* [online]. 32 (1), pp.16-23. [Accessed 6/09/2013].
- Colle, L., Baron-Cohen, S., Wheelwright, S., vander Lely, H.K.J. (2008) Narrative discourse for adults with high functioning autism or Aspergers Syndrome. *Journal of Autism and Developmental Disorders*. 38 (1), pp.28-40.
- Compton, D.A., ed. (1997) *Issues in Therapeutic Recreation: A Profession in Transition*. Champaign: Sagamore Press.
- Craig, J. and Baron-Cohen, S. (2000) Story telling ability in children with autism and Asperger Syndrome: A window into the imagination. *International Journal of Psychiatry Related Science*. 37 (11), pp. 64-70.
- Cresswell, J.W. and Clark. L.P. (2011) *Designing and conducting mixed methods research*. London Sage Publishing.
- Cummins, R.A. (2012) Email to Sue Smith, 12/11/2012.
- Cummins, R.A (2005a) Caregivers as managers of subjective wellbeing: a homeostatic perspective. *Journal of Applied Research in Intellectual Disabilities* [online]. 18 (4), pp.335-344. [Accessed 21/04/14].
- Cummins, R.A. (2005b) Moving from the quality of life concept to a theory. *Journal of Applied Research in Intellectual Disabilities* [online]. 49 (10), pp.699-706. [Accessed 02/04/2011].
- Cummins, R.A. (2002) *Vale ComQol: Caveats to using the Comprehensive Quality of Life Scale. Welcome: The Personal Wellbeing Index*. Available from: deakin.edu.au [Accessed June 2011].

- Cummins, R.A. (1997) *The Comprehensive Quality of Life Scale- Intellectual/Cognitive Disability. 5th Edition (ComQol-I5-manual)*. School of Psychology. Deakin University.
- Cummins, R.A. (1996) The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research* [online]. 38 (3), pp.303-328. [Accessed 02/04/2011].
- Cummins, R.A. (1994) Validity studies the Comprehensive Quality of Life Scale (COMQOL): Instrument development and psychometric evaluation on college staff and students. *Educational and Psychological Measurement*. 54 (2), pp.372-382.
- Cummins, R.A and Gullone, E. (2000). Why we should not use 5 point Likert scales: The case for subjective quality of life measurement. Proceedings, *Second International Conference on Quality of Life in Cities*, pp. 74-93. Singapore: National University of Singapore. [Accessed 12/02/2012].
- Cummins, R.A and Lau, A.L.D, (2005) *Personal Wellbeing Index- Intellectual Disability. 3rd Edition. Manual*. School of Psychology, Deakin University: Deakin University.
- Cummins, R.A, Lau, A.L.D., Davey, G., McGillivray, J. (2010) Measuring subjective wellbeing: The Personal Wellbeing Index- Intellectual Disability. In: Kober, R., ed. (2010) *Enhancing the Quality of Life of People with Intellectual Disabilities. From Theory to Practice*. London: Springer, pp.33-46.
- Cummins, R.A. and Lau, A.L.D (2003) Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities* [online]. 16 (2), pp.145. [Accessed 04/12/2012].
- Cummins, R.A and Lau, A.L.D (1997). *Comprehensive quality of Life scale- Intellectual/Cognitive Disability. 5th Edition. Manual*. School of psychology, Deakin University: Deakin University.
- Cummins, R.A., McCabe, M.P., Romeo, Y. and Gullone, E. (1994) The Comprehensive Quality of Life Scale (ComQol): Instrument development and psychometric evaluation on college staff and students. *Educational and Psychological Measurement* [online]. 54 (2), pp.372-382. [Accessed 12/02/2012].
- Daves, M. (2011) *The Impact of an Asperger Syndrome Diagnosis: A Phenomenological Exploration into the Lived Experience of Asperger Syndrome*. Unpublished Professional Doctorate, Regent's College, London.
- Dawson, M., Soulieres, I., Gernsbacher, M.A., Mottron, L.(2007) Research report: The level and nature of autistic intelligence. *Psychological Science*. 18 (8) pp. 657-662.
- Denier, E., Lucas, R. (1999) Personality and subjective wellbeing. In: Kahneman, D., Deiner, E., Schwartz , N., ed. (1999) *Wellbeing: The Foundations of Hedonic Psychology*. pp.213-229.

Department of Constitutional Affairs (2005) *Mental Capacity Act Code of Practice*. The Stationery Office: HM Government.

Department of Health (2010)a *Equity and Excellence. Liberating the NHS*. The Stationery Office: HM Government.

Department of Health (2010)b *Fulfilling and Rewarding Lives. The Strategy for Adults with Autism in England*. The Stationery Office: HM Government.

Department of Health (2010) *Implementing Fulfilling and Rewarding Lives 15204*. (2010) Available from: <http://www.dh.gov.uk/publications>.

Department of Health (2007) *Valuing People Now: From progress to transformation - a consultation for the next three years of learning disability policy* (2007) The Stationery Office: HM Government.

Department of Health (2006) *Let Me In- I am a Researcher! The Learning Difficulties Research Team*. The Stationery Office: HM Government.

Department of Health (2003) *Seeking Consent: Working with people with learning disabilities*. The Stationery Office. HM Government.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century*. The Stationery Office: HM Government.

Department of Health (1997) *The New NHS: Modern, Dependable*. Gateway reference 1997. The Stationery Office: HM Government.

Dye, L., Hendy, S., Hare, D.J. and Burton, M. (2004) Capacity to consent to participate in research? A recontextualization. *British Journal of Learning Disabilities* [online]. 32 (3), pp.144-150. [Accessed 23/04/2010]

Eaves, L.C. and Ho, H.H. (2008) Young adult outcome of Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders* [online]. 38 (4), pp.739-747. [Accessed 04/12/2012].

Ellem, K., Wilson, J., Chui, W.H. and Knox, M. (2008) Ethical challenges of life story research with ex-prisoners with intellectual disability. *Disability & Society* [online]. 23 (5), pp.497-509. [Accessed 14/03/2012]

Ellem, K., O'Connor, M., Wilson, J. and Williams, S. (2013) Social work with marginalised people who have a mild or borderline intellectual disability: Practicing gentleness and encouraging hope. *Australian Social Work* [online]. 66 (1), pp.56-71. [Accessed 02/12/13].

Ellem, K., Wilson, J., O'Conner, M. and MacDonald, S. (2012) Supporting young people with mild/borderline intellectual disability exiting State out of- home care: directions for practice. *Developing Practice* [online]. (32), pp.53-65. [Accessed 02/12/13].

Emerson, E., Hatton, C., Robertson, J., Roberts, H. and Banks and Glover, G., (2011) *Improving Healthcare and Lives of People with Learning Disability in England*. Report number: IHAL2011-02. Department of Health: Learning Disability Observatory.

Endermann, M. (2013) Predictors of health-related and global quality of life among young adults with difficult-to-treat epilepsy and mild intellectual disability. *Epilepsy & Behavior: E&B* [online]. 26 (2), pp.188-195. [Accessed 02/12/13].

Engelhardt, C.R., Mazurek, M.O. and Sohl, K. (2013) Media use and sleep among boys with autism spectrum disorder, ADHD, or typical development. *Pediatrics* [online]. 132 (6), pp.1081-1089. [Accessed 02/03/2014].

Ferrari, M. (2009) Borderline intellectual functioning and the intellectual disability construct. *Intellectual & Developmental Disabilities* [online]. 47 (5), pp.386-389. [Accessed 12/02/2012].

Frame, M.W., Uphold, C.R., Shehan, C.L. and Reid, K.J. (2005) Effects of spirituality on health-related quality of life in men with HIV/AIDS: Implications for counseling. *Counseling & Values* [online]. 50 (1), pp.5-19. [Accessed 27/04/2014].

Frith, U. and Happé, F. (1998) Why specific developmental disorders are not specific: On-line and developmental effects in autism and dyslexia. *Developmental Science* [online]. 1 (2), pp.267-272. [Accessed 02/04/2011].

Ganz, J.B, Heath, A.K, Davis, J.K, Vannest, K.J. (2013) Effects of a self-monitoring device on socially relevant behaviours in adolescents with Asperger disorder. *Assistive Technology*. 25 (3), pp.149-57.

Garbutt, R., Tattersall, J., Dunn, J. and Boycott-Garnett, R. (2010) Accessible article: involving people with learning disabilities in research. *British Journal of Learning Disabilities* [online]. 38 (1), pp.21-34. [Accessed 12/02/2012].

García-Villamizar, D., Dattilo, J. and Matson, J.L. (2013) Quality of life as a mediator between behavioral challenges and autistic traits for adults with intellectual disabilities. *Research in Autism Spectrum Disorders* [online]. 7 (5), pp.624-629. [Accessed 01/04/2011].

Gates, B. and Waight, M. (2007) Reflections on conducting focus groups with people with learning disabilities. *Journal of Research in Nursing*. 12 (2), pp.111-126.

Gerber, F., Bessero, S., Robbiani, B., Courvoisier, D.S., Baud, M.A., Traoré, M., Blanco, P., Giroud, M. and Galli Carminati, G. (2011) Comparing residential programmes for adults with autism spectrum disorders and intellectual disability: Outcomes of challenging behaviour and quality of life. *Journal of Intellectual Disability Research: JIDR* [online]. 55 (9), pp.918-932. [Accessed 05/05/2012].

- Gerber, F., Baud, M.A., Giroud, M. and Carminati, G.G. (2008) Quality of life of adults with pervasive developmental disorders and intellectual disabilities. *Journal of Autism & Developmental Disorders* [online]. 38 (9), pp.1654-1665. [Accessed 12/02/2012].
- Gernsbacher, M.A., Dawson, M., Mottron, L. (2006) Autism: Common, heritable, but not harmful. *Behavioural and Brain Sciences*. 29 (4), pp. 413-414.
- Ghaziuddin, M., Ghaziuddin, N. and Greden, J. (2002) Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders* [online]. 32 (4), pp.299-306. [Accessed 12/02/2012].
- Gilchrist, A., Green, J., Cox, A., Burton, D., Rutter, M. and Couteur, A.L. (2001) Development and current functioning in adolescents with Asperger Syndrome: A comparative study. *Journal of Child Psychology and Psychiatry* [online]. 42 (2), pp.227-240. [Accessed 14/09/2013].
- Giles, D.C. (2014) 'DSM-V is taking away our identity': The reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* [online]. 18 (2), pp.179-195. [Accessed 08/05/2014].
- Gillman, M., Heyman, B. and Swain, J. (2000) What's in a name? The implications for people with learning difficulties. *Disability and Society*. 15, pp.341-409.
- Green, J. and Thorogood, N. (2014) *Qualitative Methods for Health Research*. Third Edition ed. London: SAGE.
- Greene, J.C. and Caracelli, V.J. & Graham, W.F. (1989) Towards a framework for mixed methods evaluation designs. *Educational Evaluation and Policy Analysis*. 11 pp.255-274.
- Hammersley, M. (2010) Creeping ethical regulation and the strangling of research. *Sociological Research Online*. 15.(4)16.<http://www.socresonline.org.uk/1514/16.html>.10.5153/510.2255. [Accessed 01/03/2011].
- Hammersley, M. and Atkinson, P. (2007) *Principles in Practice*. 3rd ed. Abingdon: Routledge.
- Happé, F.G.E. (1994) Wechsler IQ Profile and Theory of Mind in Autism: A Research Note. *Journal of Child Psychology and Psychiatry* [online]. 35 (8), pp.1461-1471. [Accessed 2/02/2012].
- Harris, P. (1995) Who am I? Concepts of disability and their implications for people with learning difficulties. *Disability and Society*. 10, pp.341-351.
- Hensel, E., Rose, J., Kroese, B.S. and Banks-Smith, J. (2002) Subjective judgements of quality of life: a comparison study between people with intellectual disability and those without disability. *Journal of Intellectual Disability Research: JIDR* [online]. 46 pp.95-107. [Accessed 14/06/2012].

