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Thesis title: The subjective well-being of people with a learning disability: What factors contribute?
Qualification: DClinPsy

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**The Subjective Well-Being of people with an Intellectual Disability:
What Factors Contribute?**

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Thesis submitted for Doctor of Clinical Psychology

University of Sheffield

Declaration

I declare that the work contained within this thesis has not been submitted for any other qualification, or to any other institution.

Structure

This thesis has been prepared in accordance with the following guidelines:

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Journal of Applied Research in Intellectual Disabilities

Word Counts

Literature Review excluding references:	7,984
Research Report excluding references:	11,997
Appendices:	6,845
Total word count excluding references and appendices:	19,993
Total word count including references and appendices:	29,750

Abstract

Research suggests a ‘tenuous link’ between objective life circumstances, and subjective appraisals of well-being and satisfaction (Cummins, 2005; Emerson & Hatton, 2008). There is currently a lack of research exploring the subjective well-being (SWB) of adults with an intellectual disability.

The literature review presents a critical overview of the existing body of empirical research pertaining to the SWB of people with an intellectual disability. It concludes that, though the study of SWB is expanding, it is in the early stages of development and further replication of findings is required before conclusions can be drawn. In addition, considerable disparity was found in the definition and measurement of SWB, suggesting the concept would benefit from being operationalised and some consensus reached regarding its measurement.

The research report documents an inclusive research project which brought together researchers with a variety of skills to qualitatively explore the views of 23 people with an intellectual disability who report high SWB. Participants described the importance of environmental factors such as relationships, choice and independence, and their interaction with personal characteristics such as contentment, acceptance and ‘looking on the bright side’. These results also suggest a third factor which operates between the individual and their environment to ‘enable or disable’ SWB. This factor comprised of staff, family and ‘boundaries’ including transport and finance. These findings have implications for those wishing to maximise the SWB of people with an intellectual disability including policy-makers, service-providers, clinicians, staff and family members.

Acknowledgements

Thank you to my co-researchers Darren, Carl, Michelle and Stephen for the joy you brought to this process. The sense of shared vision and achievement, not to mention the many laughs, made this project a truly wonderful thing to be part of. I look forward to whatever we do next....

Thank you to my supervisors, Professor Nigel Beail, Dr David Newman and Dr Zara Clarke. I am extremely grateful for your wisdom, experience, patience and hard work. Thank you also to Mandy and Neil who helped enormously in the recruitment for this study.

Thanks to all the people who agreed to take part in this study. Hearing about your lives was a privilege and we were all extremely grateful for your bravery in talking to us.

Finally, special thanks to the wonderful people in my personal life. Thank you to Greg for your support, love, encouragement and reassurance- I will never forget how great you've been throughout this process. Thank you to my friends who have never failed to amaze me with the amount of support and love you give. Thank you to my family, who have listened and supported me practically and emotionally (thanks Mum!). And thank you to Cathyrn- I cannot tell you what a difference walking this difficult road with you has made.

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Section 1

Literature Review

A review of research exploring the subjective well-being of adults with an intellectual disability

Abstract

This review presents a critical overview of the existing body of empirical research pertaining to the SWB of people with an intellectual disability. Twenty studies are included and rated for methodological rigor using an amended version of the Downs and Black's Quality Checklist (1998). Limitations are discussed along with theoretical and clinical implications and suggestions made for further research.

Considerable disparity is evident in both the focus and outcome of research and pervasive methodological limitations prevent firm conclusions being drawn. This review concludes that results should be replicated using larger, randomised samples and suggests that the concept of SWB should be further operationalised to enhance construct validity and facilitate greater consensus regarding its measurement.

Keywords: Subjective well-being, Subjective Quality of Life, Intellectual Disability, Learning Disability

1 Introduction

1.1. Subjective Well-being

Quality of Life (QOL) has been an increasing focus of research since the 1970s with numerous studies seeking to identify and measure the personal and environmental factors which impact upon it (Brown & Brown, 2005). Though the majority of research has utilised a 'normative' sample from the general population, there has been a marked increase in studies considering QOL in specific populations such as people with an intellectual disability (Schalock, Bonham & Marchand, 2000).

The field of intellectual disabilities has also experienced a substantial shift during this time, with the emergence of movements such as social role valorisation (Wolfensberger, 2000), and inclusion (Schalock et al., 2000). These approaches have sought to move away from a 'deficit' model of disability toward one which promotes valued roles and fulfilling lives for people with an intellectual disability (Dykens, 2006). Subsequently, QOL has increasingly been utilised as an outcome measure by policy makers and service providers seeking to assess the impact of developing services on the lives of service users (Parmenter, 1992; Schalock, 2004). It has also been effectively utilised by researchers seeking to enhance the opportunities and life satisfaction afforded to people with an intellectual disability (Matikka, 1996).

QOL is widely accepted to be a multidimensional concept which is broken down into 'objective' and 'subjective' indicators (Ryan & Deci, 2001). The QOL of people with an intellectual disability has historically been measured by objective life circumstances such as housing, healthcare and community inclusion (Cummins, 1997; Schalock et al., 2000; Felce & Perry, 1997). However, there is a growing consensus that objective life circumstances share a 'tenuous link' with subjective appraisals of well-being and satisfaction with life, both in the general population and for people with an intellectual disability (Cummins, 2005; Emerson & Hatton, 2008). Studies have reported 'low or no correlation' between objective life circumstances and subjective well-being (SWB) (Schalock, 2004; Hensel, Rose, Kroese & Banks-Smith, 2002). As such, a person may score highly on objective measures of life circumstances, but report low levels of life satisfaction or vice versa. This may account for the finding that people with an intellectual disability report similar or higher levels of SWB than the general population, despite lower levels of objective life circumstances such as material wealth, community participation and health (Cummins, 1997; McGillivray, Lau, Cummins & Davey, 2009).

The importance of exploring both objective and subjective domains of QOL appears clear; however research examining the factors which contribute to SWB of people with intellectual disabilities remains sparse (Schalock et al., 2002). This may be due in part to the methodological difficulties associated with eliciting self-

report data from people with an intellectual disability which include reliability, acquiescence and suggestibility (Finlay & Lyons, 2001).

1.2 Aim and rationale

This review aims to present a critical overview of the existing body of empirical research pertaining to the SWB of people with an intellectual disability. The study of SWB is important in ensuring people with an intellectual disability are able to experience both objectively and subjectively satisfying lives. This may be particularly pertinent given the continued reliance by policy-makers and service-providers on objective measures of QOL, which may not directly result in improved life satisfaction for service users (Cummins, 1997). The theoretical and clinical implications of this review will be explored.

1.3 Definitions

1.3.1 Subjective Well-being (SWB)

Despite the substantial body of research considering SWB in both general and specific populations, there continues to be a lack of clarity surrounding its definition and measurement within the literature (Cummins, 1999; Schalock et al., 2002; Felce et al., 1997). There is a growing consensus that SWB can be broken down into two components; 'hedonic' factors concerned with positive and negative affect, and 'eudaimonic' factors which reflect an individual's cognitive appraisal of their lives or 'life satisfaction' (Ryan & Deci, 2001). For the purpose of this review the

definition of SWB provided by Diener (1994) was utilised as it reflects the dominant understanding of SWB evident in the literature. Diener (1994) defines SWB as;

'the global experience of reactions to one's life, which includes all of the lower-order components such as life satisfaction and hedonic level'.

1.3.2. Theory of Well-Being Homeostasis

The Theory of Well-Being Homeostasis is well documented in several papers by Cummins (1997; 2003; 2005) and seeks to explain the seeming stability of wellbeing despite changes or deficits in objective life circumstances. Cummins outlines how cognitive and affective processes compensate for changes in specific domains of SWB by increasing the importance and satisfaction attributed the other domains, thus maintaining a constant level of global well-being. This system may fail if numerous domains drop below the level at which well-being can be maintained, resulting in homeostatic 'defeat' (Cummins, 2005). The evidence for this theory is considered throughout this review due to its prevalence in the literature.

1.4 Search Strategy

As the term 'subjective well-being' is yet to be uniformly defined it was necessary to include multiple search terms to identify the relevant literature (see Figure 1). The terms 'subjective well-being', 'life satisfaction' and 'subjective quality of life' were included as they were deemed to fit the above definition. The terms were

entered into the Ovid SP database on the 27th March 2011 along with learning disability, intellectual disability, developmental disability, mental handicap and mental retardation. Further articles were identified from references in the selected papers.

1.5 Inclusion and Exclusion Criteria

Studies were included that empirically explored the SWB of adults with an intellectual disability as defined by Diener (1994), and were published in a peer reviewed journal after 1990. Studies prior to this were excluded to provide a contemporary view of SWB and reflect the conceptual shifts in intellectual disability research.

Studies that utilised a sample of adolescents or children were excluded as the factors that impact upon SWB are likely to be related to their stage of life. Studies were also excluded if the focus was only one domain of life satisfaction such as satisfaction with living arrangements, rather than a global appraisal that corresponds to the definition of SWB. Discussion papers considering the nature of SWB, or the utility of its application with people with an intellectual disability were also excluded. Due to concerns about the validity of data derived from proxy respondents such as staff and family members (Cummins, 2002a), studies were excluded that consider only proxy responses. QOL research suggests that objective and SWB should be considered as separate constructs (Ryan & Deci,

2001), therefore studies which combined objective and SWB scores in their analysis were excluded.

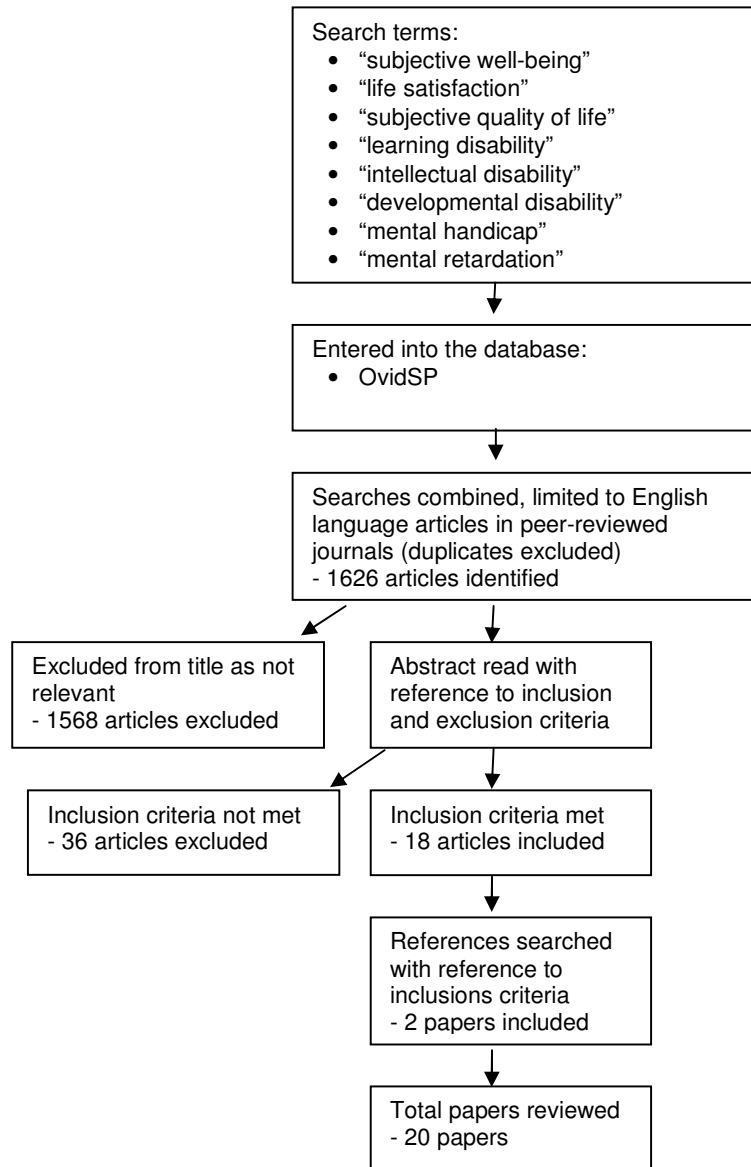


Figure 1: Search strategy and Inclusion Process

1.6 Review Strategy

In total, 20 studies were included in the review. Studies were rated for methodological rigor using an adapted form of Downs and Black's Quality Checklist (1998; see Appendix 7). Scores were used to generate the percentage of scale maximum (%SM) for each study and are reported along with the major limitations in Table 1. Further limitations specific to each study are explored in text and the subsequent implications discussed. Due to the disparate definitions and conceptual understandings of SWB found in the literature, specific consideration is given to how studies define SWB, and whether any measures used are valid, reliable and justified with reference to this definition.

Considerable disparity was evident in the methodology and focus of research and studies were therefore grouped into sections for clarity. The first section reviews between-group exploratory studies that have sought to compare SWB in participants with and without an intellectual disability. The second section reviews within-group studies which examine the impact of personal characteristics, specific interventions or services on SWB. The third section will provide a brief overview of the discrete literature on SWB in people with profound and multiple intellectual disability (PMID).

Table 1: Summary of Studies

<i>Authors</i>	<i>Design and Focus</i>	<i>Analysis</i>	<i>Sample</i>	<i>SWB Measure</i>	<i>Quality Scale score</i>	<i>Major limitations</i>
Arias, Overjero & Morentin (2009).	Cross-sectional; exploring the relationship between 'love', related variables and SWB	Structural Equations Modelling	n=376 Incidental sample of adults with a mild intellectual disability (ID)	7 items from Scale of Assessment of Quality of Life in People with ID (Verdugo, Gomez, Arias & Schalock, 2009).	62% SM	'Love' scale not normalised on ID population. Non-representative sample. Validity & reliability of SWB measure not reported.
Banks, Jahoda, Dagnan, Kemp & Williams (2010)	Longitudinal, mixed method; investigating the impact of job breakdown on SWB	ANOVA Qualitative analysis	n=49 Persons with an ID in supported employment	ComQoL, (Cummins, 1993b)	62% SM	Small sample size. No report of analysis of qualitative data. Probability values not reported. Parametric statistical test used on small dataset.
Bayer, Brown, Akandi & Rapley (2009)	Group comparison of SWB and objective QOL of people with an ID accessing supported employment and day services, and non-disabled workers in employment.	Mann-Whitney <i>U</i> -tests	n=54 27 people with an ID in supported employment 10 people with an ID accessing a day centre. 17 non-disabled co-workers	ComQoL, (Cummins, 1993b)	57% SM	Small non-representative sample. Groups not matched for demographic variables. Probability values not reported. No measure of ID.
Bramston, Chipuer & Pretty (2005).	Group-comparison of participants with and without an ID examining SWB, stress, social support and community	Linear Regression Analysis	n=200 80 volunteers with an ID working in a supported employment scheme aged 17-25. 120 young persons without an ID aged 16-23	ComQoL, (Cummins, 1993b)	53% SM	Aims and hypotheses not clearly stated. Probability values not reported. No formal measure of ID. Non-representative sample used. Experimental groups not matched.
Emerson & Hatton (2008)	Exploratory analysis of pre-existing dataset	MANOVA, ANOVA	n=1,273 Pre-existing dataset of persons with an ID in the UK	Five questions deemed by the researchers to 'indicate subjective wellbeing'	46% SM	Characteristics of participants not included in analysis not described. No formal measure of ID. Validity and reliability of SWB scale not reported. No empirical rationale for items used to construct SWB reported.

Hensel, Rose, Sternfert Kroese & Banks-Smith (2002)	Matched-group comparison of SWB, health checks and satisfaction with G.P.	MANOVA, Spearman's Correlation	n=62 Staff-identified sample of 31 persons with an ID. Matched control group of 31 persons without an ID	ComQol, (Cummins, 1993b)	44% SM	Small sample size analysed using parametric statistical tests. Multiple analyses increased likelihood of Type I error. Convenience sample utilised and implications not discussed. No formal measure of ID used.
Hergenroder & Blank (2009).	Cross-sectional; examining SWB in adults with cerebral palsy with and without an ID.	Spearman's Correlation	n=35 Purposefully sampled adults with cerebral palsy. n- 7 with an ID	Bern Questionnaire on SWB, adult form (BSW/A; Grob, 1995)) and the Life Satisfaction-Checklist (LiSat-11; Fugl-Meyer, Merlin & Fugl- Meyer, 2002)	67% SM	Small sample size. No formal measure of ID reported. SWB measure not validated for use with ID population
Jahoda, Kemp, Riddell & Banks (2008)	Literature review of the impact of employment on QOL and SWB	Literature review	n=6 studies pertaining to QOL and subjective wellbeing	Quality of Life Questionnaire (QOLQ, Schallock & Keith, 1993) Ideographic measures	n/a	
Kober & Eggleton (2005)	Group comparison of SWB of people in open and sheltered employment	Mann-Whitney U-tests	n=117 people with an ID in sheltered or open employment	QOLQ, (Schallock & Keith, 1993)	56% SM	Low response rate (16.5%). Comparison groups not matched for demographics. No formal measure of ID.
Matikka (1996)	Cross-sectional; exploring the correlation between personality traits; awareness of disability; individual resources; values; living conditions and SWB	Multiple Regression Analysis	n=416 Systematic cluster sample of Finnish people with an ID	Questionnaire data. SWB calculated by combining the domains of happiness, a positive view of life and stress.	60% SM	Characteristics of participants not included in analysis not described. Validity and reliability of SWB measure not reported. No formal measure of ID used.
McGillivray, Lau, Cummins & Davey (2009)	Cross-sectional; providing psychometric data for PWI-ID	Unequal variance t-test	n=114 Convenience sample of Australian persons with an intellectual disability	Personal Well-being Index-Intellectual Disability (PWI-ID; McGillivray et al., 2009)	71% SM	36% of data excluded due to scoring scale maximum. Non-random sample. No measure of ID.
Miller & Chan (2008)	Within-group exploratory study examining the impact of life skills and higher-order predictors on the SWB	Hierarchical regression	n=56 Convenience sample of people with an ID	QOLQ, (Schallock & Keith, 1993)	62% SM	Small, convenience sample. Probability values not reported. No measure of ID.

