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Subjective Wellbeing in People with Intellectual Disabilities

Being a thesis submitted for the degree of Doctorate of Clinical Psychology

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By

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Overview

The portfolio has three parts these being: the systematic literature review, the empirical study and the appendices.

Part one is a systematic literature review into the influences on the subjective wellbeing of people with intellectual disabilities. It presents an understanding of people with intellectual disabilities, how wellbeing as a concept is currently understood and how their subjective wellbeing can be influenced.

Part two is an empirical paper which used different methods to explore how young people with intellectual disabilities perceive their experiences of attending a sports group with their peers of similar abilities and how this experience influences their subjective wellbeing. To achieve this eight young people aged 9 – 13 years old completed an adapted wellbeing measure to quantify their subjective wellbeing. A semi structured interview, incorporating creative methods to collect data was employed to ensure that this often under represented group could have a voice. The themes of this research are discussed and linked to previous research to identify clinical implications and the methodology is also discussed and future research opportunities are identified.

Part three comprises the Appendices to support the work in the first two parts of the thesis including a reflective account of the research process.

Contents

Part One

Systematic Literature Review

Influences of subjective wellbeing in people with intellectual disabilities:

A systematic review.

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Synopsis

Objective: People with intellectual disabilities (ID) face greater inequalities than people without disabilities and this effects wellbeing. This review aims to integrate existing research to understand the current conceptualisation of wellbeing and the influences on the subjective wellbeing of people with intellectual disabilities.

Design: Publications were identified using selection criteria being applied to the results of defined searches in electronic databases and of manual searches of articles' references. The quality of each study was evaluated and the main findings were extracted.

Results: Thirteen studies were reviewed, ten employed quantitative methodology and three employed qualitative methods. The main findings extracted from the studies related to making sense of wellbeing for people with ID, their parents or carers, the influencing role of relationships and of influencing factors to improve subjective wellbeing.

Conclusions: People with ID are often passive participants in the monitoring of their wellbeing and are not engaged directly in understanding their perceptions. The findings suggested that people with ID are able to discuss the influencing factors of their subjective wellbeing (SWB) if appropriately supported in doing so. Relationships with others that understand people with ID are important and understanding the influences on the SWB of people with ID is of upmost importance for the people themselves, their families, carers and service providers.

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Influences of Subjective Wellbeing in People with Intellectual Disabilities: A Systematic Review.

Subjective wellbeing (SWB) research has been growing in recent decades (Deiner, Suh, Lucas & Smith, 1999; Stratham & Chase, 2010 and Seligman, 2011), although defining wellbeing has proved to be elusive (Forgeard, Jayawickreme, Kern & Seligman, 2011). This paper attempts to define the current understanding of wellbeing and goes on to explore the necessity for a standarised definition in its measurement to aid in evaluating and intervening in services.

Defining wellbeing has proven difficult for researchers and as such, descriptions and definitions have competed for precedence (Dodge, Daly, Huyton & Sanders, 2012). A primary description of wellbeing is that it is a multifactorial, multidimensional concept that encapsulates complex frameworks of varying levels, incorporating biological, sociological and psychological constructs of both subjective and objective measures (Forgeard, Jayawickreme, Kern & Seligman, 2011). Wellbeing is discussed within all multidisciplinary fields of healthcare, education and social care. Defining the term wellbeing within the literature is complicated as there are overlapping concepts and descriptions including the terms happiness, self-esteem (Lyubomirsky, Tkach & Dimatteo, 2006) quality of life, life satisfaction and health (Seligman, 2011). These terms often have similar explanations of what they are attempting to explore and measure, however there are also differences in the concepts. To disentangle these concepts to one unifying model that is agreed by all researchers and policy makers is difficult to attain (Diener, 1984, 2009; Diener, Suh, Lucas & Smith, 1999; Diener, Lucas & Scollon, 2006; Diener, Napa, Scollon, & Lucas, 2003).Varying concepts have been agreed to provide a unifying, if less than comprehensive paradigm in which to operate (Gasper, 2010).

Wellbeing has been conceptualised from both an objective and subjective perspective to gain a holistic understanding of a person’s experience. Objectively a person’s wellbeing has been measured from factors including those of educational attainment, financial circumstances and living environment (Schalock & Felce, 2004; Seligman, 2011). However, these objective measures have been repeatedly demonstrated to be poor indicators of subjective wellbeing (Forgeard, Jayawickreme, Kern & Seligman, 2011; Dodge, Daly, Huyton & Sanders, 2012). Various investigators argue that objective indicators alone do not and cannot accurately reflect an individual’s experience of wellbeing, because they overlook how people perceive their circumstances (Campbell, Converse & Rogers, 1976). Research into subjective experiences, particularly subjective quality of life (QOL) (Brown, & Brown, 2005) led the way in measuring individual’s perceptions, which were unable to be predicted by objective measurement alone (Brown, Schalock & Brown, 2009). SWB research stemmed from this early subjective QOL research (Christopher, 1999) and Seligman (2011) recently proposed that wellbeing is a construct that consists of five elements that individuals are attempting to attain. These elements were positive emotions, engagement, relationships, meaning and accomplishment, thus creating what Seligman described as the PERMA model. These elements influence a person’s SWB by firstly, having positive emotions and by not ruminating on negative experiences, they should be engaged with their life, through having positive relationships with significant people that should be combined with accomplishments that are perceived as meaningful to them. Seligman (2011) describes these elements as what people strive to achieve to bring them wellbeing.

There are other examples of how wellbeing is regarded, and some go to great lengths to compartmentalise wellbeing into those of health, education or social wellbeing, however a unified model of wellbeing is required to view the individual as a holistic being in which one aspect of a person’s life will affect another. In addition to Seligman’s theory, it is important to understand how the PERMA model relates to the world in which each individual lives. Various researchers have explored models of wellbeing whereby it is predominantly in a state of equilibrium and only temporarily improves or decreases with a change of circumstances (Headey & Wearing, 1989; Headey, 2006). Cummins (2010) reviewed a number of large scale studies which indicated that data obtained through a variation of life satisfaction questions averaged across a number of domains. The author demonstrated that levels of satisfaction were broadly similar for people regardless of life events or returned to a normal level after a challenging life event, in keeping with previous research (Suh, Diener & Fujita, 1996), thus achieving equilibrium. Cummins (2010) discovered that when responses are standardised onto a scale with a range of 0 to 100%, then population scores remained similar (M = 75, SD = +/- 2.5). The proposition is that SWB operates under a system of homeostasis, the maintenance of which appears to be managed by cognitive mechanisms with the purpose of maintaining a positive outlook on life. These mechanisms relate to internal and external factors. The former are discussed as those factors that individuals are able to utilise when thinking about themselves or their sense of self and focusing upon previous positive experiences regarding particular situations, thus raising the individual's self-efficacy when faced with a challenge. The external mechanism relates to the environment and other people within a person's system, Cummins regarded this as influential although unable to be significantly influenced by the individual.

Dodge, Daly, Huyton and Sanders (2012) argue that Seligman's theory does not define wellbeing and that SWB is not a construct but a state to be achieved. Their proposition is that SWB is a point between an individual's available resources and the challenges they face, thus being a dynamic rather than a homeostatic process, as Cummins proposes, in which to maintain a stable level of wellbeing. The researchers propose that this definition could be used to aid an accessible measurement of wellbeing and further the understanding of this concept. The best model available would be an amalgamation of the PERMA elements to achieve a desired equilibrium state requiring the development of resources and internal buffers; this could only be achieved through repeated exposure to the PERMA elements through experiences, situations and environments in a bidirectional relationship.

People with Intellectual disabilities and wellbeing

Wellbeing is required regarding people with intellectual disabilities (PwID) and research is required to improve their involvement (Bray, 1999; Bach, 2007; Schalock, 2004). The American Association of Intellectual Disabilities (AAID) postulates that the Social Model of Disability is now the prevalent paradigm in understanding the needs of people with intellectual disabilities (Brown, 2007). ID is defined by the AAID as a multidimensional concept including intellectual ability, adaptive behaviour, participation, context and individualised support. Schalock et al (2010) reported the approach to classification is in line with the movement within the field of intellectual disability towards an ecological focus and support paradigm. The environment is seen as the disabling factor for people whereby the ecological structure creates and reinforces disability as the prevailing construct which people face (Yazbeck, McVilly & Parmenter, 2004). With the paradigm shift to understanding the ecological perspective as creating the circumstances for disability, service providers can understand how to implement structures, resources and the systems in which people live (Emerson, Baines, Allerton & Welch (2012). Therefore understanding the conceptualisation and influencing factors of wellbeing for PwID are important and inequalities are experienced by this population. Emerson, Baines, Allerton and Welch (2012) explored the health inequalities of PwID. They reported that these inequalities begin early in life and are the result of barriers to accessing appropriate services which affects exposure to experiences to develop internal cognitive buffers and resources. The literature substantially supports the evidence that PwID are a minority group within society and proportionately are much more likely to have, higher stigmatisation (Cooney, Jahoda, Gumley & Knott, 2006; Davies & Jenkins, 1997; Jahoda, Markova & Cattermole, 1988), lower socioeconomic status, higher incidences of both physical (McGuire, Daly & Smyth, 2010) and mental health difficulties (Brown & Radford, 2007), are more likely to be victims of crime and perpetrators of crimes and have a vastly reduced social network (Faust & Scior, 2008).

PwID consistently score much lower than the non-intellectually disabled people on both objective and subjective wellbeing measures (Svetaz, Ireland & Blum, 2000). Emerson, Baines, Allerton and Welch (2012) discussed that young people with ID are more than five times more likely to have a psychiatric disorder than young people without an ID. Their study highlighted that this difference was predominately due to the cumulative risk of exposure to social disadvantages and ecological structure (Li, Tam & Man, 2006).

Rationale

Understanding the exact nature of the influences of SWB in a literature review is required to examine in a comprehensive manner how society can understand how to influence SWB for PwID. Furthermore an understanding of the nature of the interconnecting systems that are operating to construct society's ecological system will facilitate considerations in determining how the system can influence the SWB of people with ID.

Aims

1. To discover how wellbeing is understood by people within the ecological systems of PwID

2. To explore research on wellbeing and how the information is utilised

3. To research methods which have been identified as influences on SWB

4. To assess the overall quality of the literature base for wellbeing influences for PwID

Method

Search strategy

A search of the literature up to and including April 2013 was conducted using electronic resources. The following databases were employed: PsycINFO, PsycARTICLES, MEDLINE, ERIC, Sciencedirect and NHS libraries including Scopus and Web of Science. A start date was not employed to ensure as wide a search as possible. Reference lists were also manually searched to discover any papers that did not appear on the electronic searches. In addition, a search was carried out for existing review papers in this area, by using the electronic databases to ensure that there would be no replication of previous work.

The terms intellectual disabilit* AND wellbeing were entered into the databases as part of the initial search. Further search items were selected from the key words that were stated most often by the articles generated during this search. These included quality of life (QoL), life satisfaction, self-esteem and happiness. A search of the population terms included development* disabilit*, learning disabilit*, mental retardation*. These were further refined to those terms that produced articles relevant to the question under review and which met the criteria. The final list of all search terms is shown in Appendix 2. All possible combinations of these items were systematically entered into each database to retrieve articles that featured the terms in their titles, abstract, subject or keywords. Relevant articles were identified from their titles and the selection criteria were applied to the abstract. In case of uncertainty, full copies of potentially suitable articles were obtained so that the selection criteria could be applied fully to assess the article’s eligibility. Additionally, manual searches of reference sections from the articles included within the review were conducted to identify further articles of relevance. The abstracts of these articles were assessed and copies of the full text were obtained in relevant cases.

Study selection criteria

The selection criteria were developed and refined from reading abstracts retrieved from the scoping search. The rationale for the inclusion and exclusion criteria can be found in Appendix 3. Studies had to meet all of the inclusion and none of the exclusion criteria to be included in the review.

Inclusion criteria

- All individuals with ID including; children, adolescents and adults, both male and female.
- SWB measures taken from parents and/or carers (proxy responders) that explain the influences of subjective wellbeing on the individuals with intellectual disabilities.
- People with mental health difficulties if their intellectual disabilities were predominant in their difficulties.
- Definitions pertaining to SWB in the literature including; Quality of life, life satisfaction, self-concept.

Exclusion criteria

- Studies that focused on people without ID.
- Studies that examined specific constructs concerning wellbeing but where this was not explicitly explored within the research.
- Studies that focused upon the SWB of members of the social system but not the person with intellectual disabilities.
- Literature reviews or other non-empirical papers.

- Case studies.
- Studies that had not been peer reviewed.
- Studies that were not printed in English `

Data extraction

Data was extracted from studies using a pro-forma designed specifically for recording data for this review (Appendix 4 and 5).

Data synthesis

Statistical methods of data synthesis were not conducted as outcome measures and methodologies of the studies were too diverse. Extracted data was collated and reported within the review thus enabling findings from the studies to be described in detail.

Study quality assessment

Studies were not excluded from the review based upon quality ratings as there was not a sufficient literature base from which the studies could be drawn whilst meeting all of the inclusion criteria. Therefore rather than using quality as an exclusion criterion, the quality of each paper was rated and then reported within the data synthesis table (Table 1). Quality ratings allowed the reviewer to make informed judgements as to how strong the findings from the studies were during the analysis. Additionally, due to inclusion of studies of variable quality, this enabled a critique of the research literature available to be conducted and recommendations for future research to be made.

Quality checklists developed by the reviewer were employed for the studies which were identified for inclusion (Appendix 4 and 5). These were developed based on quality assessment measures by the National Institute for Health and Clinical Excellence (NICE,

2009) and Downs and Black (1998). Questions assessing the quality of general aspects of research were selected to form the checklists as these reflected the types of studies generated by the database searches. A point scoring system was employed to allow comparisons across studies. Checklists were rated as either ‘excellent’, ‘sound’, ‘poor’ or ‘no/unsure’ for each study, and scores of either 0, 1, 2 or 3 were given. Each study was given an overall rating, determined by summing the number of ratings. The maximum scores obtainable were 63 for qualitative studies and 69 for quantitative studies. To ensure the reliability of the ratings an independent rater who was experienced in psychological research also assessed a random sample of three studies. The Cohen’s Kappa coefficient was employed to assess inter rater reliability. The reliability was .72 ($p < 0.0001$), which is considered by Landis and Kock (1977) as substantial agreement.

Results

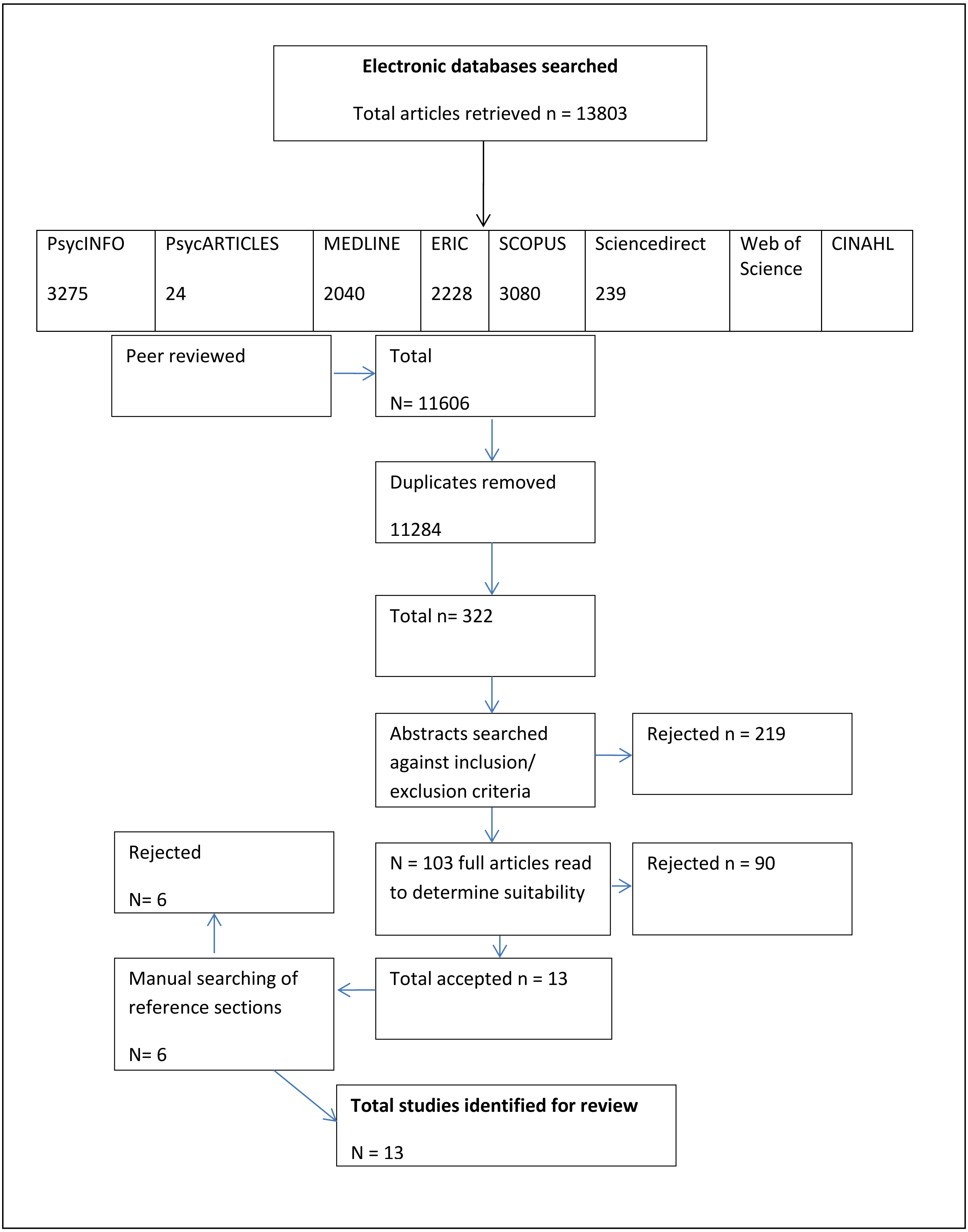
Overview of search results

Quantitative and qualitative studies were included in the review to provide as broad a range of data as possible for the review. In total thirteen studies satisfied the selection criteria and were therefore included in the review. The study selection methodology is shown in figure 1.

Details of included and excluded studies

In total, the search strategy produced 13803 articles; these were limited to those that were from peer reviewed journals, which reduced the number to 11606 articles. After examining these for duplications the total number of articles was reduced to 322. Of these 322 articles were read from their title information and the abstracts were read, articles were then removed as the selection criteria were applied. Therefore the remaining 103 articles were obtained and the full articles were read, 90 articles were excluded after applying the selection criteria and the remaining 13 were fully reviewed. In addition 6 articles were selected from manual searches but were all excluded when access to the full text showed that they did not fulfil the criteria.

