

**An exploration of the quality of life of people labelled with intellectual disabilities,
and their capabilities as assessed by the Short Parallel Assessments of
Neuropsychological Status (SPANS).**

Thesis submitted in part fulfilment of the degree of

Doctorate in Clinical Psychology

(DClinPsy)

University of Leicester

By

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Supervised by: Dr Gerald Burgess

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Declaration

I confirm that the literature review and research reported in this thesis are an original piece of work. It was submitted in part fulfilment of the Doctorate in Clinical Psychology (DClinPsy) and has not been submitted for any other academic award. This thesis was checked for completion prior to submission.

**An exploration of the quality of life of people labelled with intellectual disabilities,
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Thesis Abstract

Enhancing quality of life has become a central focus in the intellectual disabilities (ID) field, corresponding with the emergence of a social-ecological model of disability. An on-going narrative shift towards understanding *capabilities* and the interplay between individual ability and the environment is influencing service provision. Identifying cognitive strengths and weaknesses is one way of better understanding such capabilities and thus contributing to maximising environments, for example, by informing support needs and other pertinent factors that play a role in overall quality of life.

Literature Review

Personal and environmental factors that contribute to the quality of life of people labelled with ID were reviewed. Fourteen quantitative papers were synthesised and indicated a particular association between cognitive ability, environments that foster agency, choices and personalisation, and quality of life. Diverse methodologies, sampling, and broader inclusion of predictor variables could enrich future quality of life research.

Research Report

This study explored the initial validation of a neuropsychological measure: the Short Parallel Assessment of Neuropsychological Status (SPANS), with a sample of 29 adults with ID and 29 typically-developing (TD) adults. Among TD samples, the SPANS 'measures' a range of cognitive domains such as memory and learning, attention/concentration, and conceptual flexibility. In ID test performances may contribute to increasing understanding and promoting personalisation of support.

A mixed methods approach revealed that the SPANS appears to measure different constructs to the general population, and as hypothesised the TD outperformed the ID group in every domain. Interviews captured that participants generally enjoyed the SPANS, were reminded of daily tasks, and had a sense of awareness of their own abilities which impacted their confidence and performance.

Critical Appraisal

The critical appraisal details lessons learned from the research process and methodological reflections, along with commentary on personal and professional development.

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The intellectual disabilities community team who made this project possible have my utmost gratitude. Thank you for supporting me and opening up the opportunity for me to work alongside you and to meet with some of your fantastic clients. It will be my privilege to return to work with you post-qualification.

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Part One: Literature Review

A systematic review of personal and environmental predictors of quality of life of adults labelled with intellectual disabilities.

(Guidelines to authors for journal targeted for literature review can be found in Appendix A)

Abstract

Background

Identifying factors that influence the quality of life (QOL) of people diagnosed with intellectual disabilities has become a central aspect of quality of life research. The recognition of such contributors may identify enhancement strategies that inform practice. The current review aimed to critically examine the literature on personal and environmental predictors of quality of life.

Methods

A systematic search of the literature was carried out using the following inclusion criteria: (i) studies were theoretically aligned with Verdugo and Schalock's (2002) eight-domain QOL model; (ii) adult samples; (iii) QOL outcomes were explicitly mentioned in the study aims. Fourteen studies met the inclusion criteria. Findings were synthesised and reported according to personal and environmental predictor variables.

Results

The reviewed literature suggested a combination of personal and environmental factors influence the QOL of people with intellectual disabilities. Those with a lower level of intellectual functioning and thus greater support needs generally experienced lower QOL. More independent employment and living circumstances that matched individual needs were consistently predictive of better QOL outcomes. Specific variables may be associated with particular quality of life domains.

Conclusions

A QOL framework may support improved practice internationally. Further research ranging in methodology is needed to more robustly explore predictors of quality of life and thus inform enhancement strategies; particularly in the lower IQ range. Alternative models to the eight-domain model require consideration.

1. Introduction

1.1 'Intellectual Disability'

The World Health Organisation (WHO; 2017) characterises 'intellectual disability' (ID) as:

'a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development'.

In their meta-analysis, Maulik *et al.*, (2011) estimated the prevalence of ID to be around 1% of the population worldwide. A combination of developmental factors, injury (e.g. traumatic brain injury), and disadvantaged social environments are considered in the epidemiology of ID (Ramakers & Ponsioen, 2007). Despite internationally shared characterisation of ID, persons with ID do not reflect a homogeneous group. The validity of defining ID and subsequent assessments has generated contention and on-going debate within the literature (e.g. British Psychological Society, 2015). The WHO summarises this debate in its 'World report on disability' (WHO, 2011), reflecting the conceptual shift from a medical model of understanding ID towards social-ecological models of disability that encompass personal and environmental factors.

1.2 Ecological Model of Disability

The social-ecological model of disability (e.g. Hughes & Paterson, 1997) suggests that ability and disability are dynamic spectrum-based concepts that reflect interactions between the person and the environment. According to this model, those with ID are distinguishable from the general population as a result of the mismatch between environmental demands and individual capabilities. 'Disability' is proposed to be context-driven which indicates that whilst person-environmental interactions can be disabling, individual factors may interact with different environments to *create* abilities. This highlights the importance of understanding 'person-environment fit' and the systems that impact on human functioning (Schalock *et al.*, 2010).

Bronfenbrenner's (1979) ecological theory provides a framework for considering the diverse contexts that impact the way those with ID function. As Figure 1 illustrates, the individual is at the centre and is influenced by interrelated systems that directly (i.e., microsystems that

include the person, social, family etc. networks), and more widely (i.e., macrosystems that include cultural patterns and economic status etc.) shape human experiences. Ecological models of ID have supported acknowledgement of the fluidity and heterogeneity of ID as a concept, and highlighted the responsibility of society to accommodate variation of individual needs (e.g. Brown *et al.*, 2009).

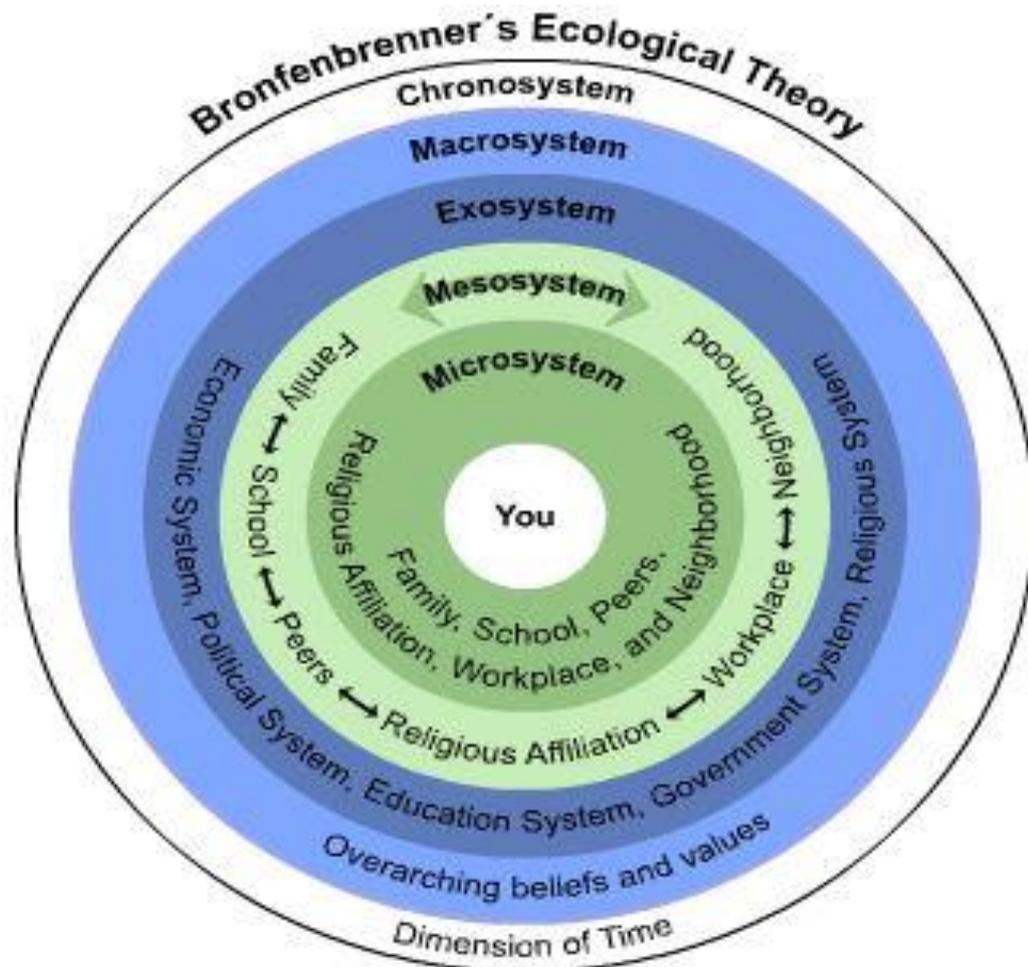


Figure 1: Diagram to show Bronfenbrenner's Ecological Systems Theory

1.3 'Quality of Life'

One framework that seeks to inform practice based on recognising the importance of the interaction between 'systems' and people with ID, is the 'quality of life' (QOL) framework.

QOL is a broad concept characterised by Schippers (2010) as 'the perception of what is important, necessary and satisfying to human beings throughout their lives' (pp.279). Over the past three decades, analogous with the development of social-ecological models of ID, the concept of QOL has become increasingly central to social policies and practice related to

persons with ID, consequently becoming a key outcome measure (Simoes & Santos, 2017). Schalock *et al.*, (2002) considered the socio-political context of this undertaking and proposed three core drivers of QOL and ID interest: a) the attitudinal shift away from medicalising ID and towards understanding the influences of wider environmental factors on people's lives; b) increased governmental drive to 'normalise' disability and transition from institutions to community-based living/support; and c) civil rights movements that promote person-centred planning and individual rights. In order to enhance understanding of the QOL of those with ID, the WHO Quality of Life group (WHOQOL) have been dedicated to the scientific investigation of the concept of QOL and its measurement (e.g. WHO, 1993).

1.4 Quality of Life and Intellectual Disabilities

Some of the key efforts in the QOL and ID field of research have been: i) the conceptualisation of QOL (e.g. Schalock *et al.*, 2002), ii) emphasis on the importance of objective and subjective QOL studies (e.g. Antaki & Rapley, 1996), iii) consideration of the impact of deinstitutionalisation on QOL (see Chowdury & Benson, 2011, for a review), iv) exploration of how to improve QOL (e.g. Fabian, 1991), and v) the development and validation of QOL measurement tools (e.g. Brown 1997).

Lyons (2010) carried out a book review of QOL for persons with ID. Lyons reflected a general consensus within the literature that QOL conceptualisation should be analogous for those with and without ID. Whilst different definitions and conceptualisations of QOL exist, four key features that underpin the varying frameworks have emerged (Verdugo *et al.*, 2012). These are: 1) the concept of QOL is multidimensional (i.e. influenced by several factors at an individual and community level), 2) overall QOL includes objective (i.e. measurable components, such as frequencies) and subjective (i.e. views of the individual) indicators, 3) QOL has universal and cultural properties (i.e. QOL factors are shared across all human beings and are related to cultural factors), and 4) QOL is influenced by personal (i.e. individual factors) and environmental (i.e. service provision) characteristics.

Lyons (2010) described the significance of global assessments of QOL including both subjective and objective measures, although Schalock and Felce (2004) noted the importance of tailoring measurement tools to the aims of the specific research being undertaken. One particularly contentious aspect of assessing QOL in ID literature has been the validity of using proxies (the report-of-others). This is a particularly common approach when individuals with ID lack capacity to give their subjective views, and in the lower intellectual ability range (Lyons). Where studies have been able to investigate levels of agreement between proxy and self-

ratings, mixed findings are reported. This methodological concern continues to be debated across QOL and ID research (e.g. Perry & Felce, 2002) and several authors state the importance of understanding and creatively exploring the determinants of subjective QOL (e.g. Bramston *et al.*, 2002).

Pertinent to the current review, research exploring the impact of particular personal and environmental characteristics on QOL has become a central focus in better understanding the complex interplay of QOL related factors. This focus reflects the ecological model of disability and understanding the way individuals are impacted by their environments and vice versa (Gomez *et al.*, 2016). Within the literature, ‘personal characteristics’ have been frequently operationalised as demographic and function-related factors (such as age, sex, ID functioning, and mobility), and ‘environmental characteristics’ in terms of social inclusion, life activities, person-centred supports etc. (Schalock *et al.*, 2010). However, there is inconsistency about this operationalisation across studies (e.g. Schippers, 2010).

A range of personal and environmental factors have been shown to influence QOL, including: intellectual functioning (e.g. Memisevic *et al.*, 2015), social support (e.g. Campo *et al.*, 1997), employment (e.g. Kober & Eggleton, 2005), control and choices (i.e. ‘self-determination’) (e.g. Lachapelle *et al.*, 2005), support strategies (e.g. Claes *et al.*, 2012), adaptive behaviour (i.e. independent living skills) (e.g. Schalock *et al.*, 1994), and residency (i.e. living in semi-independent versus group homes, e.g. Felce *et al.*, 2008). The extent and directionality of the impact of these variables on QOL has yielded mixed findings; therefore the role that such variables play in QOL outcomes is unclear (Schalock *et al.*, 2010). Variation in the operationalisation of variables and the specific factors explored probably account for some of the inconsistent results. Discrepancies may also be attributable to the range of measurements tools used in the QOL literature; many of which fail to accommodate the multi-dimensionality of QOL (Potter, Cantarero & Wood, 2012).

1.5 Eight-domain QOL Model (Verdugo & Schalock, 2002)

Efforts have been made in the ID literature to agree upon the assessment and application of QOL-research (Schalock *et al.*, 2002). This may improve comparability across studies allowing for a clearer sense of the variables that impact the QOL of those with ID. Verdugo and Schalock’s (2002) eight-domain model has featured substantially across this literature and will guide the current review.

In a review of the conceptualisation and measurement of QOL, Heck *et al.*, (2017) identified that Verdugo and Schalock's (2002) model is being applied across different fields and therefore supports universality (e.g. De Maeyer *et al.*, 2009); has featured in many empirical studies in the ID field (e.g. Claes *et al.*, 2009a; Van Loon *et al.*, 2014); is progressing towards theory development specific to ID (Schalock *et al.*, 2016); and in comparison to other models has shown the best model fit to individual quality of life (Gomez *et al.*, 2011).

This model proposes eight core QOL domains, derived from extensive review of QOL literature, that capture the broad, multi-dimensional nature of personal well-being (see Table 1). Notwithstanding, Verdugo and Schalock (2002) noted the importance of holistically considering the individual and paying less concern to the specific number of domains. The model holds that QOL is a dynamic concept influenced by the systems in which people live. This model pays particular attention to the extent to which the following three systems might interact, influence and enhance QOL: individual (micro), organisational (meso), and societal (macro) (Bronfenbrenner, 1979). Therefore both personal/ individual and environmental/ systemic factors require exploration and understanding.

Table 1: Table to show the eight core QOL domains of Verdugo and Schalock's (2002) model

Higher Order Factors	Eight-QOL Domains	Definition/ indicators
Independence	<i>Personal Development</i>	Education, personal competence and performance
	<i>Self-Determination</i>	Autonomy/personal control, goals and personal values and choices
Social Participation	<i>Interpersonal Relations</i>	Interactions, relationships and supports
	<i>Social Inclusion</i>	Community integration and participation, community roles and social supports
	<i>Rights</i>	Human (respect, dignity and equality), and legal
Well-Being	<i>Emotional Well-Being</i>	Contentment, self-concept and lack of stress
	<i>Physical Well-Being</i>	Health, health care, activities of daily living and leisure
	<i>Material Well-Being</i>	Financial status, employment and housing

1.6 Aims of the Current Review

The interaction between an individual and their environment is likely to impact personal outcomes, as proposed by social-ecological models of disability and the QOL framework.

Understanding how QOL is influenced by such variables could support the identification of QOL enhancement strategies, and better inform policies that govern ID service provision. The main aim of this review was to critically appraise QOL research that has investigated predictors of QOL in adults with ID.

In light of the evidence that supports the validity of the eight-domain QOL model (Verdugo & Schalock, 2002), and to support comparability of study findings, this review selected studies that were theoretically underpinned by this model only.

2. Method

2.1 Search Strategy

In line with the Critical Appraisal Skills Programme (CASP, 2014) a search strategy was developed to seek papers that most adequately addressed the review question. To encompass a wide range of literature from medical and social sciences a systematic search of the following databases was carried out: PsychInfo, Scopus, Cumulative Index to Nursing and Allied Health (CINAHL), and MedlineOvid. The Cochrane Database of Systematic Reviews (CDSR) was searched for existing reviews; none were found that specifically related to predictors of QOL for those with ID. Scoping of grey literature, such as Google Scholar, retrieved guidance articles and policy papers that supported contextualisation of the review.

Key words were developed from previous literature related to QOL and ID research (e.g. Brown 2017; Buntinx & Schalock, 2010). Various combinations of three main search strings were used: quality of life, outcomes and intellectual disabilities (“quality of life” OR “well-being” OR wellbeing*) AND (“personal outcomes” OR person* outcome* OR indicator* or predict*) AND (intellect* OR learning OR mental* OR development* disabilit* OR impair* OR retard* OR deficien*). Searches were carried out between May and July 2017.

2.2 Study Identification and Inclusion

The following search limits were applied to support the retrieval of important and relevant studies:

- 1) A time period between 2004 and 2017; in 2004 an international group of QoL researchers who were members of the Quality of Life Special Interest Research

Group (QoL SIRG) of the International Association of the Scientific Study of Intellectual Disabilities (IASSID) developed a set of criteria for future QoL research (Schippers, 2010). These criteria have informed ongoing research and therefore supported comparability across studies;

- 2) Studies published in English language; to support readability;
- 3) Peer-reviewed journals; to ensure academic credibility;
- 4) An adult population (18 years and above); because children are covered under different legislation. Where international policy considered 'adults' to be from age 16, studies were included. Studies that focused specifically on 'older adults' were excluded to reduce age effects.

In addition to the above limits, inclusion and exclusion criteria determined whether titles and abstracts were read and retained. Studies were included if (a) the term 'quality of life' was a key word; to support with focusing the review on literature embedded in QOL terminology, as depicted by the QoL-SIRG (Schippers, 2010), rather than similar constructs, such as 'life satisfaction', that might become unwieldy, (b) the study sample reflected a non-specific/unknown ID aetiology; to reduce the potential influence of specific ID-related characteristics that might encompass its own body of literature, (c) indicators of QOL were explored as part of their main aims; to retain papers that explored the contribution of different variables to QOL (d) articles explicitly mentioned assessing QOL outcomes; to focus on factors that might *affect* QOL.

Studies were excluded if they concentrated on a specific aspect of QOL (such as health-related QOL which is articulated within its own body of literature; Heck *et al.*, 2017) focused on the development and validation of QOL instruments, or on proxy and self-report agreement levels. Methodological weakness also determined the exclusion of several papers ($n = 6$). This was defined as studies with extremely small samples and studies that only included correlational data that sought out an association between variables, because the current review was investigating the potential predictive relationship between factors. If the use of the eight-domain QOL model (Verdugo & Schalock, 2002) was not indicated in the aims or methods sections of papers, these were eliminated; this resulted in the exclusion of ten papers.

Recommendations from the PRISMA group guided the stages of study selection which are presented in Figure 2 (Shamseer *et al.*, 2015). A reference management software programme supported the retention of articles (RefWorks).

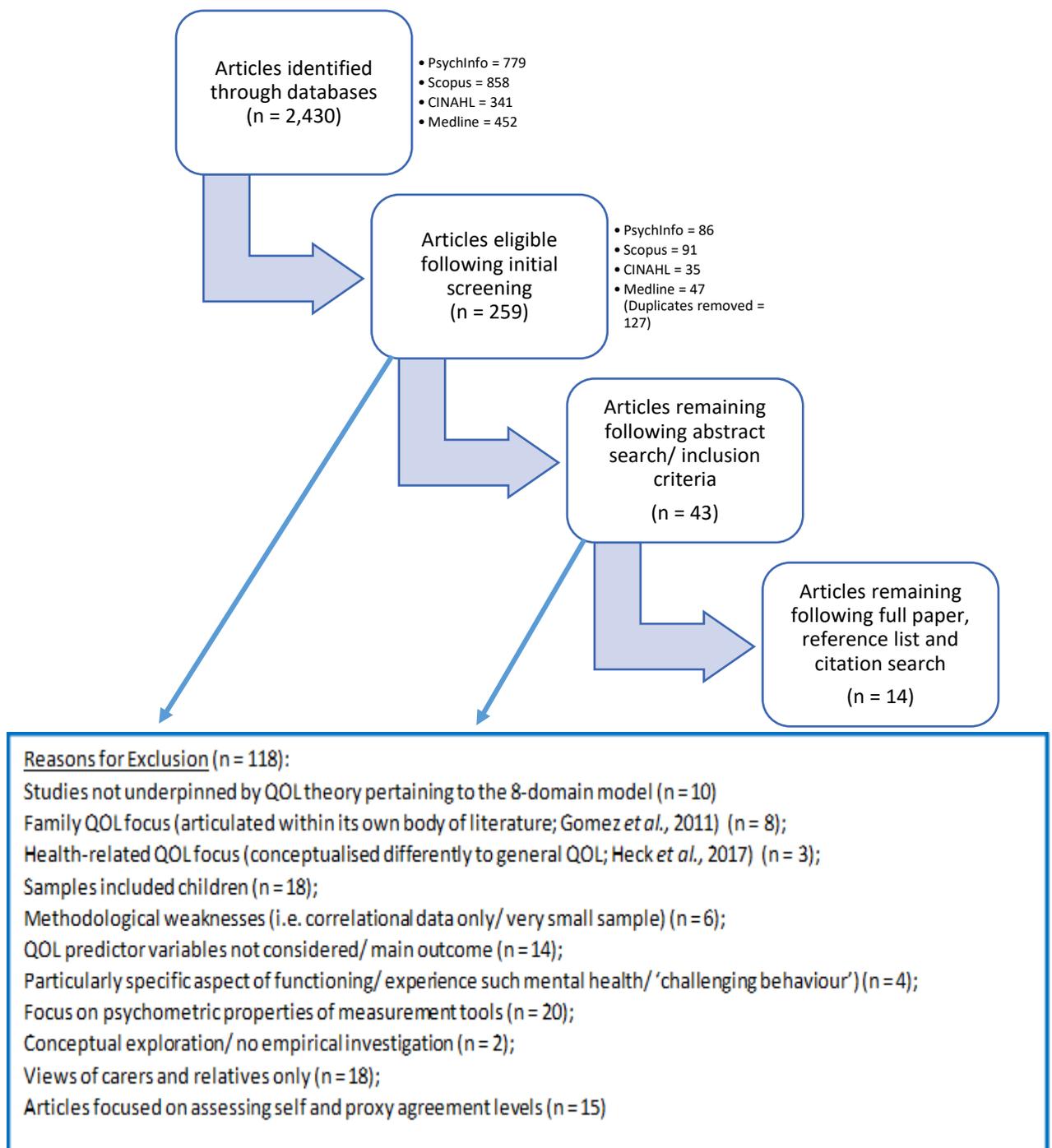


Figure 2: Flow Chart to Show Search Process

2.3 Data Extraction

The Cochrane Non-Randomised Studies Methods Group (NRSMG) guidance for data extraction in non-randomised studies was adhered to (Reeves *et al.*, 2008). Data were extracted into the Cochrane Public Health Group Data Extraction and Assessment Template (Cochrane Public Health Group, 2011). Extraction concentrated on general study features including sample

characteristics, data analysis, results, and researcher attempts to overcome biases such as selection bias. This extraction informed the extent to which the results of studies may have been influenced by their methodological design and/or procedure (Higgins *et al.*, 2011), along with subsequent study quality appraisal.

2.4 Quality Appraisal

Critical appraisal of the shortlisted studies related to the assessment of study design, execution, reporting, and the extent to which studies addressed the research question. In their systematic review, Sanderson, Tatt and Higgins (2007) reported a lack of quality appraisal tools that specifically focused on cross-sectional studies. In light of this, Downes *et al.*, (2016) recently conducted a Delphi-process which resulted in the development of the 'Appraisal Tool for Cross-sectional Studies' ('AXIS'). This tool comprises twenty questions (detailed in Appendix B) that address study design, quality of reporting and risk of bias in cross-sectional studies; advantageous over alternative current tools that do not address poor reporting (e.g. Cochrane risk of bias tool; Higgins *et al.*, 2008). The AXIS does not include a numerical scale to rate the overall quality of studies, therefore a degree of subjectivity was required when using this tool, along with following detailed interpretative guidance from Downes *et al.* The AXIS pays particular attention to the credibility and reliability of the aims, methods, and results; studies that reported these clearly - as assessed against the AXIS - were included in the final review (Appendix C).