Petry & Maes (2006)	Exploratory study of behavioural indicators of SWB in persons with PMID	Critical incident coding	n=6 Convenience sample of people with PMD ranging from 8-29 years of age	Individual affect profile	75% SM	Small sample size purposefully selected by staff members.
Petry, Kuppens, Vos & Maes (2010).	Cross sectional; exploring correlation between scores on MPIQ and scores for aberrant behaviour	Confirmatory factor analysis. Chi Square, Pearson Correlations	n=354 Participants with PMID and their caregivers	Mood, Interest and Pleasure Questionnaire (MIPQ; Petry et al., 2010)	83% SM	Sample identified by staff members. Response rate of 67%.
Schallock, Bonham. & Marchand (2000)	Participatory action-research cross-sectional exploratory study	Path Analysis	n=237 Random sample of persons with an ID (61.5% male)	Modified version of the Quality of Life Questionnaire (Schallock & Keith, 1993)	91% SM	Correlational design prohibits assumptions regarding causality. Factor analysis did not identify 'dignity' as a clean factor.
Simon, Rosen, Grossman & Pratoski (1995)	Cross-sectional; exploring the relationship between facial emotion recognition, social skills and SWB	Pearson Correlation Coefficients	n=46 Convenience sample of adults with an ID	Perceived Stress Affect Loneliness Scale (PALS; Rosen, Simon & McKinsey 1995)	62% SM	Small sample size. Probability values not reported. Non-randomised sample. Parametric tests used despite small sample size.
Van Puyenbroeck & Maes (2009)	Cross-sectional; exploring the impact of a reminiscence group on SWB	Multi-level/ mixed models regression, Fishers exact test, Multiple one-way ANOVAs	n=41 Purposeful sample of people with an ID aged over 50.	Short version of the Intellectual Disability Quality of Life (IDQOL; Hoekman et al., 2001). Mood Interest & Pleasure Questionnaire (MIPQ; Ross & Oliver, 1999)	57% SM	Small, non-random sample. No measure of ID. SWB measure not normalised for use with people with mild/moderate ID. Characteristics of participants not included in analysis not described.
Verri, Cummins, Petito, Vallero, Monteath, Gerosa & Nappi, (1999).	Group comparison of SWB	MANOVA, ANOVA	n=413 n=70 random sample of Italian persons with an ID and n- 100 Australian persons without an ID. n=92 convenience sample of Italians without an ID and n=151 Australian persons with an ID	ComQoI, (Cummins, 1993b)	67% SM	64% of ID sample excluded due to scoring scale maximum. Not all samples randomised. Probability values not reported. Groups not matched on demographic variables.

Vos, De Cock, Petry, Van Den Noortgate & Maes (2010)	Within-group exploratory study examining factors that contribute to the SWB of persons with PMID	Hierarchical linear regression	n=354 Purposeful sample of participants with PMID living in residential care facilities in Flanders	Mood, Interest and Pleasure Questionnaire (MIPQ; Petry et al., 2010)	67% SM	Participant characteristics not clearly described. Validity and reliability of SWB measure not reported.
Vos, De Cock, Petry, Van Den Noortgate, & Maes (2010)	Small scale, within-group exploratory study of physiological measures of SWB	Repeated measures ANCOVA, Tukey post-hoc comparisons	n=3 Convenience sample of adults with PMID	Physiological response to stimuli including respiratory, heart and electro dermal parameters	64% SM	Small sample size. Parametric statistical tests used and probability values not reported.

2 Literature Review

2.1 Summary of Findings

Each study was rated according to their methodological rigor using the adapted version of Downs and Black's checklist (1998; see Appendix 7). The studies included in this review achieved between 44-91% SM on the quality measure; however the mean score was only 64%. This indicates pervasive methodological limitations, the most common of which were small, non-random samples which were often analysed using inappropriate parametric statistical testing, lack of measures of intellectual disability, and a lack of matching of demographic variables in group comparison studies. However, even the studies which scored highly on the quality measure were subject to limitations associated with their definition and measurement of SWB. These limitations will be further explored in subsequent sections.

2.1 Between-group Studies

Between group studies have tended to utilise specific well-being measures with parallel versions that can be applied to the general population and people with an intellectual disability to allow for direct comparison. Three studies were identified that utilised the Comprehensive Quality of Life Scale (ComQol, Cummins, 1993b) to compare the SWB of people with and without an intellectual disability. One study examined the SWB of a subset of people with an intellectual disability within a wider 'disabled' sample.

The ComQol (Cummins, 1993b) measures objective and subjective QOL within seven 'life domains'; material well-being, health, productivity, intimacy, safety, place in the community and emotional well-being. Respondents are required to rate the importance of and satisfaction with each domain, and these scores are combined to provide an overall score of SWB ranging from 0-100 (Cummins, 1993a). Objective QOL is measured through 'an aggregate score of three items'. For example medication, frequency of access to G.P. and presence of disability are used as objective measures of 'health' (Cummins, 1997). The ComQol-ID is specifically designed for use with people with an intellectual disability and includes a pre-testing procedure which ascertains to what extent each participant can use a Likert scale, as well as testing for acquiescence and suggestibility. Both versions of the ComQol demonstrate acceptable levels of internal validity and test-retest reliability.

Verri et al (1999) utilised parallel forms of the ComQol (Cummins, 1993b) in a sample of Italian and Australian people with and without an intellectual disability. Though the Australian general population sample demonstrated the highest level of objective wellbeing, the Italian participants with an intellectual disability reported the highest SWB. Participants with an intellectual disability scored significantly lower on the objective measures of health, productivity and community, which may reflect findings that suggest people with a disability are at higher risk of community exclusion, unemployment and poor health (Verri et al., 1999; Emerson & Hatton, 2008). However, there was no significant difference in SWB between the groups,

with the exception of the Italian participants with an intellectual disability who reported significantly higher SWB.

People with an intellectual disability scored lower on both objective measures and the importance attributed to health; however satisfaction with health did not differ significantly between groups. This finding is particularly interesting given that people with an intellectual disability typically report higher levels of ill-health than the general population (Dagnan, 2008). The authors speculate that this finding may be explained by the Theory of Well-being Homeostasis (Cummins, 2005), with the lower importance placed on health seen as an attempt to moderate the impact that ill-health may have on SWB. However, this may also be attributed to other variables such as less health awareness in people with an intellectual disability, or the lifelong nature of conditions such as epilepsy which may lead to adaptation (Uppal, 2006).

In a similar study with a smaller sample size, Hensel et al (2002) utilised the ComQoL-ID, but included a measure of the 'health promotion checks' each group had undertaken in the previous 12 months and satisfaction with their G.P. Like the previous study, results indicated that participants with an intellectual disability scored significantly lower than the general population sample in the objective measures of health, but also in productivity, community and emotion. The authors did not report the overall SWB scores, though domain differences in satisfaction between the two groups were only observed in productivity and material well-being,

with participants with an intellectual disability scoring significantly higher. Unlike the previous study however, participants with an intellectual disability reported significantly lower satisfaction with health, and no correlation was demonstrated between the importance that participants ascribed to a domain and either the objective or subjective measures. This study therefore failed to replicate the findings of Verri et al (1999).

It is of note that this sample was smaller than that used in Verri et al (1999) and that participants were 'well known to special services' (pp 105) which will have introduced a sampling bias. This may have been further exacerbated by the fact that the sample was identified by staff at day centres and community nurses, as staff members may have been more likely to nominate those that would report higher levels of SWB. Multiple parametric statistical tests were used despite the relatively small sample size, and though a Bonferroni correction was used to adjust the p-value, this may have increased the likelihood of a type I error.

The ComQol was further utilised by Bramston, Chipuer and Pretty (2005) in a comparison of young adults with and without an intellectual disability. Unlike the previous study, results indicated that people with an intellectual disability rated the importance of all domains of QOL significantly lower than the comparison group, with the exception of material well-being. As with Verri et al (1999), the sample of people with an intellectual disability reported higher satisfaction in the domain of health, and lower satisfaction in the domains of intimacy and community

involvement. Regression analysis indicated that ComQol-ID scores on the domains of safety, emotional well-being and satisfaction with health were significantly predicted by social support for both groups. For participants with an intellectual disability, social support was also a significant predictor of material well-being.

Though all three studies utilise the same SWB scale, they yield very different results in terms of the importance and satisfaction reported by participants. Though the study by Verri et al (1999) scored the highest in the quality measure it still only obtained 67%SM. There was a high chance of sampling bias as only one sample was randomised, with the others relying on staff identifying possible participants or volunteers. The studies all utilised different methods of analysis (MANOVA, linear regression and Spearman's correlation) making it more difficult to directly compare the findings.

It may be of note that the studies were conducted in different countries; therefore the conflicting results may indicate cultural differences in SWB. The impact of culture of SWB is yet to be fully understood in both the general population and in people with an intellectual disability, and therefore requires further exploration (Ryan & Deci, 2001).

Though the Theory of Well-being Homeostasis (Cummins, 1997) was proposed as a model to understand the findings of the first study, the conflicting results of the

subsequent studies indicate that, despite its popularity in the literature, further empirical support is also required.

Several issues also arise from these studies which relate to the use of reduced option Likert scales for people with an intellectual disability. The most basic scale involves only two options which are represented by 'happy' and 'sad' faces. The authors of the scale advise that participants who provided maximum scores for each domain be excluded from the study to protect the integrity of the data, however this may be more likely when only two options are presented. In the study by Verri et al (1999) a total of 67 participants with an intellectual disability were excluded from the samples, though no participants were excluded from either of the general population samples. Though only this study describes exclusion as a result of this, it poses a difficult question as participants are either excluded or the data may be contaminated.

In contrast to the above studies which compare the SWB of people with a learning disability to that of the general population, Hergenroder and Blank (2009) examined the SWB of a subset of people with an intellectual disability within a wider 'disabled' sample of German adults with Cerebral Palsy (CP). Of the original sample of 50 people, only half were able to provide data for analysis with the 'dropout' group more likely to have severe disabilities. Results indicated that participants with CP but without an intellectual disability were less satisfied with the domains of daily living, family life, somatic health and psychological health than

those with an intellectual disability. The authors do not hypothesise as to why these domains were rated higher by the participants with an intellectual disability, but this seems to support the findings of Cummins (1993b) that people with an intellectual disability report average or higher levels of satisfaction than the general population. In addition to the limitations outlined in Table 1, it is of note that neither of the measures used were designed for use with people with an intellectual disability. As such these findings should be interpreted with appropriate caution.

This section reveals the need for more methodologically robust research that compares the SWB of people with an intellectual disability with that of the general population.

2.2 Within-group Studies

Three exploratory studies were identified which utilised a range of measures to explore the SWB of people with an intellectual disability. Nine further studies sought to identify the impact of specific personal or environmental factors in predicting or contributing to SWB.

2.2.1 Exploratory studies

McGillivray, Lau, Cummins and Davey (2009) sought to develop the ComQoL-ID in an attempt to address some of the aforementioned methodological issues. The resulting Personal Well-being Index-Intellectual Disability (PWI-ID; McGillivray et al., 2009) was piloted with a sample of 114 Australian adults with an intellectual

disability. This scale differs from the ComQol-ID in that a score for domain 'importance' is not calculated, and therefore the global SWB score, termed the 'Personal Well-being Index', is calculated from the mean of domain satisfaction scores. The objective measures of life quality were also omitted and the domain of 'future security' was added in line with the emerging literature from objective QOL studies. The scale continues to include the pre-testing protocol to test for acquiescence and suggestibility, and a reduced option Likert scale. The Cronbach Alpha was reported as 0.76 which is acceptable, though the test-retest coefficient was lower at 0.58.

The mean score for the Personal Wellbeing Index scores was 77.08 (SD 16.64), which was slightly higher than the range of 73.4-76.4 reported by the general population. Satisfaction with the domains of 'personal relationships', 'community', 'life achievement' and 'safety' were all above the scale mean. The authors cite this as further evidence of the Theory of Well-Being Homeostasis, though no measure of objective life circumstances was included to allow for comparison between objective and subjective measures.

This study scored 71% SM on the quality measure, though demonstrated some additional methodological weaknesses. Thirty-six percent of the sample data was excluded due to scoring the scale maximum, which may indicate that the pre-testing procedure aimed at eliminating participants that demonstrate acquiescence was not adequate. Alternatively, it suggests that reduced scale Likert options

increased the likelihood that participants will score at the scale maximum. The authors acknowledge that there is no 'absolute justification' for excluding this data however, and suggest that the decision rests with the individual researcher (McGillivray, 2009).

In a further exploratory study, Schalock, Bonham and Marchand (2000) employed a modified version of the Quality of Life Questionnaire (QOLQ; Schalock & Keith, 1993) with a relatively large group of randomly sampled people with an intellectual disability. The QOLQ measures the domains of satisfaction, work, independence and community integration, and this study included 10 additional questions pertaining to 'dignity'. In the only example of participatory research in this review, this study employed self-advocates with an intellectual disability to administer the questionnaire. Two staff members were identified to act as proxy respondents for participants who were unable to respond verbally to the interview process. Path analysis was utilised to produce a model with life satisfaction as the dependant variable. The two domains of 'dignity' and 'work' positively contributed directly to life satisfaction, with dignity having the greatest impact in explaining 27% of the variance. Independence and community integration affected life satisfaction through their impact on dignity and work, and availability of transport impacted on life satisfaction through its effect on community integration.

Due to concerns about the validity of data derived from proxy respondents (Cummins, 2002a), this data was then analysed separately to explore whether the

model was altered. Though the model remained the same, proxies rated the domain of 'dignity' significantly higher than the participants that responded for themselves. The authors hypothesised that this may be due to reluctance on behalf of staff members to rate the dignity with which participants are treated less highly due to the possible negative connotations for their and their colleagues' practice.

This study scored 91% SM on the quality measure, and as such is the highest scoring study in this review. Schalock et al (2000) utilised a relatively large sample and sophisticated statistical analysis to provide a useful model of the factors which affect the SWB of people with an intellectual disability. However, in a critique of the QOLQ, Cummins (1997) points out the notable absence of domains relating to health and material wellbeing which may decrease its construct validity in relation to SWB. Cummins (1997) also raises questions as to the complexity of some of the items, citing the example of 'Do you feel your job or other daily activity is worthwhile and relevant to either yourself or others'? This level of abstraction may have impacted upon participants' ability to reliably respond to questions. The authors do not fully examine the process or impact of including researchers with an intellectual disability, or the impact of having two researchers present during the interviews. Also, as the authors point out, factor analysis conducted on the measure corroborated the first four factors of the QOLQ, but did not identify the ten items added to measure dignity as a 'clean' factor. The importance of dignity to the resulting model lead the authors to conclude that the model needs 'more work',

however the robust methodology indicates the findings should be weighted as such and the resulting model used as a basis for further research.

In a departure from research utilising specific well-being scales, Emerson and Hatton (2008) sought to further identify the factors associated with SWB by analysing an existing dataset of 1,273 people with an intellectual disability in the UK. Demographic and personal characteristics were extracted from the dataset along with a measure of SWB constructed from responses to five interview items including 'How do you feel about your life at the moment'? Results indicated that participants reported 71% of the scale maximum for SWB, which supports the assertion by Cummins (1997) that the normal range of responses on SWB measures lies between 70-80% regardless of which measure is used. Significant relationships were reported between SWB and socioeconomic status, increased variety of community activities, and contact with friends with an intellectual disability. Single marital status was significantly associated with higher wellbeing scores for women only. In addition, relationships with others with an intellectual disability were shown to be a protective factor from feelings of helplessness.