Figure 1: study selection process



Summary of studies

Following the study selection process as illustrated in figure 1, thirteen studies were included in the review of which ten employed quantitative methods and three qualitative methods. The quantitive studies used a variety of methods to measure wellbeing and may be described as quality of life, life satisfaction, self-construct or self-esteem. These terms are discussed by Cummins (2010) as either being cognitive mechanisms in maintaining a positive sense of wellbeing or as being measured as significant constructs of wellbeing. Measures have been used to assess different aspects of wellbeing as understood by Dodge al (2012) and Seligman (2011), as the concept is yet to be agreed upon by researchers of other aspects of wellbeing. In addition to questionnaires other studies have used likert scales to assess PwID sense of wellbeing; all of these measures have been included within the literature due to the lack of a unified concept or measure for wellbeing. The quantitative studies aimed to examine the experiences or insights of people with ID and their parents or carers in relation to the influences of events, situations or relationships on their sense of their SWB. These studies have provided data concerning the influences regarding SWB, however due to the lack of qualitative data this subsequently reduces the richness of information available. This does not enable the reader to fully infer the phenomenology of the individuals concerned, rather the results of the majority of the studies and the subsequent discussion points were based on psychometric scores. Qualitative studies were fewer and only one had explored adults with ID own views regarding their SWB through an interview and employed a Thematic Analysis design. The other studies were asking parents and/ or carers their views regarding the SWB of an individual with ID.

Quality of assessment

The quality rating scores of the quantitative studies ranged between 28/69 and 51/69. The qualitative studies scored between 38/63 and 50/63. The primary strengths of the studies identified that their rationale and objectives were clearly focused with appropriate choice of data examination methodology. In the majority of cases higher ratings were awarded for detailed demographic information, strategies for sampling and data collection methods. In addition a high number of studies provided rigorous data analysis, however, there were serious limitations in terms of their evidence leading to the methods employed, selection criteria and reporting of limitations and implications. Alongside these limitations, population representatives were recruited from specific cultures or schools and therefore these studies may not be able to be generalised across all populations.

Table 1: explanation from the studies included in the review

	Reference (Country)	**Aims of the study**	**Participants**	**Design and analysis**	**Measure (s)**	**Main findings**	**Quality rating**
1.	What things make people with an LD happy and satisfied with their lives: An inclusive research project. (Haigh, Lee, Shaw, Hawthorne, Chamberlain, Newman, Clarke & Beail, 2013) UK	Qualitative measures into SWB of adults with ID to discover what makes happy people with ID happy.	23 participants (M = 12; f = 11) (age 23 - 67 y/o) Mild ID	Thematic analysis. Interviewed 23 people who said they were 'happy and satisfied' with their lives.	PWI – ID – 3rd	20 people scored higher than previously reported 77/100 on the PWI-ID 3 key themes Environmental factors (choice and independence, activities, valuable social roles, relationships) Enabling and disabling (staff, family, boundaries) Personal characteristics	41/63
2.	Adolescents with Learning disabilities: Risk and protective factors associated with emotional wellbeing: Findings from the national longitudinal study of adolescent health. (Svetaz, Ireland & Blum, 2000) USA	To identify differences in emotional wellbeing among adolescents with and without ID and identify risk and protective factors associated with emotional distress	20, 738 of grade 7 -12 in high school (17,661 parent respondents for young people with ID). (M=48%; F=52%)	Cross sectional analysis. T-test, chi square of variables and logistic regression analysis to identify factors.	Adolescent in home interview National Longitudinal Study of Adolescent Health	Adolescents with ID were twice more likely to be at risk of emotional distress. Odd Ratio= (OR) 1:1.89. Males/ females with ID OR = 2:1. YP with ID much more likely to suffer emotional distress OR = 3/:1. Connectedness to parents and school identified as protective factors for SWB.	39/69

3.	Self-reported wellbeing of women and men with intellectual disabilities in England. (Emerson & Hatton, 2008) UK	To investigate association between SWB, personal characteristics, socio economic and social relationships.	1, 273 adults with ID	Likert scales covering a range of measures related to the aim. Millenium Poverty Social Exclusion Survey.	Personal characteristics and living situation, self-reported wellbeing, socioeconomic position and social connectedness.	Relationships with friends who had ID appeared to be a protective factor against feeling helpless. Socioeconomic disadvantage related to lower wellbeing scores. Gender differences related to intimate relationships, with women with ID having lower wellbeing scores than general population.	29/69
4.	What makes them feel like they do? Investigating the subjective wellbeing in people with severe and profound disabilities. (Vos, Cock, Petry, Van Den Noorgate & Maes, 2010) Belgium	To explore the client and service characteristics contributing towards wellbeing for people with severe and profound ID.	354 direct support staff informants for 36 people with severe and profound ID (<40 IQ)	Multi-level or hierarchical linear models approach	MIPQ (25 item questionnaire, 5 point likert scale)	(Overall M=67.6%; range 16.3-100). Severe ID M=64.42; profound ID M=73.69) Lower overall scores of wellbeing than people with mild ID and non ID populations. This was primarily due to medical problems.	22/69
5.	Relationship between individual quality of life and family quality of life for people with intellectual disability living in Italy. (Bertelli, Bianco, Rossi, Scuticchio & Brown, 2011) Italy	Relationship between QoL scores of individuals with ID and their families	27 parents (M age=70.8) and 27 adults with ID (M age=41.9)	Cohen's K Coefficient	FQoLS; QoL-IP. Answered using a 5 point likert scale.	The relationship between family and individuals with ID are complex. Both have different wellbeing scores that could negatively affect each other. No significance between overall individual and family scores.	43/69

6.	Self and proxy rating of quality of life in adults with intellectual disabilities: results from the DISQOL study (Schmidt, Power, Green, Lucas – Carrasco, Eser, Dragomirecka & Fleck, 2010) Germany	To analyse association between self and proxy reports of QoL between European centres.	N=614 people with ID (M=59%; F=41%) and n=874 proxies.	ANOVA between measures; regression analysis	WHOQOL-DIS WHODAS BCOS (Physical, psychological, social, environment & disability domains)	Significant moderate to strong associations between PwID and their proxies. People with ID rated their QoL higher than their proxies except for two physical and/or medical factors.	28/69
7.	Quality of life in persons with intellectual disabilities and mental health problems: An explorative study. (Morisse, Vandemaele, Claes, Claes, & Vandevelde, 2013) Belgium	Does QOL paradigm apply to clients with ID and cooccurring mental health problems.	N = 7 persons with ID and mental health problems and n = 10 staff members/ professionals	No qualitative analytical method stated.	Related to Schalock et al (2005) QoL construct domains.	Themes were ranked as most important in terms of: interpersonal relationships, self-determination (professionals), and social inclusion (families). Interpersonal relationships, self-determination, social inclusion, emotional wellbeing (persons with ID.	45/63
8.	Comparing the self-construct of students with and without learning disabilities. (Gans, Kenny & Ghany, 2003) USA	To compare self-concept between children with and without LD	N = 50 children with ID and n= 70 without ID (primarily Hispanic)	2x2x2 MANOVA 2x2x2 ANOVA	Piers-Harris Children's Self-concept scale (PHCSCS)	Students with ID scored lower on the self-concept measure than their peers without ID (LD = M=11.36, SE .44; Non LD=M=12.90, SE .38).	28/69

9.	Life satisfaction in persons with intellectual disabilities (Cramm & Nieboer, 2012) Spain	To discover how people with ID are satisfied with their lives	N = 99 persons with ID M age=38.84; 59.6% male.	SWLS range from 5 -35. Reliability Cronbach's alpha >0.70. Exploratory factor analysis, construct and convergent validity were analysed.	SWLS, WHOQOL – BREF,	Persons with ID were satisfied with their lives (SWLS 25-29, M=25.89, SD: 7.55), internal consistency was .79. Persons living in residential institutions had lower life satisfaction scores.	30/69
10.	Longitudinal study of parents' impact on quality of life of children and young adults with intellectual disabilities. (Cramm & Neiboer, 2011) The Netherlands	To discover parents impact on the QOL of children and young people with ID.	Parents of children and young people aged 0 -24. IQ range 70 to 85 with behavioural problems.	Longitudinal study To (n=147) & (after 6 months) T1 (n=108) Cronbach's Alpha	Proxy version of ID – QOL – 24	Social wellbeing of parents, changes of parents social wellbeing & changes in children's wellbeing (p>0.01). Changes in parent's social wellbeing predicted QOL for children with ID. Changes in emotional wellbeing of children and parents predicted QOL of children with ID. (0.83 T0 & 0.84 T1 Cronbach's alpha).	51/69
11.	Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff (Petry, Maes & Vlaskamp, 2005) Belgium	To discover how parents and support staff operationalised basic QOL domains	N = 76 parents and support staff on population sample	Cross case analysis Qualitative then related to basic QOL domains	Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications	52% spontaneous responses 88.2-100% explicit responses. People with profound needs were dependant on others for gratification of their needs/QOL	36/69

12.	Social comparison, self-esteem- and depression in people with intellectual disability (Dagnan & Sandhu, 1999) UK	To explore social comparison, self-esteem and depression in people with ID	N=43 people with mild & moderate ID. F=18, m=25. 55.8% living with family.	The participants were identified as having the verbal skills necessary and the scales were adapted.	Social comparison scale (Gillbert & Allen, 1994), Self-esteem scale (Rosenberg et al, 1989), Zung depression scale (Zung, 1965)	Depression was significantly negatively correlated with positive self-esteem (r=-0.39, P<0.05). Self-esteem was positively correlated with social comparison (r=0.34, P<0.05)	38/69
13.	Can physical training have an effect on wellbeing in adults with mild ID? (Carmeli, Zinger-Vakin, Morad & Merrick, 2005) Serbia	To investigate the effect of physical training on balance, strength and general wellbeing in adults with ID	N=22 with mild ID age 54-66 y/o.	Physical training 3 times per week for 6 months from 112 non randomly selected permanent residents in foster care in Israel. .	Direct interview questionnaire consisting of 37 structural statements. Harter's self-perception profile.	Multiple regression analysis suggested positive relations between physical benefits and wellbeing Significant improvement in wellbeing scores between T0 – T1 (68-83; P>0.05)	43/69

Wellbeing and quality of life measures abbreviations related to the table above

PWI – ID 3rd edition	**MPIQ**	**QoL-IP**	**FQoLS**	**WHOQOL**	**BCOS**	**SWLS**	**ID – QOL 24**
Personal wellbeing index – intellectual disability	Mood, interest and pleasure questionnaire	Quality of Life – Instrument package	Family Quality of Life Survey	World health Organisation quality of a life	Bcas Caregiving Outcome Scale	Satisfaction with Life Scale	Intellectual disability –Quality of Life measure – 24 items

Main findings

Three key areas were identified as the focus of the studies.

1. Understanding the concept of wellbeing

2. Psychosocial influences on wellbeing with people with ID

3. Further influences of subjective wellbeing influences for people with ID

1. Understanding the concept of wellbeing

How the literature has changed over time

The concept of wellbeing has yet to be defined concisely and comprehensively by researchers. Various constructions have been proposed attempting to understand and measure how individuals experience the environment and how this can be quantified through objective and subjective assessments. The conceptualisation of the term SWB has been a long process and incorporates propositions regarding interconnecting constructs of wellbeing and/ or QOL. The research includes objective and subjective wellbeing as well as terms used to define wellbeing across the holistic perspective of physical, psychological and social perspectives. Wellbeing is understood by researchers differently to the individuals and families whom they study and by society generally and this has caused problems in defining the concept (Haigh, Lee, Shaw, Hawthorne, Chamberlain, Newman, Clarke & Beail, 2013). Studies have discussed the factors that are involved in the construction of wellbeing; however the question remains as to what they are measuring.

Inter-relatedness to quality of life constructs

Within the literature regarding wellbeing is the concept of QOL. This term is often used interchangeably with wellbeing as in Petry, Maes & Vlaskamp (2005). QOL has been discussed as encapsulating individuals and society's status as positive and healthy. To this end it is important to examine what sub constructs have been discussed within the literature to understand how to conceive and measure QOL and wellbeing. Regarding how researchers define wellbeing is an ongoing debate; however there are various different definitions that researchers have employed. These include more commonly quantifying life satisfaction on a scale, by asking the question *'how satisfied are you with your life'* (Lucas-Carrasco & Salvador-Carulla, 2011). Further related concepts include exploring a person's happiness and self-concept. Literature discussing wellbeing postulates that the concept is multifaceted and cannot merely be defined as exploring a person's satisfaction in life or their happiness. Rather QOL explores a multi orientated view of a person's world both objectively and subjectively. However due to the confusing nature of exploring wellbeing for people with intellectual disabilities and what the studies are attempting to define, a number of studies have been included with this in mind.

All but three of the studies examined in this review used quantifiable measures, and very few studies are available that work with individuals who have ID and receive their subjective responses related to their experience. Moreover proxy responding, that is responders who are doing so in lieu of the primary target responder, for example the parents or carers, in this instance for the individual with ID, is prevalent within the research and therefore a number of these studies have been included within this review. It is of importance to understand further how these proxy responding scores interrelate to the individuals with ID SWB.

Only one study (Haigh, Lee, Shaw, Hawthorne, Chamberlain, Newman, Clarke & Beail, 2013) within this review asked adults with ID, through interview, *'What makes you happy?'* This paper utilised a team of people from various groups and involved adults who had ID, which enabled a wider skills mix to undertake the research. SWB is the focus of this review as examining wider objective measures obscures what this really means to individuals, which is how they view their lives. Individuals with ID may face more challenges than those without these disabilities (Ali, Hassiotis, Strydom & King, 2012), therefore to understand the relational factors of influences of wellbeing are important to understand and promote. In Gans, Kenny & Ghany (2003), self-construct was compared between children and young people with and without ID and found that those with ID had a lower sense of self construct with regards to their intellectual ability than their peers as similarly discussed in Hensel, Rose, Kroese, & Banks-Smith (2002). This relates to the social comparison between the two groups, although moderating factors were discussed. These factors were relationships with other peers who had similar intellectual, communication and physical abilities, which appeared to be an important factor in positively influencing wellbeing.

Defining 'wellbeing'

For the purposes of this review, wellbeing refers to the subjective experiences of those individuals with ID. It refers to the challenges people face and what resources they have to face these challenges and maintain equilibrium of SWB. Wellbeing has been defined within the studies as relating to Seligman's (2011) PERMA principles as discussed with the introduction. These principles are discussed as what individuals are aiming to attain namely; to have positive emotions, engagements, relationships, meaning and accomplishments. These are determined by the environment in which people operate and their wider systems. Studies utilising a variety of QOL measures indicate that generally individuals with mild ID have marginally lower wellbeing scores than individuals without ID. Furthermore individuals with severe or profound disabilities were found to have significantly lower scores on wellbeing and QOL, which may be attributed to the social and health inequalities they face. Four key themes relating to wellbeing and included within Haigh et al (2013) were analysed using Thematic Analysis and drew out environmental factors as being high important which relates to Cummins' proposition that external buffers are mediating factor in maintaining wellbeing.

Further discussion behind these themes encapsulated issues pertaining to choice and independence for the individuals, access to activities and valuable social roles and relationships. These factors were described as being beneficial for the participants and related to features including self-determination, interpersonal relationships and social inclusion that are discussed in Morisse, Vandemaele, Claes, Claes & Vandevelde (2013). Indeed, across the studies one of the primary protective factors of wellbeing was important social relationships, especially connectedness with their parents as their primary care providers and sources of attachment, support and resources.

2. Psychosocial influences on wellbeing in people with ID

Relationships with parents

Bertelli, Bianco, Rossi, Scuticchio & Brown (2011) and Cramm & Neiboer (2011) both discussed the bidirectional relationship of the individuals with ID and their parents. These relationships have complex dynamics that are difficult to disentangle and define causality. Cramm & Neiboer (2011) demonstrated that changes in social interactions predicted QOL for children with ID and changes in positive emotions of children and their parents predicted changes in overall QOL of the children with ID. This proxy reported study and that of Bertelli, Bianco, Rossi, Scuticchio & Brown (2011) highlight that the wellbeing of the child or the parent can negatively or positively influence each other. Furthermore as parents had increased opportunities to meet others and be supported this then positively influenced their own wellbeing, which then is more likely to have a direct influence regarding the wellbeing of their children. In other words if parents of children with ID expose themselves to more social contact then this will in turn improve the social relationships for their children too, therefore influencing their wellbeing.

Relationships with carers

Haigh et al (2013) and Svetaz, Ireland & Blum (2000) specifically relate to interactions with carers and their influence upon the individuals with ID SWB. Both papers discuss the importance of these relationships in mediating their wellbeing, the reason being that they are sources of support from people who are able to understand their needs and their abilities and cater for them. Carers are employed and paid to support individuals with ID and are therefore monetarily motivated to influence wellbeing; they are also people who have chosen to do the job so are often emotionally motivated to assist (Scmidt, Power, Green, Lucas-Carrasco, Eser, Dragomirecka & Fleck, 2010). Operating within a system of a positive, motivated support network has been identified as being of importance by people with ID in influencing their happiness (Haigh et al, 2013). They are able to not only be supported emotionally and psychologically, but also materially. The access to resources is often managed by others, even though increasingly the finance is being managed by the people with ID, the transport, communication, planning of activities or initiating a network of resources requires the support of carers. As Haigh et al (2013) discusses, this enables facilitation to meeting others and further increasing their social network and therefore influencing their SWB.

Relationships with peers

Wellbeing broadly has been related to people connecting with others in positive relationships. Kinderman, Schwannauer, Potin and Tai (2011), highlighted that a primary mediating factor to a reduction of stressful life situations and therefore influencing wellbeing was having positive social support. Both Cummins' (2010) and Headey and Waring's (1989) models' of equilibrium supports the postulation that people require appropriate resources to meet the challenges they face. Studies Haigh et al (2013), Svetaz, Ireland & Blum (2000), Emerson & Hatton (2008), and Morisse, Vandemaele, Claes, Claes, & Vandevelde (2013) examine how relationships with peers who had ID was important to maintaining their SWB. Having meaningful relationships with people whom a person can relate to is evident throughout the literature on wellbeing and it is evident that this is equally, if not more important, for people with ID. These relationships enable an individual's self-concept to be compared against those with similar abilities in navigating the world (Beart, 2005). The model of self-efficacy discusses that individuals are able to measure their own ability to set goals and achieve tasks and this is within the context of comparison to other people. Judge, Bono, Llies and Gerhardt (2002) argued the concepts of locus of control; self-efficacy and self-esteem measured the same, single factor and Cummins (2010) discussed these as being related constructs to wellbeing. Therefore Gans, Kenny & Ghany's study (2003), which explores self-concept, measuring how the individuals view themselves when compared to other people, highlighted their own internal cognitive buffers as suggested by Cummins (2010). Individuals are comparing themselves to people who are of a higher ability then consequently their self-concept rating or SWB is reduced (Garaigordobil & Perez, 2007). In contrast, when individuals with ID compare themselves with people of a similar ability (Davies & Jenkins, 1997) then how they construct their view of themselves, their self-efficacy and consequently their SWB, will be positively influenced. This appears to similarly be evident in Vos, Cock, Petry, Van Den Noorgate & Maes (2010), whereby people with severe and profound disabilities were scored by proxy responders using the MIPQ measure and indicated that those individuals scored had a lower sense of SWB than their peers who had less disability. This may be due to the responder bias or due to being supported by people with much higher ability as well as requiring the support of others to do things for them. It is important to note however how these concepts overlap in how they are understood and measured within the literature.

