Quality of Life in Adults with Intellectual Disability

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Thesis submitted in fulfilment of the degree of
Doctor of Philosophy

June 2024

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Declaration

I, Helen Buxton, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Enhancing Quality of Life (QoL) is a key goal in supporting people with intellectual disability. A psychometrically sound measurement tool is essential to evaluate the effectiveness of services and interventions based on their impact on QoL. The Personal Outcomes Scale (POS) was developed to measure the QoL of adults with intellectual disability, but the psychometric properties of the English language version have never been tested. Sensitivity to change of POS in any language has not been tested.

My PhD investigated the measurement properties of POS for adults (18+) with intellectual disability in the UK. Using data from 310 adults, confirmatory factor analysis was conducted. Convergent and divergent validity were assessed with data from 100 participants, and sensitivity to change was evaluated with data from 83 participants collected 12 months apart. Analyses also compared health and social care costs to POS scores.

The factor structure did not confirm the theoretical QoL model. A significant proportion of variance in POS scores was due to interviewer effects. POS showed moderate correlation with convergent and divergent measures and an independent association with leisure engagement. However, there was low probability that POS was sensitive to change over 12 months. Individuals who experienced better QoL did not incur higher or lower costs than those with poorer QoL

Further research is needed before POS can be recommended as outcome measure for research and evaluation. My studies revealed gaps in knowledge regarding the nature of change in QoL. Contextualisation of findings in relevant theory suggest

QoL may not have utility as impact measure. Interventions should be evaluated with discrete measures which are directly linked to activities and known to be sensitive to change.

Impact Statement

It is widely accepted that enhancing QoL should be the overarching goal of the provision of care and support for adults with intellectual disability. However, there is no universally accepted method to measure changes in QoL that has been tested for use with this population. Identifying such a measure would enable the evaluation of interventions and approaches based on what truly matters to individuals. This information could inform decision making with regards to policies, service provision and cost effectiveness.

In this thesis I have assessed the psychometric properties of a scale designed to measure QoL of adults with intellectual disability. Data presented in this thesis constitute the first assessment of sensitivity to change of any QoL measure designed for use with this population, and the first study to explore the direct association between QoL and costs of health and social care. By rigorously testing POS, I uncovered significant issues with its reliability, sensitivity to change, and overall utility as a QoL measure. These findings emphasize the need for more precise tools tailored to the specific intervention under evaluation, incorporating both externally verifiable objective measures and subjective well-being assessments. I highlight the need to expand thinking on inclusive practices to increase the pool of individuals who can self-report.

Research impact: My study assessing the factor structure of POS (chapter three) has been published in an international peer-reviewed journal (Buxton et al., 2024). I am preparing the other three studies in my PhD for publication. My study on sensitivity to change (chapter five) is the first assessment of this property for any QoL scale designed for use with adults with intellectual disability. Publication will help to raise awareness of the critical importance of considering sensitivity to change in QoL measures.

Dissemination: To ensure that my research reaches a wider audience I have presented my findings at various conferences, including the 14th Congress of European Association for Mental Health in Intellectual Disability (EAMHID) 2023, and at Seatle Club Conference 2023. Additionally, I have raised awareness of the importance of QoL for adults with intellectual disability among researchers in training by delivering lectures to students on the MSc Mental Health Research at UCL. I have also collaborated with academics and practitioners worldwide to contribute to the content for a POS handbook.

Contributing to change in practice: My PhD has been conducted in collaboration with Mencap. I have developed an interviewer guide to refine and further standardise POS items. Preliminary findings from my study have been shared with decision makers at Mencap to help inform decisions about use of POS as evaluation metric. I am exploring further avenues to disseminate findings through the organisation, such as a workshop with key stakeholders.

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Acknowledgements

I am very grateful for the supportive relationship I've had with my primary supervisor Vaso Totsika. She has been approachable, engaged and insightful and I thank her for helping me develop my ideas throughout this PhD. I am also grateful for input from my other supervisors, Manuel Gomes for his guidance and support particularly with the costing study, and Zac Taylor at Mencap for his support to implement data collection and understand implications for practice.

I have had valuable input from my thesis committee chair, first through Afia Ali and then Rafael Gafoor. Their guidance has helped shaped this project.

I am grateful to my funders the Economic Social Research Council (ESRC) through the UCL, Bloomsbury and East London Doctoral Training Partnership, and Mencap.

This research would not have been possible without the commitment of staff at Mencap to data collection. Particularly Ellen Kennedy, Alice Leuenberger and Lee Dunn who were so instrumental in supporting with the development of data collection procedures. Maria McClean-Brown and Kelly SweetingWeston gave their time and enthusiasm to support with interviews. I would also like to thank the staff who work in residential services. I am aware that staff were overstretched in the aftermath of the COVID-19 pandemic and making time for research activities was a significant ask.

I'd like to thank all the adults with intellectual disability who gave up their time to take part in interviews, welcomed me into their homes and talked about their lives. Thank you all for the joy you have added to this project.

Elements of my PhD were co-produced with adults with intellectual disability. I would like to thank Vijay Patel and Dan Newton for their input into the development of participant information materials and for involvement from Mencap’s Inclusion Consultants.

Outside of UCL and Mencap I would like to thank my family for their support. Especially my mum for listening to me vent on the phone. I am very lucky to have an excellent circle of friends. Special thanks to those who aid and abet my many obsessions and have kept me never short of distractions throughout the past four years.

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Chapter 1 Introduction

Quality of Life and people with intellectual disability

The enhancement of Quality of Life (QoL) is often cited as the overarching goal of policies, services and interventions designed to support people with intellectual disability. When a person is supported to have a good QoL they are likely to be enabled to make their own choices, to spend their time doing things they enjoy and can learn from, and to be connected to the people and communities which are important to them. This emphasis on QoL underscores a shift away from merely meeting basic needs towards empowering individuals to lead fulfilling lives aligned with their personal aspirations.

There is objective evidence that conditions of life are generally better for people with intellectual disability today than they were 50 years ago (Felce, 2017). It is no longer acceptable for people with intellectual disability to be segregated away from society in large institutions (Chowdhury & Benson, 2011), and the concept of person-centred support is embedded in contemporary social care policies (e.g. Care Act 2014 (The Care Act, 2014), People at the Heart of Care 2021 (Department of Health & Social Care, 2021). Yet there have been incidents of systematic abuse of people with intellectual disability uncovered in the UK in recent history (Willis, 2020), and over 2000 people with intellectual disability or autism remain living in long-stay hospitals (Glasby et al., 2024).

Beyond these stark injustices there is also evidence to suggest that although most people with intellectual disability now live in community settings this is not synonymous with being part of a community (Felce, 2017). The day-to-day experiences of many people with intellectual disability reveal persistent barriers to employment, social isolation and inadequate access to essential services and support networks (McCarron et al., 2019).

A focus on QoL demands that provision considers the whole person and that support both meets the person's needs and provides opportunities for the person to enrich their life (Śişka & Beadle-Brown, 2021). To be fully operationalised QoL must be integrated into service design, ensuring that support is tailored to each person's goals (Schalock et al., 2002). Enhancing QoL should be ingrained into staff working patterns, enabling people to actively engage in all aspects of their lives (Bigby et al., 2012). Measuring an individual's QoL serves as a mechanism to evaluate care provision based on personal significance. This data provides valuable insights that can inform and refine service design and staff practices, thereby completing a continuous feedback loop aimed at enabling people to live the lives they wish (Claes, van Hove, et al., 2012).

However, although there have been many approaches to operationalise QoL measurement in the field of intellectual disability, these efforts often focus on evaluating QoL in relation to services provided – for example the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al., 2012). Although such evaluations yield useful data, they fall short of capturing the full scope of an individual's wishes and their current state in relation to those wishes. There is a need to identify and test a QoL measure which evaluates all aspects of life that comprise QoL from the perspective of the individual.

People with intellectual disability in the UK

There are over 1.2 million people in England with intellectual disability (Kennedy et al., 2021). The term Intellectual Disability is defined as being:

“..characterized by significant limitations both in intellectual functioning and adaptive behaviour which covers many everyday social and practical skills.”(American Association on Intellectual and Developmental Disabilities, 2021). These limitations need to be present in the developmental period. In the UK, the term ‘learning disability’ is most commonly used; though internationally the term is associated with specific learning disorders (i.e., persistent difficulties in reading, writing, arithmetic, or mathematical reasoning skills (American Psychiatric Association, 2013). The term intellectual disability will be used throughout this paper.

There is no singular cause for intellectual disability, but the disability occurs when a person’s brain development is affected, either before the person is born, during their birth or in early childhood. This can be a result of genetic conditions (Karam et al., 2015); the mother being ill during pregnancy (Leonard et al., 2006); complications during birth (Langridge et al., 2013); or illness during early childhood (e.g. meningitis) (Bedford et al., 2001). However, the cause of disability has limited relevance to the day to day lives of people with intellectual disability. Of more relevance is developing an understanding of how the disability impacts the person’s capacity to function independently and the personalized supports the person needs to lead a more successful and satisfying life (American Association on Intellectual and Developmental Disabilities, 2021).

For a person to be diagnosed with intellectual disability, an assessment of their intellectual functioning and their adaptive behaviour skills is required (Tassé et al., 2016). Adaptive behaviour is defined as conceptual, social and practical skills which have been learnt and are performed by people in their everyday lives; and these have been measured on standardized scales since the 1960s (Tassé et al., 2012). Intellectual functioning is measured by IQ test (Tassé et al., 2016). Until 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM-4) still used the term mental retardation; and diagnosis prioritised an IQ score of less than 70; prior to an assessment of adaptive skills (Harris, 2013). DSM-5 updated the terminology used to Intellectual Disability Disorder and give equal weighting to both deficits in intellectual functions and adaptive behaviour for diagnosis (Harris, 2013). The DSM-5 classifies four levels of intellectual disability: mild, moderate, severe and profound. Differentiation between level of intellectual disability is largely dependent on the degree of support a person requires, and how independently they are able to live. (Boat et al., 2015).

People with intellectual disability have a higher likelihood than the general population to have: additional neurodivergent conditions such as Attention Deficit Hyperactive Disorder (ADHD) (Al-Khudairi et al., 2019) or Autism Spectrum Disorder (ASD) (Sappok et al., 2010); mental health conditions such as depression or anxiety (Cooper et al., 2015); and other health conditions such as epilepsy, diabetes and asthma (Liao et al., 2021). People with intellectual disability also have greater likelihood of experiencing inequalities; they are more likely than the general population to die younger (University of Bristol, 2020); to be unemployed (Kennedy et al., 2021), and to be more reliant on long term social care support (NHS Digital, 2017). Although these statistics can help to identify the challenges that people with intellectual disability face, they do not necessarily help to understand how to overcome those challenges.

Just as people with intellectual disability face individual challenges, they also have individual strengths and capabilities which can be built upon as the basis of their support. This approach enables the expression of interaction between the person with intellectual disability and the environment. People with intellectual disability are positioned as causal agents in their lives, setting goals, expressing choices and preferences, and making decisions, as long as they are provided the opportunities and systems of support necessary to develop and express these skills and attitudes (Shogren et al., 2006). Rather than identifying what a person cannot do, efforts to understand people with intellectual disability aim to identify what support each individual needs to be more successful in life activities (Thompson et al., 2014). These approaches are broadly referred to as person-centred support. The overarching goal of these approaches is often the enhancement of QoL.

Factors associated with variance in QoL of adults with intellectual disability

There exists a substantial body of cross-sectional research exploring factors associated with QoL of people with intellectual disability. Because there is variation in the way that QoL is defined and measured across studies - including variation on who reports (self or proxy) - findings from studies are not directly comparable. However, evidence from multiple studies supports the finding that personal characteristics are associated with variance in QoL. Specifically the severity of a person’s intellectual disability (Claes, van Hove, et al., 2012; Knüppel et al., 2018; Lombardi et al., 2016; Nota et al., 2007; Perry & Felce, 2003; Snoeijen-Schouwenaars et al., 2019) and the level of their adaptive behaviour skills (Knüppel et al., 2018; Lombardi et al., 2016; Perry & Felce, 2005b; Simões, Santos, Biscaia, et al., 2016) are associated with variance in QoL scores.

There is also evidence of an important association between health and mental health status and QoL score. Studies have found that both the presence of health problems (Van de Woestyne et al., 2022), and self-reported heath status (Rand &

Malley, 2017; Simões & Santos, 2016a) are associated with variance in QoL. The presence of impaired mental health has been evidenced through symptoms of anxiety/ depression (Rand & Malley, 2017); psychological distress (Endermann, 2013); and psychiatric symptoms (Knüppel et al., 2018; Koch et al., 2015), all of which have been found to be associated with reduced QoL. In addition, the presence of behavioural issues often thought to stem from unmet need in relation to mental or physical health needs have been found to be associated with reduced QoL (Knüppel et al., 2018; Koch et al., 2015).

There is evidence that modifiable factors in a person's life also mediate QoL. Since the 1980s there has been widespread closure of institutions and move to community living. This has created the opportunity for quasi-experimental study designs to compare pre-post community living conditions and their relation to QoL outcomes. Two systematic reviews have synthesised the findings of multiple studies which collected data from adults as they went through this transition period (Chowdhury & Benson, 2011; McCarron et al., 2019). Overall, community living was found to have a positive impact on QoL in both reviews, although the earlier review concluded that QoL tended to plateau after one year of living in the community (Chowdhury & Benson, 2011). The mechanisms by which living in the community results in better QoL were community integration, access to events and services and the individual's personal choice to decide how to spend their time (Chowdhury & Benson, 2011). Both reviews position staff-directed support as a critical enabler to activate these mechanisms (Chowdhury & Benson, 2011; McCarron et al., 2019). These findings are echoed in cross sectional studies which have demonstrated evidence of association between QoL and living arrangements (Claes, van Hove, et al., 2012; Felce et al., 2011; Neely-Barnes et al., 2008), social support systems

(Emerson & Hatton, 2008) (Lunsky & Benson, 2001), self-determination (Lachapelle et al., 2005; Neely-Barnes et al., 2008) , daytime activities (Felce et al., 2011; Simões & Santos, 2016b) (Knüppel et al., 2018) and staff directed support strategies (Claes, van Hove, et al., 2012; Lombardi et al., 2016; Perry & Felce, 2005a).

Approaches to the measurement of QoL of adults with intellectual disability

The findings discussed above are based on diverse methods to measure QoL, and the different methods used can limit the comparability of findings. The provision of adult social care encompasses wide ranging goals, and it is important that measures of QoL incorporate evaluation of a wide range of outcomes to account for this. Some studies have taken the approach of using a battery of standardised measures of constructs thought to be associated with QoL to capture this range e.g. (Endermann, 2013; Felce et al., 2011; Neely-Barnes et al., 2008). Examples of constructs measured include: choice making, community involvement, social networks, participation in activities of daily living (Felce et al., 2011). However, this approach requires the collection of large amounts of data and it is not clear what conclusions can be drawn when data are collected across multiple measures which do not always move in the same direction (Felce, 2017). In addition, the choice of measures used differs from study to study and this impedes comparability of findings. In place of combining multiple measures to approximate QoL, researchers have attempted to develop standardised measures of QoL. However, under the broad umbrella of QoL, not all standardised tools are designed to measure the same construct and it is important to understand the limits of the scope of each tool.

The concept of health related QoL (HrQoL) has sometimes been used as outcome measure in studies involving adults with intellectual disability e.g. (Hunter et al., 2020; Strydom et al., 2020). Typically, assessment of HrQoL involves a standardised measure which evaluates domains of health (defined as physical, psychological and social (World Health Organization, 1995)) such as the EQ-5D-Y (Ravens-Sieberer et al., 2010).

However, improving health is not the main goal of services designed to support people with intellectual disability. These services go beyond health and seek to support individuals to live as full a life as possible, and aspects such as autonomy, social inclusion, quality of relationships and subjective well-being require consideration. HrQoL measures do not have a broad enough scope to capture all the domains of QoL which service provision for people with intellectual disability is designed to affect. An empirical comparison of well-being measures with HrQoL measures confirmed that health has limited overlap with measures of subjective well-being (Mukuria et al., 2016).

A different approach to valuing outcomes from social care is offered through the Adult Social Care Outcomes Framework (ASCOF): a suite of measurement tools designed to assess social care related QoL (SCrQoL) (Netten et al., 2012). The instruments are developed for use in economic evaluation of social care e.g. (Longo et al., 2023). An easy-read version of the measure has been developed and tested for use with adults with mild-moderate learning disability (Rand et al., 2020). However, the tool is only designed to evaluate areas of QoL sensitive to outcomes of social care services, therefore domains of health and emotional well-being are not included in the measure. The measure has been developed through a top-down approach through consultation with experts. It is therefore a measure designed to be sensitive to outcomes of interest for policy and intervention, but not those outcomes identified as most relevant by the person themselves (Bowling, 2014). ASCOF has been criticised as measuring outputs rather than outcomes and failing '*to develop an understanding of what it is that matters to individuals and how they wish to live their life*' (Institute of Public Care & Oxford Brookes Univerity, 2020). As such neither SCrQoL nor HrQoL instruments capture the full range of impact that services and interventions for people with intellectual disability are designed to effect and are not sufficient to evaluate the broad scope of interventions designed to support people with intellectual disability (Benedetto et al., 2023).

The Care Quality Commission (CQC) has recently operationalised the QoL construct through the development of a QoL framework and tool (Care Quality Commission, 2021). The tool evidences QoL based on observation, discussion with staff, and documentation (Care Quality Commission, 2021). The framework is innovative as it evaluates services based on how they support an individual to achieve the things that matter to them. However, the individual's QoL is only assessed and judged by criteria external to their subjective experience.

In addition to these approaches which consider QoL in relation to health or services, other standardised measurement tools have been designed to evaluate an individual's global QoL based on the things which matter to the person. Examples of some of these measures include the Quality-of-Life Questionnaire (QOLQ) (Schalock & Keith, 2004), INICO-FEAPS (Gomez et al., 2015), the Personal Outcomes Scale (POS) (Claes, van Hove, et al., 2012), the Comprehensive QoL scale (ComQoL-ID) (Cummins, 1991). To understand the relative strengths and limitations of these tools it is necessary to understand the methodological issues inherent in the theoretical construct of QoL and the specific accessibility issues the construct presents when used to measure QoL of people with diverse range of communication and comprehension capacities.

Methodological issues in the definition and measurement of QoL of people with intellectual disability

QoL is a term used in everyday life and the concept is widely understood. However, the concept can incorporate many different things to different people, and such a catch-all conceptualisation is not well-suited to academic research (Gill & Feinstein, 1994). Academically there have been many attempts to theoretically define QoL, but these tend to divert depending on the context they were developed for or the utility they were developed for.

In general, theorists of QoL do agree that QoL is the product of an individual's appraisal of all aspects of their life. As such, QoL is multi-dimensional – models of QoL need to incorporate domains which together comprise the totality of a person's life (Felce & Perry, 1995; Schalock et al., 2002). People with intellectual disability need to be involved in the development of models to define QoL, however the final model should be applicable to all people and not considered a model specific to people with intellectual disability (Schalock et al., 2002). The domains which constitute QoL are considered to be universally applicable to all people. However, the individual's appraisal of each domain is influenced by a person's culture and their own value system, expectations and aspirations (Schalock, 2004). Likewise, the relative value placed on one domain over another will be specific to the person and may change over time as a person's priorities change (Schalock et al., 2002). For the individual the result of this personal life appraisal will be felt through their state of well-being. It follows that any measurement tool designed to capture this process of personal appraisal of objective conditions is dependent on capturing data directly from the individual whose quality of life is being assessed (Cummins, 2002a).

However, QoL is distinguished from well-being, which - although a domain of QoL- is not broad enough to capture the whole construct. Because QoL is an appraisal of life, the concept includes both the objective conditions of life (e.g. the quality of a person’s home, the size of their social network, the frequency with which they do things they enjoy) as well as their subjective evaluation of those conditions (e.g. how they feel about their home, social life, activities) (Felce & Perry, 1995). Well-being is often defined as being purely subjective – although it should be noted that consensus on the definition of well-being is as elusive as consensus of the definition of QoL and these terms are often used interchangeably (Jarden & Roache, 2023). However, there is compelling evidence that measures of satisfaction or subjective well-being are relatively static over time (Diener et al., 2013). There is concern that evaluation which is based on a person’s own appraisal of their well-being will not be sensitive enough to detect when objective conditions fall below acceptable levels (Hatton & Ager, 2002).

Previous research has only been able to demonstrate a weak relationship between a person’s satisfaction and the objective externally verifiable conditions of their life (Cummins, 1995). A systematic review of satisfaction measures used globally in the general population found that change in satisfaction measures is unlikely to be detected in periods under five years (Diener et al., 2013). The review also found that multi-item measures of satisfaction demonstrated greater stability over time than single item measures (e.g. on a scale on 1-10 how satisfied would you say you are with your life these days). The stability of subjective well-being has been described in detail by Cummins (Cummins, 2016). He proposes a psychological mechanism termed homeostasis of mood, whereby individuals have pre-determined ‘set points’ to which their moods have a strong likelihood to return irrespective of objective experience. As such, a person may find ways to make the best of a bad situation and therefore not report any level of dissatisfaction with their objective circumstances (Cummins, 2016). Cummins argues that this does not preclude subjective well-being from utility as a metric by which to evaluate service provision, as there will be times when objective conditions change to such a degree that the homeostatic mechanism fails, and subjective well-being will change accordingly (Cummins, 2001). He hypothesises that people with intellectual disability may be more likely to experience homeostatic failure as their resilience is tempered by the constant background of challenge they face due to their disabilities (Cummins, 2001). Hatton and Eger have countered that this justification creates circular reasoning (Hatton & Ager, 2002). If a drop in subjective well-being is only to be expected once a person has undergone conditions aversive enough to cause failure of the homeostatic system, it seems more logical to measure externally verifiable circumstances as they will provide earlier warning of unsatisfactory conditions (Hatton & Ager, 2002).

In addition to the influence of homeostasis of mood, there are concerns that the use of measures of subjective well-being with people with intellectual disability may introduce bias. People with intellectual disability may have limited experience of life circumstances and they therefore may have low expectations of what they are entitled to (Hatton, 1998). This may translate as relatively high satisfaction with conditions which would objectively be considered as poor. Some research indicates low reliability of self-report scales among people with intellectual disability due to acquiescence bias (e.g. more likely to say yes), or recency bias (e.g. more likely to choose the last option provided) (Hatton & Ager, 2002; Russell et al., 2018). In addition to these considerations there are also a sub-section of the population of people with intellectual disability who do not have capacity to provide their own answers to standardised questions regarding their subjective well-being and satisfaction (Hatton, 1998).

Proxy measures are often used in place of self-report. However, there is substantial evidence to suggest that proxy report is not directly comparable to self-report (Cummins, 2002a; Perry & Felce, 2002). Research from the general population has demonstrated that the assessment of QoL varies dependent on who the rater is. Individuals tend to rate their own QoL as greater than an observer rates their QoL (Shogren, Bonardi, et al., 2021). This finding stands whether the observer is a clinical professional or a family member. As a result the collection of self-report QoL data is standard practice in the general population – but is less frequent among people with intellectual disability (Shogren, Bonardi, et al., 2021).

The discrepancy in levels of QoL between self-report and proxy-report is an issue which is particularly pertinent to individuals with disability. The disability paradox is termed to refer to this discrepancy and it refers to situations where a person with disability is assessed by proxy to have poor QoL, when the person themselves does not consider this to be the case (Albrecht & Devlieger, 1999). The disability paradox is a key concept within disability rights, as failure to recognise this discrepancy between viewpoints could result in decisions being made in relation to a person’s treatment and life which are incongruent with the person’s wishes. However, although the disability paradox is widely recognised, proxy measures to evaluate QoL of people with intellectual disability are often used by default, on the premise that proxy report will provide answers with greater validity and reliability than those from the person themselves (Russell et al., 2018; Westerman et al., 2008).

Self-report scales often carry a high cognitive load which can be a barrier to accessibility for many people with intellectual disability (Shogren, Bonardi, et al., 2021). An example is the widely used ONS well-being indicator: ‘Overall, how satisfied are you with your life nowadays?’ (Office for National Statistics, 2023). A given respondent is required to first interpret the term ‘satisfied’, and then prioritise their overall state above anything which may be affecting them in the immediate moment. In addition, they must translate their assessment into a rating on a scale from 0 – 10 and communicate their response (verbally or otherwise) (Fujiura, 2012). Such a high degree of cognitive processing will make this scale, and others like it, inaccessible to many people with intellectual disability. However, the inaccessibility of scales such as this should not be confused with inaccessibility of self-report itself (Shogren, Bonardi, et al., 2021).

There is a vast array of self-report measurement tools which have been developed specifically for use with people with intellectual disability in attempts to overcome barriers to accessibility. Techniques include adjustments to scale design such as: the simplification of language (Bell et al., 2018; Finlay & Lyons, 2001), the reduction of response options (e.g. reducing a Likert scale from seven to three response options) (Hartley & MacLean, 2006), inclusion of visual aids (Dagnan & Ruddick, 1995; Finlay & Lyons, 2001), and reducing the number of questions to reduce concentration time (Bell et al., 2018). Other techniques to increase accessibility have focused on adjustments to scale administration such as: involvement of communication partners (e.g. trusted staff member), flexibility in wording or order of scale items to enable flow of conversation, provision of breaks as needed (Chinn & Homeyard, 2017; Nicolaidis et al., 2020; Terras et al., 2021). There is some evidence to suggest that these techniques do increase the accessibility of scales, although study designs are often limited to an assessment of face validity with small samples as an initial stage of scale development (Chinn & Homeyard, 2017).

Notwithstanding the challenge of finding a self-report tool which is accessible and has sound psychometric properties, theorists also argue that use of the scale should not result in exclusion of people who have more severe or profound intellectual disability (Schalock et al., 2002). Therefore, although everything should be done to expand the pool of people who can self-report (Fujiura, 2012), a QoL scale should be designed to collect self-report by default and proxy data from those who cannot self-report.

Models of QoL developed for use with people with intellectual disability

Models of QoL aim to provide a framework which covers all areas of a person's life which will impact on their overall QoL. These areas are called domains, and the models propose that the domains are universally applicable to all people regardless of their personal characteristics (e.g. ethnicity, socio-economic status, gender, age or disability etc.) (Schalock et al., 2002). As such, models do not propose to be specific to people with intellectual disability but are designed to be applicable for all people (Schalock et al., 2002). Domains are defined so that practitioners can focus efforts to enhance each domain, and so that methods can be developed to assess each domain. Although there are many models of QoL which have been developed, there is considerable overlap between models. This overlap is demonstrated in table 1.1 which displays three QoL models that have involved participation of adults with intellectual disability in their development. The number of domains in each model ranges from five to eight. When the models are displayed side by side it is clear that the substance of what each model covers is similar, and any differences between them are a result of differences in classification rather than content (Schalock et al., 2010).

The model which is most widely accepted within the field of intellectual disability is the Schalock & Verdugo 8-domain model of QoL (Schalock et al., 2010). This model has been developed through research into the QoL construct as applied to people with intellectual disability (Schalock, 2004). Research has confirmed that the 8-domains are considered relevant in different cultural settings and contexts (Jenaro et al., 2005; Schalock et al., 2005; Wang et al., 2010) and that the eight domains can be collapsed under three higher-order domains: Independence (personal development and self-determination); Social participation (interpersonal relationships, social inclusion and rights); Well-being (physical, emotional and material well-being) (Wang et al., 2010).

Table 1.1 Domains of QoL as detailed in three models

(Felce & Perry, 1995)	(Cummins, 1991)	(Schalock et al., 2010)
Physical wellbeing (health, fitness, safety)	**Health** (physical and perceived)	**Physical wellbeing** (health/ health care, activities of daily living, leisure)
Material wellbeing (income, quality of living environment, privacy, possessions, transport, neighbourhood)	**Material wellbeing** (disposable income, living conditions, financial security) **Safety** (security, privacy and control	**Material wellbeing** (financial status, employment, housing)
Social wellbeing (interpersonal relationships; community activities, community acceptance)	**Intimacy** (family & friends) **Place in community** (social class, education, job status, community integration)	**Interpersonal relations** (interactions, relationships, supports) **Social inclusion** (community integration and participation, community roles, social supports)
Development & activity (self-determination, choice/control, pursuit of functional activities: work; leisure; contribution)	**Productivity** (work, personal growth, development)	**Personal development** (education, personal competence, performance) **Self-determination** (autonomy/ personal control, goals, personal values, choices) **Rights** (Human – respect, dignity, equality; legal – citizenship, access, due process)
Emotional wellbeing (affect or mood, satisfaction, fulfilment)	**Emotional wellbeing** (general happiness, leisure, energy)	**Emotional wellbeing** (contentment, self-concept, lack of stress)

Standardised tools to measure QoL of adults with intellectual disability

In the preceding sections I have outlined the essential criteria required to measure QoL of adults with intellectual disability: the scale should be based on a defined model of QoL and items must measure all domains in the model; domains should be evaluated through both objective and subjective measures; all efforts should be made to enable responses to be collected via self-report; but a proxy report version of the scale should be available to ensure inclusion of those people who do not have capacity to provide their own answers. In addition, the scale should demonstrate adequate psychometric properties. Although there exist many tools designed to measure QoL of adults with intellectual disability, when we apply these essential criteria, the number of suitable tools quickly reduces.

The requirement to measure the whole construct of QoL and not just component parts suggests measuring just HrQoL or SCrQoL provides incomplete and insufficient information. Another measure which is widely used in the general population is the WHOQoL-Bref, developed by the World Health Organisation (The WHOQOL Group, 1998a). Although not specifically developed for use with adults with intellectual disability, the tool has been amended for use with people with intellectual disability through the addition of the disability module (WHOQoL-Dis) (Power et al., 2010). Psychometric properties of the scale have been assessed using data from a sample of adults with intellectual disability in Brazil and evidence in support of validity and reliability has been demonstrated (Bredemeier et al., 2014). However, the instrument has only been tested with people with mild ID; and there is only self-report available (Bredemeier et al., 2014). In addition, the model of QoL the

WHOQoL scale is designed to measure has been criticised for being pre-determined without adequate justification (Hagerty et al., 2001). The scale only includes subjective indicators and is therefore arguably more a measure of well-being than QoL.

The requirement to assess QoL by both objective and subjective indicators quickly reduces the number of tools under consideration. A systematic review identified nine self-report instruments to measure QoL of people with ID (Li et al., 2013). Only three of the instruments measured both subjective and objective QoL: The Comprehensive QoL measurement scale (ComQoL-ID), Quality of life Questionnaire (QOLQ), Personal Outcomes Scale (POS)) (Li et al., 2013). However, the authors of two of these scales (ComQoL-ID & QOLQ) no longer advocate for their use.

Scale authors of ComQoL-ID were unable to demonstrate good fit of the factor structure of the scale and have since advocated that scales should not try to measure both objective and subjective indicators within one construct. Instead the authors of ComQoL-ID developed the Personal Wellbeing Index for people with ID (PWI-ID) (Cummins et al., 2010). PWI-ID only measures subjective indicators and only provides self-report version (Cummins et al., 2010). In addition, to use the tool, participants must first answer questions to test their capacity to not acquiesce, and this leads to the exclusion of significant numbers of people with ID (McGillivray et al., 2009).

QOLQ is a scale developed by Schalock and colleagues prior to their specification of the 8-domain model of QoL. It is based on a 4-domain model of QoL, and factor analysis of data returned through QOLQ could not adequately explain variance (Kober & Eggleton, 2002). POS is the only instrument identified by Li and colleagues which may be fit for purpose yet at the time of the review psychometric research into POS was scarce (Li et al., 2013). In addition to inclusion of both subjective and objective indicators in the assessment of QoL, POS is based on the Schalock and Verdugo 8-domain model of QoL (Schalock et al., 2010), it is optimised to enable self-report from as many people as possible, yet also offers proxy report if required.