- Howlin, P. (2003) Outcome in High-Functioning adults with Autism with and without early language delays: In the differentiation between Autism and Asperger Syndrome. *Journal of Autism and Developmental Disorders* [online]. 33 (1). pp.3-13 [Accessed 03/12/12].
- Howlin, P., Goode, S., Hutton, J. and Rutter, M. (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* [online]. 45 (2), pp.212-229. [Accessed 02/12/13].
- Hughes, C., Bogseon, H., Jin-Ho, K. and Eisenman, L.T. and Killian, D.J. (1995) Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation*. 99 (6), pp.623-641.
- Humphrey, N. and Lewis, S. (2008) 'Make me normal': The views and experiences of pupils on the Autism Spectrum in mainstream secondary schools. *Autism: The International Journal of Research and Practice*. 12 (1), pp.23-48.
- Hungelmann, A.M. (2001) An Analysis of TEACHH-Based Home Programming for Young Children with Autism [online]. *ProQuest Information & Learning*. [Accessed 30/08/2013].
- James, I.A., Mukaetova-Ladinska, E., Reichelt, F.K., Briel, R. and Scully, A. (2006) Diagnosing Aspergers syndrome in the elderly: a series of case presentations. *International Journal of Geriatric Psychiatry* [online]. 21 (10), pp.951-960. [Accessed 05/02/2013].
- Jennes-Coussens, M., Magill-Evans, J. and Koning, C. (2006) The quality of life of young men with Asperger syndrome: a brief report. *Autism: The International Journal of Research and Practice* [online]. 10 (4), pp.403-414. [Accessed 04/12/2012].
- Jones, R.S.P., Zahl, A. and Huws, J.C. (2001) First-hand accounts of emotional experiences in autism: A qualitative analysis. *Disability & Society* [online]. 16 (3), pp.393-401. Accessed 02/04/2011].
- Kaehne, A. and O'Connell, C. (2010) Focus groups with people with learning disabilities. *Journal of Intellectual Disabilities*. 14 pp.133-142.
- Kamio, Y., Inada, N. and Koyama, T. (2013) A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders. *Autism: The International Journal of Research and Practice* [online]. 17 (1), pp.15-26. [Accessed 01/04/2011].
- Kandalaf, M.R., Didehbani, N., Krawczyk, D.C., Allen, T.T. and Chapman, S.B. (2013) Virtual reality social cognition training for young adults with high-functioning autism. *Journal of Autism and Developmental Disorders* [online]. 43 (1), pp.34-44. [Accessed 29/04/2014].

- Kappett, S.K., Gillespie-Lynch, K., Sherman, L.E. and Hutman, T. (2013) Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology* [online]. 49 (1), pp.59-71. [Accessed 29/04/2014].
- Knapp, M., Romeo, R. and Beecham, J. (2009) Economic cost of autism in the UK. *Autism : The International Journal of Research and Practice*. 13 (3), pp.317-336.
- Keith, K.D. (2001) International quality of life: Current conceptual, measurement, and implementation issues. *International Review of Research in Mental Retardation*. 24 pp.49-74.
- Kern, J.K., Trivedi, M.H., Grannemann, B.D., Garver, C.R., Johnson, D.G., Andrews, A.A., Savla, J.S., Mehta, J.A. and Schroeder, J.L. (2007) Sensory correlations in autism. *Autism: The International Journal of Research & Practice* [online]. 11 (2), pp.123-134. [Accessed 04/03/2014].
- Kober, R., ed. (2010) *Enhancing the quality of life of people with intellectual Disabilities: From Theory to Practice*. London New York: Springer.
- Kong, N.H. and Chow, P.K. (2013) Conflict of interest in research - The clinician scientist's perspective. *Annals of the Academy of Medicine, Singapore* [online]. 42 (11), pp.623-628. [Accessed 29/04/2014].
- Krcek, T.E. (2013) Deconstructing disability and neurodiversity: controversial issues for autism and implications for Social Work. *Journal of Progressive Human Services* [online]. 24 (1), pp.4-22. [Accessed 29/04/2014].
- Kuhlthau, K., Orlich, F., Hall, T.A., Sikora, D., Kovacs, E.A., Delaha, J. and Clemons, T.E. (2010) Health-Related Quality of Life in Children with Autism Spectrum Disorders: Results from the Autism Treatment Network. *Journal of Autism & Developmental Disorders* [online]. 40 (6), pp.721-729. [Accessed 14/06/2012].
- Lai, R., Elliott, D. and Ouellette-Kuntz, H. (2006) Attitudes of research ethics committee members toward individuals with intellectual disabilities: The need for more research. *Journal of Policy & Practice in Intellectual Disabilities* [online]. 3 (2), pp.114-118. [Accessed 20/05/2012].
- Lerman, D.C., Hawkins, L., Hoffman, R. and Caccavale, M. (2013) Training adults with an autism spectrum disorder to conduct discrete-trial training for young children with autism: a pilot study. *Journal of Applied Behavior Analysis* [online]. 46 (2), pp.465-478. [Accessed 29/04/2014].
- Lerna, A., Esposito, D., Conson, M., Russo, L. and Massagli, A. (2012) Social-communicative effects of the Picture Exchange Communication System (PECS) in autism spectrum disorders. *International Journal of Language & Communication Disorders* [online]. 47 (5), pp.609-617. [Accessed 29/04/2014].

Lewis, A., Newton, H. and Vials, S. (2008) Realising child voice: the development of Cue Cards. *Support for Learning* [online]. 23 (1), pp.26-31. [Accessed 02/01/2013].

Lewis, A. and Porter, J. (2004) Interviewing children and young people with learning disabilities*: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities* [online]. 32 (4), pp.191-197. [Accessed 10/02/2012]

Lorence, D. (2007) Examining online chat within a domain of uncertainty: the case of Asperger's syndrome. *Health Information and Libraries Journal* [online]. 24 (2), pp.128-136. [Accessed 01/04/2011].

Loyd, D. (2013) Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities* [online]. 41 (2), pp.133-140. [Accessed 29/04/2014].

Lucas-Carrasco, R. and Salvador-Carulla, L. (2012) Life satisfaction in persons with Intellectual Disabilities. *Research in Developmental Disabilities* [online]. 33 (4), pp.1103-1109. [Accessed 29/05/2014].

Lyons, G. (2010) Quality of life for persons with intellectual disabilities: A review of the literature. In: Kober, R., ed. (2010) *Enhancing the Quality of Life of People with Intellectual Disabilities from Theory to Practice*. London: Springer, pp.73-126.

Mackenzie, R. and Watts, J. (2009) The Autism Bill 2008/2009: implications for people with Autism Spectrum Disorder (ASD) and their families, carers and professionals, and the need to differentiate between differences and disabilities. *Tizard Learning Disability Review*. 14 (3), pp.33-37.

Mackenzie, R., Watts, J. and Howe, L. (2012) Supporting aspirations – or not? Recent reforms on equality, the green paper on Special Educational Needs and the potential of a neurodiversity spectrum statement. *Tizard Learning Disability Review* [online]. 17 (1), pp.36-48. [Accessed 29/04/2014].

Mak, W.W.S., Ng, I.S.W. and Wong, C.C.Y. (2011) Resilience: Enhancing well-being through the positive cognitive triad. *Journal of Counseling Psychology* [online]. 58 (4), pp.610-617. [Accessed 29/02/2012].

Man, D.W.K., Lee, Z.W.T., Tong, E.C.H., Yip, S.C.S., Lui, W.F. and Lam, C.S. (2004) Health services needs and quality of life assessment of individuals with brain injuries: A pilot cross-sectional study. *Brain Injury* [online]. 18 (6), pp.577-591. [Accessed 21/09/2012].

Mandell, D.S., Novak, M.M. and Zubritsky, C.D. (2005) Factors associated with age of diagnosis among children with Autism Spectrum Disorders. *Pediatrics* [online]. 116 (6), pp.1480-1486. [Accessed 01/04/2011].

- Marquez-Caraveo, M. and Albores-Gallo, L. (2011) Autistic spectrum disorders: Diagnostic and therapeutic challenges in Mexico. *Salud Mental* [online]. 34 (5), pp.435-441.
- Maton, K. (2008) Habitus. In: M. Grenfell, ed. *Pierre Bourdieu: Key Concepts*, Acumen, pp.49-65.
- Matson, J.L. and Shoemaker, M. (2009) Intellectual disability and its relationship to autism. *Research in Mental Disabilities*. 30(6), pp.1107-1114.
- Mazurek, M. (2013) Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism: The International Journal of Research and Practice* [online]. 18(3), pp.223-32. [Accessed 12/05/2014].
- McCabe, M.P. and Cummins, R.A. (1998) Sexuality and quality of life among young people. *Adolescence* [online]. 33 (132), pp.761-761. [Accessed 12/04/2014].
- McDermott, S., Hathaway, K. and Saunders, C. (2014) Developing good practice for clinical research nurses. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)* [online]. 28 (26), pp.40-44. [Accessed 04/05/2011].
- McGillivray, J.A., Lau, A., Cummins, R.A. and Davey, G. (2009) The utility of the Personal Wellbeing Index Intellectual Disability Scale in an Australian sample. *Journal of Applied Research in Intellectual Disabilities* [online]. 22 (3), pp.276-286. [Accessed 14/09/2011].
- McLeod, A. (1999) Growing pains: The potential impact of unidentified Asperger Syndrome on the overall development of the child. *Good Autism Practice*. 2, pp. 32-45.
- McVilly, K.R., Burton-Smith, R. and Davidson, J.A. (2000) Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual & Developmental Disability* [online]. 25 (1), pp.19-39. [Accessed 25/08/2011]
- Mencap (2007) Death by Indifference: Mencap. www.mencap.org.uk/deathbyindifference. [Accessed 20/03/2009].
- Micalos, A.C. (1985) Multiple discrepancy theory (MDT). *Social Indicators Research*. 8, pp.385-442.
- Mitchell, P., Parsons, S. and Leonard, A. (2007) Using virtual environments for teaching social understanding to 6 adolescents with autistic spectrum disorders. *Journal of Autism and Developmental Disorders* [online]. 37 (3), pp.589-600. [Accessed 28/03/2014].
- Moore, D.J. (2014) Acute pain experience in individuals with autism spectrum disorders: A review. *Autism: The International Journal of Research and Practice* [online]. DOI 10.1177/1362361314527839. [Accessed 08/05/2014].