3. Further influences of subjective wellbeing for people with ID

There have been a number of studies reviewed in this paper highlighting the relationships between proxy responders, those being parents or carers and individuals with ID and their responses regarding what influences their SWB. Carmeli, Zinger-Vakin, Morad & Merrick (2005) demonstrated how engaging in physical activity has an influence on SWB through a training programme that was performed three days per week for six months. The measure was an adapted self-concept measure and revealed that between the programme start and finish dates SWB scores significantly increased. Based on the previous work within this review paper this finding may be understood from a biopsychosocial perspective (Maiano, Ninot & Errais, 2001); however Carmeli et al. (2005) hypothesise that an increase in endorphins from the cardiovascular exercise can explain these results, which may be a reductionist approach as it focuses wholly upon the neurobiological aspect. It should be noted however that this is only one study and further evidence should be sought to finalise the assertion that these programmes have a positive impact upon wellbeing. Petry, Maes & Vlaskamp (2005) discuss, from interviewing support workers and parents, the basic QOL domains that they thought were important to the people with ID who they cared for. This was measured in two ways; firstly it depended upon whether the responders mentioned these domains spontaneously or secondly, through direct verbal prompts. The results indicated that the constructs of QOL/ wellbeing domains were seen differently in several aspects when compared to other populations. Domain measures of physical, material, social and emotional wellbeing alongside development and activities were all shown to be significant indicators of total QOL/SWB alongside depression and anger as being negatively correlated to positive wellbeing (Benson & Ivins, 1992). In this way thought needs to be given as to how society organises the environments we build for ourselves including for those individuals with ID. Additional factors that have specifically explored how wellbeing may be influenced for individuals with ID has had limited research beyond discussing with parents and/ or carers what they feel these may be. However the social environment above all has the widest reaching influence on wellbeing in keeping with the conceptualisation of the Social Model of Disability (Schlock et al, 2010), this also focuses upon social comparison with people deemed not to have a disability and the associated depression with perceived lower social comparison (MacMahon & Jahoda, 2008).

Discussion

The systematic literature review aimed to examine studies that investigated the factors influencing the SWB of people with ID. The findings identified in the majority of the 13 studies are quantified assessments across thousands of individuals. However, two of the papers were completed by parents or proxy reporters for people with ID. These papers were included to provide a wider context to the review into what influences SWB, although there are reported difficulties and potential inaccuracies with this approach. Only two studies used direct interviews with people who have ID and only one of those using semi structured interviews; however three key areas were identified from the findings that were shared through the studies. These areas were; understanding the wellbeing/ QOL concept, psychosocial influences on people with ID and important wellbeing influences.

Overview of research findings

The findings suggest that everybody from researchers, health care providers, to individuals and families, conceive wellbeing differently and there is as yet no unified approach to define SWB. Various models and measures are in place for understanding an array of concepts which are discussed as being useful when considering the question ‘*what* is SWB?’ A number of the factors have been identified in the literature relating to the concept. These are broadly QOL and health and various other concepts have been determined as being either directly or indirectly related to SWB, these being: self-concept, self-efficacy, self-esteem (Dagnan & Sandhu, 1999), optimism, life satisfaction and happiness. Individuals have reported a number of influencing SWB factors through the measures. These are predominately associated with having positive social relationships to the people in their lives and the environment in which they live. The significant relationships included those who cared directly for the PwID in addition to people within their peer group. However research suggests that relationships with peers who do not have ID decreases their sense of self concept (Crocker & Major, 1989) compared with peers who have similar cognitive abilities which can positively SWB through social comparison. Consequently peer relationships are important, but people with ID should have access to other people with ID to assist in their opportunities to compare themselves within their social environment, as this will which influence their self-concept and ultimately their wellbeing.

Parental and family relationships are also identified as being of great importance for influencing SWB. The reasons behind these relationships are complex, influencing each other through bi-relational causality. In other words this means that as one person’s wellbeing is increased or reduced this in turn affects their family member’s wellbeing. Being part of a loving, caring and supportive system that enables the provision of resources is hugely important throughout clinical psychology and attachment research. It is reported across the literature as being hugely important to a sense of SWB within people with ID as within people without ID. The literature suggests, however that these parental relationships are of greater significance for people with ID (Bauminger & Kimhi-Kind, 2008) and for longer periods as people with ID may stay within the family home longer due to the level of support they require (Greenberg, Seltzer & Greenley, 1993) and may not engage in as many significant and/ or romantic close relationships as people without ID. In fact one study Emerson & Hatton (2008) highlighted that particularly for women being married may decrease their SWB, perhaps due to the additional stress and complexity of engaging in such a relationship and these relationships may potentially be less equal due to powerful male partners.

Further factors identified as being important for people with ID, are the ability and resources to communicate (Ashdown, & Bernard, 2012), have good health, live in a safe environment and be involved within a positive ecological system of support, enriching activities and respected choice. As explored previously people with ID are at much greater risk of health and wellbeing inequalities and often have much less opportunity to manage certain aspects of their lives. Therefore these elements must be considered carefully by agencies to ensure people with ID are fully supported in accessing these services. These findings are in keeping with previous research related to Seligman's PERMA elements and equilibrium models as they discuss the resources necessary to influence and maintain wellbeing.

In one study physical exercise has demonstrated having an effect on wellbeing for adults with mild intellectual disability, the assumption by the researchers was that this was due to physiological effects; however previous evidence suggested that the increase in the wellbeing measure scores may also be related to the increase in social contact of peers not just purely the cardiovascular activity (Bult, Verschuren, Jngmans, Lindeman & Ketelaar, 2011). Interestingly, although people with ID described how their relationships were of most significance within various studies this was not always identified when proxies were reporting in the research. This discrepancy may indicate that parents and carers may not be fully aware of the important SWB influences of people with similar abilities to socialise with.

Limitations of the review

The search items produced a number of results which enabled a great amount of articles to be reviewed for inclusion in this study. Initially many of the papers appeared to explore the concepts of SWB of people with ID, however upon further investigation they focused upon a variety of other perspectives. Many focused upon others experiences of caring for, supporting, or having a family member who had an ID. In some cases, surprisingly, a great deal of research has been devoted to the negatives of having family members who have ID and how this affected their sense of wellbeing. A large amount of the literature suggested the difficulties that the carers face and the sense of loss of having a child with ID. Another difficulty faced, which is in line with these problems and that has been discussed within the review, is that SWB has yet to be defined satisfactorily by researchers. Various search terms were utilised and different combinations were then addressed and re-classified to ensure that as full a range of papers could be reviewed as possible. As a large amount of research articles were read this made the literature searching a time consuming process.

Due to the often complex and confusing definitions used to define SWB, the inclusion and exclusions criteria was similarly difficult to define. SWB has been defined using multiple definitions and incorporated into other concepts that are integrated, overarching or share similar elements. QOL research often confuses this definition further and these articles needed to be explored in depth to extrapolate the research that related directly to the key areas for review. To ensure that appropriate data was not excluded, papers that did not explicitly state that they were defining SWB were included as this would also have had the effect of reducing the available papers for review and providing fewer contexts. Moreover a direct perspective on SWB concerning views directly from people with ID would not have been beneficial to gain a broader view of the influences of SWB. This approach is supported by the fact that the majority of the evidence demonstrated that proxy responders, especially parents, are particularly important to the SWB of people with ID. They have also been discovered to have the closest reporting rates to their children in terms of being able to identify the salient influences; however more involvement of PwID is of vital importance.

Summary and implications

Understanding the factors that influence SWB for a person with ID is of vital importance as this population is exposed to life challenges greater than those people without ID. Therefore the influencing factor of SWB is required to be explored and reviewed concisely. The review discovered that although individuals with ID are able to be interviewed regarding their experiences and how these relate to their SWB, this has only been fully and inclusively undertaken once. The majority of evidence is found in the use of measures and the interviewing of proxies, which although is useful, is not permitting the full picture of wellbeing influences to be evident. The overwhelming view is that social relationships with peers and supportive carers especially is of highest importance because people with ID are then able to engage in challenging, enjoyable and meaningful activities (Cummins, 2005). They are also able to participate in these activities with people that can share their experiences and compare themselves too. This ensures that they are achieving what they feel is important with their peers. The implications of this are important for all parts of the system in which people with ID reside being conceived using ecological systems and family systems models. That is to work with polices, organisations and people in ensuring that children and adults who have ID are able to access groups with a variety of different purposes. The current research highlights that people with ID are often more isolated and suffer greater health inequalities than non-disabled populations. The evidence suggests that making available specifically sports and social programmes will increase levels of self-identity (Ninot, Bilard, & Sokolowski, 2000), and in turn self-concept and wellbeing. Programmes are in existence for people with ID to access, however there are a number of difficulties, whether that is support required to reach these services or the nature of them being unsuitable or inappropriate for the target population (Bodde & Seo, 2009). These programmes however are focused upon specific skills, and are understood as this by funders on the whole rather than with the aim of holistically influencing wellbeing. These services should be seen primarily as influencing SWB in people with intellectual disabilities and therefore significant in reducing other health inequalities and consequently higher long term costs.

The focus of future research

SWB research is a steadily growing field to explore the experiences of people with ID. However to date there is only one study available that has directly interviewed these individuals to discover what are the important factors that influences their SWB. The majority of research has used proxy responders and quantifiable measures, again these forms of evidence have shown limitations to understand the subjective experiences. The key findings from the research demonstrate that positive relationships are of high significance for people with ID and require to be focused upon in greater clarity. Key relationships are with people who are cognitively at a similar ability as this affects their value judgements when comparing themselves with others, which in turn affects their self-efficacy, self-concept and mood in terms of depression and consequently their wellbeing. Research may need to be conducted to understand how parents and carers understand the necessity of ensuring they support their children in accessing other people with ID. Further studies to explore the subjective experience of people with ID would be valuable to examine which factors are perceived as influencing their SWB by the individuals themselves. This review has found that this had only been undertaken once and the underutilisation and underrepresentation of individuals with ID is needed to be addressed to gain a clear perspective of their views. These should then be given much greater priority rather than other people responding for them. In short we should explore further the social model of disability and understand how it applies to the research that is conducted. The use of proxy responders have been shown to have little evidence in being able to predict another person’s experience of their inner world and interpretations of their external environment. These responders however are primarily utilised due to ease of research with these informants regardless of validity of evidence. Evidence also needs to be reported with the individuals regarding the effectiveness of services and programmes in terms of positively influencing SWB. In addition the evidence from this review would suggest that programmes should be encouraged and supported that ensure that parents and family members along with individuals with ID have opportunities to meet. The increase in SWB will influence each other and in turn improve outcomes for the wider system in which people live. The quality of the papers reviewed varied greatly in how they were presented and the methodology employed. Standardised measures of wellbeing are not being utilised. This may be due to the current difficulties researchers are having in defining wellbeing and in turn the finalisation of an assessment that reliably and validly measures the components. There is also a noticeable lack of qualitative research where individuals with ID are interviewed to determine the factors which they themselves feel influence their SWB. Therefore in future more attention should be given to clarifying this situation to ensure that information can be sought in to discovering the factors which can be agreed upon to assess the influences of wellbeing for this underrepresented population.

References

Ashdown, D & Bernard, M (2012) Can explicit instruction in social and emotional learning skills benefit the social – emotional development, wellbeing and academic achievement of young children? *Early Childhood Education Journal; 39, 397-405.*

Ali, A, Hassiotis, A, Strydom, A & King, M (2012) Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review*; Research in Developmental Disabilities.* 33, 2122-2140.

Bauminger, N & Kimhi-Kind, I (2008) Social information processing, security of attachment and emotion regulation in children with learning disabilities; *Journal of Learning Disabilities.* 41, 315.

Beart, S. (2005) 'I won't think of me self as a learning disability. But I have': social identity and self-advocacy; *British Journal of Learning Disabilities*. 33(3), pp. 128 – 131.

Benson, B & Ivins, J (1992) Anger, depression and self-concept in adults with mental retardation; *Journal of Intellectual Disability Research.* 36, 169-175

Bertelli, M, Bianco, A, Rossi, M, Scuticchio, D & Browm, I (2011) Relationship between individual quality of life for people with intellectual disability living in Italy; *Journal of intellectual Disability Research*. 1136-1150. *

Bodde, A & Seo, D (2009) A review of social and environmental barriers to physical activity for adults with intellectual disabilities; *Disability and Health Journal.* 2, 57-66.

Braun, V & Clarke, V (2006) Using thematic analysis in psychology; *Qualitative Research in Psychology.* 3 (2) pp 77-101.

Bray, A. (1999). *Research involving people with Intellectual Disabilities: Issues of informed consent and participation.* (Research report). Dunedin, New Zealand: Donald Beasley Institute.

Brown, I. (2007) What is meant by intellectual and developmental disabilities? In I. Brown & M. Percy (Eds.) *A comprehensive guide to intellectual & developmental disabilities* (pp. 3-16). Baltimore: Paul H. Brookes.

Brown, R & Brown, I. (2005) The application of quality of life; *Journal of Intellectual Disability Research. 49*(10), 718-727

Brown, I & Radford, J (2007) Historical overview of intellectual and developmental disabilities. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual & developmental disabilities* (pp. 17-34). Baltimore: Paul H. Brookes.

Brown, R, Schalock, R & Brown, I (2009) Quality of life: Its application to persons with intellectual disabilities and their families – Introduction and overview; *Journal of Policy and Practice in Intellectual Disabilities.* 6, 2-6. *

Bult, M, Verschuren, A, Jngmans, M, Lindeman, E & Ketelaar, M (2011) What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in Developmental Disabilities.* 32, 1521-1529.

Campbell, A., Converse, P. E., & Rodgers, W. L. (1976) *The quality of American Life: Perceptions, evaluations and satisfactions*. New York: Russell Sage Foundation.

Carmeli, E, Vaknin-Zinger, T, Morad, M & Merrick, J (2005) Can physical training have an effect on wellbeing in adults with mild intellectual disability; *Mechanisms of Aging and Development.* 126 (2) 299-304. *

Christopher, J (1999) Situating psychological well-being: Exploring the cultural roots of its theory and research; *Journal of Counselling & Development.* 77, 141–152.

Cooney, G, Jahoda, A, Gumley, A & Knott, F (2006) Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations; *Journal of Intellectual Disability Research. 50, 432-444.*

Cramm, J & Nieboer, A (2012) Longitudinal Study of Parents Impact on Quality of Life of Children and Young Adults with Intellectual Disabilities; *Journal of Applied Research in Intellectual Disabilities*. 25, 20-28. *

Crocker, J & Major, B (1989) Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review. 96*(4), 608-630.

Cummins, R (2005) Caregivers as managers of subjective wellbeing: A homeostatic perspectives. *Journal of Applied Research in Intellectual Disabilities. 18*(4), 335-344.

Cummins, R (2010) Subjective wellbeing, homeostatically protected mood and depression: A synthesis; *Journal of Happiness Studies. 11, 1-17.*

Dagnan, D & Sandhu, S (1999) Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research. 43* (5), 372-379.

Davies, C & Jenkins, R (1997) 'She has different fits to me': How people with learning difficulties see themselves; *Disability & Society*. 12 (1), pp. 95-110.

Diener, E. (1984) Subjective wellbeing; *Psychological Bulletin. 95*, 542–575.

Diener, E. (2009) Subjective wellbeing. In E. Diener (Ed.).*The science of well-being* (pp. 11–58): New York: Springer.

Diener, E., Lucas, R. E., & Scollon, C. N. (2006). Beyond the hedonic treadmill: Revision of the adaptation theory of well-being; *American Psychologist. 61* (4), 305-314.

Diener, E., Napa Scollon, C., & Lucas, R. E. (2003) The evolving concept of subjective well-being: The multifaceted nature of happiness; *Advances in Cell Aging and Gerontology. 15*, 187-219.

Diener, E., Suh, M., Lucas, E., & Smith, H. (1999) Subjective well-being: Three decades of progress; *Psychological Bulletin. 125* (2), 276–302.

Dodge, R, Daly, A, Huyton, J & Sanders, L (2012) The challenge of defining wellbeing; *International Journal of Wellbeing. 2, 222-235.*

Downs, S & Black, N (1998) The feasibility of creating a checklist for the assessment of the methodological quality both of randomized and non-randomized studies of health care interventions; *Journal of Epidemiology Community Health*. 52, 377-384.

Emerson, E (2011) Health status and health risks of the 'hidden majority' of adults with intellectual disability; *Intellectual & Developmental Disabilities*. 49:155-65.

Emerson, E & Glover, G (2010) Health Checks for People with Learning Disabilities: 2008/9 & 2009/10; Durham: *Improving Health & Lives: Learning Disabilities Observatory*.

Emerson, E & Hatton, C (2008) Self-reported well-being of women and men with intellectual disabilities in England; *American Journal on Mental Retardation*. 113 (2), 145-155. *

Emerson E, Baines S., Allerton, L & Welch, V (2012) Health Inequalities and People with Learning Disabilities in the UK: Improving Health and Lives: *Learning Disabilities Observatory.*

Faust, H., & Scior, K. (2008) Mental health problems in young people with learning disabilities: the impact on parents. *Journal of Applied Research in Intellectual Disabilities. 21* (5), 414–424.

Felce & Perry (1995) Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications *Research in Developmental Disabilities*. 16, 51–74.

Forgeard, M, Jayawickreme, E Kern, M. & Seligman, M (2011) Doing the right thing: Measuring wellbeing for public policy. *International Journal of Wellbeing*. *1* (1), 79-106.

Gans, A, Kenny, M & Ghany, D (2003) Comparing the Self Concept of students with and Without Learning Disabilities; *Journal of Learning Disabilities.* 287-295. *

Garaigordobil, M & Perez, J (2007) Self-concept, self-esteem and psychopathological symptoms in persons with intellectual disability. *The Spanish Journal of Psychology. 10* (1), 141-150.

Gasper, D. (2010) Understanding the diversity of conceptions of well-being and quality-of-life. *Journal of Socio-Economics. 39*, 351-360.

Greenberg, J, Seltzer, M & Greenley, J (1993). Aging parents of adults with disabilities: The gratification and frustrations of later life caregiving. *Gerontologist. 35*, 542-550.