Since the publication of the systematic review by Li and colleagues, three further QoL measurement scales have been developed which measure the 8-domain model of QoL: San Martin (Verdugo et al., 2014), GENCAT (Verdugo et al., 2010) & INICO-FEAPS (Gomez et al., 2015). However, these tools serve different purposes than the measurement of QoL from the perspective of the individual. GENCAT is intended to assess quality of service and therefore only collects data via proxy (professional) based on direct observation of a person's life (Verdugo et al., 2010). San Martin is designed to measure QoL of people with profound and multiple intellectual disability and is designed to be answered from the perspective of an external observer who knows the person well (Verdugo et al., 2014). The INICO-FEAPS tool includes both self and proxy report measures to enable subjective and objective evaluation. Author guidance stipulates that both self and proxy data should be collected, which would hinder inclusion of people with more severe intellectual disability. At 72 items the scale is already lengthy to administer and the requirement to conduct both self and proxy report presents significant limits to the use of INICO-FEAPS at scale (Davidson et al., 2017). It has also been argued that the content of the items used in POS is a better fit to the concept of personal outcomes as defined by Schalock and colleagues (Carbo-Carrete et al., 2015)

The Personal Outcome Scale is the scale which presents as most fit for purpose. Since the publication of the systematic review by Li and colleagues (Li et al., 2013) further research has been published to assess the psychometric properties of POS, and I present a summary of that research here.

The Personal Outcomes Scale

POS is the only identified measurement tool designed to measure both subjective and objective experience which ensures inclusion of all people regardless of severity of communication and capacity needs. To achieve this, firstly interviewers are trained to use a semi-structured approach to administration, which enables interviewers to adjust language and context to the participant's capacity needs (Claes et al., 2008). Secondly, a proxy version of the tool has been developed to enable collection of response from staff or family member where participants do not have capacity to self-report.

POS provides a set of six indicators for each of the 8-domains of QoL (Claes et al., 2008). POS is completed through a semi-structured interview between a trained POS interviewer and an adult with intellectual disability (if self-reporting) or a proxy informant (member of staff or family member). POS authors developed a manual for administration and standardization (Claes et al., 2008). POS administration is designed to allow flexibility to accommodate a variety of participant communication needs, such as using prompts, augmentative and alternative communications, working with a communication partner who knows the participant well, or changing the order of POS items to begin with items which are most easily understood by the participant (Claes et al., 2008). The POS manual stipulates that interviewers must undergo two days of training prior to conducting interviews. During the training, interviewers conduct at least one practice interview and must also observe another practice interview (Claes et al., 2008). The training is designed to ensure that although raters may not use the exact phrasing or communication aid, they are all operating with a shared understanding of the meaning of the items, and this supports inter-interviewer reliability. However, inter-interviewer reliability is not required to be estimated as part of the training process (Claes et al., 2008).

Development of POS

POS was developed in 2008 to operationalise the model of QoL proposed by Schalock and Verdugo (Schalock et al., 2010). Initially a pool of over 100 items were identified from literature and each item was scored using a 3-point Likert scale (i.e., always, sometimes, and never) (Claes et al., 2010). Items were initially written in English. The content of the items was then reviewed and rated through consultation with experts from Belgium, Netherlands and the United States. Items were subsequently translated into Dutch by the scale authors (van Loon, personal communication, December 16, 2021). Focus groups were conducted in Belgium and the Netherlands (including people with intellectual disability, family, direct support staff and experts) to review the value and importance of the Dutch language version of the items (Claes et al., 2010). A parallel version of the scale was developed for proxy report (family members and/or staff) and pilot data were then collected from the Dutch language version of both self-report and proxy report from respondents in community-based services in Belgium and the Netherlands (Claes et al., 2010). Insight from the consultation process and the pilot data was used to reduce the number of items to 48. Although POS was originally written in English, data collected from the English language version of POS have never been empirically tested.

It is best practice when using a scale in a new setting to adjust the language to the target population and ensure the test is suitable for end users (International Test Commission, 2017). However, there is no published documentation to describe the process scale authors followed to translate the original items from English to Dutch. To prepare POS for use in Portugal, researchers subjected POS to a rigorous forward and back translation process from English to Portuguese (Simões & Santos, 2014b). A ten-person committee (including academics, family members, staff) rated each item according to its relevance, comprehensiveness (clarity) and readability (simplicity and ambiguity) (Simões & Santos, 2014b). Data were then collected using the Portuguese version of the scale to examine agreement of items through calculation of Content Validity Index and Cohen's Kappa statistic (Simões & Santos, 2014b). Researchers in other countries have not described the process of scale translation and content validity in published studies. Nuance in interpretation of items could be contribute to variation in POS scores and the lack of systematic process in translation of POS items presents a potential limitation in interpretation of data when POS is used in new settings.

Overview of psychometric evidence related to POS

Presented here is a summary of the published evidence in relation to the use of POS to measure QoL of people with ID. Research has been published from multiple countries to assess the psychometric properties of POS. Table 1.2 provides details of each study and the psychometric properties examined in each of the published studies.

Most participants involved in these studies were living in residential services, though some studies have also involved people living in private family homes. The initial study to examine psychometric properties of POS involved 79 adults with mild or moderate intellectual disability drawn from four residential services (three in the Netherlands, one in Belgium) (Claes et al., 2010). A further 161 adults with mild (76%) or moderate (24%) intellectual disability were recruited from residential services in the Netherlands (Claes, Vandevelde, et al., 2012). In Italy 176 adults (61% male) were recruited from residential services. 48% of participants had mild/moderate ID and 52% severe (Balboni et al., 2013). In Portugal 1,264 adults (47% female) were randomly recruited from 45 residential facilities and private homes. Adults with mild intellectual disability constituted 60% of the sample and the adults with moderate intellectual disability constituted the remaining 40% of participants (Simoes et al., 2015). In Spain 529 adults with ID were recruited through convenience sampling from seven regions of Spain (Carbo-Carrete et al., 2015). The greater proportion of participants were described as having mild/ moderate intellectual disability, but the study did engage a smaller proportion of participants with severe intellectual disability (Carbo-Carrete et al., 2015). In Ireland 85 adults who attended a community-based service were recruited (Burke et al., 2022). Participants included people who lived in residential services (38%) as well as people who lived in the community but attended outreach or local services during the day (Burke et al., 2022). The most recent published study recruited 128 adults with intellectual disability in Japan. Unlike the European studies most participants lived in their family home (79%) (Tatsuta et al., 2023). The study also recruited a larger proportion of adults with severe intellectual disability (44%) than the preceding studies (Tatsuta et al., 2023). Findings from these studies are summarised below.

Table 1.2 Published studies examining psychometric properties of POS

Study	Country	Sample size	Participant severity of intellectual disability	Psychometric properties examined
Claes et al 2008	Netherlands and Belgium	79	Mild/ Moderate	Internal consistency, inter-respondent reliability (self vs proxy, proxy vs proxy), face validity, convergent/divergent validity
Claes et al 2012	Netherlands	161	Mild/ Moderate	Inter-respondent reliability (self vs proxy, proxy vs proxy)
Balboni et al 2013	Italy	176	Mild/ Moderate/ Severe	Inter-respondent reliability (self vs proxy, proxy vs proxy)
Simoes & Santos 2014	Portugal	355	Mild/ Moderate	Internal consistency, inter-respondent reliability (self vs proxy, proxy vs proxy)
Carbo-Carrete et al 2015	Spain	529	Mild/ Moderate/ Severe	Internal consistency, convergent validity, confirmatory factor analysis
Simoes et al 2015	Portugal	1264	Mild/ Moderate	Internal consistency, test re-test reliability, convergent validity, confirmatory factor analysis
Simoes & Santos 2016	Portugal	69	Mild/ Moderate	Internal consistency, inter-respondent reliability (self vs proxy, proxy vs proxy)
Simoes et al 2016	Portugal	1264	Mild/ Moderate	Confirmatory factor analysis
Burke et al 2022	Ireland	85	Mild/ Moderate/ Severe	Internal consistency
Jacinto et al 2023	Portugal	21	Mild/ Moderate/ Severe	Inter-respondent reliability (self vs proxy)
Tatsuta et al 2023	Japan	128	Mild/ Moderate/ Severe	Internal consistency, test re-test reliability, inter-respondent reliability (self vs proxy, proxy vs proxy)

Assessment of psychometric properties of POS

Internal consistency

POS data drawn from studies in the Netherlands, Portugal, Spain. Ireland and Japan have been assessed to ascertain internal consistency of POS domains (Burke et al., 2022; Carbo-Carrete et al., 2015; Claes et al., 2008; Simões et al., 2015; Tatsuta et al., 2023). In all studies, alpha coefficients have been used to estimate internal consistency of each of the 8-domains of the QoL model. Analyses have been conducted on self-report and proxy data as independent datasets.

Across studies internal consistency was excellent (α > .80) when POS was assessed as a unidimensional scale for both data collected by proxy and by self-report. However, this may be an effect from the high number of items (48) in the scale as mathematically errors of measurement have more opportunity to average out in longer scales (Panayides, 2013). When internal consistency of the 8-domains was examined independently, results were mixed. The domains of rights, physical well-being and material well-being consistently demonstrate poor internal consistency across studies. The other domains demonstrate moderate internal consistency and there is no domain which has acceptable internal consistency *(*α > .70) across all studies. However, analyses of data drawn from participants in Ireland and Portugal demonstrated acceptable internal consistency (α > .70) across the three higher order sub-scales (independence, social participation, well-being) (Burke et al., 2022; Simões et al., 2015).

Test -retest reliability.

The reliability of the scale to return similar information when used at different time points can be assessed by retesting the scale with the same participants and assessing agreement between the original and retest data. Test-retest reliability of POS has been examined in studies in Portugal (Simões et al., 2015) and Japan (Tatsuta et al., 2023). In Portugal, POS interviews were repeated within two to three weeks of the original interview for a sample of 160 participants. Test-retest agreement was assessed by calculating Pearson's correlations. Results indicate high test-retest agreement for all domains for both self-report and proxy report (*r* ≥. 70). Assessment of test-retest agreement of data from participants in Japan used a much smaller sample (*n* = 6 proxy report and *n* = 10 self-report). Data indicated very high test-retest agreement for proxy data (all domains *r* > .75), but there was indication of poor test-retest agreement for the self-report version in the domains of emotional well-being (*r* = .54) and physical well-being (*r* = .36). However, interpretation of the Japanese data is limited by the very small sample size.

Inter-respondent reliability

POS features both a self-report and a proxy report version of the scale. Several studies have examined the degree of agreement between respondents. Studies have looked at agreement between self and proxy report, and they have also looked at agreement between type of proxy respondents (e.g. staff vs family member).

Data from self-report have been compared to proxy report in a study in the Netherlands. Based on data from 161 participants, the study found that although there was fair correlation between self-report and proxy report across domains (*r* > .40), there was significant difference in mean score for the domains of interpersonal relationships, social inclusion, physical wellbeing and total QoL score, dependent on whether respondent was the person themselves or a proxy respondent (Claes, Vandevelde, et al., 2012). People tend to score themselves higher than proxy respondents do. Study authors note that although there is correlation between self-report and proxy report, the significant differences between respondents highlight the need to prioritise self-report where possible, and to collect proxy report from more than one respondent (Claes, Vandevelde, et al., 2012).

Further analysis has been conducted to explore inter-respondent agreement based on data from Portugal, and Japan (Jacinto et al., 2023; Simões & Santos, 2016c; Tatsuta et al., 2023). These studies have produced similar findings to those from the Netherlands. Overall, there is evidence of fair correlation between domains for both self and proxy respondents (whether staff or family caregiver), but significant differences have been found in the domains of personal development, emotional well-being, physical well-being and material well-being. Greater degrees of error within these domains may be explained due to the difficulty of a proxy respondent to assess how a participant subjectively experiences their world. This is supported by findings from other studies which have demonstrated that staff respondents tend to score participants' QoL lower than they would score themselves for subjective domains (Cummins, 2002a; Perry & Felce, 2002); this is particularly the case with participants with greater support needs (Beadle-Brown et al., 2009). Authors of the Portuguese study note that evidence of score disagreement by respondent should not be interpreted as a lack of reliability, but rather as respondent's different perceptions (Simões & Santos, 2016c). They argue that therefore data sources are not interchangeable and different viewpoints should be considered in the QoL assessment, underscoring as Claes and colleagues did that proxy report should not be considered substitute for self-report. This principle offers much to practice, but it is unclear how to operationalise the multi-perspective approach for the purposes of research and evaluation.

Researchers in Italy attempted to understand what may cause higher correlation between the participant's report and the report of someone else. They found stronger correlation between self and staff caregiver report when staff members were asked to give the answer they thought the participant would give, rather than their own assessment of the participant's QoL (Balboni et al., 2013). Stronger correlation was also found between caregivers when they were asked to rate as they thought the person would themselves. This provides a clear recommendation for practice – that proxy respondents are asked to answer according to how they think the participant would rate their life as opposed how they as the person's carer rate the participant's QoL.

Inter-interviewer reliability

A key property of reliability is that of the reliability of response when the same individual is assessed by two or more interviewers. There are no published data to suggest that this property has been examined in relation to the POS. This is surprising as the high degree of flexibility allowed in administration of POS could introduce variability in the score.

Construct validity

Confirmatory Factor Analysis (CFA) is a statistical technique used to explore how well observed data fit a theoretical model. POS data can be examined through CFA to explore if data support the 8-domain QoL theoretical model (Boateng, Neilands, et al., 2018). CFA was run with the Portuguese data (*n* = 1,264) (Simoes et al., 2015). Eight of the 48 items failed to load adequately to the proposed domains for both self-report and proxy report data sets and were therefore dropped from analysis. The 40 retained items demonstrated good support for the 8-domain model of QoL (Simoes et al., 2015). Further CFA was run to explore statistical evidence in support of the three higher order factors (independence, social participation and wellbeing). Results did support a second order model, but findings were not as robust as those in support of the eight first order domains. Both self-report and proxy report datasets supported these findings (Simoes et al., 2015).

Researchers in Spain also conducted CFA to examine factor structure for self-report, report of professional and report of family proxy reporters (Carbo-Carrete et al., 2015). All three models considered the existence of eight first order factors and three higher order factors. The models reported acceptable fit and all factor loading values were statistically significant ($p < .001$) (Carbo-Carrete et al., 2015). The model for report of professionals most closely confirmed the factor structure, but all three models had acceptable agreement. Findings from the CFA in Portugal and Spain suggest that the robustness of support for the QoL theoretical model can vary from country to country and highlight the importance of conducting CFA when POS is used in new geographical settings. However, both these studies from Portugal and Spain were able to confirm the factor structure of POS is the same regardless of the type of informant (Carbo-Carrete et al., 2015; Simoes et al., 2016). These findings suggest that QoL is the same construct and has the same domain structure regardless of who is reporting on it thereby suggesting that the combination of self-report and proxy data for the purposes of future CFA is possible.

While existing CFAs have not explored whether one global QoL score is a good fit for POS data, most studies which have used POS in research have reported scores as one global QoL score across all the domains or items (e.g. out of a possible total score of 144). Global QoL scores have been reported when POS is used as outcome measure (Bergmann et al., 2021; Pruijssers et al., 2017) and in cross sectional analysis to explore factors associated with QoL (Bermudez et al., 2023; Claes, van Hove, et al., 2012; Memisevic et al., 2017). Further CFA is required to investigate QoL as a first order one factor structure (i.e., a total score across all 48 items), or a second order factor resultant from either the three higher order sub-domains or the eight first order domains.

Convergent validity

Concurrent validity can be assessed by comparing data from POS with data from a robustly validated scale which measures the same theoretical construct (the gold standard). However, there is no gold standard measure by which to assess QoL of adults with intellectual disability. Studies have used various measures of QoL to assess convergent validity – the degree to which variance in measure correlates with variance in other measures it is expected to be associated with.

Previous studies (Carbo-Carrete et al., 2015; Simoes et al., 2015) have compared POS data to data from the GENCAT scale (Verdugo et al., 2010) and the WHO-QOL BREF (The WHOQOL Group, 1998a). GENCAT is based on the same model of QoL as POS and is designed to capture quality of service and only collects proxy report of objective indicators of QoL (Verdugo et al., 2010). Nonetheless POS data collected from people with intellectual disability in Spain demonstrated moderate to good convergent validity with GENCAT across the eight QoL domains (*r* = .45 to .68). WHO-QOL BREF on other hand, only measures subjective QoL and is based on a different theoretical model of QoL than POS (The WHOQOL Group, 1998b). Concurrent validity was tested between the domains of WHO-QOL BREF (physical, psychological, social relations and environment) and the POS domains using data from a sample of people with intellectual disability in Portugal. Authors only reported correlations found to be statistically significant, and these related to POS domains of interpersonal relations, social inclusion, emotional well-being and physical well-being. Coefficients demonstrated moderate correlation between POS emotional well-being and WHOQOL BREF psychological domain (*r* = .43); and between POS physical well-being and WHOQOL BREF physical domain (*r* = .49). However, authors do not report correlations with associated p values > .05 and therefore no data in presented in relation to correlation between POS interpersonal relationships and social inclusion and the WHOQOL BREF domain of social relations (Simoes et al., 2015). Results from these two studies demonstrate the importance of consideration of how underlying theoretical constructs overlap when choosing the alternative scale by which to assess convergence.

Sensitivity to change.

No study has examined sensitivity to change of POS. A systematic review of self-report QoL measurement scales for use in this population found that for the nine scales identified, there were no published data related to scale responsiveness (Li et al., 2013). To the best of my knowledge, this property has not been assessed in any studies in intellectual disability research. Yet, as discussed above, the notion that data generated through the measurement of QoL will provide ways to evaluate programmes and services over time is integral to the justification of the utility of these tools.

POS as research tool

Since development in 2008, POS has been used in several research studies. Ten studies were cross sectional and explored factors associated with QoL (Balboni et al., 2020; Bermudez et al., 2023; Carbó-Carreté et al., 2016; Claes, van Hove, et al., 2012; Memisevic et al., 2017; Memisevic et al., 2016; Ramerman et al., 2018; Simões & Santos, 2016a; Simões, Santos, Biscaia, et al., 2016). Sample sizes for these cross-sectional studies ranged from 93 to 1264 adults with intellectual disability. A consistent finding across all these studies is the association between level of ID and/or adaptive behaviour skills and QoL – the greater a person's adaptive behaviour skills the greater their QoL.

Other factors found to be associated with higher POS scores were being in employment (Claes, van Hove, et al., 2012; Memisevic et al., 2016); engaging in daytime activities (Simões & Santos, 2017); engaging in physical activities (Carbó-Carreté et al., 2016) and health status (Memisevic et al., 2017; Simões & Santos, 2016a).

POS has also been used as outcome measure in five intervention studies (Bergmann et al., 2021; Bruinsma et al., 2024; Chou et al., 2019; Diz et al., 2021; Pruijssers et al., 2017). These studies ranged in sample size (min 12 to max 160). The smallest study used a single group pre-post design to evaluate effect of the intervention, but all the others were controlled evaluations. Two studies were cluster randomised control trials (Bruinsma et al., 2024; Pruijssers et al., 2017). POS was used as the secondary outcome measure in all five studies and was measured by proxy response in three (Bruinsma et al., 2024; Diz et al., 2021; Pruijssers et al., 2017) and self-report in the other two studies (Bergmann et al., 2021; Chou et al., 2019). One study reported no effect of physical activity on either primary outcome (fitness) or POS score (Diz et al., 2021). Two studies were able to demonstrate the intervention under study had had a significant effect on the primary outcome measure, but not on the secondary measure of POS score (Bergmann et al., 2021; Pruijssers et al., 2017). The interventions evaluated were a psycho-educative approach to foster social and emotional competencies (Bergmann et al., 2021) and a diagnostic guideline for anxiety and challenging behaviour (Pruijssers et al., 2017). A fourth study found no effect of a sexual health intervention on POS score except at a two-year follow-up (Chou et al., 2019). The fifth study reported results from a cluster-controlled trial of positive behaviour support (Bruinsma et al., 2024). The trial reported significant improvement in two domains of QoL (personal development and self-determination), but significant reduction in the domains of interpersonal relations and social inclusion (Bruinsma et al., 2024). There was no significant change reported across the other four domains of QoL (rights, emotional, physical and material well-being). The inclusion of POS as a secondary outcome in these evaluation studies suggests that the interventions tested (a variety of them) were expected to improve QoL, at least indirectly. The absence of change in POS scores in four out of the five studies points to several possibilities: no change experienced, or that change in QoL requires more time than these studies allowed for in their follow up measurement. A further possibility is that POS is not sensitive enough to detect change in QoL experienced by participants. It is clear that if POS is to be used as outcome measure to understand the impact of interventions on QoL further research is needed to evaluate sensitivity to change.

POS Psychometric properties – next steps

Psychometric research presented above suggests that other language versions of POS have demonstrated good reliability and validity across some indices, but there remain gaps where further investigation is needed. The psychometric properties of POS have never been evaluated using the English version of the scale. There is a need to demonstrate validity of the scale when used to measure QoL of adults with intellectual disability in the UK through confirmatory factor analysis.

In addition, the utility of instruments designed to measure change in a person over time is dependent not only on their reliability and validity but also on their ability to detect change (Guyatt et al., 1987). We do not know if POS can detect change nor how much change in POS score represents a meaningful change in QoL.

PhD study aims

My PhD is an in-depth investigation of the use of POS in residential services in the UK and its potential to be used as an outcome measure for research and service evaluation. My PhD comprises four studies. These studies make novel contribution to the evidence base as they constitute the first psychometric evaluation of the English language version of POS. In addition, my third study will be the first time that sensitivity to change of any tool designed to measure QoL of adults with intellectual disability has been assessed.

Primary aims of the four studies are listed below:

- To evaluate the factor structure of POS when used to measure QoL of adults with intellectual disability in the UK.
- To evaluate convergent validity of POS through analysis of factors expected to be associated with variance in POS score.
- To assess POS sensitivity to change over a 12-month period.
- To explore the association of health and social care cost with variance in QoL

The use of QoL within residential service provision

The use of QoL to evaluate the quality and value of services delivered to people with intellectual disability is a compelling idea not just for use in trials of specific interventions, but also in the broader context of residential service provision. Adult social care is tasked both with ensuring people receiving care are enabled to meet their basic needs, and with ensuring that peoples' individual well-being is promoted (The Care Act, 2014). The measurement of QoL is considered a mechanism by which to measure outcomes from adult social care in a way which is both meaningful for the individual and provides data which can be translated into an evidence base to inform future service delivery.

Mencap is a UK charity which provides accommodation and personal care services to approximately 4,000 adults with intellectual disability across 1,200 homes in the UK (Royal Mencap Society, 2023). In 2018 Mencap began a pilot trial of the collection of POS data to measure the QoL of the people they support. A study in collaboration with Mencap offered a unique opportunity to investigate POS in the UK context at scale. All data presented in this thesis has been collected from people supported by Mencap, and from staff at Mencap services.

Mencap supports people living in registered care homes, supported living settings, housing association properties and their own homes. Almost all the direct care services Mencap delivers are funded by local authorities (Royal Mencap Society, 2023). Mencap intends to use QoL as outcome measure to evaluate quality of routine service delivery and plans to measure QoL of every person they support on an annual basis (Royal Mencap Society, 2023).

Mencap’s organisational commitment to the collection of POS data provide a unique opportunity for applied research to explore pertinent questions in relation to the proposed utility of POS as outcome measure.

Chapter 2 Methods

Overview

My PhD consists of four studies designed to assess the psychometric properties of POS when used to measure QoL of adults with intellectual disability in the UK. These studies make novel contribution to the evidence base as they constitute the first psychometric evaluation of the English language version of POS. In addition, my third study includes the first ever investigation of sensitivity to change of any tool designed to measure QoL of adults with intellectual disability.

Primary aims of the four studies are listed below:

1. To evaluate the factor structure of POS when used to measure QoL of adults with intellectual disability in the UK.
2. To evaluate convergent validity of POS through cross sectional analysis of factors expected to be associated with POS.
3. To assess POS sensitivity to change over a 12-month period.
4. To explore the association of health and social care cost with variation in QoL

There were two distinct phases to the design of my PhD. Phase 1 involved the analysis of pre-existing data which were used in pursuit of objective one. Phase 2 involved collection of data in pursuit of study aims and data was used in pursuits of PhD objectives two, three and four.

Phase 1: Analysis of pre-existing data

Study one: Evaluating the factor structure of POS when used to measure QoL of adults with intellectual disability in the UK.

Study aims

Primary aim: Evaluate the factor structure of the English language version of the Personal Outcomes Scale (POS) when used to measure the QoL of adults (18+) with intellectual disability in the UK.

Secondary aims:

I. Investigate internal consistency of POS domain and sub-domain score by report type.
II. Explore factors associated with variance in POS score

Ethical approval

Ethical approval for this study was granted by the University College London Research Ethics Committee on 18 August 2021 (Ref: 19259/002 Appendix A). All data were robustly anonymized by Mencap prior to supply to UCL.

Overview of study design

Study one uses pre-existing data which were collected by one UK based adult social care service provider (Mencap) between June 2018 and December 2021 inclusive. Data relate to adults who are recognised by adult social care services as having intellectual disability and with whom Mencap holds a contract to provide personal care and support. POS data collection was conducted as part of routine service provision and the sample is therefore comprised of people who were selected according to service provider convenience. The supplied data comprised 310 adults with intellectual disability. Demographic data were made available from service registers. Confirmatory factor analysis was performed to evaluate model fit from the data.

Sample size

Sample size requirements for CFA are dependent upon several factors such as the ratio of indicators to latent constructs (Kyriazos, 2018; Wolf et al., 2013); the number of parameters to be estimated (Westland, 2010; Wolf et al., 2013) and the strength of those parameters (Westland, 2010). I estimated a minimum sample size of between 110 – 200 unique participants based on the minimum effect size found in POS CFA studies in Portugal (Simoes et al., 2016). A sample size between 110-200 was sufficient to detect a minimum effect of 0.38 for eight first order factors at 80% power and an alpha level of 5% (Soper, 2021).

Description of measurement instruments

Personal Outcomes Scale (POS): POS is a measure of QoL developed specifically for use with adults with intellectual disability (Claes et al., 2008) and based on the 8-domain QoL model (Schalock et al., 2010). POS consists of 48 questions over eight sub-scales. Each item is scored on a 3-point scale and items are summed to give subscale and total scores. Overall QoL score ranges from 48 – 144 with higher scores indicating enhanced quality of life. POS was developed in 2008 through a process of expert consultation and focus groups with key stakeholders (including clients, family, direct support staff and experts). Psychometric testing by the measure’s developers was used to reduce the pool of items to six per domain, and a parallel version of the tool was also developed to enable both self-report and proxy report (family members and/or staff) for individuals who are unable to provide their own responses (Claes et al., 2008). Scale authors have published data relating to reliability indices from pilot studies in the POS manual. Data relating to internal consistency and inter-respondent correlation coefficients from these pilot studies are displayed in table 2.1. Cronbach's Alpha Coefficients indicate adequate internal consistency for both self and proxy report versions of POS (α ≥ .70) with the exception of the rights domain, and the three domains related to well-being. Pearson's correlation coefficients indicate moderate (*r* ≥ .30) to strong (*r* ≥ .50) corelation between self and proxy report across all domains.

Table 2.1 Validity and reliability coefficients reported in POS manual

POS domain	Internal Consistency (Cronbach's Alpha) (*n* = 399)		Pearson's correlation between self-report and proxy report (*n* = 79)
	Self-report	Proxy report	
Total POS score	.88	.85	.83
Personal development	.70	.69	.78
Self-determination	.75	.80	.72
Interpersonal relationships	.67	.70	.52
Social inclusion	.73	.74	.74
Rights	.47	.40	.80
Emotional well-being	.72	.69	.42
Physical well-being	.59	.60	.63
Material well-being	.25	.25	.71

Note. Data reproduced from POS manual (Claes et al., 2008)

Data from service registers: Pre-existing data were available to indicate participant gender, age, and geographic locale.

Data collection methods

POS data were collected as part of regular service provision, prior to the PhD. POS was completed through a semi-structured interview between a trained POS interviewer and an adult with intellectual disability (if self-reporting) or a proxy informant (member of staff). POS authors developed a manual for administration and standardization (Claes et al., 2008). POS administration is designed to allow flexibility to accommodate a variety of participant communication needs, such as using prompts, augmentative and alternative communications, working with a communication partner who knows the participant well, or changing the order of POS items to begin with items which are most easily understood by the participant (Claes et al., 2008).

The POS manual stipulates that interviewers are trained in POS administration, scoring and interpretation (Claes et al., 2008). Interviewers must be familiar with the concept of QoL, and with the scale items and meanings. Mencap have operationalised the training guidelines through a two-day workshop which includes one day of interview practice.

To ensure the reliability of response irrespective of the rater, POS training provides in depth review and discussion of the QoL concept and the items and their meaning. During the training, interviewers conduct at least one practice interview and must also observe another practice interview (Claes et al., 2008). This training ensures that although raters may use variable phrasing or communication aids, they are all operating with a shared understanding of the meaning of the items, and this supports inter-interviewer reliability. However, inter-interviewer reliability was not estimated as part of the training process as this is not specified as a requirement by scale authors (Claes et al., 2008). The training is certified by Ghent university which specifies that trainers must have completed at least 20 interviews and been observed by a master trainer for three of these before they can qualify as trainers (Claes et al., 2008).

All interviews were conducted by members of Mencap staff who had completed standardised training. Staff self-selected to be POS interviewers as a professional development opportunity. Training was delivered by Mencap staff who had qualified at POS ‘master trainer’ level and POS ‘co-trainer’ level. The Mencap POS training workshop is co-facilitated by colleagues with intellectual disability.

POS self-report interviews were conducted face to face in the person’s home. If the person requested support, a member of staff was present during the interview. POS interviews with proxy respondents were either conducted face to face in the home of the person whom the interview was about, or on MS Teams or the phone.

Ethical approval to process data for research purposes

This study uses pre-existing data which was anonymised by Mencap prior to being supplied to me for analysis. I was granted ethical approval from the UCL Research Ethics Committee (Project ID: 19529/002 Appendix A) to handle these data and conduct the analysis.

Data were collected by Mencap under legitimate interest according to General Data Protection Regulation (GDPR) guidelines ("The General Data Protection Regulation," 2016) and according to processes approved by Mencap’s Data Protection Officer. As the data were not initially collected as part of a research project, there was no ethical review by an external ethics committee.

The principles of The Mental Capacity Act (MCA) (Department of Health, 2005) and voluntary informed participation were integral to the enrolment processes. All interviewers were trained to understand and interpret the MCA when collecting data. Where required, a best interest approach was followed to seek advice from consultees to ascertain if service users would likely want to take part. For service users who were likely to have capacity to provide independent consent, information was provided, and consent sought to proceed. A record of consent was kept.

Information provided included: description of study activity, what participation entailed; freedom to decline or withdraw from the study without any negative impact; how to complain and who to contact at Mencap if any further questions.

However, the consent Mencap gained when collecting the data did not include consent for re-analysis for research purposes. Therefore, in collaboration with Mencap, and as approved by the UCL ethics committee, I produced a short video to inform people who had taken part in the interviews that their data would be shared anonymously for research purposes. Staff in services where each participant lived were asked to play the video to the participant. Participants were given the option to request that their data not be shared in this way by the cut-off date of 30 September 2021.

Dataset available for analysis

A total of 350 interviews were conducted between August 2018 and December 2021 inclusive. Of these, 250 were self-report interviews and 100 were proxy report. Of the 350 interviews, 35 were repeat interviews (on the same person) and for five the proxy respondent was a family member as opposed to a staff member. These 40 interviews were excluded from analysis and thus the POS data set is comprised of 310 unique participants.

As shown in table 2.2, most interviews were conducted in the first two years of data collection (2018 to 2019: 65%), while 89% of interviews were conducted prior to the start of the UK COVID-19 lockdowns. Just 3/4 of interviews were self-report, and as found in previous studies mean proxy scores were about 15 points lower than those for self-report scores (Carbo-Carrete et al., 2015; Claes et al., 2012; Simoes et al., 2015).

Description of participant characteristics

All participants were adults (18+) with intellectual disability for whom Mencap provides personal care and support. Participants lived either in supported living, residential care services or in their family home. Mencap involvement varied from a 24-hr staff presence to staff who visit once or twice a week, as required by the participant's support needs. Mencap provided additional data to help describe participants. These included gender, age, geographic location, and date of interview.