- Morisse, F., Vandemaele, E., Claes, C., Claes, L. and Vandeveldde, S. (2013) Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. *The Scientific World Journal*. 2013 pp.Article ID 491918- 8 pages. [Accessed 14/02/2014],
- Müller, E., Schuler, A. and Yates, G.B. (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism: The International Journal of Research & Practice* [online]. 12 (2), pp.173-190. [Accessed 29/03/2011].
- Murray, D., ed. (2006) *Coming out Aspergers, diagnosis, disclosure and self-confidence*. Jessica Kingsley Publishers.
- Muskat, B., Burnham Riosa, P., Nicholas, D.B., Roberts, W., Stoddart, K.P. and Zwaigenbaum, L. (2014) Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism: The International Journal of Research and Practice* [online]. DOI:10.1177/1362361314531341. [Accessed 08/05/2014].
- National Audit Office (2009) *Supporting People with Autism through Adulthood*. Report number: 9780102955033. National Audit Office.
- National Autistic Society (2014) *SPELL information leaflet*. Available from: <http://www.autism.org.uk/living-with-autism/strategies-and-approaches/spell> [Accessed 11/05/14].
- National Institute for Health and Care Excellence (NICE) (2012) *Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum in Adults CG142*.
- Nind, M., (2008) *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. Report number: NCRM/012. Economic and Social Centre for Research Methods: Economic and Social Research Council.
- Nydén, A., Myrén, K. and Gillberg, C. (2008) Long-term psychosocial and health economy consequences of ADHD, autism, and reading-writing disorder: a prospective service evaluation project. *Journal of Attention Disorders* [online]. 12 (2), pp.141-148. [Accessed 08/05/2014].
- Nylander, L. (2013) Email to Sue Smith, 10/10/2013.
- Ochs, E., Kremer-Sadlick, T., Gainer-Sirota, K. and Solomon, O. (2004) Autism and the social world: An anthropological perspective. *Discourse Studies*. 6 (2), pp.147-183.
- Office for National Statistics. *Statistical bulletin: Personal wellbeing across the UK, 2012/13*. <http://www.ons.gov.uk/ons/rel/wellbeing/measuring-national-wellbeing/persona-wellbeing>. [Accessed 09/12/13].

- Pasco, G. and Tohill, C. (2011) Predicting progress in Picture Exchange Communication System (PECS) use by children with autism. *International Journal of Language & Communication Disorders* [online]. 46 (1), pp.120-125. [Accessed 08/05/2014].
- Peeters, T. (1997) *Autism: From Theoretical Understanding to Educational Intervention*. England: Whurr Publishers Ltd.
- Persson, B. (2000) Brief Report: A longitudinal study of quality of life and independence among adult men with autism. *Journal of Autism & Developmental Disorders* [online]. 30 (1), pp.61. [Accessed 01/09/2012].
- Petry, K., Maes, B., Vlaskamp, C. (2005) Domains of quality of life of people with profound and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*.18, pp 35-46.
- Phillips, D. (2006) *Quality of life. Concept, policy and practice*. London, Routledge.
- Plimley, L.A. (2007) A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities* [online]. 35 (4), pp.205-213. [Accessed 14/03/2011].
- Potvin, M., Snider, L., Prelock, P.A., Wood-Dauphinee, S. and Kehayia, E. (2013) Health-related quality of life in children with high-functioning autism. *Autism: The International Journal of Research and Practice* [online]. 43(2), pp. 445-457. [Accessed 14/02/2014].
- Punshon, C. and Skirrow, P. and Murphy, G. (2009) The not guilty verdict: psychological reactions to diagnosis of Asperger Syndrome in adulthood. *Autism: The International Journal of Research and Practice*. 13 (3), pp.265-283.
- Qureshi, M. (2012) *'Now I Know Why I Feel Like Everyone has a Ticket for the show Except Me!': Developing a Measure of the Utility of an Autism Spectrum Disorder Diagnosis*. Unpublished PhD thesis, University College London.
- Rapley, D. (2006) *Quality of Life: Concept, Policy and Practice*. London and New York: Routledge.
- Robertson, S.M. (2010) Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges. *Disability Studies Quarterly* [online]. 30 (1), pp.27-27. [Accessed 29/04/2014].
- Robson, C. (2009) *Real World Research*. 2nd ed. Blackwell Publishing.
- Ross, J., Marcell, J., Williams, P. and Carlson, D. (2013) Postsecondary Education Employment and Independent Living Outcomes of Persons with Autism and Intellectual Disability. *Journal of Postsecondary Education & Disability* [online]. 26 (4), pp.337-351. [Accessed 29/04/2014].

Roux, A.M., Shaltuck, P.T., Cooper, B.P., Anderson, K.A., Wagner, M. and Narendorf, S.C. (2013) Post-secondary employment experiences among young adults with an autism spectrum condition. *Child and Adolescent Psychiatry*. 52(9), pp. 931-939.

Royal College of Nursing (2013). Meeting the health needs of people with learning disabilities. RCN guidance for nursing staff. Royal College of Nursing. www.rcn.org.uk/_data/assets/pdf_file/0004/78691/003024. [Accessed 1/03/14].

Saldaña, D., Alvarez, R.M., Lobatón, S., Lopez, A.M., Moreno, M. and Rojano, M. (2009) Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. *Autism: The International Journal of Research and Practice* [online]. 13 (3), pp.303-316. [Accessed 14/09/2013].

Savage, J. (2000) Ethnography and healthcare. *British Medical Journal*. 321 pp. Sept 2011-1400.

Sawatzky, R., Ratner, P. and Chiu, L. (2005) A Meta-Analysis of the Relationship Between Spirituality and Quality of Life. *Social Indicators Research* [online]. 72 (2), pp.153-188. [Accessed 13/02/2014].

Schalock, R.L. (2000) Three Decades of Quality of Life. *Focus on Autism & Other Developmental Disabilities* [online]. 15 (2), pp.116. [Accessed 04/03/2013].

Schwartz, C. and Rabinovitz, S. (2003) Life satisfaction of people with intellectual disability living in community residences: perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research* [online]. 47 (2), pp.75-84. [Accessed 05/03/2013].

Schalock, R.L. (2010) The measurement and use of quality of life-related personal outcomes. In: Kober, R., ed. (2010) *Enhancing the Quality of Life with People with Intellectual Disabilities. From Theory to Practice*. London: Springer, pp.3-16.

Schalock, R.L. and Keith, K.D. (1993) Quality of life questionnaire. In: Schalock, R.L., ed. (1993) *Quality of life. Volume 1: Conceptualisation and Measurement*. American Association.

Sheldrick, R.C., Neger, E.N., Shipman, D. and Perrin, E.C. (2012) Quality of life of adolescents with autism spectrum disorders: concordance among adolescents' self-reports, parents' reports, and parents' proxy reports. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation* [online]. 21 (1), pp.53-57. [Accessed 04/03/2013].

Shipman, D.L., Sheldrick, R.C. and Perrin, E.C. (2011) Quality of life in adolescents with autism spectrum disorders: reliability and validity of self-reports. *Journal of Developmental and Behavioral Pediatrics: JDBP* [online]. 32 (2), pp.85-89. [Accessed 04/02/2012].

Shrubb, R. (2010) How getting a diagnosis helps. *Learning Disability Practice*. 13 (1), p.9.

Slocombe, K., Alvarez, I., Branigan, H.P., Jellema, T., Burnett, H.G., Fischer, A., Li, Y.H., Garrod, S. and Levita, L. (2013) Linguistic alignment in adults with and without Asperger Syndrome. *Journal of Autism and Developmental Disorders*. 43 (6), pp. 1432-26 doi 10.1007/s10803-012-1698-2. [Accessed 04/03/2013].

Social Care Institute for Excellence (2013). *Fair Access to Care Services (FACS): Prioritising Eligibility for Care and Support 33*. Social Care Institute for Excellence: Great Britain.

Solomon, M., Ono, M., Timmer, S. and Goodlin-Jones, B. (2008) The effectiveness of parent –child interaction therapy for children on the autism spectrum. *Journal of Autism and Developmental Disorders*. 38(9), pp. 1767-76. Doi: 10.1007/s10803-008-0567-5. [Accessed 02/10/2013].

Spencer, D., Marshall, J., Post, B., Kulakodlu, M., Newschaffer, C., Dennen, T., Azocar, F. and Jain, A. (2013) Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics* [online]. 132 (5), pp.833-840. [Accessed 02/12/2013].

Spradley, J.P. (1979) *The ethnographic interview*. Harcourt Brace Jovanovich College.

Strunk, J.A., Pickler, R., McCain, N.L., Ameringer, S. and Mrs, B.J. (2014) Managing the Health Care Needs of Adolescents With Autism Spectrum Disorder: The Parents' Experience. *Families, Systems & Health: The Journal of Collaborative Family Healthcare* [online]. 25(60), pp. 445-452 [Accessed 12/12/2013].

Tavernor, L., Barron, E., Rodgers, J. and McConachie, H. (2013) Finding out what matters: validity of quality of life measurement in young people with ASD. *Child: Care, Health and Development* [online]. 39 (4), pp.592-601 [Accessed 04/12/2013].

Terrett, G., Rendell, P., Raponi-Saunders, S., Henry, J., Bailey, P. and Altgassen, M. (2013) Episodic future thinking in children with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders* [online]. 43 (11), pp.2558-2568. [Accessed 04/12/2013].

Tetzchner, S.V. and Jensen, K. (1999) interacting with people who have severe communication problems: ethical considerations. *International Journal of Disability, Development & Education* [online]. 46 (4), pp.453-462. [Accessed 02/03/2012].

Townsend-White, C., Pham, A.N.T. and Vassos, M.V. (2012) Review: A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours. *Journal of Intellectual Disability Research* [online]. 56 (3), pp.270-284. [Accessed 12/12/2013].