Haigh, A, Lee, D, Shaw, C, Hawthorne, M, Chamberlain, S, Newman, D, Clarke, Z & Beail, N (2013) What things make people with a learning disability happy and satisfied with their lives: An Inclusive Research Project; *Journal of Applied Research in Intellectual Disabilities.* 26, 26-33. *

Headey, W (2006) *Happiness: Revising set point theory and dynamic equilibrium theory to account for long term change.* Berlin: DIW German Institute for Economic Research.

Headey, B & Wearing, J (1989) Personality, life events, and subjective well-being: Towards a dynamic equilibrium model; *Journal of Personality and Social Psychology*. 57, 731-739.

Hensel, E., Rose, J, Kroese, B & Banks-Smith, J (2002) Subjective judgments of quality of life: a comparison study between people with intellectual disability and those without disability; *Journal of Intellectual Disability Research. 46* (2), 95-107. *

Jahoda, A., Markova, I., & Cattermole, M. (1988) Stigma and the self-concept of people with a mild mental handicap; *Journal of Mental Deficiency Research*. 32(2), pp. 103–115.

Judge T, Bono J, Ilies R, Gerhardt M (2002) Personality and leadership: A qualitative and quantitative review; *Journal of Applied Psychology*. 87, 765–780

Kinderman, P, Schwannauer, M, Pontin, E & Tai, S (2011) The development and validation of a general measure of wellbeing: the BBC wellbeing scale; *Quality of Life Research.* 20, 1035-1042.

Landis, J & Koch, G (1977) The measurement of observer agreement for categorical data; *Biometrics.* 33 (1): 159–174.

Li, E, Tam, A, & Man, D (2006) Exploring the self-concepts of persons with intellectual disabilities; *Journal of Intellectual Disabilities. 10* (1), 19-34.

Lucas-Carrasco, R & Salvador-Carulla, L (2012) Life satisfaction in persons with intellectual disabilities; *Research in Developmental Disabilities. 33 (4)* 1003-1109. *

Lyubomirsky, S, Tkach, C & Dimatteo, M (2006) What are the differences between happiness and self-esteem? *Social Indicators Research. 78* (3), 363-404.

MacMahon, P & Jahoda, A (2008) Social comparison and depression: People with mild and moderate intellectual disabilities. *Journal of Intellectual Disability Research. 113* (4), 307-318. *

Maiano, C, Ninot, G & Errais, B (2001) Effects of alternate sport competition in perceived competence for adolescent males with mild to moderate mental retardation; *International Journal of Rehabilitation Research*. 24, 51–58.

McGuire, E, Daly P &Smyth F (2010) Chronic pain in people with an intellectual disability: Under-recognised and under-treated? *Journal of Intellectual Disability Research*. 54:240-45.

Morisse, F, Vandemaele, E, Claes, C, Claes, L & Vandevelde, S (2013) Quality of Life in Persons with Intellectual Disabilities and Mental Health Problems: An explorative study; *The Scientific World Journal.* Vol. 2013 (2013), ID 491918. *

National Institute for Health and Clinical Excellence (January 2009) *The guidelines manual. London: National Institute for Health and Clinical Excellence*. Available from: www.nice.org.uk.

Ninot, G, Bilard, J, Delignières, D & Sokolowski, M (2000) The effects of sport participation in perceived competence for mentally retarded adolescents; *Adapted Physical Activity Quarterly. 17*, 184-197.

Petry, K, Maes, B & Vlaskamp, C (2005) Domains of Quality of Life of People with Profound Multiple Disabilities: the Perspective of Parents and Direct Support Staff; *Journal of Applied Research in Intellectual Disabilities.* 18, 35-46. *

Schalock, R. L. (2004). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies. 14*(4), 204-215.

Schalock, R, Borthwick-Duffy, A, Bradley, V, Buntinx, W, Coulter, D, Craig, E, et al. (2010). *Intellectual Disability: Definition, classification and systems of support* (11th Ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R, & Felce, D (2004) Quality of life and subjective well-being: Conceptual and measurement issues. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *International handbook on applied research in intellectual disabilities.* (pp. 261-279.). Chistester, West Sussex: John Wiley & Sons.

Schmidt, S, Power, M, Green, A, Lucas-Carrasco, R, Eser, E, Dragomirecka, E & Fleck, M (2010) Self and proxy rating of quality of life in adults with intellectual disabilities: Results from the DISQOL study; *Research in Developmental Disabilities.* Vol. 31, No. 5, 09.2010, p. 1015-1026.*

Seligman, M (2011) *Flourish – A new understanding of happiness and well-being – and how to achieve them.* London: Nicholas Brealey Publishing.

Stratham, J & Chase, E. (2010) *Childhood wellbeing – A brief overview*; Loughborough: Childhood Wellbeing Research Centre.

Suh, E, Diener, E & Fujita, F. (1996) Events and subjective well-being: Only recent events matter; *Journal of Personality and Social Psychology. 70*(5), 1091–1102.

Svetaz, M, Ireland, M & Blum, R (2000) Adolescents with Learning Disabilities: Risk and Protective Factors Associated with Emotional Wellbeing: Findings From the National Longitudinal Study of Adolescent Health; *Journal of Adolescent Health*. 27. 340-348. *

Vos, P, De Cock, P, Petry, K, Van Den Noortgate, W & Maes, B (2010) What makes them feel the way they do? Investigating the subjective wellbeing in people with severe and profound disabilities; *Research in Developmental Disabilities.* 1623-1632*

Yazbeck, M., McVilly, K & Parmenter, T (2004) Attitudes towards people with Intellectual Disabilities. *Journal of Disability Policy Studies*, *15*(2), 97-111.

References marked with an asterisk (*) indicate studies included in the review

Part Two

Empirical Research

Subjective wellbeing for young people with intellectual disabilities: An exploratory study into the experiences of young people with intellectual disabilities attending a sports group.

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Abstract

This study aimed to explore how young people with intellectual disabilities experienced attending a sports group that was attended by peers with similar disabilities and how it impacted upon their subjective sense of wellbeing. Eight young people aged between 9 – 13 years old with intellectual disabilities (n=7 males and n=1 female) who had regularly attended a sports programme were recruited, alongside five parent participants.

The young people participants completed a subjective wellbeing measure and a semi structured interview alongside their parents. This involved the use of visual aids and behavioural observational methods to complement the verbal data. The content was analysed using Thematic Analysis. The themes suggested that these young people found that attending the sports group supported them in connecting with others, feeling accepted within an inclusive environment, enabled positive emotions and bringing physical health benefits. The data collection methods and future research are explored as new ways of exploring subjective experiences of a population that has often been difficult to access.

This empirical study has been prepared for publication in the Journal of Applied Research in Intellectual Disabilities (JARID).

(Word count: 9673, including tables)

What is wellbeing?

A number of researchers have attempted to describe and define wellbeing over the recent decades (Dodge, Daly, Hayton & Sanders, 2012). Researchers have described wellbeing as a multifactorial, multidimensional concept that encapsulates complex frameworks of varying levels. These incorporate biological, sociological and psychological constructs both measured subjectively and objectively (Cummins, 2005). The wellbeing construct is discussed within all multidisciplinary fields of healthcare and other services such as education and social care and has received an increasing amount of research focus in recent years (Brown, Schalock & Brown, 2009). In the literature, wellbeing is identified as having overlapping concepts including; quality of life (QOL), life satisfaction, health and happiness (Diener, Lucas & Scollon, 2006). To disentangle these concepts into one unifying model is difficult to achieve (Brown, Schalock & Brown, 2009), therefore one overarching explanation that is agreed by all researchers and policy makers is difficult to attain. Varying concepts have been explored to provide a unifying, if less than comprehensive paradigm in which to operate (Diener, 2009; Gasper, 2010). Wellbeing has been understood from both an objective and subjective perspective to gain a holistic understanding of a person’s experience (Felce & Perry, 1984; Diener, Suh, Lucas, & Smith, 1999). Objectively a person’s wellbeing has been assessed using various in measurements of educational attainment, financial circumstances and living environment amongst others. However these measures have proved to be poor predictors of subjective wellbeing (Forgeard, Jayawickreme, Kern, & Seligman, 2011). Seligman (2011) developed a definition of wellbeing as a construct and discussed that it consists of the “nurturing” of one or more of five elements: The PERMA acronym is used to stand for; Positive emotions, Engagement, Relationships, Meaning, and Accomplishment. Seligman (2011, pp 101), states that these five elements are *“the best approximation of what humans* *pursue for their own sake"* and reconciles differing perspectives on the theory and measurement of wellbeing.

Wellbeing equilibrium models

An important development of SWB concept has been in understanding wellbeing as an equilibrium model (Cummins, 1995, 1998). Cummins outlined in a number of research papers, a model for the homeostatic maintenance of SWB in what might be understood as a bio-psycho-social model of wellbeing, proposing that wellbeing may be regulated across cultures. Consequently, from the perspective of Cummins' Homeostatic Theory, individuals are able to achieve a normative range of SWB in diverse personal circumstances. This means that regardless of the challenges that individuals face in their lives a return to 'normal' wellbeing balance is achieved after a period of time. Cummins goes on to explain however that when the strength of an extrinsic influence exceeds the adaptive capacity of the individuals homeostatic system to return their sense of wellbeing to the normal range then the SWB of the person will change. Cummins developed a haemostatically protected mood (HP mood) model which is described as being determined by 'cognitive buffers'. These buffers are discussed as being both internal and external. External buffers are determined by the environment and relationships with others and internal buffers consist of three factors (Cummins & Nistico, 2002). These include the self-esteem (Kernis & Goldman, 2002), Optimism (Carver & Scheier, 1990; Chang, 1998) and perceived control of the behaviour of the individual and cognitive attempts to change their external world to make it more acceptable (Cummins, 2010). Therefore to influence an individual's wellbeing researchers need to understand whether the ecological system allows for a perceived sense of control over themselves and their environment, whether a person can have hope for their future and whether the system allows individuals to evaluate their self-concept in comparison to others as favourable. Recently Dodge, Daly, Huyton and Sanders (2012) developed an equilibrium model disagreeing with Seligman’s contention that wellbeing is a construct and describing it as ‘*state of being’*. The researchers proposed that wellbeing is a balancing point between an individual’s available resources and the challenges they face, thus being a dynamic rather than a homeostatic process as Cummins proposed. The researchers propose that this definition could be used to aid an accessible measurement of wellbeing and further the understanding of this ‘*state of being’*. Seligman (2011) argues that this state can be achieved through the promotion of the PERMA elements, which in turn will increase the resources in which to face the life challenges that both Cummins and Dodge et al (2012) propose. These are currently the best models in which to understand the wellbeing concept and therefore how to influence wellbeing.

Socially constructed models

The American Association of Intellectual Disabilities (AAID) postulates that the Social Model of Disability is now the prevalent paradigm in understanding the needs of people with intellectual disabilities (ID) as described by Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter, Craig, et al, (2010). This model focuses upon classification of intellectual disability in a multi-dimensional perspective. It includes all the dimensions and features that affect human functioning, such as intellectual abilities, adaptive behaviour, health, participation, context and individualised support (Bach, 2007). The environment is seen as the disabling factor for people whereby the ecological structure creates and reinforces disability as the prevailing construct which people face (Brown, 2007). Barriers are psycho-emotional, thereby negatively affecting an individual’s identity, and in this sense will affect that individuals sense of self, their self-esteem, self-efficacy and therefore their subjective wellbeing (Buttner & Hasselhrn, 2011).

Alongside changes considering the social model of disability there has been a paradigm movement concerning childhood (Shakespeare & Watson, 1998). Childhood has been re-conceptualised and what has emerged is a view that children are seen as individuals who make decisions, operate consciously and are a particular social group (Davis & Watson, 2002). As this study is focusing on children with intellectual disabilities these defining models must be considered in the ecological systems in which they operate.

Emerson, Baines, Allerton and Welch (2012) identified significant health inequalities experienced by people with ID and their families. The literature suggested that the general health status of people with intellectual disabilities is much worse than those without these social difficulties (Emerson & Heslop, 2010). Emerson and Hatton (2007) highlighted that this difference was predominately due to the cumulative risk of exposure of social disadvantage and the social construction of disability. These inequalities across the biopsychosocial aspects are influenced by the system in which these individuals and families live and need to be fully considered when developing solutions to positively influence SWB (Emerson, 2010).

Sports, activity, exercise and wellbeing.

Engaging in exercise has long shown positive physical health effects, in addition to this, positive well-being effects have been reported for adults (Boutcher, 2000; Callaghan, 2004; Atlantis, Chow, Kirby & Singh, 2004). A few studies on the effect of physical training on general well-being and self-image in adults and children with ID have been reported (Carmeli, Vaknin-Zinger, Morad, & Merrick, 2005; Golubovic, Maksimovic & Glumbic, 2012). These studies have explored the positive effects of exercise on fitness levels, Ninot, Bilard and Sokolowski (2000) researched competing in athletics as a vehicle for improving the self-image of PwID. They discovered that athletics could improve the wellbeing of an individual if the activities were within the physical possibilities of what the participant could achieve, because if it was too difficult this would then have a negative effect on their wellbeing. Similarly Dykens, Roser and Butterbaugh (1998) demonstrated that exercise and sports in young people with developmental disabilities improved physical and psychosocial elements on a quantifiable measure. It is therefore likely that when exploring the SWB concept with young people then they may be able to qualify previous research highlighting what elements of attending a sports group are important in influencing their SWB. However, to the author’s knowledge, there have been no studies exploring the qualitative experiences of children with intellectual disabilities attending a sports group and how this may affect their SWB. Indeed people with ID have been underrepresented from research that explores SWB from the perspective of the individual and the people who know them well. This means that it is unlikely that theoretical models will be developed to ensure that people with ID can be included in understanding the influences to enhance their well-being.

Rationale

This study seeks to address this important gap in current literature by adopting creative and theoretically robust ways of enabling young people with ID to participate in research.

Aims

1. To explore how people experience attending a sports group and how this influences their wellbeing.
2. To understand how to engage an underrepresented group of people in research.
3. To develop methods to collect and analyse data to provide a form of expression for this population.

4. To evaluate whether a wellbeing measure, which incorporates the latest wellbeing research, can be utilised for young people with ID.

Method

Design

This study used qualitative methods to explore how young people with intellectual disabilities experience participating in a sports group. A discovery-orientated approach that evolved as the research methods developed was taken and data was analysed using Thematic Analysis (TA). This was employed to explore how the participants understood attending a sports group in relation to their personal and social worlds and the interpretations they had regarding their relationships and the benefits and difficulties they faced within the group. Thematic Analysis was chosen as its theoretical perspectives are well placed for this study in that it affords the opportunity to utilise a variety of data collection methods and interpretation techniques (Braun and Clarke, 2006). A detailed rationale for the use of Thematic Analysis for this study is included in Appendix 6.

Measures

1. A subjective wellbeing measure (Kinderman, Schwannauer, Pontin, & Tai, 2011)was adapted to quantify the young person’s perception of their SWB.

2. An interview was conducted with the participants, with the purpose to explore their experiences. This included drawings which were discussed by the young person participants and described in the results.

3. Behavioural observations of the young person participants.

The analysis of observations and drawings followed the same principles regarding TA as discussed in Braun and Clarke (2006).

Subjective wellbeing

Participants were asked to undertake a two part data collection interview. The first part involved completing an adapted BBC wellbeing measure (Kinderman, Schwannauer, Pontin, & Tai, 2011) (Appendix 7). This measure was used to assess the participant's wellbeing scores objectively, to understand if there were any exceptional issues that may have influenced their responses when answering questions within the interview and to explore if a wellbeing measure could be constructed for this population. If a young person participant mentioned anything regarding a lack of basic needs or access to healthcare then this may have affected their responses on the, whilst not being related to their experiences of the group. This measure was also introduced to understand if a subjective measure could be appropriately adapted for a population of young people with ID. Question 23 was removed as this was not appropriate to ask children under 18. With the removal of this question the mean score was included artificially to ensure that the scores could still be compared with the original response scores (Kinderman, Schwannauer, Pontin & Tai, 2011). The responses remained on a four point likert scale with smiley face pictures complementing and used alongside the written response. An example of the adapted question '*Are you satisfied with the quality of your sleep?'* to *'Do you get enough good sleep?*' with the responses still being *'extremely'*, *'very much'*, '*a little bit'* and *'not at all'.*

Figure 1: Example of responses with smiley faces

1: *Not at all*	2: *A little bit*	3: *Very much*	4: *Extremely*
			

Self-reported experiences of sports group

The second part of the study was a semi-structured interview. The questions followed guidelines regarding questioning children with intellectual disabilities. The responses were often single word answers and therefore further questioning needed to be included to elicit further information from the participants. Sections of the interview used cue cards of illustrated emotional faces to help identify the psychological states in question relating to specific environments (Prosser & Bromley, 1998). Participants' hand-drawn illustrations (Appendix 12) were used and aided in the description to enable further exploration of the young person's participant experiences. The question asked to the participants was '*draw a picture of what you think of the sports group'*.

The parents of five of the participants were also involved in the semi structured interviews to assist the young people in their responses and provide further information to the verbal data regarding their child's experiences, they were also participants. The use of their interview responses again is informed through the use of previous research and the results of the pilot study. This is discussed further in the study.

Behavioural observations

This method is important as it supplemented the self-reported interviews. Following a literature review and pilot study behavioural observations could afford non-verbal communication within the interview and the systemic observation of the social interactions with the group members. This measure afforded the opportunity to provide further richness to the data and give a clearer picture of the children's experiences (Petry & Maes, 2006) as described through their verbal responses. Some of the participants were unable to provide a concise verbal response to some of the questions and therefore observations of their body and facial language were used to provide further information through alternative communication i.e. nodding or shaking of their head to provide yes or no answers to questions. Systemic observations were also used to discover the experiences of the individuals and the group as a whole. This was used to confirm, disprove or ask further questions regarding interview responses and lead to further investigation. Throughout the interview, the verbal responses were recorded using a voice recorder and behavioural responses were recorded by writing them down for each question and a timing was made for this recording. This was to ensure that if, or when the young people did not or could not respond verbally then their responses could still be recorded.

Procedures

Ethical considerations

The School of Health and Social Care at the University of Hull research and ethics committee approved the study. The interviews all took place in a private room at the sports centre where the participants attended the sports group. The participant's parents were asked if they wished to attend the interview to support the children, of which five elected to do so. The participants were asked only to provide information and responses which they felt comfortable sharing and were informed that the information they provided would be anonymised. During the interviews no risk to any participant was identified and none of the participants required any extra support (Bray, 1999). Additionally none of the participants wished to exercise their right to withdraw from the study. The recorded interviews were stored securely on encrypted and password protected computer software and destroyed after they were transcribed. All names and distinguishing features were anonymised and pseudonyms were used. The participants were ascribed a unique identifying number and the master list was kept separate from the collected data.