There was a relatively large proportion of missing data relating to gender of participants (*n* = 95; 31%). Where gender was known there was a higher proportion of male participants (*n* = 121; 39%) than female (*n* = 94; 30%). The median age of participants was 53 years (Inter Quartile Range (IQR) 42-62 years) and participants were drawn from across England and Wales; the highest concentration (37%) being from London, Southeast and East Anglia. Participant characteristics are displayed in table 2.2. Approach to analyses is described in chapter three.

Table 2.2 Phase 1: Participant characteristics and interview administration

	n	(%)	POS Score	
			Mean	(SD)
Age (years)				
- [18-35]	22	(7.10)	112.32	(14.43)
- [36-50]	95	(30.65)	114.32	(11.22)
- [51-70]	129	(41.61)	110.71	(12.95)
- [70+)	29	(9.35)	106.00	(11.70)
- Missing	35	(11.29)	119.63	(8.05)
Gender				
- Female	94	(30.32)	112.81	(11.94)
- Male	121	(39.03)	110.68	(12.86)
- Missing	95	(30.65)	114.51	(11.99)
Location				
- London and Southeast and East Anglia	113	(36.45)	112.62	(12.25)
- Wales, Southwest, and Midlands	101	(32.58)	112.05	(12.37)
- Yorkshire and North of England	65	(20.97)	109.06	(12.97)
- Northern Ireland	28	(9.03)	121.21	(7.55)
- Missing	3	(0.97)	116.00	(4.58)
Year of interview				
- 2018	86	(27.74)	112.73	(12.04)
- 2019	115	(37.10)	112.53	(11.67)
- 2020	77	(24.84)	112.06	(14.27)
- 2021	31	(10.00)	112.68	(11.61)
- Missing	1	(0.32)	-	-
Interview conducted before start of COVID-19 national lockdowns in the UK (March 2020)				
- Post March 2020	34	(10.97)	113.21	(11.24)
- Pre-March 2020	275	(88.71)	112.39	(12.56)
- Missing	1	(0.32)	-	-
Type of report				
- Self-report	236	(76.13)	115.86	(10.32)
- Proxy report	74	(23.87)	101.78	(12.39)

Phase two: Collection of longitudinal data

Study aims

Phase two involves three distinct studies. Study aims are:

- Study two aimed to evaluate convergent validity of POS through analysis of data from time point 1 (T1). Analysis explored factors expected to be associated with variance in POS score based on existing QoL research.
- Study three assessed sensitivity to change of POS score by comparing data from time point 1 (T1) and time point 2 (T2).
- Study four explored the association of health and social care cost with variance in QoL through cross sectional analysis of data from T1.

Ethical approval

The London Southeast Research Ethics Committee confirmed favourable ethical opinion for this project on 18 Jan 2022 (reference 21/LO/0901 Appendix B). The committee was satisfied that requirements of the Mental Capacity Act 2005 (England and Wales) (Department of Health, 2005) were met in relation to research carried out as part of this project and in relation to people who lack capacity taking part in this project.

Overview of Study design

This is an observational longitudinal study design, prospectively following a group of 100 adults with intellectual disability over a period of 12 months. Participants were drawn from multiple supported living and residential care services across England. POS data (Claes et al., 2008) were collected at both time points, either through self or proxy report. Additional measures were taken at both time points via online survey to staff respondent.

Sample size and sampling methodology

Participants were enrolled in the study through convenience sampling. Sampling was designed this way to account for anticipated challenges to data collection due to the COVID-19 pandemic. (For further information see section on challenges to data collection). Complete data were collected from 100 participants at T1 and 83 participants at T2.

Analysis conducted in study two involved multivariate regression analysis of T1 data involving seven independent variables. A-priori sample size calculation (Harrell et al., 1984) estimated a minimum sample requirement of 79 independent observations to estimate effect size, at 80% power and .05 probability with seven predictor variables (Soper, 2024).

Analysis conducted in study three involved estimation of sensitivity to change of POS proxy and self-report data based on responsiveness to internal criteria and Receiver Operating Characteristic (ROC) analysis to estimate sensitivity to change of POS proxy and self-report data based on responsiveness to external criteria.

A simulation study has demonstrated that analyses used to estimate sensitivity to change based on internal criteria are reliable even in sample sizes as small as 25 (Zou, 2005). Sample size requirements for ROC analysis are highly sensitive to probability of change (Serdar et al., 2021), therefore I used probability of change as estimated through the internal criterion above as the parameter for sample size estimate using the Stata module Power One-ROC (Linden, 2022). These estimates are presented in chapter five.

Analysis conducted in study four involved multivariable robust regression analysis to explore the association between POS score and cost of access to health and social care while adjusting for the effect of level of adaptive behaviour skills. Robust regression techniques are recommended for use in small samples, and the sample size of 80 participants was therefore adequate to conduct this analysis (Varin & Panagiotakos, 2020).

Study schedule

Data were collected from participants at two time points 12-months apart. Specifically, T1 data collection ran from February to October 2022 and T2 data collection ran from February to September 2023. Recruitment was rolling for T1, data were collected shortly after participant had been enrolled in the study. At T2, data collection was organised in two-month trances, to ensure that T2 data collection for each participant occurred 12 months after data had been collected in T1. The study aimed to include 150 participants at both time points. Proposed analysis for T1 required a minimum of 93 participants so the target of 150 participants allowed for participant drop out. Due to challenges resultant from additional pressures on service delivery staff in response to the COVID-19 pandemic, it was not possible to reach this sample size (see section describing challenges to data collection). A total of 124 participants were enrolled in the study at T1, but complete data was returned for 100 participants. These 100 participants were approached for follow up at T2, and complete data was collected for 83 participants.

Description of measurement scales used in this project

All measures to be used in this study are detailed in Table 2.3. Further details are provided in text. Coefficient alpha (α) and omega (ω) were calculated to assess internal consistency of the different scales used in the study. An often overlooked assumption of coefficient alpha is that of tau equivalence, i.e. all the scale items being tested are assumed to have the same relationship to the underlying construct (QoL) (Padilla, 2019). This assumption is rarely met in applied research. More often scale items are congeneric i.e. the measurement of all items will depend on the strength of the underlying construct, but the extent of this dependence will vary by item. Coefficient omega is a more appropriate measure of consistency of congeneric items (Padilla, 2019). None of the studies which have examined internal consistency of POS scores have reported coefficient omega (Carbo-Carrete et al., 2015; Claes et al., 2008; Simoes et al., 2015). I therefore report both alpha and omega to allow comparison with results from previous studies, but I will interpret my results based on omega coefficient. As with coefficient alpha, omega values >.70 are generally taken to represent acceptable internal consistency (McNeish, 2018).

Table 2.3 Overview of measurement scales used in this project

Tool	Construct being measured	Items (*n*)	Av. Time	Respondent	Data collection method	Data collection frequency
POS self-report [a]	Quality of life	48 items	45 mins	Participant	F2F interview	T1 & T2
POS proxy report (Claes et al., 2008) [a]	Quality of life	48 items	30 mins	Staff	F2F interview /MS Teams	T1 & T2
Short Adaptive Behaviour Scale (Hatton et al., 2001)	Adaptive behaviour	24 items	6 min	Staff	Online survey	T1
Global assessment of change (Shim & Hamilton, 2019)	Change in QoL	1 item	1 min	Staff	Online survey	T2
Brief QoL scale (Bowring et al., 2020)	Quality of life	8 items	3 min	Staff	Online survey	T1 & T2
Behaviour Problems Inventory – Short form (Rojahn et al., 2012)	Challenging behaviour	30 items	10 min	Staff	Online survey	T1
Depression screen (Westlake et al., 2021)	Depression symptoms	14 items	3 mins	Staff	Online survey	T1 & T2
Negative Life Events Checklist (Hermans & Evenhuis, 2012)	Life events	11 items	5 mins	Staff	Online survey	T1 & T2
Activity checklist (Bu et al., 2020)	Engagement with activities	18 items	2 mins	Staff	Online survey	T1 & T2
Client Service Receipt Index, (adapted from (Beecham, 1995))	Resource use	49 items	15 mins	Staff	Online survey	T1 & T2

[a] For each participant one version of POS will be administered – either self-report or proxy report dependent on participant capacity to provide their own answers.

Personal outcome scale (POS)

A description of POS (Claes et al., 2008) is provided in methods for phase one. Coefficient alpha and omega are displayed in table 2.4. Coefficients for both proxy and self-report data suggest excellent internal consistency of the overall POS score and the three subscales (independence, social participation, and wellbeing); but not the eight domains. Differences between coefficient alpha and omega are minor across the domains, with the exception of rights. Coefficients reported here support recommendations made from a previous study, that the three subscales (independence, social participation, and wellbeing) should be considered more reliable psychometric scales than the eight domains (Burke et al., 2022).

Short Adaptive Behaviour Scale (SABS)

Adaptive behaviour refers to how well individuals cope with the demands of their environment and performance of everyday tasks. A standardised measure of adaptive behaviour has great utility in research as it enables a more accurate description of participants' severity of intellectual disability/ level of need. SABS is a shortened version derived from the Adaptive Behaviour Scale - Residential and Community (Nihira et al., 1969), a standardised measure developed for use with adults living in residential and community settings. The shortened version measures 24 items (Hatton et al., 2001). SABS has shown adequate psychometric properties (Hatton et al., 2001) and been used in many research studies since its development. My data demonstrated excellent internal consistency ($\alpha = .96$ $\omega = .96$).

Table 2.4 Internal consistency of POS by report-type, subscale and domain

	Items (*n*)	Self-report (*n* = 64)		Proxy (*n* = 36)	
Domain		Alpha (95% CI)	Omega (95% CI)	Alpha (95% CI)	Omega (95% CI)
POS Quality of life scale	48	.87 (.80 to .93)	.88 (.84 to .93)	.90 (.87 to .94)	.91 (.86 to .96)
POS Independence subscale	12	.76 (.66 to .87)	.71 (.59 to .84)	.78 (.65 to .92)	.76 (.66 to .89)
POS Social Participation subscale	18	.80 (.73 to .86)	.82 (.75 to .89)	.86 (.80 to .93)	.86 (.80 to .93)
POS Well-being subscale	18	.70 (.60 to .80)	.69 (.59 to .81)	.73 (.62 to .85)	.72 (.68 to .85)
Personal Development	6	.72 (.61 to .83)	.73 (.63 to .84)	.52 (.36 to .68)	.57 (.35 to .78)
Self Determination	6	.68 (.48 to .87)	.69 (.57 to .81)	.77 (.60 to .94)	.79 (.69 to .90)
Interpersonal relationships	6	.67 (.50 to .84)	.66 (.53 to .80)	.72 (.56 to .89)	.66 (.48 to .83)
Social inclusion	6	.66 (.54 to .77)	.69 (.75 to .81)	.81 (.70 to .92)	.82 (.72 to .91)
Rights	6	.55 (.42 to .68)	.63 (.49 to .79)	.62 (.49 to .75)	.73 (.61 to .88)
Subjective wellbeing	6	.67 (.46 to .88)	.64 (.50 to .79)	.61 (.41 to .82)	.70 (.53 to .87)
Physical wellbeing	6	.53 (.42 to .65)	.64 (.50 to .79)	.58 (.39 to .78)	.60 (.40 to .81)
Material wellbeing	6	.29 (.10 to .48)	.54 (.38 to .71)	.71 (.56 to .86)	.74 (.60 to .87)

Global Assessment of Change in QoL (GAC)

Based on the structure of the Clinical Global Impressions-Improvement (CGI-I) scale (Busner & Targum, 2007) staff informants were asked if they thought participant quality of life has improved greatly, improved a bit, remained unchanged, deteriorated a bit or deteriorated greatly since the baseline. GAC provides a 5-point global rating of change. Using GAC as an external criterion of change is a well-established methodology in research outside of the field of intellectual disability e.g. (Braun et al., 2021; Schwartz et al., 2019).

Brief Quality of Life scale (BQoL)

BQoL consists of an 8-item staff completed measure of quality of life (QoL), with a 5-point Likert scale for each item (Bowring et al., 2020). Scores range from 0 – 40 with higher scores indicating enhanced QoL. The original version of the tool featured 22 questions and was developed for use with children with intellectual disability (Kincaid et al., 2002). The scale has since been adapted and shortened to suit adult audiences, and has demonstrated good internal consistency (Bowring et al., 2020). It provides a brief objective measure of the global construct of QoL. Previous population studies have identified statistically reliable change (RC) in BQoL scores can be quantified as a 7.02 point difference for adults with intellectual disability based in the UK (Bowring et al., 2020). Internal consistency at T1 was good as assessed by alpha and omega coefficients ($\alpha = .74$ $\omega = .74$).

The Behaviour Problems Inventory – Short form (BPI-S)

BPI-S is an informant-based behaviour rating instrument which assesses the frequency and severity of 30 behaviours organised into three subscales: Self Injurious Behaviour, Aggressive Destructive Behaviour, and Stereotyped Behaviour

(Rojahn et al., 2012). The scales provide two sub scores for each type of behaviour – one for frequency and one for severity. BPI-S is a shorter version of the pre-existing Behaviour Problems Inventory-01 (Rojahn et al., 2001). BPI-S contain 19 fewer items than the original tool. BPI-S has been demonstrated to have good psychometric properties (Rojahn et al., 2012).

Internal consistency for BPI-s should be estimated separately for frequency and severity. Overall items related to the frequency of behaviours had excellent internal consistency (α = .83 ω = .77) and items related to severity of behaviours had good internal consistency (α = .77 ω = .77). Coefficients reported for frequency of the self-injurious subscale indicated inadequate internal consistency (α = .53, omega would not converge). Internal consistency of items related to severity of self-injurious behaviour was also inadequate (α = .56 ω = .52). Items indicating frequency of aggressive behaviour demonstrated good internal consistency (α = .73 ω = .76). Items related to severity of aggressive behaviour had excellent internal consistency (α = .79 ω = .80). Data is only collected in relation to frequency of stereotyped behaviour and items demonstrated excellent internal consistency (α = .78 ω = .80).

Depression symptoms

Depression symptoms were measured through 14 items drawn from the Aberrant Behaviour Checklist (Aman, 2012) and validated against depression diagnoses based on the mini PAS-ADD for adults with intellectual disability (Westlake et al., 2021). The scale provides a total score that ranges from 0 – 42 with higher scores indicating greater presence of depression symptoms. Sensitivity and specificity analysis has determined cut-off scores for the scale’s capacity to detect depression: a score of 16 or more indicates depression among people with low to moderate intellectual disability or a score of 23 or more for people with severe intellectual disability (Westlake et al., 2021). Internal consistency as assessed by alpha and omega coefficients was excellent (α = .90 ω = .92)

Leisure engagement

The scale is designed to capture data on leisure activities which are easily accessible (e.g. can be done in the person's home, or nearby). Items list a series of six leisure activities. Respondents were asked to focus on a single day, but to avoid the cognitive burden of estimating the 'typical' day, respondents were asked to focus on the last weekday they were working with the participant. Each item is measured on a 4-point scale derived from response options: Did not do; did for less than 30 minutes; did for 30 minutes to two hours; did for more than two hours. I adapted an existing scale designed for use with the general population and intended to measure time spent engaged in activities during the period of national lockdown in response to the COVID-19 pandemic (Bu et al., 2022). The original scale was designed for self-report, and I adapted this to be suitable for staff proxy report. I also removed items which were not related to leisure (e.g. doing housework and chores, looking after children) and an item related to passive leisure (watching TV). The six leisure activities included are exercise, spending time with friends or family (face to face or digitally); arts and crafts; other hobbies; and being outside. To estimate the active engagement score I assigned numerical values 0-3 to the ordinal categories returned for each item. The total score ranged from 0 to 15 with higher scores indicating more time spent engaged in active activities. The scale demonstrated moderate internal consistency (α = .61 ω = .62).

Client service and receipt Index

The CSRI used in this study was amended from a validated tool developed to measure total resource use and which has been used in previous evaluations involving people with intellectual disability (Beecham, 1995). Amendments were made based on study requirements and feasibility of data capture. At T1 the tool collected data on staffing levels at the person’s home; support package the person receives; access to day activities; use of community-based health and care services; use of hospital-based services; use of medication; involvement with criminal justice services. For most participants only items relating to access to day activities and use of community-based health and care services were repeated at T2. Items relating to staffing levels and support package were repeated if respondent indicated there had been a change since T1. Analysis of T1 data found very low frequency of engagement with items related to use of hospital-based services and involvement with criminal justice services so these items were not repeated. Items related to use of medication were not repeated due to the need to decrease survey response time and increase response rate (see section on challenges to data collection). Resource use was used to estimate unit cost (Curtis, 2020).

Negative Life Events Checklist

The negative life events checklist used in this study was developed through a process of selection and adaptation of existing items from life events scales as well as co-production with four people with intellectual disability and one support worker (described below). Twelve items were included in the final checklist and asked if the participant had experienced the event within the last 12 months: Participant’s friend or family member had a serious illness; Participant’s friend or family member died;

Participant went through a relationship break up; Participant lost their job or voluntary placement; Participant moved house; Participant had a serious illness; Participant had overnight stay(s) in hospital; Participant made significant lifestyle changes for health (e.g. diet, exercise, regular monitoring); A regular member of staff left; Participant was physically restrained; Participant contracted COVID-19; Participant's friend or family member stopped visiting (or visited much less frequently). Data were collected on participant experience of these 12 items within the 12-month period prior to data collection. A total score ranging from 0-12 is derived to provide a count of overall negative life events, as all items were equally weighted.

Development and co-production of the negative events checklist

As a first step, I reviewed existing life events checklists (Brugha et al., 1985; Hastings et al., 2004; Hermans & Evenhuis, 2012). The Threatening Life Events checklist (Brugha et al., 1985), was developed for use in the general population and included 12 categories of events which were rated as having moderate or marked long term effect on psychological disorders (Brugha et al., 1985). A modified checklist is included in the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PAS-ADD) (Moss et al., 1998). A large sample study (*n* = 1,155) has used this checklist to explore the association between recent exposure to life events and psychiatric disturbance among adults with intellectual disability (Hastings et al., 2004). Authors report a small but significant relationship between life events exposure and psychiatric problems in adults with intellectual disability. However a limitation noted in this study was that because the scale was originally developed for people without an intellectual disability, events significant in the lives of people with intellectual disability may not be sufficiently represented (Hastings et al., 2004).

A life events checklist specifically designed to capture events of significance in the lives of people with intellectual disability was developed for use in a study involving 988 participants (Hermans & Evenhuis, 2012). The 28-item modified checklist was based on the checklist used in the PAS-ADD interview but also included consideration of life events mentioned in other studies and experience of professionals (Hermans & Evenhuis, 2012). The checklist includes some positive life events such as going on holiday. Events specific to living in a residential or supported care setting were included such as: change in staff in residential setting of day care; new resident moving in; problems with fellow resident; loss of leisure-time activities (Hermans & Evenhuis, 2012). The study found that accumulation of negative life events resulted in a higher frequency of increased depressive and anxiety symptoms. Specific events were independently associated with increased depression and anxiety symptoms: minor illness or injury; problems with fellow residents; decline or loss of mobility; loss of leisure-time activities and; change at or from work/day care (Hermans & Evenhuis, 2012). Theoretically the association of negative events to increased depression and anxiety symptoms could be on the causal pathway to reduced QoL. Data related to experience of significant negative events could therefore provide an anchor against which to assess sensitivity to change of POS.

For the purposes of my study, it was necessary to develop a checklist of life events which were considered negative by people with intellectual disability. I also needed to ensure that the checklist captured data on activities which were commonly experienced by people with intellectual disability as due to my relatively small sample size I was less likely to capture data on rarer events. The 28-item checklist developed by Hermans & Evenhuis was too broad to meet my requirements as it included both negative and positive events. In addition, although the 28-item list was compiled through consultation with professionals (physicians, psychologists and caregivers); authors do not mention consultation with people with intellectual disability themselves (Hermans & Evenhuis, 2012). Review was also necessary to explore if the collective experience of the COVID-19 pandemic had changed people's perceptions of what they consider significant negative events.

Co-production presented an opportunity to review existing life events checklists and gain insight from people with intellectual disability regarding what type of event has significant negative impact on their lives. Co-production workshops took place in June 2021, and due to ongoing restrictions in response to the COVID-19 pandemic, workshops took place online. I used the collaboration software Mural to manage the workshops (LUMA institute, 2020). The co-production team consisted of four of Mencap's Inclusion Consultants and a member of direct support staff. Inclusion Consultants are people with intellectual disability who live in services supported by Mencap and are paid by Mencap to provide consultation on accessibility of information.

The construct of life events was described to colleagues as: things that change in your life. Going through these changes can make you feel sad or anxious. Life events are most often out of your control. At the beginning of the workshop colleagues were warned that it was possible that things we would talk about may remind them of something sad. Colleagues were asked if there was anything specific, they did not wish to talk about. One colleague asked not to talk about family members getting sick or dying as they had recently been bereaved. We did not talk about this in the workshops, but the item was added to the final checklist.

Based on a semi-structured conversation guide colleagues discussed events which had affected them. As each person shared their experience other colleagues were prompted to remember and share similar experiences which had happened to them. We then collectively reviewed any items not yet mentioned from the Hermans & Evenhuis checklist to see if colleagues thought these items should be added. A list of 12 items was agreed by the group to be those events which had made them feel sad or anxious and which are commonly experienced by people with intellectual disability.

It is worth noting that some of the items on the Hermans & Evenhuis checklist were not included, not because they were not common, but because colleagues did not consider them to have a significant impact. For example, there are two items relating to other residents on the 28-item checklist (Hermans & Evenhuis, 2012). Colleagues felt that staff would support them to deal with any issues which came up with other residents so this should not be included on the checklist. A more detailed report from the co-production workshops is included in Appendix F.

Administration of data collection

POS Interview

Eight interviewers including myself participated in data collection at T1. All interviewers had undergone POS training as described previously for phase 1 of the project. Administration of POS interview did not differ from processes described in phase 1.

Six interviewers including myself participated in data collection at T2. All interviewers underwent POS refresher training prior to starting T2 data collection. Refresher training was delivered by me and designed to increase interviewer calibration. Wherever possible the same interviewer was allocated to the same participant at T2. However, due to staff turnover and conflicting priorities, the majority of T2 interviewers were conducted by me and two Mencap staff interviewers. This meant that 50% of participants were allocated a new interviewer at T2.

Interviewer calibration

During T1 data collection I observed each interviewer conducting at least one proxy and one self-report interview. During each observation, I scored the POS in parallel, independently of the main interviewer. 10 interviews were observed and doubly scored. The kappa statistic indicated very good interrater reliability (k = .87). However, this statistic should be interpreted with caution as it is based on observation of interviewer rather than two interviewers independently assessing the same participant a short time apart. I also assessed interviewer calibration qualitatively during the observations. I took verbatim notes to capture interviewer phrasing of items; expansion of items to aid comprehension; and use of response options.

Overall based on qualitative observation, Mencap POS interviewers were well versed in the POS tool. They all built exceptional rapport with respondents (whether participant or staff respondent) and used reflective skills to engage with respondents. Interviewers were adept at adapting POS questions to be relatable to the person and using language which was comprehensible to the person.

However, there was variability observable among interviewers. Some interviewers did not clarify response options with the respondent (e.g. would you say that’s always or sometimes?). In addition, there was variability in how interviewers interpreted certain items, and this affected the additional descriptors they gave to aid participant understanding. For example, one question in the interpersonal relationships domain asks: Do you have a support network – people you can go to for advice and help? When observed some interviewers specified that this support network could not be paid staff members, whereas others accepted staff as a person’s support network. Following discussion with Mencap we agreed that this question should be answered from the person’s perspective, if they feel supported this item should be answered as yes regardless of whether that support is from paid staff or an organic support network.

It was clear from the observations that there was a need to calibrate interviewer understanding of items. In addition, I identified a need to catalogue techniques used by interviewers to prompt by adding context and expanding on item meanings so they could be used as an additional training resource. I produced a summary of observation findings, highlighting any discrepancies in item interpretation. I reviewed the original POS manual to clarify intended meaning of each item and reviewed all items with one of the most experienced POS interviewers on the study, Ellen Kennedy. I produced a Mencap POS administration manual (see appendix I). The manual includes item by item description and provides verbatim examples of how POS interviewers phrase items to expand on meaning. The manual formed the basis of the POS refresher training which I delivered to POS interviewers involved in data collection at T2.

Online survey for staff-reported outcomes

The respondent for all measures aside from POS, was a member of staff who had worked with the participant for at least three months. The response mechanism was via online survey. Prior to data collection, the online survey was piloted with three service managers who were asked to provide dummy data based on the profile of a person who receives support in their service, but without providing any identifying details. Testers provided information on length of time taken to complete (approx. 30 mins) and ease of access.

Staff respondents received the link to the online survey hosted on the Research Data Collection Service (REDCap) survey tool (University College London, 2021) once the POS interview had been completed. Respondents were asked to complete the survey within two weeks. In the first instance respondents were asked to complete the online survey without study team assistance, but if assistance required respondents were instructed to contact me.

When response was not received within two weeks, I followed up with up to two emails, and one phone call. For respondents from whom I received no response, I contacted the service manager and the regional operational manager to ask them to follow up or allocate a new respondent. When new respondent was allocated, I followed the same process (survey sent plus two follow up emails). Where no response was received data were treated as missing.

Participant enrolment and consent processes

The study inclusion criteria (outlined below) include participants with varying degrees of support needs. To do so ethically requires that the participant’s capacity to consent to research is considered in relation to this specific activity as per guidelines outlined in the Mental Capacity Act 2005 (Department of Health, 2005). A thorough protocol was developed for participant enrolment to ensure that adequate assessment of concurrent participant capacity to provide independent consent was conducted. This protocol is illustrated in figure 2.1 and described below.

- ***Inclusion criteria***: adults aged over 18 with whom Mencap holds a contract to provide at least three hours of support at home, and for whom a POS interview is being planned by Mencap in the next six months. It is feasible for the participant to be interviewed, and the participant consents.
- ***Exclusion criteria:*** There were no specific exclusion criteria except for people who do not meet the inclusion requirements.

I. Participant Identification

Identification of prospective participants was managed by the study partner, Mencap, through engagement with service managers. A recruitment notice was placed in Mencap’s autumn/winter 2021 internal newsletter (see document A1 in appendix G) to service managers inviting them to recommend people who met inclusion criteria from the people supported in the services they manage to take part in the study. Details of the study and the recruitment notice were also on the agenda of all regional management meetings from December 2021 through to June 2022.

II. Initial assessment of capacity to provide independent consent to participate in the research study.

Advice was sought from the service manager in relation to the prospective participant’s capacity to consent to research (document A2 in appendix). Specifically, the service manager was asked to read the participant information sheet and to answer the questions:

1. In your opinion, will the potential participant be able to *comprehend and retain* information from the participant information sheet?
2. In your opinion, will the potential participant be able to *weigh or use* the information to decide whether to consent to the study or not?

If the service manager answered no to either of these questions, a consultation process was initiated. Consultation was initially sought with personal consultee (friend or family member) or with nominated consultee (staff member) where personal consultee was not available.

If the service manager answered yes to both these questions, the service manager was asked to show the prospective participant a short video which introduced the study. After watching the video, the service manager asked the prospective participant to assent to meet with an interviewer to find out more about the study. A meeting was then set up directly with the prospective participant to provide study information and seek consent. As part of this process a structured capacity assessment was undertaken with the prospective participant prior to seeking informed consent.

III. Consultation to determine whether prospective participant would likely wish to take part in the study (for participants who likely do not have capacity to consent)

The service manager was asked to identify a personal consultee, and to post or email study information (document C1 & C2 in appendix G) to the consultee. The consultee was asked to declare whether they thought the prospective participant would likely wish to take part in the study. If the personal consultee did not respond within two weeks the service manager made two attempts to contact them by phone. If the personal consultee was non-contactable, a nominated consultee was sought from among the prospective participant’s support staff. In addition to consultee opinion, the prospective participant was asked to assent to participate. Participants were withdrawn from the study if they said they did not wish to participate regardless of advice from consultees.

Lack of capacity to provide independent consent was not always equivalent to lack of capacity to self-report to POS questions. Service managers were also asked to provide an opinion on which report type would be most appropriate for use with the participant. Wherever possible participants were encouraged and supported to self-report. However, for participants who did not have capacity to provide their own answers, the service manager was asked to identify a member of staff who could answer by proxy. The member of staff must have worked directly with the participant for a minimum of three months to be eligible to provide proxy response.

IV. Participants who likely have capacity to consent to participate in a research study.

Where the service manager advised that the prospective participant likely had capacity to provide independent consent, a trained POS interviewer was allocated to the participant. The interviewer met with the prospective participant (either via MS Teams or face to face) to talk through the participant information (document B2 in appendix G) which has a capacity assessment embedded within it. The use of a brief set of questions to assess understanding has been used as part of consent conversations in previous studies e.g. (Lofthouse, 2013; Totsika, 2008). The capacity assessment asked four questions which were designed to assess the prospective participant's capacity according to the definition of capacity as set out in the Mental Capacity Act. These questions were:

- What are some of the things we are going to talk about?
- How many times do we want to speak to you?
- Are there any risks to taking part?
- What will you do if you change your mind about taking part?

If the participant was unable to provide the correct answer to any of the above questions, the interviewer did not seek participant consent to participate. Instead, the interviewer would refer to the service manager and ask that they initiate the consultation process.

If the participant was able to demonstrate capacity the interviewer proceeded to seek consent. Where consent was sought face to face prospective participants were asked to sign or otherwise mark the consent form if they had physical capacity to do so. If they did not a member of staff witnessed their verbal consent and signed on their behalf. Where consent was sought remotely the interviewer recorded consent verbally using the record function within MS Teams. A 24-hour 'cooling off' period was implemented in the study design to allow participants time to process the information and change their mind if they wished. As such all interviews were conducted at least 24 hours after consent had been obtained.

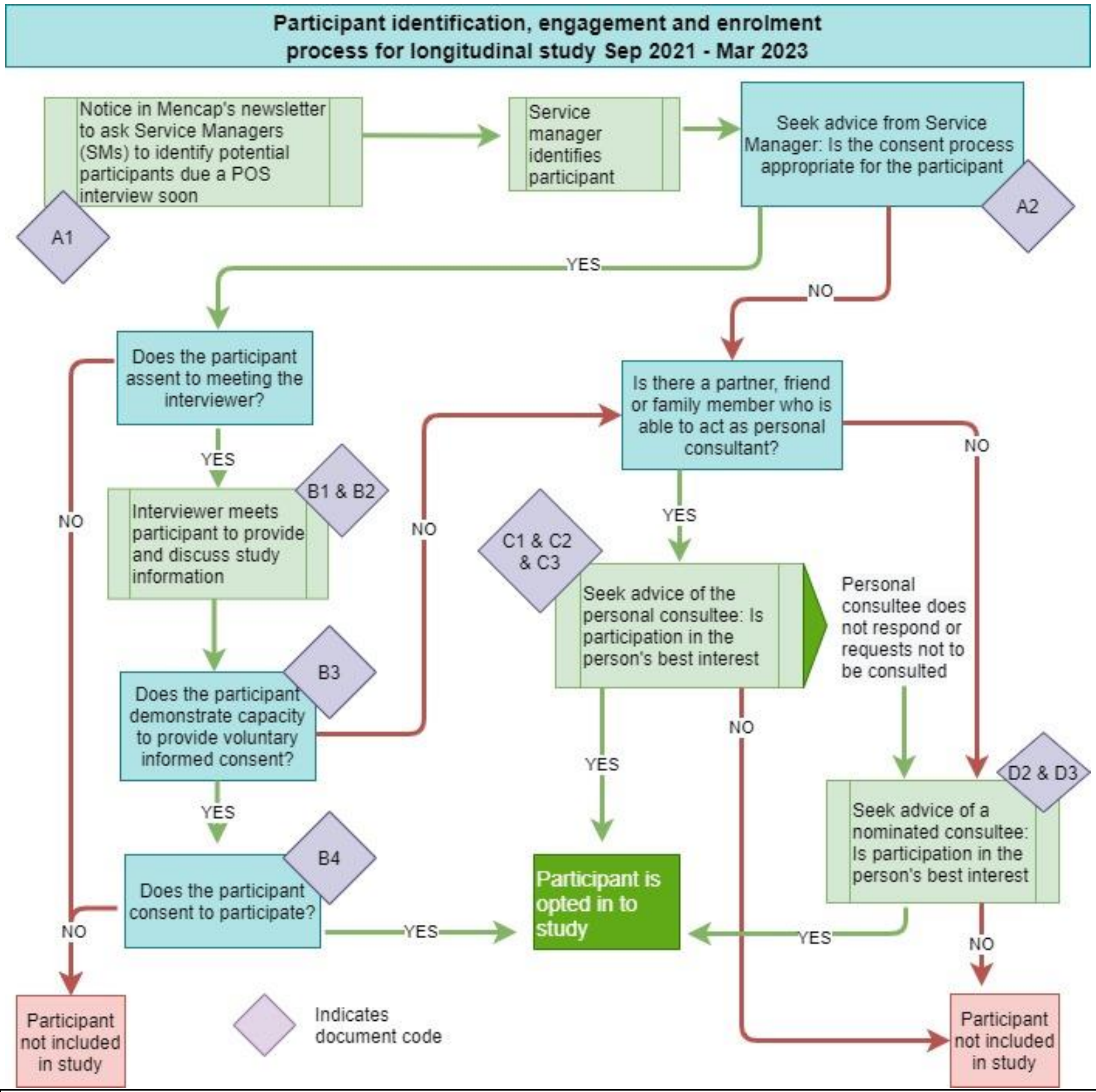
V. Withdrawal criteria and procedures

Participants were withdrawn from the study if they refused consent, or if they changed their mind after initially providing consent. The participant information provided (B2) included contact details of who should be contacted if they wished to withdraw consent. Participants could also inform a member of their support staff to make their wish to withdraw consent known to the study team.