- Tuffrey-Wijne, I., Bernal, J. and Hollins, S. (2008) Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities* [online]. 36 (3), pp.185-190.[Accessed 13/06/20012].
- van Duijvenbode, N., Didden, R., Korzilius, H.P., Trentelman, M. and Engels, R.C.M, E., C. (2013) Executive control in long-term abstinent alcoholics with mild to borderline intellectual disability: The relationship with IQ and severity of alcohol use-related problems. *Research in Developmental Disabilities* [online]. 34 (10), pp.3583-3595 [Accessed 14/05/2014].
- van Duijvenbode, N., Didden, R., Voogd, H., Korzilius, H.P. and Engels, R.C. (2012) Cognitive biases in individuals with mild to borderline intellectual disability and alcohol use-related problems. *Research in Developmental Disabilities* [online]. 33 (6), pp.1928-1936. [Accessed 13/03/2013].
- van Heijst, B.F. and Geurts, H.M. (2014) Quality of life in autism across the lifespan: A meta-analysis. *Autism: The International Journal of Research and Practice* [online]. DOI: 10.1177/1362361313517053. [Accessed 03/03/2014].
- van Teljlingen, E.R., Douglas, F. and Torrance, N. (2008) Clinical governance and research ethics as barriers to UK low-risk populations-based health research. *BMC Public Health- Open Access*. <http://dx.doi.org/10.1186/117-2458-8-396>. [Accessed 12/05/2013].
- Vannucchi, G., Masi, G., Toni, C., Dell'Osso, L., Marazziti, D. and Perugi, G. (2014) Clinical features, developmental course, and psychiatric comorbidity of adult autism spectrum disorders. *CNS Spectrums* [online]. 19 (2), pp.157-164. [Accessed 04/03/2013].
- Veenhoven, R. (1991) Is happiness relative? *Social Indicators Research*. 24 pp.1-31.
- Verdugo, M.A. and Schalock,R.L. (2009) Quality of life: From concept to future applications in the field of intellectual disabilities. *Journal of Policy & Practice in Intellectual Disabilities* [online]. 6 (1), pp.62-64. [Accessed 07/03/2012].
- Verri, A., Cummins, R.A., Petite, F., Vallero, E., Monteath, S., Gerosa, E. and Nappi, G. (1999) An Italian-Australian comparison of quality of life among people with intellectual disability living in the community. *Journal of Intellectual Disability Research* [online]. 43 (6), pp.513-522. [Accessed 02/03/2011].
- Vinkers, D., J. (2013) Pre-trial reported defendants in the Netherlands with intellectual disability, borderline and normal intellectual functioning. *Journal of Applied Research in Intellectual Disabilities* [online]. 26 (5), pp.357-361. [Accessed 08/05/2014].

Walmsley, J. (2001) Normalisation, Emancipatory research and inclusive research in learning disability. *Disability & Society* [online]. 16 (2), pp.187-205. [Accessed 06/06/2012].

Waltz, M. (2007) The relationship of ethics to quality: a particular case of research in autism. *International Journal of Research & Method in Education* [online]. 30 (3), pp.353-361. [Accessed 04/05/2011].

Westby, C., Burda, A. and Mehnta, Z. (2003) *Asking the Right Questions in the Right Ways. Strategies for Ethnographic Interviewing*. Available from: <http://www.asha-org/publication/leader/2003/030429/F0304296.htm>. [Accessed 11/10/2013].

White, S.W. and Roberson-Nay, R. (2009) Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *Journal of Autism & Developmental Disorders* [online]. 39 (7), pp.1006-1013. [Accessed 17/03/2014].

Williams, R. (1973) 'Base and Superstructure.' *New Left Review*. 83, pp.3-16.

Wing, L. (1996) *The Autistic Spectrum: A Guide for Parents and Professionals*. London: Constable.

Wing, L., Gould, J. and Gillberg, C. (2011) Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities* [online]. 32 (2), pp.768-773. [Accessed 21/05/2012]

Wolfensburger, W. (1995) Let's hang up 'quality of life' as a hopeless term. In: Goode, D., ed. (1995) *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. pp.124-141.

Wong, J., Clare, I.C.H., Holland, P.C., and Gunn, M. (2000). The capacity of people with a 'mental disability' to make health care decisions. *Psychological medicine*. 30, pp. 295-306.

Worley, J.A. and Matson, J.L. (2012) Comparing symptoms of autism spectrum disorders using the current DSM-IV-TR diagnostic criteria and the proposed DSM-V diagnostic criteria. *Research in Autism Spectrum Disorders* [online]. 6 (2), pp.965-970. [Accessed 20/03/2013].

Zapft, W. (1984) Individuelle wohlfahrt und wahrgenommene lebensqualität, in Glatzer, W. Zapft, Lebensqualität in der Bundesrepublik Deutschland. Objektive Lebensqualität und subjektives wohlbefinden. Frankfurt/New York pp13-26.

Bibliography

An, E.T., Gallien, T.L., Bian, H. and Moulton, M. (2013) The Relationship Between Spiritual Well-Being and Health-Related Quality of Life in College Students. *Journal of American College Health* [online]. 61 (7), pp.414-421. [Accessed 21/12/2013].

Balboni, G., Coscarelli, A., Giunti, G. and Schalock, R.L. (2013) The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities* [online]. 34 (11), pp.4248-4254. [Accessed 04/11/2013].

Baron-Cohen, S. (2002) The extreme male brain theory of autism. *Trends in Cognitive Sciences* [online]. 6 (6), pp.248-254. [Accessed 14/16/2010]

Berney, T. (2004) Asperger syndrome from childhood into adulthood. *Advances in Psychiatric Treatment* [online]. 10 (5), pp.341-351.

Blaikie, N. (2010) *Designing social research (2nd Edition)*. Cambridge: Polity Press.

Bowling, A. (2005) *Measuring Health. A review of quality of life measurement scales*. 3rd ed. Open University Press.

Bradley, E. & Bolton, P. (2006) Episodic psychiatric disorders in teenagers with learning disabilities with and without autism. *British Journal of Psychiatry*. 189 pp.361-6.

Cummins, R.A. (2002b) The validity and utility of subjective quality of life: a reply to Hatton and Ager. *Journal of Applied Research in Intellectual Disabilities* [online]. 15 (3), pp.261-268. [Accessed 04/09/2010].

Cummins, R.A. (1997) Self-rated Quality of Life Scales for People with an Intellectual Disability: A Review. *Journal of Applied Research in Intellectual Disabilities* [online]. 10 (3), pp.199-216. [Accessed 04/05/2011].

Cummins, R.A. (1991) The Comprehensive Quality of Life Scale—Intellectual Disability: An instrument under development. *Australia & New Zealand Journal of Developmental Disabilities* [online]. 17 (2), pp.259-264. [Accessed 02/04/2011].

Cummins, R.A., McCabe, M.P., Romeo, Y., Reid, S. and Waters, L. (1997) An initial evaluation of the Comprehensive Quality of Life Scale - Intellectual Disability. *International Journal of Disability Development and Education* [online]. 44 (1), pp.7-19. [Accessed 04/03/2012].

García-Villamizar, D.A. and Dattilo, J. (2010) Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research* [online]. 54 (7), pp.611-619. [Accessed 02/04/2011].

- Gomez de la Cuesta, G. (2009) Trends in the economic cost of autism. *Tizard Learning Disability Review*. 14 (3), pp.41-44.
- Kamp-Becker, I., Schroder, J., Remshmidt, H. and Bachmann, C. (2010) Health related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. *GMS Psychosocial Medicine*. 7 pp.1860-5214.
- Kober, R. and Eggleton, I.R.C. (2009) Using quality of life to evaluate outcomes and measure effectiveness. *Journal of Policy & Practice in Intellectual Disabilities* [online]. 6 (1), pp.40-51 [Accessed 02/03/2011].
- Koudys, J. (2014) The Picture Exchange Communication System: A community implementation study [online]. *ProQuest Information & Learning*. [Accessed 21/10/2014]
- Lasgaard, M., Nielsen, A., Eriksen, M. and Goossens, L. (2010) Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism & Developmental Disorders* [online]. 40 (2), pp.218-226. [Accessed 04/03/2013].
- Lefort, S. and .F., M. (2002) Quality of life measurement and its use in the field of learning disabilities. *Journal of Intellectual Disabilities*. 6 pp.223-238.
- Li, C., Tsoi, W.S., Zhang, C.S. and Wang, C.K.J. (2012) Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: A systematic review. *Journal of Developmental & Physical Disabilities*. Volume 25, Issue 2, pp 253-270.
- Lin, J., Ju, Y., Lee, S., Lee, C., Wang, H., Teng, Y. and Lo, S.K. (2009) Do physical disabilities affect self-perceived quality of life in adolescents? *Disability and Rehabilitation: An International, Multidisciplinary Journal* [online]. 31 (3), pp.181-188. [Accessed 14/08/2013].
- Magee, C.A., Miller, L.M. and Heaven, P.C.L. (2013) Personality trait change and life satisfaction in adults: The roles of age and hedonic balance. *Personality and Individual Differences* [online]. 55 (6), pp.694-698. [Accessed 23/02/2014].
- McCormack, B. and Farrell, M. (2009) Translating quality of life into service action: use of personal outcome measures in the Republic of Ireland. *British Journal of Learning Disabilities* [online]. 37 (4), pp.300-307. [Accessed 06/02/2012].
- Oppenheim, A.N. (1998) *Questionnaire design and attitude measurement*. 1st ed. Pinter.
- Payakachat, N., Tilford, J.M., Kovacs, E. and Kuhlthau, K. (2012) Autism Spectrum Disorders: a review of measures for clinical, health services and cost-effectiveness applications. *Expert Review of Pharmacoeconomics & Outcomes Research* [online]. 12 (4), pp.485-503. [Accessed 29/04/2014].

Perry, J. and Felce, D. (1995) Objective assessments of quality of life: How much do they agree with each other? *Journal of Community & Applied Social Psychology* [online]. 5 (1), pp.1-19. [Accessed 15/06/2012].

Poon, K.K. (2011) The activities and participation of adolescents with autism spectrum disorders in Singapore: findings from an ICF-based instrument. *Journal of Intellectual Disability Research* [online]. 55 (8), pp.790-800. [Accessed 29/04/2014].

Seeman, M. (1991) *Alienation and anomie*. In: Robinson, J.P., Shaver, P.R. and Wrightsman, L.S., eds. (1991) [online]. San Diego, CA US: Academic Press, pp.291-371.

While, A.E. and Clarke, L.L. (2010) Overcoming ignorance and stigma relating to intellectual disability in healthcare: a potential solution. *Journal of Nursing Management* [online]. 18 (2), pp.166-172. [Accessed 04/05/2012].