Quality of the studies varied in relation to particular strengths and weaknesses. Studies considered the 'highest' quality were those which demonstrated greater population representativeness (Bonham *et al.*, 2004; Lombardi *et al.*, 2016; Rand & Malley, 2016); addressed the research question most adequately by comprehensively covering the eight-domain model (i.e. measurement tools used clearly mapped onto this model) (Bonham *et al.*; Lombardi *et al.*, 2016; Simoes *et al.*, 2016; Simoes & Santos, 2016, Simoes & Santos, 2017); and employed methods to overcome potential biases (Bonham *et al.*; Simoes & Santos 2016; Simoes & Santos, 2017). These studies were given greater weight and more frequently reported in the results section synthesis. Studies considered to be of 'weaker' quality were still included in order to contribute to the review of relevant research.

2.5 Final Articles

Fourteen studies most adequately met the inclusion and quality appraisal criteria. All studies were quantitative by design, supporting comparability of the methods and findings. A meta-

analysis could not be conducted due to substantial variation across studies in the use of outcome measures, QOL domains, and predictor variables. A * in the reference section of this review indicates included studies. A summary of included study characteristics is provided in Appendix D.

3. Results

The results are presented using the following categories: i) samples, ii) measures, iii) specific predictor variables, including subsections related to personal and environmental characteristics.

3.1 Samples

3.1.1 Design

All included studies utilised a cross-sectional design, capturing just one point in time. Non-randomised convenience sampling was employed by thirteen studies. One study randomly selected participants, although notably from a pool of participants accessing publicly funded adult social care services (Rand & Malley, 2016). All studies conducted regression analyses to explore the contribution of predictor variables to domain-specific or overall QOL outcomes.

3.1.2 Participant Characteristics

Samples were recruited from the Netherlands (1), Bosnia and Herzegovina (1), UK (1), Australia (1), Italy (2), US (2), Spain (3), and Portugal (3). Sample sizes ranged from 56 (Miller & Chan, 2008) to 13,643 participants (Rand & Malley, 2016); the median of all samples was 193. All included studies reported less than 10% variation between gender groups, except Nota *et al.*, (2007) who included over twice as many men as women. Age ranged from 16 to 111 years across studies.

Eleven studies limited their sample to individuals labelled with ID only (of these studies, only one indicated the percentage of 'non-specified and specified ID' in the sample), two included a control group of 'typically developing' adults, and one study compared five groups (45.5% of the sample made up the ID group). Studies differed in the 'level of ID' categories reported; three described 'mild', 'moderate', 'severe', 'profound', three described mild, moderate, and severe, five described mild and moderate, and three did not report level of ID. When studies

did report level of ID only four described and referenced the assessment information that determined ID diagnosis and level of ID categorisation.

Eleven studies recruited participants in receipt of commissioned ID services. Two studies recruited participants from ID employment schemes and one recruited from housing projects (institutional and supported group housing).

3.2 Measures

3.2.1 Methods

Three studies administered measures that were informant-based and therefore completed by proxies only (Badia *et al.*, 2013; Gomez *et al.*, 2016; & Nota *et al.*, 2007). Proxies were identified as support staff, carers or relatives who had known the person with ID for at least three months. Five studies used self-report tools only (unless an advocate was deemed necessary) (Bonham *et al.*, 2004; Bramston *et al.*, 2005; Memisevic *et al.*, 2015; Rey *et al.*, 2013; & Simoes & Santos, 2016). Six studies used measures that captured proxy and self-report data (Claes *et al.*, 2012; Lombardi *et al.*, 2016; Miller & Chan, 2008; Rand & Malley, 2016; Simoes *et al.*, 2016; Simoes & Santos, 2017).

Thirteen studies employed a structured one-to-one interview approach using Likert-type questionnaires with those with ID and/or proxies; one study collected data online (Rand & Malley, 2016). One study recruited individuals with ID to carry out interviews with participants (Bonham *et al.*, 2004); all other interviews were conducted by trained professionals (i.e. psychologists) or research assistants. Four studies explicitly reported that researchers with ID experience carried out interviews. Four studies included adapted measures to support comprehension (Bonham *et al.*; Bramston *et al.*, 2005; Miller & Chan, 2008; Rand & Malley); reading and comprehension support was offered by interviewers to all participants with ID.

3.2.2 QOL Tools

Ten studies utilised QOL tools that included both objective (i.e. recordable circumstances) and subjective (i.e. self-appraisal) measures. For example, six studies administered the Personal Outcomes Scale ('POS'; Van Loon *et al.*, 2009) which has some evidence of cultural validity and has shown internal reliability across different settings (e.g. Claes *et al.*, 2009b). Notwithstanding, Memisevic *et al.*, (2015) noted that the POS had not been validated in Bosnia and Herzegovina (where this study took place) raising cross-cultural validity concerns. The Portuguese version of this tool differs from the UK version and so the final questions included

varied between studies. Two studies used subjective QOL measures only, whilst one used an objective QOL measure only.

Nine studies utilised measures that clearly mapped onto the eight-domain model/ measures that were specifically derived from this model. Three of these studies did not report specific domain-related findings, rather, overall QOL outcomes.

3.3 Predictor Variables

This section synthesises the most commonly investigated personal and environmental variables across the included studies.

3.3.1 Personal Characteristics

Age, gender, diagnosis/ 'level of ID', and support needs were the most frequently explored personal characteristics. Table 2 presents significant findings related to personal characteristics.

3.3.1.1 Age

Five studies reported that age did not significantly influence QOL scores. Significant findings varied across the remaining studies. Bonham *et al.*, (2004), Gomez *et al.*, (2016), Lombardi *et al.*, (2016), and Simoes and Santos (2016) found that younger age (it is unclear how 'younger' and 'older' age were operationalised) predicted *higher* QOL scores in the domains of Personal Development and Interpersonal Relations. These authors also found that older age predicted *lower* scores in the Material Well-being domain, whereas Gomez *et al.*, found the reverse; Bonham *et al.*, did not reach significance in this domain. In contrast, Rand and Malley (2016) found that being over 65 years old predicted *higher* overall QOL scores.

3.3.1.2 Gender

Pertaining to gender (characterised as male or female), four studies did not yield significant findings. Rand and Malley (2016) reported that being male was associated with *lower* scores in general QOL whilst Gomez *et al.*, (2014) described the opposite. Notably, gender was not a significant predictor across all domains in both of these studies but contributed to the significance of the overall regression models. Nota *et al.*, (2007) found that being female predicted *higher* scores in the Self-Determination domain, whereas Gomez *et al.*, found this for males. Bonham found that being male predicted *higher* Rights scores than women and the opposite in the Material Well-being domain. Simoes and Santos (2016) and Simoes and Santos (2017) noted the small predictive power of gender (according to Cohens d ; $d = \leq 0.49$ [Cohen,

1988]) for overall QOL scores in these studies. As observed by Bonham *et al.*, both gender and age had small effects on one or two domains across the studies.

3.3.1.3 Diagnosis

Eight studies entered 'diagnosis' into their regression model, although this was operationalised differently across studies. For example, some authors referred to mild, moderate, etc. 'level of ID', some utilised single IQ scores; some compared those with and without an ID diagnosis. One study did not indicate ID level as a significant predictor of QOL (Badia *et al.*, 2013). Presence of an ID compared to non-ID populations significantly predicted *lower* overall QOL scores (Gomez *et al.*, 2016; Simoes & Santos, 2016). Claes *et al.*, (2012), Lombardi *et al.*, (2016), Memisevic *et al.*, (2015), and Nota *et al.*, (2007) reported that having a 'mild ID' was predictive of *higher* overall QOL scores compared to moderate/more severe ID. 'Mild ID' was associated with *higher* scores in the specific domains of Personal Development, Self-Determination, and Rights.

3.3.1.4 Support needs

The intensity of 'support needs' was entered into analyses in three studies; all of the studies utilised the same measurement tool (Support Intensity Scale; Thompson *et al.*, 2004). Lombardi *et al.*, (2016) found that higher support needs predicted *lower* QOL scores across all eight domains; this variable was the most predictive of overall QOL in this study, explaining 27% of the variance. Simoes *et al.*, (2016) found support needs had little explaining power ($r^2 = < .09$) of overall QOL index scores, however increased support needs were predictive of *lower* scores in the Personal Development, Self-Determination and Rights domains. In contrast, Claes *et al.*'s., (2012) findings did not reach significance for this variable.

Table 2: Significant Findings Related to Personal Characteristics

Study Author(s) and Date	Description of Predictor Variable(s)	Outcome Variable(s)	Relationship between predictor and outcome variable (β coefficient)
Bonham <i>et al.</i> , (2004)	<i>Age – 18+ (upper age limit and mean age not reported)</i>	Personal Development	-.06*
		Interpersonal Relations	-.07**
		Rights	.05*
	<i>Gender - male (57%) or female (43%)</i>	Material Wellbeing	-.05*
	<i>Cognitive Ability – profound, severe, moderate, mild ID.</i>	Self-determination	.05*
		Rights	.09**
Claes <i>et al.</i> , (2012)	<i>Diagnosis – level of intellectual functioning – borderline, mild, moderate, severe</i>	QOL Total Score	0.24**
Gomez <i>et al.</i> , (2016)	<i>Age - 16-111 years. (M = 59.37) (ID group: 58% = male).</i>	Personal Development	-0.07**
		Interpersonal Relations	-0.06**
		Material Wellbeing	0.05**
		Self-Determination	-0.05**
		Social Inclusion	-0.08*
	<i>Gender – being male</i>	Emotional Wellbeing	0.62**
		Physical Wellbeing	0.18**
		Self-Determination	0.73**
		Rights	0.37**
	<i>Diagnosis of ID</i>	Personal Development	1.30**
		Physical Wellbeing	-1.06**
Self-Determination		3.27**	
Social Inclusion		0.50*	
Rights		1.99**	
Lombardi <i>et al.</i> , (2016)	<i>Age – 16-80 years (M = 41.7)</i>	Personal Development	-0.26*
		Interpersonal Relationships	-0.18*
		Social Inclusion	-0.15*
		Physical Wellbeing	-0.19*
		Material Wellbeing	-0.16*
	<i>Diagnosis – mild, moderate, severe ID</i>	Rights and Empowerment	0.14*
	Material Wellbeing	0.26*	

Memisevic <i>et al.</i> , (2015)	Age – 18-69 years (<i>M</i> = 31.2)	QOL Total Score	0.12
	Gender (male-female)	QOL Total Score	0.01
	Diagnosis – mild (77%) or moderate (23%) ID	QOL Total Score	-0.25*
Nota <i>et al.</i> , (2007)	Diagnosis – IQ score	Self-Determination in various daily activities	-0.42*
		Self-Determination in activities and commitments	-0.32*
Rand & Malley (2016)	Age – ‘over 65 years old’ entered into analysis.	Control over Daily Life	0.27**
		Personal Cleanliness	0.70*
		Food and Drink	0.27**
		Accommodation	0.30**
		Personal Safety	0.28**
		Dignity	0.84**
	Gender – being male	Personal Cleanliness	-0.40**
		Food and Drink	-0.13**
		Accommodation	-0.33**
		QOL Total Score	-0.29**
Simoes & Santos (2016)	Age – 18-66 years (<i>M</i> = 31.4)	Personal Development	-0.28**
		Interpersonal Relations	-0.15**
		Material Wellbeing	-0.08**
		QOL Total Score	-0.12**
	Gender – male (52.5%) or female (47.5%)	Interpersonal Relations	-0.12**
		Social Inclusion	-0.10**
		Rights	-0.10**
		Physical Wellbeing	-0.11**
		QOL Total Score	-0.10**
	Diagnosis – with mild or moderate ID versus without ID	Personal Development	-0.48**
		Self-Determination	-0.32**
		Interpersonal Relations	-0.16**
		Social Inclusion	-0.22**
		Rights	-0.21**
Material Well-being		-0.15**	
QOL Total Score		-0.32**	

Simoes & Santos (2017)	Age- 18-66 years (<i>M</i> = 31.4)	Independence	-0.15**
		Social Participation	-0.09**
		QOL Total Score	-0.10**
	Gender – male (52.5%) or female (47.5%)	Social Participation	-0.14**
		Wellbeing	-0.12**
		QOL Total Score	-0.11**
	Diagnosis – mild or moderate ID	Independence	-0.39**
		Social Participation	-0.24**
		Wellbeing	-0.07*
		QOL Total Score	-0.28**

Key: * $p < .05$; ** $p < .01$; *M* = mean; *ID* = intellectual disability

3.3.2 Environmental Characteristics

Living circumstances, employment status, support strategies were the most frequently explored variables across the included studies. Table 3 presents significant findings related to environmental characteristics.

3.3.2.1 Living Circumstances

Eight studies considered the predictive ability of ‘living circumstances’. This information was entered differently across studies. For example, some authors recorded location and modality of residency, some considered housing design and the way this met individual needs, whilst some distinguished between living with family, independently (own home), or in supported accommodation. Two studies did not yield significant findings (Badia *et al.*, 2013; Lombardi *et al.*, 2016). Living with family was reportedly associated with *higher* Emotional Well-being scores but *lower* Social Inclusion scores (Bonham *et al.*, 2004), indicating that different living arrangements might impact specific QOL domains differently. Living in residential services was predictive of *lower* Social Inclusion and Rights scores (Bonham *et al.*; Simoes & Santos, 2016; Simoes *et al.*, 2016). Living more independently and in housing that matched individual needs was consistently predictive of *higher* overall QOL (e.g. Claes *et al.*, 2012).

3.3.2.2 Employment Status

‘Employment status’ was entered in six studies. Again, studies varied in the operationalisation of employment information, for example, Claes *et al.*, (2012) and Lombardi *et al.*, (2016) considered the same four types of employment, whereas Simoes and Santos (2016) simply dichotomised ‘employed’ versus ‘unemployed’. Nonetheless, findings consistently indicated *higher* QOL scores for employed participants. Employment was particularly associated with the Material Well-being domain (Bonham *et al.*, Lombardi *et al.*, Simoes & Santos). More

independent employment (e.g. competitive employment) predicted *higher* Material Well-being scores (Bonham *et al.*). Employment status in all of the studies reached statistical significance at the $p < .01$ level and was the most prominent predictor in three studies.

Badia *et al.*, (2013) acknowledged the link between leisure activity and community integration and conceptualised this similarly to the role of employment. They considered leisure participation and found that leisure preferences and constraints were predictive of Physical, Emotional and Material Well-being. This indicated that mere participation in activities did not necessarily enhance QOL. Claes *et al.*, (2012) post-hoc tests suggested employment or volunteering was significantly associated with better QOL outcomes in comparison to general daytime activity (e.g. attending day centres). These findings echoed Badia *et al.*'s, observations that choices and opportunities to engage in *meaningful* daytime activity may be important subjective QOL factors.

3.3.2.3 Support Strategies

Three studies considered the effect of support strategies/ services on QOL outcomes. Claes *et al.*, (2012) and Lombardi *et al.*, (2016) quantified supports in the same way (i.e. staff-directed supports, availability of natural supports and prosthetics), whereas Gomez *et al.*, (2016) more broadly explored receipt of specialist services for particular client groups. Claes *et al.*, found that the availability of prosthetics, natural supports, staff-directed supports, and the provision of technology significantly predicted *higher* overall QOL outcomes, accounting for 10% of the variance. Whilst Lombardi reported that specific support strategies predicted scores in particular QOL domains, they found a more marginal influence of support strategies on general QOL outcomes, adding 1% to the total variance only. Particularly, staff-directed supports (described as practices such as giving client incentives, e.g. recognition and roles, providing education and training, facilitating community involvement, etc.) significantly predicted *higher* QOL scores in all domains except Emotional Well-being.

Having more perceived social support (e.g. social network; support from friends etc.) was predictive of *higher* QOL scores (Bramston *et al.*, 2005; Miller & Chan, 2008; Nota *et al.*, 2007). Additionally, those with greater social abilities (e.g. ability to express own wishes, ability to manage interactions) were found to be in the *higher* QOL group. Notably, participants with more severe ID showed lower basic social abilities (Nota *et al.*,) which was predictive of *lower* Self-Determination. Pertinent to these findings, Rey *et al.*, (2013) reported that 'emotional competence' (e.g. ability to identify, use and manage feelings), specifically, greater ability to regulate one's own emotions and appraise the emotions of others in social interactions, was a

significant predictor of QOL, accounting for 12.6% of their variance. Furthermore, Bonham *et al.*, (2004) also reported that reported frequency of transportation was predictive of greater Social Inclusion scores, indicating the importance of resources to support social participation.

Table 3: Significant Findings Related to Environmental Characteristics

Study	Description of Predictor Variable(s)	Outcome Variable(S)	Relationship between predictor and outcome variable (β coefficient)
Badia <i>et al.</i> , (2013)	<i>Leisure Activity (participation, preferences, interests & constraints) – assessed using the Leisure Assessment Inventory (LAI; Hawkins et al., 2002).</i>	Material Wellbeing	
		Leisure Preferences	0.25*
		Leisure Constraints	-0.27*
		Emotional & Physical Wellbeing	
		Leisure Preferences	0.21*
		Leisure Constraints	-0.29*
Bonham <i>et al.</i> , (2004)	<i>Living Circumstances – lived alone/with housemates, with family, supported units, foster homes or state institutions.</i>	Social Inclusion	
		Lives with family	-0.07*
		Emotional Wellbeing	0.10*
	<i>Employment Independence – competitive employment, supported employment, vocational programmes, day programmes, no programmes.</i>	Material Wellbeing	0.09**
Bramston <i>et al.</i> , (2005)	<i>Perceived Social Support – assessed using the Social Support Scale (Cutrona & Russell, 1987)</i>	Safety	.29**
		Emotional Wellbeing	.31**
		Material Wellbeing	.31**
		Productivity	.21*

Claes <i>et al.</i> , (2012)	<i>Support strategies – technology-based, prosthetics, staff-directed supports, professional supports, natural support</i>	QOL Total Score	
		Technology	0.11*
		Staff-directed supports	0.14**
	<i>Living environment – living on own, apartment, small group.</i>	QOL Total Score	0.17*
	<i>Employment status – paid job, volunteer extern, volunteer Arduin, day care centre</i>	QOL Total Score	0.26**
Gomez <i>et al.</i> , (2016)	<i>Receiving Specialist Service Support</i>	Material Wellbeing	-0.63**
		Physical Wellbeing	-1.75**
		Self-Determination	2.27**
		Rights	2.13**
Lombardi <i>et al.</i> , (2016)	<i>Support Needs – based on Support Intensity Scale (SIS; Thompson et al., 2004)</i>	Personal Development	-0.58**
		Self-Determination	-0.55*
		Interpersonal Relationships	-0.55**
		Social Inclusion	-0.49**
		Rights and Empowerment	-0.49**
		Emotional Wellbeing	-0.49**
		Physical Wellbeing	-0.23**
		Material Wellbeing	-0.19*
		Personal Development	
		Staff-directed support	0.24*
		Technology	0.11*
		Self-Determination	
		Staff-directed support	0.30**
		Interpersonal Relationships	0.21*
Staff-directed support	0.21*		
Social Inclusion			
Staff-directed support	0.34**		
Rights and Empowerment	0.17*		

		Staff-directed support	0.44*
		Emotional Wellbeing	
		Natural support	0.30*
		Physical Wellbeing	
		Staff-directed support	0.44*
		Material Wellbeing	
		Staff-directed support	0.30*
Memisevic <i>et al.</i> , (2015)	<i>Employment – employed versus unemployed</i>	QOL Total Score	-0.30**
Miller & Chan (2008)	<i>Perceived Social Support – measured using the Personal Resource Questionnaire (PRQ-85; Brandt & Weinert, 1981)</i>	QOL Total Score	0.44**
Nota <i>et al.</i> , (2007)	<i>Social Abilities</i>	Self-Determination in various daily activities	-0.17*
		Self-Determination in activities and commitments	-0.45*
		Self-Determination in own choices and desires	-0.25*
Rand & Malley (2016)	<i>Home Design – rating of the suitability of the design of home in terms of mobility and ability to reach things</i>	Control Over Daily Life	-0.44**
		Personal Cleanliness	-0.24**
		Food and Drink	-0.46**
		Accommodation	-0.44**
		Personal Safety	-0.25**
		Social Participation	-0.28**
		Occupation	-0.53**
		Dignity	-0.12**
		Total QOL Score	-0.76**
Rey <i>et al.</i> , (2013)	<i>Emotional Competence – ability to identify, use and manage feelings – assessed using the Wong & Law (2002) Emotional Intelligence Scale (WLEIS).</i>	Total QOL Score	
		Regulation of Emotions (ROE)	0.32**

Simoes & Santos (2016)	<i>Living Circumstances – own home, family home, care facility</i>	Social Inclusion	0.09*
		Rights	-0.39**
		QOL Total Score	-0.08**
	<i>Employment Status – employed versus unemployed</i>	Self-Determination	-0.08*
		Rights	-0.14**
Emotional Wellbeing		-0.11**	
Material Wellbeing		-0.48**	
	QOL Total Score	-0.19**	
Simoes, Santos & Biscaia (2016)	<i>Support Needs – based on the SIS (Thompson et al., 2004)</i>	Personal Development	-0.47**
		Self-Determination	-0.24*
		Interpersonal Relations	-0.18*
		Social Inclusion	-0.23*
		Rights	-0.31**
		-0.35**	
Simoes & Santos (2017)	<i>Living Circumstances – own home, family home, care facility</i>	Social Participation	-0.15**
		QOL Total Score	-0.08**
	<i>Daytime activity (employment) – paid job, vocational training, occupational activity centres, no daytime activity.</i>	Independence	-0.32**
		Social Participation	-0.17**
		Wellbeing	-0.28**
	Total QOL Score	-0.31**	

Key: * $p < .05$; ** $p < .01$; M = mean; ID = intellectual disability

4. Discussion

The current review aimed to appraise literature that explored personal and environmental predictors of QOL of adults with ID. Fourteen quantitative cross-sectional studies that integrated Verdugo and Schalock's (2002) eight-domain QOL model were reviewed. The findings are discussed with reference to Bronfenbrenner's (1979) ecological systems theory.

4.1 Overview of Findings

Findings related to the personal characteristics of age, gender, diagnosis and support needs were synthesised. Age tended to be a significant predictor for particular QOL domains, however, findings were contradictory within the literature. The predictive power of gender also revealed contradictory findings, though additionally studies were plagued with low power. Some evidence suggested that more intense support needs predicted lower QOL scores, although this was not a consistent finding. 'Diagnosis' as a predictor variable revealed a more consistent pattern indicating that 'mild ID' was associated with higher QOL scores.

Interaction effects were reported that suggested lower intellectual functioning and higher support needs co-varied with lower QOL outcomes.

Findings related to environmental characteristics of living circumstances, employment, and support strategies were also synthesised. Living more independently and in housing 'suited' to individual needs was consistently predictive of greater QOL scores, particularly in the Rights domain. Employment also emerged as a significant predictor of higher QOL scores, with more independent employment more strongly predicting greater outcomes. Support strategies yielded findings that were less clear; some support was reported for the use of staff-directed supports and particular support strategies may be associated with particular QOL domains. Perception of having social support was related to higher QOL outcomes.

4.2 Clinical Implications

The clinical implications of the findings can be considered with reference to the micro, meso, and macro-systems described in Bronfenbrenner's ecological systems model (Bronfenbrenner, 1979). Table 2 illustrates these systems levels, QOL-related principles and ideas for enhancement strategies as cited by Schalock *et al.*, (2016).

1) Micro-systems

The findings that moderate to severe ID co-varied with lower QOL outcomes may indicate a particular vulnerability of this group. Therefore, attention needs to be paid to the factors that may moderate or mediate this effect (Schalock *et al.*, 2016). Authors noted that it is unlikely to be the mere presence of low intellectual functioning that is affecting QOL and suggest considering the societal barriers that may be associated with this, such as limited choices (e.g. Nota *et al.*, 2007). Continuing to shift attitudes away from a diagnostic model and to a social-ecological model may reduce the impact of diagnosis. Emphasising the context in which the individual lives, the way this interacts with individual ability, and the subsequent support that is received to engage in community-based settings, is crucial to shaping narratives and therefore individual experiences of those with ID (e.g. Simoes & Santos, 2017).