There were a few participants who took part in the interview at T1 but did not wish to participate in the interview at T2. Analysis of pseudonymised data from T1 had already been completed by the time these participants withdrew from the study. Participants were asked if they wished data held about them to be deleted and not used in future analyses, no participant made this request.

Participants who lacked capacity to provide independent consent were withdrawn from the study if the outcome of the consultation process was that it was not in their best interest to take part. In addition, if the participant gave any indication that they did not wish to take part, then they were withdrawn from the study irrespective of the conclusion of the consultation process.

Figure 1 Enrolment and recruitment flow chart



Document key	
• A1: Recruitment notice in Mencap's Manager's newsletter. • A2: Manager's advice on participant capacity • B1: Instruction for interviewer • B2: Participant information and capacity assessment PowerPoint • B2a: Participant information print out	• B3: Capacity to consent assessment • B4: Consent form • C1: Personal Consultee letter • C2: Personal consultee information sheet • C3: Personal consultee declaration • D2: Nominated consultee information sheet. • D3: Nominated consultee declaration

Co-production of participant information

As per the Mental Capacity Act (Department of Health, 2005), prospective participants must be provided with accessible information in order to make independent decision to consent. Research studies involving people with intellectual disability often create ‘easyread’ versions of participant information sheets – incorporating principles of accessibility such as simple language, no jargon, and photos or symbols to illustrate meaning (NHS England, 2018). However, a meta-narrative review of evidence evaluating the impact of accessible information for people with intellectual disability found that adaptions had limited impact on understanding of text (Chinn & Homeyard, 2017). The provision of accessible information is defined as having two facets 1) the content of the information resource and 2) the dialogue that accompanies the provision of the information to aid understanding (Terras et al., 2021). For this project, participant information and the process of its provision, was co-produced with people with intellectual disability and staff members with experience of the provision of direct support. Co-production aimed to increase both the understanding of the information, and the number of prospective participants for whom the information was accessible.

I collaborated with three members of staff at Mencap to co-produce the participant information materials, including two Mencap staff with intellectual disability. Co-production also involved Mencap Inclusion Consultants – a group of Mencap employees with learning disability who specialise in assisting with accessibility of communication. Initially the information was provided on A4 paper with large font and the use of Photosymbols (copyright @2024 Photosymbols) to illustrate meaning. Due to the breadth of information required as a minimum by the

Research Ethics Committee (REC) the length of the document was very long. Feedback from those involved in the co-production process was that this felt overwhelming and hard.

We decided to present the information on PowerPoint document instead. The use of PowerPoint enabled information to be broken down into more digestible chunks displayed by slide, alongside appropriate pictures to illustrate meaning. Most importantly the interviewer was able to talk the participant through each slide making the delivery of information feel more like a conversation.

Another study interviewer and I observed each other testing participant information with the inclusion consultants and we made iterative changes to the information based on each test.

We found we were able to include the capacity assessment in the flow of the PowerPoint. The inclusion consultants said that this way the questions felt like part of the conversation, rather than a test which people could pass or fail. PowerPoint had the additional advantage of being fit for purpose when participant consent was sought remotely rather than face to face.

The finalised version of the participant information sheet (B2 in Appendix G) gave details of the purpose of the study and explained what would happen to the prospective participant if they chose to participate. The information made clear it was the person’s choice to participate, and that if they chose not to, this would have no effect on the service they receive from Mencap. Participants were told they had the right to change their mind, and how to do so, at any point. The information detailed any potential risk or benefits to participation. Participants were told how to raise any complaints and how to contact the study co-ordinator, or the project manager at Mencap if they needed to. They were invited to ask questions.

Challenges encountered during data collection

In the initial study protocol, I had allowed six months for each round of data collection (e.g. Jan 2022 – June 2022). However, data collection took longer than anticipated and was extended to October 2022. The primary reason for delays was rising numbers of COVID-19 infections across England in Spring 2022. The infection rate impacted data collection in the following ways:

- Outbreaks in Mencap services meant that some services were unable to participate initially. Mencap support for the study was organised through their Quality Improvement Team, and this team understandably had to prioritise coordinating organisational response to COVID-19 outbreaks.
- Staff in services continued to operate under pressurised conditions. Rising levels of COVID-19 community infections led to higher rates of staff sickness and a backlog of routine activities. This impacted the study in the following ways. Firstly, staff allocated to conduct POS interviews had to prioritise service support over study activities. Secondly, data collection required engagement with staff in services to identify participants and complete study enrolment procedures, arrange interviews, support participants through the interviews and complete the online survey for each participant. Conflicting priorities meant that staff were slow to respond to requests by interviewers to arrange interviews, and slow to complete survey requests.

As a result, very few data were collected between February – April 2022, though numbers did pick up later in the year. The online survey presented a further challenge, and numbers of complete surveys lagged behind the numbers of POS interviews throughout T1 data collection. I followed up with respondents who had completed the survey to try to understand barriers to completion. A major barrier was the length of time it took to complete (approx. 30 minutes). Respondents explained that it was rare for a support worker to have 30 minutes of uninterrupted time, and they would find when they came back to the survey following interruptions it would have timed out. Although it was possible to get back into the survey once this had happened, this required that respondents made note of the survey ID number, and most respondents instead started again. The time commitment was a significant barrier for participants who received low levels of support hours. E.g. if the participant only received five hours of support a week, it was harder for their support worker to carve out the time to complete the survey.

A further issue was how to source information, respondents explained that some of the questions were things they knew and could answer easily (e.g. daily activities), but other questions required accessing participants service registers (e.g. medicine taken). Dependent on their role, not all respondents had full access to service registers.

Finally, some respondents said they felt uncomfortable answering some of the questions from the SABS instrument without consultation with the participant. They felt that the participant should have opportunity to state what they could or could not do.

As a result of these issues by the time I closed T1 data collection there were 24 participants for whom the survey had not been completed. Although I had the

POS interview for these participants, I had access to no other data and for this their data were excluded from subsequent analyses.

To address some of the issues identified with the online survey at T1, changes were made to streamline online survey data collection in T2. Some of the items were not repeated at T2. Very low numbers of participants had accessed hospital services at T1. As a result, I did not ask these questions again at T2. The questions relating to participant medication were not repeated at T2. Two questions were added: Has the participant moved home in the last 12 months and has the participant's support package changed in the last 12 months. If the answer was no, questions related to home and support package were not asked at T2. By design, SABS data were not collected at T2. The streamlined online survey at T2 took 10 minutes to complete.

T2 data collection faced fewer challenges and, overall, there was prompt and positive response from service staff. Wherever possible, each participant or proxy respondent was interviewed by the same interviewer at both time points. However, due to staff turnover the study team was reduced and the majority of T2 interviews were conducted by me and two staff interviewers. As a result, 50% (*n* = 42) of participants were allocated a new interviewer at T2 (*n* = 27 (52%) self-report; *n* = 15 (48%) proxy report).

T2 data collected achieved an 83% response rate. Among the 17 people who did not participate in the follow-up reasons were: because they had moved service providers (*n* = 7); because of participant request to withdraw (*n* = 4); or lack of response (*n* = 5).

Description of study participants

Participants at T1 included 100 adults with intellectual disability, and sample characteristics are shown in table 2.5. The participant group was well-balanced with respect to gender (48% Male, 52% female). The average age of participants was 56.09 years (range 23 - 83 years). Participants lived either in supported living (*n* = 81; 81%), residential care services (*n* = 14; 14%) or in their family home (*n* = 3; 3%). Staff support varied from 24-hr staff presence (*n* = 84; 84%) to daily visits or less (*n* = 15). Participants mean adaptive behaviour score was 55.79 (min 2 Max 111). On average, participants received 1:1 support for 22.98 hours a week (range 0 to 168). At T2 there were 83 adults with intellectual disability still enrolled in the study, however proportionally participant characteristics did not vary greatly from T1 to T2. There was a slight increase in mean number of support hours received among participants still enrolled at T2 (Mean Difference (*MD*) = 1.84 hours).

Analysis methods for each of the studies are described in the relevant chapters.

Table 2.5 Phase two: Participant characteristics at T1 & T2

Characteristic	T1 Participants *n* = 100	T2 Participants *n* = 83
Type of QoL report		
Self-report	64 (64%)	52 (63%)
Proxy report	36 (36%)	31 (37%
Gender		
Male	48 (48%)	39 (47%)
Female	52 (52%)	44 (53%)
Age: mean (*SD*)	56.27 (14.13)	56.04 (14.26)
Missing age (*n*)	5	3
Geographic locale		
City	34 (34%)	28 (34%)
Large town	35 (35%)	30 (36%)
Small town or village	31 (31%)	25 (30%)
Type of accommodation		
Residential care home	14 (14%)	10 (12%)
Supported living	84 (84%)	68 (84%)
Family home	-	3 (4%)
Missing	2 (2%)	2 (2%)
Living alone		
Participant lives alone	17 (17%)	15 (18%)
Participant shares house with others	83 (83%)	68 (82%)
Staffing pattern		
24-hour staff presence	84 (84%)	69 (83%)
Staffed during the day, not overnight	12 (12%)	10 (12%)
Visiting staff less than once a day	3 (3%)	3 (4%)
Missing	1 (1%)	1 (1%)
Number of 1:1 hours person contracted to receive: mean (*SD*)	22.98 (31.71)	24.82 (33.56)
Adaptive behaviour score: mean (*SD*)	55.79 (26.93)	54.93 (26.78)

Chapter 3 Factor analysis of the Personal Outcomes Scale when used to measure quality of life of adults with intellectual disability in the United Kingdom

Introduction

Having an intellectual disability is associated with an increased risk of physical health conditions such as epilepsy, diabetes and asthma (Liao et al., 2021), mental health conditions such as depression or anxiety (Cooper et al., 2015) and increased experiences of isolation and loneliness (Merrells et al., 2018); conditions which are associated with poorer Quality of Life (QoL) outcomes. Supporting people to live fulfilling lives is often cited as the goal of support provision and the measurement of QoL could provide a mechanism by which to monitor the quality of support services (Lombardi et al., 2019). However, there is a lack of standardized measures of QoL in routine use and this limits comparability of approaches (Chowdhury & Benson, 2011; McCarron et al., 2019).

The Personal Outcome Scale (POS) is one measurement tool designed to measure QoL of people with intellectual disability. As I outlined in the introduction POS is based on a model of QoL developed by Schalock and Verdugo (Schalock et al., 2010). The Schalock and Verdugo model considers QoL as multi-dimensional – comprised of eight core domains, all of which must be taken into consideration to understand a person’s QoL (Schalock et al., 2010). The domains are personal development, self-determination, interpersonal relationships, social inclusion, rights, and emotional, physical, and material well-being. There is some evidence that the eight domains of QoL in this model can be aggregated into three higher order domains: independence (personal development and self-determination), social participation (interpersonal relationships, social inclusion and rights) and wellbeing (physical, mental and material wellbeing), and that this hierarchical structure may be more universally applicable across different cultural contexts than the 8-domain model (Wang et al., 2010).

Unlike some other scales (e.g. The Personal Wellbeing Index (Cummins et al., 2010); POS is designed to ensure inclusion of all people regardless of severity of communication and capacity needs. To achieve this, firstly interviewers are trained to use a semi-structured approach to administration, which enables interviewers to adjust language and context to the participant's capacity needs (Claes et al., 2008). Secondly, a proxy version of the tool was developed to enable collection of response from staff or family member where participants do not have capacity to self-report. Studies investigating inter-respondent reliability between self -report and proxy report have demonstrated moderate to high correlation (*r* = .42 to .82) across the eight QoL domains, with subjective well-being consistently demonstrating the weakest correlation across studies. Proxies tend to score participants' QoL lower than participants would themselves (Carbo-Carrete et al., 2015; Claes, Vandevelde, et al., 2012; Simoes et al., 2015). These findings are aligned with previous research across a range of QoL measurement scales, especially in subjective domains (Cummins, 2002a; Perry & Felce, 2002).

Although POS authors conducted research into the psychometric properties of POS at the time of development, they did not conduct factor analysis (Claes et al., 2008). Factor analysis is a statistical technique to evaluate how well observed data support the conceptual model a scale proposes to measure (Brown, 2015). Factor analysis assessment conducted in Spain (*n* = 529) demonstrated strong support for an eight-factor structure and adequate support for a hierarchical 8+3 factor structure (Carbo-Carrete et al., 2015). Another analysis with a larger sample (*n* = 1,264) conducted in Portugal (Simoes et al., 2015) found that eight of the 48 items from the

POS failed to load adequately and were therefore dropped from analysis on the basis that the removed items did not adequately discriminate from those retained.

When analysis was repeated with the remaining 40 items both the eight-domain model and the hierarchical 8+3 factor structure were found to have adequate fit as estimated through small Root Mean Square Error of Approximation (RMSEA ≤ .55) and large Normed Fit Indices (NFI ≥ .97) and Relative Fit Indices (RFI ≥ .95) (Simoes et al., 2015). However, the eight-domain model showed higher absolute and incremental goodness-of-fit indices, compared to the hierarchical model. (Simoes et al., 2015). Statistics indicating good fit are defined as RMSEA < .06; CFI > .95; TLI > .95 (Brown, 2015). Both these studies have confirmed that the factor structure of POS is the same regardless of the informant (Carbo-Carrete et al., 2015; Simoes et al., 2016), which supports combining self-report and proxy data for the purposes of future factor analyses.

The factor structure of POS as used in the English language has yet to be established. The differences in factor analysis findings for POS scales in Portuguese and Spanish versions demonstrate the importance of conducting factor analyses when POS is used in new settings. These studies have also not investigated the evidence for reporting POS scores as one global QoL score across all the domains or items (e.g., either a first order single factor, or a second-order factor resultant from the eight first order factors) nor have they investigated evidence in support of the three sub-domains of QoL as first order factors.

The present study aimed to address these two gaps in the evidence, drawing on existing POS data collected as part of regular service provision by the UK charity Mencap (http://www.mencap.org.uk). The first objective of this study was to test the factor structure of the 48-item POS with data from people with intellectual disability living in the UK. I also intended to replicate the factor analyses conducted in Portugal with a reduced version of POS (40-items) (Simoes et al., 2016) to examine whether this would provide a better fit. All configurations were tested by combining data from self-report and proxy report responses.

Methods

Design

POS data were collected during interviews with adults recognised by adult social care services as having an intellectual disability; and were conducted as part of routine service provision. The sample is therefore comprised of people who were selected according to service provider convenience. Demographic data were made available from service registers. A total of 350 interviews were conducted between August 2018 and December 2022 inclusive. Of these, 250 were self-report interviews and 100 were proxy report. Of the 350 interviews, 35 were repeat interviews (on the same person) and for five the proxy respondent was a family member as opposed to a staff member. These 40 interviews were excluded from analysis and thus the POS data set is comprised of 310 unique participants.

Participants

All participants were adults (18+) with intellectual disability for whom Mencap provides personal care and support. Participants lived either in supported living, residential care services or in their family home. Mencap involvement varied from a 24-hr staff presence to staff who visit once or twice a week, as required by the participant’s support needs. Mencap provided additional data to help describe participants. These included gender, age, geographic location, and date of interview.

There was a relatively large proportion of missing data relating to gender of participants (*n* = 95; 30.65%). Where gender was known there was a higher proportion of male participants (*n* = 121; 39.03%) than female (*n* = 94; 30.32%). The median age of participants was 53 years (Inter Quartile Range (IQR) 42-62 years) and participants were drawn from across England and Wales; the highest concentration (36.45%) being from around London, Southeast and East Anglia. Participant characteristics are displayed in Table 2.2 in chapter two.

As shown in table 2.2 in chapter two, most interviews were conducted in the first two years of data collection (2018-2019: 64.84%), while 88.71% of interviews were conducted prior to the start of the UK COVID-19 lockdowns. Just three quarters of interviews were self-report, and as found in previous studies mean proxy scores were about 15 points lower than those for self-report scores (Carbo-Carrete et al., 2015; Claes, Vandevelde, et al., 2012; Simoes et al., 2015).

Measures

The POS contains 48 items which are rated on a 3-point Likert scale (Claes et al., 2008). The measure is described in full in the methods chapter.

Administration

The data I used in this analysis were pre-existing data which had been collected by the charity Mencap during an organisational pilot to gage the feasibility of collecting POS data. Data were collected between June 2018 and Dec 2020. As is to be expected during a pilot there were iterative changes made to how data were collected.

Interviews were conducted by Mencap staff who had completed POS training. Many staff were involved in data collection (*n* > 54), and the number of interviews conducted per interviewer varied from 1 to 20. As a result, most interviewers were novice interviewers.

In addition to variance in interviewer experience Mencap also introduced some minor changes to item and response option wording in 2019. Changes were required as some of the item wording was ambiguous or inappropriate to a UK context, due in most part to the quality of the English translation. To address this Mencap held a workshop with six of their most experienced interviewers to review item wording.

Analysis

Confirmatory factor analysis of POS

The original eight factor 48-item POS scale was tested using Confirmatory Factor Analysis (CFA). Alternative configurations were tested using the 48 items including a 3-factor structure (independence, social participation and well-being), 8+3 higher order domains: 8+1 higher order and one global QoL factor. A reduced 40-item scale, based on findings published in a previous study (Simoes et al., 2016) was also tested using CFA.

Sample size is an important consideration for CFA, however the minimum sample required is inversely related to the model degrees of freedom (*d*) (MacCallum et al., 1996). All the models tested have large *d* due to the relatively large number of items in the POS scale (48), suggesting I can be confident that the sample is adequate to assess model fit. Factorability of the correlation matrix was further tested through Bartlett’s test of sphericity and the Kaiser-Meyer-Olkin (KMO) test of sampling adequacy. Factor analysis is dependent on a *p* value ≥ .05 for Bartlett's test, and KMO values ≥ .80.

Fit statistics are used to evaluate model fit on the basis of absolute fit, parsimony correction and comparative fit (Hu & Bentler, 1999). The use of multiple indices is recommended as the performance of fit statistics and their associated cut-off values have been demonstrated to vary according to aspects such as degree of misspecification, size of factor loadings and number of factors (Brown, 2015). Absolute fit can be evaluated though the chi-square test which assesses the magnitude of discrepancy between the sample and the fitted co-variance matrix. Small *p* values (< .005) are interpretated as confirming the null hypothesis that limited discrepancy is detected (Hu & Bentler, 1999). However, the chi-square test assumes multivariate normality and is sensitive to large or small sample sizes (Brown, 2015). As per recommendations in the literature, fit was further evaluated based on the Standardised Root Mean Square Residual (SRMR), the Tucker Lewis Index (TLI), the Comparative Fit Index (CFI) and the RMSEA (Hu & Bentler, 1999; Kline, 2015). The SRMR is a fit index which provides estimation of overall fit and values ≤ .08 were considered good fit (Brown, 2015; Hu & Bentler, 1999). An index which estimates parsimony correction (i.e. allows for fewer unknown parameters) is the RMSEA. Values ≤ .06 were considered close fit (Hu & Bentler, 1999). Comparative fit was evaluated through the CFI and the TLI; with values ≥ .95 considered good fit (Hu & Bentler, 1999).

Understanding reasons for observed fit

Descriptive statistics, including response proportions for each item and inter-item correlations were generated and inspected for evidence of problematic items (Sexton et al., 2013). As data are ordinal, polychoric correlations were calculated. To extract components from the data measured variables must be sufficiently intercorrelated, and the majority of correlations should exceed .30 (Hair et al., 2014).

Due to the semi-structured nature of administration of POS, and the large number of interviewers involved in data collection, I hypothesised that a large proportion of variance in the data set was influenced by between-interviewer variability. There are a number of ways interviewers could have introduced error into the data – this could be at participant selection e.g. in the way that they made contact and gained cooperation from participants, or it could be measurement error introduced in the way that interviewers deliver questions (West & Blom, 2017).

To explore interviewer-specific effect Multi-Level Models (MLM) with interviewer ID as random intercepts were conducted. Based on complete case analysis 36 interviewers conducted a median of two interviews each (IQR 1-3). However, the number of interviews ranged from 1 to 26. Only four interviewers conducted more than 10 interviews.

MLM allow the variance to be partitioned into two levels – POS scores were regressed on demographics (age, gender, and geographic location) and interview administration (year and type of interview) while random intercepts at level 2 (interviewer ID) allowed for clustering at that level. I initially estimated an unadjusted model and computed the Intra-class Correlation coefficient (ICC) - the proportion of variability in the total QoL score that exists between interviewers. Participant level demographic variables (age, gender, and geographic region) were then added, followed by process variables (year of interview, pre/post start of COVID-19 lockdowns, self, or proxy report) to explore if the interviewer effect was attenuated by any of these variables. Model significance was tested through the serial likelihood ratio test, which if statistically significant ($p < .05$), indicated that the covariate-adjusted model is a better fit to the data than the unadjusted model (where only the interviewer-specific random effect was included).

Missing data

The STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) diagram illustrates the patient selection process in figure 1. There were 310 unique interviews available for analysis - 236 interviews were self-report and 74 were proxy report. 270 of the interviews (87.10%) had complete data for all POS items. The greatest amount of missing data per participant was nine items but this was for only one participant. Data is missing for items if the participant chose not to answer a specific question, the answer is unknown or due to input error. As the proportion of observations with missing data was relatively small and visual inspection revealed no systematic missing data pattern or predictors of missingness, complete case analysis (n = 270) was conducted for CFA.

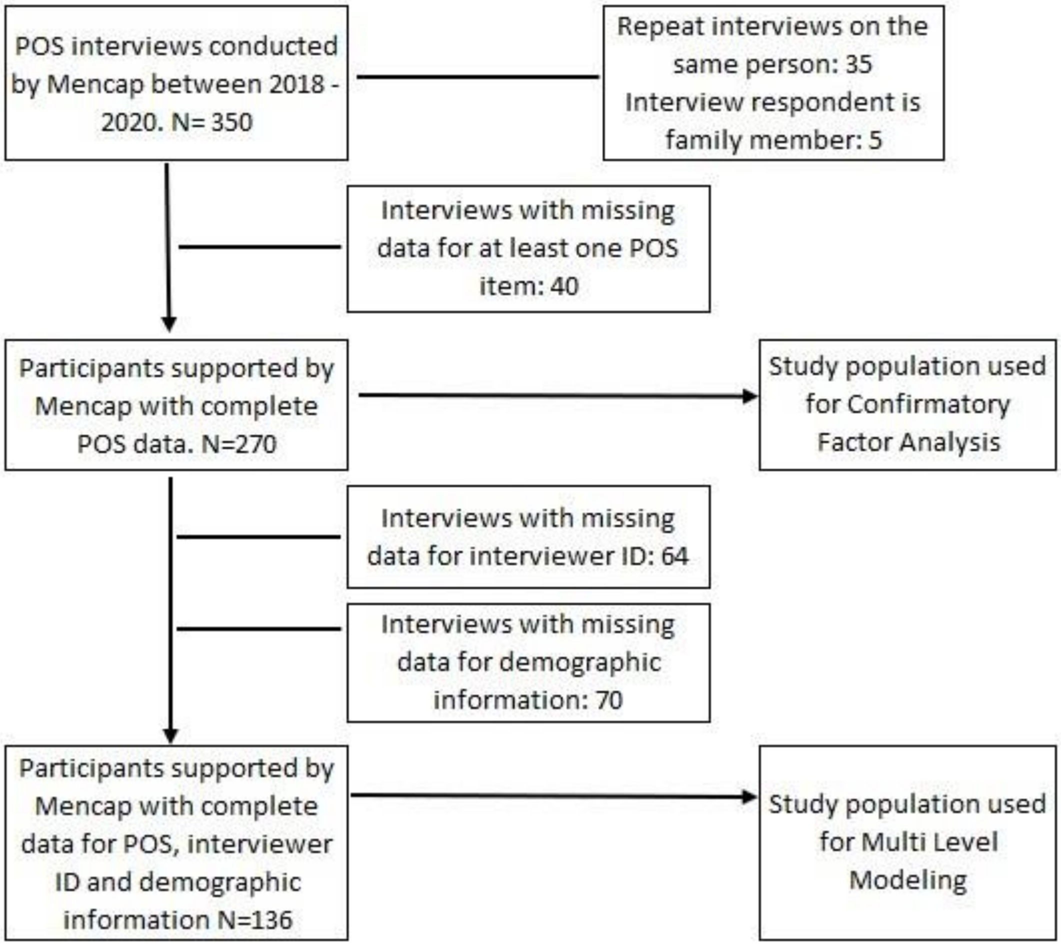
MLM analysis required data on interviewer ID and participant demographics. 64 interviews were missing data on interviewer ID, all of which were conducted prior to February 2020 when Mencap was using a less robust form of data capture (MS Forms). Data are missing through user error (leaving field blank, entering their name inconsistently e.g., just first name or initials). Because interviewer ID was used to define the higher-level group in MLM, those interviews with data missing on interviewer ID were excluded from analysis. Data were taken from Mencap service registers to provide demographic information to participant observations. However, variables are not mandatory fields on Mencap's databases and inconsistent use resulted in missing data. A further 70 observations were missing data on at least one of the following variables: interviewer ID, gender, age, or geographic location. Multilevel analysis therefore comprises a reduced sample of 136 observations across 36 interviewers. This analysis assumed that, conditional on both individual characteristics and interviewer ID being present, the data were missing completely at random.

Implementation

MPlus (version 8) was used for all factor analyses (Muthén & Muthén, 2017). For CFA the Weighted Least-Squares Mean and Variance-adjusted (WLSMV) estimator was used to account for the categorical nature of the items (Bandalos, 2014; Muthén & Muthén, 2017). Stata v17 (StataCorp, 2019) was used to describe the data and for multi-level modelling.

As the study was a secondary analysis of routinely collected service data, POS interview data and demographic information were linked by the data owners (Mencap) prior to sharing an anonymised database with the research team. Ethical approval for the current study was provided by UCL research ethics committee (Project ID: 19259/002 Appendix A).

Figure 3.1 *STROBE diagram: Illustrating selection of samples used for study analyses.*



Results

Results of confirmatory factor analyses

Results from the CFA to test the theoretical QoL measurement models are displayed in table 3.1. Fit indices indicated poor fit to the data for all possible factor structures of the 48-item scale. Items were then reduced to 40 to replicate previous CFA from Portugal (Simoes et al., 2016). However, fit did not improve with the 40-item POS data.

Table 3.1: Goodness of fit statistics for POS (*n* = 270)

Model	**Chi square (*p*)**	**CFI**	**TLI**	**RMSEA (90% CI)**	**SRMR**
8 factor, 48 items	1967.13 (< .001)	.75	.73	.06 (.05 to .06)	.12
3 factor, 48 items	2509.23 (<.001)	.55	.53	.07 (.07 to .07)	.09
8 + 3 factor 48 items	2088.96 (< .001)	.72	.71	.06 (.06 to .06)	.13
8 + 1 factor 48 items	2072.00 (< .001)	.73	.71	.06 (.06 to .06)	.13
1 factor 48 items	2362.26 (< .001)	.65	.60	.07 (.06 to .07)	.14
8 factor 40 items [a]	1357.56 (< .001)	.74	.73	.06 (.05 to .06)	.12

[a] Model includes 40 items retained following CFA with POS data in a previous study (Simoes et al., 2016)

Investigating observed model fit

Suitability of data for factor analysis

Although statistical test results indicated that data were suitable for factor analysis (*p* value: Bartlett's test < .001; KMO: .812), examination of the polychoric correlation matrix for POS data found insufficient intercorrelations. Only 44.22% of all possible between item correlations reached the minimum expected cut off .30, and a further 30.02% of possible values returned negative correlations.

Factors accounting for variance in POS scores

Examination of correlation matrices by interviewer indicated that there was variance in between-item correlation dependent on person who had conducted the interview.

To explore this further I conducted analysis on only the data which was complete across all demographic and process variables. Predicted POS score for the 136 observations when clustered by the 36 interviewers was 113.51 (95% CI 110.76 to 116.25). The variability in random intercepts for interviewers is illustrated by caterpillar plot (figure 2). The wide confidence intervals displayed are likely a result of small numbers of interviews per interviewer, nonetheless the plot depicts variation among interviewer cluster means. Unexplained interviewer level variance was calculated at 30.44 (95% CI 10.82 to 85.68) and unexplained residual variance at 88.93 (95% CI 67.83 to 116.60). The ICC statistic indicated that the proportion of total variance that is accounted for by clustering at the interviewer level was 25.50% (95% CI 00.99 to 0.516).

Models were rerun inclusive of participant characteristics and interview administration variables (see table 3.3). None of the participant characteristics was found to be significantly associated with POS score, but type of report (self or proxy) did demonstrate association. The ICC coefficient for the model with type of report included at participant level further supports the finding that a large proportion of total variance in POS score is accounted for by interviewer cluster (ICC: .24 95% CI .08 to .52).