These results must be viewed within the context of the limitations associated with analysing an existing dataset for a purpose other than it was originally intended, and the subsequent limitation in the variables that could be explored. SWB scores were calculated using five questions deemed by the researchers to 'indicate subjective wellbeing' rather than by a specific measure, which may have affected

construct validity. However, the study utilised a relatively large, randomly selected sample of people with an intellectual disability and may provide a useful basis for further research.

2.2.2. Studies Examining Personal Characteristics

Simon, Rosen, Grossman and Pratoski (1995) explored the hypothesised relationship between facial emotion recognition, social skills and SWB in a sample of 46 adults with a mild or moderate intellectual disability. No significant relationship was found between the variables, with the exception of IQ and facial emotion recognition. While this did not support the research hypothesis, the authors argued this could be attributed to the limited opportunity for social contact in the residential facility in which the research took place and suggest the study be replicated with a larger, more diverse sample.

Matikka (1996) also aimed to consider the correlation between personal characteristics and SWB, focussing on personality traits, awareness of disability, individual resources, values and living conditions as measured on a 189 item questionnaire. SWB was calculated by combining the domains of happiness, a positive view of life and stress. The predictor variables were able to account for 22% of the overall variance in SWB. Self-esteem, self-image, positive sense of others' view of self, and sense of autonomy predicted 36% of the variance in 'a positive view of life'. Low self-esteem, desire for more autonomy, and feeling that disability impacted upon life predicted 32% of the variance in 'stress'. Of the

demographic and living condition variables, only gender contributed to SWB, as women reported higher levels of stress than men. This supports the findings of Emerson et al (2008) that gender may be an important variable when considering SWB.

This study indicates the possible importance of psychological factors as predictors of SWB. However the use of regression analysis, and the consideration of living conditions and personal characteristics as separate constructs, did not allow for the exploration of possible moderating or mediating variables. Teasing out these effects may be important in further understanding the relationship between these variables and SWB. The validity of grouping happiness, a positive view of life and stress as a measure of SWB may be questioned, along with the validity and complexity of the items used to measure these domains. For example, the items 'Do you enjoy music?' and 'Are you happy with your sex life?' were used to contribute to the mean score for happiness, and 'Have you felt recently that scary thoughts are going through your mind?' contributed to the mean score for stress. A rationale for the content and structure of these questions were not supplied by the author.

Arias, Overjero and Morentin (2009) utilised structural equation modelling to specifically consider the impact of attitudes and experiences of romantic 'love' on the SWB of a relatively large sample of Spanish people with an intellectual disability. The authors devised a 'love' scale from four pre-existing scales used in

the general population; though this was then piloted on a student sample which may have negatively impacted upon its validity for people with an intellectual disability. Results indicated that 'love' had a moderate effect on SWB, though this increased to explain 34% of the variance when combined with 'family variables' which included family interference and self-determination. Thus, family variables were seen as a 'moderating variable in the relation between love and emotional well-being' (pg 212).

It may be important to note that studies of SWB in the general population have reported a relationship between self-determination and SWB (Diener, 1994), therefore further analysis of the factors contributing to the 'family variables' may have been important in teasing out the affects of each of the components. Indeed, when the effect of 'family variables' on SWB was considered directly the value was 0.51, compared to the indirect effect via 'love' which was only 0.15. This model requires further consideration to understand the extent of the relationship between 'love' and SWB.

Miller and Chan (2008) examined the contribution of life skills (such as interpersonal and leisure skills) and 'higher order' variables such as social support and self-determination on the SWB of 56 purposefully sampled people with an intellectual disability. The combined sets of variables predicted 44% of the variance on SWB scores which is the highest in this review, and the 'higher order' variables were reported to contribute significantly to SWB when life skills were controlled for.

Partial regressions indicated that interpersonal skills and social support were the greatest predictors of SWB, which suggests the importance of the amount and quality of social interactions. These findings should be replicated using a larger, randomised sample as this study utilised inappropriate statistical tests given that insufficient numbers of participants were recruited to reach power.

2.2.3 Studies examining specific environmental factors

Van Puyenbroeck and Maes (2009) considered the effect of a reminiscence group on the SWB of older adults with an intellectual disability, supplementing data derived from SWB measures with structured interviews carried out with the participant's support workers. Though the standardised measures indicated no change in SWB as a result of the intervention, qualitative interview data and researcher observations suggested the positive impact of social contact, social cohesion as a group and being part of a meaningful activity. The authors concluded that some of the more subtle gains in SWB may not be reflected by measures which document satisfaction with broad life domains.

Numerous studies have sought to consider the impact of employment on the QOL of people with an intellectual disability and some have included measures of SWB. Jahoda, Kemp, Riddell and Banks (2008) conducted a review of studies published between 1967 and 2005, identifying 6 studies that specifically considered the impact of employment on SWB. The studies indicated that people with an intellectual disability in employment reported lower levels of depression, higher

overall life satisfaction and higher self-esteem than those that were unemployed, thus contradicting the widely reported finding that well-being scores remain stable regardless of life circumstances (Cummins, 2005).

Two studies were identified that were published since this review. Kober and Eggleton (2005) reported that participants in open (more independent) employment scored higher on a measure of SWB than those in sheltered (less independent) employment. Bayer, Brown, Akandi and Rapley (2010) reported that people with an intellectual disability in supported employment scored higher on a measure of SWB than people with an intellectual disability accessing a day centre, and a group of non-disabled co-workers. Interestingly they also reported that the non-disabled group scored significantly higher on the objective QOL measure. This provides support for the assertion that the link between objective and subjective QOL is 'tenuous' (Emerson and Hatton, 2008).

It is of note that these studies also only scored 56% and 57%SM on the quality measure respectively due to small sample sizes and lack of group matching. These are the same limitations outlined by Jahoda et al (2008), which indicates pervasive methodological flaws in this area of research.

In the only example of a longitudinal, mixed methods study in this review, Banks et al (2010) report the impact of employment breakdown on the SWB of people with an intellectual disability. Though SWB scores did not demonstrate significant

changes for those that lost their jobs during the research period (n=13, 27%), data derived from qualitative interviews indicated the negative impact of job loss, and the importance placed on employment by the participants. Thus, the authors also conclude that questions should be raised regarding the sensitivity of SWB measures.

These findings could be accounted for using the Theory of Well-Being Homeostasis, however the authors do not report whether satisfaction with other life domains altered as a result of a decrease in satisfaction with work. In addition the authors do not report whether systematic analysis of qualitative data was undertaken, but appear to have selected quotes to illustrate their discussion. Further mixed method research which utilises robust qualitative analysis could aid further understanding of the subjective impact of employment and wider life events on the SWB of people with an intellectual disability.

Within group studies have indicated possible relationships between SWB and numerous variables including dignity, work, socio-economic status, social support, marital status and personal characteristics such as self-esteem and self-determination. However, these studies represent pockets of research which are subject to a variety of methodological issues and contain disparate definitions and measures of SWB. The studies in this section scored from 46-91%SM on the quality measure, with the higher quality studies suggesting the positive impact of environmental factors such as being treated with dignity, accessing supported

employment and community integration on SWB. However, though this body of literature raises interesting questions, none of the findings have been suitably replicated, and further enquiry should be completed before conclusions can be drawn.

2.2.4 Severe and Profound Intellectual Disability

A distinct body of research has grown in response to the unique challenge of measuring the SWB of persons with profound and multiple intellectual disabilities (PMID) and associated communication difficulties. As discussed earlier, questions over the validity of proxy responding to SWB measures have been raised (Cummins, 2002a), posing the extremely difficult question of how to measure the SWB of people that cannot verbally communicate, without relying on proxy response. Vos et al (2010) pioneered the use of physiological measures of SWB in a sample of three people with a profound intellectual disability. They reported significant differences in the 'respiratory, heart and electro-dermal parameters between the positive-stimuli situations and the negative-stimuli situations, and a correlation between physiological parameters and behavioural observations', (p. 373). Though the findings for this innovative measure of SWB are promising, this methodology should be developed using larger samples, and the direct application of physiological measures should be demonstrated.

Attempts have also been made to develop SWB measures for people with PMID. Lyons (2005) developed the Life Satisfaction Matrix which develops an 'affect

profile' for the individual documenting the observable behaviours which indicate preference using positive and negative affect. Petry and Maes (2006) successfully utilised this scale with six adults with PMID, arguing that people with a PMID 'express their happiness through consistent behavioural repertoires' (p. 13), and that the successful development of individual profiles is central in measuring and understanding their SWB. This methodology was further developed with the Mood, Interest and Pleasure Questionnaire (MIPQ; Petry, Kuppens, Vos & Maes, 2010) which also utilises pre-identified behavioural indicators of affect to document positive and negative mood and interest. This scale reported acceptable psychometric properties and demonstrated a negative correlation with scores from measures of lethargy and social withdrawal. The authors argue that this demonstrates construct validity and lends weight to the claim that SWB can be measured using behavioural indicators for people with PMID.

In the first study examining the factors that contribute to the SWB of persons with PMID, Vos et al (2010) explored the relationship between scores on the MIPQ and personal characteristics, living conditions and support requirements. Results indicated that participants with PMID demonstrate lower SWB scores than the general population and people with mild and moderate intellectual disability. One in five participants scored less than 50% of the scale maximum, which indicates the need to further consider the SWB of people with a PMID who may be at risk of low SWB, and subsequent psychological health difficulties such as depression. Hierarchical linear regression indicated that 'higher age, medical problems, medical

treatment (sedatives), the need for support, additional sensory disability and challenging behaviour' were related to lower SWB scores (Vos et al., 2010; pp 1630).

This study highlights a wider issue in the field of PMID and SWB research, as the focus remains on the observable dimension of 'affect' but is as yet unable to measure the other dimension of SWB- 'life satisfaction'. It is clear that this is a developing area with innovative solutions being proposed to overcome the communication difficulties experienced by this population. These developments should continue, especially with regard to the factors that upon impact SWB in people with PMID.

3.0 Discussion

The number of empirical studies exploring the SWB of people with an intellectual disability is expanding and subsequent hypotheses are being developed as to the factors that contribute to improved well-being. This can be seen as a positive step forward in understanding the components of satisfying and fulfilling lives for people with an intellectual disability. Theories which seek to provide a model of well-being are also emerging, such as the Theory of Well-being Homeostasis (Cummins, 2005). However, the literature is in the early stages of development and considerable exploration and replication of findings is necessary before any conclusions can be drawn. Pervasive methodological limitations were identified

which may limit the generalisability and utility of results, including small, non randomised samples and lack of matching in group comparison studies.

This review also highlights the continued disparity in the definition and measurement of SWB, which may reduce construct validity, inhibit the systematic study of the area and make drawing comparisons between studies more difficult. The term 'subjective well-being' should therefore be operationalised, and some consensus reached regarding its measurement. This should include greater consensus as to the domains to be included in SWB scales, and the optimum Likert scale format to ensure that meaningful data can be provided and retained for people with a wide range of functional ability.

3.1 Suggestions for future research

In light of the methodological limitations outlined above, researchers should seek to replicate findings using larger, randomised samples, utilising measures specifically designed for people with an intellectual disability. This should include further studies examining the impact of culture and gender on SWB as both were implicated in this review and may have significant implications for the generalisability of results if replicated.

It is of note that no studies have employed qualitative methodology to explore the SWB of people with an intellectual disability. This is particularly important given the qualitative changes in the well-being of participants reported by Van Puyenbroeck

et al (2009) and Banks et al (2010), which were not demonstrated on the broader measures of SWB. Exploratory studies which have utilised a number of variables have only been able to account for between 27-44% of the variance in SWB, indicating the potential role of variables yet to be identified. Further research should therefore utilise robust qualitative methodology to explore the perspectives of people with an intellectual disability.

All but one of the studies included in this review have been cross-sectional, therefore further longitudinal studies may be necessary to explore the stability of SWB over time. This may be particularly useful in demonstrating whether domain satisfaction does indeed change to compensate for deficits as suggested by the Theory of Well-being Homeostasis (Cummins, 2005). It is also of note that many of the aforementioned studies are correlational in design and therefore no assumptions of causality can therefore be made. Researchers should continue to employ well-being scales with parallel forms to allow for useful, direct comparison with the general population.

Unlike many areas of intellectual disability research, the focus of SWB research has not remained exclusively with people with a mild or moderate intellectual disability, but has expanded to include innovative methods of measuring SWB in people with profound and multiple disabilities. This is important giving the initial findings of Vos et al (2010) that people with PMID have lower levels of SWB. These findings should also be replicated and expanded upon.

3.2 Clinical Implications

The findings of this review suggest that a wide range of factors over and above objective life circumstances may impact upon an individual's SWB. Though more research is necessary to examine these factors further it appears that service-providers should include broader measures of SWB alongside objective measures when evaluating the QOL of service-users. The initial findings of Vos et al (2010) suggest that people with PMID are at risk of experiencing lower levels of SWB, which has clinical implications given the increased related risk of psychological difficulties such as depression (Cummins, 1997).

3.3 Final Conclusions

Though this area of research is expanding to include people with an intellectual disability, more clarity is required regarding both the definition and measurement of SWB. However, this remains an important area of research for those wishing to improve the life satisfaction of people with an intellectual disability, and as such, further research should seek to replicate and build upon the findings outlined in this review.

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Section Two

Research Report

The Subjective Well-Being of adults with an Intellectual Disability: What Factors Contribute?

1 Abstract

Background: Research suggests a ‘tenuous link’ between objective life circumstances, and subjective appraisals of well-being and satisfaction (Cummins, 2005; Emerson & Hatton, 2008). Research exploring the factors which contribute to the subjective well-being (SWB) of people with an intellectual disability is currently inconclusive and exclusively quantitative in design.

Materials and Method: This inclusive research project utilised qualitative methodology to explore the views of 23 people with an intellectual disability who report high SWB.

Results: Participants described the importance of environmental factors such as relationships, choice and independence, and their interaction with personal characteristics such as contentment, acceptance and ‘looking on the bright side’. These results also suggest a third factor which operates between the individual and their environment to ‘enable or disable’ SWB.

Conclusion: These results build on previous SWB research and have far reaching implications for those wishing to maximise the well-being of people with an intellectual disability.

1 Introduction

1.1 People with an intellectual disability and quality of life (QOL)

The field of intellectual disabilities has experienced a substantial shift since the 1990s, with the emergence of movements such as social role valorisation (Wolfensberger, 2000) and inclusion (Schalock, Bonham & Marchand, 2000). These approaches have facilitated a move away from a 'deficit' model of disability toward one which promotes valued roles and fulfilling lives for people with an intellectual disability (Dykens, 2006). The concept of 'quality of life' (QOL) subsequently emerged as a valid outcome and area of research for people with an intellectual disability (Emerson & Hatton, 2008; Brown & Brown, 2005; Schalock, 2004).

QOL is a multidimensional concept which can be broken down into 'objective' and 'subjective' components. Objective components comprise of measurable life circumstances such as health, socioeconomic status and employment. The subjective component of QOL is often termed 'subjective well-being' (SWB) and is defined by Diener (1993) as;

'the global experience of reactions to one's life, which includes all of the lower-order components such as life satisfaction and hedonic level'

Within this widely accepted definition, SWB comprises of an individual's overall appraisal of their life, their satisfaction and corresponding affect such as happiness.

Much of the research and policy aimed at improving the QOL of people with an intellectual disability has focussed on objective life circumstances such as housing, access to employment and health care (Parmenter, 1992; Cummins, 1997; Felce & Perry, 1997; Schalock et al., 2000). However, research with both the general population and people with an intellectual disability has reported a 'tenuous link' between objective life circumstances, and SWB (Cummins, 2005; Emerson & Hatton, 2008). This suggests the need for further research which explores the SWB of people with an intellectual disability from a 'positive' psychology perspective; teasing apart happiness and life satisfaction from mere 'life circumstances' (Dykens, 2006).

1.2 People with an intellectual disability and SWB

Evidence from the general population suggests that individuals typically report high levels of SWB, scoring between 70-80% of the scale maximum on SWB measures (Diener & Lucas, 2000). Several studies have demonstrated that people with an intellectual disability report equivalent, or higher levels of SWB than the general population, despite reporting lower levels of objective life circumstances such as health and socioeconomic status (McGillivray, Lau, Cummins & Davey, 2009; Hergenroder & Blank, 2009; Dagnan, 2008; Emerson & Hatton, 2008; Bramston, Chipuer & Pretty, 2005; Hensel, Rose, Sternfert Kroese & Banks-Smith, 2002).

One theory which seeks to explain the seeming stability of SWB despite deficits in objective life circumstances is The Theory of Well-Being Homeostasis (Cummins,

1997; 2003; 2005). Cummins outlines how cognitive and affective processes compensate for deficits in specific domains of SWB by increasing the importance of and satisfaction attributed to the other domains, thus maintaining a constant level of global well-being. This system may fail if numerous domains drop below the level at which well-being can be maintained, resulting in homeostatic 'defeat' (Cummins, 2005). Though some studies have sought to provide support for this theory, research is still in its infancy and results should be replicated before the utility of the model can be comprehensively judged.