Participant identification

Table 1: participant inclusion and exclusion criteria

Inclusion	**Exclusion**
YPwID Ages between 9 – 18 years old	If parental consent was unobtainable
If the participant had been attending the group regularly (at least 50 % of the time over a period of at least 6 months)	Non English speaking
Identified as having an intellectual disability	Did not have an intellectual disability
Able to understand verbal communication	Did not have a mental health problem or learning disability that was primary to their intellectual disability

A purposeful sampling approach was used to recruit participants from one specific community sports group which was available for young people and adults with intellectual disabilities. The researcher presented the proposed study to the community group's administrators and group leaders in the first instance, and then to the parents of the potential participants to explain the rationale and procedure of the study and to consult regarding any potential issues they may have had about the process. The community sports group administrators agreed to the study with the consent of the parents. The parents were then asked to provide initial consent if they agreed that their children could be asked if they wished to be interviewed. At this point the inclusion and exclusion criteria were discussed to identify the participants who were attending the group. Up to 15 potential participants were identified and were approached over the subsequent weeks with a verbal and visual explanation of the intended study and provided with an information sheet for themselves and their parents (Appendix 10). If the young person was interested in taking part, they and their parents were asked to complete the consent form. Their contact details were collected at this point and they consented to be contacted by the researcher. This consent form was then collected directly by the researcher or by the group leaders and then passed onto the researcher. There was no incentive offered to participate in the study.

Process

The researcher contacted the potential participant and their parent and/ or carer when the consent form (Appendix 10) was received and a suitable time and date to conduct the interview was arranged. As all of the participants were under the age of 18 their parents were asked and encouraged to consult with their children about attending the interview process. On five occasions the parents attended. On the three occasions parents did not attend, they remained within the same building.

The data collection was a three part process involving interviews with the young people and their parents, behavioural observation of the young people during the interview and the drawings of the young people. The interview process commenced with a set structure of reviewing the information sheet and the consent form and a verbal and visual explanation of the format the interview would take (Antaki & Rapley, 1996). This included a structured interview of the adapted BBC Wellbeing questionnaire, followed by a semi-structured interview with offered parental supports and participation and finally by the completing a drawing and explaining the drawing of what they thought about the sports group. The participants were all informed that if they wished to stop the interview at any time they could, and that the interview may take place over a number of sessions. This happened on two occasions and was due to the various potential barriers that are present when interviewing participants from this population, such as concentration and attention levels and expressive language difficulties which led to increased tiredness and/or anxiety (Antaki, 1999; Finlay & Lyons, 2001). The participants were advised that approximately three months after the interviews had taken place and the data analysed that they and their parents would be invited to meet with the researcher to validate the themes of their interview.

The participants and parents were all encouraged to ask any questions regarding the study before and after the interview with the researcher. The participant's level of distress was monitored by the researcher and their parent, if they had attended the interview, and the participants had the opportunity to seek an immediate source of support from their parents or group leaders at any point during the interview. At no time were any of the participants distressed during or after the interview, this was also checked with the parents and the children themselves on subsequent meetings and with the group leaders. The participants were invited to attend a meeting to discuss the findings of the study and were all subsequently sent a summary of the results.

Participants

Eight young people participants were interviewed and five parent participants were recruited. Five parents accompanied their children to support them emotionally and communicatively within the interviews and their responses were also analysed. The interview was conducted in tandem with their child. This was to ensure that both parties heard and understood each other's responses and the parents were able to add verbal richness to their child's responses. The young people's age range was 9 – 13 years old (M = 11 years and 4 months; SD = 1.19). The participants had been attending the sports group for at least six months and had attended over 50 % of the sessions available within the period. The participants were interviewed between December 2012 and February 2013, after being recruited from the community sports group. The participants had been identified from a very young age as having an intellectual disability and were either attending a specialist secondary school for young people with intellectual disabilities or had been identified by their primary school and their Local

Education Authority as having an intellectual disability. The demographic information regarding the participants is provided in Table 2.

Table 2: participant demographics

Participant pseudonym	Age	Gender	With proxy responder	% of sports sessions attended ion 6 months from August 2012 – February 2013.
1. Joseph	11	M	N	82
2. Kevin	12	M	Y	100
3. Andy	9	M	Y	78
4. Brian	11	M	N	60
5. Oliver	12	M	Y	100
6. Jim	11	M	Y	100
7. Evan	12	M	Y	100
8. Bethany	13	F	N	76

Pilot study

A pilot study was conducted to ensure that the structure and format of the interview process was appropriate for the population, and this was completed in consultation with the young people and their parents. One of the primary barriers of conducting a qualitative study with the young people with ID who are participants is the reduction in the capacity of expressing language along with cognitive deficits. The interview questions, prompts and the drawing exercise were adapted following the pilot study and consultation with the interested parties.

This pilot study was conducted with three young people and three parents as participants in an interview process. This was required as a primary study had not been undertaken before with young people with ID is this way and therefore further information was required to understand how this would be done successfully. From this pilot study it was discovered that further methods of data collection were required to attempt to gain richer data and explain the young people’s experiences where more conventional methods could not have achieved this. This was predominately due to the verbal and cognitive difficulties that are inherent in working with this population. However it did not mean that it could not be achieved, rather it meant that more creativity was required ensuring that these individuals could be given a voice that was less constrained by the boundaries of analysing verbal interviews alone.

With this goal in mind the data collection methods were adapted and behavioural observations were decided to be included to overcome some of the inherent difficulties of interviewing a population that may not respond in the way that mainstream populations and indeed research designers would wish. Alongside the use of behavioural observations to record nonverbal communication, drawings were decided to be used as a medium to afford the participants a vehicle in which to communicate their experiences without the often difficult task of verbalising these.

In addition the BBC wellbeing questionnaire measure (Kinderman, Schwannauer, Pontin, & Tai, 2011) is a valid measure for assessing an individual’s wellbeing. It was adapted to ensure it was accessible for children with serious consideration being given how the measures constructs may have been altered. The author was contacted and agreed to the changes.

Data analysis

The three sources of information were analysed using TA. The interviews were all recorded using a voice recording device and were then transcribed into text by the researcher which further enhanced the immersion with the data. The transcripts were written and analysed one at a time in the order they were gathered.

The process for analysing the observational data followed the same development. The behavioural data was recorded in real time during the verbal interviews and then coded, overlaying the verbal responses when these where being transcribed and were mapped according to the time recorded.

The drawings were also analysed using this process as these were discussed with the participants either during or immediately after the image was produced. A scaffolded questioning technique was employed so that the young people could describe their drawings, the meaning and context of them. This included what characters were in the drawings, any relationships that were present, the facial and body expressions and if there was any significance of these and the context in which these images were imagined. In this way the young people were able to describe their experiences using a tangible image that was shared between them and the researcher and because of this allowed for freer expression of their experiences and a reduction in their anxieties when in an interview situation.

The data analysis procedure was consistent with the Thematic Analysis (TA) process as described by Braun and Clarke (2006). Every transcription was read and re-read several times and exploratory comments and emerging themes were identified, and those that appeared to be connected were grouped together. This process was ongoing for several weeks and discussed with a group of researchers to discover any inconsistencies. Following this process, themes were clustered together and subsequent group discussions were sought. A cross case analysis was then undertaken to identify common themes among the transcripts which were then comprehensively integrated to identify the four key themes. The significance of these themes assessed in relation to the research questions. An example of this data analysis is demonstrated in Appendix 13. To further increase the validity of these interpretations members of the researchers group and academic supervisors were involved in the analysis process to ensure they were grounded in the research data. These validation checks ensured that themes were openly discussed and re-organised to create the final identified themes.

Results

Data from the adapted BBC wellbeing measure

The data collected from the study included a quantitative measure (BBC Wellbeing Measure (Kinderman, Schwannauer, Pontin, & Tai, 2011) to understand the young people's perception of their SWB. This measure was adapted for the population and the results are illustrated below.

Table 3: Quantitative results from adapted BBC wellbeing questionnaire

	Participant pseudonym	General mean scores
	Whole sample	**69.13**
1.	James	51
2.	Kevin	65
3.	Andy	51
4.	Brian	71
5.	Oliver	76
6.	Jim	76
7.	Evan	67
8.	Bethany	96

These results show that the general wellbeing scores (Mean = 69.13; Median = 69, SD = 14.63; minimum 51, maximum 96) were higher with those of the validity study, Mean = 54.56 (Median = 54; SD = 12.99). The mean score is higher than that recorded by the reliability and validity study conducted by Kinderman, Schwannauer, Pontin, & Tai (2011). The scores across all of the measures and sub factors were higher than those discussed in the original paper.

Themes drawn from the analysis

The young people generally experienced attending the group in the same way. There were elements that were shared by the participants and these generated themes which were then clustered into four core themes. In Appendix 11, supporting quotes for each theme are documented; these verbal themes are supported by using behavioural observations, emotional faces identification and hand drawn pictures (Appendix 12). All of these data collection methods have been included to support the extrapolated themes and discussed.

The four themes were *'feeling the same as other people', 'positive emotions', 'connected to others'* and '*fitter and stronger'.*

Feeling the same as other people

All of the child participants and their parents made reference to the sports group being populated by their peers and that it offered a unique environment in which the children could operate outside of school or home environments. As the sports group had different structures, boundaries and objectives from these other environments it ensured that the young people's behaviour was able to be different due to these altered constructions. It was mentioned by the participants that they were able to meet people who were the same in terms of cognitive and physical ability. Generally the participants felt that due to the nature of the group they did not feel threatened and were able to enjoy the group in an environment which was very different to what they generally experienced in other environments. It was generally reported that the sports group offered the only other social outlet for these young people during the week and afforded the only opportunity to engage in play and games with people who were accepting of them, communicated similarly to them and could socially compare themselves too.

"I come because I don't get picked on as much. At school people batter me" (Bethany, 113 – 114)

Bethany describes that when she attended the group she was accepted by her peers and with this acceptance she could then connect with others and make positive relationships. This lifted her mood and self-esteem and encouraged her to continue to attend the group to re-affirm her relationships. This had differed to situations with young people in school or other situations where she felt different and other young people recognised that she was different leaving her open to bullying and social exclusion.

Similarly the participant's parents described how their child was accepted at the group and can connect with others, which is not possible in other groups that are not populated by their peers. Being judged, criticised and isolated were common scenarios when the participants were attending mainstream activities or socialising in their local environments. Whilst at the group the structure ensures that the children are accepted by the other children and the adults.

"He's not judged here everyone is the same" (James' parent, 75)

In addition to the reduction in negative reactions from others, there was an increased confidence for the young people where they understood that they will not be judged in ways that they may have previously found in former situations and can engage in a circumstance that is affirming and non-judgemental.

"For me he's different because he's at a mainstream school and when he came here he fit in they can all play together. He settled in straight away which is completely different to when he started school" (Andy, 52 – 53)

This change in social environment enabled Andy to feel more capable and increased his level of self-efficacy and self-concept. In turn this had lifted his confidence due to the activities and engagement and afforded him an increase in perceived social resources to meet the decreased challenges. The opportunity to socially learn and compare with others of similar abilities and within the same ecological system is important in enabling learning to occur in which the young people are able to reflect upon relationships that could be different to those contained by the restraints of hierarchical social systems in which inevitably young people with ID would be organised as being toward the bottom of these structures.

Positive emotions

When the participants were asked to describe why they attended the group they were able to discuss different emotions which were predominately positive. They all used the word ‘happy’ or 'very happy' when asked to point to a picture on the list of emotional faces. This was in contrast to responses when asked to describe the emotions they felt in other environments, for example at home and at school which were often much more complex, conflicting and confused. A much wider range of emotions were described in these circumstances, often related to the more complex and difficult social situations where these young people strived to navigate.

“*Yeah, I never felt sad when I come here. It’s just made me feel a little bit happier”* (Bethany, 34)

The young people participants and their parents stated that they were often isolated from social groups. Negative emotions were associated with other aspects of their lives thus reducing their SWB; however the sports group environment facilitated a decrease in social challenges and a perceptual change in available resources to face the challenges present in the sports group environment but also enabling that sense of positivity into other situations.

“It helps me feel better” (Evan, 101)

The participants were able to identify the positive emotions and the connection with how being at the group and even thinking about the group when not there made them feel. It appeared that the group had less confusing or conflicting emotions associated with it than the home or school environment.

"Most of the time I feel happy" (Andy, 80)

The participants all confirmed that the group produced positive feelings which they did not often experience within other environments. Both 'happy' and 'excited' were the primary emotions reported by the participants when attending the group.

"I mean at one time he was really fed up because he didn't really do anything. So just the fact that he does something every week and he is involved. Everything is perfect now, I don't have any trouble. He doesn't have any tantrums." (Jim's parent, 159 – 161)

The positive emotions and interaction with others had been attributed by some parents to their child's improved self-esteem and emotional regulation. The suggestion is that the moods and therefore behaviours of some of the young people were low prior to attending the group and interacting with the other children in an inclusive environment. This appears to be associated to a number of factors as previously mentioned due to the relationship between the young person and the environment the group created.

Behavioural observations

The participants were often observed smiling and jumping about with excitement when engaging in the activities. When they were verbally responding to the interviews they were nodding vigorously, smiling and laughing. When asked to speak about how they felt about the group, it was evident that the presented emotions were honest and that the children gained a great deal of positivity from attending the group which was in stark contrast when discussing other social situations.

Hand drawn images

The eight participant drawings demonstrated them smiling in the pictures that they drew. When asked to describe their pictures the participants responded that they were engaged in an activity which was memorable because they were enjoying themselves and were ‘happy’. They were able to recall a particular event in which they were playing a game they enjoyed, interacting with their peers and achieving at an activity. The discussions surrounding these drawing became excitedly animated and enabled the participants to be able to speak more freely using the drawing as a vehicle in which to communicate their experiences.

Emotion faces

All of the participants pointed to the ‘happy’ face on the list, with four of the participants also stating that they were excited when they attended the group. This was in contrast to more varied responses when asked to describe home and school environments which resulted in a range of emotions. These results further demonstrated that by participating in the sports group the young people experienced, aimed for and achieved positive emotions.

Connected to others

The participants all mentioned that they attended the group as they had met people who they described as friends. These included their peers and the group leaders and it was one of the primary drivers to attendance for the participants and their parents reflected this in their supporting statements.

“I have my best friend here. I met him here. My friends are here.” (Bethany, 119)

The opportunity to meet other individuals with similar experiences, interests, cognitive and physical abilities appeared to be of great benefit for the participants and one of the very few opportunities to do so outside of the school environment.

"I think it's great, it's X and X that I think are really great. Cos they're kinda my friends yeah and they're really great for meeting them at first and then playing with them." (Evan, 77 – 78)

The environment of the sports group provided an opportunity to meet people that were unconnected to other aspects of the young people's lives. Therefore the children have no other interpretation to bring to understand their peers other than that facilitated by the group. The activities were inclusive and enabling this allowed all the children to participate and achieve within the group.

The parents were very positive about the impact of participating in the sports group for their children and identified that it was part of their emotional growth and improved their communication skills, confidence and self-efficacy.

"He's always been shy. At one time he would never have spoken to you full stop, it's difficult for him to communicate with his speech and stuff but now he doesn't shut up." (James' parent, 97 – 98)

The sports group afforded opportunities for the children to learn and practice their social and sports skills in an environment that fostered exposure to stimulating experiences and people that were not available in other areas of their lives. The parents reported that this has enabled their children to increase their verbal development and this may be linked to cognitive development.

Behavioural observations

The participants were usually always involved in group sports and at the break periods were sitting with other members of the group. At the end of the sessions the children sat in a circle with their peers for a session debrief. This enabled the children to feel connected to one another as a group of people defined by the purpose of the group rather than by their disability. The young people were able to learn each other's names and congratulate those who had achieved something particular within the group sessions, whether that was playing with more effort, scoring more points in a game or helping someone who had fallen over. These positive behaviours were rewarded and seen as positive by the group and were inclusive with each young person being offered the opportunity to have their attributes recognised by their peers.

Hand drawn images

In five of the drawings the children illustrated pictures where they were experiencing the group with other people who they were able to name and describe the activity that they were engaged with. This demonstrated that when thinking about the group, the participants thought about being with and connecting to other people and perceiving this as a positive experience.

Data collected from emotional faces

When asked to describe why the participants were 'happy' the young people discussed that it was due to another young person they were playing with or that it was because another person positively engaged with them in a game situation or socially outside of the formal activities. This evidence related to the relationships that were being understood and navigated within the environment by all of the young people and indeed by their parents and sports leaders.

Fitter and stronger

Many of the participants recognised that engaging with the group activities ensured that they were improving their health through exercising and that that was a positive outcome for them. Through the interviews it was identified that the group was the only opportunity to engage in physical activity outside of school. However at school these opportunities were seen as being structured in a different way. This was due to the nature of the social dynamics present in the relationships with their school peers and teachers.

"I have noticed I can do a lot more things. I feel fitter and I have been able to run faster. Even my friends have noticed that I can run faster." (Brian, 36 – 37)

When interviewing the participants regarding why they attended the group a theme emerged regarding enjoying the activity aspect of the group which was perhaps the most overt reason for attending. Through participating in the activities, health benefits were noticed by the children and their parents alike.

"I like playing football and basketball" (Oliver, 49)

The activities were identified as being enjoyable experiences that the participants wished to be replicated. The sports group offered a number of different activities that were accessed by the young people. Therefore there were always different activities that appealed to their individual abilities and they were able to stay engaged due to this variety.

"Cos its good and its exercise and stuff like that" (Bethany, 63)

Additionally, most of the participants recognised that the activities had physiological effects, which encouraged them to continue.

"It's perfect for me because it really just gets me going. It's like an exercise for me, so it's like all the sports, getting involved" (Evan, 54 – 55)

Some of the participants' identified that the activities had health benefits and were positive for their physical health and that was a positive reason for being involved with the group. Being active also appeared to make them feel better for undertaking an activity that was socially expected. Therefore the sports group appeared to emerge as a vehicle for the young people to socially engage with one another in a structured way that would bring direct health benefits, however there was much more to the group and other concepts and ideas were brought forward by the participants before discussing the primary purpose of the group.

Discussion

Overview of findings

The present study explored the experiences of young people with intellectual disabilities attending a peer populated sports group and how this impacted upon the sense of wellbeing. The study aimed to discover how to investigate the phenomenology of young people and how to understand and measure these experiences.