Ways that skills and attributes associated with higher QOL might be developed for individuals with ID, responsive to ability levels, could help to enhance QOL outcomes. For example, functional training and education around social skills and emotional regulation/ appraisal skills might serve to empower people and support them to develop aspects of functioning that seemingly contribute to improved QOL (e.g. Miller & Chan, 2008). Furthermore, the importance of environmental 'fit' (i.e. housing design and support strategies that suit

individual needs) should be acknowledged and identified to support individuals to have greater choice and decision making in this process (e.g. Rand & Malley, 2016).

2) Meso-systems

The importance of employment, and particularly independent employment, suggests a need for organisations to increase the opportunities of employment for those with ID. Such opportunities are consistently cited in the literature as limited for people with ID (e.g. Department of Health, 2001), more so in particular countries (e.g. in Bosnia and Herzegovina very few people are employed; Memisevic *et al.*, 2015), depriving people of choices and chances to develop and contribute their knowledge and skills to society (Thompson *et al.*, 2014). Importantly, providing activities that are meaningful to the individual is crucial; the mere offer of activities was shown to be inadequate and therefore support to identify and engage in personally desired activity/ job roles may improve overall QOL (e.g. Claes *et al.*, 2012), especially for those in the 'mild ID' range.

The social-ecological model of disability considers that those with ID require additional support to the 'typically developing' population to take part in daily life/ community activities (Thompson *et al.*, 2009). Given that increased support needs were related to lower QOL scores, services and public policies need to continue focusing on providing individualised supports that recognise and respond to these needs. If support needs were addressed adequately; it is probable that the intensity of support needs would be inconsequential (e.g. Lombardi *et al.*, 2016).

There has been a significant shift towards more independent accommodation and smaller-residential housing for people with ID (e.g. Chowdury & Benson, 2011), and the findings indicated a difference in the QOL outcomes of people continuing to live in larger residential housing. Therefore ongoing development of housing options that promote independence, or perhaps most importantly, personalisation, choice and opportunities for people with ID is essential. This would require more funding for social care resources to make smaller accommodation more available and tailored. Further exploration of QOL domains that particular living environments affect (i.e. living with family was found to predict lower Social Inclusion scores; e.g. Bonham *et al.*, 2004) is also crucial to identifying specific QOL domains that may require enhancement strategies.

3) Macro-systems

Group differences (i.e. lower overall QOL scores for those with ID; Simoes & Santos, 2016) indicated that there continues to be a gap between citizens. Incorporating the QOL framework across international public policies may contribute to building systems that attend to the person-environment interplay, and therefore improve accessibility by adapting environments (and supports) to respond adequately to people’s needs (Buntinx & Schalock, 2010).

Additionally, having a supportive social network was related to enhanced QOL outcomes (e.g. Bramston *et al.*, 2005). Whilst agencies may support opportunities for engagement, establishing such networks is also contingent on societies that promote inclusion and involvement for people with ID (i.e. communities that are equitable, respectful and inclusive) (Schippers, 2010).

Table 4: Ecological Systems and QOL Principles (Schalock *et al.*, 2016)

Systems Level	QOL-related principles	Potential enhancement strategies
Individual (<i>Microsystem</i>)	Empowerment	Decision/choice making, risk taking, goal setting, self-advocacy, self-management
	Skill Development	Functional training, use of technology to enhance cognitive, social and practical skills
	Involvement	Participation, inclusion, knowledge and ability sharing.
Organisation (<i>Mesosystem</i>)	Opportunity development	Integrated employment, inclusive education, community-based, less restrictive options, community integration activities, transportation, social networks.
	Safe and secure environments	Environments characterised by safety, security, predictability, and personal control
	Supports alignment	Aligning individualised supports to personal goals and assessed support needs.
Society (<i>Macrosystem</i>)	Accessibility	Ensuring human and legal rights.
	Attitudes	Knowledge and positive interactions.
	Environmental enrichment	Nutrition, cleaner and safer environments, reduced abuse and neglect, adequate housing and income.

4.3 Methodological Issues

Authors of the included studies highlighted the limitations of employing a cross-sectional design because causal links cannot be inferred. Additionally, convenience sampling likely captured the views of those more willing to share their experiences, which may limit generalisability to others. Notably, QOL is more legislatively central in some countries than others, for example, in the Netherlands services are committed to a QOL framework (Claes *et al.*, 2012), whereas Spain are not clearly guided by such a framework (Badia *et al.*, 2013). Variation in commitment and implementation may explain some of the differences across the findings. Methodological improvements, such as longitudinal studies and research across a diverse range of settings that incorporate a QOL framework will be important to the on-going identification and exploration of predictors of QOL.

The relationship between lower ability and lower QOL remains unclear and may, in part, be associated with the way that 'ability' and QOL were measured across studies. Defining ability and what constitutes a good quality of life is rooted in social and cultural norms (Whitaker, 2013). Therefore, measurement of both ability and QOL will reflect factors which our society gives value to at a particular point in time; thus influencing what society deems individuals 'should' be able to cope with. In further exploring the association between ability and QOL, attention must be paid to the underlying assumptions that have determined the 'measurement' of 'better QOL', and the subjectivity of this to change over time according to social norms (as opposed, perhaps, to the individual views of those with ID).

The majority of studies gathered data through services commissioned to support people with ID; findings for those not accessing such services may have differed. In addition, studies that administered subjective measures directly to persons with ID relied upon adequate verbal skills; inadvertently omitting those with limited verbal skills. This is a common critique of general ID literature (e.g. Lyons, 2010) and overcoming these barriers requires further attention. Research specifically exploring QOL of those with more severe ID is currently emerging (e.g. Beadle-Brown *et al.*, 2016). This is important because factors associated with 'higher' QOL that have emerged in the current review, such as independent employment, may not be possible for those in the lower range of intellectual functioning and so within-group differences need to be accounted for and QOL enhancement strategies matched to the target population.

Regression analysis offers an indication of the explanatory power of the variables entered. However, causality cannot be inferred. Also many of the authors noted that whilst some

factors did not statistically predict outcomes, this did not mean that they did contribute to QOL in some way (e.g. Simoes & Santos, 2017). The variance accounted for across studies was no larger than 63% (Claes *et al.*, 2012); suggesting many other variables may be contributing to QOL. There are many potential confounding variables (e.g. relationship and comfortability with the researcher), as well as variables that may be much more difficult to reduce to numerical scales (e.g. personal values) that could have contributed to overall variance. The very nature of investigating complex psychological concepts, such as QOL and well-being, and the tendency to aggregate multiple factors into an overall QOL score risks over-simplification (Toomela, 2010). Nonetheless, the theoretical underpinning of an ecological model of disability, and drawing from a multi-dimensional QOL model (e.g. Schalock & Verdugo, 2002) somewhat supported the current review to reduce this risk.

4.4 Study Quality Appraisal

The AXIS (Downes *et al.*, 2016) tool used to assess the quality of included papers raised some limitations. Downes *et al.*, acknowledged that this tool does not yield a numerical scale for quality assessment; therefore study inclusion was subjectively determined which may have impacted interpretation. Nonetheless, subjectivity also improves flexibility of appraisal and avoids reductionism and/or over-simplification that often goes ‘hand-in-hand’ with using numerical scales (e.g. Higgins *et al.*, 2011). To improve quality assessment in future reviews, independent application of the AXIS from a peer, followed by comparing assessments could reduce the risk of bias and increase internal reliability of the appraisal process.

One particular quality issue that extended across the majority of studies was the failure to report or adequately describe allocation and grouping of participants to ‘level of ID’ categories. It was indicated that even when such description was provided, level of ID was attributed to a single IQ score. Such classification remains contentious in the literature (e.g. BPS, 2015) and sources of error related to the stability and reliability of IQ tests in the lower range have been reported (e.g. Whitaker, 2015). Measured IQ is not necessarily reflective of true ability and this highlights the caution that is needed when exploring QOL of adults with ID. At the very least, explicit reference to these processes and decisions may improve the quality of inferences made about the relationship between these factors, and thus the quality appraisal of studies in future reviews.

4.5 Limitations of Current Review

The current review attempted to limit included articles to those underpinned by Verdugo & Schalock's (2002) model; however the method employed to do this may have been sensitive to bias. Study selection relied on the reviewer subjectively deciding whether papers were 'adequately' underpinned by the 8-domain model, simply through the initial screening process. A more robust procedure with clear, replicable guidance about how adequacy was determined would be useful in future reviews. In addition to this, despite attempting to provide a theoretical lens for this review, variation of the measurement tools used led to difficulties with interpretation of the findings. This was further compounded by differences in the selection and operationalisation of predictor variables. A more robust inclusion criteria, such as selecting studies that utilised the same tool, may have enriched comparability. Additionally, a more focused review, for example exploring a particular QOL domain or set of predictor variables may have enhanced specificity of the findings. Nonetheless, QOL is a multi-dimensional construct with interrelated domains and so narrowing this focus raises validity concerns. Finally, where self-report and proxy-reports were described, the current review only reflected self-report findings. This was because of the varied levels of agreement reported in the literature (Lyons, 2010), however, future reviews could note these findings and further contribute to these investigations.

4.6 Conclusions

A growing body of research has investigated personal and environmental characteristics that influence QOL outcomes with the aims of identifying enhancement strategies for those with ID. There is some suggestion from the studies reviewed, which predominantly included those with mild to moderate ID, that opportunities for more independent living, employment and social networks may enhance overall QOL. More research is needed to explore the ways in which particular groups, such as those with more severe ID, might be supported to improve their QOL. Further research employing a range of methodologies could enhance understanding about the complex interplay between personal and environmental variables and the QOL of those with ID.

5. References

***Indicates final included articles**

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Part Two: Research Report

Initial validation and qualitative analysis of the Short Parallel Assessments of Neuropsychological Status (SPANS) in a sample of adults labelled with intellectual disabilities.

Abstract

Introduction

Understanding the capabilities of those with intellectual disabilities is essential to providing personalised support and enhancing 'person-environment fit'. Neuropsychological assessment may contribute to such understanding. The Short Parallel Assessments of Neuropsychological Status (SPANS) comprises seven domains assessing a range of cognitive constructs. This tool had not been utilised in an intellectual disabilities sample; therefore the current study was a pilot study exploring the construct validity and clinical utility of the SPANS.

Method

Twenty-nine adults labelled with intellectual disabilities completed the SPANS. Construct validity of this measure was assessed by correlational analysis of the SPANS and IQ test (Wechsler Adult Intelligence Scale-Fourth Edition; WAIS-IV) scores. Performance across the seven SPANS domains was compared to a pre-existing control group of 'typically-developing' adults. Seven participants were interviewed about their experience of completing this measure and these accounts were subjected to thematic analysis.

Results

Support for construct validity of the SPANS when compared to the WAIS was mixed. SPANS domains correlated more highly with each other in this sample and particularly strongly with the working memory domain of the WAIS. The typically developing group significantly outperformed the intellectual disabilities group across every domain. The latter group revealed greater variation in their SPANS performances. Two main themes emerged from the qualitative data that indicated engagement with the SPANS had been 'stimulating', and that 'confidence' contributed to participants experiences.

Conclusions

The SPANS may reflect a different pattern of neuropsychological functioning in people with intellectual disabilities. This reiterates the importance of developing normed data sets for the population under assessment. Variation within the intellectual disabilities group reflected heterogeneity of this group in particular. Participant accounts are essential in developing the SPANS and understanding performance.

1. Introduction

1.1 Neuropsychological assessment

Neuropsychology encompasses brain-behaviour relationships using theory from neurology and psychology (e.g. Berlucchi, 2009). The key premise being that different behaviours and skills are associated with different functional systems in the brain; these are seemingly shaped by the interaction of intrinsic and environmental factors (Luria, 1980). The development of assessment tools has been analogous with increasing knowledge and clinical evidence of cognitive domains associated with particular functional systems of the brain (Ricchio & Reynolds, 1998). Neuropsychological assessment applies a performance-based approach to assessing this range of cognitive functioning abilities (Harvey, 2012).

1.1.1 Neuropsychological Assessment and Intellectual Disability

Specialist services are increasingly under pressure to quantify who is eligible for their support. In light of this, and the dominant diagnostic paradigm operating in Western society (British Psychological Society; BPS, 2015a), neuropsychological assessments (particularly intellectual functioning tests) represent a core feature of the diagnosis of an 'intellectual disability' (ID). Importantly, several authors (e.g. BPS, 2015b; Laird & Whitaker, 2011) highlight that in order to gain a robust understanding of an individual's cognitive capacity and level of function, neuropsychological assessment must include a diverse set of measures *beyond* intellectual ability.

The role for neuropsychological assessment tools within the ID field extends far beyond diagnosis. Four key assets of neuropsychological testing with people who have been diagnosed with, or are suspected of having an ID were recently identified by the BPS (2015b): i) tests may provide exploration of whether individuals with ID are being over/underestimated in their abilities, ii) may support the identification of deterioration in cognitive ability over time; iii) could contribute to the recognition of specific strengths and weaknesses to improve formulation and support understanding, management and intervention planning, and, iv) enhance personalisation of care by providing information about how an individual learns and remembers best. The BPS also indicated that neuropsychological tests should be administered to answer specific questions about the cognitive functioning of an individual and should inform a wider, holistic formulation.

People labelled as 'intellectually disabled' are more likely to be in receipt of support services, face barriers to inclusion, have fewer choices and control, are less likely to be employed (e.g. Emerson *et al.*, 2011); and are more likely to live in supported accommodation (e.g. Bigby & Beadle-Brown, 2016); factors evidenced to impact overall quality of life (e.g. Schalock *et al.*, 2010). As public policy is increasingly informed by a social-ecological model of disability (World Health Organisation, 2011), more attention and consideration is being paid to the importance of 'person-environment fit' (e.g. Hughes & Paterson, 1997). Focus on support strategies that are tailored to individual capabilities and needs are now central aspects of policy (e.g. Department of Health, 2015). Neuropsychological testing of individuals in this population could be useful in identifying person-centred factors that contribute to the clinical assessment of mental capacity, parenting, detection of organic changes, care management planning, and identifying support needs (BPS, 2015b). Thus, assessment information may add to increased awareness of factors that impact quality of life outcomes, and subsequently inform support needs and the development of particular skills associated with enhanced quality of life.

It is controversial and yet common practice that instruments normed with 'typically developing' (TD) populations are generically applied to ID populations, often without adaptation (Masson, Dagnan & Evans, 2010). Particular concerns with this approach have been widely documented in the literature in relation to the over-reliance on verbal skills and communication for such measures (e.g. Masson *et al.*), limited and/or invalid reference data for a particular population (e.g. Rognoni *et al.*, 2013), and increased measurement error in the lower ability range (e.g. Whitaker, 2015). In order to assess cognitive functioning as accurately as possible, neuropsychological instruments must draw from normative data that are representative of the population to which the individual being assessed belongs (Garcia-Alba *et al.*, 2017). However, there is currently a lack of validated standardised tests and standardized sample data relating to ID populations (Esteba-Castillo, Novell & Ribas, 2014).

1.2 Short Parallel Assessments of Neuropsychological Status (SPANS)

The Short Parallel Assessments of Neuropsychological Status ('SPANS'; Burgess, 2014) comprises a short battery of tests designed to assess cognitive, perceptual and language abilities across seven indices. The SPANS was developed in response to a perceived deficit of robust measures in acquired brain injury settings and was intended to be utilised across other settings working with clients who may have difficulty tolerating longer assessments. The measure is used to identify difficulties at the level of perception and comprehension. With a parallel version the SPANS provides the ability to reliably track progress or decline while

minimising practice effects. Thus far, normative data and validation studies have been gathered from an acquired brain injury sample and a 'healthy' sample (i.e. no history of brain injury or other neurological conditions, and an 'average' level intellectual functioning).

If used in conjunction with other tests, such as intellectual functioning assessments e.g. the Wechsler Adult Intelligence Scales (WAIS) (e.g. Wechsler *et al.*, 2008), the SPANS could contribute to a more detailed neuropsychological understanding of an individual. With a range of subtests (e.g. conceptual flexibility, memory, language, and visuo-motor ability) and an approximate administration time of 30-70 minutes, the SPANS could provide a quick and yet comprehensive assessment; conducive to reducing clinical/clinician and test-burden demands. The validity and reliability, and thus clinical utility of this test had not yet been explored with an ID population.

1.3 Research Aims

This research was a pilot study of the SPANS with a sample of people labelled with ID. The main aim was to preliminarily assess some aspects of construct validity of the SPANS in an ID sample. Specifically, convergent and divergent validity (that is, the extent to which the domains of the SPANS correlate with theoretically similar constructs and/or differ to dissimilar constructs) of the SPANS was explored by comparing scores on the SPANS and WAIS instruments. The second aim of the research was to determine whether there was a difference in performance between an ID group with low intellectual ability, as indicated by receiving support from an ID specialist service, and a 'typically developing' group with average intellectual ability, as indicated by the Wechsler Adult Reading Test ('WTAR'; Wechsler, 2001).

This research also aimed to explore ID participants' experiences of completing the assessment. It was hoped that exploration of participants' experiences would contribute to the growing body of literature that includes the voices of those with ID (e.g. Beail & Williams, 2014). Such views are an important part of assessing the ecological validity and utility of test batteries and indicating experiential information about the assessment (e.g. Owen, 2012).

1.4 Key Research Questions

1. Do the SPANS indexes demonstrate convergent and divergent validity, within theoretical expectation, and/or similar to SPANS original validation studies? ?
2. Is there a difference in performance on the SPANS between an ID group and a 'typically developing' group of adults?

3. What do the performances of the ID group indicate about their neuropsychological profile (i.e. strengths and weaknesses), as measured by the SPANS?
4. What are participants' experiences of completing the SPANS, and what do they relate the SPANS subtests to 'remind' them of in their everyday life?

1.5 Research Hypotheses

Construct validity hypotheses were drawn from the SPANS manual initial validation studies (Burgess, 2014), and literature that suggests the relative functional differences between the left and right hemispheres and their dominance for visuo-spatial and language processing (e.g. Bethmann et al., 2007; Vogel *et al.*, 2003). Furthermore, construct validity has been found for the WAIS-IV (Wechsler *et al.*, 2008; 2010), which was used in the current study, in ID samples (e.g. Reynolds *et al.*, 2013). Specifically, it was hypothesised that perceptual-based domains of the WAIS and SPANS would correlate with each other and verbal domains would correlate with each other.

It was hypothesised that there would be a difference in performance between groups. As ID is characterised by lower IQ, and performance on neuropsychological tests has been evidenced to co-vary with IQ (e.g. Russell, 2012), it was hypothesised that the control group of adults with an estimated average IQ would perform better on the SPANS than the ID group. The null hypothesis was that there would be no significant group differences.

A data-driven approach to the qualitative interviews was taken because very little literature has examined the experience of people with ID completing neuropsychological assessment. Therefore, the researcher attempted to remain as free as possible of analytic preconceptions (Braun & Clarke, 2013).

2. Method

2.1 Design

A mixed methods cross-sectional design was employed. For the quantitative aspect of the study a between-groups design was used with a convenience sample of adults labelled with ID. A comparison group of 'typically developing' (TD) individuals with 'average IQ' was gathered from pre-existing data from the original SPANS validation studies. For the primary analysis of comparing SPANS scores across groups, the independent variable was the group (ID versus TD)

and the dependent variables were the seven SPANS domain scores. For the qualitative phase of the study, semi-structured interviews were carried out with a sub-sample of the ID group. Qualitative data addressed the research question of participants' experiences of completing the SPANS, and supported contextualisation of the quantitative findings (Creswell *et al.*, 2003).

2.2 Ethical Approval

In the first instance, University staff members and the service user reference group affiliated with the University peer reviewed and approved the research proposal for this study (see Appendix E for a chronology of the research process). Following this, ethical approval was sought and granted by the NHS Local Research Ethics Committee, Health Research Authority, documented in Appendix F.

2.3 Research Context

This research was carried out alongside an intellectual disabilities community support team in the Midlands region of the UK. This service accepts referrals for individuals who meet the criteria for the diagnosis of an ID in accordance with BPS guidelines (significant impairment of intellectual functioning and adaptive functioning; onset before adulthood; BPS, 2015a). Specialist assessment and support is offered to individuals accessing this service.

2.4 Participant Identification

2.4.1 Intellectual disability (ID) group

Data for the ID group were collected between July 2017 and February 2018 from participants who were accessing the service at that time. Potential participants were identified by clinicians in the team based on the following recruitment criteria:

Inclusion criteria

- Male or female;
- Aged 18-74 (aligned with the SPANS normed data-set);
- Diagnosed with non-specific ID; to reduce the potential effects of genetic-specific disabilities;
- Having English as a first language, because the SPANS is yet to be cross-culturally validated;
- Evidence of expressive and communication skills and visual hearing/motor skills adequate to complete the SPANS tasks/ interview;

- Individuals with pre-existing WAIS scores or agreement to complete a WAIS prior to final data analysis;
- Individuals able to give informed consent.

Exclusion criteria

- Presence of neurodegenerative conditions, acquired brain injury, and specific genetic-related ID (e.g. Downs Syndrome) that may be related to particular cognitive functioning difficulties and/or patterns;
- Individuals experiencing psychological difficulties that may be exacerbated by SPANS testing and/or impact SPANS performance.

2.4.2. Comparison Group

Data for the TD comparison group was gathered from an anonymised archive of data from the initial SPANS validation studies (Burgess, 2014). These data were collected between 2009 and 2013, and included males and females aged between 18 and 74, with an estimated average IQ ranging between 90 and 110. Participants were recruited from the Midlands and South regions of the UK. A sample of participants were selected to match the ID group on the basis of sample size, age, gender, and English as a first language.

2.5 Quantitative Method

2.5.1 Prospective Power Analysis

To determine the sample size for the quantitative analysis a priori power analysis was carried out for correlation and multivariate analysis of variance (MANOVA). In adherence with Cohen's (1992) guidance, the power analysis was carried out based on alpha (α) = 0.05 and power set at 0.80. For a one-tailed hypothesis a sample of at least 25 participants per group for the MANOVA was required to detect a large effect size (Cohen's f : 0.4) (Clark-Carter, 2004). For correlation analysis the same levels were set; a total sample of 38 participants was required to detect a large effect size.

2.5.2 Sample Characteristics

2.5.2.1 ID Group

A total of 29 participants made up the ID sample; the data in Table 1 are related to participant characteristics. Men and women were relatively equally represented; age ranged between 18

and 65 years ($M = 33.1$); the majority of participants were in the 18-30 age range (48.3%). An estimated IQ range, as assessed by the WAIS-IV (Wechsler *et al.*, 2008; 2010), between 50 and 67 represented 87.4% of the sample. The mean IQ of the ID sample was 61.8. Twenty-eight participants identified as 'White-British', one identified as 'White-British Mixed'.

Table 1: Sample Characteristics of the ID group ($N = 29$)

Variable	Number of participants (% of n)
Gender	
Male	14 (48.3)
Female	15 (51.7)
Age	
18-30	14 (48.3)
31-45	10 (34.5)
46+	5 (17.2)
Full Scale IQ*	
50-55	7 (29.1)
56-61	6 (25.0)
62-67	8 (33.3)
68-94	3 (12.5)
Occupation	
Unemployed	14 (48.3)
Paid employment	2 (6.9)
Voluntary work	9 (31.0)
In further education/ Student	4 (13.8)

**As estimated by the WAIS-IV (Wechsler *et al.*, 2008; 2010); some data missing ($n = 5$)*

2.5.2.2 SPANS original study group and sub-sample for analysis of the TD Group

As data presented later in this report refers to findings from the original SPANS samples, demographic information about the overall norming sample are presented in Table 2.1.

Table 2.1: Demographics and Wechsler Adult Reading Test (WTAR) mean and (SD) of the original SPANS study participant groups.