1.2.1 Factors which contribute to SWB

Ryan and Deci (2001) reviewed the literature pertaining to the 'antecedents' of SWB in the general population and suggest the importance of both environmental and personal factors. The most compelling evidence suggested the positive impact of relationships and subsequent feelings of 'relatedness'. Other variables were also implicated including personality traits such as extraversion, health, demographic factors such as age, autonomy and self efficacy. Research exploring the impact of socioeconomic status was inconclusive, with wealth predicting higher SWB only in less economically developed countries (Ryan & Deci, 2001).

Several studies have sought to identify the factors which specifically contribute to the SWB of people with an intellectual disability, reporting a range of variables including dignity, work, relationships, socio-economic status, social support, marital

status, self-esteem and self-determination (Emerson & Hatton, 2008; Bramston, Chipuer & Pretty, 2005; Schalock et al., 2000; Matikka, 1996).

One variable which has received considerable attention in intellectual disability research is 'relationships' (Cummins & Lau, 2004; Bramston, et al 2005). Miller and Chan (2008) sought to identify the predictors of SWB in a sample of 56 people with an intellectual disability by examining the contribution of life skills (such as interpersonal and leisure skills) and 'higher order' variables such as social support and self-determination. When combined, the variables predicted 44% of the variance in SWB, with both social support and interpersonal skills individually associated with SWB. The authors concluded that both 'the quantity and quality of interpersonal interactions, in particular, greatly contribute to the amount of satisfaction reported by participants' (Miller et al., 2005. p 1044). Emerson and Hatton (2008) also reported a significant positive relationship between SWB and the frequency of contact with friends who also have an intellectual disability.

Another variable that has been an increasing focus of SWB research is employment. In a review of the literature, Jahoda, Kemp, Riddell and Banks (2008) identified six studies that directly explored the impact of employment on SWB. Results indicated that people with an intellectual disability in employment reported lower levels of depression, higher overall life satisfaction and higher self-esteem than unemployed comparison groups. Two subsequent studies also indicated a positive correlation between SWB and the level of independence experienced by

the individual at the workplace (Kober & Eggleton, 2005; Bayer, Brown, Akandi & Rapley, 2010).

The importance of 'work' was also demonstrated by Schalock, Bonham and Marchand (2000) in a sample of 237 people with an intellectual disability. Path analysis was utilised to produce a model with 'life satisfaction' as the dependant variable. 'Dignity' and 'work' positively contributed directly to life satisfaction, with dignity having the greatest impact in accounting for 27% of the variance. Independence and community integration also affected life satisfaction through their impact on dignity and work. Availability of transport also impacted on life satisfaction through its effect on community integration.

It is of note that many of the aforementioned studies were correlational in design, meaning that assumptions of causality cannot be made. For example, all of the studies included in the review by Jahoda et al (2008) utilised this design, leading the authors to conclude that 'the differences in well-being may well reflect differences in participant characteristics' which may in turn make it more likely they would gain employment (Jahoda et al., 2008).

Other methodological weaknesses also exist in this area of research which potentially impact upon the reliability and validity of results. This includes the construct validity of SWB, which was threatened by the disparate definitions and measures used. Studies also relied upon convenience samples that were often

insufficient in size, few employed a measure of intellectual disability, and groups were rarely matched in terms of demographic characteristics. It is also of note that studies have only been able to account for 27-44% of the variance in SWB, suggesting the potential role of variables yet to be identified.

Though qualitative methodology is often used to explore areas where research is sparse, or to explore theories or hypotheses from the perspective of participants (Camfield, Crivello & Woodhead, 2009), only two studies were identified that utilised mixed-methodology. Van Puyenbroeck and Maes (2009) considered the effect of a reminiscence group on the SWB of 41 older adults with an intellectual disability, supplementing data derived from SWB measures with structured interviews carried out with the participant's support workers. Though the measures indicated no change in SWB as a result of the intervention, interview data identified the positive impact of social contact, social cohesion as a group and being part of a meaningful activity. Though it is unclear whether staff members are able to reliably document changes in respondent's mood (Cummins, 2002a), the authors concluded that some of the more subtle gains in SWB may not be reflected by questionnaires which document satisfaction with broad life domains.

Banks, Jahodav, Dagnan, Kemp and Williams (2010) also utilised mixed-methods research to explore the impact of employment breakdown on the SWB of a group of 49 people with an intellectual disability, as measured by the Comprehensive Quality of Life Scale (ComQoL; Cummins, 1993b) and semi-structured interviews.

Of the original sample, 13 experienced employment breakdown during the 12 month research period. As with the study by Van Puyenbroeck and Maes (2009), SWB scores did not demonstrate significant changes. However, data derived from qualitative interviews indicated the negative impact of job loss and the importance placed on employment by the participants. As such, the authors also queried the sensitivity of SWB measures

The SWB of people with an intellectual disability is becoming an increasing focus of research; however there is some way to go before conclusions can be drawn. Researchers should seek to replicate findings using larger, randomised samples, and SWB measures which are valid and reliable. There is also a need for further research which utilises robust qualitative methodology to explore the experiences and perspective of people with an intellectual disability. These results should be used to inform the further development of SWB scales, and gauge to what extent people with an intellectual disability are able to talk about the factors which contribute to their SWB.

1.4 SWB and Participatory Research

The concept of SWB in research has historically stemmed from sociological explorations of the wellbeing of nations or communities and the evaluation of social policies and practices (Cummins, Lau, Mellor and Stoke, 2009). Camfield, Crivello and Woodhead (2009) presented a review of research conducted in developing countries and highlighted the importance of 'capturing local perspectives and

standards' to both define and subsequently measure wellbeing. They suggest utilising qualitative and quantitative methods to provide a 'rich description' of wellbeing and generate further areas for research. Camfield et al (2009) also suggest the utility of employing 'peer analysts' to approach the concept of wellbeing from within the community, thus increasing participation and diminishing the historical power imbalance between the researcher and the 'researched upon' (p. 29).

Participatory research has become a priority in the area of intellectual disabilities; a development that has been driven in part by people with an intellectual disability themselves who have voiced their wish to be more included in the research that is 'done about them' (Aspis, 2000). This may reflect a wider cultural shift toward greater 'service-user involvement' in research and service evaluation (Thornicroft & Tansella, 2005). As such, people with an intellectual disability are playing increasingly active parts in every part of the research process (Bjornsdottir & Svendsdottir, 2008).

1.3 Study Aims

This inclusive research project aims to bring together researchers with a variety of skills and experiences to explore the perspectives of adults with an intellectual disability who report high SWB. It is hoped that qualitative exploration of the factors that contribute to participants' SWB will add to the existing research base and

provide a useful tool for policy-makers and service-providers who aim to maximise the SWB of their service users.

2 Method

2.1 Ethical Approval

Ethical approval was granted by Barnsley Heath and Social Care Research and Development Alliance (see Appendix 3).

2.2.1 The Research team

The research team comprised of eight people: a trainee Clinical Psychologist from the University of Sheffield who will be known as the 'non-disabled researcher' in line with the literature on inclusive research (Walmsley, 2004), four individuals who identify themselves as having an intellectual disability, two Clinical Psychologists working in community services for people with an intellectual disability and a Clinical Psychologist with a special interest in inclusive research. The data was gathered and analysed by the non-disabled researcher and the four researchers with an intellectual disability who will now be collectively referred to as the 'research group' for clarity. The role of the wider research team members was to guide the design and implementation of the research project and provide consultancy about the process of inclusive research.

The researchers with an intellectual disability were recruited from the community learning centre in Sheffield, 'S3 Allcomers'. Three of the researchers were

previously known to the non-disabled researcher; one had taken part in research projects before and another had substantial audit experience. It was stressed from the outset that this project would form part of a thesis for submission, and would be written up by the non-disabled researcher as candidate for qualification. However, it was agreed that the research group would be fully involved in anything written for publication and that the final report would be written in an accessible format which would be accompanied by a film to ensure accessibility for those unable to read.

It is acknowledged that the role of the non-disabled researcher in participatory research can sometimes be unclear and that no specific guidelines or precedent exists. This lack of clarity can hide the contribution of both the researchers with and without an intellectual disability (Walmsley, 2004). This project sought to address this by ensuring the role of the non-disabled researcher was negotiated and made clear. It was agreed that the non-disabled researcher would bring a set of skills to the project which facilitated the other members to use and contribute their skills. These included summarising and making accessible the relevant literature around SWB, attending to the practical aspects of data collection (such as location, taping and transcribing), providing training on research methods and contributing to the gathering and analysis of the data. It was acknowledged at the outset that many aspects of the research would need to be negotiated throughout the project to maintain a sense of shared ownership and this was documented in meeting minutes to ensure transparency in the decision making process. The non-disabled

researcher sought regular supervision from a Clinical Psychologist with a special interest in inclusive research to facilitate reflection on the research process.

The research group met on five occasions prior to data collection. These sessions allowed an exploration of the important components of research including ethics, confidentiality, consent and preparation for data collection. The structure of these meetings loosely followed those set out in the Burton Street Research Group paper 'Including Everyone in Research' (Abell et al., 2007). All members of the research group were involved in planning data collection, which included compiling an interview schedule based on a negotiated understanding of SWB. The research group also met regularly to review progress, and for de-briefing following data collection.

2.2.2. Researcher's Perspective

The non-disabled researcher's interest in exploring this subject stemmed from experiences gained as a support worker, teacher, service development worker, researcher and more recently assistant and trainee psychologist working with people with an intellectual disability. This generated an interest in the experience of people with an intellectual disability, with a specific focus on SWB and inclusive research. This project is not the non-disabled researcher's first experience of participatory research using qualitative methodology and it is partly the positive experiences of this in the past, as well as the political and moral agenda of

increasing the profile of people with an intellectual disability in research, that guided the design of this project.

The perspective of the co-researchers stemmed from their experiences as adults with an intellectual disability, and from the various roles they had occupied which included researcher, auditor, service-user, service planning informer, advocate and campaigner. The perspective of the research group as a whole was therefore that people with an intellectual disability can provide useful accounts of their lives which should be explored using qualitative methods, including researchers with an intellectual disability at every stage of the research process.

Great care was also taken to identify the apriori assumptions about the factors that contribute to the SWB of people with an intellectual disability which may have arisen from these experiences. Several variables were identified at the outset, which included meaningful activities, friends, relationships, a good home, health and finance. Attention was paid to these assumptions throughout the research, and quality control measures were introduced to maximise the 'permeability' and quality of results (Stiles, 2003).

2.3 Participants

Twenty-three participants were recruited from a variety of day-service provisions for people with an intellectual disability in Barnsley. All five services that were approached agreed to participate. Fourteen participants were recruited from three

day centres run by Barnsley Social Services, five from an independent advocacy project and four from an inclusive community training project. These services were chosen to represent a cross-section of the typical day provisions available to people with an intellectual disability in the region. This sample size was chosen as it provided enough data to gain an insight into the participants views and experiences, without being so large it made qualitative analysis unfeasible (Braun & Clarke, 2006).

2.3.1 Demographic Information

All participants were adults with a mild-moderate intellectual disability aged 23-67 with a mean age of 38 (m=52%, f=48%). All participants were white British, which reflects the predominantly white British demographics of people with an intellectual disability in Barnsley¹. Twenty-six percent of participants lived at home with their parents, 35% lived in a residential care home and the remainder lived in supported living accommodation. Participants were deemed able to participate if they possessed a basic level of communication and were able to give informed consent.

2.4 Sampling and Consent

Researchers initially contacted the manager of the service to explain the study and seek consent to visit. Researchers then attended the service to give a short explanation of the study (including an explanation of SWB) and answer any initial questions that arose. Participants who identified themselves as happy and satisfied

¹ 98.4%. Information provided by Information Services, Barnsley Metropolitan Borough Council. Correct July 2011.

with their lives were then purposefully selected in line with qualitative methodology (Barker, Pistrang & Elliott, 2002). Information sheets were distributed (see Appendix 4) and fully explored with potential participants. All participants that initially identified themselves agreed to take part.

All information necessary for informed consent was presented in an accessible manner appropriate to the person's level of communication. This was facilitated by a staff member that knew the person well where appropriate. In order to have capacity to consent, the participant must be able to understand and retain the information given to them long enough to make a decision, use the information in the decision making process and communicate their decision (Mental Capacity Act, 2005).

Participants were given all relevant information in the manner described above and were then asked to outline the main aims of the research to the researchers, and state the pros and cons of participating. Participants then communicated their decision and completed a consent form (see Appendix 5). All participants were able to engage with this process and gave informed consent.

2.5 Procedure

2.5.1 Qualitative Interviews

Participants were interviewed by the research group in an appropriate room at the service they attended. Interviews followed a semi-structured format with

researchers each asking a question from the interview schedule (see Appendix 8), which was then followed up by supplementary questions to clarify or further explore answers. Participants were asked open-ended questions to enable the exploration of 'complex experiences' (Barker et al., 2002) and allow participants to be active in shaping and guiding the interview process.

The full process was piloted with two participants to identify any issues in the research process. One change was made to the interview schedule as the item 'what does happiness mean to you?' was deemed too abstract by the research group and was therefore replaced with 'what things do you need to have a good life?' The data from the pilot interviews was included in the final analysis as it was not felt that this question prevented participants from giving rich accounts of their lives.

Interviews lasted between 20-35 minutes and explored:

- How participants felt about their lives
- The things that are important to them or contribute to them feeling happy and satisfied with their lives
- What happens when they are not happy or wish to change something
- Anything they would like to change, including wishes for the future

Four individuals asked to be interviewed with their romantic partner, as they felt their SWB was impacted significantly by the relationship and wished to describe their experiences together. As such two interviews were held with couples rather than individuals.

2.5.2 SWB measure

A number of studies have indicated that people with an intellectual disability may demonstrate higher levels of acquiescence and suggestibility than observed in the general population, and may therefore have falsely identified themselves as happy and satisfied with their lives (Perlman, Ericson, Esses and Isaacs, 1994; Finlay & Lyons, 2001). As such, participants were facilitated to complete the Personal Wellbeing Index-Intellectual Disability (PWI-ID 3rd Edition; McGillivray, Lau, Cummins and Davey, 2009) following their interview (see Appendix 6). This scale measures satisfaction with seven life domains and includes measures of acquiescence and 'response scale competence' to ensure participants are able to give meaningful data. Reduced choice formats (5-, 3- and 2-point scales) are available for those not able to utilise the 11-point scale, though this has not been shown to affect the score obtained (McGillivray et al., 2009). The PWI-ID generates an overall wellbeing score from 0-100.

McGillivray et al (2009) administered the PWI-LD to 114 people with an intellectual disability and found an average overall wellbeing score of 77. As such, only participants who scored 77 or higher were included in the analysis to ensure

homogeneity of the sample in line with qualitative methodology (Barker et al., 2002).

McGillivray et al (2009) demonstrated a Cronbach alpha coefficient of 0.76 which shows acceptable internal reliability. However, when the scale was repeated with 31 participants it only demonstrated a test-retest coefficient of 0.58. This measure was deemed suitable for this study as it was used to corroborate qualitative data and provides a useful measure of acquiescence.

3 Analysis

One participant was excluded due to scoring below the threshold of 77 on the SWB measure and two participants were excluded as they terminated the interview before the SWB measure could be completed. No participants were excluded due to failing the test of acquiescence. As such data from 20 participants were included in analysis. Participants scored between 77-100 on the PWI-ID, with a mean score of 88.

3.1 Thematic Analysis

The data was transcribed verbatim immediately following the interviews by the non-disabled researcher. This facilitated 'immersion in the data' (Barker et al., 2002. pg 222), and timeliness also ensured that data provided by participants with communication difficulties, including speech impediments, was not subject to unnecessary loss due to difficulties in deciphering dialogue from tape recordings.

Thematic analysis (TA) was utilised due to its flexibility in both underlying epistemology and practical implementation (Braun & Clarke, 2006). The use of TA over other qualitative methods derives from its utility in generating topics for future research and exploring existing hypotheses (such as the Theory of Well-Being Homeostasis; Cummins, 2002a) from the perspective of participants, (Boyatzis, 1998; Camfield, Crivello and Woodhead, 2009). It is also of note that the epistemological underpinning and conceptual paradigm of TA was possibly more accessible to the co-researchers with an intellectual disability than more abstract, constructionist approaches such as Interpretative Phenomenological Analysis (Smith, Jarman & Osborn, 1999); however this was not the primary justification for its use.

This research aimed to report the 'reality' described by participants, and analysis was subsequently undertaken from a realist epistemological position (Braun & Clarke, 2006) which seeks to reflect 'reality' rather than to 'unpick or unravel' it. As such, this research utilised a semantic, data-driven approach which sought to identify, describe and interpret themes directly from the data.