The first part of the study discuss the results regarding the BBC wellbeing measure (Kinderman, Schwannauer, Pontin, & Tai, 2011) and are interesting in that they are a first attempt at working with an appropriate method of quantifying SWB in this population with comparable scores for mainstream populations being registered. It is a very early start in using this measure and the results need to be understood in that way and this will require further investigation; however the results potentially suggest that it is worthy of further exploration. Completing this measure as part of this study has demonstrated, to a degree, that it is at least possible, with support, to use a standardised measure, to directly ask young people with intellectual disabilities about aspects of their lives, in order to understand their perspectives in relation to wellbeing. This is an important first step in working more with this population to understand their world view and how they interpret their environment. If this adapted wellbeing measure can be utilised further in future studies then it may be a reliable method for quantifying the young people's wellbeing. As the questions within the measures were adapted to such a degree from the Kinderman et al (2011) original study it may be argued that the meaning of the questions has changed. Of course every individual would understand these differently and conceptualise the meanings differently which may happen with any form of communication, it is important to ensure that these alterations are minimised where ever possible. However the premise of the adapted questionnaire was to initially attempt to utilise Kinderman at al (2011) measure as being the most recent wellbeing measure taking into account the changing conceptualisation of how wellbeing is currently understood to ensure that as wide a range of wellbeing questions were asked of the participants as possible. In this way it was intended that wellbeing could be explored in a greater, more understood sense and on a broader basis than other measures that have previously been used in research. Therefore although the psychometric properties have not been explored in this research there may be a rationale to explore the clinical utility of this measure for children with ID in future.

The second part of the study concerned gathering qualitative data regarding the subjective experiences of young people with ID of attending a sports group. Themes emerging from the data are in line with a limited number of previous research articles that suggested that participation in exercise improves SWB (Callaghan, 2004), although through the use of a variety of data collection methods this has been explored from an innovative, comprehensive and subjective perspective with the young people with ID and the parents also participating. The findings suggest from this study that the young people were able to make friends with their peers with similar intellectual disabilities and that this was a major factor in influencing their wellbeing because they could interact, communicate and play with people who experience the world in a more similar way than people who do not have intellectual disabilities. This is discussed in previous research by Cooney, Jahoda, Gumley & Knott (2006) whereby people make social comparisons with others and that if they are in a social group with people who are deemed to have better abilities than them then their self-concept is lowered and as a result their sense of SWB.

Positive relationships are discussed often within the transcripts of the participants and within the analysis of the drawings. The themes demonstrated that the young people were also connected to the sports leaders who were able to facilitate and promote their self-efficacy and in turn their self-esteem. This is an extremely important role that the sports leaders played within this group and ensured that the young people, who reportedly had a history of exclusion by their non-intellectually disabled peers, were able to internalise their feelings of competence. Due to this, their sense of wellbeing was being associated with their self-efficacy, demonstrating further influence on their *'state of being' that* is the aim of achieving equilibrium between the resources that the young people had versus the challenges they faced.

The children were also able to have a sense of control over their bodies and their environment and felt obvious pride at their achievements and abilities in relation to their peers (Al-Yagon, 2007). This was also evident in their feeling of comfort in communicating with their peers and the parents of the young people as well as the adult sports leaders (Ashdown, & Bernard, 2012). Young people with ID are often excluded from social networks of non-disabled children and therefore have a reduced opportunity to engage and learn, thus further limiting their cognitive and emotional progress (Rey, Extremera, Dura & Ortiz,-Tallo, 2013). However within the facilitating environment of the sports group, these limitations could be somewhat overcome (Cook & Oliver, 2011). To the knowledge of the author this is the first time that these methods have been employed for this population to gather different categories of data collection and presenting them as a coherent picture of young people with ID direct perspectives of participating in a sports group. The data collection methods suggest validity and reliability with each other and they had been explored within a research group and with the participants and their parents. In terms of previous wellbeing concepts, the results suggest that Seligman's (2011) model of wellbeing being determined by his PERMA constructs or elements appear to be evident from this research. The five constructs that Seligman discussed are evident within the transcripts and themes that have been drawn from the research. The young people reported positive emotions when attending the group, this was in contrast to when they were discussing being at home or school in that these environments were characterised as being much more socially and emotionally complex and conflicting as previous research has suggested (Cooney, Jahoda, Gumley & Knott, 2006). Moreover, the PERMA elements can be seen within the themes regarding the opportunity to engage in an activity and a group that is a vehicle in which positive relationships are created and maintained within a safe environment with peers, parents and groups leaders. Furthermore this environment affords a prospect of participating in meaningful activity in which achievements are recognised in a supportive, non-threatening way, which provides the young people with a sense of accomplishment. Therefore these findings suggest that Seligman's (2011) PERMA elements are applicable to PwID. As previously discussed this is reported as not being consistently available in other situations in which the young people live. The group facilitated engagement throughout the system that it had established with the activities which according to Dodge et al (2012) provided the experiences in which to develop the resilience and resources to manage the challenges that are faced by living in a social world that is difficult to navigate and in which they face and will face in the future as adults. These disadvantages, which research suggests will expose them to biopsychosocial challenges far more than the non-intellectually disabled population. According to Cummins (2010) internal cognitive buffers are an important mediator in achieving homeostasis of SWB. This evidence suggested from this study are that the factors are intrinsic to this are internalised state and are enhanced as the young people identified positive emotions and were able to use the sports group as an opportunity to work out the complex nature of relationships, while operating within the boundaries and structure of organised play. In this sense one can draw tentative comparisons to the resilience, attachment and therapeutic play literature. This postulates the necessity for safe, stable, reliable and consistent environments and care givers for young people to explore their understanding of their worlds, themselves and others (Ashdown & Bernard, 2012). In this way the young people are able to reflect on what the group brings to them which is more than the designers of the group may have assumed.

The participants also recognised that participating in the sports group enabled them to exercise and play and through that they felt fitter and stronger, however the social aspects of the group were the themes that were most prevalent within the transcripts of both the young people and their parents and through the descriptions of the drawings. Therefore it may be summarised that the group is important to consider the biopsychosocial effects upon an individual, and while referring to the literature base, it is difficult to define fully how the group is experienced, but that it is affecting the whole being in a ‘well’ way.

In summary, the research has demonstrated that the sports groups enabled the young people to participate in a programme that ensures their wellbeing is recognised and enhanced. This enabled them to develop better resources that are required to engage in a socially difficult world and meet complex challenges by using internal cognitive buffers to learn, reflect and utilise, thus ensuring that their wellbeing is able to be maintained in a positive state.

Limitations of the study

The study aims were to undertake data collection in formats that had not been utilised with this population before. The discovery orientated interview process was useful, however originally it was proposed that this would be analysed using Interpretative Phenomenological Analytical methods. During the process it was debated with the research team whether this would be viable due to the lack of richness in the initial verbal data that was available from the young people of the pilot study and the potential challenges this may present in the analysis. Utilising the research group it was determined to use TA as this provided much greater flexibility in the analysing process and therefore increased the potential of presenting the verbal data that the children provided. Further data collection techniques were also used including the use of cue cards and hand drawn images and these choices and images were then explained by the children. This was able to further inform the experiences of the children and provide increased richness to the available data. A data collection method that has been rarely used within traditional qualitative studies is the use of behavioural and systemic observations of the children both within the interview and within the context of the sports group. As the researcher had not utilised these methods before, it posed a number of challenges to ensure that the data was recorded in a way that was accessible to the reader and in keeping with previous literature that had described the process. These methods increased in prominence as the verbal data collection methods demonstrated the benefit of further non-verbal data collection methods.

Due to the challenge of interviewing young people with intellectual disabilities, the researcher was required to immerse themselves into the sports group to enable the data collection process. This also ensured that the participants were less anxious both verbally and behaviourally as they knew of the researcher, which was also another reason why TA was preferable. Nevertheless some of the children were only able to provide single word responses within the verbal interview, however the use of the hand drawn pictures and recording the behavioural observations were able to provide informative data that occasionally the participants were not able to verbalise. Various researchers have described these difficulties however it can be accomplished with appropriate adaptations to the format (Antaki, 1999; Nind, 2008; Bray, 1999). Objective wellbeing measures are as mentioned poor indicators as subjective wellbeing as individuals will adjust to the adversities they face, however developing the resources of individuals is important to meet their life challenges.

With this in mind it is imperative to manage programmes for individuals, especially children with intellectual disabilities to ensure their biological, psychological and sociological resources can be improved. This will then provide them with improved skills in which to face the inequalities that are present according to the social models of disability and childhood (Schalock et al, 2010).

A particular limitation of this study was that there were eight young people participants, of which five had their parents supporting them. The parents who supported their children were there primarily to support their children emotionally and verbally, however their interviews were also invaluable in helping to provide further perspective and a voice for their children. There were several issues that need to be discussed due to this unconventional dynamic when conducting this research. By the very nature of the hierarchy present in these relationships between child and parent, especially for young people with ID who rely much more on the care provided by their parent due to the difficulties they face. This presents with the possibility that the young person in that situation may not have felt able to present their views in the way they may have wished had their parent not been present. Conversely the young people who provided information without the presence of their parent may have been unable to verbalise their views as much as they wished due to their difficulties in verbal communication and cognitive ability. The challenges this issue presented are argued to offset each other in the dynamic of the young person and parent interview, whereby the young person was supported in allowing their views being put forward and their voice being heard. This is alongside the singular interviews where the young person provided information without the support of a parent but may not have been able to provide the full scope of their views and opinions.

Clinical implications and future research

The study of wellbeing has been growing in status over the last decade. The recent models of wellbeing equilibrium suggest that a sense of wellbeing is a state of being that can be achieved by striving for positive relationships and activities. This can then be moderated between the personal resources available to tackle the life challenges that individuals face within an ecological system. There are obvious benefits of resource development in terms of physical and psychosocial skills, including the potential to other children who they are able to connect with and form social relationships. This area had not been researched before from the perspective of the children who participate in these sports groups. It has been demonstrated within this study that innovative and combined research methods can be utilised successfully in order to gain an understanding of the children's experiences to attempt to influence their subjective wellbeing. However these methods need to be utilised across the range of domains in which children live, learn and play (Beart, 2005). Future research should focus further on which groups are achieving this aim and how. It is only through involving the users of services that researchers are able to gain as accurate a picture as possible into if the services on offer are realising their objectives. This research has focused on one group in one city in the UK; this area is predominately monoculturally white British. Future research should explore the programmes operating in other cities and regions and other cultures to gain a fuller understanding of the cultural aspects of groups and their participants. It is interesting to note that in addition to information provided in support of the children's views the parents wished to express their own perspective of their child attending the group, however this opportunity was outside of the scope of this research, and could be conducted in future. Furthermore, in future this interesting child and parent dynamic could be explored further regarding the effects of a parent within the interview and doing a joint interview opposed to two separate interviews. The views of the parents attending this group with their children should also be explored as it appeared that the parent’s wellbeing may be improved by socialising with parents who also have children who have ID. Following the social comparison paradigm they are able to observe their children with other young people of similar abilities. In keeping with research previously discussed, the wellbeing of the parent and/or child can influence each other’s in direct correlation. This is an important element of attending the group that requires further exploration.

All groups attempting to work with young people with ID should evaluate its service provision with the aim of being as inclusive as possible and aiming for positively influencing wellbeing. In this way more of these individuals and their families, which are facing exclusion and therefore have limited access to resource development, may have the opportunities to enhance their wellbeing by expansion of their resources to meet the ecological challenges.

The adapted BBC Wellbeing measure (Kinderman, Schwannauer, Pontin, & Tai, 2011) is an interesting avenue in which to further explore potential applications. It appears that it may be able to measure a child with intellectual disabilities' SWB; however this needs to be explored further. The language adaptations, following guidance from the research literature, appear to have retained the meaning of the original BBC wellbeing measure, although again this needs to be researched further and with different populations and levels of support. The use of focus groups of parents, carers, sports leaders and the children in this study were relatively small and this pilot research should be expanded into greater exploration of the use of the validity and reliability of the measure with this population. If a measure was universally accepted then measuring young people with ID’s wellbeing could be standardised making it easier to monitor and compare with mainstream populations who are able to access the non-adapted version.

In summary the research has drawn out some interesting elements for discussion in how to access the experiences of young people with intellectual disabilities relating to their participation in groups and how this affects their wellbeing. New attempts have been made following on from previous guidance in the adaptation of interview methods and a wellbeing measure. This has been done to demonstrate that these are valid methods to ascertain the young person's with ID experiences, which is a population that is under represented. The sports group examined and groups like them should be further evaluated as the evidence from this research demonstrates them as being useful agents of change and of use in early intervention and prevention planning by positively influencing wellbeing as a state of being and increasing the personal resources and therefore decreasing the likelihood of developing bio-psycho-social difficulties in the future.

References

Antaki, C. (1999) Interviewing persons with a learning disability: How setting lower standards may inflate well-being scores. *Qualitative Health Research. 9* (4)

Antaki, C & Rapley, M. (1996) Questions and answers to psychological assessment schedules: Hidden troubles in 'quality of life' interviews. *Journal of Intellectual Disability Research. 40* (5), 421-437.

Ashdown, D & Bernard, M (2012) Can explicit instruction in social and emotional learning skills benefit the social – emotional development, wellbeing and academic achievement of young children? *Early Childhood Education Journal. 39, 397-405.*

Al-Yagon, M (2007) Socioemotional and behavioural adjustment among school aged children with learning disabilities. *The Journal of Special Education*. 40, 205-217.

Atlantis, E, Chow, C, Kirby, A, Singh, M (2004) An effective exercise-based intervention for improving mental health and quality of life measures: a randomized controlled trial. Prev. Med. 39, 424–43.

Bach, M (2007) Changing perspectives on developmental disabilities. In I. Brown & M. Percy (Eds.). *A comprehensive guide to intellectual & developmental disabilities* (pp. 35-43). Baltimore: Paul H. Brookes.

Beart, S (2005) 'I won't think of me self as a learning disability. But I have': social identity and self-advocacy; *British Journal of Learning Disabilities*. 33(3), pp. 128 – 131.

Boutcher, S (2000) Cognitive performance fitness and ageing. In: Biddle, S.J.H., Fox, K.R., Boutcher, S.H. (Eds.), *Physical Activity and Psychological Well-being*. Routledge, London, pp. 118–129.

Braun, V & Clarke, V (2006) Using thematic analysis in psychology; *Qualitative Research in Psychology*. 3 (2) pp 77-101.

Bray, A (1999) *Research involving people with Intellectual Disabilities: Issues of informed consent and participation.* (Research report). Dunedin, New Zealand: Donald Beasley Institute

Brown, I (2007) What is meant by intellectual and developmental disabilities? In I. Brown & M. Percy (Eds.) *A comprehensive guide to intellectual & developmental disabilities* (pp. 3-16). Baltimore: Paul H. Brookes.

Brown, R, Schalock, R & Brown, I (2009) Quality of life: Its application to persons with intellectual disabilities and their families – Introduction and overview; *Journal of Policy and Practice in Intellectual Disabilities.* 6, 2-6.

Buttner, G & Hasselhrn, M (2011) Learning disabilities: Debates on definitions, causes, subtypes, and responses; *International Journal of Disability, Development and Education.* 58, 75-87.

Callaghan, P (2004) Exercise: a neglected intervention in mental health care? *Journal of Psychiatric Mental Health Nursing.* 11, 476–483.

Carmeli, E, Vaknin-Zinger, T, Morad, M & Merrick, J (2005) Can physical training have an effect on well being in adults with mild intellectual disability; *Mechanisms of Aging and Development;* 299-304.

Carver, C & Scheier, M (1990) Origins and functions of positive and negative affect: A control-process view. *Psychological Review, 97*, 19-35.

Chang, E (1998) Does dispositional optimism moderate the relation between perceived stress and psychological well-being? A preliminary investigation. *Personality and Individual Differences. 25* (2), 233-240.

Cook, F & Oliver, C (2011) A review of defining and measuring sociability in children with intellectual disabilities. *Research in Development Disabilities*. 32, 11-24.

Cooney, G, Jahoda, A Gumley, A & Knott, F (2006) Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations; *Journal of Intellectual Disability Research. 50, 432-444.*

Cummins, R (1995) On the trail of the gold standard for life satisfaction. *Social Indicators Research*. *35*, 179–200.

Cummins, R (1998) The second approximation to an international standard of life satisfaction. *Social Indicators Research*. *43*, 307–334.

Cummins, R (2005) Caregivers as managers of subjective wellbeing: A homeostatic perspectives. *Journal of Applied Research in Intellectual Disabilities. 18* (4), 335-344.

Cummins, R (2010) Subjective wellbeing, homeostatically protected mood and depression: a synthesis; *Journal of Happiness Studies*. vol. 11, no. 1, pp 1-17.

Cummins, R & Nistico, H (2002) Maintaining life satisfaction: The role of positive cognitive bias; *Journal of Happiness Studies*. 3, 37-69

Davis, J & Watson, N (2002) Countering stereotypes of disability: disabled children and resistance. In *Disability/postmodernity: Embodying disability theory*, ed. M. Corker and T. Shakespeare, 159-74. London: Continuum. .

Diener, E (2009) Subjective wellbeing. In E. Diener (Ed.).*The science of well-being* (pp. 11–58): New York: Springer.

Diener, E, Suh, E, Lucas, R, & Smith, H (1999) Subjective well-being: Three decades of progress; *Psychological Bulletin*. 125, 276-302.

Diener, E., Lucas, R., & Scollon, C. N. (2006) Beyond the hedonic treadmill: Revising the adaptation theory of well-being; *American Psychologist*. 61, 305-314

Dodge, R, Daly, A, Huyton, J & Sanders, L (2012) The challenge of defining wellbeing; *International Journal of Wellbeing. 2, 222-235.*

Dykens, E, Rosner, B & Butterbaugh, G (1998) Exercise and sports in children and adolescents with developmental disabilities: positive physical and psychosocial effects. *Child Adolescents. Psychiatry. North America. 7, 757–771*

Emerson E. (2010) Self-reported exposure to disablism is associated with poorer self-reported health and well-being among adults with intellectual disabilities in England: Cross sectional survey. *Public Health*. 124 (12):682-89.

Emerson, E. & Hatton, C (2007) Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation*. 112, 140-150.

Emerson E, Baines S., Allerton, L & Welch, V (2012) Health Inequalities and People with Learning Disabilities in the UK: Improving Health and Lives: *Learning Disabilities Observatory*.

Emerson E & Heslop P. (2010) A Working Definition of Learning Disabilities. Durham: Improving Health & Lives: *Learning Disabilities Observatory*.

Felce, D. & Perry, J. (1995) Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*(1), 51–74.

Finlay, W & Lyons, E (2001) Methodological issues in interviewing and using self-report questionnaires with people with mental retardation; *Psychological Assessment,* 13(3),pp. 319-335.

Forgeard, M, Jayawickreme, E, Kern, M. & Seligman, (2011) Doing the right thing: Measuring wellbeing for public policy. *International Journal of Wellbeing*. *1* (1), 79-106.

Gasper, D (2010) Understanding the diversity of conceptions of well-being and quality-of-life. *Journal of Socio-Economics, 39,* 351-360.

Golubovic, S, Maksimovic, B & Glumbic, N (2012) effects of exercise on physical fitness in children with intellectual disabilities. *Research in Developmental Disabilities. 33, 608-614.*

Kernis, M & Goldman, B (2002) Stability and variability in the self-concept and self- esteem. In M. Leary & J. Tangey (Eds.), *Handbook of self and identity*. New York: Guilford Press.