	ABI <1	LTNC	Norm
Sample size	<i>n</i> = 86	<i>n</i> = 50	<i>n</i> = 122
Sex M/F	70/16	35/15	63/59
Age in years	44.7 (14.3)	40.6 (13.0)	46.9 (17.3)
Education	1.81 (.7)	1.84 (.7)	1.68 (.8)
WTAR	-	99.4 (13.9)	102.6 (5.23)

Notes: ABI <1 = Acquired brain injury patients less than a year post-injury; LTNC = Long-term neurological condition patients; Norm = Healthy control sample. Education mean and (SD) was based on scoring system which 1 = completed secondary education/high school; 2 = completed some college/university or undertook +6 months of apprenticeship or vocational training; 3 = completed university degree. WTAR estimates adults' IQ with a mean of 100 and SD of 15.

Whilst every effort was made to match participants for the comparison between SPANS performances, as Table 2.2 indicates there was some variation across age due to the data that were available (*M* = 36.2 years). The researcher intended to limit the parameters to participants who had completed secondary or college education only, however, this was not possible due to the available dataset. The mean IQ of the TD sample was 103.8.

Table 2.2: Sample Characteristics of the TD Group

Variable	Number of participants (% of n)
Gender	
Male	14 (48.3)
Female	15 (51.7)
Age	
18-30	11 (37.9)
31-45	12 (41.4)
46+	6 (20.7)
Estimated IQ Level*	
90-95	2 (6.9)
96-100	9 (31.0)
101-105	5 (17.2)
106-110	13 (44.8)
Education Level	
Secondary school completed	8 (27.6)
Some college or vocational training	12 (41.4)
University degree	9 (31.0)

*IQ estimates were based on the Wechsler Test of Adult Reading (WTAR; Wechsler, 2001)

2.5.3 Materials and Measures

2.5.3.1 Short Parallel Assessments of Neuropsychological Status (SPANS; Burgess, 2014)

The SPANS is a short battery of tests designed to assess different domains of neuropsychological functioning. This measure comprises 30 subtests that make up the following seven indices: Orientation Index (ORI), Attention/Concentration Index (ACI), Language Ability Index (LAI), Memory/Learning Index (MLI), Visuo-Motor Performance Index (VPI), Efficiency Index (ECI), and Conceptual Flexibility Index (CFI). Appendix G: Part A, provides a summary of each index.

Validation studies thus far have included participants with an acquired brain injury ($n = 136$) and a 'healthy' sample group (i.e. no history of brain injury or other neurological conditions; $n = 122$).

2.5.3.1.1 Reliability of the SPANS

Internal consistency coefficients between the SPANS A and B versions delineated a Cronbach's alpha of at least $\alpha = > .73$. Inter-correlations between the seven domains evidenced some degree of unique variance between indices, with elevated correlations where domains shared subtests. Test-retest reliability was found across all seven domains with Cronbach's alpha scores yielding at least $\alpha = > .85$.

2.5.3.1.1 Validity of the SPANS

Validity studies indicated convergent and divergent validity with a range of measures within theoretically predicted domains. Significant correlations with existing tests such as the Wechsler Adult Intelligence Scale, Third Edition (WAIS-III, Wechsler, 1997a) and the Wechsler Memory Scale, Third Edition (WMS-III; Wechsler, 1997b) indicated construct validity of the SPANS. Divergent validity studies revealed relative divergence from expected constructs, however, small significant correlations were found between the WAIS-III Information subtest and the SPANS ACI and LAI domains. Unexpected significant correlations were also found between the Hospital and Anxiety Depression Scale (HADS; Zigmond & Snaith, 1983) and the SPANS VPI and MLI indices. These findings were understood in relation to the role of skills such as academic ability required for the Information subtest and listening and numerical skills necessary for the SPANS (Burgess, 2014). In relation to the HADS anxiety scale, Burgess suggested the possible role of vigilance and/or conscientiousness for completing tasks. The SPANS has also demonstrated good sensitivity and specificity in discriminating between

individuals with varying degrees of severity of cognitive impairment (i.e. long term neurological conditions and non-clinical population) (Burgess,).

2.5.3.2 Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV; Wechsler *et al.*, 2008; 2010)

Whilst the WAIS-IV was not administered as part of this project (unless not already completed), pre-existing data were included where available and so a description of this measure is provided. The WAIS-IV is an individually administered instrument designed to assess the cognitive ability of those aged 16-90. The WAIS-IV includes 10 core subtests with 5 supplemental tests, which make up four indexes: Verbal Comprehension Index (VCI), Perceptual Reasoning Index (PRI), Working Memory Index (WMI), and Processing Speed Index (PSI) (Appendix G: Part B, provides a summary of each index). Subtest scores are used to calculate an estimated Full Scale Intelligence Quotient (FSIQ). Reliability estimates have been reported as $>.80$ in relation to internal consistency. The WAIS-IV technical manual also reports consistent reliability estimates with ID subgroups; except for the Information test of the VCI yielding a lower estimate (.67) for those with 'moderate' ID.

This measure was chosen because it is currently the test of choice for contributing to the assessment of intellectual functioning (BPS, 2015b); was utilised in the original normative data gathering studies of the SPANS (Burgess, 2014); and provides information to support the analysis of convergent validity of the SPANS. The Wechsler tests account for changes in IQ over the lifetime (e.g. age effects) and scores are deemed to hold relatively stable (e.g. Carr, 2005). Notwithstanding, validity and stability concerns in the lower IQ range have been reported (e.g. Whitaker, 2010; 2012). To reduce potential sources of error, all of the WAIS data was derived from the most recent version of the WAIS (WAIS-IV; Wechsler *et al.*, 2008; 2010) and the recruitment of participants was from a specialist service that does not solely rely on IQ scores.

2.5.4 Procedure

To ensure familiarity with the SPANS, prior to starting the study an administration and interpretation training session was conducted by the research supervisor (founder of the SPANS: Burgess, 2014). This was attended by the lead researcher and members of the ID community team who were supporting data collection.

Clinicians in the team reviewed their caseloads and after identifying individuals who met the inclusion criteria, contact was made with potential participants via current practitioners and information sheets shared (Appendix H). Information sheets were as simply worded as possible and included visual aids; participant interest was registered by practitioners and

follow-up appointments arranged to complete the research. Either current practitioners who had completed the SPANS training, or the lead researcher (who had experience working in ID services) met with participants to complete the study.

To support with understanding and informed consent, information sheets were reviewed with all participants and consent forms (Appendix I) were either read to, with, or by participants according to reading ability. All participants were verbally able to paraphrase the nature of the research and its procedure when asked. Participants were reminded of their right to withdraw from the study by a particular date, and were provided with copies of the information sheet and consent forms. Confidentiality was discussed and opportunities to ask questions along with researcher contact information were provided. Support workers were present if requested by participants, however were clearly instructed not to interject at any time.

Participants were individually administered the SPANS with instructions given verbatim in accordance with the standardised protocol in the SPANS manual. The test administrators provided individualised support with terminology if necessary. Every attempt was made to avoid pauses or distraction; breaks were offered at appropriate times as indicated in the SPANS manual. Participant responses were recorded using the SPANS scoring booklet (Appendix J illustrates the scoring page of this booklet). SPANS completion time ranged between 30 and 80 minutes ($M = 59$ minutes).

The team leader of the ID support service provided socio-demographic information of participants by accessing clinical records. Information included participants' age, gender, ethnicity, employment status, and WAIS-IV index scores. Four main sites were used for data collection, each with private interview rooms in a quiet location. Participation in the study was voluntary and anonymous; participants who incurred travel costs were reimbursed.

2.6 Qualitative Method

2.6.1 Measure

A semi-structured interview schedule (Appendix K) was developed by the author, research supervisor and community ID team who supported recruitment. Prompts and visual aids were included to support comprehension.

2.6.2 Sample Size

It is well documented that there is no clear guidance about the number of participants required to perform thematic analysis. Rather, the decision about how many participants to

recruit relies on several factors, including the methodological and epistemological stance of the research (e.g. Fugard & Potts, 2014). As this research aimed to explore a heterogeneous population and their experience of completing a novel neuropsychological assessment, the researchers felt that interviews should take place with approximately 12 participants which would reflect close to 50% of the sample indicated by the priori power analysis. Adler and Adler (2012) have broadly recommended this number of participants to undergraduate and doctoral students in their guidance on carrying out qualitative research, because this is considered practical in light of time constraints.

2.6.3 Interview Recruitment

Information sheets (Appendix H) invited participants to take part in interviews if they wished to, following completion of the SPANS. Due to time restraints for participants and the researcher, and possible fatigue after completing the SPANS, seven participants agreed to take part in the interviews after completing the SPANS. Four men and three women made up the sample, aged 20-42 years ($M = 26.7$); IQ scores ranged from 54-67 ($M = 60.3$). All seven participants identified as 'White-British'; three were unemployed, four were involved in voluntary work or education.

2.6.4 Procedure

Interviews were carried out in the same room as SPANS completion. A break was offered between these stages. Interviews were recorded using a Dictaphone and in writing where necessary (i.e. some participants circled a particular face on the prompt sheet). Interviews lasted no longer than ten minutes; an extract of data can be found in Appendix L.

2.6.5 Method of Analysis and Research Position

Thematic analysis (TA) was used to identify patterns and themes across the qualitative data. TA provides flexibility of analysing qualitative data because it is not bound by a particular theoretical or epistemological position (Braun and Clarke, 2006). Whilst TA can be used within a range of theoretical frameworks, the current research adopted a critical-realist approach which captures the experiences of participants according to their 'reality' (Appendix M details a further account of the position of the researcher).

2.6.6 Reflexivity

To ensure reflexivity, the researcher maintained a reflective journal documenting observations and insights throughout the research process and after each interview. Qualitative analysis

was continually discussed with the research supervisor and transcripts were shared and collaborated upon.

3. Results

3.1 Quantitative Results

3.1.1 Evaluation of Assumptions

Statistical analysis of the quantitative data was carried out using the computer software programme SPSS (version 24.0). The data were initially explored to determine whether the assumptions of using parametric statistical analyses were met (output is presented in Appendix N: Part 1). Normality of distribution was assessed by histograms, Q-Q plots, box plots, skewness and kurtosis values, and the Kolmogorov-Smirnov test (preferred to the Shapiro-Wilk test due to the total sample size exceeding 50; Clark-Carter, 2010). Several outliers were identified by the histograms and skewness and kurtosis statistics revealed significant positive and negative results. The Kolmogorov-Smirnov test further indicated non-normality across the data ($p < .05$).

Assumption tests specific to MANOVA were also carried out (Appendix N: Part 2). Mahalanobis test further indicated three outliers in the dataset (Penny, 1996); violating the assumption of univariate and multivariate normality. Homogeneity of variance was assessed using Levene's test; variances were significantly different across the two groups for each SPANS domain ($p < .001$). Box's test was carried out to explore the assumption of homogeneity of covariance; this was significant at the $p < .001$ level. Finally, bivariate correlation analyses indicated multicollinearity between some of the variables (values exceeded 0.9).

Given these violations of assumptions, a 'log' and then 'square-root' transformation to the data were applied (Field, 2009). Data continued to violate assumptions and so z-scores were computed to generate standardized scores and outliers were 'winsorized' (i.e. outlier values were replaced with the closest next value) (Ghosh & Vogt, 2012); assumptions remained unmet. Consequently, the researcher decided to conduct a series of non-parametric tests (Appendix N: Part 3). For the correlation analysis, data were rank ordered and explored using Kendall Tau's test. To determine group differences, a series of Mann-Whitney U tests were conducted. Notably, Levene's test revealed equal variances between groups across all of the domains ($p > .05$) except for the ORI domain, where variances were significantly different

between the two groups $F(1, 56) = 14.75, p < .01$. Moses Extreme Reaction test was carried out for the ORI domain due to violating the assumption of homogeneity of variance (Field).

3.1.2 Research Question 1: do the SPANS indexes demonstrate convergent and divergent validity, within theoretical expectation, and/or similar to the SPANS original validation studies?

Correlation analyses were conducted to determine whether SPANS index scores, from the ID group only, correlated with theoretically similar or dissimilar constructs as measured by the WAIS.

Notably, in the initial validation studies construct validity of the SPANS was partially assessed against WAIS-III (Wechsler, 1997a) data. Extensive revision and changes meant that the WAIS-IV moved away from the original primary dichotomy of Verbal IQ (made up of the VCI and WMI) and Performance IQ (made up of the Perceptual Organisation Index [POI] and PSI) to the four factor structure (VCI, PRI, WMI, PSI) described in section 2.5.3.2 (Taub & Benson, 2013). To support comparability between initial studies and the current correlations, VIQ and PIQ values were calculated for WAIS-IV data by summing the relevant indexes together. However the researcher notes differences between subtests across the WAIS versions and so these findings must be interpreted with caution.

Standardized 'T-scores' were not available for scores below the 5th percentile as the SPANS does not yet have a complete range of T-score conversions (Burgess, 2014). Therefore scaled scores, derived from raw scores, were entered into the analysis. As scaled scores for the ORI do not currently exist, and the majority of participants' scores on this domain were below the 5th percentile of the current normed data, the ORI was not entered into the analysis. All other SPANS indexes were included. Hypotheses were set according to the SPANS manual correlations (Burgess).

Only significance values that reached $p < .01$ (one-tailed) were accepted given that the sample size did not reach sufficient power and the number of correlations conducted. Correlations between all of the SPANS and WAIS indexes are presented in Table 3.

Table 3: Kendall Tau’s Rank Order Correlations between the SPANS and WAIS Indexes

		WAIS Domains						
		FSIQ	VCI	PRI	WMI	PSI	VIQ	PIQ
SPANS Domains	ACI	.289 [^]	.335 [^]	.262 [^]	.609 ^{**}	.328 [^]	.529 ^{**}	.307 [^]
	LAI	.302 [^]	.241	.307 [^]	.404 [*]	.003	.393 [^]	.366 [^]
	MLI	.311 [^]	.352 [^]	.211	.501 [*]	.398 [*]	.489 [*]	.344 [^]
	VPI	.429 [*]	.412 [*]	.457 [*]	.536 [*]	.564 [*]	.540 ^{**}	.561 ^{**}
	ECI	.400 [*]	.313 [^]	.425 [*]	.689 ^{**}	.521 [*]	.572 ^{**}	.501 [*]
	CFI	.196	.233	.295 [^]	.360 [^]	.386 [*]	.352 [^]	.359 [^]

Notes: [^] $p < 0.05$; ^{*} $p < 0.01$; ^{**} $p < 0.001$; $n = 23$ for the VCI, PRI, WMI AND PSI, $n = 24$ for the FSIQ, $n = 29$ for the SPANS.

3.1.2.1 Convergent Validity

Results that approached or exceeded a ‘large’ effect size ($r = 0.5$; Cohen, 1988; Cohen, 1992) were interpreted for convergent validity testing because this allowed the most confident assumption that significant relationships between variables did not occur due to error or test situation similarities (Sullivan & Feinn, 2012). Table 4 presents correlation comparisons between the SPANS manual and the current study. The original SPANS data included a minimum n of 24 and maximum n of 44; participants (‘clinical sample’) were from the ‘post-acute’ acquired brain injury (no less than 12 weeks post-injury) and ‘stable’ neurological participant (those with a long term neurological presentation who were relatively stable) subgroups. Large effect sizes are indicated by a *. The author and SPANS developer (Burgess, 2014) identified theoretically discrepant findings along with notable differences between the magnitude of the effect sizes found between the current study and the original SPANS studies; these are highlighted in blue in Table 4.

Table 4: Correlation Comparisons between the SPANS Manual and Current Study

WAIS Domains		SPANS Domains					
		ACI	LAI	MLI	VPI	ECI	CFI
Overall VIQ	SPANS Manual	.43	.65*	.08	.33	.37	.37
	Current Study	.52*	.39	.48*	.54*	.57*	.35
VCI	SPANS Manual	.30	.42	.12	.23	.21	.36
	Current Study	.33	.24	.35	.41	.31	.23
WMI	SPANS Manual	.62*	.50*	.17	.36	.49*	.25
	Current Study	.60*	.40	.50*	.53*	.68*	.36
Overall PIQ	SPANS Manual	.49*	.27	.34	.69	.67*	.51*
	Current Study	.30	.36	.23	.56*	.50*	.35
PRI	SPANS Manual	.43	.34	.30	.56*	.59*	.60*
	Current Study	.26	.30	.21	.45	.42	.29
PSI	SPANS Manual	.35	.14	.21	.56*	.58*	.45
	Current Study	.32	.00	.39	.56*	.52*	.36

As Table 4 illustrates, convergent validity according to theoretical similarity and previous SPANS manual findings was demonstrated to some extent in this study. For example, a large effect size was found for the WMI and ACI ($\tau = .60, p < .001$); both involve the exertion of

mental control over tasks, and share some of the same/similar subtests such as 'digit span'. A significant moderate correlation was found between the WAIS PIQ and the SPANS VPI ($\tau = .41$, $p < .001$); both aim to assess visuo-spatial capabilities. A medium-large large effect size was also found for the WAIS PSI and the SPANS ECI ($\tau = .41$, $p < .01$); both include time-limited tasks.

3.1.2.1 Divergent Validity

No effect or 'small' effect sizes (0.1) were indicative of divergent validity as this suggested very little relationship between two variables. Insignificant correlations were found for some measures that were least similar theoretically, for example, there was no correlation between the WAIS PSI (a measure of processing speed) and the SPANS LAI (a measure of language comprehension). A smaller effect size was found for the WAIS PRI and SPANS LAI domains ($\tau = .31$, $p < .05$), than the WAIS PRI and the theoretically similar SPANS measure of visuo-motor performance (VPI) ($\tau = .46$, $p < .001$). This supports the hypothesis that there would be a lower correlation and thus a smaller effect size, between measures of perceptual reasoning and measures of language ability.

There were some contrasting results to the SPANS manual and findings that questioned divergent (and convergent) validity. Most notably, a medium-large effect size was found for the WAIS VCI and the SPANS VPI ($\tau = .41$, $p < .01$) indicating a significantly higher correlation than expected between these theoretically distinctive variables. A partial explanation for this may be that the tasks on the VPI each require a degree of verbal comprehension (for example, to name and recognise objects relies on verbal acquisition and retention) and the ability to link words to pictures. Further Kendall tau correlations were carried out to determine which specific VPI subtests accounted for the strongest correlations with the WAIS VCI. Significant findings are presented in Table 5.

Table 5: Significant Correlations between the WAIS VCI and SPANS VPI Subtests

SPANS VPI Subtests	Effect Size
<i>Figures Copy</i>	.46**
<i>Spatial Decision</i>	.35*
<i>Object Recognition</i>	.33*
<i>Letter-Number-Coding</i>	.31*

** $p < .01$; * $p < .05$

The greatest discrepancy in correlations between the current study and the SPANS manual was the WAIS WMI and SPANS MLI. In the SPANS manual for the norm sample, a small effect size of 0.17 was reported; the current study detected a large effect size ($\tau = .50, p < .001$). These findings were explored in follow-up correlations which revealed that each of the six subtests significantly correlated with the WAIS WMI; the largest effect size was found for the ‘*Figures Recall*’ task ($\tau = .59, p < .001$), which involved asking participants to recall and draw a set of figures from an earlier copying task. An effect size of at least 0.4 was detected for the WAIS WMI and six of the seven SPANS indexes (excluding the CFI, although significance was still reached for this domain). Whilst the WMI correlated significantly with the ACI, LAI, VPI and ECI in the SPANS manual, greater effect sizes were found in the current study. Further Kendall tau’s correlation analysis was carried out to explore the relationship between working memory and the remaining WAIS domains. This analysis was also conducted with the SPANS norming data; findings are reported in Table 6.

Table 6: Kendall Tau Correlations between WAIS Domains

WAIS Domains	Group	VCI	WMI	PSI	PRI
VCI	ID	1	.49**	.33*	.53**
	CS	1	.19	.01	.16
WMI	ID	.49**	1	.51**	.57**
	CS	.19	1	.43**	.23
PSI	ID	.33*	.51**	1	.57**
	CS	.01	.43**	1	.56**
PRI	ID	.53**	.57**	.57**	1
	CS	.16	.23	.56**	1

Notes: * $p < .05$; ** $p < .01$; Group: ID = intellectual disability group from the current sample ($n = 24$); CS = clinical sample from the original SPANS studies (VCI: $n = 27$; WMI: $n = 30$; PSI: $n = 28$; PRI [Perceptual Organisation Index in the WAIS-III]: $n = 27$).

Table 6 presents larger effect sizes between the WMI and all other WAIS domains in the ID group compared to the clinical sample. These findings tentatively suggest that working memory may play a significant role in performance across a range of tasks for those with ID.

Summary

Overall, the results provide an indication that some of the SPANS index scores for the ID group conform to expectations by significantly correlating with WAIS indices that purport to measure similar cognitive constructs, to a moderate or high degree. However, there was some crossover between theoretically dissimilar domains, indicating some differences in the current sample. In addition, the inter-correlations between the SPANS domains (Appendix N: Part 2.3) showed that there was a higher degree of similarity across the SPANS indexes for this sample. Working memory seems to be more closely related to cognitive performance across the WAIS and the SPANS tasks.

3.1.3 Research Questions 2 and 3: is there a difference in performance on the SPANS between groups? What do the performances of the ID group indicate about their neuropsychological profile (i.e. strengths and weaknesses) as measured by the SPANS?

3.1.3.1 Descriptive Statistics

Table 7 illustrates the means and standard deviations of the total raw scores for each group across the seven SPANS indexes along with the percentage of difference between mean scores.

Table 7: Mean and Standard Deviation of Raw Scores across all SPANS Domains with the Percentage of Difference of Mean Values between Groups.

SPANS Domain	Group	Mean (SD)	Percentage Difference (%)
ORI	ID	17.41 (2.83)	11.37
	TD	19.91 (0.37)	
ACI	ID	24.03 (8.33)	40.79
	TD	42.79 (2.12)	
LAI	ID	39.27 (7.49)	23.09
	TD	51.51 (1.35)	
MLI	ID	49.13 (9.53)	19.93
	TD	62.48 (2.77)	
VPI	ID	41.41 (15.04)	35.66
	TD	66.37 (2.47)	
ECI	ID	24.27 (10.08)	43.83
	TD	45.31 (2.56)	
CFI	ID	18.24 (5.72)	33.25
	TD	27.55 (0.90)	
Total SPANS Score	ID	213.79 (52.07)	30.59
	TD	315.94 (8.24)	

These values indicated that mean scores for were higher across all of the domains for the TD group. Notably, TD group mean scores far exceeded the ID group by at least 11.37%. The highest percentage of domain difference between group means was in the ECI domain. These tasks assess efficiency and speed of processing. Standard deviations indicated a high level of variance around the mean for the ID group across all domains; whereas the standard deviations for the TD group did not exceed 2.8. A remarkably large standard deviation in the VPI domain was reported for the ID group (SD = 15.04). Total SPANS score data showed that the TD group achieved an average raw score that was 30.6% greater than that of the ID group.

Total raw scores showed considerably greater variation around the mean for the ID group (SD = 52.07) compared to the TD group (SD = 8.24).

Interestingly, one of the smallest percentage differences between groups was on the MLI (19.93%), which is a measure of memory and learning via visual and verbal means. To explore this finding further, follow up descriptive information is presented in Table 8.

Table 8: Mean and Standard Deviation of MLI Subtests with the Percentage of Difference of Mean Values between Groups.

MLI Subtest	Group	Mean (SD)	Percentage difference (%)
<i>Object Recall</i>	ID	4.41 (1.27)	17.33
	TD	5.45 (0.63)	
<i>Figures Recall</i>	ID	4.52 (3.34)	44.82
	TD	9.45 (1.87)	
<i>List Learning</i>	ID	12.59 (2.89)	19.89
	TD	16.17 (1.20)	
<i>List Recall</i>	ID	4.34 (1.56)	17.83
	TD	5.41 (0.87)	
<i>List Recognition</i>	ID	11.17 (1.61)	6.92
	TD	12.00 (0.00)	
<i>Symbol-Word- Paired-Associates (S-W-P-A)</i>	ID	12.10 (2.78)	13.57
	TD	14.00 (0.00)	

As shown in Table 8, *Figures Recall* exhibited the poorest learning across the MLI domain for the ID group, along with the greatest variance around the mean. The smallest percentage difference was *List Recognition*; this task was considered one of the most ecologically valid due to relating to everyday life shopping tasks (Burgess, 2014). However, a mean difference of 0.73

between groups was still notable. The findings suggested relatively equivalent learning capacity across verbal (e.g. *List Learning*) and visual (e.g. *S-W-P-A*) memory. Follow-up analyses were conducted to quantify these findings.