The research group met prior to analysis to explore and plan the process of TA. It was agreed that the analysis would be completed by all members of the research group using the stages outlined in Braun and Clarke (2006). Researchers met

following each set of interviews to record initial reactions to the data and any points of interest. Once the data was transcribed the research group met and read through the entire dataset aloud, discussing and noting initial patterns in the data. Each interview was then systematically re-read and each piece of data was coded under a corresponding heading on flip chart paper. Codes comprised 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way' (Boyatzis, 1998 in Braun & Clarke, 2006, p88). New codes were added until all the data was accounted for, which resulted in 52 codes. The codes and corresponding data extracts were then typed up and cut out to allow researchers to physically experiment with placing them together to form broader 'themes'. This included the formation of super-ordinate, master and sub-ordinate themes. Consensus on the placement of codes within broader themes was reached within the research group and any disparities were negotiated. The extracts under each of the themes were considered to ensure they formed a 'coherent pattern' (Braun & Clarke, pg 89) and the resulting themes were then examined for internal homogeneity and external heterogeneity. An example of this process is given in Appendix 9. The entire dataset was then re-read by the non-disabled researcher to ensure the 'fit' of the themes. This was the only part of analysis not carried out as a group due to the time constraints related to reading the entire dataset aloud, and was negotiated with all group members.

3.2 Quality Control

Additional quality control measures were introduced to maximise the quality and 'permeability' of the results of this study, as suggested by Stiles (2003). The data was analysed in such a way as to allow for 'iteration'- a cyclical process by which interpretations or potential themes were constantly revisited and reworked with specific reference to the data. Consensus on the emergent themes was reached within the research group, and any disparities fully explored and negotiated. Themes were fed back to four of the participants by way of a feedback group to check for 'fit' and 'testimonial validity' (Stiles, 2003. pg 489) and were positively responded to. An audit trail of the origins of themes in the data was kept, which was audited by a peer researcher to check the 'fit' between data and the themes identified by the research team. The themes were then reconsidered in light of the feedback. Attendance at a qualitative research group of peers by the non-disabled researcher facilitated ongoing reflections on data collection and analysis which was also fed back to the research group for further consideration.

In addition to these quality control measures, the results are written in such a manner to reflect the narrative of as many participants as possible and 'ground' the themes in the data (Stiles, 2003. pg 485). Each theme is linked to the text and examples given to allow the reader to examine the relationships between the themes and the data.

4 Results

Three super-ordinate themes were identified from the data. Participants described 'environmental factors' that contributed to their SWB, and factors which 'enabled or disabled' them in maintaining high levels of SWB. Participants also described 'personal characteristics' that impacted upon their SWB. These themes are illustrated in Table 1, along with the corresponding master and sub-themes. The names of places or people have been replaced to ensure anonymity and the dialogue of the researchers are written in italics for clarity.

4.1 Environmental factors

Participants described a number of factors that they felt were important to their SWB. These were labelled 'environmental factors' in line with the current terminology used in the SWB literature, and to reflect their location in the environment in which participants operated.

Thematic Level	Theme 1	Theme 2	Theme 3
Super-ordinate	1 Environmental factors	2 Enabling or disabling	3 Personal characteristics
Master Themes	1.1 Choice & independence 1.2 Activities 1.3 Valuable roles 1.4 Relationships	2.1 Staff 2.2 Family 2.3 Boundaries and limitations	3.1 It's how you view life 3.2 Managing difficult emotions
Sub-themes	1.1.1 Where and you live with 1.1.2 'It's my way'- how you live 1.1.3 Managing difficult emotions 1.1.4 Hopes of independence 1.2.1 Self-directed activities in the home 1.2.2 'Somewhere to go and someone to go with' 1.3.1 Roles inside the home 1.3.2 Roles outside the home 1.3.3 Working towards paid employment 1.4.1 Friends 1.4.2 Belonging- friends & family 1.4.3 Intimacy and support 1.4.4 Relationships with staff	1.1.1 Gatekeeping 1.1.2 Trouble-shooting 1.1.3 Support & Care 2.2.1 Gatekeeping 2.2.2 Support & Care 2.2.3 Belonging 2.3.1 Transport 2.3.2 Finances 2.3.3 Disability	3.1.1 Acceptance & contentment 3.1.2 'Looking on the bright side' 3.1.3 Determination

Table 1: Structure of Themes

4.1.1 Choice and Independence

The theme of 'choice and independence' describes the importance placed by participants on having a life that reflects their preferences regarding where and who they live with, how they live, how they spend their spare time and how they manage difficult situations when they arise. Some participants also talked about hoping for a greater level of independence, and the skills they would like to gain to facilitate this.

Several participants described the importance of being able to choose where they live and who they live with. Helen described choosing to move out of the family home to live with friends and goes on to describe how moving closer to friends has made her 'so happy':

H: erm, last Monday I moved into a house with three other people who go to college

A: *and are you friends with them or...?*

H: yep

A: *oh, that's great, so is that something that you wanted to do?*

H: ... yes

A: *and did you choose where you live?*

H: yes

A: *and was it important to you to be able to choose where you live or...*

H: ...yes, really important

Helen outlines the important role of both her parents and her key worker in facilitating the move, introducing the important 'enabling or disabling' role of others in listening and acting on the wishes of participants. Other participants also described choosing to move out of the family home, but talked about the tension between wanting to live independently and 'do what I want', but also missing their family.

M: (pause) um, cause I've moved out from my Mum...I can do what I want

A: *So who are you living with now?*
M: Gemma
A: *And she's another...is she a friend, or..*
M: She's a housemate..but she can be a bit..bossy
A: *she can be a bit bossy?*
M: (laughs) yeah!
A: *....so moving out and not living with your Mum anymore, is that something that..*
M: it, what it is is that it upsets me when Gemma mentions about her family...it like, it gets to me.. cause I miss me Mum..
A: *So it feels like there's two things there..on the one hand it's good because you can do what you want, but on the other hand it's a bit difficult because you don't see your family as much?*
M: Yeah (emphatically) yeah
A: *Is that right?*
M: Yeah

Though Helen and Stacey had made a choice about wanting to move out of the family home, other participants also described moving into supported living following the death of their parents, and the importance of having a choice about where and who they lived with following this difficult life event.

D: *Can you tell us about the things that are important to you in your life?*
R: I live at Welsley
D: *Welsley. Is that your environment... living?*
R: Yes...
D: *right, any other questions on that, anybody?*
A: *How long have you lived there?*
R: My dad and my mum have both died. So I decided to move to Welsley
S: *Is that like a group home, is it?*
R: Well, it's supported living
A: *supported living.. and how do you feel about living there?*
R: It's alright.. yeah, we've got good staff
A: *Good*
R: I live with my two mates (names)
A: *And how did you decide to move there?*
R: erm.. me social worker...she took me round different places and I said where I wanted to live
A: *and was it important to be able to choose where you live?*
R: yeah.. cause like, it's a good home

In addition to where and who participants lived with, participants also described the positive impact of being able to make choices about *how* you live. Paul lives in supported living accommodation, and talked about the importance of quietness and time alone:

S: P, how do you feel about your life?
P: It's quiet
S: Is it quiet?
P: It's my way!
A: And is it a good thing that it's quiet?
P: Yes

Paul also talked about the importance of being able to have quietness at the day service he attended:

A: anything else that makes you happy with your life?
P: Coming to work
A: Coming to work, and is that here that you come to?
P: Yeah
A: And what is it about coming to work that makes you happy?
P: I come in taxis
A: You come in taxi. Do you come by yourself?
P: Yes
A: And is that important?
P: Yeah
D: And what's it like here?
P: it's quiet.
A: so is quietness important to you?
P: yeah
A: and going in a taxi? Going in a taxi by yourself is important...
P: yep
A: and why is that important?
P: cause I'm on me own
A: cause you're on your own.. is that.. is that cause you like to do things on your own?
P: yep
A: and are you able to do lots of things on your own?
P: yep... independent
A: and is independence important?
P: yeah
A: and how does it make you feel to have independence?
P: quiet.. I lock t'door
A: you lock the door and you get a bit of quiet
P: I do

Paul describes a way of life that reflects the importance he places on quietness and time alone. Other participants also talked about having a lifestyle that reflects their personal choices and preferences, and the positive impact of this on SWB. Luke described the calming effect of being able to come home from his day centre and spend time in his room:

L: at home..it's alright at home..I can do what I want at home, I can get me shoes off..me coat off...and I can go to me room there..I can play on me playstation..
A: have you got quite a lot of freedom at home..
L: yeah..
A: and is that important?
L: yeah...because I've come here all day and I get in...like somebody, where somebody keeps shouting and then I get in and I'm calm
A: so when you've been here all day and it's been busy and noisy then it's nice to get home and be able to do whatever you like?
L: yeah

Several participants described the importance of making choices about how they managed difficult emotions. The most frequent example was choosing what happened following the death of someone important, which included family members and friends. Karen talked about the positive impact of attending the funeral of her Nan, with whom she was very close, and went on to talk about the importance of being able to make choices without feeling pressure from others:

A: and was there anything that helped you grieve?
K: erm.. yeah, erm.. something that helped me grieve was to actually go there to the funeral
A: right, and did someone support you to go to the funeral?
K: yeah, my.. because it's it's my Mum's Mother in law, so I went to her funeral and .. erm, she helped me cause I used to go there every weekend er, and do things with her sort of thing.. so that was something that really made me grieve.. cause it were, you know.. but it was also something that made me happy because I was able to go to the funeral and say how it made me feel in the end
C: were you able to make a choice about whether you went to the funeral or not?
K: yes

Karen moved on to describe the importance of choice in how she expresses emotions following difficult events:

A: okay, so when things are bad and things that, you know. make you feel sad happen.. it's good to make choices about how you deal with that?
K: express.. express it.. yeah, yeah
A: brilliant

Unlike Karen, Richard described the importance of being able to decline an invitation to his Nan's funeral, which he felt would be too upsetting for him:

R: I were, I were invited and they asked me...to invite me to me own Nan's funeral but I said 'no' cause it were too upsetting for me
A: *so was it important to be able to make a choice?*
R: yes it is
A: *so is it important to be able to make choices about what you can do and what you don't want to do?*
R: yeah

Both participants describe making active choices about managing their emotions following the death of someone important to them, describing the positive impact of their wishes being upheld.

Many of the participants talked about areas of their lives where they would like to move towards greater independence, which often involved greater separation from parents and greater freedom. One of these areas was wanting to go on holiday with peers, rather than with parents. Several participants talked about holidays they had been on with peers and the experience of greater freedom to stay out late and drink alcohol. Margaret lives with her parents, but has had experience of going on holiday with a local advocacy project:

A: *and is there any other wishes that you have*
Ma: to go back to being abroad again, because I aint been able to go abroad because of me.. having me operations and everything so I'd like to do that.. but, but also I'd like to have in place where we go on holiday with 'MA', erm.. independently sort of things, but like in a group that's our age sort o' thing instead of going with our parents, you know what I mean.. so...
A: *right, and have you.. is that what's happened before, you've gone with your parents..*
Ma ...yeah, yeah
A: *and it's not quite the same?*
M: yeah
A: *so why is it important for you to go with people the same age as you?*
Ma: well, I've been on.. I've been on holiday before with people me own age, but with support workers instead of me Mum and Dad, now that's something I'd like to change.. to go with support workers rather then, rather than me Mum and Dad
A: *and what is different if you go with support workers instead of your Mum and Dad?*
Ma: I'd have, I'd have a bit more freedom sort o' thing...
A: *yeah*
Ma: so..

A: you'd be able to do some things that you can't do with your Mum and Dad?

Ma: yeah

A: and what sort of things would you be able to do if you went with support workers, that would be different?

Ma: I'd be able to stay out late

Participants also described the 'boundaries' which they experience as preventing them from going on holiday independently, which they identified as availability of staff and adequate finance. These will be further explored in subsequent sections.

In addition to going on holidays, participants also described hopes of developing skills that would allow greater independence such as cooking, cleaning and making hot drinks. Participants described being supported to do this by staff at home or at the day service they accessed, or by family members.

4.1.2 Activities

Many participants described the importance of having a range of self-directed activities they could access whilst at home. These activities were described as serving several functions which included relieving boredom, allowing a person to relax after a difficult day and providing recreation and leisure. Activities included puzzles and jigsaws, computer games, listening to music and watching DVDs and could be accessed with out the support of others. Kyle talked about the range of things he enjoyed doing at home:

M: can you tell us about the things that are important to you in your life?

Ky: I like doing me jigsaws.. and do me sticker books and (undecipherable)

A: and where do you do that?

Ky: at home

A: so do you have quite a lot to do at home?

Ky: yeah

A: and is that important to you?

Ky: yeah

A: *and do you do things like jigsaws by yourself, or with other people?*
 Ky: I do it on me own..
 A: *so is there anything else in your life that you feel is important to you?*
 Ky: I play all me DVDs, me CDs and listen to me rock DVDs to watch...and't radio
 A: *and do you watch them at home?*
 Ky: yeah
 A: *and can you put them on whenever you like?*
 Ky: yeah
 A: *have you got a TV of your own?*
 Ky: I've got two
 A: *wow!*
 Ky: I've got one for me DVDs and one for me videos

The importance of having leisure activities outside the home was described by all participants, and many stressed the central role of these activities in facilitating relationships with friends, romantic partners and staff. These activities included day service provision, community based activities and holidays. Stacey describes the importance of attending afternoon drop-ins and evening activities at a local advocacy project and the opportunity to make friends, get to know people and meet her boyfriend:

A: *can I ask where you met your boyfriend?*
 S: yeah, I met him in a project called 'name', and we.. me and J are both in 'name' anyway so...
 A:.. *so you met him there?*
 S: yes
 A: *so going to these places, and why is that important?*
 S: because I like making friends and doing things with other people and, you know getting close with people and having a.. having a general chat... sort of thing
 D: *right, over to me S. What things do you need to have a good life? To do all them things...*
 S: somewhere to go.. somewhere to go and somebody to go with

In addition to activities specifically set up for people with an intellectual disability, many participants talked about the importance of accessing hobbies and activities in the community. One of the most frequently described activities was football, with specific reference to supporting a particular team. Once again this was also linked with family and friends who supported the same team. Ron talks about the

importance of football and the friend he made through attending, and then moves on to talk about having attended matches with his Granddad:

A: it sounds like you've been a supporter a long time?
Ro: yeah..cause I go me season ticket
A: ah, so you've got a season ticket? Lucky you! And do you know people there..do you know people at the matches?
Ro: Only know Sarah
M: and who's Sarah?
Ro: my friend (2)
M: she's your friend..and did you meet her at football?
Ro: Yeah...cause...cause she sit at the front
A: so you sit with Sarah?
Ro: yeah, I sit at that side (gestures) and then Sarah sit at...other side

A: What about football..why is football important to you?
Ro: cause...because....cause..you know erm..me Granddad, he used to take me...a long time ago..that's why I wanted to go
A: so your Granddad took you and it became important for you to go...
Ro: yeah
A: Did your Granddad support Barnsley..
Ro: ...yeah...but he's died now..he's passed away
A: Oh..I'm sorry to hear that...(4)

Participants described a range of activities in the community including going shopping with staff, family or friends, playing pool, going for a coffee and going to bingo, and linked these with facilitating the important relationships in their lives. Jane also linked activities outside the home with maintaining a positive mood following the death of members of her family:

M: can you tell us about the things that are important to you in your life?
J: going er, going and mixing we people..er..going to Rainbow centre for me dinner on a Tuesday and a Friday..art class in't afternoon er Wednesday, and then if they have theme nights.. if there's any theme nights at (undecipherable name) Hall.. and then community centre for coffee mornings on a Friday since they closed (undecipherable name) chapel down, they literally kicked us out
A: oh dear
J: er..going to Barnsley on a Saturday, looking round 'shops and buying stuff, going walking we John on a Monday, going to Sheffield and Doncaster and Barnsley and we've been to Leeds and Wakefield as well... and I like watching Tudors on't television, and I like going and visiting old churches and old houses.. and going on bus trips..I've been as far as Glouster on't bus for day
A: so it sounds like you do a lot of things during the day..you're quite active
J: yeah
A: so why are these things important to you?

J: well, when you're in't house on your own you can get feeling down and er..when you've lost you're family an that, you know, and you've lost your little dog you used to have

M: how old is your little dog

J: well, she were only five when she died

M: ahhh

A: that's a shame

J: yeah

A: so does it improves your mood, seeing people and getting out and about?

J: yeah it does, stops you feeling down

4.1.3 Valuable Roles

Many of the participants described the importance of having roles both in and outside of the home that were valuable to them and to others. These included practical tasks around the home or at the day centre, volunteering roles, paid roles, speaking to advocacy groups and training professionals. Participants described these roles in relation to being able to do something they are good at, being important to others and the positive impact of this on their self-esteem: Brian talks about the importance of having friends and his role as president of the student forum at day centre:

A: so having friends here, that's important to you

B: and they are important to me

A: they are important to you...