List of Appendices

Appendix A: Local diagnostic pathway

Appendix B: Chart showing participants' journey through research process

Appendix C: Participant information sheet with easy words and pictures

Appendix D: FACE capacity assessment tool

Appendix E: Pictorial supports for qualitative interview

Appendix F: Visual ranking exercise

Appendix G: COMQOL-I5 tool

Appendix H: PWI-ID tool

Appendix I: Qualitative interview topic guide

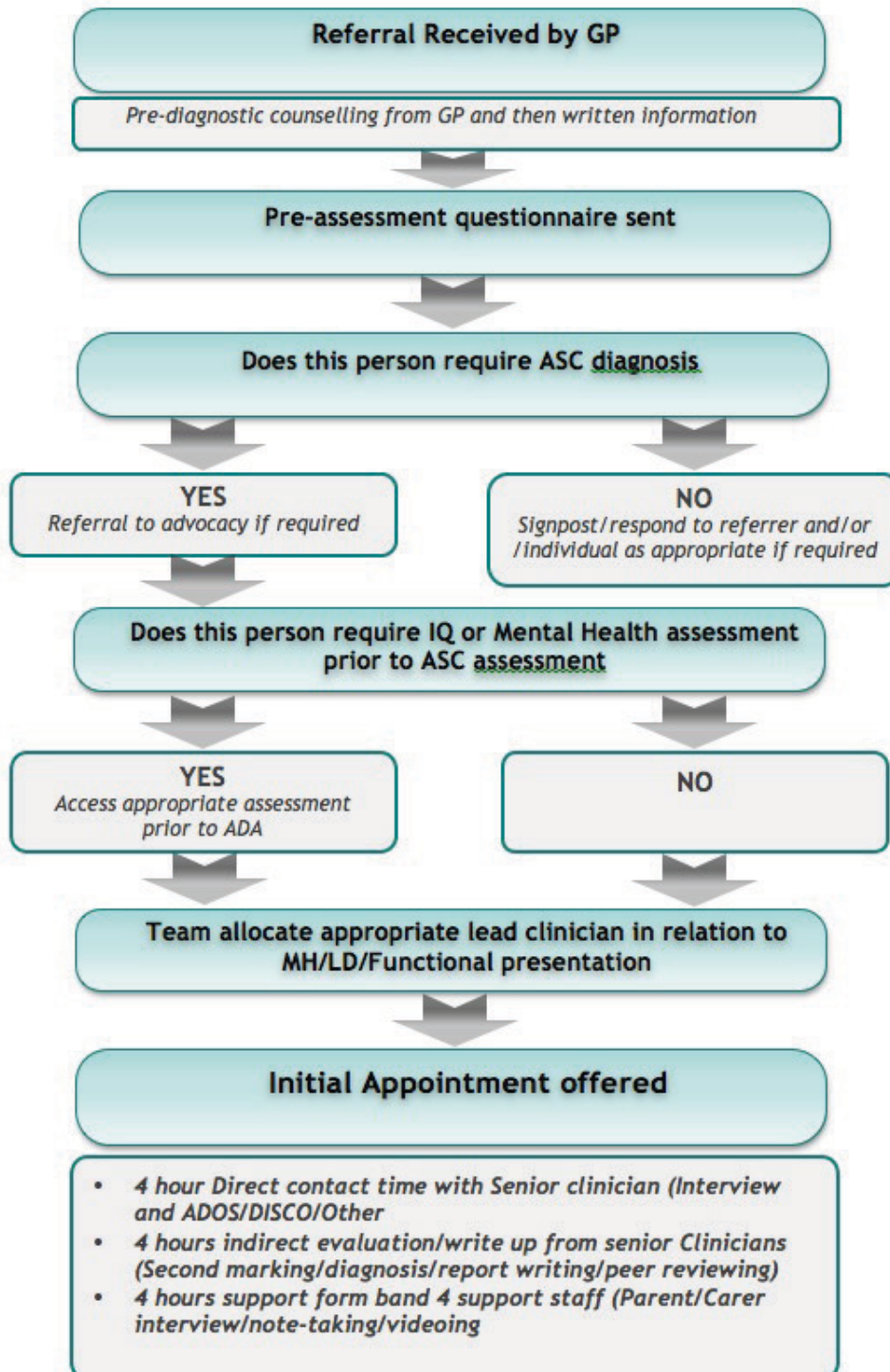
Appendix J- Post-research letter to participants