Figure 2: Caterpillar plot: Visualising variation between interviewer (*n* = 136)

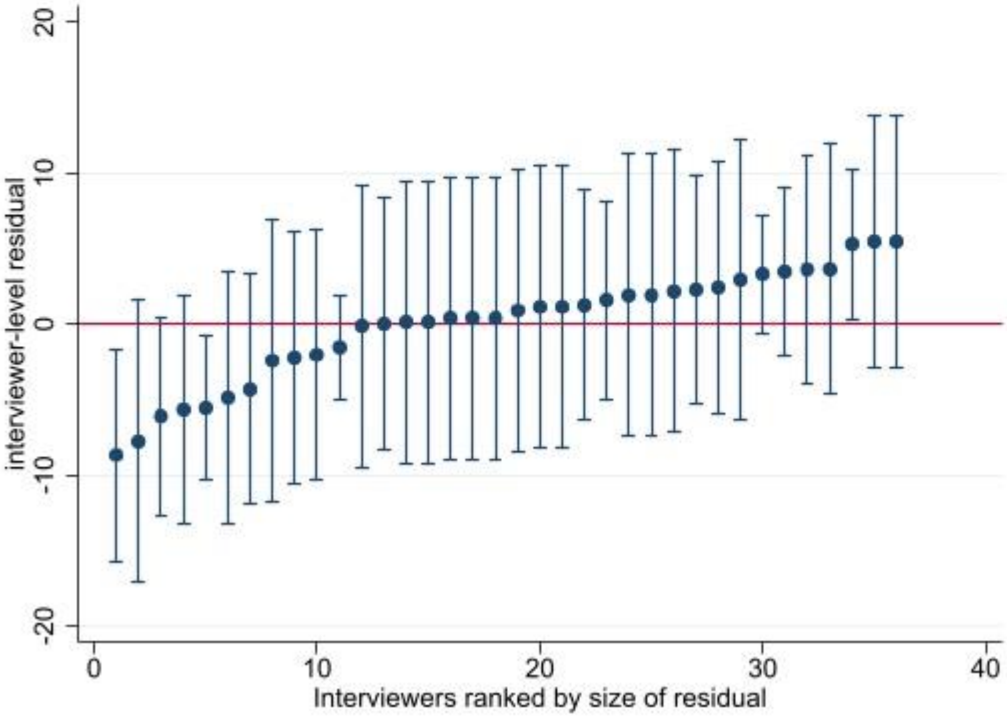


Table 3.2 Summary comparison of multi-level models (*n* = 136)

Terms	Interim model 1 (demographics) **Coefficient (95% CI)**	Interim model 2 (process) **Coefficient (95% CI)**	Final model **Coefficient (95% CI)**
	Fixed effects		
Average POS score	121.11 (113.99 to 128.23)	106.56 (100.89 to 112.23)	105.10 (101.27 to 108.93)
Gender			
- Female	1		
- Male	-3.46 (-6.91 to 0.15)		
Age	-0.09 (-0.21 to 0.03)		
Geographic area			
- London & S. E	1		
- Wales, S.W. & Central	-2.87 (-7.72 to 1.98)		
- North of England	-4.38 (-10.02 to 1.24)		
Year of interview			
- 2018		1	
- 2019		-2.01 (-6.85 to 2.82)	
- 2020		0.32 (-5.8 to 6.44)	
- 2021		-2.48 (-8.75 to 3.79)	
Type of report			
- Proxy		1	1
- Self-report		10.06 (6.23 to 13.88)	10.51 (6.81 to 14.21)
	Random effects		
- Interviewer level - variance	25.72 (8.99 to 73.53)	22.22 (6.68 to 73.91)	22.90 (7.29 to 71.97)
- Residual variance	86.16 (65.95 to 112.57)	72.59 (55.01 to 95.79)	73.21 (55.63 to 96.35)
- Intraclass coefficient	.23 (.09 to .48)	.23 (.08 to .53)	.24 (.08 to .52)
- Likelihood ratio test	chi2 = 6.37	chi2 = 29.31	
- *p* value	.173	< .001	< .001

Discussion

This study aimed to explore how well POS data from a sample of people with intellectual disability living in the UK fit the conceptual model of QoL which the scale is intended to measure. With the exception of RMSEA, fit indices indicated poor fit to the data for all tested models. Simulation studies have suggested combinational rules can be used when fit indices do not all agree with each other (Hu & Bentler, 1999). As such when RMSEA values are close to .06 as with the 8-factor model tested in the presented analysis, larger SRMR values can be indicated as acceptable fit (Hu & Bentler, 1999). However, the SRMR values reported in this study are still too large (>.09) to indicate good fit, even in the presence of acceptable RMSEA values (Hu & Bentler, 1999). Therefore, factor analyses of UK POS data did not support an 8-domain QoL model, a 3-domain, an 8+3, an 8+1, or a 1-domain QoL model.

Findings do not replicate previous evidence published from research groups in Spain and Portugal which demonstrated acceptable fit for both the 8-domain QoL model and the 8+3 domain models (Carbo-Carrete et al., 2015; Simoes et al., 2016). Potentially this could be explained by differences in participant characteristics. In both previous studies the majority of participants lived in their family home and had mild to moderate intellectual disability - in Portugal a criterion for inclusion was verbal capacity to answer the self-report measure (Simoes et al., 2016). Most participants in my sample lived in supported accommodation and data were not available to categorise participants by intellectual disability level. However, people with severe intellectual disability were included in the UK sample, and verbal capacity was not considered a pre-requisite for self-report. Where appropriate, people were supported to self-report through the engagement of communication aids and communication partners. UK data was therefore collected from people with greater variability of severity of intellectual disability than those included in previous studies. Further analysis of the data collected in Spain examined the effect of severity of intellectual disability on individual item functioning and found that the scores of a significant number of items were affected by severity (Carbo-Carrete et al., 2019). Authors suggest this indicates the need for broader discussion of the adequacy of definitions of QoL dimensions and indicators for the whole spectrum of people with intellectual disability. The poor fit found in my study may reflect in some part the question of adequacy of POS indicators when used to measure QoL of people with severe intellectual disability, but further research is required to explore this.

In my study the lack of a clear factor structure was explained mathematically by weak inter-item correlation (Hair et al., 2014). I hypothesised that this variability in item correlation may have resulted from interviewer bias – systematic error introduced through the interviewer's gathering of selective data or their influence over the participant's response (Jager et al., 2020). Multi-level models were fitted to examine the effect of interviewer and my results indicated that 23.83% of variance in POS score was accounted for by interviewer cluster.

Bias in the sample could have been introduced at selection as participants were selected according to organisation and interviewer convenience (West & Blom, 2017). (E.g. interviewers may have been more likely to approach participants at services where they already held a relationship with either staff or participants). In addition measurement error may have been introduced during the interview as interviewers are trained to apply context which is meaningful to the participant to items to aid understanding (Claes et al., 2008), and any slight variation in interviewer style or technique (e.g. being suggestive or hasty); in attitude of the interviewer; or in interviewer interpretation of items could introduce variability. A high number of staff members (> 54) were engaged in conducting interviews. This meant that some participants were interviewed by novice interviewers and their relative inexperience may have resulted in difference in item interpretation.

A review of the literature on interviewer effect (Schaeffer et al., 2010) found that survey questions which were attitudinal, sensitive, ambiguous, complex or open-ended were more likely to introduce variable interviewer effects. POS questions are not open-ended, but some could be classed as sensitive (e.g. do you think you are important to your family?); ambiguous (e.g. Are you able to demonstrate the skills that you have and the things that you can do?) or complex (e.g. Could you have a partner if you wanted one?). These types of questions may provide more opportunity for probing or using a more conversational format to deliver questions (West & Blom, 2017). Although previous studies have shown that these techniques tend to have a positive effect on response quality (West & Blom, 2017) the dynamic between interviewer and interviewee may result in higher likelihood of acquiesce bias (e.g., through leading questions) or recall bias (e.g., through excessive probing) (Bergen & Labonté, 2020). In addition, previous studies have found that interviewer demographics such as gender, age and race are related to response quality (West & Blom, 2017). In my study data related to interviewer demographics is not available to examine this further.

Increased interview standardisation has been shown to reduce interviewer effect (Jager et al., 2020), however the flexibility of scale administration is a key property to recommend POS for use with people with intellectual disability. POS authors have specified that interviewers be trained to administer the scale as a conversation, sensitive to the communication needs and styles of the person being interviewed, and ordering the questions aligned with the natural flow of conversation (Claes et al., 2008). A conventional measurement scale with fixed order and wording of items would result in the unnecessary exclusion of many people from self-report due to varying communication and comprehension needs. Theoretically, QoL must include consideration of a person's subjective experience, which pragmatically means that wherever possible the person whose QoL is being measured should be the one to rate themselves against given criteria (Schalock et al., 2010). Therefore, efforts to increase standardisation of the scale itself to reduce interviewer bias could be counterproductive by introducing selection bias into the sample.

Measures which use a semi-structured interview process to assess a quantitative metric have been shown to have good reliability (e.g. (Ford et al., 2018; Lobbestael et al., 2011), therefore the flexibility allowed in POS administration should not automatically be assumed to be a challenge to reliability. However, to my knowledge no study has formally examined inter-interviewer reliability of POS interviewer. POS data collection in both the Portuguese and Spanish studies used large numbers of interviewers and although interviewers were trained in POS administration, these studies do not report methods to ensure calibration of interviewers (Carbo-Carrete et al., 2015; Simoes et al., 2016). Data were not available to estimate inter-interviewer reliability. However, the estimated size of the proportion of variance accounted for by interviewer clustering suggests that a significant proportion of the variability introduced into POS scores was attributable to the interviewer. Further research is needed to explore the inter-interviewer reliability of the measure.

Anecdotally, flexibility in the administration results in high acceptability of the measure by support staff and participants (Mencap, personal communication, May 2022). Potentially, this flexibility is further enhanced by Mencap's employment of direct support staff as interviewers. Direct support staff are highly skilled and experienced in adjusting their communication style and tactic knowledge to the needs of the people they support (Barken & Armstrong, 2018). Authors note from observing POS interviews that interviewers clarify and avoid bias by applying context from previous questions to further explore a response. As a qualitative interview technique this demonstrates expertise (Lavee & Itzchakov, 2021), but for the purposes of extracting a quantitative score from the interview, it is dependent on interviewers sharing exact interpretation of each of the questions and response options. The questions used in the POS scale are intended to be broad enough to apply to multiple contexts, for example, the question 'Are you learning to do new things?' could refer to formal courses undertaken at college, or to tasks around the home done with one-to-one support, such as chopping vegetables. Interviewers must share awareness of the broad applicability of these items, in order to prompt interviewees further. Any slight variation in interviewer interpretation could introduce extra variability into the measure, and this may explain some of the variation seen in the results of this study.

A further consideration which may be impacting goodness of fit statistics of self-report POS data is the inclusion of both subjective and objective indicators within the domains of QoL. Schalock and colleagues position the measurement of QoL as blending two meanings of quality, "that which is commonly understood by human beings throughout the world and that which has become valued by individuals as they live their lives" (Schalock et al., 2002). Hence a key tenant within the measurement of QoL is that it must combine both objective and subjective measurement (Schalock et al., 2002). POS authors have operationalised this through the provision of proxy and self-report. Claes and colleagues note that subjective and objective indicators are two separate facets which need to be measured separately (Claes et al., 2010). As such they consider self-report to be equivalent to subjective measurement of QoL and proxy report to be equivalent to objective measurement (Claes et al., 2010). However, this simple binary is misleading as self-report as method of response is not synonymous with measuring the subjective dimension of QoL. Previous scales have collected data related to both objective and subjective indicators of QoL through self-report methods e.g. COM-QoL-ID or QOLQ (Cummins, 1991; Schalock & Keith, 2004). However psychometric analyses of these scales were unable to demonstrate good fit to the proposed models (Cummins et al., 2010; Kober & Eggleton, 2002; Verdugo et al., 2005). The lack of good fit was not however attributed to the use of self-report methods to collect objective data. Rather Cummins and colleagues attributed lack of good fit of the Com-QoL-ID data to the combination of objective and subjective items within one measure (Cummins et al., 2010).

The self-report version of POS contains both subjective and objective indicators within most domain items. For example, the domain interpersonal relationships is measured by the objective indicator: “How often do you participate in social activities like eating with friends, going to parties or meeting friends?” Alongside the subjective indicator: “Do you feel that you are important to your family?” (Claes et al., 2008). Conversely POS proxy report only collects data on indicators which are objectively verifiable. For example, although POS proxy report includes a domain related to emotional well-being, indicators are based on direct observation e.g. “How often have you seen the person show signs of happiness (smiles, grins, laughs)” (Claes et al., 2008). It is therefore more accurate to classify the POS proxy report as objective measure of QoL and the POS self-report as a measure of QoL which combines objective and subjective indicators.

Just as previous research has been unable to confirm good fit in QoL tools which have combined subjective and objective indicators within one measure (Cummins et al., 2010; Verdugo et al., 2005), the combination of these dimensions within the POS self-report may have contributed to lack of evidence of good fit.

Limitations

This study analysed data collected in the context of regular service provision by a single provider. As such, participants were recruited according to convenience, and this could have introduced selection bias into the sample. In addition, as data were only collected by one provider, I cannot say how the inclusion of participants from different providers may have influenced results. Results may not be widely generalisable.

A high degree of missing data was observed for participant demographic information, while other important participant descriptors (e.g., verbal communication skills, level of intellectual disability severity) were not available. It is therefore not possible to understand how differences between respondents interact with the psychometric properties of POS. For example, the standard deviation in POS score is much lower among participants in Northern Ireland, but I cannot explore this difference further due to the scarcity of demographic information available. The large proportion of missing demographic data resulted in reductions in the sample size available as I restricted cases according to criteria of available demographic data. In addition, the sparsity of observations per cluster resulted in less precise estimates. Although my results were not able to demonstrate a statistically significant association between POS score and gender, age, or geographic location I would caution that this is likely the result of inadequate sample for the complexity of analysis.

My results suggest that interviewer effect is compounding variability in the data already present due to the multi-item nature of the questionnaire, but I cannot conclude that other factors, such as severity of intellectual disability are not also a source of score variability. Further research is required to explore these factors.

The data I used in this analysis were pre-existing data which were collected during an organisational pilot. In the methods section I outline iterative changes made to how data were collected during the pilot, such as small changes to item wording and changes to the method of recording data. Data were not available for me to assess the impact of these changes on score variability. However, it is a reasonable assumption that irregularity of data collection may contribute towards the weak inter-item correlation found within the dataset.

Recommendations

My study findings highlight the need to establish better scoring consistency among interviewers prior to administration of the POS. During POS interviewer training, further emphasis should be placed on calibration between interviewers of interpretation of response options. Strong inter-interviewer reliability may need to be established prior to interviewing people. Aligned with methodology used in a previous study (Ford et al., 2018), interviewers could be asked to watch and independently assess recorded demonstration interviews until all interviewers reach

≥ 80% agreement with expert ratings. Following calibration of interviewers formal assessment of inter-interviewer reliability should be conducted through duplicate interviewing of the same participant (Gisev et al., 2013). The lack of studies assessing inter-interviewer reliability across any of the existing POS literature may be due to not wishing to overburden participant time. However, my study highlights that the flexibility in administration of the scale may undermine the validity of the POS and warrants investigation.

Although the results of this study were not able to confirm the factor structure of POS as a quantitative measure of QoL, the identification of systematic variability within the dataset has identified that inter-interviewer reliability is a potential limitation of the POS tool and requires further research.

I recommend that CFA be repeated on a new sample of POS data which is collected under stricter protocol to reduce the amount of variability introduced into the sample. Specifically, I recommend data be collected through a small pool of interviewers (4-6) who have demonstrated high calibration through peer observation. In addition, although there is no evidence from previous studies to suggest that self-report data has a different factor structure from proxy report, I would recommend for methodological purity that CFA should be conducted on separate samples, one to assess the factor structure of POS when self-report is used to measure QoL of adults with mild to moderate intellectual disability and one when proxy report is used to measure QoL of adults with severe or profound intellectual disability. This will allow items within the self-report data to be classified into subjective vs objective dimensions and consideration of this can be included in the factor analysis. The minimum sample size I calculated for the CFA reported in chapter three was 110-200 participants. I recommend using the upper limit of this estimate. Sample size should therefore be 200 participants for both report types.

If evidence is found to support factor structure in the new samples, I would recommend further analysis such as RASCH analysis be conducted to identify items which may be redundant in the measure (Boone, 2016). Currently the length of POS and the time it takes to administer is a significant consideration when assessing feasibility of using POS at scale (Bowling, 2014).

Chapter 4 Construct validity of the Personal Outcome Scale: Factors associated with Quality of Life of adults with intellectual disability in England

Introduction

A valid and reliable measure of QoL of adults with intellectual disability would be a powerful tool to aid understanding of how different approaches and activities make a meaningful difference to people’s lives. Studies have been conducted in other countries to evaluate the psychometric properties of POS such as reliability and validity (Carbo-Carrete et al., 2015; Claes et al., 2008; Simões, Santos, & Biscaia, 2016; Simoes et al., 2015), but they have yet to be fully assessed when POS is used to measure QoL of people with intellectual disability in England. To have confidence in results of any analysis that uses QoL as measured by POS as the outcome, it is essential that the psychometric properties of POS are shown to meet minimum requirements of reliability and validity.

Construct validity is an important step in scale evaluation. Validity refers to the ability of a set of items to measure what they are supposed to measure (Padilla, 2019). Construct validity is one way to assess this. In the case of POS, the construct under evaluation is global QoL. This construct is described in full in the introduction chapter but in sum QoL is comprised of eight domains which can be collapsed into three higher order sub-domains and includes both subjective and objective indicators of person centred outcomes (Claes et al., 2008). POS authors developed two versions of the tool, one to collect data from participant self-report and one from proxy report. Although the proxy report collects data based on observation, the items are designed to mirror each other regarding content (Claes et al., 2008).

One way to assess construct validity is the assess concurrent validity - the association of POS score with other measures of QoL (Raykov & Marcoulides, 2011). There is however no ‘gold standard’ measure of QoL for use with adults with intellectual disability, and therefore convergent validity – where scale data are compared to data from other measures which are expected on theoretical grounds to be related - is a more viable approach to testing construct validity for POS. Previous studies have compared POS data to data from the GENCAT scale (Verdugo et al., 2010) and the WHO-QOL BREF (Carbo-Carrete et al., 2015; Simoes et al., 2015; The WHOQOL Group, 1998a). GENCAT is based on the same 8-domain model of QoL as POS and is designed to capture quality of service and only collects proxy report of objective indicators of QoL (Verdugo et al., 2010). Nonetheless both self-report and proxy report POS data collected in relation to people with intellectual disability in Spain demonstrated moderate to good convergent validity with GENCAT across the eight QoL domains (Carbo-Carrete et al., 2015) Coefficients indicated stronger agreement between GENCAT and staff report (*r* = .54 to .72) than GENCAT and participant self-report (*r* = .45 to .68). WHO-QOL BREF on the other hand, only measures subjective QoL and is based on a different theoretical model of QoL than POS (The WHOQOL Group, 1998b). Concurrent validity was tested between the domains of WHO-QOL BREF (physical, psychological, social relations and environment) and the self-report POS domains using data from a sample of people with intellectual disability in Portugal. Authors only reported correlations found to be statistically significant, and these relate to POS domains of interpersonal relations, social inclusion, emotional well-being and physical well-being. Coefficients demonstrated moderate correlation between POS emotional well-being and WHOQOL BREF psychological domain (*r* = .43); and between POS physical well-being and WHOQOL BREF physical domain (*r* = .49). However there was no correlation reported between POS interpersonal relation and social inclusion and the WHOQOL BREF domain of social relations (Simoes et al., 2015). Results from these two studies demonstrate the importance of consideration of how underlying theoretical constructs overlap when choosing the alternative scale by which to assess convergence.

A proxy QoL scale which theoretically should provide points of convergence to POS is the Brief QoL scale (BQoL) (Bowring et al., 2020). BQoL is an adapted version of an earlier scale developed as an outcome measure for positive behaviour support interventions (Kincaid et al., 2002). The Schalock and Verdugo QoL model (Schalock et al., 2010) which POS is designed to measure was also taken into consideration during the development of the original version of BQoL. As such, BQoL includes indicators that tap on to five of the eight theoretical domains of QoL: interpersonal relationships, self-determination, social inclusion, personal development and emotional well-being. Hypothetically, BQoL data would be expected to be positively related to POS data, as the two scales propose to measure similar constructs.

Existing research exploring factors associated with QoL of adults with intellectual disability provides further parameters by which to assess convergent validity. There is an established body of evidence that QoL is related to adaptive behaviour skills, i.e. the greater adaptive behaviour skills a person has, the higher they are likely to score on QoL (Claes, van Hove, et al., 2012; Lombardi et al., 2016; Perry & Felce, 2005b) (Simões, Santos, Biscaia, et al., 2016). Convergent validity of POS could therefore be assessed through exploration of association with a measure of adaptive behaviour. It is also possible to assess divergent validity by comparison of POS score with constructs which are expected to have an inverse relationship with QoL such as levels of challenging behaviour (Carr et al., 2002) and depression (Rand & Malley, 2017).

A further assessment of construct validity is ‘known groups’ validity. POS scores are compared between groups which are theoretically and empirically expected to differ in QoL (Boateng, Collins, et al., 2018; Churchill, 1979). Based on available evidence, QoL of people with intellectual disability is expected to differ based on: type of accommodation (residential care vs supported accommodation (Chowdhury & Benson, 2011; Neely-Barnes et al., 2008); job status (Claes, van Hove, et al., 2012; Knüppel et al., 2018) and access to day services (Simões & Santos, 2016a). Conversely there is no expectation of difference in QoL scores based on gender (Burke et al., 2022; Rand & Malley, 2017; Simões & Santos, 2016a). The same factors were identified as associated with QoL whether data were collected through self-report or proxy.

In addition to assessment of construct validity, data presented here provide a further opportunity for exploratory analysis. The association between engagement in leisure and improvements in subjective well-being and quality of life is well established in research spanning different cultures, contexts and sub-populations (Iwasaki, 2007; Newman et al., 2014). Leisure can be defined as activities which are freely chosen and are intrinsically motivated (e.g. doing what you like) and includes activities such as sports, exercise, arts and crafts and other hobbies. There is some evidence to support the association between engagement in leisure and improvements in subjective well-being and quality of life of people with intellectual disability e.g. (Duvdevany & Arar, 2004; Hankle et al., 2022). Theoretically engagement in leisure activities can interact with multiple domains of QoL. For example, leisure activities may be group activities which can provide opportunity for people to build social relationships. Exercising choice and developing personal mastery of a hobby may positively impact identity and self-esteem. People are also likely to feel positive emotions when engaging in the activity (Brajša-Žganec et al., 2011). A previous study involving adults with intellectual disability found participation in leisure activities was predictive of better material, emotional and physical well-being (Badia et al., 2013). Support which is designed to increase a person's engagement in leisure could therefore be a key mechanism to improving quality of life.

However, a recent scoping review found that participation in leisure activities by people with intellectual disability can be limited, and this is especially the case for adults with severe and profound intellectual disability (Heister et al., 2023). People with intellectual disability face specific barriers to engagement in leisure which make it hard to attain positive outcomes. Some of these barriers are structural, especially when it comes to access to community leisure activities – such a lack of suitable organised activities, or a lack of transport to reach them (Haythorne et al., 2022). However, participation in leisure activities has been defined as consisting of play, sports, culture, crafts, hobbies, and social activities (Dijkers, 2010); activities which do not always require formal organisation.

Even in situations where people are not able to access leisure facilities there are still leisure activities which can be done at home with minimal resource which may activate this positive relationship with quality of life. Studies undertaken with the general population during the period of national lockdowns in response the COVID-19 pandemic found that engagement in at home (or nearby) leisure activities resulted in positive impact on people's well-being (Fancourt et al., 2020; Morse et al., 2021). Data collected for this study included the measure designed by Fancourt and colleagues to monitor accessible activity engagement. I collected this data because I wanted to explore if there existed a relationship between accessible leisure engagement and POS score.

Theoretically, it is clear that leisure engagement will not be the only factor which is associated with QoL, and therefore assessment of the association between leisure engagement and QoL requires consideration of other factors which are theoretically and empirically expected to be associated with QoL. The evidence presented to direct the selection of factors used to assess construct validity can also be synthesised to enable the pre-specification of a set of variables from which to model the independent association between leisure engagement and QoL. Potential confounders can be identified on the basis of previous research which has demonstrated an association between the factor and QoL score: specifically, level of adaptive behaviour skills (Heister et al., 2023; Perry & Felce, 2005b), depression (Rand & Malley, 2017), job status (Knüppel et al., 2018) type of accommodation (Chowdhury & Benson, 2011) access to day services (Simões & Santos, 2016b) and type of report (proxy vs self-report) (Simões & Santos, 2016b).

The primary aim of this study is to investigate construct validity of POS when used to measure QoL of a sample of adults with intellectual disability in England. This will be done through comparison of measures expected to converge or diverge with QoL and through comparison between those aforementioned groups that are expected to differ on QoL outcomes.

A secondary aim of this study is to explore evidence of an independent association between QoL and accessible leisure engagement, when all other variables expected to be associated with QoL are adjusted for.

Methods

Data collection

Participants included 100 adults with an intellectual disability, participants are described in full in the methods chapter. Data collection procedures are described in the methods chapter.

Measurement tools

A full description of measurement tools used in this study is provided in the methods chapter. Internal consistency assessment through alpha and omega coefficients for each of the measurement tools is provided in the methods chapter.

The personal outcomes scale (POS) (Claes et al., 2008) was used to measure QoL and the validity of this measure is the main focus of this study. Data were collected by either self-report or staff proxy report dependent on participant capacity. The Brief QoL (BQoL) (Bowring et al., 2020) was used as an alternative staff-reported measure of participant QoL. Participant adaptive behaviour skills were measured by the Short Adaptive Behaviour Scale (SABS) (Hatton et al., 2001). Depression was measured by the depression screen (Westlake et al., 2021) and challenging behaviour was measured by the Behaviour Problems Inventory - short form (BPIs) (Rojahn et al., 2012).

Leisure engagement was measured through five of the questions collected to describe the activity profile of participants on an average day (Fancourt et al., 2020). The full scale asked staff respondents to report how long the participant had spent on the last weekday engaging in eight activities: work or volunteering; housework; exercise, spending time with friends or family; arts and crafts; other hobbies; being outside; and watching TV. Each activity was rated as: Did not do, < 30 mins, 30 mins to 2 hours, > 2 hours. Respondents were asked to focus on a single day, but to avoid the cognitive burden of estimating the 'typical' day, respondents were asked to focus on the last weekday they were working with the participant. Five of the items from this scale tally with the definition of leisure provided in the introduction: exercise, spending time with friends or family; arts and crafts; other hobbies; being outside. To estimate total leisure engagement, a score ranging from 0-15 was calculated from the five items. Work or volunteering and housework were excluded from the measurement scale as although they constitute meaningful activity, they do not constitute leisure. Watching TV was excluded from the estimate of leisure engagement as this is considered a passive activity (Teychenne et al., 2010).

Approach to missing data

Missing data were examined for each of the measurement scales. Although all scales included some missing data, the number of missing items per participant was low (see Table 4.1). As there were no systematic patterns of missing data discernible in any of the scales, I defined a measure as usable if at least 90% of scale items had been completed. The breakdown of participants with usable data to allow the estimation of a scale score is provided in table 4.1. To enable comparison between analyses the same sample was used for all models, which resulted in 97 participants

Table 4.1 Number of participants with usable data

Scale name	Total number of items in scale	Maximum number of missing items possible (10%)	Number of participants with usable data
POS overall Quality of life score	48	5	100
POS Independence sub domain	12	1	100
POS Social Participation sub domain	18	2	100
POS Well-being sub domain	18	2	100
SABS (overall)	67	7	98
Brief quality of life scale	8	1	97
Leisure engagement scale	5	0	100

Approach to analysis

Study aim 1: Investigate the construct validity of POS when used to measure QoL of a sample of adults with intellectual disability in England.

Analysis will explore construct validity of the full POS scale and the three sub-scales of independence, social participation and well-being. Proxy and self-report data will be combined based on evidence presented in the introduction which suggests QoL is associated with similar factors whether measured objectively or subjectively. Assessment of internal consistency of POS data used in this study suggests good internal consistency of the overall POS score and the three subscales (independence, social participation, and wellbeing); but not the eight domains (see table 2.4 in methods chapter). Previous analyses to estimate internal consistency of POS have produced mixed results and the domain of rights and the three domains which constitute well-being have consistently fallen short of adequate internal consistency (Burke et al., 2022; Carbo-Carrete et al., 2015; Claes et al., 2008; Simoes et al., 2015). Utilising the three sub-domains as outcomes of interest is supported by recommendations made from a previous study, that the three subscales (independence, social participation, and wellbeing) should be considered more reliable psychometric scales than the eight domains (Burke et al., 2022).

Assessment of convergent validity

Based on a priori hypotheses this study explored association between POS score and two other related measures: BQoL (Bowring et al., 2020) – a brief objective measure of QoL and SABS (Hatton et al., 2001) – the measure of adaptive behaviour skills. I expected POS score to be positively associated with both BQoL and SABS score.

Convergent validity is often assessed through correlational analysis, however correlational analysis cannot quantify the association into meaningful units (Hébert & Miller, 1991). Bivariate regression analysis enables calculation of standardised beta coefficients which can be used to compare the effect of each individual independent variable to the dependent variable. I conducted bivariate regression analysis with POS as the dependent variable for each of the measurement scales. I report beta coefficient and associated *p* value.

Assessment of divergent validity

Based on a-priori hypothesis the study explored the association of participant QoL with depression and challenging behaviour. I expected to find inverse relationship to QoL for both variables, and I did not expect to find a strong association. As per the assessment of convergent validity, I conducted both correlational analysis and bivariate regression analysis. I report beta coefficients and associated *p* values.

Exploration of variability of POS data in relation to other constructs (known group validity)

Bivariate regression analysis was conducted to determine strength of association of POS score to factors expected to be associated with QoL.

Analyses assessed evidence of differentiation in POS score by type of accommodation (residential care home vs supported living or family home); job status (having a job or voluntary position vs not); and access to day services (at least once a week vs less than once a week or not at all). In addition, discriminant validity was tested by assessing if there was any evidence that POS score differentiates by gender.

Association of QoL with engagement in leisure

Study aim 2: explore evidence of an independent association between QoL and leisure engagement.

Bivariate regression analysis was conducted to explore evidence of relationship between POS and the measure of leisure engagement. To assess whether the relationship existed independently of other factors which are known to influence QoL, a multivariable model was estimated. Selection of model variables was based on assumptions drawn from empirical data about the role of independent variables e.g. those variables which are theoretically expected to be associated with QoL were selected (Heinze et al., 2018). As discussed in the introduction there is a strong evidence base that certain factors are associated with QoL and could therefore confound the strength of the relationship with leisure engagement. Variables prespecified as co-variates were therefore: adaptive behaviour score, depression score, type of accommodation, employment status, access to day services and type of report. Forced entry regression was used so that all co-variates were entered into the model at once. The model estimated allows consideration of the association between leisure engagement and POS score when other variables expected to be associated with QoL are adjusted for.

Four models were fitted to explore the association of leisure engagement with overall QoL and each of the sub-domains of independence, social participation and well-being.

Sensitivity analysis

To compare conclusions drawn from use of POS data as the outcome measure, I replicated multivariable regression analysis to estimate the independent association between leisure engagement and QoL using the alternative QoL outcome (BQoL) as the outcome measure. All statistical analyses were conducted using Stata v17.

Results

Quality of life scores

Quality of life scores are described in table 4.2. The overall mean POS score for participants was 113.87 (range 83 to 140). When compared by report type participants whose QoL had been rated by proxy scored on average 10 points lower than participants who had provided self-report data.

Table 4.2 POS scores for quality of life and its sub-domains

	Combined data (*n* = 100)		Self-report (*n* = 62)		Proxy (*n* = 35)	
Scale	Mean (*SD*)	Range	Mean (*SD*)	Range	Mean (*SD*)	Range
POS Quality of life scale	113.87 (13.66)	83 to 140	117.42 (12.14)	89 to 140	107.55 (14.08)	83 to 133
POS Independence sub domain	28.88 (4.58)	15 to 36	30.46 (3.81)	18 to 36	26.06 (4.52)	15 to 34
POS Social Participation sub domain	39.47 (6.97)	26 to 52	41.05 (6.49)	28 to 52	36.67 (7.01)	26 to 52
POS Well-being sub domain	45.52 (4.50)	34 to 54	45.91 (4.17)	35 to 54	44.83 (5.02)	34 to 52

Assessment of convergent and divergent validity

Table 4.3 displays data related to association of POS scores with other variables. Correlational analyses found evidence of moderate, positive relationship between POS score and the alternative measure of QoL: BQoL ($r = .51$). Bivariate analysis confirmed strong evidence of positive association ($\beta = .47$ $p < .001$). Analysis also confirmed evidence of moderate relationship between POS score and adaptive behaviour score ($\beta = .55$ $p < .001$).

POS data demonstrated divergence from data related to both frequency and severity of challenging behaviour (frequency $\beta = -.20$, $p = .048$; severity $\beta = -.20$, $p = .051$). Frequency and severity of self injurious behaviour demonstrated strongest evidence of divergence from POS score (frequency $\beta = -.25$, $p = .012$; severity β = -

.24, *p* = .018). There was also evidence of divergence from QoL found in data related to depression (*β* = -.20, *p* = .042).

Assessment of known group validity

Bivariate analysis confirmed association between POS data and type of report (*β* = -.35 *p* < .001), type of accommodation (*β* = .25 *p* = .014), job status (*β* = .36 *p* < .001) and access to day services (*β* = .27 *p* = .007) (see table 4.3). POS data was not associated with gender (*β* = .10 *p* = .338).