B: They're all important to me

A: and it sounds like you're important to them as well

B: yeah, I am.. cause I'm the director of the forum of this place

A: what do you do sorry?

B: I'm director of the student forum here

A: so you have a job that you do here?

B: yeah

A: and how do you feel about that?

B: brilliant

A: brilliant

B: cause I'm a good writer, like...

D: ..yeah

B: yeah

A: so doing things that you're good at, is that important?

B: yeah, yeah

Participants described the importance of having personal roles in the home which related to domestic tasks such as cooking, cleaning and gardening. Paul talks about his role of taking out the wheelie bin each week:

A: So, Is there anything else that seems important that makes you happy with your life?
P: Wheelie bin
A: Say that again, sorry?
P: Wheelie bin
C: Wheelie bin
A: Wheelie bin! The wheelie bin makes you happy with your life.. and what makes you happy about that?
P: I put it out
A: You put it out.. so, is that a job that you do?
P: I do
A: you do... and is that important then, having jobs that are yours, jobs that you do?
P: Yeah

Richard talked about being able to cook dinners for his housemates:

S: R, How do you feel about your life?
R: erm.. in my life I can do lots of things
S: like what?
R: like cleaning, tidy up, make tea when I go home.. and I cook and play music and I start singing along when I'm cooking
S: yeah.. what do you cook?
R: I cook for Ryan and Lee sometimes...I make lots of things
A: and are you able to do these things by yourself?
R: staffs help me
A: staff help you.. and how does it feel being able to do the cooking
R: it makes me feel happy
A: it makes you feel happy?
R yeah

Some participants talked about the importance of being able to help others, or make others happy. Jane discussed the volunteering she does at a local children's hospice:

A: so it sounds like you do a lot of things during the day..you're quite active
J: I like to help people..children from hospice, you know Hospice shop in Doncaster..Sunshine Place
A: and do you help there..what do you do there?
J: well I just crochet blankets and I give em to (indecipherable)
A: ahh, and what's good about Sunshine Place..about doing the crocheting, why is that important?
J: because, because there's terminally ill children there, and a lot of em never come out
A: so is that about helping them?

J: yeah,
A: *you feel good about being able to help them?*
J: yeah (2)

Many participants also described the positive impact of paid employment on their mood and self-confidence. Some participants were not currently in paid employment but were either working towards securing a job, or were hopeful they would be able to get a job in the future. The main reasons for wanting to work were to increase income, meet other people and get out of the house more. Stephan described his plans to gain employment in an office:

St: I'm trying to get a new.. like a job.. but its, it's end of this year I'll look for one.. but I know where it is
A: *and is it important to you to have a job?*
St: ah, cause I've never had one before
A: *and what would be different if you had a job?*
St: I like a filing job
A: *filing?*
St: Yeah, like going in't office and that
A: *and how would it feel if you had a job and you were able to do that?*
St: great
A: *great.. and what would be different in your life if you had a job?*
St: be more things in me life cause I ain't been going out more time.. you know, like going to different places

Participants talked about the people in their lives that could help them achieve this which included staff at home or day centres, family members and employment consultants. Some participants talked about roles they would like to occupy which included office or bar work.

4.1.4 Relationships

All participants described the important relationships in their lives which included romantic relationships, friends, family and staff. These relationships served many

functions which include providing intimacy, a sense of belonging, support, care, laughter and fun.

Participants described the importance of friendships, which often included the people they lived with as well as people they met outside the home. Luke discussed the importance of his relationships with his friends at the day centre and at home, and the positive impact on his mood:

D: I'll say it again.. what things do you need to have a good life?

L: er.. I can't, err.. just friends and good relationships and..

D: good relationships?

L: yeah

A: and do you have good friends?

L: yeah, I got some of me friends 'ere and some of me friends where I live

A: and why do you need friends.. what's good about having friends?

L: it's better be happy than miserable

A: so having friends makes you happier?

L: yeah

This was echoed in many of the interviews with participants describing the importance of having friends that 'are always there for me'. All friendship and romantic relationships described by the participants were formed with other people with an intellectual disability, which fostered a sense of belonging. For example Kyle talks about having friends that are 't'same as me':

D: right, on to me. What things do you need to have a good life?

Ky: well, I've got good mates... good friends

D: good friends?

Ky: and they're brilliant in my life... they've always been there for me and all that

A: and why is that important?

Ky: cause it is

A: cause it is

Ky: I love it that way, there t'same as me

Participants also described the importance of belonging to their family. Greg talks about the importance of his family who have the same name as him:

A: *so what else is important, what things are important in your life?*
G: me family
A: *your family, right*
G: they come next
A: *they come next*
G: yeah
A: *and who's in your family?*
G: about...all o' family that I know
A: *so have you got quite a big family?*
G: yeah
A: *and do you see them very often?*
G: yeah
A: *and that's important?*
G: yeah
A: *and why is that important to you?*
G: cause I come from t'same.... same name as me, they come from the 'C' family
A: *so they have the same name as you... and do you feel like you belong with them?*
G: yeah I do

Romantic relationships were also described as important, with a greater focus on intimacy and closeness. Karen describes the important role of her boyfriend in providing support and someone to talk to privately:

A: *and what's good about having a boyfriend, how does that make you happy?*
K: erm, it makes me feel like I've got somebody close to me and..
S: *someone to go out with*
K: someone I can go out with and someone I can talk privately to if you know what I mean.. confidentially
S: *mmm*
K: things like that

Greater closeness and intimacy were also something that some participants talked about wanting in their lives, either through making a 'best friend' or through developing a romantic relationship with someone.

Participants talked about the strong relationships they built with the staff that supported them both at home and at day centres and other activities. These relationships served several functions which will be further explored in subsequent sections, but were also talked about in terms of providing social contact, laughter

and fun. Some participants also described the loss of relationships following the closure of services or staff leaving employment, and the negative impact of this. Peter describes losing a relationship with a staff member following the demolition of a day service he attended:

A: They're going to knock it down, is that right?

Pe: Yep. Knocking it down.

A: Oh, no. And how does that feel?

Pe: I play snooker with Andrew.. he's left me

A: You play snooker with...?

Pe: Andrew

A: And who is Andrew?

Pe: A torment!

A: He's a torment! And is Andrew a member of staff or is he a friend?

Pe: Staff

A: He's a staff. And where does he work?

Pe: Bayfield.. I don't go there now, I come here

A: Right, So you used to go to that place but you come here now

Pe: Yes.

A: So when you moved from there you lost the staff that you used to see, so you lost Andrew?

Pe: Yes

4.2 Enabling or Disabling

Several factors were described by participants as 'enabling' or 'disabling'. This refers to factors which impact indirectly on SWB by 'enabling or disabling' access to the environmental factors previously described, or directly by 'enabling' participants to maintain high levels of SWB despite limitations, boundaries and adverse situations.

4.2.1 Staff

The important role of staff was a prominent theme and was described in depth by the majority of participants. Staff were described as occupying three roles which

'enabled or disabled' participants: 'gatekeeping'; trouble-shooting'; and 'support and care'.

One way in which staff were described as 'enabling or disabling' participants was through their role as 'gatekeepers'. This refers to the reliance of participants on staff to facilitate many of the environmental factors described above, including access to social activities, social contact with friends and romantic partners, holidays, employment and hobbies. Staff were described as enabling participants in a number of ways which included organising transport, providing support to manage finances, providing information and supporting participants to make and implement choices.

Matthew describes his recent move into a new home with greater numbers of staff and talks about the benefits of being able to get out more:

M: You can go out more, go shopping and that.

A: and do you go shopping with staff or do you go by yourself?

M: With staff.

A: With staff. And do they go whenever you want to go, are you able to say "I want to go shopping" and they'll go with you?

M: Yes.

A: Great. So it sounds like you've got quite good staff, is that...?

M: I've got good staff.. like the person on tonight, there's one called Trevor...

A: And is that important for having a good life, having good staff?

M: It is

Richard discussed saving up to go on holiday, and the support he receives from staff to plan his finances.

D: so you want to go on holiday?

R: yeah...but you got to plan it

D: mmm

R: yeah?

D: yeah

R: you got to save up, talk to staff what you can save.. and just basically sit down and add up your money, your finance and that, and if like you're on holiday you got to try and save your money up first

D: so you sit down with staff...

R: and they help you, yeah... they like plan it with you

Only one participant described the negative impact of staff as 'gatekeepers', who he experienced as preventing access to holidays and activities. Stephan described being aware that he is not allowed to go on holiday as 'staff can't tek me'. Stephan then moves on to describe times he has requested to go out but has been 'turned down' by staff, and the negative impact of this on his mood:

St: and I want to go on holiday, cause I ain't been on holiday cause staff can't tek me

A: and why can't staff take you?

St: it's not allowed

A: It's not allowed? And what's that like.. that it's not allowed to go on holiday?

St: sometimes it's hurting and sometimes, you know it's there cause it's not allowed cause they (indecipherable) and then I hurt.. but I can understand, I know what they're saying

A: so sometimes it's difficult and it hurts you but you can understand why?

St: yeah

D: have they said why you're not allowed to go on holiday?

St: uh uh (shakes head no) sometimes I get miserable.. err sometimes they turn me down cause I don't go anywhere

A: so sometimes you want to go somewhere...

St: .. but they turn me down, yeah.. they do that sometimes

Though Stephan's description highlights the possible negative impact when the role of staff as 'gatekeepers' prevents access to activities and holidays, he also talks about the positive impact of staff who care for him when he is unwell. This illustrates the numerous and sometimes conflicting roles that staff may occupy, being both 'enabling' and 'disabling'.

In addition to staff 'enabling' participants through practical support, participants also described being supported to develop skills to maximise their independence. These skills included cooking, cleaning, making hot drinks and independent-travel. Jane describes moving from the family home following the death of her parents and how her new staff enabled her to increase her independence by facilitating self-travel:

A: so you're quite independent

J: mmm

A: so is that important to you, to be independent?

J: yep, well what it is, me Mother wouldn't let me go on't buses.. she wouldn't let me go about on me own, I had to have me Dad or my Sister we' me

A: right..

J: anyway, when they all died.. one day I went t'Barnsley with one of t'support workers.. and they put me on bus and said 'off you go, you can do it', and I were scared as anything as I'd never been on me own before...but after that I got...me confidence and now I go everywhere by myself, and t'staff helped me.. they helped me get more independent

A: so before your family died you weren't allowed to do things by yourself, but staff helped you to learn

J: yeah

The majority of participants also described the importance of staff providing emotional and practical support when they encountered difficult situations. Richard described a situation in which a person at his day centre was shouting and swearing. He talked about being able to tell a specific member of staff, who was able to handle the situation by speaking to the other person involved. Richard also highlighted the importance of being able to share things in private:

D: can you tell us about a time when you were not happy with something in your life?

R: like somebody's shouting and swearing and banging doors and screaming..

D: who...who did you and what...

R: I tell one o'staff like Debbie..

D: ...and what..what happened next

R: and then Debbie sort it out..and then Debbie said....and..speaking to Debbie about...sorry..about shouting and screaming and I see Debbie and then Debbie says..and then Debbie tell 'em off, 'stop shouting and screaming'..

A: so you are able to talk to Debbie?

R: I tell her..if I want Debbie I'll tell her in private cause if I've..if I've not told her in private then everybody tells...they hear us then....

A: ...so having someone to talk to in private, is that important?

R: yeah

A: right

Like Richard, many of the other participants described the importance of being able to speak directly to a member of staff, which was often a named individual in the form of a keyworker, manager or personal tutor. Some participants directly linked having people to talk to with managing feelings of anger:

L: well.. if I'm too upset.. erm, me..me social worker comes out and explains and I tell Mark, I tell Mark what happened

A: so you are able to talk to Mark about what's happened... and is that important, having people around for you to talk to?

R: yeah, and me keyworker as well, Paul

A: and why is it important to have people around you can talk to?

R: because I don't get angry then

A: right, so when you talk to people you don't get angry?

R: yeah

In addition to the role of 'gatekeepers' and 'trouble-shooters', participants also described staff as providing support and care. Peter describes the importance of being cared for by staff, who he described as 'looking after' him and being 'helpful':

M: what things are important in your life?

Pe: staff at home

M: staff at home?

Pe: yeah! (4)

A: and why are they important

Pe: er.. they.. they look after me

A: they look after you?

Pe: yeah

A: and do you get on well with them?

Pe: yeah, I do yeah.. they're helpful

A: helpful?

Pe: definitely, yeah

A: so staff at home are important because they look after you....

Pe: ...yeah...

A: and they're helpful

Pe: yeah

Participants also described the importance of 'support and care' when they felt unwell or were upset by something.

4.2.2 Family

The role of family was also described as 'enabling or disabling', with family members also acting as 'gatekeepers' and providers of 'support and care'. However, the role of family was described differently to that of staff in that participants did not describe a 'trouble-shooting' role, but talked about the importance of 'belonging'.

Participants described the role of family members as 'gatekeepers' to accessing activities and maintaining social contacts, in the same way as staff. Margaret describes how she would like to go out and sing for people, and how her Dad works as a taxi driver and provides her with transport. Margaret described the difficulties that arose when her wanting to go out clashes with her Dad's job or other family member's needs, and experiencing not being able to go out as 'punishment':

A: what stops you getting out and singing for people

Ma: there, there's things that are only open at night, and.. and my Dad works and he's the transporter sort of things for me.. cause me Mum goes out to different places, and er she's unable to do that when she's not around you know what I mean, so...

A: so one of the things that kind of limits you is transport.. is that right?

Ma: yeah, yeah

A: so if you've got the transport you can do things, if you haven't then you can't?

Ma: yeah, yeah

A: ok, and is that something you'd like to change?

Ma: yeah

A: right, ok.. and when you can't go out, what's that like...

Ma: ...it feels like punishment

A: it feels like punishment

Ma: yeah

Families were also described as providing many of the 'care-giving' roles occupied by staff, such as providing transport, support with finances and support with daily living tasks like cooking and cleaning.

4.2.3. Boundaries and Limitations

Participants described some 'disabling' factors they experience which they termed 'boundaries' or 'limitations'. These factors included transport, finance and having a disability.

Margaret described the difficulties associated with transport when describing the 'gatekeeping' role of family members; however this was also described by other participants who shared the positive impact of having regular access to transport and the limitations associated with restricted availability. Finance was also described as either an 'enabling or disabling' factor, especially with regards to accessing holidays. For example, Richard described struggling to pay for holidays due to the extra cost associated with paying for staff:

D: what's the delay.. why you having to wait, you know before you can go on holiday?

R: like.. you got to save up in me (undecipherable) first thing

A: money?

R: money wise

S: so how much is it for you to go to Barcelona?

R: erm.. we have staff as well and we got to pay for their sleep ins

S: where you've got to stay...

R:... overnight, yeah

A: so that's something that's a problem, so if you go on holiday you've got to pay for your staff and that's more money?

R: yeah

Lorraine also talked about the importance of finance for having a good life and providing the freedom to 'go to different places':

A: anything else you think is important to have a good life?

Lo: erm, well for people to have a good life, is really down to.. like I've said, if there's not much available to have money to go to different places then I think erm, that people should be able to do that.. to have the money to go where they want.. and to have the freedom

The final 'disabling' factor was having a disability, though this was only talked about by one participant. Kelly described her physical difficulties as a boundary to getting married and living with her boyfriend of two years:

A: you'd like to get married to your boyfriend, and what stops you getting married?

K: my disability

A: ok, and how does that stop you?

K: because like, I'm unable to walk down the aisle because of my, because of my balance and everything.. you know what I mean, so...

S: and whereabouts.. whereabouts would you like to live?

K: with him

A: you'd like to live together?

K: yeah, yeah

A: and how, have you talked about it with him?

K: yeah we have

A: and what does he say?

K: he thinks yeah it's a good idea, but at the same time.. there is, there is boundaries where I can't get around again.. cause like if we're on our own and there's no one around to.. to support us then it's a bit pressured in.. into things that might need to change that might not be possible, you know what I mean?

4.3 Personal characteristics

Participants described personal characteristics that impacted upon the way they viewed and responded to negative life events and the boundaries previously described. These characteristics included acceptance of boundaries, contentment, 'looking on the bright side of life', determination and managing difficult feelings.

Many participants described themselves as content, or 'happy as I am'. Those who described 'disabling' factors also described accepting 'that's just the way things are'. As well as accepting some of the disabling factors they experienced, participants described 'looking on the bright side' as a way of maintaining SWB despite difficult or adverse conditions. For example, though Kelly described her disability as a barrier to marriage, she talks positively about the freedom she experiences and the importance of 'how you view life':

S: right, is there anything else you would like to say about what makes you happy and satisfied with your life?