A Wilcoxon Signed-Ranks Test revealed that within the ID group, the median *S-W-P-A* ranks were significantly higher than the median *List Learning* ranks, $Z = -2.06$, $p < .039$, with a medium effect size ($r = .27$). There was no significant difference between these two subtests and the third teaching situation subtest: *Object Recall*. In contrast, there were no significant differences within the TD group (output presented in Appendix N: Part 3.1). This suggests that for the ID group only, the *S-W-P-A* task which teaches associations between a word and a symbol was a relatively more conducive situation to learning material for the ID group, compared to the *List Learning* teaching situation which solely relies orally-presented information. To summarise, in the ID sample, these SPANS tasks revealed that the memory and learning task that married verbal and visual information elicited a better performance than a task which utilised only a verbal learning strategy.

3.1.3.2 Between Group Analyses (output presented in Appendix N: Part 3.2)

Null hypothesis (H_0): an intellectual disability group and a typically developing group show no difference in the ranks of performance on the SPANS.

Alternative hypothesis (H_1): there is a difference between the ranks of performance between groups on the SPANS.

Due to multiple comparisons, to reduce Type 1 error rate Bonferroni's correction was applied (Armstrong, 2014) and indicated a critical value of .007; therefore (p) value significance was set at $p < .007$.

Moses Extreme Reaction test showed that the TD group ($Mdn = 43.50$) performed significantly better on the ORI domain than the ID group ($Mdn = 14.50$), $p < .001$, $r = -.79$.

Mann Whitney U tests revealed significant differences between groups across the six domains entered into the analysis:

The TD group ($Mdn = 43.50$) performed significantly better on the ACI domain than the ID group ($Mdn = 15.50$), $U = 1.50$, $z = -6.52$, $p < .001$, with a large effect size, $r = -.85$.

The TD group ($Mdn = 38.5$), performed significantly better on the LAI domain than the ID group ($Mdn = 15.50$), $U = 21.00$, $z = -6.25$, $p < .001$, with a large effect size, $r = -.82$.

The TD group ($Mdn = 43.00$), performed significantly better on the MLI domain than the ID group ($Mdn = 14.5$), $U = 72.50$, $z = -5.42$, $p < .001$, with a large effect size, $r = -.71$.

The TD group ($Mdn = 44.00$), performed significantly better on the VPI domain than the ID group ($Mdn = 15.00$), $U = 7.00$, $z = -6.45$, $p < .001$, with a large effect size, $r = -.84$.

The TD group ($Mdn = 45.00$), performed significantly better on the ECI domain than the ID group ($Mdn = 14.50$), $U = 5.00$, $z = -6.48$, $p < .001$, with a large effect size, $r = -.85$.

The TD group ($Mdn = 47.00$), performed significantly better on the CFI domain than the ID group ($Mdn = 14.50$), $U = 38.50$, $z = -6.14$, $p < .001$, with a large effect size, $r = -.80$.

The TD group ($Mdn = 45.00$) performed significantly better overall on the SPANS domains than the ID group ($Mdn = 15.00$), $U = 3.50$, $z = -6.48$, $p < .001$, with a large effect size, $r = -.74$.

These results indicated that the null hypothesis should be rejected and the alternative hypothesis accepted: there was a significant difference in the ranks of performance on the SPANS; median values showed that the ID group were outperformed by the TD group in every domain. Cohen's effect size (Cohen, 1992) suggested the magnitude of group differences was large.

3.1.3.2.1 MLI Analysis

Further Mann Whitney-U tests were carried to explore the effect sizes of the MLI subtests that indicated one of smallest percentage difference in group means. It can be concluded that the TD group performed significantly better across each of the separate MLI subtests ($p < .05$). Figure 1 illustrates effect sizes of the MLI subtests between groups. Medium to large effect sizes were found for the *List Learning* and *Figures Copy Recall* subtests, each accounting for 5% of variability in the ranks, and the most perceptible difference between group performances.

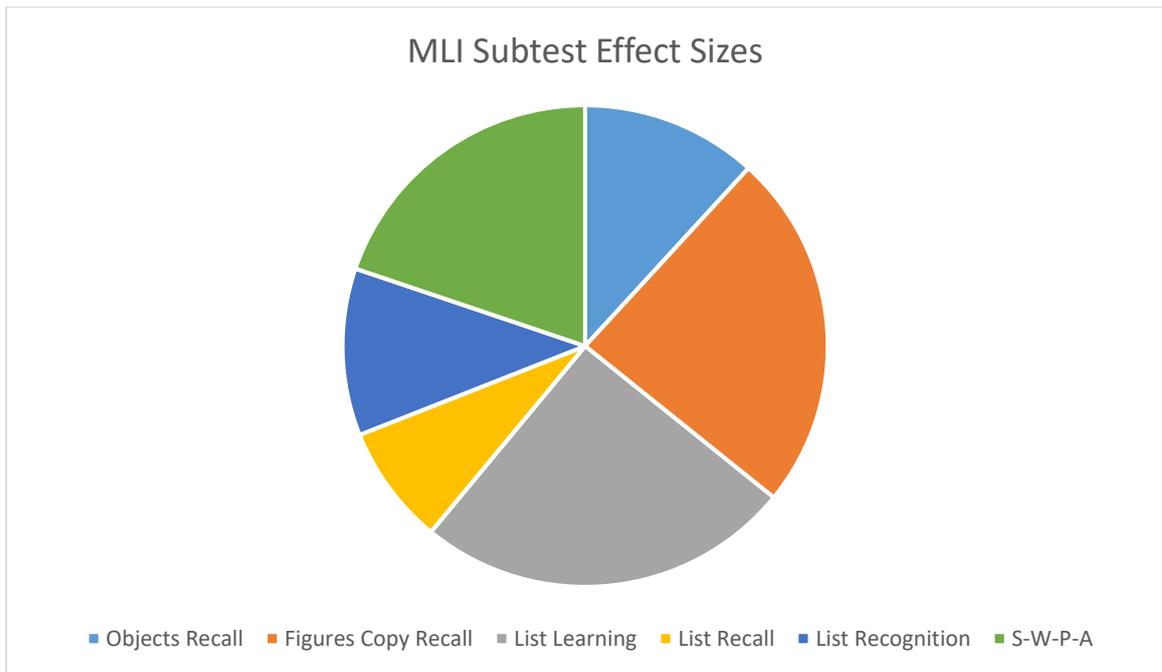


Figure 1: MLI Subtest Effect Sizes

3.1.3.2 Post-hoc Power Analysis

As a result of the statistical analyses in this study changing in light of the violation of assumptions described in section 3.1.1 (Evaluation of Assumptions), a post-hoc power analysis was conducted to determine whether this study had adequate power. The statistical software programme G*Power (Faul *et al.*, 2007) revealed the statistical power for this study was 1.0 for detecting a large effect size. Thus, there was more than adequate power (power = .80) at the large effect size level.

3.1.3.3 Quartile ranges

Given the large difference between TD and ID participants on SPANS index scores, and the high scores established by the current TD SPANS norming sample, it became apparent that to provide some preliminary interpretative norms to guide interpretation would be useful, clinically. Therefore a cumulative frequency table was developed with each of the seven SPANS domains, which appears in Table 9. This table presents the highest, lowest and middle quartile scores on the seven domains along with the total SPANS scores for the ID group and the norm and clinical samples from the original SPANS studies (Burgess, 2014). As the current study is under-powered to generate normed data and given the small sample size, only quartiles are presented.

Table 9: Quartiles for all SPANS Domains for the ID Group and norm and clinical samples from the original SPANS studies (Burgess, 2014).

Domain (max raw score)	Sample	Lowest Score	Quartile 1	Quartile 2	Quartile 3	Highest Score
			(25%)	(50%)	(75%)	
ORI (22)	ID	5	17	18	19	20
	CS	5	14	21	22	22
	TD*	18	20	20	20	20
ACI (46)	ID	5	19	26	30	39
	CS	5	30	37	42	46
	TD	25	40	43	45	46
LAI (53)	ID	12	37	40	44	52
	CS	9	42	48	50	53
	TD	33	50	51	52	53
MLI (67)	ID	30	42	49	58	66
	CS	11	34	50	60	67
	TD	24	55	61	64	67
VPI (70)	ID	5	31	42	57	63
	CS	0	46	56	62	70
	TD	36	63	66	68	70
ECI (48)	ID	0	17	23	32	42
	CS	0	27	34	41	48
	TD	27	41	46	47	48
CFI (28)	ID	1	14	19	22	28
	CS	6	20	24	27	28
	TD	12	26	28	28	28
SPANS Total (334)	ID	59	171	217	255	308
	CS	51	221	262	299	328
	TD	180	300	314	320	331

Notes: *ID* = intellectual disability group from the current study ($n = 29$); *TD* = typically developing group from the original SPANS studies ($n = 117$ except for VPI and ECI where $n = 91$); *CS* = clinical sample from the original SPANS studies ($n = 93$). *For TD group, maximum score available on the ORI was 20.

3.2 Qualitative Results

Research Question 4: What are participants' experiences of completing the SPANS, and what do they relate the SPANS subtests to 'remind' them of in their everyday life?

3.2.1 Analytic Approach

Braun and Clarke (2006) highlight that the inherent flexibility of TA requires that a number of important, explicit decisions about its application to a particular dataset are made *prior* to carrying out analysis. The current study engaged with the data using an inductive, data-driven, semantic-level approach. This meant that themes within the data were derived from participants' explicit, surface level accounts rather than being driven by pre-existing research and ideas. Braun and Clarke's six-step method of TA was followed; detailed in Figure 2.



Figure 2: Six Phases of Thematic Analysis (Braun & Clarke, 2006)

3.2.2 Findings

During phase three and four of the analysis an initial thematic map of the main themes was produced and can be found in Appendix O. Figure 3 illustrates the final thematic map which shows two main overarching themes and six subthemes.

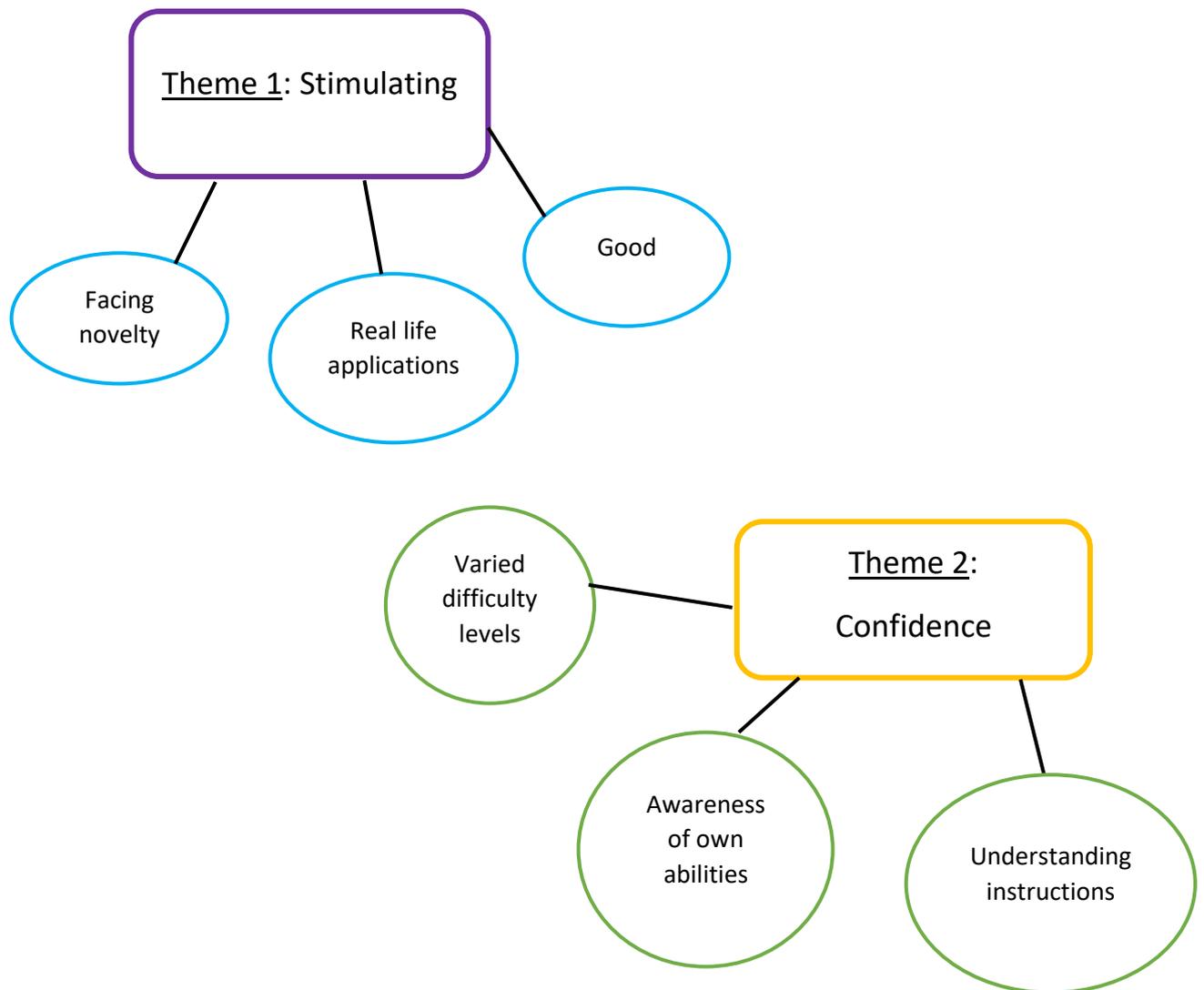


Figure 3: Final Thematic Map

3.2.2.1 Overarching theme 1: **Stimulating**

The first theme ***stimulating*** reflects the accounts of participants who indicated that completing the SPANS was stimulating, unique, engaging and thought-provoking. There was a sense that the SPANS was challenging in that participants faced novel tasks and applied themselves to this. This theme was analysed and coded into three subthemes: *facing novelty*, *real life applications*, and *good*.

Subtheme 1: *Facing novelty*

Participants described that completing the SPANS was an interesting and different experience. An opportunity to do something new was reflected and enthusiasm for learning from the tasks:

Participant 4: "...that's the first time I've done that type of one"

Participant 1: "...got to think about things"

Participant 6: "it was interesting learning different signs and answering questions and all that"

Subtheme 2: *Real life applications*

Whilst the SPANS tasks offered something different, participants also reflected that some tasks reminded them of 'real life' experience. Reminders of everyday aspects of life mainly came from the monetary tasks and shopping list task.

Participant 1: "the money tasks reminded me of counting it up"

Participant 3: "the shopping tasks was like other things I do"

There was also some prompting of personal aspects of real-life that the SPANS reminded participants of, such as a pet.

Subtheme 3: *Good*

There was a patterned response across the data reflecting that participants found the SPANS 'good'. The word 'good' was used by six of the participants and gestured using the visual aids on the interview schedule by one participant. Participants had difficulty when asked what they had found 'good' about the tasks; feedback seemed to reflect that this may be linked to reasons for engagement. Some altruistic reasons for engagement were reported, for example, Participant 2 described that they "felt good doing the tasks because it will help others in the long run". For some, this was linked to a broader stimulation and perhaps personal enjoyment of engaging with particular SPANS tasks:

Participant 6: "...found the tasks very good and very interesting"

Participant 5: "I found tasks excellent. Enjoyed doing the tasks. I liked counting from 20"

Participant 7: [gestured two thumbs up when asked how they had found the tasks] "I liked the symbol one, think that's my favourite"

3.2.2.2 Overarching theme 2: **Confidence**

Participants' narratives repeatedly echoed factors related to confidence in their SPANS performance and general abilities. Three subthemes emerged: *varied difficulty levels*, *awareness of own abilities*, and *understanding instructions*.

Subtheme 1: *Varied difficulty levels*

Variation across the levels of difficulty on the SPANS tasks for individuals seemed to impact and shape their confidence and engagement with the individual tasks. Low confidence was particularly evident for number-related tasks which included monetary calculations and counting backwards:

Participant 1: "The money ones were hard"

Participant 2: "there was somethings I like... struggled on... like the maths ones were hard, I couldn't do them very well, like taking away numbers"

Participant 3: "Maths was a bit hard"

Participant 5: "I found the numbers backwards hard"

Participant 7: "I weren't too keen on the numbers, they were quite hard"

Subtheme 2: *Awareness of own abilities*

There was a sense of awareness of individual abilities in relation to particular tasks on the SPANS. This seemed to both support and limit performance on the tasks, for example, participants frequently did not attempt the monetary calculation tasks due to perceiving that they were unable to do this, so didn't try. This echoed the above reflections. On the other hand, there was also a sense of encouragement of confidence and self-awareness stimulated by some of the SPANS tasks:

Participant 2: "[It was good because] I could remember some of the pictures and some of the way things were put"

Participant 1: "I can count some [money] but not all of them... I struggle with notes but I know coins"

Participant 3: "It was good... bit of the reading task because I used to not be able to read"

Subtheme 3: *Understanding instructions*

The final subtheme reflected participants' accounts of the ease of the instructions for tasks on the SPANS. The majority of participants described these as being "easy to understand"; one participant said that the instructions were "OK to understand" (Participant 6). Familiarity with the test administrator seemed to be an important factor for participants to feel confident, comfortable and to reduce anxiety:

Participant 2: "I felt confident because I knew the person doing the research... if it was a stranger then it would have been more difficult"

4.0 Discussion

4.1 Summary of Research Findings

This research was a pilot study of the SPANS neuropsychological battery in a sample of adults labelled with intellectual disabilities. Construct validity and group differences were examined. Interviews were carried out to explore participant experiences of completing the SPANS, with the aim to conjecture the meaning of the tests to the participants' everyday lives. The quantitative findings are discussed with support and contextualisation from the qualitative data.

4.1.2 Construct Validity

Key findings

Correlation analyses showed varied, and sometimes unexpected, support and non-support for convergent and divergent validity of the SPANS with the WAIS index scores, which aims to assess several theoretically similar constructs (see Table 4 for direct comparison of intercorrelations of ID vs. control samples). The profile of intercorrelations between the SPANS and WAIS indexes differed in parts to the original SPANS validation studies with the general population (Burgess, 2014), and of note are the larger effect sizes in the ID sample compared to the TD sample. One of the most theoretically discrepant findings was that the Verbal IQ domain of the WAIS correlated significantly with the VPI domain of the SPANS. Moreover, performance on the WAIS WMI co-varied with all of the SPANS indexes with medium-to-large effect, suggesting a particular strong and symbiotic relationship between all SPANS tasks and ID participants' working memory capability.

Theoretical Implications

Important questions about whether or not the SPANS taps into the cognitive processes that it is 'supposed' to measure are raised by these findings. The SPANS was designed to measure seven related but distinct constructs. In this sample, the pattern of intercorrelations indicated limited distinction between constructs.

The SPANS was designed to be sensitive and specific to detecting neurological impairment in adults with ABI; therefore, whilst tasks aimed to challenge typically developing/ non-impaired adults, a relatively high 'ceiling' effect was generated in the norming sample (Burgess, 2014). This was likely to insufficiently 'measure' true ability and/or knowledge in the TD group; nonetheless, distinct cognitive constructs were indicated in these data which supported the ability of the SPANS to tap into a range of abilities. By contrast, in the ID sample the SPANS captured a broad range of performance but with less distinction between domains. This may indicate that the SPANS is sensitive to differences between those with ID and those without cognitive difficulties, and also of variance within this group. It is possible that for those with ID the SPANS may be a measure of *fewer* constructs.

One possible explanation of these findings is that the mental structures/ neuropsychological profiles of those with ID are different to those of the general population and those who have acquired an injury later in life (e.g. Numminen *et al.*, 2002). Empirical studies have demonstrated a trend of higher correlations between factors on neuropsychological tests for people with lower IQ (e.g. Detterman & Daniel, 1989; Reynolds *et al.*, 2013), however these findings have been contested by other studies that have demonstrated the opposite effect (e.g. MacClean *et al.*, 2011). Sampling differences might account for some of the contrast in these findings. A probable conclusion is that regardless of direction, there could be differences in correlations between cognitive tests at different ability levels. This reinforces the importance and need for neuropsychological tests to include standardisation across a range of groups and to not simply draw from data that is normed on the general population (e.g. Rognoni *et al.*, 2013).

The strong relationship between working memory and the SPANS tasks appears to reflect a fundamental aspect of cognition and processing that may be unique to the ID population. Working memory (as assessed by the WAIS WMI), visual capacity (as assessed by the SPANS VPI), attention (as assessed by the SPANS ACI) and processing speed (as assessed by the SPANS ECI) seemed to be skills in ID that were fundamental to all other task performances. For example, if the amount of information given is too much (e.g. subtest instructions), or the

pace at which it is given is too fast, the person with ID may fall too far behind and tasks may not be completed, or not completed accurately enough to score test points. This further supports the notion of adapting measures for use with ID populations and ensuring a 'fair' reflection of ability.

It was unexpected and unclear that visual-based tasks that assess the ability to accurately see, pay attention to detail, eye track, retain visual material in working memory, use drawing to reproduce visual material, and make sense of what is visually presented, correlated so strongly with verbal tasks that purport to, and would seem to assess 'crystallised intelligence' (the ability to use and retrieve previously learned knowledge; Kensinger, 2009). A range of studies have demonstrated divergent validity for verbal and visual-based tasks (e.g. Kearney-Ramos *et al.*, 2014) including WAIS validation studies (e.g. Wechsler *et al.*, 2008), signifying the need for further research to explore the unexpected relationship found in this study. These findings may simply be specifically related to the current sample.

It could be that performance on the VPI tasks was reflective of existing skills that in one's lifetime have supported learning, and/or also some characteristic or 'trait' that is contributing to performance. The original SPANS validation studies highlighted the potential influence of characteristics such as conscientiousness and vigilance on significant correlations between seemingly unrelated constructs (Burgess, 2014). Perhaps there was also a role for conscientiousness, or striving, or another characteristic, like confidence that was indicated in the qualitative data that partially helps to understand the relationship between verbal and visuo-motor based tasks.

4.1.3 Group Comparisons

Key findings

Significant differences in performance between an ID ($n = 29$) and TD ($n = 29$) group across all of the SPANS domains were found. Large effect sizes were reported with the TD group obtaining a higher median on all of the domains. The findings adhere to previous literature that has shown people with ID perform more poorly across a range of neuropsychological tests (e.g. Wechsler *et al.*, 2008). Findings from thematic analysis of interviews indicated that confidence may have impacted on scores for the ID group; for example, a general difficulty was reported for tasks involving numbers. This would appear to have been backed up by the quantitative findings that indicated the greatest percentage of difference between the groups on the ACI and ECI; domains which included numbers-based tasks. An exploration of

differences between performances by the ID group on the numbers versus visual tasks would provide a useful insight into whether perceived difficulty reached statistical significance.

Interestingly, one of the smallest percentages of difference and consequent effect size of the mean average scores between groups was on the memory and learning domain. These findings may simply be a product of the tasks that the SPANS subjected participants to, as opposed to meaningful differences or a particular cognitive strength in the sample. Notwithstanding, this outcome was also supported by the qualitative data whereby participants reported varying levels of difficulty across subtests and particularly highlighted tasks (such as the S-W-P-A) from the MLI as 'most enjoyable' in their accounts. Importantly, significant differences were found between groups across each of the MLI subtests and so these findings, whilst indicating the possibility of advantageous learning situations for those with ID, require larger data sets and more robust exploration.

Theoretical Implications

The ID group are more likely to struggle on a range of tasks that require verbal and visual abilities, processing and working quickly. Importantly, the SPANS MLI involves tasks that marry visual and verbal materials and reflected the relative 'best' ability of the ID group. Whilst there was still a significant difference between groups, the use of such tasks may go some way to 'bridging the gap' between populations. One consideration is that neuropsychological tests and their reliance on specific skills and knowledge's, such as the ability to understand and follow instructions may better suit the general population by nature, and therefore have contributed to the size of the difference between groups (Uekermann & Daum, 2001). Furthermore, qualitative accounts highlighted the role of confidence in task completion. It is possible that participants experiencing a lack of confidence on particular subtests did not try them or feel able to approach them which may have lowered their overall scores. Visual-based learning situations yielded better performances in the ID group; perhaps these tasks were associated with greater confidence due to the widely documented service expectations to use visual aids in communication (e.g. Royal College of Speech and Language Therapists, 2013).