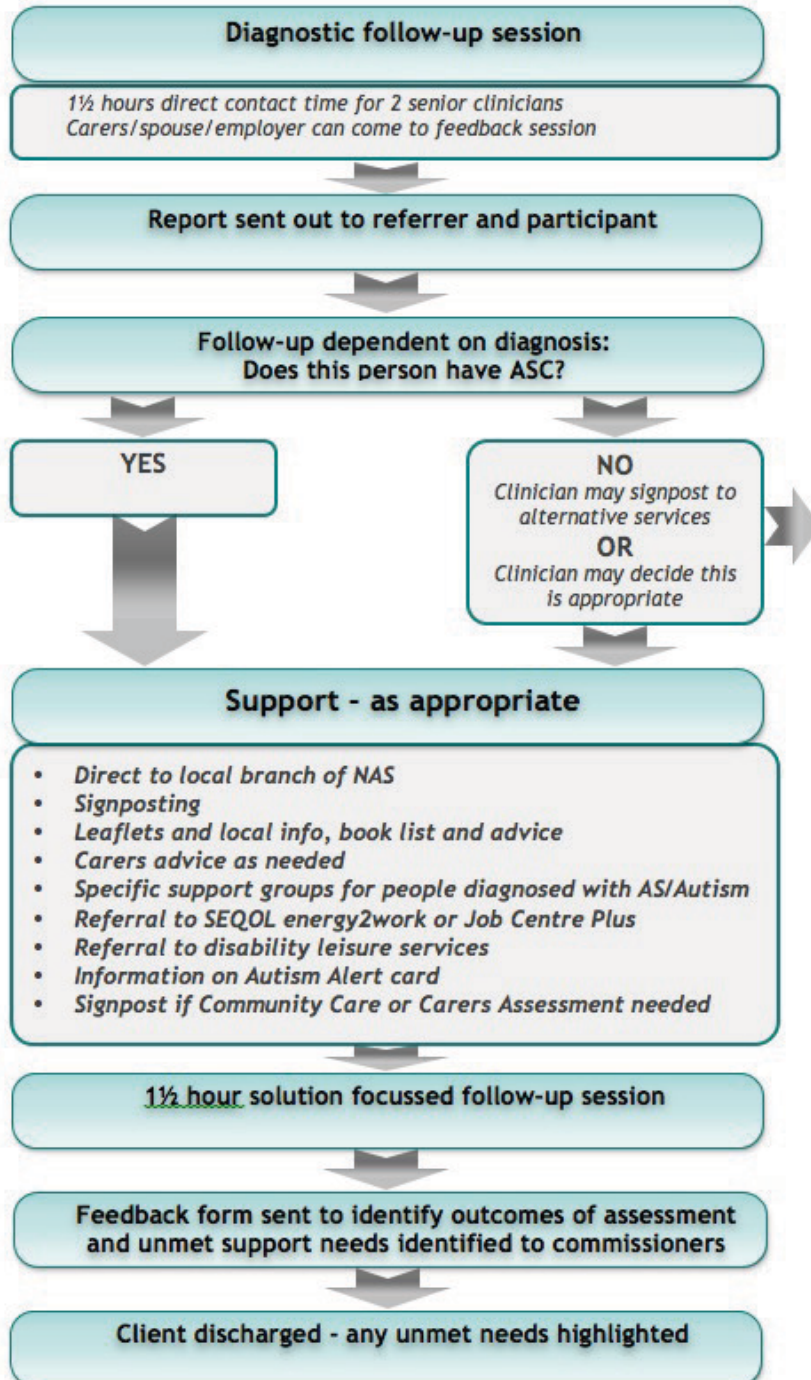
Appendix K: Details of participants

Appendix A



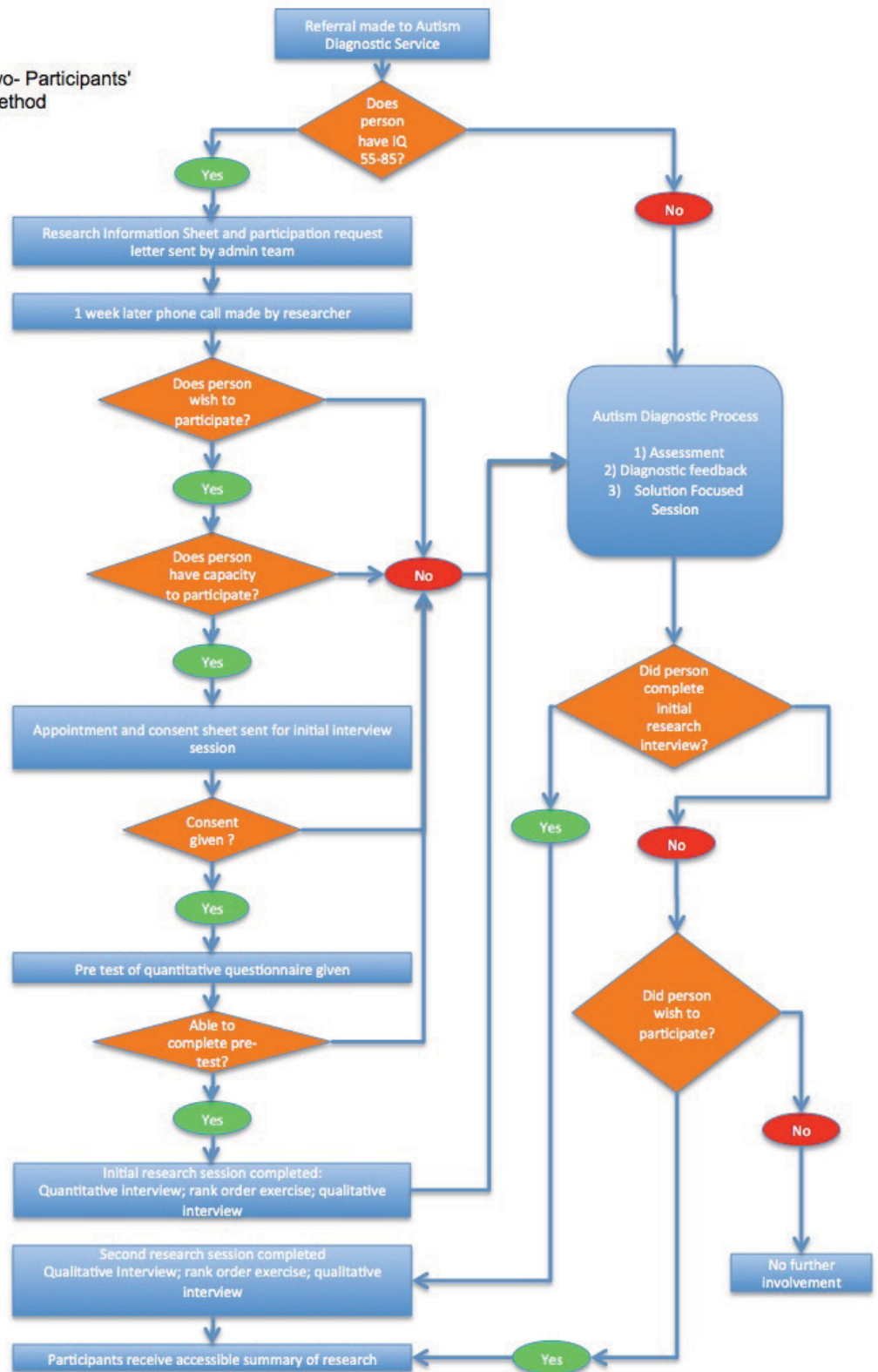
Care Pathway for Adult Autism Diagnosis





Appendix B






Appendix Two- Participants' journey in method



Appendix C



Clarence House,
Euclid Street
Swindon
SN1 2SG

    	<p>Dear</p> <p>My name is Sue Smith and I am doing some research with people with learning disabilities who might have autism. I would like you to help me.</p> <p>I also work in the <u>Swindon</u> Autism Team and I am one of the people who you could see when you come for an appointment about an autism diagnosis.</p> <p>I have written a sheet to help you understand the research. I have called this 'Information for people helping with my research'.</p> <p>Take you time to read it and you can ask friend or family to help you read it.</p> <p>If you would like some help from me with understanding all this information you can ring me on 01793 644712. I can speak to you on the phone, or come and see you.</p> <p>I could also send you this information on a CD, so that you could listen to it.</p> <p>Thank you for reading this information and thinking about helping with my research.</p> <p>Sue Smith Researcher</p>
--	--

Information sheet for people helping with my research:



What is my research about?

I am going to ask some people about their lives before and after they come to the Swindon Autism Service

Why have you been given this sheet?

I am asking you to help me with this research.



You do not have to decide straight away. I will ring you in about a week to see whether you want to help.

You could talk to friends and family to help you decide.
Please ask me if you need any help from me to understand this sheet.










My number is 01793 466712.



Part 1 of this sheet tells you what you would have to do. This should help you decide if you want to help with the research.

Part 2 will tell you the things you need to know if you decide to help.

	<p>What would happen in the meetings</p> <p>I will explain my research and ask you to talk about some parts of my research and some pictures I might use.</p>
 	<p>Who will be in the meeting?</p> <ul style="list-style-type: none"> • I will be there, and one staff member from the learning disability service will be helping me. • There will no more than four other people in the group. You can bring a <u>carer</u> or friend but they will need to stay out <u>fothe</u> group sessions.
	<p>How will I be recording our meeting</p> <ul style="list-style-type: none"> • I want to video and sound recording the meetings. • I will take some notes. • If you are happy to be video and sound recorded then I would ask you to sign a form to say this is ok.
	<p>Do you have to help with the research?</p> <ul style="list-style-type: none"> • No, you can say 'no' to the research at any time. This will not affect to the help that you get from the <u>Swindon</u> Autism Service.
 	<p>What will happen if you say 'yes'?</p> <ul style="list-style-type: none"> • I will ring you and make sure you understand the research. • I will send you a letter with a date and time to meet.



Payment

- I cannot pay you to help with the research.
- I will make sure you get back any money you spend travelling to see me.



What could be good about helping with the research?

- I would listen carefully to what you have to say.
- Things you say will be important to my research.



What could be the bad things about being in the research?

- Sometimes talking in a group can be hard work. I will make sure I help you to have a turn to speak if you want it.
- I need you to travel to two meetings that are two hours long. It could be quite tiring. We can have breaks,



What would happen after the two meetings?

I will send you a letter that will tell you, with easy words and pictures, what I learnt from the research.

If you want to help will you definitely be involved?

No. I might decide that I cannot ask you to help. I will let you know as soon as I can if you will be helping. This sometimes happens in research and does not mean that anything is wrong.



Will your information be kept private?

- Yes I will keep your information as private as possible.
Part 2 will tell you more about how I plan to do this.
- If you tell me anything that makes me think you are in danger or anyone else is in danger I have to tell someone who could stop this danger.



What do I need you to do now?

- If you think you might like to help with this research then you will need to read **Part 2** to give you more information.
- If you have decided now that you do not want to help, that is fine, and you do not need to read **Part 2**.



Part 2

What if there is a problem?

- If you are not happy about something in the research, you can tell me or you can contact PALS (Patient Advice and Liaison Service). The person to talk to is Annie ~~Naji~~ on 01793 433571.



Harm

- If you feel something bad happened to you because you did the research, I cannot to pay you to make up for this.
- If you think something bad happened to you because you did the research then you can ask for legal help but you may have to pay for this yourself.



Will other people know about the things that you say in the research?

- All the things I record or write down will be kept as private as possible. If you tell me something that makes me think you or someone else is in danger, I will have to tell someone.
- If I talk about or write about the research, your name will not be used.



Who is making sure the researcher does this research properly?

- The University of the West of England is making sure I do this research properly.
- I have to tell them all the things I am doing and they also give me advice on making the research better.



Thank you for reading this information sheet

Sue Smith

Appendix D

(Used with the permission of the publisher)

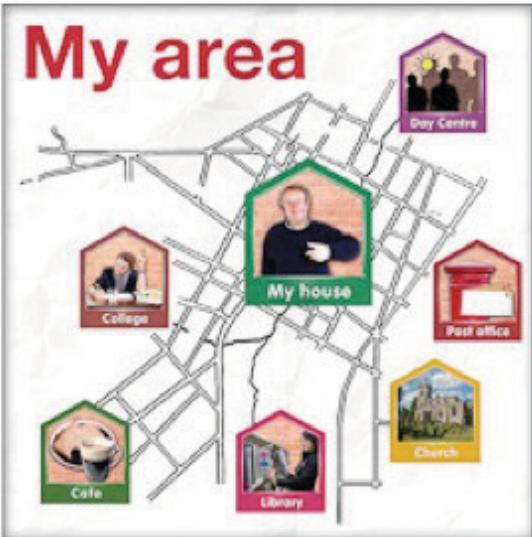


Name:		Main ID:		Completed by:					
FACE Mental Capacity Assessment									
Assessment context <i>(Remember assessment of Mental Capacity must be decision specific)</i>									
What triggered the need for this assessment? <i>(Have all reasonable steps been exhausted and shown not to work)</i>									
This individual has indicated an interested in participating in rsearch. This research involves answering questions in relation to quality of life and also involves being video recorded being interviewed and having pictures taken of data produced during a visual ranking exercrise									
What is the nature of the decision? <i>(If this is a review, detail previous decision about capacity)</i>									
Does this person have the capacity to decide for themselves to participtae in research that involves the activitiyies described in the section above									
Key roles	Person closest to person	None <input type="checkbox"/>	Lasting or Enduring Power of Attorney (LPAO or EPAO)	N/A <input type="checkbox"/>	Independent Mental Capacity Advocate (IMCA)	N/A <input type="checkbox"/>	Court of Protection Deputy (CPD)	N/A <input type="checkbox"/>	
	Name								
	Role								
	Tel. No.								
Who was consulted about decision? <i>(Give names and roles. In addition, if case conference held detail attendees)</i>									
Details:									
Determination of capacity <i>(This is specific, not general determination. Note any documentation referenced)</i>									
Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?				Permanent impairment	<input type="checkbox"/>	Temporary impairment	<input type="checkbox"/>	No	<input type="checkbox"/>
Details:									
Person has ability to understand information related to the decision to be made?						Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Details:									
Person has ability to retain information related to the decision to be made?						Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Details:									
Person has ability to use or assess the information whilst considering the decision?						Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Details:									
Person has ability to communicate their decision by any means?						Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Details:									
Can the decision be delayed because the person is likely to regain capacity in the near future?				Yes	<input type="checkbox"/>	Not likely to regain capacity	<input type="checkbox"/>	Not appropriate to delay	<input type="checkbox"/>
Details:									

Name:		Main ID:		Completed by:				
Advance decisions <i>(Note any documentation referenced)</i>								
Is there an advance decision relevant to the decision?		No	<input type="checkbox"/>	Yes	<input type="checkbox"/>	<i>If yes why?(detail)</i>	Similar treatment <input type="checkbox"/>	Similar circumstances <input type="checkbox"/>
Details:								
Advance decision type		Written	<input type="checkbox"/>	Verbal	<input type="checkbox"/>	Date of advance decision		
What was the decision? <i>(Give details. If advance decision was verbal, detail to whom, in what circumstances)</i>								
Details:								
Is this advance decision still applicable?		Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	<i>If No select reason and give details</i>		
Withdrawn	<input type="checkbox"/>	Unanticipated circumstances	<input type="checkbox"/>	LPOA or EPOA granted regarding decision	<input type="checkbox"/>	Inconsistent behaviour regarding decision	<input type="checkbox"/>	Detained under Mental Health Act 1983 <input type="checkbox"/>
Details:								
Determination of best interest <i>(Note any documentation referenced)</i>								
Views of the lead professional? <i>(Include name and role)</i>								
Details: Sue Smith Researcher								
Views of other professionals? <i>(Include names and roles)</i>								
Details:								
What is most important to the person as regards this decision? <i>(Current and past views, e.g. advance statement)</i>								
Details:								
Views of interested others <i>(e.g. family, friends, carers, LPAO, IMCA, CPD. Give names and roles. If no-one justify)</i>								
Details:								
Describe any possible conflicts of interest with regard to this decision?								
Details:								
Assessment summary								
Decision requires arbitration?		No	<input type="checkbox"/>	Independent mediation		<input type="checkbox"/>	Court of Protection <input type="checkbox"/>	
Considering all the factors what final decision has been reached? <i>(If arbitration required detail)</i>								
Details:								
<i>This decision is the least restrictive option or intervention possible. Special considerations for life sustaining treatment have been considered or are not applicable. This decision is not been biased by age, appearance, condition, gender or race. Every effort has been made to communicate with the person concerned.</i>								
Decision-maker				Role				
Organisation				Telephone no.				
Signature				Electronic		<input type="checkbox"/>	Decision date	

Appendix E

Appendix Five





Appendix F



Most Important





1  Being with the people you want to be with

2 
 Feeling safe

3 
 Doing the things you want to do and feeling you have done them well


4 
 Being fit, well and happy

5  Having all the things you need to feel Ok

6 
 Knowing the people you want to in your local area

7  Feeling things will be OK in the future

Least Important



Appendix G

14

Objective Scale

1(a) Where do you live?