K: yeah, having the freedom I do have

A: ok, so let me. I'm trying to work out in my mind about that.. so on the one hand it sounds like you have a lot of freedom and you make a lot of choices about where you want to go...

K: ...yeah..

A: but on the other hand..

K: there's boundaries like me disability and, and me money and everything

A: right

K: that stops me doing the things that I want

A: but you're happy with the freedom that you do have

K: yeah, yeah

A: and what helps you to feel happy even though there are these boundaries?

K: that I can still be with him even though... even though we can only see each other now and again

A: so would you say you're one of those people that looks on the bright side of life...

K: ...rather than the dark side, yeah

A: is that you?

K: yeah

A: and is that something that helps you feel happy with life

K: oh yeah, definitely

A: so it's how you view life

K: yeah

Participants described a determination to overcome difficult situations when they arose. For example, Jane described sustaining a leg injury and the importance of determination and deciding 'it weren't getting the better of me':

J: I've had a twisted leg last year

A: ouch

J: tumbling down..nearly tumbling down the sweet shop stair, step at black country museum..

A: ..*gosh*

J: but it's alright now

A: *so when, when your leg was twisted it was harder for you to get out and about?*

J: Oh no, I kept going out an about

A: *You just kept doing it anyway (laughs)*

J: (laughs) well, it weren't getting the better of me..this thing (pats knee)

A: *Yeah*

J: (laughs)

The importance of managing difficult feelings was also talked about and participants described a range of things they used to manage feelings of sadness, anger and loss which included singing, music and reading. Participants described how these things served as distractions from problems and a way to relax:

D: Can you think of a time when you were not happy with something in your life?

What did you do? What happened next?

R: I got upset because I lost my mum and my dad.

D: What helped you cope with that, who did you go to?

R: I like reading....

D: ...reading?

R: yep.. to tek me mind off things

C: I like reading.

R: And I like football as well.

D: so do reading and football help you get away from your problems?

R: Yep

5 Discussion

5.1 Theoretical Implications

These results support the assertion of Bramston et al (2005) that SWB is 'influenced by personal and environmental factors and their interaction' (p. 728). This also supports the findings from research conducted with the general population (Ryan & Deci, 2001). Participants described important environmental factors such as relationships, choice and independence, and their interaction with personal characteristics such as contentment, acceptance and 'looking on the bright side'. However, these results also suggest a third factor which operates between the individual and their environment to 'enable or disable' SWB. This factor comprised staff, family and 'boundaries' such as transport and finance.

These findings may be viewed within the context of the Theory of Well-being Homeostasis, which suggests that people with an intellectual disability may report high levels of SWB despite deficits in objective life circumstances (Cummins, 2005). Many of the participants described areas of their lives that they wished to change or develop, but all reported higher than average levels of SWB. The theme 'personal characteristics' may also be seen as demonstrating some of the affective and cognitive processes proposed by the Theory of Well-being Homeostasis as central to the maintenance of SWB, (Cummins, 2005).

This study identified a range of environmental factors which participants described as important to their SWB. This contributes to the literature from objective QOL

research and may inform the further development of SWB scales, with particular reference to the domains measured. Support was provided for studies which highlighted the importance of relationships and social support (Emerson et al., 2008; Bramston et al., 2005; Cummins et al., 2004), and the importance of transport to the SWB of people with an intellectual disability (Schalock et al., 2002). Support was found for studies that highlight the importance of employment (Jahoda et al., 2008); however participants talked about this in relation to occupying roles that are valuable to them and to others, including voluntary as well as paid roles.

It is of note that little attention was paid by participants to 'health', despite the inclusion of this domain in the majority of SWB models. Given that people with an intellectual disability are at higher risk of poor health (Dagnan, 2008), these results may be understood using the Theory of Well-being Homeostasis (Cummins, 1993a) as an attempt to moderate the impact that ill-health may have on subjective well-being. However, these findings may also be explained by other variables, such as less health awareness in people with an intellectual disability (Uppal, 2006). As such, more research is needed before conclusions can be drawn.

5.2 Implications for future research

This study supports the assertion of Matikka (1996) that people with an intellectual disability can talk with considerable insight about the factors that contribute to their SWB. Participants had varying levels of communication, but all were able to identify the factors that are important for them to be happy and satisfied with their

lives. This has important implications for future research which should seek to further utilise qualitative methodology to explore the perspectives of people with an intellectual disability. Further quantitative research should also be conducted to explore the relationship between the factors described by participants, and SWB further. This should concentrate on establishing causality further and cultivating a greater understanding of whether the factors lead to an increase in SWB or vice versa.

This study was participatory in design, and researchers with and without an intellectual disability worked as a team throughout the research process. All members of the research group reflected on the benefits of this methodology for the resulting study and to the individual researchers. Full participation allowed a sense of shared ownership and achievement, and the perspective and insight of the researchers with an intellectual disability added greatly to the design process and writing of the accessible article for publication. The power imbalance between the non-disabled researcher and the researchers with an intellectual disability may have been reduced by the previous research experience of some of the researchers with an intellectual disability, but also by the strong relationships built by the research group and the ethos of 'different skills but equal value'. Researchers wishing to undertake this type of research are advised to attend to this relationship building process, be mindful of assumptions that may relate to the past roles occupied by people with an intellectual disability (especially if people with an intellectual disability have not been colleagues before) and ensure that the

decision making process is documented and transparent to prevent the power residing with the non-disabled researcher alone. The importance of 'plain English' was also stressed by the research group, who shared a dislike of jargon which they found exclusive and alienating. Future research should continue to involve people with an intellectual disability to enable 'those that are researched upon' to become 'those that research'.

This study also has implications for the administration of SWB measures. Several previous studies have described the exclusion of data due to participants scoring the scale maximum on SWB measures (Verri et al., 1999; Hensel et al., 2002). However, the use of reduced option Likert scales means that some participants are presented with only two options when responding, and may therefore be more likely to score the scale maximum. Three participants (13%) in this study scored at the scale maximum, all of whom utilised the two-option Likert scale. As such, researchers employed supplementary questions to explore participants' answers further. Each participant was able to describe their rationale for answering positively to each item, and none were subsequently excluded from the study. This suggests that supplementary questions may be useful in differentiating between participants who respond positively due to acquiescence or suggestibility, and participants who are expressing satisfaction with their lives.

5.3 Clinical implications

The findings of this study suggest that interventions aimed at increasing or maximising the SWB of people with an intellectual disability may be effectively applied at several levels.

It may be possible to manipulate environmental factors to increase opportunities to make relationships, exercise choice and maximise independence, occupy valuable social roles and increase meaningful activities. Service-providers should continue to provide environments where people with an intellectual disability can meet together to socialise and form relationships, however participants also described the importance of activities in the wider community. This has implications at a societal level and highlights the importance of increasing accessibility and community inclusion.

Interventions may also be effective at the level of staff and family and includes the provision of adequate staff ratios and psycho-education about the negative impact of limited choice, independence and access to activities. The results of this study describe the subjective experience of participants as 'disabled' by a lack of transport and limited finances. This supports the findings of Emerson et al (2008) that people with an intellectual disability continue to experience financial limitations and suggest the need for greater access to transport and finance.

Finally, therapeutic interventions at the individual level may be effective in maximising psychological well-being, in spite of adverse life events or deficits in an individual's environment, by promoting personal characteristics such as 'determination' and 'contentment'. However, this should not be used to increase the acceptability of inferior life circumstances or abusive practices.

5.4 Limitations

Conducting research with participants with an intellectual disability necessitates adaptations to traditional research methods, which may impact upon outcomes. Barker et al (2002) describe the need to adopt an 'active, paraphrasing style' when interviewing people with an intellectual disability to overcome communication and cognitive difficulties (p.106). This increased participation may result in researchers having a greater impact on data. Attention was paid to this throughout the study and transcripts examined to ensure that interviewers did not 'lead' participants.

It is also of note that all participants were white British, and attended some form of day service, which may impact upon the degree to which the experiences described reflect those of people from other ethnic backgrounds and people who do not access day service provision.

It may also be of note that the scale used to corroborate reports of SWB was developed and normed on an Australian sample (McGillivray et al., 2009). The move toward supported living in the UK may have reduced the validity of the scale,

with particular reference to the test of acquiescence. Participants were required to answer negatively to the item 'did you choose the person that lives next to you?', however further exploration revealed that several participants had indeed been an active part in selecting the person that lived next door to them. As such this item was not seen as culturally valid and was not used. This observation suggests that there may be differences that impact upon the cross-cultural validity of SWB measures.

Though there is some evidence to suggest that employing 'peer researchers' has a positive impact on participation and the research process (Camfield et al., 2009), it is not possible to evaluate whether the presence of researchers with an intellectual disability may also have had a negative impact on the data. Demand characteristics may have been experienced more keenly by participants, who may have wanted to stress their value to people with an intellectual disability who were clearly occupying the valued role of 'researcher'. In addition, participants may have been more worried about being judged by a researcher with an intellectual disability (Ryan, Kofman & Aaron, 2010).

It may also be argued that, though a SWB measure was utilised, it is not possible to conclude that the participants all experienced high SWB. Sinason (1986) describes the 'ubiquitous handicapped smile' and 'outward friendliness' of people with an intellectual disability, which she argues serves as a defence against negative societal attitudes toward disability. It may be that some participants

experience a wider demand characteristic or 'secondary handicap' which may have negatively impacted upon the extent to which they were able to report low levels of SWB.

6.0 Conclusion

This participatory study utilised qualitative methodology to explore the perspective of people with an intellectual disability regarding the factors that contribute to their SWB. Participants described 'environmental factors' that contributed to their SWB, as well as factors which 'enabled or disabled' them in terms of maintaining high levels of SWB. Participants also described 'personal characteristics' that impacted upon their SWB. These results have far-reaching implications for those wishing to maximise the SWB of people with an intellectual disability, including policy-makers, service-providers, clinicians, staff and family members.

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Appendices

Appendices

i) Formats

- 1 Letter of approval of specified journal from Research Tutor
- 2 Copy of author guidelines for Journal of Applied Research in Intellectual Disabilities (JARID)

ii) Ethical Approval

- 3 Letter of approval from Barnsley Health and Social Care Research Governance

iii) Information sheets, consent forms, measures and materials

- 4 Participant Information Sheet
- 5 Participant Consent form
- 6 Personal Well-being Index- Intellectual Disability 3rd Edition
- 7 Literature Review Quality Measure (Adapted from Downs & Black, 1998)
- 8 Interview Schedule

iv) Other

- 9 Example of analysis

Appendix 1- Letter of approval of specified journal from Research Tutor



Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Telephone: 0114 2228550
Fax: 0114 2228610
Email: c.harrison@sheffield.ac.uk

20th July 2011

Anna Haigh
Third year trainee
Clinical Psychology Unit
University of Sheffield

Dear Anna

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Applied Research in Intellectual Disabilities

Research Report: Journal of Applied Research in Intellectual Disabilities

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

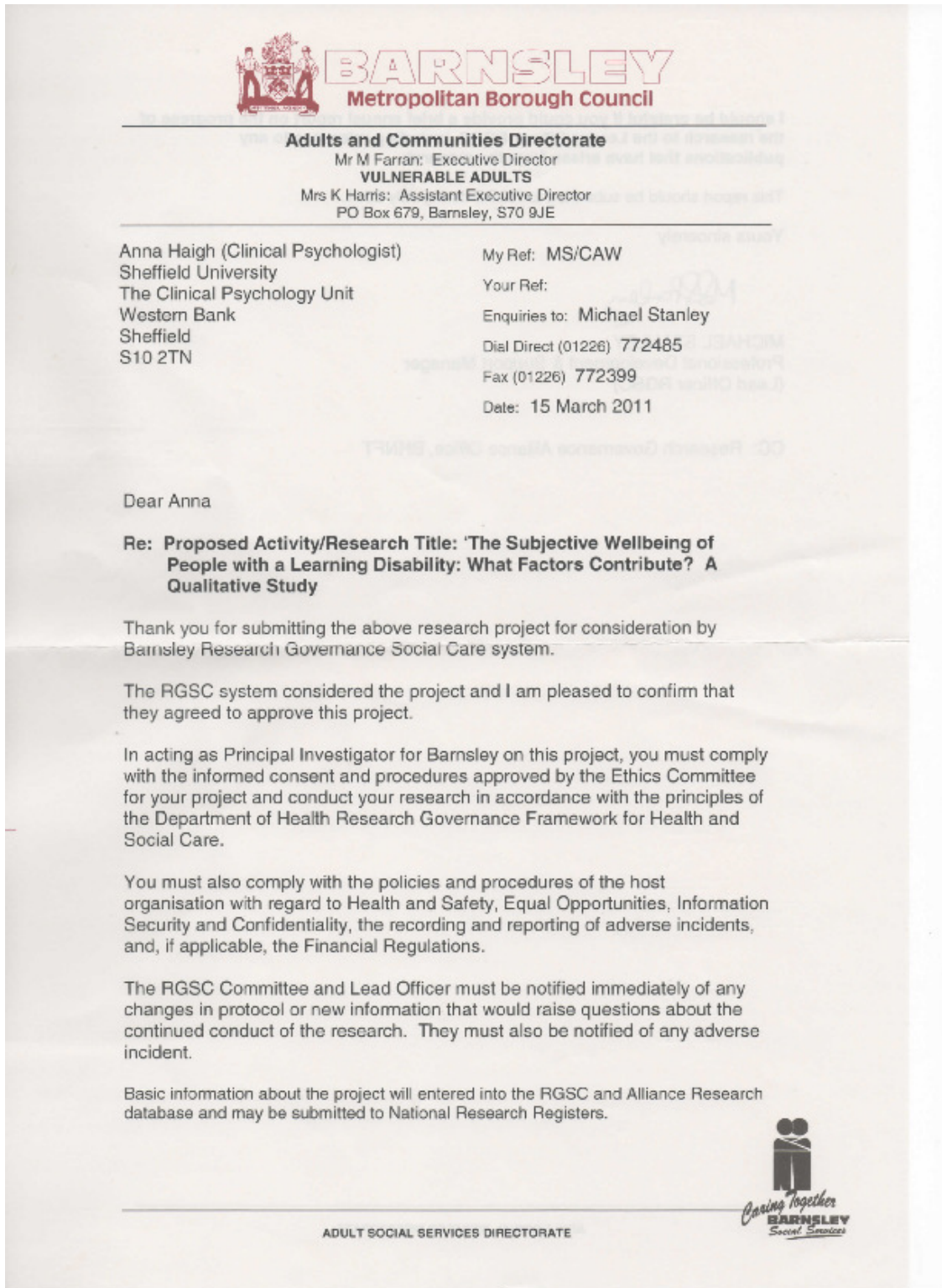
A handwritten signature in blue ink, appearing to read 'A.T.', written over a light blue grid background.

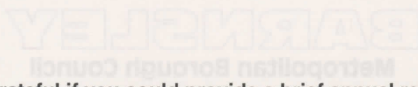
Dr Andrew Thompson
Director of Research Training

Appendix 2- Author guidelines for submission to JARID

The author guidelines have been removed to protect copyright. These can be found at <http://www.wiley.com/bw/submit.asp?ref=1360-2322>

Appendix 3- Letter of approval from Barnsley Health and Social Care Research Governance





I should be grateful if you could provide a brief annual report on the progress of the research to the Leader Officer RGSC, including reference to any publications that have arisen from the research.

This report should be submitted to RGSC during July 2011.

Yours sincerely

MICHAEL STANLEY
Professional Development & Support Manager
(Lead Officer RGSC)

CC: Research Governance Alliance Office, BHNFT

Dear Anna
Re: Proposed Activity Research Title: The Subjective Wellbeing of People with a Learning Disability: What Factors Contribute? A Qualitative Study

Thank you for submitting the above research proposal for consideration by the Research Governance Alliance (RGA) and I am pleased to confirm that the RGA system considered the proposal and I am pleased to confirm that they agreed to approve the project.

In acting as Principal Investigator for this project, you must comply with the informed consent and procedures approved by the Ethics Committee for your project and conduct your research in accordance with the principles of the Department of Health Research Governance Framework for Health and Social Care.

You must also comply with the policies and procedures of the host organisation with regard to Health and Safety, Equality, Information Security and Confidentiality, the recording and reporting of adverse incidents, and if applicable, the Financial Regulations.

The RGA Committee and Lead Officer must be notified immediately of any changes in protocol or new information that would raise questions about the continued conduct of the research. They must also be notified of any adverse incidents.

Basic information about the project will be entered into the RGA and Alliance Research Database and may be submitted to National Research Register.

Appendix 4- Participant Information sheet



Department Of Psychology.
Clinical Psychology
Unit.