Kinderman, P, Schwannauer, M, Pontin, E & Tai, S (2011) The development and validation of a general measure of wellbeing: the BBC wellbeing scale. *Quality of Life Research.* 20, 1035-1042.

Nind, M (2008) Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. *National Centre for Research Methods* NCRM/012.

Ninot, G., Bilard, J., Sokolowski, M (2000) Athletic competition: a mean of improving the self-image of mentally retarded adolescent? *International Journal of Rehabilitation Res*earch. 23, 111–117.

Petry, K & Maes, B (2006) Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities: the perspectives of parents and direct support staff. *Journal of Intellectual and Developmental Disability.* 31, 28-38.

Prosser, H & Bromley, J (1998) Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.), *Clinical psychology and people with intellectual disabilities* (pp. 99-113). Chichester: Wiley.

Rey, L, Extremera, N, Dura, A & Ortiz,-Tallo, M (2013) Subjective quality of life of people with intellectual disabilities: the role of emotional competence on their subjective wellbeing. *Journal of Applied Research in Intellectual Disabilities.* 26,146-156.

Schalock, R, Borthwick-Duffy, S, Bradley, V, Buntinx, W, Coulter, D, Craig, E, et al. (2010). *Intellectual Disability: Definition, classification and systems of support* (11th Ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Seligman, M (2011).*Flourish – A new understanding of happiness and well-being – and how to achieve them.* London: Nicholas Brealey Publishing.

Shakespeare, T & Watson, N. (2002) The social model of disability: an outdated ideology? *Research in Social Science and Disability.* 2, 9-28.

Part three: Appendices

Appendix 1 – Guidelines for authors for the systematic literature review and the empirical paper

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1. GENERAL

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The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.
It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

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Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.
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4.1 Manuscript Files Accepted

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To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

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Original Articles, Review Articles, Brief Reports, Book Reviews and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

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Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found athttp://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:

-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research*5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

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http://www.endnote.com/support/enstyles.asp
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http://www.refman.com/support/rmstyles.asp
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6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

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Appendix 2 – Search terms used for the systematic literature review

	Search items
Intellectual disabilities	Intellectual disabilit*
	Learning disabilit*
	Developmental disabilit*
	Mental retardation
	Mental handicap*
	Learning diff*
	Intellectual diff*
Wellbeing	Subjective wellbeing
	Emotional wellbeing
	Psychological wellbeing
	Quality of life
	Self-concept
	Self esteem
	Happiness
	Life satisfaction

Appendix 3 – Rationale for the inclusion and exclusion criteria used within the systematic literature review

Inclusion

- Ages between 9 – 18 years old
- People with mental health difficulties as long as their intellectual disabilities were predominant in their difficulties.
- If the participant had been attending the group regularly (at least 50 % of the time over a period of at least 6 months)
- Identified as having an intellectual disability
- Able to understand verbal communication

Exclusion criteria

- If parental consent was unobtainable
- Did not have an intellectual disability
- Did not have a mental health problem or learning disability that was primary to their intellectual disability
- Definitions pertaining to SWB in the literature including; Quality of life, life satisfaction, self-concept research, if this research could map onto the wellbeing literature according to the research discussed with the review. This is to ensure as comprehensive range as possible is covered regarding this population
- Studies that were focused upon the SWB of members of the social system but not the person with intellectual disabilities.

- Literature reviews, other non-empirical papers, case studies. Not considered as in the case of literature reviews they would not provide any new evidence. If a paper was unpublished then it may not have the same rigorous standard as a peer reviewed study
- Studies that were not printed in English. The articles were not translated into English due to time and financial restraints

Appendix 4 – Quality checklist for qualitative studies and data extraction

Qualitative Research Quality Checklist

Paper Title	
Author(s)	
Date:	
Journal:	

Quality rating

	Excellent	**Sound**	**Poor**	**No/Unsure**
	3	2	1	0
Quality assessment questions • Clearly focused research question/aims/objectives • Clearly focused rationale/hypotheses • Qualitative methodology most appropriate • Underpinning values and assumptions discussed				
Participants • Participants demographics stated • Inclusion and exclusion criteria stated • Sample representativeness to the population being assessed • Participant rate/dropout rate reported				
Methodology • Time of course of the study reported • Sampling strategy reported • Data collection methods reported				

Ethical approval reported	
Data analysis • Data analysis strategy reported • Data analysis appropriate to data collected • More than one rater • Rigorous analysis • Rich data	
Main findings coherent/valid/relevant	
Main conclusions relate to main question	
Implications of study reported	
Limitations of study reported	
Total score (Maximum total score: 21 x 3 = 63)	
Comments	

Appendix 5 – Quality checklist for quantitative studies and data extraction

Quantitative Research Quality Checklist

Paper Title	
Author(s)	
Date:	
Journal:	

Quality rating

	Excellent	**Sound**	**Poor**	**No/Unsure**
	3	2	1	0
Quality assessment questions • Clearly focused research question/aims/objectives • Clearly focused rationale/hypotheses • Qualitative methodology most appropriate • Underpinning values and assumptions discussed				
Participants • Participants demographics stated • Inclusion and exclusion criteria stated • Sample representativeness to the population being assessed • Participant rate/dropout rate reported				
Methodology • Time of course of the study reported • Sampling strategy reported • Data collection methods reported				

Ethical approval reported	
Data analysis • Data analysis strategy reported • Data analysis appropriate to data collected • Confidence intervals reported • Probability factors reported? • Clearly reported data	
Main findings coherent/valid/relevant	
Main conclusions relate to main question	
Implications of study reported	
Limitations of study reported	
Total score (Maximum total score: 22 x 3 = 69)	
Comments	

Appendix 6 – Rationale behind choosing thematic analysis and credibility check

Rationale for using Thematic Analysis

Thematic analysis (TA) was chosen as it allows flexibility when organising data and capturing the intricacies of meaning within a data set. It is a common method for identifying, analysing and reporting patterns or themes within the data and the flexibility allowed the application of multiple theories across a range of epistemologies. As the participants were young people with intellectual disabilities, the TA method allowed for analysis from single word responses to lengthier monologues. As the combined data sets were using different methods of data collection then thematic analysis was much more suited to this type of analysis

Thematic analysis is related to phenomenology as it focuses upon the subjective human experience. The use of TA emphasises the participants, perceptions, feelings and experiences as the object of study. This allows a theoretical freedom to provide a rich and detailed, yet complex account of the data. However there is a stringent methodology for utilising TA Flexibility and follows a six phase model of to analyse the data. Even with this guidance the author wanted to make the data and results as accessible as possible and using TA ensures that the results are more accessible. Further advantages of the model include being able to allow for social as well as psychological interpretations of data, thus being useful for producing qualitative analyses suited to informing policy development. This is especially true for this research as it may be used to inform future research and evidence of the effectiveness of programmes for this population.

The author initially chose to use IPA as this method can be utilised to explore how a person experiences a particular situation. This would have fitted the focus of the study well, however due to the greater rigidity of the process; it was felt that it may not offer the possibilities to utilise the variety of data sets that were needed to measure this particular population.

Appendix 7 – Example of adapted BBC Wellbeing measure

BBC Wellbeing measure (Kinderman et al, 2011)

Adaptation for use with children and/ or people with intellectual disabilities. Picture cue cards are also available for the questions.

- **Please take as much time as you need to think about them. There are no right or wrong answers.**
- **The best thing would be to be as open and honest as you can.**

	1: Not at all	2: A little bit	3: Very much	4: Extremely
				
1. *Are you satisfied with your physical health?* Are you happy with your body?				
2. *Are you satisfied with the quality of your sleep?* Do you get enough good sleep?				
3. *Are you satisfied with your ability to perform your daily living activities?* Can you do things OK in your day?				
4. *Are you satisfied with your ability to work?* Can you do things OK at school?				
5. *Do you feel depressed or anxious?*				

Do you feel sad or worried?				
6. *Do you feel that you are able to enjoy life?* Do you like your life?				
	1: Not at all 	2: A little bit 	3: Very much 	4: Extremely 
7. *Do you feel you have a purpose in life?* Do you think you have a goal or aim?				
8. *Do you feel in control over your life?* Can you control your life?				
9. *Do you feel optimistic about the future?* Will the future be good for you?				
10. *Do you feel satisfied with yourself as a person?* Are you happy with who you are?				
11. *Are you satisfied about your looks and appearance?* Do you like how you look?				
12. *Do you feel able to live your life the way you want?*				

Can you live your life how you want?				
13. *Are you confident in your own opinions and beliefs?* Do you think what you know is right?				
14. *Do you feel able to do the things you choose to do?* Can you do things that you want to do?				
	1: Not at all 	2: A little bit 	3: Very much 	4: Extremely 
15. *Do you feel able to grow and develop as a person?* Do you think you can get better at things?				
16. *Are you satisfied with yourself and your achievements?* Are you happy with what you have done?				

17. *Are you satisfied with your personal and family life?* Are you happy with your family?				
18. *Are you satisfied with your friendships and personal relationships?* Are you happy with your friends?				
19. *Are you comfortable about the way in which you relate to and connect with others?* Can you make friends easily?				
20. *Do you feel able to ask someone for help with a problem if you needed to?* Can you ask somebody for help if you needed it?				
	1: Not at all 	2: A little bit 	3: Very much 	4: Extremely 
21. *Are you satisfied that you have enough money to meet your needs?* Do you or your family have enough money to buy things you need?				

22. Are you satisfied with your opportunity for exercise and leisure activities? Are you happy that you can play and exercise when you want to?				
23. Are you satisfied with your access to health services? Can you see a doctor, nurse or dentist if you need to?				

- Thank you very much for answering the questions.
- These questions have been asking you about how you think and feel about yourself.
- If you would like to see any of the questions again then please see them. It would be very good if you did.
- If you would like to change any of the answers then that is OK to do.

Appendix 8 – Semi structured interview schedule

Interview schedule and prompts

We are going to look at three things today. The first part is that I will ask you some questions about what you think and feel about yourself and your life. Would that be OK?'

'The second part will I will ask you how you think and feel about coming to the Able and Active group. Would that be OK?'

'In the third and last part I will ask you to draw a picture of what you think about or see in your mind when you think about the Able and Active group. Would that be OK?'

Research question 1:

How do young people with intellectual disabilities perceive attending a sports group?

1. What brought you to this group?

   Prompt: How did you hear about this group?

2. Tell me about this group?

   Prompt: tell me why you come here?

3. How does the group make you feel?

   Prompt: Do get a feeling inside you when you are in the group?

4. What is it about the group that makes you attend?

   Prompt: is there a reason why yo come to the group?

Research question 2:

How do young people with intellectual disabilities feel about the group in relation to other aspects of their lives?

1. Has the group affected any other part of your life?

   Prompt: Does it make you think or feel any differently about yourself?

Prompt: Do you think anything has changed for you since you joined the group?

2. Does the group help you with any sad feelings you may have when you are not at the group?

   Prompt: Has being at the group helped you feel better or worse in any way?

   Prompt: have you felt differently about yourself since joining the group?

   Prompt: is there anything you have noticed about yourself since joining the group?

3. What is life like for you outside the group?

   Prompt: When you are not in the Able and Active group what is life like is for you?

Research question 3:

What impact do other people have on their experience of attending the sports group?

1. Can you tell me about the other people in the group?

   Prompt: What do you think of other people who attend the group?

   Prompt: Why do you like them (or not like them)?

   Prompt: Could you tell me a little bit more about them?

2. What do your parents think about the group?

   Prompt: Do your parents ever tell you their ideas or thoughts about you coming to the group?

   Prompt: What might they say or think about your coming to the group?

3. Can you tell me anything about the group leaders?

   Prompt: What do you think about the group leaders here? (Say name)

Appendix 9 – Participant and parental information packs

Information sheet (Children)

Your experience of the Able and Active group

My name is Chris Garrod and I would like to find out what you think about the Able and Active Sports group

I am going to talk to lots of children and young people who have some difficulties with learning.

I want to find out what you like and do not like about the group

<u>Why am I asking these questions?</u>

I would like to know how attending the Able and Active group makes you feel.

I would like to know if attending the group makes any difference to your life

What will you be asked to do?

I will ask everyone to fill in a questionnaire

I will then ask you to come back and speak with me about how they feel about the Able and Active group.

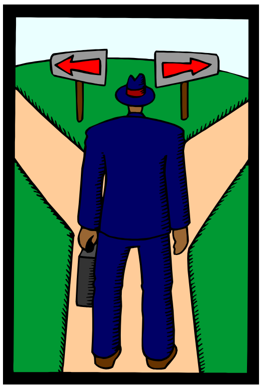
The talk will be in private, although you can have your parents with you if you or they would like that.

I will be using a tape recorder to help me remember what we say.

I will spend about an hour talking with each person, I hope that this can be done during your Able and Active group session times.

Everything people tell me will be kept private

Do I have to take part?

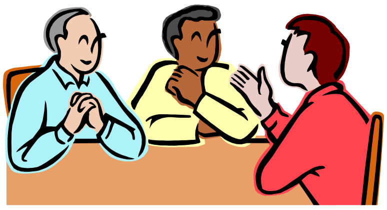


No. It is up to you and your parents whether you take part.

If you would like to take part, you can say no afterwards.

Nothing bad will happen to you.

Who can I talk to if I need more information?



I can come and talk with you before you say “yes” or “no”

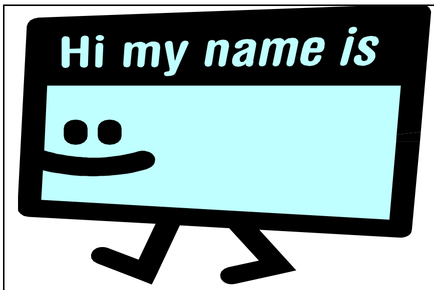
Your parents can contact me on email or telephone

You can talk to your parents or carers

Informed consent (i)

Please go through each statement with the group member ensuring understanding. Tick yes once they indicate agreement & understanding.

		YES	NO
	I understand that I can say NO to taking part in the study. I also understand that if I do not want to take part in this study it will not affect my attendance on the Able and Active programme.		
	I understand that I can walk away from the study at any time without having to give a reason.		
	I understand that I can ask for everything I say about the Able and Active programme to be destroyed.		

	I understand that my name will not be used when I tell people about the research.		
	I understand that if I agree to take part in the study today I can change my mind at any time afterwards.		
	I understand that any information I give about the course will be locked away. Members of the Able and Active team or parents are not allowed access to my information. All my information will be treated sensitively.		
	I understand that I maybe voice recorded during the interview section of the study. This is only so what you say will not be forgotten, however nobody will hear it other than the researcher.		
????	I have had my questions answered so I know what is happening.		

	I understand that hand written notes will be taken during the interview. Notes will be taken about the material, my (members) understanding & what I say about the programme.		
	I understand that what I say about the Able and Active programme will be recorded and may be used to write about the programme and what it does or does not do for the group members.		

Please tick once you agree and understand

- I am happy to talk about my experiences and ideas with another person, for example, the researcher
- I understand that the Able and Active programme is a programme for people with a learning disability. I am happy to share my views about my experience of the programme.
- I give my free and informed consent to take part in the BBC Wellbeing questionnaire and possibly the interview part of the Able and Active programme

Your name…………………………………………………………..

Your parents name and signature……………………………………………

Date………………………………………………………………………………………

Information about the project (ii)

This is about seeing how you feel and what you think about the Able and Active group

This is a short book to give you some information on the project

There is also an informed consent form to complete if you would like to do the study.

The study will be done by a person who studies at the University of Hull and has the permission of the Able and Active programme leader.

The study is in two parts and is for your child or the person you care to complete.

1. **Everybody would be asked to complete the BBC Wellbeing measure**. This is a 24 item questionniare to find out how you feel about yourself, your life and the world.

2. The second part will you will be **be invited to talk about their experiences** about coming to the Able and Active group and what effect it may have on your lives. I would like to ask you some questions to find out how you feel about yourself, other people, the world you live in and what things you might enjoy.

- These people can tell us what they think about the Able and Active group. This will be in a meeting with a person who will ask you questions about it. This may take up to 1 hour.
- The things you say will be written down
- If you decide to tell us what you thin, you will be interviewed by………………………., who studies at the……………………….. He is not connected to the…………………..
- Please ask for an informed consent sheet if you have not already been given one.

Informed consent sheet (ii)

This is a version of an informed consent for which the young people will have. If you would like to help them complete the form, that will be ok. However it must be their decision and you should not try to persuade them one way or another to take part in the study.

The research person would like to know what you think about the Able and Active programme. I would like to know what you think about the Able and Active sports group and if it affects how your life is. In order for you to tell us what you think about the Able and Active Group you need to provide us with informed consent. Informed consent means knowing exactly what you have agreed to do. It means you know all of the facts, options and likely outcomes of any decision you may make.

Guidance

- The documents should be read with the group member, ensuring understanding.
- No decision about participating in the filling in the **BBC Wellbeing questionnaire** need be made at the time of the first read through of the informed consent sheet. However, group members are able to sign the sheet at this time if they so wish. They should be told they can change their minds at any time.
- No decision about participating in the **interview** part of need be made at the time of the first read through of the informed consent sheet. However, group members are able to sign the sheet at this time if they so wish. They should be told they can change their minds at any time.
- Group members will be reminded when and where the one to one’s & focus groups will take place. Nearer the time, they can indicate interest in taking part & sign the consent form.
- Participants should be told that they can take the sheet away and think about what they want to do.
- They are allowed to ask questions about the study.
- They do not have to take part in the study.

Informed consent for parents

Please go through each statement with the group member ensuring understanding. Tick yes once you and they indicate agreement & understanding.

	YES	**NO**
I understand that I can say NO to taking part in the study. I also understand that if I do not want to take part in this study it will not affect my attendance on the Able and Active programme.		
I understand that I can walk away from the study at any time without having to give a reason.		
I understand that I can ask for everything I say about the Able and Active programme to be destroyed.		
I understand that my name will not be used when I tell people about the research.		
I understand that if I agree to take part in the study today I can change my mind at any time afterwards.		
I understand that any information I give about the course will be locked away. Members of the Able and Active team or parents are not allowed access to my information. All my information will be treated sensitively.		
I understand that I maybe voice recorded during the interview section of the study. This is only so what you say will not be forgotten, however nobody will hear it other than the researcher.		
I have had my questions answered so I know what is happening.		
I understand that hand written notes will be taken during the interview. Notes will be taken about the material, my (members) understanding & what I say about the programme.		
I understand that what I say about the Able and Active programme will be recorded and may be used to write about the programme and what it does or does not do for the group members.		

Please tick once you agree and understand

- I am happy to talk about my experiences and ideas with the researcher
- I understand that the ……………….programme is a programme for people with a learning disability. I am happy to share my views about my experience of the programme.
- I give my free and informed consent to take part in the study

Group member name……………………………….

Group member signature……………………………

Parent/ guardian name………………………………

Parent/ guardian signature………………………….