Table 4.3 Bivariate association between POS score and other variables expected to converge or diverge with QoL

Continuous variables	Mean (*SD*)	Range	Correlation coefficient (Pearson's *r*)	Beta (*p* value)
BQoL	33.30 (5.00)	18 to 40	.51	.47 (< .001)
SABS	55.79 (26.93)	2 to 101	.54	.55 (< .001)
Leisure engagement	7.00 (3.62)	0 to 15	.33	.33 (.001)
Depression	6.68 (7.06)	0 to 30	-.20	-.20 (.042)
Challenging behaviour (frequency)	3.9 (6.74)	0 to 33	-.20	-.20 (.048)
Challenging behaviour (severity)	2.04 (3.51)	0 to 17	-.20	-.20 (.051)
Self-injurious behaviour (frequency)	1.05 (2.05)	0 to 9	-.25	-.25 (.012)
Self-injurious behaviour (severity)	0.78 (1.52)	0 to 7	-.24	-.24 (.018)
Aggressive behaviour (frequency)	1.37 (2.77)	0 to 8	-.15	-.15 (.139)
Aggressive behaviour (severity)	1.26 (2.67)	0 to 12	-.12	-.13 (.223)
Stereotyped behaviour (frequency)	1.48 (3.00)	0 to 15	-.14	-.14 (.176)

Categorical variables	*n*	Mean POS score (*SD*)	Independent sample *t* test (*p* value)	Beta (*p* value)
Type of report				
Self-report	64 (64%)	117.42 (12.15)		Ref
Proxy report	36 (36%)	107.56 (14.08)	3.68 (< .001)	-.35 (< .001)
Type of accommodation				
Residential care home	14 (14%)	105.57 (14.66)		Ref
Supported living or family home	84 (84%)	115.15 (13.11)	-2.49 (.015)	.25 (.014)
Job status				
No job or voluntary position	86 (86%)	111.89 (13.33)		Ref
Participant has job or voluntary position	14 (14%)	126.00 (8.67)	-3.82 (< .001)	.36 (< .001)
Access to day services				
Less than weekly/ none	46 (46%)	109.89 (14.19)		Ref
At least weekly access	54 (54%)	117.26 (12.34)	-2.78 (.007)	.27 (.007)
Gender				
Male	48 (48%)	112.50 (14.53)		Ref
Female	52 (52%)	115.13 (12.82)	-0.96 (.338)	.10 (.338)

Assessment of validity with POS subdomains as outcome of interest

Analysis was repeated to assess the association with variables expected to converge or diverge with QoL for each of the POS sub-domains. Data are presented in table 4.4.

Independence

Bivariate analysis confirmed evidence of positive association between independence and BQoL (β = .32 *p* < .001). Analysis indicated evidence of a strong relationship between independence and adaptive behaviour score (β = .73 *p* < .001).

Independence had an inverse relationship to data related to both frequency and severity of challenging behaviour (frequency: β = -.18 *p* = .073 severity β = -.20 *p* = .051). However, *p* values are large, and the association may be due to chance. When association between type of challenging behaviour and POS score was assessed there is strong evidence of an inverse relationship between both frequency and severity of self-injurious behaviour (frequency: β = -.28 *p* = .004 severity β = -.28 *p* =.005). There is no statistical evidence of a relationship between depression and POS score (β = -.09 *p* = .399).

Bivariate analysis confirmed association between independence and type of report (β = -.46 *p* < .001), type of accommodation (β = .33 *p* = .001) and job status (β = .40 *p* < .001). There was no evidence of association between independence and access to day activities (β = .13 *p* = .198). Gender was not associated with variance in independence score (β = .13 *p* = .188)

Social participation

Bivariate analysis confirmed evidence of positive association between social participation and BQoL ($\beta = .49$ $p < .001$) and between social participation and SABS ($\beta = .38$ $p < .001$). Social participation had an inverse relationship to data related to both frequency and severity of challenging behaviour (frequency: $\beta = -.20$ $p = .049$ severity $\beta = -.21$ $p = .038$). As with independence when association between type of challenging behaviour and POS score was assessed there was strong evidence of an inverse association with self-injurious behaviour (frequency: $\beta = -.22$ $p = .031$ severity $\beta = -.22$ $p = .026$). There was no statistical evidence of a relationship between depression and POS score ($\beta = -.18$ $p = .081$).

Bivariate analysis confirmed association between social participation and type of report ($\beta = -.30$ $p = .002$), job status ($\beta = .27$ $p = .006$) and access to day activities ($\beta = .34$ $p = .001$). There was no evidence of association between social participation and type of accommodation ($\beta = .12$ $p = .254$) or gender ($\beta = .04$ $p = .678$).

Well-being

The domain of well-being was demonstrated to be positively associated with BQoL ($\beta = .38$ $p < .001$) and SABS ($\beta = .32$ $p < .001$). An inverse relationship was demonstrated between well-being and depression ($\beta = - .26$ $p = .009$). There was no evidence of a relationship between well-being and either frequency or severity of challenging behaviour (frequency: $\beta = -.12$ $p = .226$ severity $\beta = -.07$ $p = .479$).

Evidence was also found for association between well-being and type of accommodation ($\beta = .23$ $p = .025$) and between well-being and job status ($\beta = .26$ $p = .008$). Well-being was not found to be associated with type of report ($\beta = -.11$ $p = .255$), nor with access to day services ($\beta = .16$ $p = .100$) or gender ($\beta = .09$ $p = .354$).

Table 4.4 Bivariate association between POS sub-domains and other variables

Continuous variables	**Independence** Beta (*p* value)	**Social Participation** Beta (*p* value)	**Well-being** Beta (*p* value)
BQoL	.32 (.001)	.49 (< .001)	.38 (< .001)
SABS	.73 (< .001)	.38 (< .001)	.32 (.001)
Leisure engagement	.24 (.018)	.39 (< .001)	.15 (.129)
Depression	-.09 (.399)	-.18 (.081)	-.26 (.009)
Challenging behaviour (frequency)	-.18 (.073)	-.20 (.049)	-.12 (.266)
Challenging behaviour (severity)	-.20 (.051)	-.21 (.038)	-.07 (.479)
Self-injurious behaviour (frequency)	-.28 (.004)	-.22 (.031)	-.14 (.169)
Self-injurious behaviour (severity)	-.28 (.005)	-.22 (.026)	-.08 (.409)
Aggressive behaviour (frequency)	-.11 (.268)	-.16 (.114)	-.09 (.364)
Aggressive behaviour (severity)	-.09 (.335)	-.15 (.146)	-.05 (.645)
Stereotyped behaviour (frequency)	-.11 (.292)	-.15 (.137)	-.07 (.470)
Categorical variables			
Type of report (self-report vs proxy)	-.46 (< .001)	-.30 (.002)	-.11 (.255)
Type of accommodation (residential care homes vs supported living or family home)	.33 (.001)	.12 (.254)	.23 (.025)
Job status (participant has job or voluntary position vs no position)	.40 (<.001)	.27 (.006)	.26 (.008)
Access to day services (at least weekly vs less than weekly or not at all)	.13 (.198)	.34 (.001)	.16 (.100)
Gender (male vs female)	.13 (.188)	.04 (.678)	.09 (.354)

Modelling the association between QoL and leisure engagement

Correlational analysis suggested moderate relationship between POS score and leisure engagement (*r* = .33). A bivariable regression model was used to assess the relationship between POS score and leisure engagement. Evidence of a relationship was found ($\beta = .33$ $p = < .001$).

A multivariable model was estimated to assess the independent association between leisure engagement and POS score. The model accounts for 43% of variance in POS score ($R^2 = .43$) and leisure engagement constitutes the second largest beta value in the model ($\beta = .23$ $p = .024$), following adaptive behaviour score.

Table 4.5 Multivariable model: leisure engagement and POS score

*$R^2 = .43$ **Variable**	**Beta (*p* value)**
Leisure engagement	.23 (.024)
SABS score	.37 (.003)
Type of accommodation	.20 (.028)
Depression score	-.13 (.147)
Job status	.20 (.030)
Access to day services	.06 (.551)
Type of report	.02 (.851)

Multivariable analyses were repeated with POS sub-domains of independence, social participation and well-being as outcome measure. The models account for 60% of variance in independence score ($R^2 = .60$), 30% of variance in social participation score ($R^2 = .30$), and 26% of variance in well-being score ($R^2 = .26$). The higher R^2 value for the independence model is driven by strong association between adaptive behaviour score and independence score ($\beta = .63$ $p < .001$).

As shown in table 4.6, multivariable analysis was unable to demonstrate evidence of independent relationship between independence and leisure engagement ($\beta = .10$ $p = .234$) nor between well-being and leisure engagement ($\beta = .14$ $p = .218$). However, there was evidence of independent relationship between leisure engagement and social participation ($\beta = .29$ $p = .010$).

Table 4.6 Multivariable model: leisure engagement and sub-domains of QoL

	Independence	**Social Participation**	**Well-being**
R^2	.60	.30	.26
Variable	**Beta (*p* value)**	**Beta (*p* value)**	**Beta (*p* value)**
Leisure engagement	.10 (.234)	.29 (.010)	.14 (.218)
SABS score	.63 (<.001)	.15 (.275)	.25 (.080)
Type of accommodation	.21 (.004)	.12 (.269)	.21 (.042)
Depression score	-.02 (.817)	-.09 (.374)	-.24 (.019)
Job status	.13 (.088)	.17 (.098)	.21 (.042)
Access to day services	-.01 (.858)	.12 (.260)	<. 01 (.969)
Report type	.03 (.751)	-.07 (.545)	.14 (.249)

Sensitivity analysis

I repeated the analysis using the staff reported brief QoL (BQoL) measure. A multivariable model was estimated using the same variables as those input into the previous models. The model explained 35% of variance in BQoL score ($R^2 = .35$) and leisure engagement constituted the largest beta value in the model ($\beta = .46$ $p < .001$).

Model residuals were inspected and found to follow normal distribution and to demonstrate heteroscedasticity for all four reported models.

Table 4.7 Multivariable model: leisure engagement and BQoL score

*R^2 = .35 **Variable**	**Beta (*p* value)**
Leisure engagement	.46 (< .001)
SABS score	.12 (.343)
Type of accommodation	.09 (.310)
Depression score	-.16 (.080)
Job status	< -.01 (.972)
Access to day activities	.13 (.207)
Report type	-.05 (.688)

Discussion

Construct validity of POS when used to measure QoL of adults with intellectual disability in England has not been tested previously. Evidence was found in support of convergent validity of POS when data from a sample of 100 adults with intellectual disability were assessed in relation to an alternative QoL measure (BQoL) and a measure of adaptive behaviour skills (SABS). Divergent validity of POS was indicated through the inverse relationship between POS and depression and between POS and challenging behaviour. Validity of POS data was also supported through known group analysis which demonstrated that POS scores varied as expected based on type of accommodation, job status and access to day activities. In addition, as expected, no variation in POS score was associated with participant gender. When the relationship between POS sub-scales and other constructs were examined, the relative strength of association was consistent with theoretical expectations. Specifically adaptive behaviour skills were most strongly associated with the sub-scale of independence ($\beta = .73$ $p < .001$), depression score was most strongly inversely associated with well-being ($\beta = -.26$ $p = .009$) and frequency of challenging behaviour score was most strongly inversely associated with social participation ($\beta = -.20$ $p < .049$). When association with challenging behaviour was assessed by type of behaviour, evidence of the strongest association was found between frequency of self-injurious behaviour and the sub-scale of independence ($\beta = -.28$ $p < .004$).

Findings from this study are encouraging and go some way to support construct validity of POS for use with this population. Similar to findings from other studies which have accessed construct validity of POS (Carbo-Carrete et al., 2015; Claes, van Hove, et al., 2012; Simões & Santos, 2014a) evidence of weak to moderate association was found between POS score and factors expected to be associated with QoL.

The current study found that QoL as measured by POS was positively associated with leisure engagement. This association was maintained after adjustment for other factors theoretically expected to be associated with QoL. However, when models were replicated using the three subscales of POS (independence, social participation and well-being) as the outcome measure, only social participation retained the association with leisure engagement. This finding is contrary to a previous study which found that engagement in leisure was associated with the well-being subscale of QoL, but not the other subscales (Badia et al., 2013). The measure of leisure engagement used in the previous study was the Leisure Assessment Inventory (LAI) (Hawkins et al., 1998). The LAI goes beyond an assessment of frequency of leisure activities to also assess preference, interest levels and constraints which impede participation. The measure of leisure engagement used in this study was limited as it is a simple approximation of time spent doing specific activities. Leisure by definition is not just the act of doing something, but must be an activity which a person has freely chosen to do and is interested in (Buttimer & Tierney, 2005). The leisure engagement information collected in this study is unable to differentiate between activities which are freely chosen and those which are not. This may go some way to explaining why leisure engagement was found to be associated with different domains of QoL, though further research would be needed to explore this further. In addition, one of the items used to measure leisure engagement in this study collected data on time spent with friends or family. This item may replicate too closely data collected in the social participation domain of POS. It could be that the existence of interpersonal relationships is the factor creating positive impact on participant QoL, rather than time spent at leisure with the people who constitute those relationships.

The measure of leisure engagement used in this study did not specifically collect data related to community leisure activities (although some of the items may include instance of community leisure activities e.g. exercise). The five leisure engagement items are specific to accessible leisure – activities which could be done at home or in the near vicinity. This is not to suggest that the leisure choices of people with intellectual disability should be restricted by such parameters, but it is insightful that even when so restricted there exists a positive relationship between leisure and QoL. Studies have shown that support staff have a key role to play in providing opportunities for people to choose activities and to support people to participate in them. Data from this study supports recommendations from a previous study that staff time should be allocated for supporting leisure in a similar way it is to other priorities such as personal care (Zijlstra & Vlaskamp, 2005).

Limitations

This study has some limitations. Firstly, participants were drawn by convenience sampling, and cannot therefore be said to be representative of the whole population of people with intellectual disability in England. In addition, all participants were in receipt of services from the same care provider and the majority of participants were living in supported living services. Results may not be generalisable to people living in family homes, or to people receiving care from another provider.

The participant group includes a wide range of support needs as measured by the adaptive behaviour score, and this resulted in use of proxy report for some participants. Proxy and self-report data were combined in the analysis as previous research has not demonstrated evidence that QoL scores as measured by POS show differential associations with other factors dependent on type of respondent (Claes, van Hove, et al., 2012; Simões & Santos, 2016a). However, it is plausible that there is an interaction between adaptive behaviour skills and the constructs used to assess validity which may be masked by including participants with such a broad range of support needs in the same analysis. This is especially the case with the data related to challenging behaviour, as there is an established evidence base that severity of intellectual disability is associated with a higher risk of challenging behaviour (Bowring et al., 2017).

A further consideration regarding respondent is that all measures of convergent and divergent constructs were based on data collected by proxy. Comparison of self-report data across constructs may find stronger evidence of association, especially in relation to subjective domains of QoL.

Exploratory analysis found evidence of an independent association between QoL and leisure engagement when all other variables known to be associated with QoL were adjusted for. However, the measure of leisure engagement used in this study was an adaptation of a measure used to assess activity engagement in the general population and has not been tested for use with adults with intellectual disability. Items do not account for all possible activities participants could engage with. The measure also asks staff respondents to report data from the last day they worked with the participant. This may introduce bias into the measure if the last day was atypical from an average day. In sum the measure of leisure engagement used in this study was simple and needs further testing and development. However, it is perhaps an indication of the strength of the relationship between engagement in leisure and quality of life that irrespective of the simplicity of the measure used in this study evidence of significant association with QoL was still demonstrated.

Areas for further research

Data presented in this study suggest QoL as measured by POS has a moderate relationship to QoL as measured by another measure (BQoL) and moderate to weak relationship with other measures expected to be associated with QoL. Although encouraging, further research could expand measures used to assess convergent and divergent validity. Within the POS self-report tool, a number of domains collect objective data, it would be insightful to select subjective measures which could be used to assess convergent validity. For example, within interpersonal relationships, POS asks if the person has people they think of as friends, and how often they participate in social activities and spend time with friends and family. Convergent validity of these objective items could be assessed against a subjective measure such as loneliness. Similarly there are questions within the POS domain of personal development which could be compared to a subjective measure of how worthwhile a person thinks the things they do in their life are (Office for National Statistics, 2023).

Further research could look at how constructs converge when different methods of data collection are used. For example, is there a relationship between data collected through observation and POS data. The leisure engagement data collected in this study is an example of objective externally verifiable data and it may be possible that objective data could be used as a predictor of QoL. This would not necessarily replace the more in-depth collection of QoL data, but objective data could be used in the interim between QoL assessments. Hypothetically objective data may be more sensitive than a QoL measure to changes in a person’s circumstances and could therefore constitute early warning indicators. For example, repeat measures of leisure engagement would be able to detect changes in the person’s routine which may predict changes in QoL. There are other objective measures which theoretically may predict QoL for example, frequency of contact with friends and family, access to day services, exposure to negative life events. Further research is needed to first assess the relationship between QoL and these objective measures, and secondly to assess whether these measures can be used to predict future QoL outcomes. If such a relationship exists, this may support the use of externally verifiable indicators as proxy QoL outcome measures in clinical trials.

The analysis presented in this chapter supports established theories of a relationship between engagement in leisure and QoL (Duvdevany & Arar, 2004; Iwasaki, 2007) but replication of study findings among larger samples of participants are needed to confirm this. The measure of leisure engagement used in this study does not capture the full concept of leisure. Further research could use standardised measured such as the revised Guernsey community participation and leisure assessment (GPCLA-R) (Baker et al., 2021) which provides a more expansive list of leisure activities (including community engagement). Alternatively, or in addition a measure such as the LAI could be used to also assess preference and interest in the activities (Hawkins et al., 1998). The use of this more expansive measure of leisure engagement could lead to further understanding of the mechanisms by which leisure interacts with QoL for adults with intellectual disability. This would enable further exploration of how the strength of association differs in relation to the expression of preference.

Conclusion

Validity of POS is supported by score correlation with other psychological constructs (adaptive behaviour, challenging behaviour, depression) in ways which are consistent with theory. Validity is further supported by strength of correlation between POS subscales and psychological constructs. This finding, and the data presented in relation to internal consistency suggests that POS score should be interpreted in relation to the three sub-domains of QoL (independence, social participation and well-being).

Chapter 5 Sensitivity to change of the Personal Outcomes Scale when used to measure quality of life of adults with intellectual disability in England

Introduction

The collection of POS data is designed to assess the 8-domains of QoL thus enabling a person, and their support team, to identify areas or outcomes of importance to work towards, and to monitor the impact of any changes on overall QoL (van Loon et al., 2010). In addition, the QoL construct is argued to have utility beyond an individual's appraisal of their own life. Schalock and colleagues argue that QoL conceived as a multi-dimensional construct provides a means to design and evaluate the provision of support (Schalock et al., 2018). Aggregate data based on indicators of QoL can be used to evaluate services and to inform decision making on resource allocation (Schalock et al., 2018). QoL is therefore positioned as an outcome measure by which to determine impact of interventions and service improvement strategies. This utility is premised on the assumption that QoL scores are sensitive to change and can reflect change over time (Schalock et al., 2018).

According to published literature, POS has been used as outcome measure in three controlled evaluation studies. In these studies, POS was used as a secondary outcome measure of overall QoL to evaluate different types of interventions involving people with intellectual disability. Specifically, the interventions evaluated were: the application of a diagnostic guideline with the primary outcome of decreasing anxiety/depression and challenging behaviour in the Netherlands (*n* = 59) (Pruijssers et al., 2017); Autism-Competence-Group (AutCom): a psycho-educative intervention to foster social and emotional competencies in Germany (*n* = 12) (Bergmann et al., 2021); and training of staff in positive behavioural support (PBS) with the primary outcome or reducing irritability in the Netherlands (*n* = 167) (Bruinsma et al., 2024). POS proxy report was used to measure QoL for two of these interventions (Bruinsma et al., 2024; Pruijssers et al., 2017). Self-report was used to measure QoL in the evaluation of the AutCom intervention (Bergmann et al., 2021). Two of the studies only included participants with mild to moderate intellectual disability (Bergmann et al., 2021; Pruijssers et al., 2017), but the trial of PBS included participants across the spectrum of abilities (Bruinsma et al., 2024).

All three of these studies demonstrated evidence for impact of the intervention based on primary outcome measures. However, there was no evidence of improvement in QoL among study participants following either the AutCom intervention (Bergmann et al., 2021) or the application of the diagnostic guideline (Pruijssers et al., 2017). Evidence for impact of PBS on QoL was mixed as the intervention reported evidence of statistically significant improvement in the QoL domains of personal development and self-determination, yet reduction in score for the domains of inter-personal relations and social inclusion (Bruinsma et al., 2024). Authors do not report data for an overall QoL score (Bruinsma et al., 2024).

Therefore, the limited evidence available on POS as a measure of QoL in evaluation studies suggests relative stability even when change is demonstrated in factors which theoretically are assumed to be associated with QoL (e.g. mental health outcomes). POS is not the only QoL measure which has been found to remain robustly stable in response to objective change. A systematic review of the effectiveness of interventions for adults with intellectual disability identified three randomised controlled trials which tested mental health interventions and used QoL as outcome measure (Koslowski et al., 2016). QoL was measured using the Quality of Life Questionnaire (QoLQ) (Schalock & Keith, 2004), the Manchester Short Assessment of Quality of Life (MANSA) (Priebe et al., 2002), the World Health Organisation Quality of Life Scale (WHOQoL-Bref) (Lin et al., 2019) and the

Comprehensive Quality of Life Scale – Intellectual Disability (ComQoL- ID) (Cummins, 1991). However, regardless of the measure used, none of these intervention studies yielded a significant overall effect on QoL (Koslowski et al., 2016).

In the aforementioned evaluations, findings were interpreted as indicative that QoL had not changed as a result of the intervention under evaluation. None of the authors discuss the possibility that the QoL scale used may not be sensitive to change in QoL. Sensitivity to change is defined as the ability of an instrument to detect a change in state (Terwee et al., 2003).

No study to date has examined sensitivity to change of POS nor, to my knowledge, of any of the QoL measurement scales designed for use with people with intellectual disability. A systematic review of self-report QoL measurement scales for use in this population found that for the nine scales identified, there were no published data related to scale responsiveness (Li et al., 2013). While there has not been a more recent systematic review, it is unlikely that any studies since 2013 have evaluated sensitivity to change of QoL measures for people with an intellectual disability. Despite the dearth of evidence, the notion that data generated through the measurement of QoL will provide ways to evaluate programmes and services over time is integral to the justification of the utility of these tools.

Evaluation requires the use of standardised tools to measure desired outcomes against, and established guidelines are available to assess the psychometric properties of validity and reliability e.g. (Boateng, Neilands, et al., 2018). However, the assessment of sensitivity to change - considered by some to be the most essential property of an evaluative instrument (Terwee et al., 2003) - is often overlooked. The importance of sensitivity to change is even more critical when we consider that Schalock and colleagues have argued in favour of the measurement of QoL not specifically to evaluate the impact of an intervention, but more generically to monitor service quality (Schalock, 2004; Schalock et al., 2018). The service provider Mencap, with whom my study is run in partnership with, share this aspiration to use QoL as a core indicator to monitor service quality. This aspiration is central to Mencap's New Big Plan – their five-year strategy – which was launched in 2021 and in which they positioned QoL of the people they support as a key performance indicator (Royal Mencap Society, 2023). It could be argued that the magnitude of change experienced in 'service delivery as usual' would be less than that expected to result from a well-defined intervention accompanied by a theory of change. This increases the need to be confident that a scale can detect change to justify investment in routine data collection.

An indicator of sensitivity to change is data variability which is over and above that which can be attributed to measurement variation – e.g. the change in score relative to the variation among the sample (Tordrup et al., 2014). This is known as internal responsiveness, which is a dimension of sensitivity to change that complements but is distinct from external responsiveness – the extent change in a measure relates to corresponding change in a reference measure (Husted et al., 2000). The assessment of both internal and external responsiveness provides complementary information to establish a measure's sensitivity to change.

In simple pre-post designs the difference between repeated measures over time may be evaluated based on the *p* value of a paired *t* test. However, whether a change is statistically significant or not says very little about the magnitude of change, nor whether this change should be interpreted as relevant (Middel & Van

Sonderen, 2002). The calculation of a *t* test, reliant as it is on the standard error of difference, is highly influenced by sample size. Methods to estimate internal responsiveness via calculation of the Standardised Response Mean (SRM) of difference can reduce influence of sample size (Dankel & Loenneke, 2021); and SRM is the most appropriate statistic when evaluating responsiveness at group level (Terwee et al., 2003). There are examples in the literature of the application of threshold values set by Cohen (Cohen, 2013) to determine the magnitude of change on the basis of SRM values (Acaster et al., 2011; Goranitis et al., 2016). However, the use of threshold values in this way is problematic as the denominator of Cohen's Effect Size (ES) is the pooled standard deviation (SD) as opposed to the SD of change which is used to calculate SRM (Middel & Van Sonderen, 2002). Interpretation based on Cohen's thresholds may lead to over or under estimation of the magnitude of change as a result of correlation between assessments over time (Middel & Van Sonderen, 2002).To avoid this, Zou has proposed that the SRM is instead transformed into a probability of change (*P*^) (Zou, 2005). This can be interpreted as the probability that the scale scores a randomly selected 'improved' participant more highly than a randomly selected 'non improved' participant. This technique has been used to assess the responsiveness of the Warwick Edinburgh Mental Well-being Scale (WEMWBS) using adult and children samples (Maheswaran et al., 2012; Shah et al., 2018). Data from 12 studies were assessed to compute the probability of change and authors found WEMWBS to be responsive at group level for 8/12 studies. They defined responsiveness as returning a probability of change statistic (*P*^) above .7 (Maheswaran et al., 2012).

Internal responsiveness is a necessary prerequisite of external responsiveness, but further investigation is needed to understand if any detected internal responsiveness equates to true change in QoL (Husted et al., 2000). External responsiveness can be conceived of as the scale's ability to discriminate those who have improved from those who have not, as determined through change in a gold standard measure. In the absence of a gold standard measure of change in QoL, a global assessment of change (GAC) question is often used as external criterion by which to anchor change (Liang, 2000). Using GAC as an external criterion of change is a well-established methodology in research outside of the intellectual disability field e.g. (Braun et al., 2021; Schwartz et al., 2019). An example of a GAC measure which is frequently used in clinical trials is the Clinical Global Impressions-Improvement (CGI-I) scale (Busner & Targum, 2007). The clinician is asked to rate the patient's condition compared to admission on a seven-point scale from very much improved to very much worsened. This clinician assessment of change in health status or pain has been demonstrated to be strongly correlated with patient self-reported health-related QoL in a number of studies e.g. (Falissard et al., 2016; Le et al., 2013; Thwin et al., 2013). Based on this strong correlation, authors were able to use GAC as the external criterion of change to estimate the probability of the self-report measures to detect change. (Falissard et al., 2016; Le et al., 2013; Thwin et al., 2013). Findings from these studies support the use of proxy rater of global change by which to anchor change of POS score against. This approach could facilitate research in intellectual disability where not all people have the capacity to self-report on their own QoL change and, therefore, proxy expert raters from the person's close environment could provide a valid assessment for every participant.

In this study, I aim to assess sensitivity of POS data to detect change in QoL over a 12-month period in relation to both internal and external criteria. This will provide valuable insight into the utility of POS as an outcome measure for routine monitoring of services and intervention evaluations. As my study is not collecting data to evaluate a specific intervention (expected to affect QoL directly or indirectly), I do not have an experimental manipulation that exposed study participants to conditions that were very likely to have affected their QoL. As my study is a prospective, single-group design, I need to measure whether exposures likely associated with QoL change took place during the study period. For this, I shall also measure participant level change in negative life events, depressive symptomatology, and levels of engagement in leisure activity.

The selection of ‘change indicators’ was guided by evidence from previous studies. Literature supports a positive relationship between engagement in leisure activities and QoL for people with intellectual disability (Duvdevany & Arar, 2004; Hankle et al., 2022), so changes detected in leisure engagement would hypothetically be correlated to corresponding changes in QoL. A narrative review of studies involving adults with intellectual disability found some evidence that exposure to discrete stressful life events, such as moving home or bereavement are associated with greater risk of psychological disorders (Hulbert-Williams & Hastings, 2008) in people with an intellectual disability. Psychological distress and symptoms of anxiety/ depression have been found to be associated with reduced QoL in previous studies (Endermann, 2013; Rand & Malley, 2017). Therefore, it is reasonable to hypothesise that increased exposure to negative life events, and changes in depression symptomatology would be correlated to change in QoL.

In sum, my study aims to assess sensitivity to change in QoL of POS over a 12-month period through internal and external criteria; and to assess evidence that change has occurred in relation to factors which are hypothetically expected to be associated with QoL.

Methods

Data Collection

Participants were recruited from multiple supported living and residential care services across England with support from a supported/residential service provider. In the initial phase of data collection (February to October 2022) voluntary informed consent was sought from all participants following a brief assessment of mental capacity, consistent with UK legislation (Mental Health Act, 2007). Data collection for time point one (T1) took place between February and October 2022 and participants were followed up for time point two (T2), 12 months later.

POS was administered as a semi-structured interview and where participants provided self-report, interviews were most often conducted face to face at the person’s home, as opposed to proxy report which was most often conducted via MS Teams. The interview team consisted of myself and six trained interviewers who were employed by the residential provider. Interviewers had completed two days of inhouse standardised training on QoL theory and POS administration. Wherever possible each participant or proxy respondent was interviewed by the same interviewer at both time points. However, due to staff turnover and interviewers’ conflicting work priorities, only myself and two staff interviewers were still available to interview at T2. As a result, 50% (*n* = 42) of participants were allocated a new interviewer at T2 (*n* = 27 (52%) self-report; *n* = 15 (48%) proxy report). I explore the impact of allocation of new interviewer in the results section.

In addition to the POS interview, an online survey was completed by a member of staff who had known the participant for at least three months. The online survey captured data on demographic information, home and support package and the other measures used in this study.

Participants

At T1, the sample consisted of 100 adults with intellectual disability, and 83% of participants were retained at 12-month follow-up. Among the 17 people who did not participate in the follow-up, reasons were: because they had moved service providers (*n* = 7); because of study withdrawal (*n* = 4); or lack of response (*n* = 5).

For the purposes of the analysis conducted in this study, the sample consisted of the 83 participants for whom POS and survey data were available for both time points. Participants characteristics are displayed in table 2.5 in the methods chapter. Participants were well-balanced with respect to gender (47% Male; 53% female) and the average age of participants was 56 years old (range 23 to 83). Participants lived either in supported living (*n* = 68; 84%), residential care services (*n* = 10; 12%), or family home (*n* = 3, 4%). Most participants lived in homes with 24-hr staff presence (*n* = 69; 83%) but a smaller proportion lived in homes which were only staffed during the day (*n* = 10; 12%) or less than once a day (*n* = 3; 4%). Participant mean adaptive behaviour score was 54.94 (min 0 max 111 – with lower scores indicating higher levels of adaptive skills. On average, participants received 1:1 support for 24.82 hours a week (range 0 to 168).

A strength of POS is that it enables collection of QoL data in relation to people with more severe intellectual disability via the proxy report. Previous research across a range of measurement scales has shown that data collected by proxy is not directly comparable to self-report data. Proxies tend to score participants' QoL lower than participants would themselves, especially in subjective domains (Cummins, 2002a; Perry & Felce, 2002). Studies exploring the relationship between proxy and self-report POS data have demonstrated similar findings. Inter-respondent reliability coefficients between the two report types vary in strength dependent of which domain is assessed (Carbo-Carrete, Guardia-Olmos, & Gine, 2015; Claes et al., 2012; Simoes, Santos, & Claes, 2015).

Therefore, self-report and proxy report scores are similar in terms of the nature of the construct measured but not directly comparable in terms of level of QoL scores. For all analyses in this study, I consider participants who reported by proxy (*n* = 31) a distinct sub-sample from those who self-reported (*n* = 52).

Measurement tools

A full description of measurement tools used in this study is provided in the methods chapter. To assess internal consistency alpha and omega coefficients for each of the measurement tools in relation to self-report and proxy report participants are shown in table 5.2. Acceptable values of Cronbach's alpha range from α = .70 to .95 (Tavakol & Dennick, 2011). All scales used in this study fall within that range with the exception of SABS which may include some redundant items (α = .96) and the leisure engagement scale which is at the lower end of acceptable values (α = .67). Omega coefficients provide near identical assessment of internal consistency.