The close associations between SPANS indexes and working memory in this study may account for some of the difference between groups. Working memory is considered a core component of general executive functioning; an umbrella term depicting a diverse range of processes central to cognitive development, i.e. planning, inhibition, attention etc. (e.g. Carretti *et al.*, 2010), and has been implicated in scholastic abilities such as arithmetic/mathematics (e.g. Bull & Scerif, 2001), language comprehension (e.g. Friedman & Mayaki, 2004), and reading (e.g.

Alloway *et al.*, 2005). Working memory impairments have been associated with specific learning disabilities such as dyslexia (e.g. Pickering, 2006), and arithmetic difficulties (e.g. Van der Sluis *et al.*, 2006). In light of this, it has been suggested that working memory contributes to learning problems (e.g. Hulme & Mackenzie, 1992).

The finding that working memory processes were more closely related to cognitive performance and differentiated the ID group to the original SPANS clinical sample has been replicated elsewhere. For example, in their WAIS-IV invariance study, Reynolds *et al.*, (2013) reported that the general factor of intelligence was more strongly correlated to working memory in an ID group ($r = 1.00$) when compared to a matched control group ($r = .67$). Carretti *et al.*, (2010) found that the specific process of 'working memory updating' (the ability to maintain accurate representations of information changing over time; Ecker *et al.*, 2010) accounted for the greatest variance ($d = 0.58$) between an ID group ($n = 28$) and a 'matched mental age' group ($n = 28$). Working memory updating has been shown to predict 'fluid intelligence' (e.g. Chen & Li, 2007), and difficulties with updating has been linked with poor comprehension in general (e.g. Palladino *et al.*, 2001).

It is possible that the TD group possesses a basic, even taken for granted, level of working memory and that its effect 'disappears' in analysis even for those with ABI/LTNC, whereas working memory reveals itself to be the foundation of better performances across the board in ID group performances. Interestingly, despite Reynolds *et al's.*, (2013) findings that working memory distinctly correlated with general intelligence, factor analysis yielded support for the four-factor structure of the WAIS-IV with an ID sample. This suggests that tests vary in their demonstration of measurement invariance across groups and such variance has been particularly noted in the lower IQ range (e.g. Whitaker, 2010). Thus, the observed pattern in the current study may reflect underlying processing structures that are uniquely associated with the ID population; it might merely reflect the sample in this study; low variance in the TD group could account for some of this difference; or it may reflect variability due to the properties of the test itself (e.g. Toomela, 2010). Notably, the relatively small sample size in Reynolds *et al.*, ($n = 104$), and smaller sample in the current study ($n = 29$ for the ID group) means that these results must be interpreted with caution.

The variance of scores across the SPANS domains *within* the ID group was a notable and important finding. In this small sample, heterogeneity and diversity of this population is revealed, who arguably exhibit greater differences than the 'general population'. Whilst the MLI follow-up analyses revealed some differences between task performances in the ID group,

greater exploration of within group differences is required. These findings support the current focus on individualised, person-centred supports (e.g. in public policy; e.g. Department of Health, 2015) for people with ID in order to enhance quality of life (e.g. Schalock *et al.*, 2010). Participants' accounts reflected this sense of variability with regard to the tasks that people enjoyed or found difficult. Previous research has identified and encouraged focus on intra-group differences in order to explore potentially meaningful subgroups within this diverse population (e.g. Fletcher *et al.*, 2004; Van der Molen *et al.*, 2009).

4.2 Clinical Implications

This study reflected some of the risks of applying neuropsychological tests that have been standardised in the general population to people with ID. It is important to more robustly understand the story that test performances are telling about a particular group, specifically, the constructs that are being 'measured'. Individual differences should also never be overlooked. The findings showed that the SPANS assessed some aspects of functioning of the ID sample, although these were not necessarily the same as what the SPANS purports to assess in the general population. Whilst the sample was small, this study preliminarily reinforces the importance of developing normative reference data to support more accurate reporting of ability (Garcia-Alba *et al.*, 2017). A greater, more specific understanding of the constructs that the SPANS is tapping into for this population could aid the clinical utility and future adaptation of this measure.

Qualitative accounts indicated that doing something novel and challenging was particularly appealing about the SPANS and this may have increased engagement. It is possible that the very act of participating in a research study generated a sense of being valued (McDonald, Conroy & Olick, 2016). Having opportunities that are engaging and promote feeling valued for people with ID is crucial to quality of life (e.g. Schippers, 2010). There was also some suggestion that the SPANS reminded participants of their own achievements and sense of ability, which may increase confidence, although this theme seemed to both contribute to and hinder/impact task performance. Insight into the experience of completing these types of measures is an important way of capturing both the views of participants and the relevance that the test may have to daily life. Having a sense of the individuals experience is crucial to robustly assessing intellectual functioning (BPS, 2015b). The subtheme of 'real life applications' demonstrated some ecological validity of the SPANS tasks. As Ruff (2003) states, the future of neuropsychological testing requires focus on ecological validity and ensuring cognitive construct tests are linked with daily functions.

As stipulated by the BPS (2015b) neuropsychological assessment should be undertaken in relation to a specific query. The SPANS may contribute useful information that supports the assessment of matters such as capacity, learning style, employment related queries, and support needs. For example, one of the tasks on the SPANS provides an insight into the person's ability to sequence and hold in mind increasingly complex directions. Information such as this may be beneficial to share with employers and support teams so that the person is not overloaded or over/under estimated. However, prior to fully understanding the clinical utility of the SPANS further validation studies are crucial.

4.3 Methodological Strengths and Limitations

The SPANS (Burgess, 2014) is a relatively new neuropsychological battery that had never been used with individuals labelled with ID. This study forms part of an initial exploration of the construct validity of the SPANS with an ID population and therefore contributed to an emerging collection of SPANS validation studies. The study uniquely adopted a mixed methods approach which enabled the researcher to maintain a connection to individuality and meaning-making (Braun & Clarke, 2013), as well as exploring observable performance. The study captured the voices of people who had completed the assessment tool which will contribute to the growing body of qualitative research with those with ID (Beail & Williams, 2014). Notwithstanding, mixed methods designs can result in the narrowing of a particular method (Giddings & Grant, 2007), and ambiguity in relation to epistemological positions (e.g. Mackenzie & Knipe, 2006). As a pilot study, the breadth of analysis has highlighted several potential avenues for further exploration.

The sample size for correlation analysis did not reach sufficient power and so these findings must be interpreted with caution. Although the sample size reached sufficient power for the remaining analyses, it represents a very small sample from one particular region accessing a specific service, and therefore may have limited generalisability to others. In addition, convergent and divergent validity was only assessed against the WAIS and this is a significant limitation of the study. To more robustly assess construct validity, a range of measures should be included. Variables such as age that have been shown to impact scores (Burgess, 2014) and categorically differ in the SPANS and WAIS interpretative manuals were not considered in the current study and this may have influenced the results. Also of note are the potential effects of comparing data from the WAIS-III in the original SPANS validation studies to WAIS-IV data in the current study. Whilst subtest names remained the same across each WAIS version, tasks differed and therefore the constructs measured may not be equivalent (Taub & Benson, 2013).

Taub and Benson reported that the WAIS-IV was superior in measurement and scoring of FSIQ to the WAIS-III which indicates greater validity of this measure, nonetheless, validity concerns of the WAIS in general in the lower IQ range (e.g. Whitaker, 2015) are important to consider in future SPANS construct validity studies.

The sample for the qualitative data only reflected seven participants and so the voices of other participants were not reflected. There is on-going debate about the 'richness' of qualitative data from people with ID due to reliance on verbal skills (Beail & Williams, 2014). Nonetheless, Smith and Osbourne (2008) outline varying types of 'richness' and qualitative research with people with ID should not be dismissed or considered to produce less valuable accounts. The responsibility lies with the researcher to think carefully about the way questions are asked and to consider the use of communication aids (Bunning, Heath & Minnion, 2009). This study did use some visual aids and the researcher had experience working in ID settings. However, interviews yielded very short responses (as can be seen in the extract in Appendix L) and were administered by the SPANS administrator which may have impacted participant's comfort level in expressing their views. The latter point in particular was considered due to the overwhelmingly positive and 'good' feedback about the SPANS. To reduce this potential bias interviews in future studies could be conducted by a separate member of the research team following SPANS completion.

Neuropsychological assessment, particularly with somebody unknown to the individual, can be an anxiety-provoking experience (i.e. Uekermann & Daum, 2001); this may have impacted on performance. One participant reflected this in their interview, attributing comfortability and performance factors to knowing the administrator. Furthermore, the nature of neuropsychological tests is dependent upon the operationalisation of complex conceptual variables that are inherently difficult to 'measure' (e.g. Shields & Rangarajan, 2013), and to measure reliably due to sources of error (Laird & Whitaker, 2011). For example, the use of WAIS data comes with its own methodological limitations that include conceptual controversies related to 'intelligence' (e.g. Whitaker, 2013), validity concerns in the lower IQ range (e.g. Whitaker, 2010), reliability differences between versions (e.g. Taub & Benson, 2013), and limitations in the standardization of population data (e.g. Rognoni *et al.*, 2013). These factors are important to hold in mind when administering, interpreting or developing any neuropsychological assessment.

4.4 Recommendations for Future Research

On-going validation of the SPANS is required to more vigorously inform the development of this tool for use across ID settings. To develop norm-referenced data, much larger samples need to be derived from different regions and ethnic groups. Further tests of validity should include a range of theoretically similar and dissimilar measures including those that have been adapted for use with ID.

The use of qualitative interviews alongside collecting quantitative data will continue to provide a unique insight into the experiential accounts of people with ID completing this assessment. However, greater attention should be paid to qualitative methodology, for example, considering the impact of ID on communication through interviews (Beail & Williams, 2014). Qualitative accounts were of the SPANS in general and it may be helpful for tool development to focus on each subtest in more detail with the intention of meaningfully adapting the SPANS for this population and improving ecological validity. For example, by conducting interviews and/or focus groups about the construction of tasks that reflect daily living specific to the population. This may be especially helpful for the numbers-based tasks that seemed to raise difficulties across the sample qualitatively and quantitatively. Whilst there was a sense that the SPANS instructions were 'easy' to understand from the qualitative data, future research could include the accounts of test administrators to more specifically explore the suitability of these instructions for people with ID.

The clinical usefulness of the SPANS is not yet known. Longitudinal research exploring ways that the SPANS might inform intervention or enhance communication in services could be clinically beneficial. A range of methodologies could be employed, such as conducting interviews with clinicians who use the SPANS, comparing an ID group who have had the SPANS administered and are receiving some kind of specific support guided by the findings of the SPANS to a control group, and getting staff feedback about the way that the SPANS contributes to understanding individuals. However, these research ideas rely on further validation and likely adaptation of the SPANS before they are feasible.

Future research should seek to further investigate differences in performance between clinical populations on the SPANS and *between* people with ID. Exploring performance differences between people labelled with ID could indicate patterns or 'clusters' of cognitive profiles within this population. Greater exploration of specific subtest level differences would provide useful information about the tasks that indicate potential strengths and areas of particular difficulty for those with ID. However, such studies would require careful design as profiles

between different neuropsychological measures, such as IQ tests, have been shown to have very little agreement (e.g. Whitaker & Gordon, 2009).

4.5 Conclusions

This study has provided an initial exploration of the validity of the SPANS with an ID sample and offered a unique account of what it was like for participants to complete the SPANS. The importance of developing and refining neuropsychological measures that reflect the population they are being used with should not be overlooked. Including the voices of those who complete these kinds of tests is an important way of maintaining a connection between numerical scales and human experience. There are several future research ideas that are crucial to the ongoing development of the SPANS in the ID field. Further research might enhance understanding of construct validity and within group differences, and subsequently improve understanding of the clinical utility of this measure.

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Part Three:

Critical Appraisal

1. Introduction

This appraisal details my critical reflections of the research process. It will consider methodological decisions, challenges, strengths and limitations. There have been many learning experiences throughout, both personally and professionally and it is hoped that the critical appraisal captures the most salient of these.

1.1 Choice of Topic

1.1.1 Thesis

Prior to clinical psychology training I worked as an Assistant Psychologist in a community team with people labelled with intellectual disabilities (ID). I began to learn about how brilliantly heterogeneous this 'population' are and experienced an overwhelming sense to understand more. I knew that if I had the opportunity to undertake research in the future, it would be with this client group. When I embarked on clinical training and the opportunity to conduct research arose, I was able to pursue this area of interest.

Research interest presentations were given within the first two months of clinical training. At this time there was a sense of urgency to quickly identify a research topic. I was instantly drawn to the SPANS project. There was a shared enthusiasm to carry out research that was potentially clinically useful and that included the voices of often silenced, unheard people with ID. The project seemed to match my hopes for research in the ID field and I was also particularly open about coming alongside a pre-existing research idea. On reflection, I was perhaps so enthused by the working partnership and shared vision that I underestimated the complexity of a neuropsychology based project. Nonetheless, this topic has given me the opportunity develop my knowledge of neuropsychological testing and has reiterated the importance of marrying such assessment with qualitative information and observation.

1.1.2 Literature review

In May 2017 a teaching session was delivered that provided guidance about the literature review and thesis. It was during this teaching that it became clear that the literature review topic needed to link with the thesis, but mustn't directly capture literature that could risk duplication and plagiarism in the thesis write-up. My initial leaning was to update my literature review from our first year of training that focused on working memory characteristics of adults with ID. However, I quickly came across a recently published review. I

saw the opportunity to shift focus and incorporate my broad, general interest in ID with the very specific and focused research project. This led to hopes of conducting a theoretical review that explored the concept of 'intellectual disabilities' from a social constructionist stance. However, the remit of the doctorate course specified that literature reviews must be based on empirical, not conceptual, writings. One particular theme that seemed to recur across my reading was that of 'quality of life' (QOL).

QOL emerged across a range of literature; it seemed to be at the centre of research and writing with a focus on maximising quality of life for those with ID. I paid increasing attention to this widely used phrase and its implications. As I read more about the surge of QOL research I was drawn to its theoretical underpinning. The QOL framework held in mind the context in which a person lives (e.g. Schalock *et al.*, 2016); a position that resonated with my personal and professional stance. Immersing myself in the QOL literature was assuring because of the dedication of many researchers and clinicians to moving away from locating disability within people, and to recognising the way that the environment shapes (dis)ability (e.g. Schippers, 2010). It was both stimulating and hopeful reading about these ideas and the way that THEY were beginning to dominate ID research and public policy. The multi-dimensional and holistic concept of QOL helped me to think about both the potential value and risks of utilising neuropsychological tests.

1.1.3 Linking the Literature Review and Research Project

After working in ID services I experienced the positive impact that neuropsychological testing can have on people's lives. For example, I worked with many people who struggled to find and/or maintain employment, but were not entitled to supports, such as benefits, because of uninformed perceptions and frequent overestimation that they were able to 'cope' in our intellectually demanding world. Their voices were silenced and yet 'evidence', such as neuropsychological test scores and observations, were a useful tool for supporting such claims, and informing support needs in places of employment. The dominant narrative in Western society of having 'expert', 'tangible evidence' to 'prove' (dis)ability does not sit comfortably with me. However, having valuable information about the cognitive strengths and areas of difficulty that an individual experiences and the way such understanding can enhance support, which may ultimately improve quality of life, is crucial. As a psychologist, I believe in doing what we can with the position and power we have, and using this for the benefit of clients.

1.1.4 Literature Review Write-Up

During the literature review write up stage, I repeatedly experienced a strong sense of discomfort with the quantitative methodology of exploring the broad and complex phenomena of QOL. Although this enabled researchers to access large samples, I found myself questioning the validity and robustness of numerically categorising quality of life-related factors. Several authors noted the interrelatedness of QOL domains and the importance of considering both specific aspects of QOL and overall QOL (e.g. Bonham *et al.*, 2004). I was alert to the idiosyncrasy of QOL; the way that QOL can vary tremendously from one person to another and the things that they consider central to enhancing their QOL (Lyons, 2010). The extent to which individual differences accounted for some of the variation in findings was unclear. Perhaps the quantitative approach did not capture such idiosyncrasies. Therefore, a slight change to the question I posed could have changed the trajectory and content of the review, for example, to include 'richer' qualitative data of individual accounts that were less aligned to a specific model.

1.2 Recruiting Participants

After being granted ethical approval for this research I was eager to begin data collection, namely, because I was getting married in September 2017 and I ambitiously planned to complete data collection by this time. I had never completed research in an NHS context before; I hadn't anticipated the challenges that recruitment can bring. I was relying heavily on a team of very busy clinicians to identify and approach potential participants and then to feedback in order for me to follow-up. On paper, this sounded feasible, however, in practice this was a real challenge. I found myself frequently feeling 'out of the loop', needing to pursue team members and feeling uneasy about this pursuit. Fortunately, the team leader was responsive and communicative throughout and this was an important source of reassurance. The experience was a real insight into conducting research in the NHS; a climate with very little space for time-consuming research.

When I first met with the team who were supporting recruitment, we agreed that each clinician would aim to complete the SPANS with 2-3 participants each, whilst I would aim to meet with at least 9 participants. On reflection, this was not a realistic expectation and ultimately I met with 20 of the final 29 participants. I started to collect data in July 2017 and unsurprisingly did not finish by September 2017, in fact, I didn't meet with my final participant

until February 2018. This aspect of the research process gave me insight into the importance of managing expectations. It has also helped me to learn more about the barriers of 'being a clinician' and conducting research – both directly and indirectly.

1.3 SPANS Administration and Interviews

Meeting with participants was the most enjoyable aspect of the research process. Every participant was completely unique; no one person was like the other and this reminded me of one of the many things I valued about working in the ID field. Of course, we are all unique individuals but I think that the practice of applying an ID label can imply some form of homogeneity that I am yet to observe. I had a lot of fun administering the SPANS and this was because the participants I met with seemed to be enjoying it. We laughed together and shared joy when people felt a sense of accomplishment with tasks. The short subtests seemed to eradicate any sense of failure that I have often observed and felt with other neuropsychological instruments.

One aspect of the study that was not included in the final analysis was clinician accounts of administering the SPANS, which was maintained in diary form. These reflections would have been interesting to analyse and have given insight into the experiences of clinicians who supported the research. Notably, as I collected the majority of the data these accounts would have predominantly reflected my own views. Perhaps in the ongoing development of the SPANS with this population, test administrator views, especially from clinicians working within services, could further contribute to the qualitative exploration of the utility and suitability of this measure in ID. As support workers were present for several participants this would have, and could in the future, also uniquely contribute to the qualitative exploration of the SPANS.

Time constraints limited the number of interviews I was able to conduct and this was a frustrating experience. For people who did engage in interviews, this was both a privilege for me and a source of uncertainty. The challenges of carrying out qualitative research within the ID field (e.g. Beail & Williams, 2014) are widely cited in the literature. There were two key challenges I faced: 1) did participants fully understand what they were agreeing to take part in? and, 2) how easy was it for participants to be open about their experiences whilst sitting with the person who was so invested in the research and who they did not know very well? The first challenge was more easily overcome because of the support I received from the research team who knew the participants well and also the presence of support workers. The second challenge continues to reflect one of the major limitations of the research and this could have been approached differently. For example, interviews could have taken place with

a clinician in the team shortly (i.e. one day) after SPANS completion to allow time between the stages of the research and familiarity with the interviewer.

1.4 Statistical Analyses

It is not uncommon for statistics to be a source of anxiety in psychology students (e.g. Ruggeri *et al.*, 2008). My relationship with statistics has been fruitful throughout the research process. As I approached data analysis stage of the empirical piece, I immersed myself in statistics books (e.g. Field, 2009) and worked methodically to understand the steps needed to ensure a good quality analysis. This was time consuming and perplexing and equally rewarding and interesting.

A particularly unsettling and challenging stage in the data analysis process was when I was met with violated assumptions. Field's (2009) guidance to 'not bend your data to fit the statistical analyses' and rather, take an alternative route according to your dataset supported me to shift my thinking. As my original plan was to conduct a MANOVA, I felt uncertain about my next steps as there was not a simple non-parametric equivalent to this test. It was at this time that I experienced a real sense of 'stuck-ness' and wished for a more sophisticated understanding of statistical analyses.

To overcome this challenge, continued reading and guidance in research supervision and from university-based staff was extremely helpful, reassuring and cathartic. With increased confidence and familiarity with my data and statistical analyses I soon found myself carrying out further tests and exploring the data in great detail, with great enthusiasm. My interests were particularly in the variation of performances by the ID group across the subtests and I was eager to explore this more closely. Word limits, time restraints and ensuring the project remained within the parameters of the research aims restricted ongoing exploration. It was a surprising experience for me to move from a position of perplexity about the data analysis to constraining myself to conclude investigations. I have learned that statistical analyses encompasses a complicated range of decisions that require genuine understanding and methodologically sound justification in order to ensure transparency and authenticity.

1.5 Qualitative Analysis

The addition of a qualitative aspect to this study further demanded a host of reading and understanding about such methods. Whilst I was guided by writings by Braun and Clarke (2006; 2013) to conduct thematic analysis, there is no clear or consistent agreement about

how to conduct thematic analysis within the literature and so I was unsure of the adequacy and quality of my approach. This was in stark contrast to the quantitative analysis that involved very specific guidance and directions for analysis.

Having the qualitative data supported me to remain aware and connected to meaning that cannot be reduced to numbers (Braun & Clarke, 2013). Although I felt most passionate about capturing qualitative accounts, I found that I spent more time with the quantitative data. This was likely because of the challenge I experienced with understanding and ensuring rigour in the quantitative analysis and the amount of statistical analysis that became possible. Also, the scarce qualitative data that was gathered from the interviews accounted for some of this variation. Whilst I have developed skills across both qualitative and quantitative methodologies, this required a challenging shift in approach and concentration and it could have been more beneficial to focus specifically on one research question in detail. For example, focus groups could have yielded rich group discussion about the SPANS, shared experiences, differences, and ideas for improvement etc.

1.6 Research Write-Up

A substantial amount of time was spent preparing the research proposal, navigating ethical approval, collecting data etc. and yet the write-up of the empirical piece seemed confined to 12-15 weeks prior to the deadline. As I started to panic about this, research supervision helped to steer these worries and consider ways of managing the workload. My supervisor reminded me that whilst collecting data other aspects of the write-up could be taking place alongside this, such as writing the 'methods' section. If I were to complete further research, I would employ this strategy much earlier than I did in this case.

One dominant narrative on clinical training, from my experience, is that the most challenging aspect of the course is 'juggling' competing demands. I have experienced this acutely during the thesis write-up stage of this process. Whilst attempting to write my research report I have also been on a split placement and therefore each weekday I have found myself somewhere different. This has meant 'changing hats' on a daily basis. Although overwhelming at times, the discipline, self-direction and determination that managing these demands has required will undoubtedly serve me well in qualified roles.

Personally, I have developed a great sense of pride for applying myself to this project and completing it. In many ways this piece of work symbolises the final steps of my journey to becoming a qualified clinical psychologist. Having the 'end goal' in sight has helped to make

the research write-up feel quite exciting as well as incredibly challenging. Of course, the work doesn't stop here, but I have a new-found belief in myself that I can meet the requirements of training that are designed to support qualified life.

1.7 Ethical Dilemmas

Clinical training in general facilitates critical thinking and understanding from a range of epistemological positions. The research process has elicited ethical 'pulls' in certain directions that at times have felt uncomfortable and/or conflicting. In particular, given the population of interest in this project, I experienced being drawn into using diagnostic and concrete (often contested) labels and concepts. This project relied heavily on socially constructed concepts, such as 'intelligence' and 'intellectual disability', and whilst I tried to remain sensitive and critical of the limitations of these concepts, the method of comparing performance on the SPANS between 'groups' in particular felt crude and differentiating at times.

My enthusiasm for the project came from a place of hope in exploring a measure that might offer information that could complement and enhance understanding of abilities. Nonetheless, I was astute to the way that such tests can often become dominant descriptors of those with ID and the risks of drawing inferences about cognitive abilities based on this kind of assessment (e.g. Laird & Whitaker, 2011). The need to explicitly 'measure' and report our interpretations is a central part of research and ensuring an evidence-base within the psychology profession. The learning point for me has been the importance of remaining transparent about these challenges. The use of supervision, reflection, and peer supervision has helped me to balance what is required for the purposes of research and maintaining integrity to my personal and professional values. I am hopeful that holding onto a critical perspective of my research will equip me to develop and refine my work in the future.

1.8 Dissemination

Fortunately, I will be working with the team who supported recruitment of participants once qualified and so intend to disseminate the research with them in addition to continuing to collect data and informing SPANS development. When I embarked on this project, I was determined to produce a research report that was accessible to participants and will draw on the support of the field team to do this as effectively as possible.