A house	<input type="checkbox"/>	Do you own the place where you live or do you rent?
A flat or apartment	<input type="checkbox"/>	
A room (e.g. in a hostel)	<input type="checkbox"/>	
		Own <input type="checkbox"/>
		Rent <input type="checkbox"/>

(Prompt: Think about the things you own, like your clothes, furniture, etc.)

(b) How many personal possessions do you have compared with other people?

More than almost anyone	More than most people	About average	Less than most people	Less than almost anyone
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(c) What is your personal or household (whichever is most relevant to you) gross annual income before tax?

Less than \$10,999	<input type="checkbox"/>	\$41,000 – \$55,999	<input type="checkbox"/>
\$11,000 - \$25,999	<input type="checkbox"/>	More than \$56,000	<input type="checkbox"/>
\$26,000 - \$40,999	<input type="checkbox"/>		

2(a) How many times have you seen a doctor over the past 3 months?

None	1 - 2	3-4 (about once a month)	5-7 (about every two weeks)	8 or more (about once a week or more)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(b) Do you have other disabilities or medical conditions? (other than an intellectual or cognitive disability) (e.g. visual, hearing, physical, health, etc.)

Yes No

If **yes** please specify:

*Name of disability
or medical condition*

*Extent of disability
or medical condition*

e.g. Visual
Diabetes
Epilepsy

Require glasses for reading
Require daily injections
Requires daily medication

_____	_____
_____	_____
_____	_____

(c) What regular medication do you take *each day*?

If none tick box

or

Name(s) of medication

**3(a) How many hours do you spend on the following *each week*?
(Average over past 3 months)**

Hours paid work	0	<input type="checkbox"/>	1-10	<input type="checkbox"/>	11-20	<input type="checkbox"/>	21-30	<input type="checkbox"/>	31-40+	<input type="checkbox"/>
Hours formal education	0	<input type="checkbox"/>	1-10	<input type="checkbox"/>	11-20	<input type="checkbox"/>	21-30	<input type="checkbox"/>	31-40+	<input type="checkbox"/>
Hours unpaid child care	0	<input type="checkbox"/>	1-10	<input type="checkbox"/>	11-20	<input type="checkbox"/>	21-30	<input type="checkbox"/>	31-40+	<input type="checkbox"/>

(b) In your spare time, how often do you have **nothing** much to do?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(c) Do you watch TV? How much TV do you watch? (average over a typical week).

Hours per day

None	1 – 2	3 – 5	6 – 9	10 or more
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4(a) Do you have a close friend?
How often do you talk with your friend?

Daily	Several times a week	Once a week	Once a month	Less than once a month
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(b) If you are feeling sad or depressed does someone show they care for you?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(c) If you want to do something special, how often does someone else want to do it with you?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5(a) Do you sleep well?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(b) Are you safe at home?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(c) Are you ever worried or anxious during the day?
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6(a) Below is a list of leisure activities. Indicate how often in an *average month* you take part in or attend each one for your leisure (not for employment).

Activity	Number of times per month
(1) Go to a club/group/society	_____
(2) Go to a hotel/bar/pub	_____
(3) Watch live sporting events (Not on TV)	_____
(4) Go to a place of worship (e.g. church)	_____
(5) Chat with neighbours or shopkeepers	_____
(6) Eat out	_____
(7) Go to a movie	_____
(8) Visit family or friend	_____
(9) Play sport or go to a gym	_____
(10) Other (please describe)	_____

(b) Do you belong to any club, group, or society?

Yes No If no, go to question (c)

Do you hold an *unpaid* position of responsibility?

If 'yes', please indicate the highest level of responsibility held:

- Committee Member
- Committee Chairperson/Convenor
- Secretary/Treasurer
- Group President, Chairperson or Convenor

(c) **Do people *outside your home* ask for your help or advice?**
How often?

Almost every day	Quite often	Sometimes	Not often	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7(a) **Can you do things you *really* want to do?**
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(b) **When you wake up in the morning, do you ever wish you could stay in bed *all day*?**
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(c) **Do you have wishes that *cannot* come true?**
How often?

Almost always	Usually	Sometimes	Not Usually	Almost never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix H

2. Scale Administration continued

Test Step 5B: Happy with Life as A Whole and Personal Wellbeing Index-Intellectual Disability (Reduced-choice Scale)

Procedure and Instructions:

- Procedure:**
1. Select the faces-scale that corresponds to the respondent's maximum level of discriminative competence in Pre-test Step 4 - Phase 3.
 2. Show this scale to the respondent and continue with the corresponding instruction provided below.

Instruction: “Good. Now, I am going to ask you a few questions about how happy you feel, using these [Point] faces.”

(i) If ‘2-face’ diagram

“As you have seen before, this face means you feel happy [Point].
This one means you feel sad [Point]

When I ask you the questions afterwards, point to the face which tells me how happy you feel.”

“Is that ok ?”

If ‘yes’: Proceed to next item.

If ‘no’: Repeat instruction but just once. Then proceed to next statement.

“Using these faces, ...” [Proceed to ask each test item below]

(ii) If ‘3-face’ diagram

“As you have seen before, this face means you feel happy [Point].
This one means you feel sad [Point]

The one in the middle means you feel neither happy nor sad [Point]

When I ask you the questions afterwards, point to the face which tells me how happy you feel.”

“Is that ok ?”

If ‘yes’: Proceed to next item.

If ‘no’: Repeat instruction but just once. Then proceed to next statement.

“Using these faces, ...” [Proceed to ask each test item below]

(iii) If '5-face' diagram

“As you have seen before, this face means you feel very happy [Point].
 This one means you feel a little bit happy [Point]
 This one means you feel very sad [Point]
 This one means you feel a little bit sad [Point]
 The one in the middle means you feel neither happy nor sad [Point]
 When I ask you the questions afterwards, point to the face which tells me how happy you feel.”

“Is that ok ?”

If 'yes': Proceed to next item.

If 'no': Repeat instruction but just once. Then proceed to next statement.

“Using these faces, ...” [Proceed to ask each test item below]

Test Items: (Record the respondent’s answers according to the following code, in the appropriate boxes below)

Code:	(a) 2-faces (2-pt)	(b) 3-faces (3-pt)	(c) 5-faces (5-pt)
	Sad = 0 Happy = 1	Sad = 0 Neither Happy nor Sad = 1 Happy = 2	Very Sad = 0 A Little Bit Sad = 1 Neither Happy nor Sad = 2 A Little Bit Happy = 3 Very Happy = 4

Respondent's Rating

2-pt **3-pt** **5-pt**
 (0-1) (0-2) (0-4)

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

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

--	--	--

Part 2: 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?

--	--	--

2. Scale Administration continued

5. how safe you feel?
6. doing things outside your home?
7. how things will be later on in your life?

Test Step 5A: Happy with Life as A Whole and Personal Wellbeing Index- Intellectual Disability (11-point Scale)

Procedure and Instructions:

Procedure: Continue to show the 0-10 happiness scale, which was shown to the respondent in Pre-test Step 3.

Instruction: “Good. Now, I am going to ask you a few questions about how happy you feel, using this Zero to 10 scale.”

“As I said before, Zero means you feel very sad [Point to the left side of the scale].

10 means you feel very happy [Point to the right side of the scale].

And the middle of the scale is 5, which means you are neither happy nor sad [Point].”

“Using this zero to 10 scale.....” [Proceed to ask each test item below]

Test Items: Record the respondent’s ratings in the appropriate boxes below.

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?

Appendix I

Appendix Nine – Topic guide

| Topic guide

Themes for Qualitative Interview (~~version 1~~ written 20th January)

This will be carefully developed in relation to literature review and learning from focus group

These will be reviewed by external groups of people with learning disability and autism before they are finalised

Context Setting:

Initial grand tour question

Tell me what a normal day would be like for you

The progression of this question will be lead by the responses of the participant and will focus on encouraging them to describe their day, through their eyes with their thoughts feelings and experiences.

Example Prompts. Tell me about your day today?, What did you do first today, describe that to me.

Could specify time slots during the day/specific days. Will have visual supports to show a day in calendar form

What are the most important parts of your day? Can you tell me what happens/what would I see you doing?

Are there parts of you day that you don't like/do like can you talk me through them

Mini tour Questions

These will attempt to support the individual to describe more their life more specifically In relation to quality of life parameters

The progression of these questions will be lead by the responses of the participant but will aim to include all the topics

Standard of Living

Tell me about the place that you live. ~~If we walked into it now what would we see.~~ What do you think/feel when you talk about your ~~house~~.

What is important to you in your home?

Can you tell me anything you don't like about your ~~home~~

Can you tell me how you decide to spend you money. How to you decide, what things do you think about, what kind of things do you spend you money on. What are you thinking and feeling when you spend your money?

Health

Can you tell me what sort of things make you stay fit and well or feel less well?

Can you tell me what you do when you don't think you are fit and well?

What things have happened today/ this week that have made you feel happy?

What things have happened today/this week that have made you feel sad?

Life Achievement

Can you tell me about something that you feel you have done well/ feel proud of. Tell me how you did it and how you knew you had done it well. Can you tell me how many things you feel you have done well/feel proud of?

Personal relationships

Can you describe a friend/important person for me? Tell me about something you might do with them. Can you tell me how often you might do things with them. Can you tell me how you think feel when you are with them?

Community Connectedness

Can you tell me about the people that are important to you in your local area?

Can you tell me anything you do with people in your local area? Can you describe some of the things you do the sort of things you would talk about?

Neighbours/Church

Future Security

Can you think about what life might be like in the future, as you get older, Can you tell me about what that might be like?

If I meet you again in a few years time what do you think you will be doing, how do you think life will be for you?

Can you describe anything in the future that you feel might be good or anything you worry might not be good in the future?

Appendix J

Dear

Thanks for helping me with my research.

I learnt some really useful things from talking to you and other people about their lives.



I saw twenty people. All the people I saw had been to the autism diagnostic service and had some learning difficulties.

They all told me how about their lives and how they were feeling about their lives.

I wanted to let you know what I learnt with your help.



Most of the people in the study did not have a job and did not have much money



Most of the people in the study did not have lots of friends and did not spend lots of time with other people



A few people had paid carers. Most people relied on family or friends or had no one to support them



A few people had illnesses but most people did not visit their doctor a lot and did not feel they had an illness



Most people did **not** take part in activities in their local community



Several people had their own children or elderly parents to care for

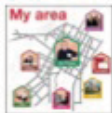
How people felt about their lives

- Mostly people in the study thought lots of different areas of their life were important.
- Most people felt that knowing people in their local area was the **least** important area of their lives
- People's feelings about their lives were not all the same. In general this group were less happy with their lives than people usually are.
- The areas they said they were happiest in were to do with the things they owned and their money and their communication and relationships.