Table 5.1 Internal consistency of measurement scales

Scale	N	Number of items	alpha coefficient	omega coefficient
POS quality of life scale	83	48	.89	.90
POS quality of life scale (self-report participants only)	52	48	.86	.85
POS quality of life scale (proxy report participants only)	31	48	.89	.91
SABS scale	82	24	.96	.96
Brief quality of life scale	82	8	.76	.78
Depression symptoms	78	14	.90	.91
Leisure engagement score	76	5	.61	.62

Approach to analysis

Sensitivity to change of POS: Internal criterion

I calculated the means and standard deviations (*SD*) of POS scores at T1 and T2 and change in scores. Normality of distribution for change in POS score was assessed by visual inspection (histogram) and using the Shapiro-Wilk test for normality. Paired *t* tests were conducted to assess evidence of statistically significant change from T1 to T2. I conducted *t* tests to explore difference in POS change scores between participants for whom both T1 and T2 interviewers were conducted by the same person, and those for whom a different interviewer was allocated at T2.

I used the distribution of data over the two time points to estimate the probability of POS to detect true change in QoL. A probability value of 0.5 is equivalent to null responsiveness, or colloquially as good as the toss of a coin, whereas a probability of 1.0 would indicate perfect responsiveness – that is to say 100% surety that the scale can detect change. To do this, I calculated the Standardised Response Mean (SRM) of difference in POS score by dividing the mean change in POS score by the standard deviation of the mean change (Zou, 2005). The SRM was transformed to a probability of change by treating the SRM as *Z*-score and finding the corresponding value in the *Z*-table. The probability of change has been shown through previous studies to be comparable to the value assigned to Area Under the Curve (AUC) calculated through receiver operating characteristics (ROC) analysis, yet does not require external criterion of change (Zou, 2005). Therefore, I can assess the diagnostic performance of the probability of change according to established cut off values used to interpret AUC values: < .60 AUC = fail; > .60 AUC < .70 = poor; > .70 AUC > .80 = fair; > .80 AUC < .90 = good; > .90 = excellent (Nahm, 2022). Following methodology from previous studies a value of P^ > .70 can be used as binary cut off to indicate responsiveness (Maheswaran et al., 2012).

A simulation study has demonstrated that SRM analyses are reliable even in sample sizes as small as 25 (Zou, 2005). I used this method to calculate and interpret probability of change values for self-report POS data and proxy report POS data.

Sensitivity to change of POS: External criteria

Data generated from the GAC question served as the gold standard evaluation of change in QoL in this study. I followed an established methodology to categorise participants as experiencing improvement in their QoL, if the response given to the GAC question was either 'improved' or 'greatly improved' (Froud & Abel, 2014). In this way, the sample was dichotomised into those who had improved QoL and those for whom it remained stable or worsened. I calculated means and *SD* of QoL scores by report type for improved vs non-improved QoL. Statistical evidence of difference between improved vs non-improved participants was assessed through *t* tests for each type of report.

To ascertain the probability of the POS score correctly identifying participants whose QoL had improved according to external criterion, ROC curves were fitted. As a first step, I needed to assess the feasibility of fitting ROC curves for the data available. To do this, I calculated Spearman's Rho correlation coefficients between the GAC measure and the difference in POS score. To determine if there exists a relationship between the measures, a minimum correlation coefficient $r > .30$ is expected between GAC score and difference in POS score. I also needed to ensure adequacy of sample size for the proposed analysis.

Sample size requirements for ROC analysis are highly sensitive to probability of change (Serdar et al., 2021), therefore I used probability of change as estimated through the internal criterion above as the parameter for sample size estimate using the Stata module Power One-ROC (Linden, 2022). Where size of correlation coefficient and data were adequate, ROC analysis was conducted and AUC was estimated and assessed according to established cut offs (Nahm, 2022).

Sensitivity analysis with BQoL as the external criterion of change

As data are available for reliable change metrics for BQoL (Bowring et al., 2020), participants can also be dichotomised into improved vs non-improved using the BQoL measure. Sensitivity analyses were planned to repeat ROC analysis of the POS data using BQoL data as external anchor.

Evidence of change in exposures hypothesised to be associated with QoL

I calculated Pearson's correlation coefficients between leisure engagement change score and POS change score by report type to explore the hypothesis that there is a positive relationship between these two variables.

I hypothesised that there would be a negative relationship between the number of negative events a person has experienced in the time frame and change in POS score. I calculated Pearson's correlation coefficients between number of events per participant and POS change score. I calculated Pearson's correlation coefficients for depression change score and POS change score to explore the hypothesis that there is a negative relationship between these variables.

Results

Sensitivity to change of the Personal Outcome Scale: internal criteria

The mean scores at T1 and T2 and Mean Difference (*MD*) in scores for POS are shown in table 5.2. Data are presented for type of report (proxy vs self-report). Changes in QoL scores for POS proxy report showed statistically significant improvement at T2. No significant difference was found for POS self-report data (*t* = -1.29 *p* = .199).

To explore interviewer effect, I also compared *MD* in POS data for participants who had been allocated a new interviewer at T2 compared to those who had the same interviewer at both time points. There was a greater *MD* between T1 & T2 when a new interviewer was allocated at T2 for both self-report and proxy. However, difference in *MD* was much greater among proxy participants (same interviewer: *MD* 3.94 vs new interviewer *MD* 12.07) than among self-report participants (same interviewer *MD* 0.72 vs new interviewer *MD* 2.15). Results from *t* test indicated strong evidence of difference in *MD* when data collected following allocation of new interviewer is compared with data collected by the same interviewer for proxy data (*t* = -2.34 *p* = .027). There was no evidence of interviewer effect within the self-report data (*t* = -0.63 *p* = .531).

Table 5.2 T1 & T2 mean scores, change scores, paired t test

Measure	n	T1 mean score [a] (*SD*)	T2 mean score (*SD*)	Mean difference (*SD*)	Paired *t* test (*p* value)
POS (Self Report)	52	117.67 (11.71)	119.13 (11.62)	1.46 (8.11)	-1.29 (.199)
POS (Proxy report)	31	106.68 (13.73)	114.55 (11.45)	7.87 (10.39)	-4.22 (< .001)

[a] POS possible scores range from 48 – 144

Data in table 5.3 provide an estimate of the probability of change for POS. Data are presented to show probability of change by type of report. POS proxy data returned the highest likelihood of detecting change (*P*^ = .77). The probability of detecting change when using POS self-report data was only slightly greater than null responsiveness (*P*^ = .57), this is classified as failure to detect change.

Table 5.3 Sensitivity to change of POS based on internal criteria

	N	SRM of difference	Probability of change (*P*^)
POS Self Report	52	0.18	.57
POS Proxy report	31	0.76	.77

Sensitivity to change: External criteria

GAC data were used to dichotomise participants into those who had experienced improvement in QoL and those who had not. The greater proportion of participants (*n* = 47, 58%) were judged to have experienced an improvement in QoL over the 12 months of the study period. I present mean QoL score and *SD* for improver vs non-improver in table 5.4. *P* values derived from *t* tests are also presented. There was no evidence of a statistical difference between POS change score in the improver vs non-improver group for either type of POS report (Self-report *p* = .091, proxy *p* = .131).

Table 5.4 Mean QoL scores and descriptive statistics for improver vs non-improver groups (as determined by GAC)

Report type	GAC assessment of QoL	*n* (%)	Improver change in mean score (SD) 95% CI	Non-Improver change in mean score (SD) 95% CI	*P* value [a]
POS (Combined)	Improved	48 (58%)	3.75 (10.36)	4.00 (8.29)	
	Not improved	35 (42%)	0.74 to 6.76	1.15 to 6.85	.907
POS Self report	Improved	30 (58%)	-0.16 (8.33)	3.68 (7.40)	
	Not improved	22 (42%)	-3.27 to 2.94	0.39 to 6.96	.090
POS Proxy report	Improved	18 (58%)	4.54 (9.93)	10.28 (10.30)	
	Not improved	13 (42%)	-1.46 to 10.54	5.16 to 15.39	.130

[a] *P* value derived from two sample *t* test (Improver vs non improver)

Feasibility of conducting ROC analysis

Pearson’s coefficients for the association between POS self-report data and GAC data show a weak negative correlation (*r* = -.20). POS proxy report and GAC data demonstrate moderate correlation (*r* = .30). In addition, sample estimates indicated that the sample size was not adequate to proceed with a ROC analysis of the POS self-report or the POS combined data (see table 5.5). The sample estimate for the POS proxy data was three participants greater than the data collected, however I decided to proceed with the analysis allowing for a degree of uncertainty in the sample estimate.

ROC analysis

Results from ROC analysis suggest the probability that the proxy scale was able to detect change in QoL (as indicated by AUC) was moderate ($\hat{P}$ = .66).

Table 5.5 POS sensitivity to change as defined by external criteria

	n	Correlation with 5-point GAC. (Spearman's Rho coefficient)	ROC required sample size estimate for 95% CI	Area Under the Curve (AUC)
Change in POS score (combined data)	83	-.03	48+48	N/A [a]
Change in POS score (self-report data)	52	-.21	254+254	N/A [a]
Change in POS score (proxy report data)	31	.30	17+17	0.66

[a] N/A – ROC curve not fitted as both strength of correlation coefficients and sample size inadequate

Sensitivity analysis with BQoL as the external criterion of change

As indicated in the approach to analysis, the BQoL measure provided an alternative external criterion of change in QoL. Data are described in table 5.6. There was very little change in BQoL scores between T1 & T2 for either proxy or self-report POS participants (proxy *MD* = -0.90; self-report *MD* = 0.16). Statistically reliable change for BQoL requires a change score of 7.02 points (Bowring et al., 2020). However, only six participants in my study had change scores greater than 7 points. This resulted in too small a sub-sample to proceed with ROC analysis. Strength of correlation between change in QoL as measured by BQoL and change in QoL as measured by POS was weak (*r* = .12) for POS self-report participants and moderate (*r* = .32) for POS proxy participants.

Evidence of change in exposures hypothesised to be associated with QoL

Mean difference in leisure engagement score is shown in Table 5.6. Mean difference was slightly higher among participants who provided self-report POS data and participants for whom POS data were collected by proxy (self-report *MD* 1.76 vs proxy *MD* 1.16) and there was strong evidence that this difference was statistically significant among participants who provided self-report POS data (*t* = -3.06 *p* = .003). Of note, correlation coefficients between leisure engagement change score and POS change score suggest a weak correlation in a negative direction (*r* = -.19). Minimal change was recorded on the depression scale for all participants (*MD* <1 point for both groups). Correlation coefficients between depression change score and POS change score were near-zero for both proxy (*r* = .03) and self-report data (*r* = -.01).

Table 5.6 Mean difference in measurement variables from T1 to T2 and association with change in POS score

Measure	Participants by POS response type	*n*	T1 mean score (SD)	T2 mean score (SD)	Change mean score (SD)	Paired *t* test (*P* value)	Correlation with change in POS score (Pearson's *r*)
Brief Quality of Life Scale [a]	Self-report	51	34.53 (4.50)	34.37 (3.97)	0.16 (3.46)	0.32 (.748)	.12
	Proxy	31	31.03 (6.38)	31.94 (4.64)	-0.90 (4.98)	-1.01 (.320)	.32
Leisure engagement score [b]	Self-report	51	8.35 (4.40)	10.12 (3.44)	1.76 (4.12)	-3.06 (.003)	-.19
	Proxy	25	6.12 (3.66)	7.28 (2.68)	1.16 (4.38)	-1.33 (.198)	-.03
Depression scale [c]	Self-report	48	6.75 (7.73)	5.85 (6.12)	0.90 (6.68)	0.93 (.358)	-.01
	Proxy	30	6.53 (5.34)	5.90 (5.98)	0.63 (6.09)	0.57 (.573)	.03

[a] BQoL scale possible scores range from 0-40

[b] Leisure engagement scale possible scores range from 0-18

[c] Depression scale possible scores range from 0-32

Data were collected at T2 to describe experience of significant negative life events. Some events were experienced by a high proportion of participants e.g. 57% of participants had experienced a regular member of staff leaving; 25% of participants had experienced the death of a friend or family member. However, as shown in table 5.7, there was a tendency for most participants to only experience one negative event (29%) and no participant experienced more than five negative events. The median number of negative events experienced per participant was 2 (IQR 1-3). The frequency of negative events was similar in both the proxy and self-report POS participant groups. Correlation coefficients indicated weak correlation between number of negative events experienced and POS score for self-report POS participants (*r* = .15) and moderate correlation in a negative direction for proxy POS participants (*r* = -.34).

Table 5.7 Number of significant negative life events experienced by participants in the duration of the study period

Number of significant negative events experienced by participant (T2)	*n* (%)	POS self-report participants *n* (%)	POS proxy report participants *n* (%)
0	12 (14.46%)	7 (15.22%)	5 (17.85%)
1	24 (28.92%)	17 (36.96%)	7 (25.00%)
2	18 (21.69%)	12 (26.09%)	6 (21.43%)
3	10 (12.05%)	4 (8.70%)	6 (21.43%)
4	6 (7.23%)	3 (6.52%)	3 (10.71%)
5	4 (4.82%)	3 (6.52%)	1 (3.57%)
Missing	9 (10.84%)	6 (8.67%)	3 (10.33%)
Mean number of events (SD)	1.81 (1.38)	1.74 (1.37)	1.93 (1.41)
Median number of events (IQR)	2 (1 to 3)	1 (1 to 2)	2 (1 to 3)
Correlation between number of events and MD POS score (Spearman's rank)	*r* = .11	*r* = .15	*r* = - .34

Discussion

In this study I aimed to assess sensitivity of POS data to detect change when used to measure QoL of adults with intellectual disability over a 12-month period. I calculated the probability of change based on the SRM of difference for each report type. For the self-report data, the probability statistic (*P^* = .56) indicated failure to detect change, whereas there was a 'fair' probability to detect change (*P^* = .77) when looking at POS change scores from proxy respondents. To assess external responsiveness of POS to change, I used proxy (staff) judgement of the participant's global change in QoL at T2 (GAC) as the anchor measure for ROC analyses. Due to weak correlations between the GAC assessment and POS score combined with inadequate sample size, ROC analysis was not conducted using the self-report data. ROC analysis with proxy data indicated poor probability to detect change (AUC = .67).

Overall, the results suggest that, based on internal criteria there was no evidence of sensitivity to change for POS self-report data. POS has fair likelihood of detecting change in proxy report data, but, in relation to a gold-standard external criterion of change, POS is not sensitive enough to capture change.

These results could indicate that the POS measure is not responsive to change in QoL, but it is also likely that participants did not experience changes in QoL over the 12-month study period. This hypothesis is supported by evidence of minimal change in mean POS scores (Table 3) or BQoL scores (Table 7). These findings highlight that over the 12-month study period, change in QoL, whether estimated by objective indicators or a combination of objective and subjective indicators, was not large enough to reach statistical significance in the present sample.

I included a range of measures to assess exposures likely to be associated with QoL, namely negative life events, depression and leisure activity engagement. Data related to leisure engagement presented a mixed picture of change. There was evidence of small but statistically significant increase in leisure engagement among participants who provided self-report data (table 7). However, leisure engagement change score was only weakly correlated with difference in POS self-report score and the association was negative (*r* = -.19). There was no evidence of change in leisure engagement among participants for whom data were collected by proxy.

Participants experienced a low number of significant negative events (table 8). There was evidence of a moderate correlation in a negative direction between number of events and POS change score for those participants from whom POS data had been collected by proxy (*r* = -.34). The negative correlation supports the hypothesis that the experience of these events impacts negatively on QoL. However, among the sample of people who provided self-report POS data the direction of the relationship between negative events and QoL is positive, albeit the strength of correlation is weak (*r* = .15). It has been proposed that the experience of negative events increases the risk of psychological distress which is linked to reduced QoL, but this hypothesis has not been empirically tested (Hulbert-Williams & Hastings, 2008; Rand & Malley, 2017). I found no evidence of change in depression symptoms (table 7) which may suggest that the magnitude of negative event experienced was not enough to result in change in QoL. The association between negative life events, mental health and QoL needs further research.

In summary, the changes captured across the different measures of exposures used in this study are minimal, suggesting that little changed over the 12-month period and likely not enough to have impacted on QoL. Yet this evidence runs contrary to the GAC assessment which classified 58% of participants as having experienced improvements in QoL. While GAC is considered a valid measure of change in studies outside of intellectual disability (Frans et al., 2014; Le et al., 2013; Thwin et al., 2013), the measure has not been validated for use in studies involving people with intellectual disability.

GAC entails the use of a proxy rater to determine change in QoL, and this has inherent methodological limitations as it requires the approximation of objective observable criteria as indicators of another person's subjective experience (Perry & Felce, 2005a). I justified the choice to use GAC on the basis of evidence from previous studies which demonstrated data from physician or researcher global judgements were adequately correlated with data from self-report QoL measures (Frans et al., 2014; Le et al., 2013; Thwin et al., 2013). However, this was not the case in this study as correlation coefficients suggested a weak negative correlation between POS self-report data and staff reported GAC ($r = -.21$). The weak correlation could suggest that GAC and POS are measuring different constructs.

POS self-report is designed to evaluate QoL based on both subjective and objective indicators; however, the GAC assessment is based on the proxy rater's judgement. Previous research has only been able to demonstrate a weak relationship between a person's subjective experience and the objective conditions of their life (Cummins, 1995). It could be that GAC provides a valid assessment of change from the point of view of proxy, but this may not tally with assessment of change from the point of view of the participant.

However, objective QoL was also measured by proxy rater via the BQoL measure. Contrary to GAC data, there was no evidence of significant change in QoL as measured by BQoL (table 7). The lack of agreement between GAC and other measures used in this study suggest GAC may be an unreliable indicator of change, at least for this population. GAC assessment may be subject to multiple sources of bias. Respondents were asked to compare the participant's quality of life to that experienced 12-months ago and this may have introduced recall bias (Coughlin, 1990). Other studies which have used similar questions often use a more memorable event as the comparator (e.g. thinking back to when the patient started treatment (Fulk et al., 2010). The 12-month time period used in this study was not anchored to a specific event and it may have been difficult for respondents to pinpoint recollections around this time.

GAC measurement may also be susceptible to present state effect bias – whereby if the respondent feels that the participant's QoL is good at the time of response they will rate their status as improved, regardless of prior state (Meyer et al., 2013). The mean POS scores for both proxy and self-report at T2 are within the uppermost quintile of total possible scores, suggesting, if valid, that participants in our sample do experience relatively good QoL, and it is therefore plausible that present state effect results in the perception of a higher proportion of 'improvers'. Social desirability bias (Blome & Augustin, 2015) may also be at play, as staff may not differentiate the negative assessment of the participant's QoL from a negative self-appraisal of the quality of support that staff offer.

Overall, when data from all measured exposures are considered, the validity of GAC is uncertain, and it is more likely, based on other data collected in this study, that participants did not experience change in QoL. The only remaining measure to indicate change in QoL is the POS data which was reported by proxy. However, the reliability of POS proxy data is disputed due to the finding that the magnitude of change was much greater among those respondents who were allocated a new interviewer at T2.

In previous analysis of a separate POS dataset, I found evidence that the person conducting the interview accounts for 24% of variance found in POS score (see chapter three). At the start of the current study, I observed each interviewer twice and observation data was used to assess inter-interviewer reliability. Kappa statistic indicated very good interrater reliability (*k* = .87). However, as this was based on observation of interviews rather than comparison of data from two raters independently interviewing the same participant, this statistic should be interpreted with caution.

Taken together the data in this study suggest that participants did not experience change in QoL in the 12-month study period. The finding that QoL score is relatively homogenous across time is not novel to this study. Stability of score among the general population is often explained through the presence of psychological adaptions such as response shift which maintain levels of satisfaction in the face of adversity (Ahmed et al., 2005). Response shift equates to a person providing equal assessment of their QoL over time, irrespective of change in objective circumstance, or, paradoxically, a person changing the parameters by which they judge QoL even though there has been no change in objective circumstance. This paradox can result from reprioritisation – the person values aspects of their life differently from before; reconceptualization – the person changes their definition of what QoL means to them; or recalibration - whereby things which were considered acceptable at the time are no longer so (Ahmed et al., 2005).

Response shift is often cited to explain homogeneity of score across a wide variety of objective experience among the general population. However, homogeneity of score among adults with intellectual disability is more often attributed to measurement error introduced through self-report (Finlay & Lyons, 2001). Studies hypothesise acquiescence, recall bias and the use of leading questions as factors that influence the responses of participants with ID (Cummins, 2001; Perry & Felce, 2002), and these arguments can be used to justify use of proxy measures among this population (Hatton, 1998). However, if QoL is conceived of as a relatively stable construct which tends to be scored highly through self-evaluation among the general population, this could also be the case for adults with intellectual disability (Hensel, 2001).

Limitations

Participants were recruited through convenience sampling, and this could have introduced selection bias into the sample. In addition, participants were recruited via one provider and results may not be widely generalisable to all adults with an intellectual disability in residential/supported living services. It is likely that the inclusion of participants from different providers may have introduced more heterogeneity into reported QoL score and other measures presented. The study is limited by sample size, which limited my ability to conduct all planned analyses of sensitivity to change. It is also possible that 12-months is too short a time in which to evidence change in QoL.

Areas for further research

The results suggest that POS score is not responsive to change in QoL, but I am unable to confirm whether this is a limitation of the scale itself or the absence of change in participant life during the study period. Further research is needed to adequately address this gap. I suggest the following steps.

The methodology used in this study to assess internal responsiveness could be repeated with a new sample of participants ensuring the same interviewer was used at both timepoints. This would require a minimum of 25 participants for each type of report (Zou, 2005). This would avoid the need for external criterion of change which limits study designs due to lack of gold standard measure of QoL for use with people with intellectual disability. Zou has argued that the advantage of searching for external criterion has yet to be convincingly demonstrated (Zou, 2005). However, if results again indicated a lack of sensitivity to change based on internal criteria, we would still be unclear whether this was resultant from limitations of POS or due to lack of change in participant QoL.

In addition, an experimental approach may provide a way to assess sensitivity to change in POS data against verifiable experience of change. To increase the probability of change within the study duration it may be advisable to use POS as an outcome measure in a trial of an intervention or approach which is theoretically linked to enhancement of QoL (Revicki et al., 2006), for example Positive Behavioural Support. An experimental approach would provide a two-group design to compare sensitivity to change among adults in intervention group to sensitivity to change among adults who have no planned change (control group). An index of change, similar to the significant events checklist used in this study could be used to monitor incidental difference between the groups. However, although the use of comparator group would provide robust indicators of objective change, the participant’s subjective evaluation of their QoL may still be influenced by response shift. Hence, we may predict decrease in QoL due to objective change, but response shift as a result of objective change may cause the participant to re-evaluate their subjective experience of QoL – potentially resulting in no change in QoL from the participant point of view.

Finally, regardless of methodology used to evaluate change, further investigation is needed to identify the length of time necessary for change in QoL to be expected. Schalock and colleagues state that the optimal interval to assess sensitivity to change of QoL is a yet-to-be answered empirical question (Schalock et al., 2018). Further longitudinal studies with repeat measurements spanning multiple years are required to define the optimal interval. This is particularly important in relation to constructs of subjective well-being. Data synthesis from life satisfaction scales of the general population has revealed the construct is relatively stable across time and periods of up to five years may be required before evidence of significant change is demonstrated (Diener et al., 2013). If the assumption is that QoL measurement should be conducted at intervals of longer than 12-months apart, the utility of this data to provide timely insight into continuous quality improvement will always be limited.

Recommendations

The directive that services and systems of support should be organised around the goal of better QoL for people with intellectual disability is indisputable. However, the utility of QoL as an evaluation metric is contested. I have discussed theories and evidence which suggest that QoL may be a stable construct which does not vary greatly due to objective conditions. If QoL does vary, literature suggests that the rate of change is slow. POS data presented in this study largely confirms the stability of QoL. The evaluation of services and interventions requires data from specific robust indicators which are related to the activities under evaluation and sensitive enough to provide prompt feedback to inform decisions. These indicators are likely to be drawn from measures that are externally verifiable such as measures of community participation and engagement in leisure. The evidence presented in this study suggests that POS will not provide data which can be used to evaluate change and inform decisions.

Chapter 6 The association of health and social care costs with quality of life of adults with intellectual disability in England

Introduction

The central aim of improving QoL and well-being is an organising principle behind UK social care policy and service provision for people with intellectual disability. Themes of wellbeing, social inclusion and autonomy are present in the 2021 White paper ‘People at the Heart of Care’ (Department of Health & Social Care, 2021), the Care Act (The Care Act, 2014), and Valuing people (Department of Health, 2001). However, funding for services for people with intellectual disability is finite, and little is known about the relationship between costs of services and enhancing QoL for recipients of those services. A clear overview of total costs, and their association with QoL can help policy makers make informed decisions about public resource allocation.

Economic analysis provides a framework which presents data on costs and benefits with the aim of assisting decision-makers to target funding where it will have most benefit. Yet reviews which have aimed to synthesise economic evidence related to services and interventions involving people with intellectual disability have reported that the field is understudied, and evidence is limited (Hunter, 2016; May et al., 2019; Romeo & Molosankwe, 2010).

Studies within the field of intellectual disability have assessed cost-effectiveness of specific interventions such as annual health checks (Bauer et al., 2019; Romeo, Knapp, Morrison, et al., 2009), psychotropic medication (Romeo, Knapp, Tyrer, et al., 2009) and interventions to reduce challenging behaviour (Hunter et al., 2020; Romeo, Knapp, Tyrer, et al., 2009) (Beadle-Brown et al., 2021). However, the majority of studies have assessed cost and quality of residential services, predominantly in relation to de-institutionalisation e.g. (Beecham et al., 1997; Emerson et al., 2000; Felce et al., 2008; Hallam et al., 2006; Myles et al., 2000). These studies have for the most part been characterised by small samples and much of the evidence base uses data from the 1980/90s (Felce, 2017). In addition, with the exception of one cohort (Hallam et al., 2006), studies are cross sectional and do not track service use over time. As a result, there is limited understanding of how costs might fluctuate over time. Nonetheless this body of work has established methodological guidance on how to conduct health economic analysis of the provision of services for adults with intellectual disability. As per UK NICE guidelines (NICE, 2012), costs are most commonly estimated from a perspective of NHS and personal and social services. Cost estimates are summarised by accommodation costs, staff costs, access to health and social care, access to day-time activities and access to respite e.g. (Hallam et al., 2006; Myles et al., 2000). In addition, some studies have also provided data to estimate cost from a societal perspective through inclusion of costs of informal care and income support e.g. (Doran et al., 2012).

A review published in 2020 identified 18 studies costing health and social care of people with intellectual disability, the majority (62%) based on data from the UK (Doble et al., 2020). The review pooled data to estimate mean annual societal costs for adults with intellectual disability. A key takeaway message from the findings was that a high degree of cost variation is dependent on severity of intellectual disability and age (Doble et al., 2020). Studies have consistently shown that costs are likely to increase as severity of disability increases due to increased health needs and increased level of staff support to manage activities of daily living (Beecham et al., 1997; Hallam et al., 2002; Myles et al., 2000). Health and social care costs associated with older adults (60+) tend to be lower than those associated with younger adults, predominantly because older adults are less active with regards day services or activities (Myles et al., 2000).

Exploration into the drivers of variation in costs is a key area of research within costing studies. There is evidence of additional factors associated with the cost variation beyond severity of intellectual disability and age, however findings are not consistent across studies. For example, there is some evidence that adults who present with behaviours that challenge incur higher costs than those who do not e.g. (Felce et al., 2003; Knapp et al., 2005). There is also some indication that costs vary according to factors related to service delivery such at type of service (e.g. group home vs supported living) or size of service (Felce et al., 2003; Stancliffe & Lakin, 2005). It is however hard to isolate the impact of these factors from participant characteristics, and most economic analysis provides estimates of cost variability based on models combining multiple factors.

Understanding the factors which drive variation in costs is useful but assisting policy makers to make informed decisions about resource allocation requires more information than cost estimates. There is a need to understand how costs relate to desired social outcomes (Felce, 2017). Previous studies have measured outcomes related to QoL but have tended to use measures of discrete components of QoL rather than a standardised measure of QoL (Beadle-Brown et al., 2021). These include (but are not limited to) measures of choice, social networks, community involvement, depression, activities of daily life, safety and physical health. However, studies have been unable to evidence a direct relationship between cost and social outcomes. In general, there is a consensus that adults with intellectual disability are better off living in the community, but the impact of this is not consistent across all domains of QoL (Felce, 2017). For example, there is some evidence to suggest that people living in the community may have worse health outcomes due to limited access to specialised services for intellectual disability (Chowdhury & Benson, 2011). There is also some evidence to suggest that individuals may feel less safe, or have greater exposure to prejudice when living in the community, although this has not been consistently measured (Felce, 2017). Arguably, interpretation of findings is limited by the lack of a standardised measures of QoL to determine the holistic impact of change or intervention across the whole construct of QoL and not just specific to individual indicators of QoL (Chowdhury & Benson, 2011).

Overall, studies have not been able to reach conclusions about cost effectiveness of services or interventions provided for people with intellectual disability. Although there is evidence to suggest that costs are to some degree linked to participant needs, higher spending does not equal better outcomes. In fact, it is possible that underlying variation in the outcomes services are designed to improve contributes to costs. For example, data drawn from a sample of 68 adults with intellectual disability in Ireland demonstrates an association between higher costs and poorer subjective well-being (Cronin & Bourke, 2017). Poorer levels of well-being were associated with higher levels of support, indicating that resources were being targeted to psychological need (Cronin & Bourke, 2017). This finding provides an indication that the relationship between cost and QoL outcomes is likely mediated by the interaction between need and level of support available to meet those needs.

The present study aims to explore the relationship between cost of health and social care and QoL. Data in this study were collected from a sample of 80 adults with intellectual disability in England at two time points 12-months apart (Spring/summer 2022 and Spring/summer 2023). Data were collected to identify costs from the perspective of the health and social care providers. Costs therefore include cost of accommodation, cost of support hours, cost of accessing health and social care services, and cost of access to day services and activities.

Data in this study were collected after the easing of national lockdown restrictions in England (spring/summer 2022). UK Data collected during the period of national lockdowns (December 2020 – September 2021) found people with intellectual disability were less regularly seeing health professionals than self-reported pre-pandemic levels (Flynn et al., 2022). For many people with intellectual disability the experience of being ‘locked down’ extended beyond the period of national lockdowns due to increased likelihood of the need to shield due to comorbidities, and challenges to funding, staffing or access to volunteer resource faced by groups and services which prevented them from restarting as lockdown restrictions were eased (Trip et al., 2022). When asked in September 2021 a high proportion of people with intellectual disability reported that compared to before the start of the pandemic they had reduced access to community activities and day services and they were going out less often with their support workers (Flynn et al., 2022). The collection of data over the two time points in this study enabled an exploration of trends in access and activity following the easing of national restrictions.

The study uses a standardised measure of QoL – the personal outcomes scale (POS) as the outcome metric (Claes et al., 2008). Data are first presented on the service use patterns and costs of health and social care use across the two time periods to explore if access was increasing over this time. Analysis then explores the association between health and social care costs and participant characteristics. Finally, analysis will explore the association between health and social care costs and QoL.

Methods

Data used in this study were collected during phase two of my PhD – the collection of longitudinal data over a 12-month period. Data collection procedures are described in full in the methods chapter.

Sample characteristics

The sample has been described in full in the methods chapter. The study includes participants for whom data were available at time point one (T1: March – Sep 2022) and two (T2: March – Sep 2023). Three participants living with family were excluded as it was not possible to estimate housing costs for them from the data available. The sample therefore consists of 80 participants.

Participant characteristics are given in table 6.1. Participants were well-balanced with respect to gender (49% male; 51% female) and the mean age of participants was 56.35 years old (range 23 to 83 years). Most participants lived in shared supported living (*n* = 57; 71%), with others in self-contained supported living (*n* = 13; 67%) or residential care services (*n* = 10; 13%). The mean adaptive behaviour score was 54.93 (min 2 max 97 – with lower scores indicating milder intellectual disability). Mean score related to behaviour problems was 5.49 (min 0 max 45 – higher scores indicate greater frequency and severity of behaviour problems). Behaviours categorised as aggressive were the greatest contributor to the behaviour problems score.