1.9 Conclusions

The research process has extended across the doctorate course with the write-up dominating the last few months. It has been a challenging, often overwhelming, and intense experience. Conducting this project, particularly along with meeting other demands of the DClinPsy, has required an incredible level of commitment and dedication. These are attributes which will undoubtedly serve me well in my career as a clinical psychologist. I have learned about the challenges of 'doing' research in an NHS context and hope to carry these research skills forwards now that I have more confidence in my abilities. On a final note, being a trainee clinical psychologist has remained an absolute privilege to me, as somebody who didn't know such a venture was possible; completing and submitting this piece of work symbolises a lifetime achievement that I will always treasure and be proud of.

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Appendices

Appendix A*: Target Journal (Journal of Applied Research in Intellectual Disabilities) Author Guidelines

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

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.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

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.

2.2 Ethical Approvals

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.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

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Journal article

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain*, 126(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sex differences in developmental reading disability: New findings from 4 epidemiological studies. *Journal of the American Medical Association*, 291(16), 2007-2012. doi 10.1001/jama.291.16.2007

Book Edition

Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

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Appendix B: Appraisal Tool for Cross-Sectional Studies (AXIS) (Downes *et al.*, 2016)

Introduction

1. Were the aims/objectives of the study clear?

Method

2. Was the study design appropriate for the stated aim(s)?
3. Was the sample size justified?
4. Was the target/reference population clearly defined? (Is it clear who the research was about?)
5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?
7. Were measures undertaken to address and categorise non-responders?
8. Were the risk factor and outcome variables measured appropriate to the aims of the study?
9. Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?
10. Is it clear what was used to determine statistical significance and/or precision estimates? (e.g. p values, CIs)
11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?

Results

12. Were the basic data adequately described?
13. Does the response rate raise concerns about non-response bias?
14. If appropriate, was information about non-responders described?
15. Were the results internally consistent?
16. Were the results for the analyses described in the methods, presented?

Discussion

17. Were the authors' discussions and conclusions justified by the results?
18. Were the limitations of the study discussed?

Other

19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
20. Was ethical approval or consent of participants attained?

[Quality of reporting questions are: 1, 4, 10, 11, 12, 16 and 18; study design quality questions are: 2, 3, 5, 8, 17, 19 and 20; possible introduction of biases questions are: 6, 7, 9, 13, 14 and 1].

Appendix C: Quality Appraisal using the AXIS tool

	Study author, year & country	AXIS Tool Items																				Comments
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
1.	Badia <i>et al.</i> , (2013), Spain	✓	✓	✓	✓	✓	✓	D/K	✓	✓	✓	✓	✓	×	N/A	✓	✓	✓	✓	✓	✓	80% of sample employed.
2.	*Bonham <i>et al.</i> , (2004), Maryland	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	Participatory action research.
3.	Bramston <i>et al.</i> , (2005), Australia	✓	✓	✓	✓	✓	✓	D/K	D/K	D/K	✓	✓	✓	×	D/K	D/K	✓	✓	✓	×	Y	Sample part of work-based project.
4.	Claes <i>et al.</i> , (2012), Netherlands	✓	✓	✓	✓	✓	D/K	×	✓	✓	✓	✓	×	N/A	Y	✓	✓	✓	×	D/K	Consent/ethical approval not clearly reported.	
5.	Gomez <i>et al.</i> , (2016), Spain	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	×	N/A	Y	✓	✓	✓	×	✓	ID group details limited.	
6.	*Lombardi <i>et al.</i> , (2016), Italy	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	×	✓	Sample selection by case managers.	
7.	*Memisevic <i>et al.</i> , (2015), Bosnia/Herzegovina	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	D/K	N/A	✓	✓	✓	✓	D/K	✓	QOL framework not in place.
8.	Miller & Chan (2008), Florida	✓	✓	✓	✓	✓	✓	D/K	Y	Y	Y	Y	Y	×	×	✓	✓	✓	✓	×	✓	Sample: 'relatively high level of adaptive functioning'.
9.	Nota <i>et al.</i> , (2007), Italy	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	D/K	✓	✓	✓	×	D/K	Consent/ethical approval not clearly reported.	
10.	*Rand & Malley (2016), UK	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	Lack of data quality related to some variables.
11.	Rey <i>et al.</i> , (2013), Spain	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	Pilot study initially completed.
12.	*Simoes <i>et al.</i> , (2016), Portugal	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	×	✓	All sample unemployed.	
13.	*Simoes & Santos (2016), Portugal	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	×	✓	Interviewers had training and experience working with ID	
14.	*Simoes & Santos (2017), Portugal	✓	✓	✓	✓	✓	✓	D/K	✓	✓	✓	✓	×	N/A	✓	✓	✓	✓	×	✓	Interviewers had ID training/experience working.	

Key: D/K = Don't Know; N/A = Not Applicable; * indicates studies deemed to be of the highest quality.

Appendix D: Summary Characteristics of Included Studies

Author (Date)	Study Aims	Sample	Measures	Key findings for review	Strengths/ Limitations
Badia et al., (2013)	To examine the relations between participation, preference, interest and constraints to leisure activities and QoL.	Convenience recruitment from various services incl: occupational centres, special employment centre and supported employment service. Total: 125 47.2%male; 17-64yrs; 44.8%=mild to borderline ID; 55.2%=mod-severe ID.	1. Leisure Assessment Inventory (LAI; Spanish version) (Hawkins <i>et al.</i> , 2002) 2. GENCAT Scale (Verdugo <i>et al.</i> , 2010) 3. Subjective subscale of Integral QOL Scale (Verdugo <i>et al.</i> , 2011)	1. Preference to perform certain leisure activities ($p < .05$) and constraints ($p < .01$) were only significant predictors of Material, Physical & Emotional Well-Being. 2. Sociodemographic factors did not contribute significantly to QOL scores. 3. Mere participation in activities did not contribute to QOL.	+Included all 8 QOL domains +Analysed moderator effects of variables +Subjective and objective measures used - Generalisability - Relatively small sample size - LAI measure limited in consideration of 'constraints'
Bonham et al., (2004)	To assess perceived QoL in adults with ID who are recipients of ID supports and services in Maryland.	923 participants recruited from 33 service providers; 18years+ (no upper limit reported). 17%=profound; 18%=severe; 20%=mod; 32%=mild; 10%=borderline;	1. Fiscal Year Survey (FY)- [validation of this survey formed part of study aims]	1. Perceived transportation availability ($p < .01$) predicted \uparrow QOL across 6 domains; 2. The more hours people received residential support, the lower the Social Inclusion they reported; 3. People living with families reported \uparrow Emotional Wellbeing but \downarrow Social Inclusion; 4. More independent employment	+Participatory action research – places individuals with ID at centre of research; accessible; face validity +Participants of all cognitive ranges able to answer survey questions -Participant info derived from agencies was inconsistent which may reflect data quality issues and QoL understanding

3%=no records.

predicted ↑ Material Wellbeing;

within organisations;

-Data from 2001

5. Younger age predicted ↑ Personal Development and Interpersonal Relations;

-Sample not random

-Data represented a single point in time;

6. Being male predicted ↑ Rights; ↓ Material Wellbeing;

-Did higher scores reflect the way indicator questions were worded?

7. 'Higher' cog ability ↑ Rights and Self-Determination;

8. Those without speaking/communication difficulties ↑ Rights and Material Wellbeing.

Bramston et al., (2005)	To explore personal, social and community determinants of subjective QoL.	Total sample: 200 80 with ID; 17-25 years; mild-moderate ID. 120 without ID; 16-23 years.	1. Comprehensive Quality of Life Scale (ComQoL) and parallel version for ID (ComQoL-ID) (Cummins, 1992) 2. Lifestress Inventory (Bramston et al., 1999) 3. Neighbourhood Youth Inventory (Chipuer et al., 1999) 4. Social Support Scale (Cutrona & Russell, 1987)	1. Social support significant predictor of satisfaction of Material Wellbeing, Emotional Wellbeing & Safety for ID group ($p < .01$). 2. Some predictive trends in social support and stress in interpersonal relationships for predicting satisfaction with health.	+Comparison group used -Relatively small sample; -All participants accessed supported employment – generalisability? -Specifically focused on young adults who may face different challenges than adults over the age of 25 -Limited demographic information reported
Claes et al., (2012)	To determine the impact of support	Recruitment from Netherlands community based programme.	1. Personal Outcomes Scale (Van Loon et al., 2008) 2. Supports Intensity	1. 63% of variance accounted for by 13 entered variables. 2. Key predictors of POS scores were: technology ($p < .05$), staff directed	+Entered several predictor variables and conducted follow-up analyses -Convenience sample

	strategies, environmental & client characteristics on QOL.	Total: 186. 54.8% male; 19-83yrs; 13.5%=borderline ID; 17.2%=mild ID; 22%=severe; 18.8%=profound.	Scale (Thompson <i>et al.</i> , 2004)	supports ($p < .01$), natural supports ($p < .05$), living arrangement ($p < .05$), employment ($p < .01$), level of ID ($p < .01$). 2. Living independently and having employment related to enhanced QOL.	-Sample from one from organisation in Netherlands +/-Netherlands committed to QOL framework -Data about support strategies collected by verbal reports -Overall QOL only – no indication of specific domain
Gomez <i>et al.</i>, (2016)	To examine influence of different types of human services in the QOL of their nested users	Total sample: 11,624; 16-111 yrs; 54% females; 45.5% of sample had ID (other diagnostic groups were: mental health & physical disability)	1. GENCAT Scale (Verdugo <i>et al.</i> , 2010)	1. Diagnosis predicted ↓ Personal Development, Self-Determination, Social Inclusion & Rights ($p < .01$). 2. Being older and accessing specialist services predicted ↑ Material Wellbeing ($p < .01$). 3. Diagnosis and accessing specialist services predicted ↓ Rights & Self-Determination ($p < .01$) 4. Accessing specialist services predicted ↑ Physical & Material Wellbeing ($p < .01$).	+Large sample -Lack of clarity in reporting of 'ID' -Not specific to ID -Descriptive, not causal findings
Lombardi <i>et al.</i>, (2016)	To determine the influence of five predictor variables on QOL	Recruitment from ANFFAS services (largest ID support service in Italy); 1,285 participants; 60% male; mild 8%; mod 27%; severe 31%; not specified 34%; Trisomy 21:	1. POS (van Loon <i>et al.</i> , 2008) 2. Support Intensity Scale (Thompson <i>et al.</i> , 2004)	1. 15 variables explained 57% of variance; 2. Support needs most robust predictor ($R^2 = 0.267$); 3. Participants with paid job/engaging in voluntary activities in community had superior QOL ($p < .001$). 3. Clients with lower IQ and higher support	+Large sample +Clearly operationalised variables and included 8 QOL domains -Sample driven by agreeable services, compromising external validity -Lack of familiarity with QOL framework in this region

12%; ASD: 6%;
Epilepsy: 6%

needs = lowest QoL.

4. Availability of staff-directed support showed significant correlation with QOL ($r = .10$).

Memise vic et al., (2015)	To examine potential predictors of QoL in people with ID;	Recruited from non-governmental support services. Total: 152; 18-69 yrs; 87:male; 65: female; 77%: mild ID; 23%: moderate.	1. POS (Van Loon <i>et al.</i> , 2008).	1. Five variables accounted for 19% of variance. 2. Level of ID ($p < .05$) and employment status ($p < .01$) only significant variables; 3. Having 'mild' ID and being employed ↑ QOL scores.	+ First study in this region to specifically explore predictors of QoL; + Indicates importance of employment opportunities; - Predictors explained just 1/5 of variance - Generalisability - POS measure not validated - Limited use of predictors
Miller & Chan (2008)	To explore the contributions of 'life skills' as predictor variables of life satisfaction .	56 participants; recruited from 2 community support agencies in Dane County 55.4% male; 98.2% European American	1. Quality of Life Questionnaire (QOLQ) (Schalock & Keith, 1993). 2. Personal Resource Questionnaire (Brandt & Weinert, 1981). 3.AAMR-ABS adaptive behaviour scale (Nihira <i>et al.</i> , 1993). 4.Leisure Activity Skills Scale (LASS) (Miller, n.d.)	1. 'Higher-order variables' (social support, self-determination, and productivity) and 'basic life skills variables' (instrumental skills, interpersonal skills, and leisure skills) all significantly contributed to life satisfaction scores. 2. Quality & quantity of interpersonal interactions greatly contributed to life satisfaction.	+Variety of variables -No information about level of ID -All participants were employed -Change of typical use of QOLQ scale for DV predictors -Correlational findings
Nota et al., (2007)	To explore the role of personal characteristics	141 participants; 16-65 yrs; 98 male; 27 mild ID; 33 mod	1. Evaluation of Self-Determination Instrument (ESI; Soresi & Nota, 2007)	1. IQ, age, self-determination and social ability scores predicted membership of high/low QoL group. 2. Higher basic social abilities scores	+Specific role of Self-Determination examined -Proxy reports only;

	tics, Self-Determination, social abilities & residential status on QoL.	ID; 38 severe ID; 43 female: 9 mild ID; 19 mod ID; 15 severe ID. 66 lived in institutions; 24 in community-based assisted group housing; 51 attended day centres.	2. Evaluation of QoL Instruments (EQLI; Nota & Soresi, 2002) 3. Social Ability Evaluation Scale for Adults with Mental Retardation (VAS-ARM; Nota <i>et al.</i> , 2001).	predicted membership of high QoL group (only factor to have loadings over 0.30). 3. Participants with most severe ID showed lowest levels of QoL, self-determination and social abilities. 4. Self-determination as a moderator when IQ was lower. 5. Women ↑ Self-Determination scores.	-Only able to obtain QOL data for 90/141 participants (specifically, those living in institutions and group housing); -Potential cultural differences in definition/ provision of 'residential day services'.
Rand & Malley (2016)	To explore individual, environmental and survey-related characteristics associated with QoL of people with ID accessing publicly funded social care in England.	13,642 adults with ID (not in residential or nursing care).	1. ASCOT (Adult Social Care Outcomes Toolkit) measure of care-related QoL (Malley <i>et al.</i> , 2012).	1. Less adequate home design for needs, higher levels of anxiety and depression = ↓ QoL. 2. Being male associated ↓ QoL. 3. White ethnicity and 65+ ↑ overall QoL.	+Large, national, randomly selected sample +Generalisability to adults in England using social care services -Cross-sectional design -Analysis limited to variables captured in ASCS dataset -Sample only includes people w/ID receiving social care provision (estimated to be around 12% of people w/ ID) -Limited information on specific demographics of sample.
Rey <i>et al.</i> (2013)	To examine whether emotional	139 participants from Spain; 78 men, 61 women;	1. Wong & Law Emotional Intelligence Scale (WLEIS; Wong & Low, 2002)	1. People who are better at perceiving and understanding the emotions of those around them, and who are more adept at	+Supports importance of exploring/discovering individual characteristics that

	competence is related to life satisfaction and happiness in people with ID.	20-59 years (M=30.84)	<p>2. Subjective Happiness Scale (SHS; Lyubomirsky & Lepper, 1999)</p> <p>3. Satisfaction with Life Scale (Spanish Version: SWLS, Atienza <i>et al.</i>, 2000)</p> <p>4. Positive and Negative Affect Schedule (PANAS; Sandin <i>et al.</i>, 1999).</p>	regulating their emotions might deal better with emotional issues and therefore experience greater psychological wellbeing.	are linked to wellbeing in order to inform support; -Small sample size limiting generalisability -Cross-sectional design.
Simoès & Santos (2016)	To compare QoL of adults with/without ID and identify predictors of QoL related to personal and environmental characteristics.	1,929 participants; 18-88 years; mild ID: 769; moderate ID: 495	1. POS (Portuguese version) (Van Loon <i>et al.</i> , 2009; Claes <i>et al.</i> , 2010)	<p>1. QOL scores higher for participants without ID across all domains except physical wellbeing domain.</p> <p>2. Highest discrepancy between Rights & Material Wellbeing domains.</p> <p>3. Participants with ID predictors: living circumstances in Rights domain ($d = -0.89$), employment status in Material Wellbeing ($d = -1.15$), health status in Physical Wellbeing ($d = 1.42$), and diagnosis in Personal Development ($d = -1.15$).</p> <p>4. Age ($d = -0.61$), health status ($d = 0.61$), & diagnosis ($-d = 0.71$) predictors with medium explanation of overall QOL.</p>	<p>+Large sample size +Several IV's considered +Recent exploration of QoL between populations</p> <p>-Sample does not include more profound (i.e. less verbally able) participants -Modified version of POS validity concerns</p>
Simoès, Santos &	To consider extent to which	Recruitment from 7 different agencies in Portugal;	1. Adaptive Behaviour Scale (ABS; Nihira <i>et al.</i> , 1993)	1. Adaptive behaviour most robust predictor of QoL. In self-report condition most robust predictor for: Personal	+Self-report as well as proxy reports collected +Unique combination of

Biscaia (2016)	measures of adaptive behaviour and support needs predict personal outcomes associated with QOL;	146 participants; 18-64 yrs ($M = 32.73$).	2. SIS (Thompson <i>et al.</i> , 2004) 3. POS (Van Loon <i>et al.</i> , 2009; Claes <i>et al.</i> , 2010)	Development ($d = 1.54$); Self-determination ($d = .61$); Social Inclusion ($d = .63$); Rights ($d = .90$); Material Wellbeing ($d = .63$); and QoL Index ($d = 1.16$). 2. Support needs predicted scores on Personal Development ($d = -1.07$); Self-determination ($d = -.05$); Rights ($d = -.65$) & QoL Index ($d = -.75$) for self-reports. 2. Overall, people with greater adaptive skills and less intense support needs experienced higher QOL.	measures and inclusion of 3 constructs (ABS, SIS, POS) -All participants unemployed – ID unemployment common in Portugal -Relatively small, convenience sample -Participants all able to communicate their preferences – representativeness?
Simoes & Santos (2017)	To examine personal and environment characteristics that may affect/predict QoL of people with ID.	Convenience sample recruited from 45 services. Total: 1,264; 18-66 yrs ($M = 31.36$); 664 male; 600 female; 769 = mild ID; 495 = moderate ID.	1. POS (Van Loon <i>et al.</i> , 2009; Claes <i>et al.</i> , 2010)	1. Diagnosis ($d = -.85$), social participation ($d = -.50$), daytime activity ($d = -.68$), and well-being ($d = -.59$) significant predictors of QoL scores. 2. Living circumstances major predictor of the Rights domain ($d = -.87$).	+Range of variables -Non-random sample -Mild and moderate ID only

Appendix E*: Chronology of Research Process

Activity	Time Period
Consultation with research supervisor	October 2015
Development of initial research proposal	April 2016 – June 2016
Research proposal reviewed by internal academic panel at the University of Leicester	June 2016
Research proposal peer reviewed by Service User Reference Group (SURG)	October 2016
Integrated Research Application System (IRAS) submission	December 2016
Research and Ethics Committee (REC) favourable opinion gained	December 2016
Research sponsorship established	February 2017
Health Research Authority (HRA) approval gained	February 2017
Letter of Access gained	February 2017
Recruitment and data collection	July 2017 – February 2018
Literature review search and write up	May 2017 – January 2018
Data analysis for research	February 2018
Research report write-up with drafts and feedback	January 2018 – April 2018
Thesis submission	April 2018

Appendix F*: Ethical Approval Letters

1. REC Favourable Opinion Letter


Health Research Authority



Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

22 December 2016

Miss Danielle Harker
Trainee Clinical
Psychologist


Dear Miss Harker

Study title: Initial validation and qualitative analysis of the Short Parallel Assessments of Neuropsychological Status (SPANS) within an intellectual disabilities sample.

REC reference: 
IRAS project ID: 

Thank you for your letter responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

2. HRA Final Approval Letter



Health Research Authority

Miss Danielle Harker
Trainee Clinical Psychologist

Email: hra.approval@nhs.net

[Redacted]
[Redacted]
[Redacted]
[Redacted]
[Redacted]

08 February 2017

Dear Miss Harker,

Letter of HRA Approval

Study title: Initial validation and qualitative analysis of the Short Parallel Assessments of Neuropsychological Status (SPANS) within an intellectual disabilities sample.

[Redacted]
[Redacted]

Sponsor [Redacted]

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS ~~organisations~~ in England.

Appendix B provides important information for sponsors and participating NHS organisations in

Appendix G: SPANS and WAIS-IV Index Summaries

Part A: SPANS Summary (Burgess, 2014)

SPANS Domain	Description/ Summary	Subtests
Orientation Index (ORI)	The ORI measures examinees' orientation to person, time, place and condition, recall of present and past political leadership, and estimation of passage of time.	<ul style="list-style-type: none"> -Orientation: <ul style="list-style-type: none"> <i>Person</i> (name, date of birth, age) <i>Time</i> (of day, day of week, month, year) <i>Place</i> (city and type/name of place) <i>Condition</i> (awareness) <i>Political</i> leadership (present and past Prime Minister) -Time Estimation (how long was duration of testing?)
Attention/ Concentration Index (ACI)	The ACI measures several aspects of attention/concentration, including span or attention capacity, sustained and divided attention with response inhibition, mental control tasks of counting backwards in ones and threes, and mental monetary calculations, adding to the ecological or face validity of the assessment.	<ul style="list-style-type: none"> -Digit Span Forward -Digit Span Backward -Sustained & Divided Listening – Round 1 -Sustained & Divided Listening – Round 2 -Counting Backwards -Monetary Calculations
Language Index (LAI)	The LAI incorporates measures to screen for aphasia, alexia and agraphia disorders, or to otherwise detect language disturbances, with subtests including confrontation naming, repetition, comprehension and free expressive language/verbal reasoning. Brief screenings of reading and writing are also included, again providing an ecologically valid assessment of everyday activities.	<ul style="list-style-type: none"> -Repetition -Naming -Yes/No Questions -Following Directions -Reading -Writing Sentences -Similarities
Memory/ Learning Index (MLI)	The MLI measures memory and learning via several means, including for verbal and visual material. Two 'recall' subtests are composed of 'learning' trials (e.g. repeated lists and associative learning), and two are composed of a single exposure to the material. Three subtests contain a five-minute delay of an intervening	<ul style="list-style-type: none"> -Object Recall -Figures Recall -List Learning -List Recall -List Recognition -Symbol-Word-Paired-Associates

(but unrelated and non-confounding) activity before the recall trial. Ecological validity was included as a feature (e.g. learning a shopping list).

Visuo-Motor Performance Index (VPI)	The VPI measures various visuo-spatial/visuo-perceptual and motor capabilities, including screening for spatial impairment and/or perceptual agnosia. Following a visual screening test, the index includes visual attention and visual recognition memory, copy of geometric figures, visuo-motor coding, spatial and object perception, reading emotion in facial expressions and visual concepts, with 'free-choice' and 'recognition' scoring criteria.	-Object Recognition -Spatial Decision -Unusual Views -Figures Copy -Letter-Number Coding -Figures Recognition -Facial Expressions -3-and-1 Concept Test
Efficiency Index (ECI)	The ECI combines the subtests with a times element, thus evaluating the speed of reacting, thinking, scanning, and visuo-motor movement in unison, for an overall estimate of the efficiency of processing.	-Sustained & Divided Listening – Round 2 -Spatial Decision -Letter-Number Coding -Counting Backwards -Monetary Calculations
Conceptual Flexibility Index (CFI)	The CFI combines two subtests that each possess elements of concept formation, thinking laterally and flexibly, and combining concepts into a superordinate category, with both visual and verbal elements.	-Similarities -3-and-1 Concept Test

Part B: WAIS-IV Summary (Wechsler *et al.*, 2008; 2010)

WAIS Index	Description/ Summary	Subtests
Verbal Comprehension Index (VCI)	This index reflects an individual's ability to understand, use and think with spoken language. It also demonstrates the breadth and depth of knowledge acquired from one's environment. It measures the retrieval from long-term memory of such information.	-Similarities -Vocabulary -Information
Perceptual Reasoning Index (PRI)	This index reflects an individual's ability to accurately interpret, organize and think with visual information. It measures nonverbal reasoning skills and taps into thinking that is	-Block Design -Matrix Reasoning -Visual Puzzles

	more fluid and requires visual perceptual abilities	
Working Memory Index (WMI)	This index reflects an individual's ability to take in and hold information in immediate awareness and then perform a mental operation on that information. It also measures the mental manipulation of number operations.	-Digit Span -Arithmetic
Processing Speed Index (PSI)	This index reflects an individual's ability to process simple or routine visual information quickly and efficiently. It measures visual and motor speed.	-Symbol Search -Coding

Appendix H*: Participant Information Sheet

INFORMATION SHEET



The British Psychological Society
Accredited

This research is for a Psychology training course.