How did people's lives seem to change after diagnostic process?

- Most people felt the same or a little bit happier.
- A small group of people seemed to feel worse about their lives.
- There was more change in how most people's lives looked after diagnosis.
- Some people had more money or better housing, some had more people to talk too or things to do or employment.
- Some people seemed to be able to go out into their local area and were doing things that made them seem more in control and looking forward to the future.
- The thing that had changed for most people was their mental health, their control in life and their hopes for the future.



What was different for this group

Talking to people helped me learn some things that seem to be important for this group:



- Having time alone as well as with people is very important



- Family is very important to feeling happy with life



- Other people can be annoying and difficult and that can make life hard



- Sensory difficulties can make life difficult and may make health difficult to manage



- Money is not the most important thing. As long as home is safe and important people, pets and possessions are available.



- Being seen as productive and valuable was very important to people

Mark

Location of research interviews: Clinic

Participant's comments on location choice: It was where he felt professional people should be seen

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area¹: Not socially deprived

Medical or psychiatric diagnosis: None

Life events during research period: Change in housing status

Issues noted during research engagement: Observable signs of anxiety. Active use made of pictorial supports

Diagnostic outcome: Autism Spectrum Disorder

¹ Data on areas of social deprivation obtained from Joint Strategic Needs Assessment for Swindon 2012. www.swindon.gov.uk/cd/foi/cd-foi-publicationsscheme/Documents/Swindon%20joint%20Strategic%20Needs%20Assessments%202012.pdf

Adam

Location of research interviews: Home - with small children

Participant's comments on location choice: Easier to manage interviewing and caring for children

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research only

Residential area: Socially deprived

Medical or psychiatric diagnosis: Investigations for stomach complaints and GP treating medically for depression.

Life events during diagnostic process: reported worsening of depression

Issues noted during research engagement: Struggled with noise of children and pets

Diagnostic outcome: Autism Spectrum Disorder

David

Location of research interviews: Clinic

Participant's comments on location choice: Felt that clinic would be a quieter, better place to meet.

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: None

Life events reported during research process: None reported

Issues noted during research engagement: Focus on employment and expressed distress in discussion about employment

Diagnostic outcome: Not autistic, Social Communication Disorder

John

Location of research interviews: Clinic

Participant's comments on location choice: Quieter environment to meet

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area: Socially deprived

Medical or psychiatric diagnosis: mild neurological disorder (not specified)

Life events reported during research process: Moved house three times, reduced contact with parents

Issues noted during research engagement: Frequent non-attender and required active process to engage

Diagnostic outcome: Autism Spectrum Disorder

Teresa

Location of research interviews: Clinic

Participant's comments on location choice: Would not trust new people to come to her house

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area: Socially deprived

Medical or psychiatric diagnosis: None specified

Life events reported during research process: Moved house

Issues noted during research engagement: Requested daughter's support worker's presence who also brought her to research sessions

Diagnostic outcome: Autism Spectrum Disorder

Valerie

Location of research interviews: Clinic

Participant's comments on location choice: Home too noisy and busy to talk

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research only

Residential area: Not socially deprived

Medical or psychiatric diagnosis: None specified

Life events reported during research process: None specified

Issues noted during research engagement: Active use of pictorial aids

Diagnostic outcome: Autism Spectrum Disorder

Pat

Location of research interview: Home

Participant's comments on location choice: Pat asked to leave and change into his interview suit as that was how he should look for an interview

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area: Socially deprived area

Medical or psychiatric diagnosis: None noted

Life events reported during research process: End of relationship with girlfriend

Issues noted during research engagement: Active use of pictorial aids

Diagnostic outcome: Autism Spectrum Disorder

Jane

Location of research interviews: Family home

Participant's comments on location choice: None

Interviews completed: Quantitative and qualitative

Relationship with researcher: Research and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: Genetic neuromuscular syndrome

Life events reported during research process: Finished college,
mother moved out of family home

Issues noted during research engagement: None noted

Diagnostic outcome: Autism Spectrum Disorder and Specific
Language Difficulties

Jim

Location of research interviews: Mother's house

Participant's comments on location: None

Interviews completed: Quantitative

Relationship with researcher: Research only

Residential area: Socially deprived area

Medical or psychiatric diagnosis: None

Life events reported during research process: Was told job was at risk

Issues noted during research engagement: Limited verbal communication noted, active use of pictorial supports

Diagnostic outcome: Autism Spectrum Disorder

Don

Location of research interviews: Participant's house

Participant's comments on location: Expressed regular concern about mess

Interviews completed: Quantitative

Relationship with researcher: Research and diagnostician

Residential area: Not a socially deprived area

Medical or psychiatric diagnosis: Depression and anxiety being treated medically by GP

Life events reported during research process: None

Issues noted during research engagement: Often not in when visits arranged and needed to be contacted via a mental health support worker

Diagnostic outcome: Autism Spectrum Disorder

Laura

Location of research interviews: Family home

Participant's comments on location choice: None

Interviews completed: Quantitative

Relationship with researcher: Research and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: GP treating depression medically

Life events reported during research process: None

Issues noted during research engagement: Limited verbal
communication active use of pictorial supports

Diagnostic outcome: Autism Spectrum Disorder

Chris

Location of research interviews: Clinic

Participant's comments on location choice: Stated that because of compulsive hoarding she would feel embarrassed to have others come to her house

Interviews completed: Quantitative

Relationship with researcher: Research and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: None

Life events reported during research process: Lost job, reunited with daughter

Issues noted during research engagement: None

Diagnostic outcome: Autism Spectrum Disorder

Nick

Location of research interview: Clinic

Participant's comments on location choice: Expressed view that home would be noisy and difficult to meet in

Relationship with researcher: Research and diagnostician

Interviews completed: Quantitative

Residential area: Socially deprived

Medical or psychiatric diagnosis: None

Life events reported during research process: Impending court case

Issues noted during research engagement: Rapid mood variation observed and active use of pictorial supports

Diagnostic outcome: Autism Spectrum Disorder

Mo

Location of research interviews: Home

Participant's comments on location choice: None

Relationship with researcher: Research and diagnostician

Interviews completed: Quantitative

Residential area: Socially deprived

Medical or psychiatric diagnosis: GP treating depression medically

Life events reported during research process: None reported

Issues noted during research engagement: Often not home for appointments and not responsive to phone calls

Diagnostic outcome: Autism Spectrum Disorder

Michelle

Location of research interviews: Home

Participant's comments on location choice: Would prefer to meet in clinic due to noise but impractical with children and travel

Relationship with researcher: Research and diagnostician

Interviews completed: Quantitative

Residential area: Socially deprived

Medical or psychiatric diagnosis: GP treating depression medically

Life events reported during research process: Fell out with neighbours who had been main social link

Issues noted during research engagement: Busy environment with children and active pets

Diagnostic outcome: Autism Spectrum Disorder

.

Cathy

Location of research interviews: Clinic

Participant's comments on location choice: Did not feel comfortable having strangers in her home

Interviews completed: Quantitative

Relationship with researcher: Research and diagnostician

Residential area: Socially deprived

Medical or psychiatric diagnosis: GP treating depression medically

Life events reported during research process: Issues noted during research engagement: Required daughter's support worker to be main contact and to support with interviews. Did not attend final interview or respond to any communications

Diagnostic outcome: Autism Spectrum Disorder

Ralph

Location of research interviews: Participant's home

Participant's comments on location choice: Needed to be seen at home due to caring responsibilities

Interviews completed: Quantitative- pre assessment only

Relationship with researcher: Research only

Residential area: Socially deprived

Medical or psychiatric diagnosis: None reported

Life events reported during research process: Wife developed illness requiring intensive treatment

Issues noted during research engagement: Did not attend without reminders and reported history of aggression that required the support of an additional staff member to visit. Ralph requested a delay to his diagnostic process due to his wife's illness which meant his research interview would not have been completed within the study timescale and his results were not included

Diagnostic outcome: Diagnostic process delayed

.

Joanna

Location of research interviews: Family home

Participant's comments on location choice: At beginning of process Joanne was not leaving the house so this was only place she was happy to be seen

Interviews completed: Quantitative

Relationship with researcher: Research and diagnostician

Residential area: Socially deprived

Medical or psychiatric diagnosis: GP treating medically for depression and anxiety

Life events reported during research process: Restarted a university course which she had failed the previous year as well as living away from home for the first time

Issues noted during research engagement: Responded well to structured and visually based aspects of tasks and expressed a dislike of any unstructured communication

Diagnostic outcome: Autism Spectrum Disorder

Mike

Location of research interviews: Family home

Participant's comments on research location: None

Interviews completed: Quantitative

Relationship with researcher: Researcher

Residential area: Socially deprived

Medical or psychiatric diagnosis: Mild physical disability

(unspecified diagnosis)

Life events reported during research process: Involvement of police in relation to vulnerable adult concerns

Issues noted during research engagement: Active use of pictorial materials and difficulty in initial engagement because of various house moves and changed mobile phone numbers

Diagnostic outcome: Not autistic. Autistic traits related to unspecified genetic condition

Carl

Location of research interviews: Clinic

Participant's comments on research location: Carl expressed negative feelings about his home and the people in it, and a desire to meet in another location

Interviews completed: Quantitative

Relationship with researcher: Researcher and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: Psychiatrist treating for depression and anxiety

Life events reported during research process: None

Issues noted during research engagement: On two occasions asked to be excluded from study and then rang back to say he wanted to participate. Arrived in heightened state of agitation, often expressing that this was related to difficulties with journey, but very quickly calmed

Diagnostic outcome: Not autistic. Autistic traits related primarily to a diagnosis of anxiety

Liam

Location of research interviews: Family home

Participant's comments on research location: Liam was struggling to leave his home environment and asked to be seen at home

Interviews completed: Quantitative

Relationship with researcher: Researcher and diagnostician

Residential area: Socially deprived

Medical or psychiatric diagnosis: Psychiatrist managing depression and anxiety medically

Life events reported during research process: None reported

Issues noted during research engagement: Very difficult to contact directly. Able to contact through email correspondence with transitional support worker.

Diagnostic outcome: Autism Spectrum Disorder and ADHD

Luke

Location of research interviews: Clinic

Participant's comments on research location: Luke expressed the view that visiting a clinic location would be an interesting activity that he would enjoy and would prefer this to being seen at home

Interviews completed: Quantitative

Relationship with researcher: Researcher and diagnostician

Residential area: Not socially deprived

Medical or psychiatric diagnosis: None

Life events reported during research process: None reported

Issues noted during research engagement: Described needing mother for organisational support to get to sessions

Diagnostic outcome: Autism Spectrum Disorder