Date…………………………………………….

Appendix 10 – example of transcription

Interview transcription: 1

Participant 1: pseudonym Eric

Age: 12

Disability/ difficulty: Mild ID; no physical health problems; ASD traits

Other: Mother provided consent and information about communicating with Eric prior to interview

- *Green writing is the interviewer's observations of the participants behaviour*

R What is it about the group that makes you attend?

I think it's about like all the sports, like, except for football, they really get me interested, they get me like motivated, they get me interested, they get me like into sports that I really want to try for the first time, yeah, if I hadn't tried a sport that's the first thing I'd do, that's pretty much about it for that question

Speaking more quickly, smiling and nodding head a little

R: OK. When you did the questionnaire you said that you sometimes get very sad and sometimes you get very worried a little. Does the group help with that at all?

Ermm yeah, yeah, yeah, mostly all of the time.

Looking thoughtful, leaning backwards and forwards, slowed speech

R: How does it help?

It helps me to like feel better, like I do at school, it's just like if I try really hard.
It's like when I got my homework as an essay to do which I've already done, I
cried at first, but then my Mum helped me and my Dad and we did it on the computer so I think it has helped me a lot, yeah

R: How has it helped you then, is that a tricky question?

Yeah, I think that is, yeah

Nodding

R: What about other people your age in the group. What do you think of those guys?

I think those are really great yeahhhhh!
Smiling, nodding, leaning forward
R: Yeah?

Yeahhhhh! I like them pretty much, yeah
Sat back a little, smiling

R: Why do you like them?

‘Cos there kinda my friends yeah and they’re really great for like meeting them at first and then playing with them. It’s just like really cool, just to get interactive with such friends
Leaning back and forward, smiling, then thinking, then nodding

R: Yeah?

Yeah, do you know what I’m talking about?

R: you seem to like them. You know when you are outside the group

Yeah

R: Like at school and home, do you have similar friends that you have here?

Yeah, yeah
Nodding, not smile – neutral face

R: What’s life for you like outside the group?
When I’m not there?

R: When you are not at Able and Active yeah, what’s life like for you?

I feel a bit ashamed ‘cos I can’t go and it keeps me fit as well, it dunt get me involved in the sports that I need to get my body fit
Turing head from side to side, looking up and then nodding

R: What doesn’t get you involved?

The sports that we’re gonna do like for instance we’re gonna do like volleyball sooner or later
Shrugging shoulders and looking quizzical

R: Yeah

R: Yeah? Can we go back to what you said before? You said it’s kind of nice to have friends here

Yeah

R: What is it about those friends that’s nice?

They help me a lot, it’s just like what was the matter ermm I can’t put it right err I forgot
Smiling and nodding, then looking down and lost

R: Take your time

Errr, I’ll pass on that one

R: OK. Your friends here, what do you think is nice?

Ermm ah another hard one. They help me a lot with stuff like team work. That could be useful.
Looking thoughtful, looking from side to side

R: Really?

Yeah

R: Why could it be useful?

Ermm ‘cos we can be like working together for example. I think that’s what we always do ermm I think I’m gonna have to end that there.

R: Let me think, have you felt differently about yourself since joining the group

Ermm have you felt differently Ermm no nothings different have you felt differently about yourself since joining the group No not really I just feel happy all the time, yeahhhh I get to be in sports yeahhhhhh That sort of thing yeah

R: Is there anything you have noticed about yourself since joining the group.

Mmm I’d still pass on that one.
Neutral face, appears to have become a little bored of the questions now

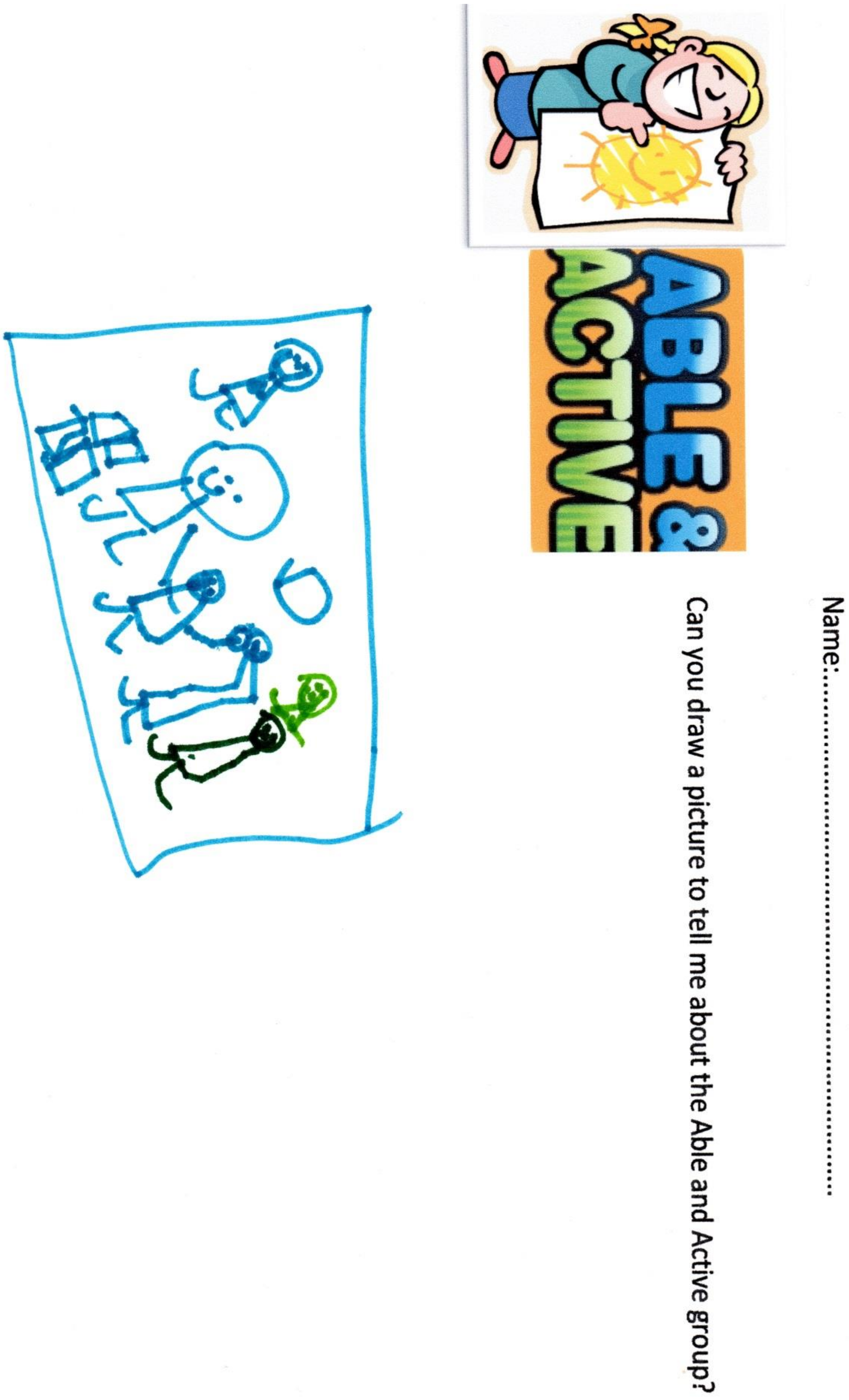
R: That’s alright. You said you feel happy ‘cos of the sports

Yeahhhhh
Smiling a little, does not seem as engaged

R: Is it better doing the sports than not doing the sports?

Yeah, it gets me more involved than doing the video games

Appendix 11 – An example of a drawing from a participant



Name:……………………………………………………

Can you draw a picture to tell me about the Able and Active group?

Appendix 12 - Example TA transcript Phase 1: reading, re-reading, initial note taking and summarising

	Interview transcript	**Note taking**
C	Has anything changed for you since you joined the group?	
B	Yeah, I seem to feel a lot happier since I joined the group.	Positive emotions associated with attending the group
C	Why do you think that is?	
B	I just really like it	Like the group
C	Yeah	
B	Yeah	
C	What keeps you attending, what keeps you coming here?	
B	I love everything about it. I love the people, I love all the stuff we do	'Love' the environment and peers
C	OK. Does it make you feel differently about yourself here?	
B	Ermm no it just…. Yeah it has made me feel happier, it hasn't made me feel sad coming here	Feeling happier
C	You feel happier? Is that because of the activities?	
B	Yeah. I never felt sad when I didn't come here. It's just that it's made me feel a little bit happier.	Group lifts mood
C	Other than being happier, have you noticed any other changes in yourself?	
B	I've noticed I can do a lot more things.	Able to do more
C	Like what?	
B	I feel fitter and I have been able to run faster	Physiological changes
C	Have you? So you feel fitter and you can run faster?	
B	Yeah. Even my friends have noticed that I can run faster.	Others aware
C	What when you are playing football at home?	
B	Yeah and at school	In different environments

Appendix 13 - Phase two: Generating sub-themes

C	Has anything changed for you since you joined the group?		
B	Yeah, I seem to feel a lot happier since I joined the group.	Happiness associated with attending the group	Happier
C	Why do you think that is?		
B	I just really like it	Like the group	Positive emotions
C	Yeah		
B	Yeah		
C	What keeps you attending, what keeps you coming here?		
B	I love everything about it. I love the people, I love all the stuff we do	'Love' the environment and other people	Socialising with people feel good
C	OK. Does it make you feel differently about yourself here?		
B	Ermm no it just…. Yeah it has made me feel happier, it hasn't made me feel sad coming here	Feeling happier	Positive feelings
C	You feel happier? Is that because of the activities?		
B	Yeah. I never felt sad when I didn't come here. It's just that it's made me feel a little bit happier.	Group lifts mood	Feeling more positive
C	Other than being happier, have you noticed any other changes in yourself?		
B	I've noticed I can do a lot more things.	Able to do more	Noticing changes
C	Like what?		
B	I feel fitter and I have been able to run faster	Physiological changes	Feeling fitter
C	*Have you?*		
B	*Yeah. Even my friends have noticed that I can run faster.*	*Others aware*	*Social comparison*
C	*Friends at home?*		
B	*Yeah and at school*	*In different environments*	

Appendix 14 - Phase three: primary themes

I am the same as other people	Other people have noticed (me getting fitter and faster)
Positive emotions	Yeah. I never felt sad when I didn’t come here. It’s just that it’s made me feel a little bit happier.
Connected to others	I love everything about it. I love the people, I love all the stuff we do
Fitter and stronger	I feel fitter and I have been able to run faster

Appendix 15 – example of coding from different data collection points that support creation of sub themes and themes

Thematic analysis

Codes					
From children's interview	**From parents supporting comments**	**Behavioural observations in interviews**	**Hand drawn pictures**	**Sub themes**	**Themes**
Friendships between peers	Understanding rules/ boundaries of sports and social situations	Occasionally incongruent with verbal responses	Playing with others	Physical competency Acceptance of needs and others	Feeling the same as others
Fun/ enjoyment of activities	How to make friends with others	More expressive than verbal responses due to anxiety in use of verbal skills	Smiling characters described as friends	Connectedness with others Inclusivity of group philosophy	Positive emotions
Support from others (group leaders, parents, peers)	Resolve conflicts between peers and group leaders	Difficulty in expressing self	Closeness to others	Social/ emotional competency and skills	Connected with others
Activities are positive experience on the whole	Have responsibility for actions	Anxiety	Visual descriptions of sports playing with others	Understand social constructs and concepts Positivity	Fitter and stronger
Sports are to be enjoyed	Learn to manage winning/ losing	Frustration		Incongruence between verbal and behavioural responses	
Positive feelings about all aspects of the group	Behaving more independently	Attention difficulties			
Relationships developing	Trusting others in	Acquiescent to			

with peers and group leaders Health and fitness is important Free from bullying, different from other aspects of life Non-judgemental attitude of all Negotiating conflict with others	games and social situations Negotiating conflict with others Free from bullying, different from other aspects of life	demands from authority figures Smiling, happy, jumping, nodding		

Appendix 16 – reflective statement

Reflective statement

Systematic literature review

The process of writing the systematic literature review was much more difficult than I first imagined. I was advised to start as early as possible and I am glad I did as the complexity involved in researching the various concepts, specifically the term ‘wellbeing’ became more and more difficult to define as I started to read more and more literature into the subject. When I first started thinking about my initial ideas for the literature review I realised that the process taken place by researchers around the world, who were tackling the issue of defining this term was dynamic and the terms were changing with every new paper being published. This is evident within the review as many of the papers I have used have only been published within the last two years. I spent a huge amount of time assessing search strategies with various terms and exploring what papers would be presented. The initial scoping searches revealed a large number of variations in the term for wellbeing and subjective wellbeing. At times this became a difficult task in determining exactly what different researchers meant when they were discussing the various terms being used. I went over various papers and examined reference lists as I was concerned that I may miss something relevant to the review. This process further highlighted the need for careful examination of the research from a range of disciplines, as wellbeing is relevant through a range of different service providers. Throughout the process I began to explore further statistical analysis models that were involved in measuring and comparing different populations and scales and realised how limited my knowledge was. This process provided an impetus to understand more about these models and become more confident at comprehending in more detail the models being used. Throughout the reviewing process I became aware that to thoroughly read and comprehend so many journals was very time consuming, however it ensured that I became much more immersed in the literature and could gain a clearer picture of where my research would sit alongside the many other reviews that had taken place concerning people intellectual disabilities.

Initially I felt that managing to research and write up two studies simultaneously would be very difficult and it was, although having the opportunity to do this ensured that as both studies were dealing with subjective wellbeing and people with intellectual disabilities I felt this reinforced the strengths of both pieces of work. The whole process felt all consuming at times and a little overwhelming, but at times I really enjoyed the process of being involved in a major piece of work. I also began to understand how with the initial review of the literature, researchers then go on to spend many years if not their whole careers devoted to one area and are able to produce many publications encapsulating similar populations, concepts or methods. I realised that it is a process that like all things when you begin can be difficult to grasp and can be a little daunting but ultimately inspires you to do more research in the future.

Empirical research

Choice of study

I always felt that choosing the PwID population to work with on a research project was the easiest part of the process. I knew that I wanted to work with a disadvantaged group of people, but to focus not upon the difficulties of their circumstances but on the reverse side of the ‘research mirror’. I have always had a keen interest in the principles and orientations of the positive psychology movement in exploring how we as a profession and as people can improve people’s lives and what are the factors that influence this processes. My particular interest is working with people who have intellectual disabilities and attempting to understand the challenges they face in society.

Choice of design

Many of the studies I had reviewed examining the lives of people with intellectual disabilities often did not use direct interviews to gather the information and relied upon parents, family members or carers to describe their experiences and interpret their children's or clients perspectives. Other approaches used questionnaires and surveys to gather the information. I wanted to work with people for my project and understand the perspectives to gain more information than can be provided from structured measure.

I felt that working with children with intellectual disabilities and exploring their experiences would be interesting as it had not been done before and I felt the research may be some of value to community groups when applying for funding for their projects. There had been a number of research projects exploring the benefits of sports groups and exercise in the mainstream literature but very little for this population.

I explored a variety of analytical methods for the data and initially chose Interpretative Phenomenological Analysis. However the further I progressed into this method I realised that this would not be the most appropriate method. After discussing this issue with my supervisor and various other researchers I committed to using thematic analysis as I felt it allows more flexibility in the approach. This ensured that I could explore avenues of data collection that would be much more beneficial in capturing the stories and perspectives of the participants of a group which have been under researched.

Recruitment

I selected my participants from one source as having previously worked with the group on a previous small scale project I felt that the population would be ideal to explore further and having met the young people, their parents, carers and group leaders everybody seemed very supportive of the study. My initial idea was to ask everyone to complete a wellbeing questionnaire and then interview those people who scored high or low on the measures to explore what factors may be influencing these scores. I was perhaps (as I think most first time researchers are) a little naïve that I could do this as the numbers in the group fluctuated greatly from week to week. I handed out numerous information packs and attended the group every week to explain the project to irregular attendees, unfortunately though I was not as successful as I first thought in recruiting the number of participants I originally planned for. Therefore I decided to slightly change this process and ask up to 15 potential participants to complete the wellbeing measure and then interview them. In the end nine participants completed the wellbeing measure and I interviewed eight of these.

Ethical considerations

Throughout the whole process I was inherently aware of the issues pertaining to interviewing children with intellectual disabilities. The power disparity in the relationship was overtly apparent with this population and this elicited a variety of reactions from the potential participants. These ranged from initially not wanting to speak to me at all to parents trying to persuade their children to participate. I overcame these difficulties as much as possible by attending the group every week and speaking with the parents about the ethical considerations for participating in research. I also engaged in many of the activities with the children and attempted to integrate myself as 'another member of the group', and would sit down with the group and do what the other members of the group did. I explained this process within the ethical proposal as initially issues were raised about working with this population. This proved effective in alleviating some of the anxieties of the group members and they felt more comfortable explaining their experiences. I was also able to speak with the young people, parents, carers and group leaders on a regular basis and observe the group and discuss the findings with the people present. The literature suggests that this process is necessary to engage with this population. I was aware that I did not want the participants to be involved in the research if they did not want to be there and at times I had to speak informally with the parents, who were keen for their children's voice to be heard. This made me feel a little uncomfortable; however I knew that I was upholding the right ethical practices. Occasionally the participants mentioned something in the interview that as a Trainee Clinical Psychologist you would want to explore further regarding issues in the school or home, although as a researcher that was not possible in the interview. This felt frustrating at times as the interviews are not the opportunity to explore these issues, although I wanted to help uncover if there were any problems they wished to discuss further. However the participants had the opportunity to explain any issues that concerned them with their parents, carers, group leaders or teachers.

Concluding reflections

I felt that the Systematic Literature Review and the empirical study provided valuable information regarding the influences of subjective wellbeing for people with intellectual disabilities. Therefore I wanted to submit to a journal that has a wide readership for multiple disciplines and has published research previously regarding subjective wellbeing for this population. I chose the Journal of Applied Research in Intellectual Disabilities for these reasons. From conception to completion this thesis has been all consuming and has on the whole been a very positive experience for me. I have been able to see a world and gain perspectives of people within that world that I have not accessed in that way before. Everyone involved made me feel very welcome and to observe and be involved with the fantastic work that the often unsung groups are doing with young people was a privilege. Having discussions with the parents was also very inspiring to understand what lengths they had to go to in order to achieve the best outcomes for their children regardless of the challenges they faced. The parents used the group for support themselves and I feel that these groups do more than provide an opportunity for the children to exercise, but also provide a space for children and their parents to meet and support each other.

The whole process has been a valuable learning experience, I feel that I have developed stronger skills in conducting high quality research, especially utilising methods to access the perspectives of people who are often under researched. I have learnt a lot throughout these studies, the primary reflection is that young people with intellectual disabilities are able, if offered the opportunity and support, to speak for themselves and this should be supported and encouraged.