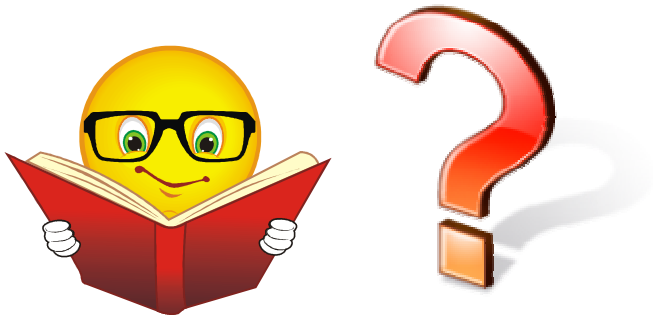
Doctor of Clinical Psychology (DClin Psy)
Programme
Clinical supervision training and NHS research
training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Participant Information Sheet

Title of Project- The Subjective Wellbeing of People with a Learning Disability: What Factors Contribute?

You are being invited to take part in a research study. It is important to read this letter carefully before you decide if you want to take part.



You can talk to other people if you want to. You can ask questions too.



Do I have to take part?

It is up to you if you want to take part. You do not have to.



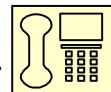
What is this study about?

This is a study about **wellbeing** with people with a learning disability. Wellbeing means things like being **happy** and **satisfied** with your life. We want to find out what things make people with a learning disability happy and well.

What will happen?

We will meet with you and ask you some questions about your life, and about how you feel. This will take about half an hour.

We will contact you again to invite you take part in a group where will talk about what we found out. You can say what you think about our findings.



There are no right or wrong answers- we are interested in what you think!

Can I change my mind?

Yes, you can change your mind at any time. You don't have to say why. No one will mind.



Who is doing this study?

Darren- My name is Darren. I am a peer advocate, researcher and elected representative for complex needs for Sheffield Partnership Board. I have also got a lot of experience on interview panels.

Stephen- My name is Stephen. I work at Launchpad in Sheffield and I really enjoy working here.

Michelle- My name is Michelle and I work at Launchpad Sheffield. I really like my job as I like working with people. I also really enjoy dancing.

Carl- My name is Carl and I work for Dimensions in Sheffield supporting people with a learning disability. I am a good listener and am sociable and enjoy meeting new people.

Anna- My name is Anna. I am training to be a Clinical Psychologist. I love my job as I enjoy meeting people and hearing about their lives. I also really like music.

Anna will be supervised by two psychologists, Nigel Beail and David Newman. This means Anna will talk to them about the research.

Where will the research take place?

If you decide to take part we will meet in a quiet room at your day centre. It will happen at a time that is good for you.

Will you tell anyone what I say?

The things you say may be used in a report, but **no one except the researchers will know your name** or where you live.



The only time we would tell anyone what you said is **if you told us you or someone else was in danger**. I will tell you if I need to do this.

All the information you give will be kept safe in a locked cabinet and will be destroyed once the study has finished.

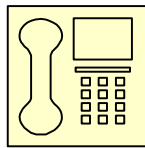
We may write some of the things you say in a report, but this will not have your name on it and no one will know who said it.

Can I talk to you first?

Yes, we would be very happy to talk to you.



You can ask questions now, or you can phone (0114) 2226650 and leave a message for Anna Haigh with your name and where you live. Anna will ring you back as soon as possible.



What if I am not happy and want to complain?

If you are worried or want to complain about something you can contact Anna's supervisor Professor Nigel Beail on 01226 777785. Otherwise you can use the University complaints procedure by writing to:

Who has reviewed this study?

This study has been reviewed and approved by Barnsley Health and Social Care Research and Development Alliance.

Appendix 5- Participant Consent form

Participant Consent Form

**Title of Project- The Subjective Wellbeing of People with a Learning Disability:
What Factors Contribute?**

Name of researcher: Anna Haigh, Darren Lee, Stephen Chamberlain, Michelle Hawthorne and Carl Shaw.

- 1) I have read the information sheet. I have had the chance to ask questions and they have been answered.



- 2) I understand that I do not have to take part. I can change my mind at any time.



- 3) I understand that information will be kept safe in a locked drawer. No one will know what I said except the researchers unless I tell them that I or someone else is in danger.



- 4) I agree to take part in this study



Name of participant.....

Date.....

Signature.....

Name of researcher.....

Signature.....

Appendix 6- Personal Well-being Index- Intellectual Disability 3rd Edition.
This measure has been removed to protect copyright full 39 page version available
at: [http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/pwi-id-
english.pdf](http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/pwi-id-english.pdf)

Appendix 7- Literature Review Quality Measure (Adapted from Downs & Black, 1998)

This measure has been removed to protect copyright. The full article can be purchased online.

Appendix 8- Interview Schedule

Semi-Structured Interview Schedule

Participants are briefed regarding purpose and length of interview, informed they do not have to answer any questions if they don't want to and can have a break or terminate the interview at any time. Check participant is comfortable before beginning. All questions may be followed up by further questions to follow up or clarify an answer.

- 1) How do you feel about your life?

- 2) Can you tell us about the things that are important to you in your life?
 - Can you tell me a bit more about that?
 - Are there any other things?

- 3) What things do you need to have a good life?

- 4) Can you think about a time when you were not happy something in your life?
 - What did you do?
 - What happened next?

- 5) Is there anything you would like to change about your life?

- 6) Do you have any wishes for the future?

- 7) Is there anything else you would like to say about what makes you happy and satisfied with your life?

At end of interview check how client is feeling and arrange further support if necessary. Thank participant for their time and inform them that they will receive feedback about the study outcomes.

Appendix 9- Example of analysis

The analysis was undertaken as a group using the stages in Braun & Clarke (2006).

This example shows the movement from initial codes to the theme 'staff'.

Data was transcribed verbatim (please see extracts in 'results' section for examples) and read aloud. Each piece of data was discussed and coded under a corresponding heading on flip chart paper (see Figures 1 and 2). New codes were added until all data was accounted for, resulting in 12 codes relating to staff.

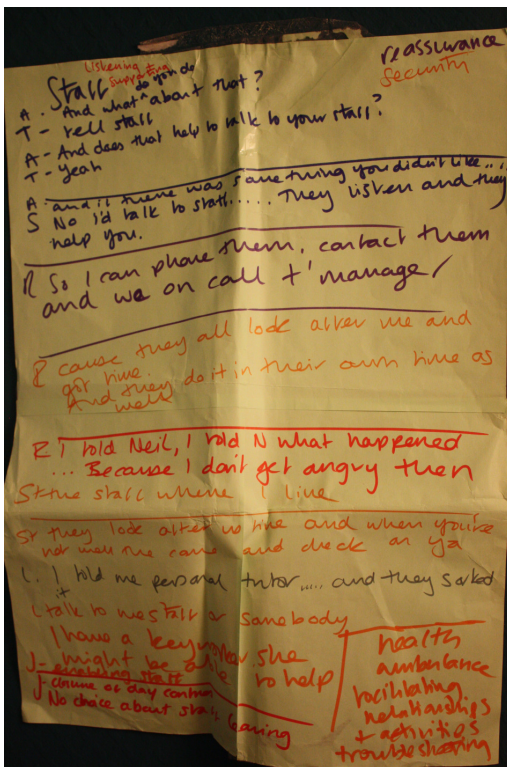


Figure 1: Data coded onto flip chart paper under the heading 'staff'

Data extract	Coded for
<p>M: Is there anything else you would like to say about what makes you happy with your life? CL: I been to Hayfield, I'm going tomorrow. A: Ah.. and what's that? CL: (Indecipherable) M: and does that makes you happy? CL: yeah A: and what do you do when you're there? CL: Talk to somebody. A: So... and is that friends that you talk to there? CL: Yep A: And is that something that's important to you? CL: Yep A: And who goes with you? CL: Staff A: Staff go with you.. so do they help you to go and meet people? CL: Yeah</p>	<p>Activities outside the home</p> <p>Activities as a means of social contact</p> <p>Friends- someone to talk to</p> <p>Staff going out with you (enabling?)</p>

Figure 2: Example of data extract with codes applied

Codes and corresponding data extracts from all participants were then typed up and cut out to allow researchers to physically experiment with placing them together to form broader 'themes' (see Figure 3).

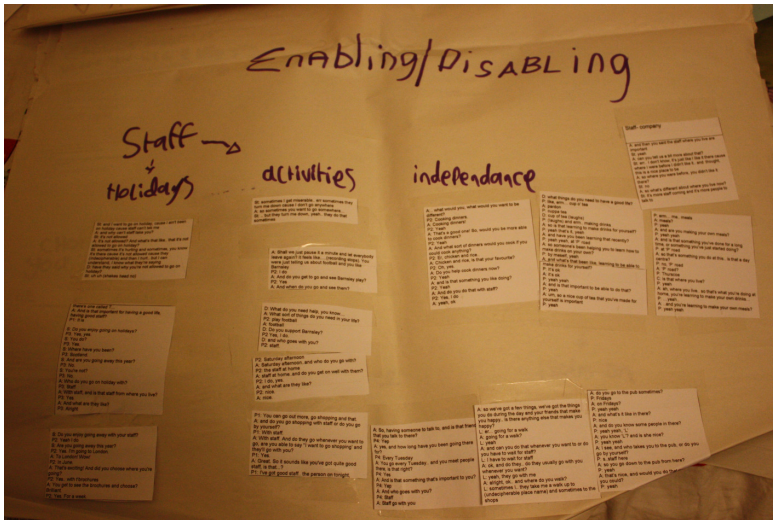


Figure 3: Data extracts cut out and moved around to form broader themes

The themes and corresponding data extracts were checked to ensure they formed a ‘coherent pattern’ (Braun & Clarke, pg 89; see Figure 4) and for internal homogeneity and external heterogeneity. The entire dataset was then re-read by the non-disabled researcher to ensure the ‘fit’ of the themes, and the full audit trail of the origins of themes in the data was audited by a peer researcher to check the ‘fit’ between data and the themes identified by the research team.

The master-theme ‘staff’ came under the superordinate theme ‘enabling and disabling and included the sub-themes ‘gatekeeping’, ‘trouble-shooting’ and ‘support and care’. The initial codes which contributed to this theme included ‘good relationships with staff at day centre’, ‘good relationship with staff where you live’, ‘staff going out with you’, ‘staff dealing with difficult situations’, ‘staff teaching new skills’, ‘having enough staff’, ‘staff managing money’, ‘loss of staff’ and ‘staff arranging transport’. It was not possible to include all the extracts pertaining to each sub-theme due to the volume of data, therefore illustrative examples were selected.

Superordinate theme	Master theme	Sub-theme	Examples of extracts
Enabling and Disabling	Staff	Gatekeeping	<p>A: Shall we just pause it a minute and let everybody leave again? It feels like.....(recording stops). You were just telling us about football and you like Barnsley</p> <p>K: I do</p> <p>A: And do you get to go and see Barnsley play?</p> <p>K: Yes</p> <p>A: And when do you go and see them?</p> <p>K: Saturday afternoon</p> <p>A: Saturday afternoon..and who do you go with?</p> <p>K: the staff at home</p> <p>A: staff at home..and do you get on well with them?</p> <p>K: I do, yes.</p> <p>A: and what are they like?</p> <p>K: nice.</p> <p>A: nice</p> <p>M: You can go out more, go shopping and that.</p> <p>A: and do you go shopping with staff or do you go by yourself?</p>

			<p>M: With staff. A: <i>With staff. And do they go whenever you want to go, are you able to say 'I want to go shopping' and they'll go with you?</i> M: Yes....yeah A: <i>Great. So it sounds like you've got quite good staff, is that...?</i> M: I've got good staff.. the person on tonight, there's one called T... A: <i>And is that important for having a good life, having good staff?</i> M: It is</p> <p>C: <i>You'd tell staff? Ok, and do you have any wishes and goals for the future? Anything you would like to do?</i> S: Move house with John C: <i>Oh, that's lovely (pause)</i> A: <i>And do you think you'd be supported to do that?</i> S: Yeah A: <i>And have you had the chance to talk about that at all with anyone?</i> S: No (pause) A: <i>No, but you feel like if you went to..who would you go to to talk about that?</i> S: Seniors A: <i>Seniors, and what are they like?</i> S: Bit bossy but they're alright A: <i>They're alright?</i> S: (laughs) Yeah</p> <p>R: you got to plan it D: <i>mmm</i> R: yeah? D: <i>yeah</i> R: you got to save up, talk to staff what you can save.. and just basically sit down and add up your money, your finance and that, and if like you're on holiday you got to try and save your money up first D: <i>and do staff help you... do they help you with that?</i> R: yeah</p> <p>St: and I want to go on holiday, cause I ain't been on holiday cause staff can't tek me A: <i>and why can't staff take you?</i> St: it's not allowed A: <i>It's not allowed? And what's that like.. that it's not allowed to go on holiday?</i> St: sometimes it's hurting and sometimes, you know it's there cause it's not allowed cause they (indecipherable) and then I hurt.. but I can understand, I know what they're saying A: <i>so sometimes it's difficult and it hurts you but you can understand why?</i> P: yeah D: <i>have they said why you're not allowed to go on holiday?</i> St: uh uh (shakes head no) sometimes I get miserable.. err sometimes they turn me down cause I don't go anywhere A: <i>so sometimes you want to go somewhere...</i> St: .. but they turn me down, yeah.. they do that sometimes</p>
		Trouble-shooting	<p>R: well. I'm too upset.. erm, me..me social worker came out and explained and I told Mark, I told Mark what happened A: <i>so you were able to talk to Mark about what happened? And is that important, having people around for you to talk to?</i> R: yeah, and me keyworker as well, Paul</p>

			<p>A: <i>and why is it important to have people around you can talk to?</i> R: because I don't get angry then A: <i>right, so when you talk to people you don't get angry?</i> R: yeah</p> <p>A: <i>So it sounds like rain and thunder is a problem and you don't like that...</i> Mi: no, I don't A: <i>and what happens when it rains and it thunders, what do you..</i> Mi: bangs... A: <i>...it bangs and that makes you jump does it?</i> Mi: yeah it does. A: <i>and what do you do when it starts to rain and thunder, do you tell somebody or..?</i> Mi: yeah I do.. I tell somebody. A: <i>and who do you tell?</i> Mi: the staff. A: <i>you tell the staff.</i> Mi: yes. A: <i>and what do they do?</i> Mi: sort it A: <i>sort it.. and how do they sort it, do they talk to you or...</i> Mi: ...take me somewhere. A: <i>they take you somewhere.</i> Mi: yeah</p> <p>A: <i>.. so if something was bothering you, what would you do?</i> P: I got t'staff A: <i>and would that be the staff here or?</i> P: staff 'ere A: <i>and what would they do?</i> P: they'd talk to me, they'd talk to me about it A: <i>and would that be important, to have someone to talk to if...</i> P: ... yeah A: <i>and does that help?</i> P: yeah, that helps me</p> <p>L: when I weren't happy.. when I were at Burton Street, I weren't happy there A: <i>ok, so you were going to Burton Street but you weren't happy...</i> L: ...someone upset me A: <i>someone upset you?</i> L: yeah A: <i>and what did you do about that?</i> L: I... told me personal tutor firstly A: <i>your personal tutor at Burton Street?</i> L: yeah C: <i>and what did they do?</i> L: er, they told me (undecipherable) just walk away from them A: <i>and did that work?</i> L: yeah A: <i>yeah, so I think like Darren was saying, having someone to talk to sounds like it's important and it helps?</i> L: yeah</p> <p>A: <i>and if there was something you didn't like about your life, would you be able to talk to your friends?</i> B: no, I'd talk to staff A: <i>you'd talk to staff?</i> B: yeah A: <i>and what do they do?</i></p>
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			<p>B: they listen and they help you A: <i>they help you, and is that important.. having people that can help you out if you need them to?</i> B: yeah, yeah</p>
		Support and Care	<p>Ro: and in here we got good staff.. we got MW and another M..and one called W, and they look after me..then a young man called J, my mate TG, (indecipherable). A: <i>So there's quite a few people here that you get on with as well.. and it sounds like having good staff here is important.</i> Ro: It does..</p> <p>A: <i>what things are important in your life?</i> Pe: staff at home A: <i>staff at home?</i> Pe: yeah! (4) A: <i>and why are they important</i> Pe: er.. they.. they look after me A: <i>they look after you?</i> Pe: yeah A: <i>and do you get on well with them?</i> Pe: yeah, I do yeah.. they're helpful A: <i>helpful?</i> Pe: definitely, yeah A: <i>so staff at home are important because they look after you....</i> Pe: ...yeah... A: <i>and they're helpful</i> Pe: yeah</p> <p>St: our staff is...like.. they go, they look after us fine and when you're not well they come and check on ya and err.. when you're poorly they send f't ambulance</p> <p>D: <i>what makes a good staff.. to do them things, to make you feel good?</i> Ch: cause they all look after me and got time D: <i>yeah</i> Ch: and they do that in their own time as well</p>

Figure 4: Resulting themes and examples of corresponding extracts