We want to see how people with a learning disability do on some tasks that look at thinking, visual, and language skills.



You will be asked to do different things like look at pictures and remember words.

This may take around one hour.



This research could help with things like:



- Knowing more about people with learning disabilities
- Learning what skills people have and what they find difficult
- Supporting people with learning disabilities with things like planning care



Some people might find some of the tasks hard.

Some people might find the tasks tiring.



Your answers to the tasks will be written on a form.

Your answers will only be used for research.



After the tasks, you will be asked some questions about how they went.

This may take up to 20 minutes.

If you don't want to answer questions, you can say no.



All of the information you give will be kept on a computer with a password.

Or in a locked cabinet.



People who check that research is done properly may access the data from your scores.

Your personal details, like your name, will not be shared.



You can decide not to take part in the research.

This decision will not change your care.

Appendix I: Consent Form



You can also change your mind and have your information taken out of the research before **January 2018**.

After this time, your information will not be able to be taken out.



We will send you a copy of the research when it is finished.



If you need support, you can talk to the person you do the research with.

Or somebody else that you trust.
You can contact the person who is working on this research by email:

██████████

OR ask your psychologist.



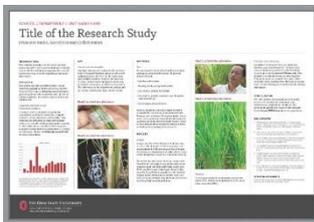
Information about this research will be kept on a computer with a password.

Your name and other personal information will not be used.



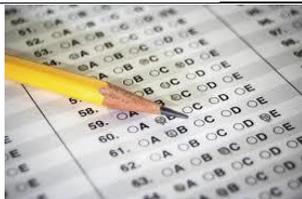
This research will be shared with other people including:

- The psychology team that support you
- The University of Leicester psychology course staff and students
- On a research poster
- Maybe in a journal for research on the internet.



People who check that research is done properly may access the data from your scores.

Your personal details, like your name, will not be shared.



We would also like to use any other scores from tasks you have done in the past, like an IQ test.



It is **your** decision to take part in this research.

If you change your mind, you can ask for your data to be taken out of the research **before January 2018.**



I understand this information.

I understand that I can change my mind before, during, or after this research.



I **agree** that my past scores on tasks can be used.

I **agree** to take part in this research.

Please sign your name here:

.....

Write your name here:

.....



Date:

.....

Appendix J: SPANS Scoring Booklet

1. SUBTEST/INDEX SCORES

Subtest/Index	Raw score	Subtest scaled score
Orientation	/ 20	
Time Estimation	/ 2	
ORI	/ 22	
Digit Span Forward	/ 6	
Digit Span Backward	/ 6	
Sustained and Divided 1	/ 10	
†Sustained and Divided 2	/ 10	
†Counting Backwards	/ 6	
†Monetary Calculations	/ 8	
ACI	/ 46	
Repetition	/ 6	
Naming	/ 12	
Yes/No Questions	/ 6	
Following Directions	/ 6	
Reading	/ 6	
Writing Sentences	/ 5	
†Similarities	/ 12	
LAI	/ 53	
Object Recall	/ 6	
Figures Recall	/ 11	
List Learning	/ 18	
List Recall	/ 6	
List Recognition	/ 12	
S-W P-A	/ 14	
MLI	/ 67	
Object Recognition	/ 3	
†Spatial Decision	/ 12	
Unusual Views	/ 4	
Figures Copy	/ 16	
†Letter-Number Coding	/ 12	
Figures Recognition	/ 3	
Facial Expressions	/ 4	
†3-and-1 Concept Test	/ 16	
VPI	/ 70	
†Sustained and Divided 2	/ 10	
†Spatial Decision	/ 12	
†Letter-Number Coding	/ 12	
†Counting Backwards	/ 6	
†Monetary Calculations	/ 8	
ECI	/ 48	
†Similarities	/ 12	
†3-and-1 Concept Test	/ 16	
CFI	/ 28	

3. ERROR SCORES

Error score	Raw score	Subtest scaled score
Commissions		
Semantic cues		
S-W P-A learning trial errors		
Perceptual naming errors		
Object Recall intrusions		
List Recall intrusions		
Memory intrusions		

4. RESULTS SUMMARY

Name:				
Age:				
Index	Raw score	T-score	Percentile	Confidence interval
ORI				
ACI				
LAI				
MLI				
VPI				
ECI				
CFI				

SCORE INTERPRETATION

Nominal classification	T-score	Percentile	Subtest scaled score
High	≥60	>75	4
Average	41–59	25–75	3
Low	31–40	<25	2
Very low	21–30	<10	1
Extremely low	≤20	<5	0

Appendix K: Interview Schedule

How has it been for you to do the tasks today?

GOOD



OK



BAD



NOT SURE



Prompts: Did it feel good doing the tasks? Did it feel bad? Was it easy to understand? Hard to understand? Fun? What was fun about it? Not fun? What was not fun?

How did you find the tasks?

GOOD



OK



BAD



NOT SURE



Prompts: Was there something that was good? What was good about it? Something that you liked? What did you like about it? Something you did not like? What didn't you like about it? Something difficult? What was difficult about it? Something you wanted to do more of? Things that were easy? What was easy about it? Things that were hard? What was hard about it?

Did any tasks remind of you anything?

Prompts: Did something make you think of other things that you do? Remind you of things you find hard to do? What things? Easy to do? Were some tasks like other things that you do? Like what?

Appendix L: Interview Transcript Extract

Participant 2

Interviewer: So, how has it been for you to do the tasks today?

Responder: Quite easy

Interviewer: Quite easy?

Responder: Because I felt confident because I knew the person.

Interviewer: Ok, so that's made a difference has it?

Responder: Yeah

Interviewer: Did it feel good doing the tasks, or bad, or...?

Responder: I felt it was a good thing because it's gonna help others in the long run

Interviewer: Was anything fun?

Responder: Yeah, the bit where I had to remember the shopping list.

Interviewer: Were there any bits that were hard to understand?

Responder: No because... I thought it was pretty easy, whereas before I'd find it really hard...

Interviewer: What, when you've done one before?

Responder: Yeah, like before I had help and stuff.

Interviewer: Was that a long time ago?

Responder: Yeah

Interviewer: What do you think the difference was?

Responder: I think it's knowing the person [who you are doing the test with]

Interviewer: Were there things that you felt you did good on?

Responder: Yeah there's things where I like, I could pick up really quickly but then there were some things I like... struggled on... like the maths ones were hard, I couldn't do them very well, like taking away numbers.

Interviewer: Did anything that we did remind you, of, kind of things that you do in day to day life?

Responder: Yeah my maths... it helped me realise what I couldn't do with my maths, like I couldn't take away properly. But I could add.

Interviewer: Were there things that you found really easy?

Responder: Yeah, my date of birth (laughs), and there was a bit in there about... I felt that spanner thing was quite easy as well cuz' I could remember what it was.

Interviewer: Did you like anything in particular about any of the tasks? Did you like one task more than another or...?

Responder: I, I liked it all because it was actually, I thought it was quite good.

Interviewer: What was good about it?

Responder: That I could remember some of the pictures and some of the way things were put.

Interviewer: Were the instructions alright to understand?

Responder: Yeah, the instructions were quite easy (laughs).

Interviewer: Great thank you that's really helpful to know, do you have any other comments about the tasks we've done today?

Responder: Just that I felt quite comfortable being around you, the fact you know, you kinda know me...

Interviewer: Yeah...

Responder: So it's really helped me

Interviewer: That's really good to hear...

Responder: Because I felt comfortable coming here because I knew it was you, but say if it was someone else I didn't know, I would be bricking myself. I'd be like...now what are we meant to do.

Interviewer: Yeah that's something that we might suggest, that it could be helpful if you knew the person doing the assessment.

Responder: I feel like it'd be helpful if you knew the person, cuz' if you go into it, and do it with a stranger, I wouldn't of done half as well cuz' I'd be too nervous.

Appendix M*: Statement of Epistemological Position

A 'critical-realist' epistemological stance was taken by the researcher. This position recognises the importance of subjective meaning in relation to 'reality', and of behavioural, observable phenomena that may support explanation and interpretation (Sayer, 2004). Critical realism proposes a 'stratified ontology' that accommodates ideas from positivist and constructionist positions in order to hold a "maximally inclusive" position (Bhaskar & Danermark, 2006). This meta-theory is well suited to mixed methods designs because it purports that research methodologies should be driven by the nature of the phenomena being studied and what one hopes to learn about this (Sayer, 2000).

Critical-realism attends to the *context* in which phenomena are studied, maintaining a focus on the specific conditions of research and the processes by which situations occur. This supported the researcher to remain critical of the situation in which the research was taking place. A core principle of critical-realism is that by increasing understanding of the underlying mechanisms which cause or contribute to social phenomenon, transformative practice can take place (Bhaskar, 2008). This philosophical underpinning aligned with the quality of life theory and research developments of the literature review and was at the centre of the current research aims.

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Bhaskar, R. (2008). *A realist theory of science*. (3rd edition). London: Verso.

Bhaskar, R. & Danermark, B. (2006). Metatheory, Interdisciplinarity and Disability Research: A Critical Realist Perspective. *Scandinavian Journal of Disability Research*, 8(4), 278.

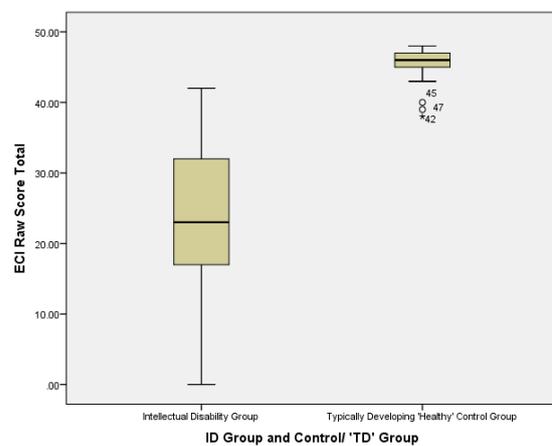
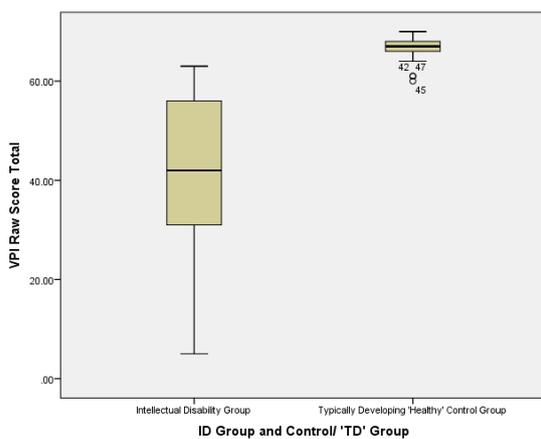
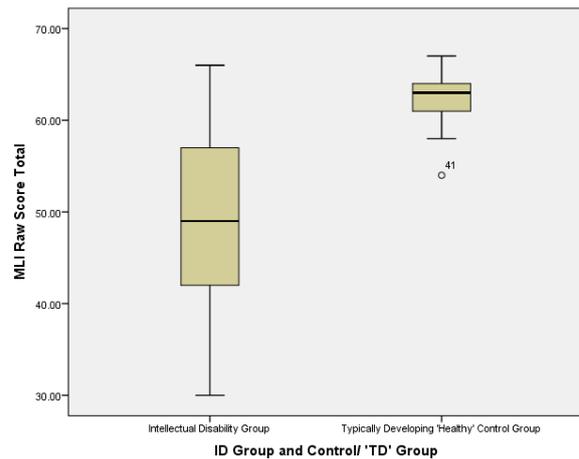
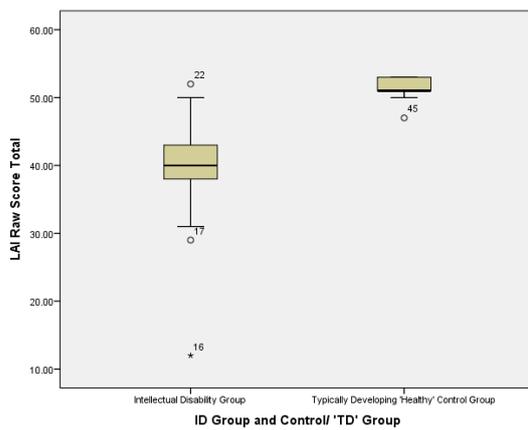
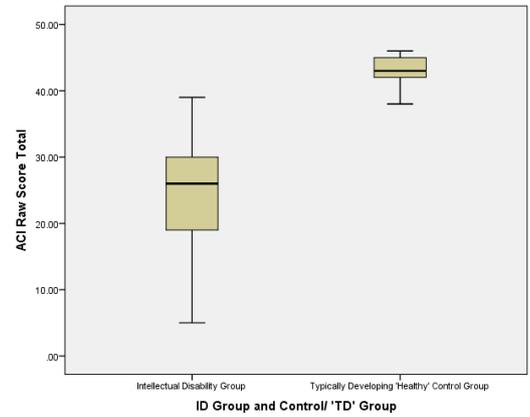
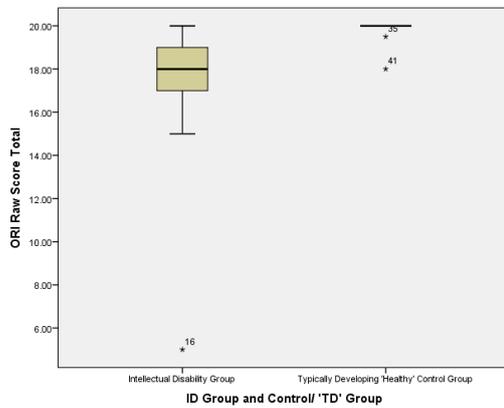
Sayer, A. (2004). Foreword: why critical realism? In: S. Fleetwood, & S. Ackroyd, S. (Eds.) *Critical Realist Applications in Organisation and Management Studies* (pp. 6-20). London: Routledge.

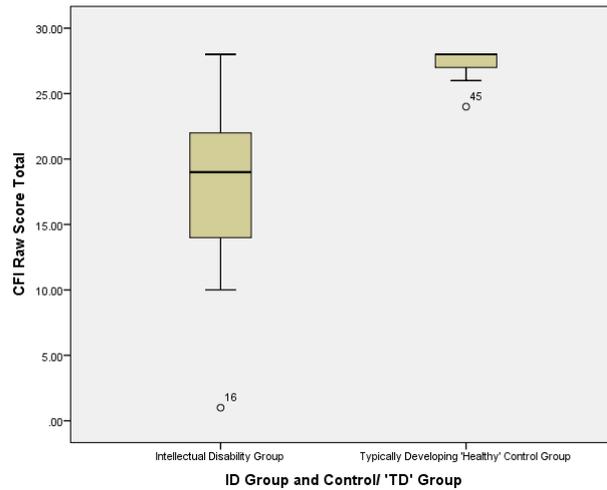
Sayer, A. (2000). *Realism and social science*. London: Sage.

Appendix N: SPSS Output

Part 1: Parametric Tests of Normality –Assumption Tests

1.1 Box-plots illustrating distribution for each SPANS domain for separate groups:





1.2 Kolmogorov-Smirnov test of normal distribution:

Tests of Normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
ORI Raw Score Total	.286	58	.000	.587	58	.000
ACI Raw Score Total	.191	58	.000	.887	58	.000
LAI Raw Score Total	.231	58	.000	.828	58	.000
MLI Raw Score Total	.198	58	.000	.868	58	.000
VPI Raw Score Total	.213	58	.000	.824	58	.000
ECI Raw Score Total	.194	58	.000	.863	58	.000
CFI Raw Score Total	.228	58	.000	.812	58	.000

a. Lilliefors Significance Correction

The scores on the ORI, $D(58) = 0.28$, $p < 0.001$, ACI, $D(58) = 0.19$, $p < 0.001$, LAI, $D(58) = 0.23$, $p < 0.001$, MLI, $D(58) = 0.19$, $p < 0.001$, VPI, $D(58) = 0.21$, $p < 0.001$, ECI $D(58) = 0.19$, $p < 0.001$, and CFI $D(58) = 0.22$, $p < 0.001$, were all significantly non-normal.

When this test was calculated for the ID and TD group separately, the following output was produced:

Tests of Normality							
	ID Group and Control/ 'TD' Group	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
ORI Raw Score Total	Intellectual Disability Group	.235	29	.000	.676	29	.000
	Typically Developing	.521	29	.000	.245	29	.000
	'Healthy' Control Group						
ACI Raw Score Total	Intellectual Disability Group	.111	29	.200*	.956	29	.258
	Typically Developing	.163	29	.047	.925	29	.041
	'Healthy' Control Group						
LAI Raw Score Total	Intellectual Disability Group	.191	29	.008	.878	29	.003
	Typically Developing	.213	29	.002	.823	29	.000
	'Healthy' Control Group						
MLI Raw Score Total	Intellectual Disability Group	.091	29	.200*	.971	29	.593
	Typically Developing	.160	29	.055	.932	29	.061
	'Healthy' Control Group						
VPI Raw Score Total	Intellectual Disability Group	.148	29	.105	.938	29	.091
	Typically Developing	.289	29	.000	.854	29	.001
	'Healthy' Control Group						
ECI Raw Score Total	Intellectual Disability Group	.163	29	.047	.946	29	.146
	Typically Developing	.227	29	.001	.819	29	.000
	'Healthy' Control Group						
CFI Raw Score Total	Intellectual Disability Group	.104	29	.200*	.952	29	.209
	Typically Developing	.413	29	.000	.566	29	.000
	'Healthy' Control Group						

*. This is a lower bound of the true significance.

1.3 Skewness and Kurtosis: z-score conversion values

Group	SPANS Domain	Skewness	Kurtosis
Intellectual disability group	ORI	-7.30*	15.56*
	ACI	-1.47	0.04
	LAI	3.80*	0.41
	MLI	-0.43	-0.69
	VPI	-0.61	-0.69
	ECI	-0.65	-0.54
	CFI	-1.87	2.01*
Typically developing group	ORI	-11.41*	29.95*
	ACI	-1.31	-0.71
	LAI	-2.66*	3.49*
	MLI	-2.34*	2.29*
	VPI	-2.77*	1.47
	ECI	-3.62*	2.77*
	CFI	-6.01*	9.19*

* = significant at the $p < 0.05$ level (Field, 2009)

Part 2: Assumptions for MANOVA Tests

2.1 Multivariate normality – Mahalanobis distance

Residuals Statistics ^a					
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.52	2.04	1.50	.433	58
Std. Predicted Value	-2.272	1.247	.000	1.000	58
Standard Error of Predicted Value	.049	.240	.094	.042	58
Adjusted Predicted Value	-.85	2.05	1.48	.528	58

Residual	-.739	.483	.000	.259	58
Std. Residual	-2.669	1.746	.000	.937	58
Stud. Residual	-2.767	3.330	.022	1.073	58
Deleted Residual	-.794	1.850	.020	.381	58
Stud. Deleted Residual	-2.977	3.737	.020	1.119	58
Mahal. Distance	.812	41.873	6.879	7.683	58
Cook's Distance	.000	4.200	.093	.550	58
Centered Leverage Value	.014	.735	.121	.135	58

a. Dependent Variable: ID Group and Control/ 'TD' Group

Mahalabnois distance identified a maximum value of 41.873; critical value table indicated that values that exceed 22.46 (Penny, 1996) reflect outliers that compromise multivariate normality. Three values in the dataset exceeded the critical value.

2.2 Homogeneity of Covariance Test - Box's M Test

Box's Test of Equality of Covariance Matrices^a

Box's M	317.468
F	9.816
df1	28
df2	10927.623
Sig.	.000

Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.

a. Design: Intercept + Group

2.3 Test of Multicollinearity

		Correlations						
		ORI Raw	ACI Raw	LAI Raw	MLI Raw	VPI Raw	ECI Raw	CFI Raw
		Score	Score	Score	Score	Score	Score	Score
		Total	Total	Total	Total	Total	Total	Total
ORI Raw Score Total	Pearson	1	.671**	.778**	.672**	.745**	.722**	.717**
	Correlation							
	Sig. (2-tailed)		.000	.000	.000	.000	.000	.000
	N	58	58	58	58	58	58	58
ACI Raw Score Total	Pearson	.671**	1	.883**	.840**	.918**	.960**	.873**
	Correlation							
	Sig. (2-tailed)	.000		.000	.000	.000	.000	.000
	N	58	58	58	58	58	58	58
LAI Raw Score Total	Pearson	.778**	.883**	1	.843**	.868**	.903**	.849**
	Correlation							
	Sig. (2-tailed)	.000	.000		.000	.000	.000	.000
	N	58	58	58	58	58	58	58
MLI Raw Score Total	Pearson	.672**	.840**	.843**	1	.839**	.851**	.733**
	Correlation							
	Sig. (2-tailed)	.000	.000	.000		.000	.000	.000
	N	58	58	58	58	58	58	58
VPI Raw Score Total	Pearson	.745**	.918**	.868**	.839**	1	.970**	.890**
	Correlation							
	Sig. (2-tailed)	.000	.000	.000	.000		.000	.000
	N	58	58	58	58	58	58	58
ECI Raw Score Total	Pearson	.722**	.960**	.903**	.851**	.970**	1	.885**
	Correlation							
	Sig. (2-tailed)	.000	.000	.000	.000	.000		.000
	N	58	58	58	58	58	58	58

CFI Raw	Pearson	.717**	.873**	.849**	.733**	.890**	.885**	1
Score Total	Correlation							
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	
	N	58	58	58	58	58	58	58

** . Correlation is significant at the 0.01 level (2-tailed).

Part 3: Non-Parametric Tests

3.1 Wilcoxon Signed-Ranks Tests (ID Group Only)

3.1.1 S-W-P-A and List Learning Subtest Comparisons:

Test Statistics^a

	RankSWPA - Rank of ListLearning
Z	-2.067 ^b
Asymp. Sig. (2-tailed)	.039

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.

3.1.2 S-W-P-A and Object Recall Subtest Comparisons:

Test Statistics^a

	Rank of SWPA - Rank of ObjectRecall
Z	-.422 ^b
Asymp. Sig. (2-tailed)	.673

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

3.1.3 Object Recall and List Learning Subtest Comparisons:

Test Statistics^a

	Rank of ListLearning - Rank of ObjectRecall
Z	-.054 ^b
Asymp. Sig. (2-tailed)	.957

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

3.2 Between Group Analyses

3.2.1 Moses Extreme Reactions Test (Ranked ORI SPANS Domain only):

Test Statistics^{a,b}

	Rank of RSORI
Observed Control Group Span	44
Sig. (1-tailed)	.000
Trimmed Control Group Span	41
Sig. (1-tailed)	.001
Outliers Trimmed from each End	1

a. Moses Test

b. Grouping Variable: ID Group and Control/ 'TD' Group

3.2.2 Mann-Whitney-U Tests (all other SPANS domains):

Test Statistics^a

	Rank of RSORI
Mann-Whitney U	59.500
Wilcoxon W	494.500
Z	-6.059
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and
Control/ 'TD' Group

Test Statistics^a

	Rank of RSACI
Mann-Whitney U	1.500
Wilcoxon W	436.500
Z	-6.529
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Test Statistics^a

	Rank of RSLAI
Mann-Whitney U	21.000
Wilcoxon W	456.000
Z	-6.258
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Test Statistics^a

	Rank of RSMLI
Mann-Whitney U	72.500
Wilcoxon W	507.500
Z	-5.427
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Test Statistics^a

	Rank of RSVPI
Mann-Whitney U	7.000
Wilcoxon W	442.000
Z	-6.459
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Test Statistics^a

	Rank of RSECI
Mann-Whitney U	5.000
Wilcoxon W	440.000
Z	-6.483
Asymp. Sig. (2-tailed)	.000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Test Statistics^a

	Rank of RSCFI
Mann-Whitney U	38.500
Wilcoxon W	473.500
Z	-6.140

Asymp. Sig. (2-tailed) .000

a. Grouping Variable: ID Group and Control/ 'TD' Group

Appendix O: Initial Thematic Analysis Mind Map (showing four main themes)