Table 6.1 Participant characteristics

Characteristic	**Total participants** ***n* = 80**
Type of QoL report	
Self-report	49 (61%)
Proxy report	31 (39%
Gender	
Male	39 (49%)
Female	41 (51%)
Age: mean (SD)	56.35 (14.32)
Missing age (n)	2 (2.5%)
Type of accommodation	
Residential care home	10 (13%)
Supported living (shared)	57 (71%)
Supported living (self-contained)	13 (16%)
Adaptive behaviour score: mean (SD)	54.93 (26.78)
Behaviour problems inventory: mean (SD)	5.49 (9.72)
Self-injurious behaviour: mean (SD)	1.68 (3.28)
Aggressive behaviour: mean (SD)	2.43 (5.35)
Stereotyped behaviour: mean (SD)	1.39 (3.04)

Health and social care costs

Estimation of service use

An adapted version of the client service receipt inventory (CSRI) (Beecham, 1995) was used to collect data on a range of demographics and services including type of accommodation, receipt of healthcare, social care and day services over the previous six months, and number of support hours the person is contracted to receive per week. Data collection was designed to identify costs from the perspective of health and social care providers. I collected data at two time points, 12 months apart (Time point one (T1): spring/summer 2022 and time point two (T2): spring/summer 2023). Respondent was a member of the participant's support staff.

Estimation of costs

The costs of health and social care were estimated at an individual level. A table detailing all unit costs and assumptions behind calculations is provided in supplementary materials. To summarise, unit costs were found for each service using publicly available sources – primarily the Personal Social Services Research Unit (PSSRU) unit costs 2022 (Jones et al., 2022) and combining this with utilisation data from the CSRI. All costs are expressed as weekly estimates as this follows methodology used in a previous study (Hallam et al., 2006), and because costs of accommodation presented in the PSSRU 2022 are weekly estimates (Jones et al., 2022).

Costs of accommodation

The PSSRU 2022 provides weekly costs for a package of accommodation and staffing for supported accommodation. However, costs for residential care were only provided for 2021, and the package of costs did not include rent. To account for this, I used the cost for residential care provided in 2021, and applied the PSS annual percentage increase for adult local services for 2021/22 (Jones et al., 2022). I then added the local housing allowance rate 2022/23 for a one bed property (Valuation Office Agency, 2023).

Costs of access to health care professionals

Costs of access to health professionals were estimated based on resource use data from the CSRI and the PSSRU 2022 (Jones et al., 2022). The CSRI collected data on number of contacts (with each given service) over the last six months. Unit cost for access to general practitioner (GP) is provided based on average length of consultation at 9.22 minutes (Jones et al., 2022). However, as it is recommended that people with intellectual disability are provided with a double appointment, I assumed this was the case and costed each GP appointment at twice the unit cost. PSSRU unit costs for all other health professionals are provided at cost per hour. Following consultation with our care provider partner I assumed average length of appointment at 30 minutes and therefore costed each appointment at 50% of the hourly cost provided. All costs are taken from 2022 with the exception of unit cost for optician. This cost was last detailed in the 2016 edition of the PSSRU; therefore, I applied the NHS cost inflation index to bring the cost up to 2022 levels of inflation.

Six-month cost estimate for access to health professionals was derived by multiplying the mean number of contacts made with each service by the unit cost of contact with service. The weekly mean cost of that service is estimated by taking the total cost of the service divided by the total number of service users divided by 26.07 weeks. Weekly costs were calculated

Costs of support hours

The CSRI collected data on the amount of one-to-one and shared support hours accessed by each participant. One to one support hours are defined as hours of support provided to one participant by one support worker. Shared support hours are defined as hours of support provided by one support worker but shared between people who live in the same service. The study care provider partner clarified that shared support would be shared on average between four people. The PSSRU 2022 provides a unit cost per hour of home care worker time. To estimate costs for weekly one-to-one support I multiplied cost per hour by number of one-to-one hours. To estimate cost per shared support hours I multiplied number of hours by 0.25 of the cost of home care worker time.

Costs of day activities

Unit costs are provided for client attendance at local authority own provision day care. I used this cost combined with data on frequency of attendance to estimate cost per week. In the CSRI I collected data on frequency of access to other activities such as voluntary work, adult education or recreation activities such as swimming. There was no available costing estimate for these activities, so I combined the frequency of activity with the national hourly living wage rate (Gov.uk, 2023).

Longitudinal analysis

I calculated the means and standard deviations (*SD*) of weekly costs by summary category at T1 and T2. Paired *t* tests were conducted to assess evidence of change in costs from T1 to T2.

Exploration of drivers of costs

I used scatter plots to visually inspect data from T1. Data were plotted to examine the relationship between estimated weekly costs and participant level of adaptive behaviour skills (as measured by SABS score), age and challenging behaviour (as measured by BPIs score). Data plots demonstrated that associations between weekly costs and the variables of interest were not linear. To account for non-linearity of the observed relationship, and the presence of outliers robust regression estimation techniques were used to assess the strength of the relationships (Jann, 2021). Specifically I used MM-Estimation - a combination of efficient estimation and high breakdown value (Yohai, 1987). Due to limited sample variability in costs associated with accommodation, it was not possible to estimate a model to explore drivers of cost of accommodation.

Exploration of association between quality and life and costs of care

Regression analysis was used to adjust for the effect of adaptive behaviour skills on costs. Robust regression estimation (MM-estimator) was used due to non-linearity of the relationship between costs and POS score, and the presence of outliers (Jann, 2021). To display results, I categorised study participants into QoL quintiles based on T1 POS score and calculated T1 mean adjusted weekly cost for each quintile. The use of quintiles enables the spread and skewness of POS data and its relationship to costs to be easily inspected visually.

Results

Comparison of costs over a 12-month period

Participant use of health and social care services was captured through the CRSI at two time points (T1: spring/summer 2022 and T2: spring/summer 2023). Data were collected for a range of services used in the six months prior to data collection at each time point. Costs are presented by summary category and estimated at a weekly rate.

Between T1 and T2 three participants moved home. However, all three moved from one supported accommodation to another. Therefore, unit costs for accommodation do not differ from T1 to T2. The estimated mean weekly cost of accommodation per participant is £1,806 (range £1,441 to £1,863).

Use of health care services including primary care and specialists

Costs associated with health care services are presented in table 6.2. Almost all the participants had contact with at least one health care professional in the six months prior to data collection at both time points (T1: 94% T2: 100%). Participants accessed a wide range of services; the most frequently accessed services were GP, podiatrist, dentist and optician at both T1 and T2 (see table 2). For most services there was an increase in the number of participants accessing the service at T2: (GP increased from 83% to 88%; dentist from 56% to 61%; optician from 38% to 53%). In general, participants were accessing health care services as and when they were required, and frequency of access to health care service professionals per participant was less than four contacts per service. However, a few participants were receiving services on a more regular basis, e.g., community nursing (daily *n* = 1, weekly *n* = 2), health care assistant (daily *n* = 1), physiotherapy (weekly *n* = 1) or support from the community mental health team (weekly *n* = 1).

Learning disability nurses were accessed by about a third of participants (30% at T1 and 35% at T2). About a quarter of participants accessed community nursing at T1 rising to 30% at T2. Fewer participants accessed mental health services; 11% accessed a community psychiatrist at both time points; a psychologist was accessed by 6% of participants at T1 and 8% at T2, and a similar proportion accessed an art/ music or drama therapist (6% and T1 and 9% at T2).

The cost of services is calculated on a weekly basis and displayed in table 6.2. The average weekly cost per participant of access to health care service professionals was £21 at T1, rising to £24 at T2.

Table 6.2 Health and social care utilisation in the six months preceding data collection at T1 and T2

Service	T1 (2022) *n (*% using)	Mean no. contacts in six months (range)	T2 (2023) *n (*% using)	Mean no. contact in six months (range)
Community specialist services				
Community Psychiatrist	9 (11%)	0.21 (0 to 6)	9 (11%)	0.19 (0 to 6)
Psychologist	5 (6%)	0.06 (0 to 6)	6 (8%)	0.15 (0 to 6)
Counsellor/ advocate	9 (11%)	0.21 (0 to 5)	7(9%)	0.11 (0 to 2)
Learning disability nurse	24 (30%)	0.47 (0 to 6)	28 (35%)	0.44 (0 to 4)
Primary care				
GP	66 (83%)	2.34 (0 to 11)	70 (88%)	3.38 (0 to 26)
Community health services				
Community/ district nurse	20 (25%)	3.25 (0 to 182)	24 (30%)	3.61 (0 to 182)
Dentist	45 (56%)	0.76 (0 to 9)	49 (61%)	0.73 (0 to 3)
Podiatrist	51 (64%)	1.86 (0 to 6)	49 (61%)	1.69 (0 to 6)
Optician	30 (38%)	0.39 (0 to 2)	42 (53%)	0.56 (0 to 2)
Audiologist	3 (4%)	0.05 (0 to 2)	5 (6%)	0.09 (0 to 2)
Physiotherapist	7 (9%)	0.49 (0 to 26)	7 (9%)	1.09 (0 to 62)
Occupational therapist	13 (16%)	0.33 (0 to 4)	21 (26%)	0.65 (0 to 12)
Speech and language therapist	9 (11%)	0.32 (0 to 1)	9 (11%)	0.32 (0 to 1)
Community Mental Health team member	3 (4%)	0.36 (0 to 26)	7 (9%)	0.15 (0 to 6)
Health care assistant	9 (11%)	2.37 (0 to 182)	14 (18%)	0.29 (0 to 5)
Art therapist	5 (6%)	1.06 (0 to 26)	7 (9%)	1.16 (0 to 26)
Alternative therapist (e.g. Reiki)	1 (> 1%)	0.33 (26)	5 (6%)	0.26 (0 to 12)
Social worker visit	29 (36%)	0.70 (0 to 6)	31 (38%)	0.60 (0 to 11)
All contact with health or social care services	75 (94%)	10.33 (0 to 188)	80 (100%)	12.93 (0 to 202)
Mean weekly cost estimate per participant (*SD*)	£21 (£29)		£24 (£29)	

Use of support hours

Support hours remained the same for 90% of participants from T1 to T2. Eight participants experienced changes to their support package between T1 & T2, seven participants were in receipt of increased support hours at T2 and one in receipt of decreased support hours. Table 6.3 presents data related to support hours for T1 & T2. Most participants had access to one-to-one support hours (90%) at both time points and almost three quarters of participants had access to shared support hours (T1: 73% T2: 74%). The mean number of support hours (combined one to one and shared support) per participant per week was 55 hours at T1 and 58 hours at T2. The average weekly cost of support hours per participant was £749 at T1 and £771 at T2.

Table 6.3 Estimate of weekly use of one to one and shared support hours at T1 and T2

Support hours	T1 (2022) *n* (% using)	Mean no. hours per week (range)	T2 (2023) *n* (% using)	Mean no. hours per week (range)
One to one support	72 (90%)	27.96 (3 to 168)	72 (90%)	28.28 (3 to 168)
Shared support hours	58 (73%)	40.83 (2.5 to 162)	59 (74%)	43.80 (2.5 to 162)
All support hours	80 (100%)	55.49 (3 to 168)	80 (100%)	58.49 (3 to 168)
Mean weekly cost estimate per participant	£749 (£775)		£771 (£802)	

Access to day services and social clubs

As shown in table 6.4 just under half of participants were accessing day centres at T1 (45%) and this number did not change greatly at T2 (46%). Little change was found from T1 to T2 in the proportion of participants accessing services for all other day activities. At T1, the most accessed activities were social clubs

(28%) and recreational activities such as swimming (22%). Smaller proportions of participants were accessing voluntary work (10%) or adult education (6%). The average weekly cost per participant of access to day activities was £95 at T1 rising slightly to £125 at T2.

Table 6.4 Estimate of weekly access and cost of day centre and social activities

	T1 (2022)		T2 (2023)	
Day activity	*n (%* using at least once a month)	Mean no. times accessed per week (range)	*n (%* using at least once a month)	Mean no. times accessed per week (range)
Day centre	35 (45%)	0.77 (0 to 5)	37 (46%)	1.01 (0 to 5)
Voluntary work	8 (10%)	0.10 (0 to 1)	7 (9%)	0.09 (0 to 1)
Adult education	5 (6%)	0.06 (0 to 1)	8 (10%)	0.10 (0 to 1)
Drop-in centre	6 (8%)	0.07 (0 to 1)	5 (6%)	0.04 (0 to 1)
Social club	22 (28%)	0.22 (0 to 1)	21 (26%)	0.25 (0 to 5)
Recreation (e.g. swimming horse riding - specify)	18 (22%)	0.20 (0 to 1)	23 (29%)	0.39 (0 to 5))
All day activities	47 (59%)	1.42 (0 to 6.25)	50 (63%)	1.88 (0 to 9)
Weekly cost estimate per participant	£95 (£147)		£125 (£172)	

Comparison of costs across time points

Table 6.5 presents collated weekly cost estimates by summary category for T1 & T2. Estimate costs of accommodation (£1,806) comprise the greatest proportion of costs (68%); and costs of support hours (£749) constitute 28% of total costs.

Results from paired *t* tests indicate that any difference in costs between T1 & T2 was not greater than would be expected by chance ($t = -1.80$ $p = .075$). When costs were examined by summary category, the estimated mean costs per week per participant are stable across T1 & T2. Descriptively there is an increase in mean cost of day activities from T1 (£95) to T2 (£124); however, the paired *t* test indicated no evidence that this difference was statistically significant ($t = -1.59$ $p = .116$). Due to stability of cost across time points no further longitudinal analysis was conducted.

Table 6.5 Comparison of costs from T1 to T2

	T1 (2022)			T2 (2023)			Difference	
Cost category	Mean value (*SD*)	Range	% of total costs	Mean score (*SD)*	Range	% of total costs	Mean difference (*SD*)	Paired *t* test (*p* value)
Total weekly costs	£2,671 (£796)	£1,442 to £5,746	n/a	£2,725 (£813)	£1,480 to £5,753	n/a	£54 (£270)	*t* = -1.80 *p = .075*
Weekly accommodation costs	£1,806 (£139)	£1,441 to £1,863	68%	£1,806 (£139)	£1,441 to £1,863	66%	0	n/a
Weekly cost of support hours	£749 (£775)	£577 to £922	28%	£771 (£802)	£593 to £950	28%	£22 (£213)	*t = -0.93* *p = .356*
Weekly cost of day activities	£95 (£147)	£62 to £127	4%	£124 (£172)	£86 to £162	5%	£29 (£165)	*t = -1.59* *p = .116*
Weekly cost of access to health care	£21 (£29)	£15 to £27	1%	£24 (£28)	£17 to £30	1%	£3 (£28)	*t = -0.96* *p = .830*

Association between costs and SABS

Bivariate robust regression analysis found strong evidence (*p* = .011) of an association between total weekly costs and adaptive behaviour score as measured by SABS (see table 6.6). The model estimates that for every one-point increase in SABS score (higher scores indicating greater adaptive behaviour skills) there is an associated £6.51 reduction in total costs. When examined by cost category there is strong evidence of association between support hours and SABS score (*p* = .001). Every one-point increase in SABS score is associated with £6.66 reduction in cost of support hours. Models do not support evidence of independent association between cost of day activities and adaptive behaviour skills, nor health care costs and adaptive behaviour skills.

Models exploring association of age with weekly costs indicate there may be a trend towards lower costs being associated with older age (-£4.20 95% CI: -£12.63 to £4.23), but statistical evidence is not strong enough to determine that this is not due to chance (*p* = .325). Similarly, models indicate a trend towards higher costs associated with challenging behaviour (£17.39 (95% CI: -£7.50 to £42.27), but there is a lack of strong statistical evidence to support this finding (*p* = .168).

Table 6.6 Bivariate association between weekly costs and adaptive behaviour, age and challenging behaviour

Cost category	Adaptive behaviour score (SABS)	Age	Challenging behaviour score (BPI-s)
	Regression coefficient (95% Confidence interval) *p* value	Regression coefficient (95% Confidence interval) *p* value	Regression coefficient (95% Confidence interval) *p* value
Total weekly cost	-£6.51 (-£11.46 to -£1.56) *p* = .011	-£4.20 (-£12.63 to £4.23) *p* = .325	£17.39 (-£7.50 to £42.27) *p* = .168
Support hours weekly cost	-£6.66 (-£10.52 to -£2.79) *p* = .001	-£2.38 (-£8.85 to £4.09) *p* = .466	£17.48 (-£40.19 to £75.15) *p* = .548
Day activities weekly cost	-£0.12 (-£1.06 to £0.82) *p* = .798	-£0.33 (-£1.91 to £1.25) *p* = -.675	-£0.61 (-£6.60 to £5.37) *p* = .839
Health care weekly cost	-£0.02 (-£0.11 to £0.08) *p* = .752	£0.14 (-£0.04 to £0.32) *p* = .124	£0.12 (-£0.19 to £0.41) *p* = .460

Note: Bivariate association estimated used Robust regression MM estimator

Association between costs and quality of life

QoL was measured using POS, which returns possible scores ranging from 48 to 144. High scores equate to good QoL. POS data were split into QoL quintiles, quintile 1 being comprised of participants with the highest QoL and quintile 5 the lowest QoL. Weekly costs are presented for each quintile in table 7. Mean weekly costs are presented for accommodation, support hours, day activities and access to health care. Following regression analysis to adjust for the association with adaptive behaviour skills, mean weekly costs were calculated per QoL quintile. Strength of evidence of the adjusted models is assessed through *p* value.

Mean adjusted costs suggest that people in the quintile with the highest QoL as measured by POS incur lower costs (£2,452) than those in the quintile with the lowest QoL scores (£2,634). However, the cost differential is not of great magnitude and the large *p* value (*p* = .184) associated with the adjusted model provides no evidence that the observed difference is not a result of chance. When costs per quintile are examined by cost summary category there is also little indication of change. Large *p* values do not support evidence of significant differences across any of models related to the summary categories (see table 6.7). Descriptively adjusted mean costs of support hours for people in the quintile with the highest POS scores were £407 compared to £690 for people in the quintile with the lowest POS scores. Adjusted mean costs for day activities suggest a minor decrease in cost when costs for people in the quintile with the highest POS score (£54) are compared to those in the quintile with the lowest POS score (£34). There is no notable difference in adjusted mean costs for access to health services. Data did not meet requirements to conduct MM robust regression estimation to adjust the cost of accommodation due to the lack of variability in cost estimate for accommodation.

Table 6.7 Mean health and social care costs per week by POS quintile and adjusted to account for effect of adaptive behaviour score

	Strength of evidence associated with adjusted model	Quintile 1 (POS score 127 to 133)	Quintile 2 (POS score 119 to 126)	Quintile 3 (POS score 110 to 118)	Quintile 4 (POS score 100 to 109)	Quintile 5 (POS score 83 to 99)
Mean POS score		130.53	122.82	114.13	105.5	93
Mean weekly cost (total)		£2,356	£2,792	£2,641	£2,810	£2,725
Adjusted mean weekly cost (total) [a]	*p* = .184	£2,452	£2,497	£2,542	£2,515	£2,634
Mean cost (accommodation)		£1,859	£1,833	£1,805	£1,806	£1,728
Adjusted mean cost (accommodation) [b]	n/a	n/a	n/a	n/a	n/a	n/a
Mean cost (support hours)		£423	£833	£610	£935	£920
Adjusted mean cost (support hours) [a]	*p* = .544	£407	£473	£540	£545	£690
Mean cost (day activities)		£58	£108	£209	£54	£40
Adjusted mean cost (day activities) [a]	*p* = .114	£54	£50	£46	£37	£34
Mean cost (health care)		£16	£17	£17	£16	£37
Adjusted results mean cost (health care) [a]	*p* = .731	£11	£11	£12	£12	£13

[a] Results are adjusted to account for effect of adaptive behaviour skills score as measured by SABS. Mean costs per POS quintile are adjusted for SABS via MM robust regression estimator

[b] Accommodation costs do not provide enough variance in value to be used with robust regression estimators

Discussion

The mean weekly cost of health and social care service provision for adults with intellectual disability was estimated to be £2,671 per person, based on service use data collected in 2022. Cost of accommodation was estimated to account for 68% of weekly total costs. Estimated cost of support hours constituted 28% of weekly total costs. The cost of day activities and access to health and social care services comprised much smaller proportions of the estimated weekly cost (4% and 1%, respectively). There was no evidence of change in costs over a 12-month period (between 2022 and 2023). When examined cross sectionally there was strong evidence that weekly costs reduced as participant adaptive behaviour skills increased. Costs were adjusted to account for adaptive behaviour and estimates were detailed by quintile of QoL. There were no significant differences in weekly cost by QoL quintile, across any cost category. In other words, individuals with intellectual disability who experienced better QoL did not incur higher or lower costs than those with poorer QoL, after adjusting for adaptive behaviour level.

Comparison of costs in this study with costs from previous studies

The average weekly total cost estimated in our study was higher than that estimated by Beadle-Brown and colleagues (Beadle-Brown et al., 2021). Their estimate of weekly cost was £1,724; however, their costs were estimated based on unit cost values at 2010-2011 prices. When Personal Social Services annual percentage increases for adult services (Jones et al., 2022) are applied to the weekly cost estimated by Beadle Brown and colleagues, the cost in 2021/22 would be inflated to £2,263. This is closer to the estimate in the present study, however there is still a substantial difference with the estimate of the present study. The present study estimated accommodation costs on the basis of the unit cost of supported housing or residential care home provided in the PSSRU Unit Costs of Health and Social Care 2022 (Jones et al., 2022). This cost was estimated based on data provided by local authorities and is a package of costs related to rent, service charge and care package. Previous studies have not used PSSRU unit costs of accommodation but have collected data specific to each specific facility to estimate costs e.g. (Beadle-Brown et al., 2021; Bigby et al., 2020; Emerson et al., 2000). Costs related to staffing tend to be listed under accommodation costs in these previous studies. However, in the present study I applied an additional estimated cost to account for support hours based on data specific to each individual. This approach could have resulted in some double counting of staff time, and this may affect the comparability of costs across studies. However, the estimation of support hours as a separate category enabled me to examine the association of costs of direct support independent of other staffing costs (e.g. management, admin). As I have applied this approach uniformly, it does not change interpretation of results of this study.

The study was designed to explore trends in variation of costs across two time points. The assumption was access to health and social care at T1 may still be less than optimal following the easing of lockdown restrictions, and that there may be an increase in access seen at T2. There was very little variation in costs across the two time points, and cost variation was consistently limited whether costs were considered overall or by summary category. Limited variation precluded further longitudinal analysis. Although results are not directly comparable, it is possible to review rates of access to health and social care of the sample of adults in the present study alongside rates of access reported among another sample of adults with intellectual disability prior to the COVID-19 pandemic (Flynn et al., 2021). In relation to access rates reported by Flynn and colleagues more people in the present study were reported to be accessing GPs, a similar number of people were accessing community nurses, but fewer people were accessing adult education (Flynn et al., 2021). More research is needed to understand long-term impact of the COVID-19 pandemic on access to health and social care for people with intellectual disability.

When data from T1 were examined, cross sectionally there was strong evidence that estimated costs decreased as level of adaptive behaviour skills increased. This difference in cost was driven primarily by reduced costs of support hours for participants with greater adaptive behaviour skills. There was some indication that costs may reduce as participant age increases, and that costs may increase as levels of challenging behaviour increase, however large *p* values meant I was unable to reject the null hypothesis that variation between these observations were due to chance.

To explore the association between costs and QoL, weekly costs were adjusted to account for association with adaptive behaviour skills. There were no significant differences in weekly cost by POS quintile, across all cost categories. Descriptively there was small (non-significant) variation in costs for support hours and day activities. Data suggest that participants who score higher on QoL do not incur significantly different costs to those who score lower. Below I discuss further the association between QoL and specific cost categories.

Cost of support hours and QoL

The link between severity of intellectual disability and cost of provision of support is well documented (Felce et al., 2008; Hunter, 2016). People who score lower on adaptive behaviour skills will need greater provision of support hours to manage activities of daily functioning. However the provision of support hours is also positioned as a mechanism by which to enhance QoL (Thompson et al., 2014). The provision of support hours should aim to go beyond supporting a person to function to also support a person to exercise choice, engage in meaningful activities and be in relationship with others or any other outcomes that are important to the person. Theoretically, if the support that a person needs is aligned with the support that a person receives, this should result in positive impact on a person's QoL (Thompson et al., 2014). We might therefore expect to see a positive relationship between the cost of support hours and QoL, rather than the inverse relationship seen in the present analysis.

There are a number of possibilities as to why greater cost of support hours was associated with lower POS scores. It may be a limitation of the measure of adaptive behaviour skills which is designed to 'evaluate coping skills considered important for personal independence and responsibility in daily living' (Hatton et al., 2001). This definition does not encompass all aspects of support needs, for example health or psychological well-being needs are not directly captured in this measure. A previous analysis of data from a sample of adults with intellectual disability in Ireland found that participants who had greater needs around psychological well-being incurred greater costs (Cronin & Bourke, 2017). Some of the participants in this study may have been in receipt of support hours for needs which were not accounted for through association with SABS score. In addition, the present study did not collect data to assess whether participants were in receipt of sufficient support hours to meet their support needs. It is possible that even those participants who incurred higher costs for support hours, scored lower on QoL as the hours they received were still not commensurate to their level of need (Simões, Santos, Biscaia, et al., 2016).

It is also possible that participants in receipt of high numbers of support hours may be provided with fewer opportunities to do more for themselves. Previous studies have found that aspects of staff culture such as the 'hotel model' of support e.g., where staff consider their role to be doing for rather than doing with, can result in reduced participant engagement in meaningful activity (Bigby et al., 2012). Greater numbers of staff to service-users has also been shown to be associated with reduced service-user engagement in activities in the home such as cleaning or cooking (Flynn et al., 2018). It is plausible that in some cases greater number of support hours results in staff doing more for participants than with, and this in turn results in poorer QoL outcomes. It may therefore be that the data which would provide most insight into what influences QoL outcomes is not that in relation to the cost of staff but rather the observation of staff to service-user interaction.

Although data suggested that participants who scored in the lower quintiles of QoL incurred higher cost in support hours, the difference between quintiles was small (under £300 approximately) and not significant. The trend should not therefore be over interpreted. Findings from a previous study concluded that local authorities paid the same fee for people receiving less enabling support as they did for people who received support which resulted in enhanced QoL outcomes (Beadle-Brown et al., 2021). Authors noted that there was no evidence to suggest employing more staff would result in better QoL outcomes, but helping those staff to work differently might (Beadle-Brown et al., 2021). Data presented in this analysis suggests a similar relationship between cost of support and QoL – participants scoring higher on QoL outcomes did not incur higher support costs. Further research to understand more about the relationship between the quality of support provided and QoL would be beneficial.

Cost of day services and QoL

Most participants (59%) were accessing some type of day activity at least once a month. Day centres were accessed by 45% of participants and social clubs by 28% of participants at least once a month. The proportion of participants accessing voluntary work (10%), or adult education (6%) were very low. To present a more nuanced picture of access to day services it would be beneficial to provide data in relation to weekly access to day activities.

When examined cross sectionally, data from this study suggest that, following adjustment for adaptive behaviour skills, participants who score in the higher quintiles of QoL incur slightly higher costs on day activities. This trend echoes previous research which has found an association between engagement in day activities and enhanced QoL (Simões & Santos, 2017). The degree of change in cost is minimal across quintiles (approximately £20) and the difference between quintiles is not significant. Further research is required to explore this potential trend further. Day activities are considered key building blocks to community integration and associated enhanced QoL, and further investigation is warranted to explore how frequency of day activities is related to QoL.

Cost of health and social care and QoL

Most participants (94%) had had contact with at least one health or social care professional in the six months preceding T1 data collection. This proportion rose to 100% of participants at T2. Data collected in relation to access to health professionals indicate some participants in the study sample had complex health needs. For example, one participant received daily visits from a community nurse. There was no indication of a relationship between variation in costs from access to health care professionals and QoL.

Limitations

This study is limited by the relatively small sample size. Although participants are drawn from services across England, they are all serviced by the same provider, and this may limit generalisability of results.

A significant limitation of this study was the use of PSSRU estimated package costs for accommodation. This meant that accommodation costs only differed according to limited criteria – whether accommodation was residential care or supported living, and whether supported living was shared with others or not. There were likely variations in costs within these categories which were not captured in this study. Previous studies e.g. (Beadle-Brown et al., 2021) have utilised management surveys to estimate much more detailed costs for accommodation through consideration of staff costs e.g. care, cleaning, catering and laundry, non-staff items for example heat, light, maintenance and overhead costs for example capital value of buildings. More detailed approaches have enabled more detailed analyses to explore drivers of accommodation costs. In the present study I was unable to estimate models of drivers of accommodation costs due to the limited variability in the costings. Because accommodation costs comprise the largest cost within the analysis presented, and costs are relatively static across the sample, inclusion of accommodation costs in analysis to explore association between cost and QoL may have obscured the strength of association. To add clarity to the analysis I modelled strength of association between QoL and each cost category, independent of accommodation cost. As with the analysis conducted with combined costs, results did not provide statistical evidence of association between QoL and costs of support hours, costs of access to health and social care nor costs of access to day activities. These stratified analyses support the finding that there was no direct association between cost and QoL. However, future research which aims to understand the relationship of cost in provision of services for people with intellectual disability may gain more insight from the collection of in-depth data to calculate cost of accommodation specific to each service under study, rather than relying on the accommodation costs estimated by PSSRU

The treatment of staff costs in the current study will have resulted in some double counting, as direct support hours are costed independently of the accommodation package cost. In addition, there are staff costs which will have been undercounted for example, data were not collected in relation to use of agency staff. The adult social care workforce survey conducted in 2021 found that among registered care homes and registered domiciliary care providers who were using agency staff, 62% were using agency staff more regularly than in the six months previously (Department of Health and Social Care, 2021). A survey carried out by Care England in 2022 reported that hourly costs for agency staff were double employee hourly rates (Care England, 2022). It is likely that if agency costs had been captured, their associated costs would have affected overall cost estimates.

Costs estimated for day activities such as volunteering or recreational activities, such as swimming, were based on the national hourly living wage rate. This provided an approximation of the likely actual cost, but the current estimate was likely an underestimate as it did not include adjustments for support needs, e.g., some activities may have involved more planning time and/or more than one paid worker. In addition, data were not collected to estimate costs in relation to transport to day activities. These could have varied greatly as some participants may have been able to access activities by local bus and others may have needed a vehicle and driver.

Conclusion

The results suggest that QoL as measured by POS was not directly related to costs, even when other factors such as adaptive behaviour skills were adjusted for. There is a positive message here – among this sample of people with intellectual disability, people who experienced better QoL did not incur greater costs than those who experienced poorer QoL. However, further research is needed to uncover more insight into what aspects are related to better QoL.

Findings from this study suggest that the cost category with the greatest variability is direct support hours. However, variance in support hours was not directly related to variance in QoL. This may suggest it is not the cost of support which matters, but the quality of interaction between staff and resident within those support hours. In addition, data in this study suggested that following adjustment for adaptive behaviour score there may be a (non -significant) trend of higher costs of day activities and higher QoL scores. More detailed observational research is needed to explore both how staff engagement with service-users and service-user engagement in day activities influence QoL.

Chapter 7 Discussion

Summary of findings

My PhD was an in-depth investigation of the use of POS in residential settings in the UK, and the potential of POS to be used as an outcome measure for research and service evaluation. The four studies presented in this PhD constitute the first psychometric evaluation of the English language version of POS and assess the relationship between service costs and QoL. Together my studies assess the utility of the POS measure to provide meaningful insights for use in research and practice.

The first study in the thesis assessed the factor structure of POS with data drawn from a sample of 310 adults with intellectual disability in the UK. Data were assessed for fit to theoretical models of QoL. Models assessed originated from the Schalock and Verdugo 8-domain QoL model and included consideration of presence of second-order factors. Data did not provide a good fit to any of the proposed theoretical models of QoL. Further exploration of reasons for poor fit revealed that a high degree of score variance (24%) was accounted for by the person conducting the interview. While findings from this study were not aligned with evidence from the use of POS in other languages, this is the first time that a study explored factors associated with POS score variance and, in addition, my study included a greater proportion of people with more severe intellectual disability than previous studies.

The second study assessed construct validity of POS data collected from 100 adults with intellectual disability in England. Findings demonstrated that POS data varied as expected in relation to factors known to be associated with QoL. In addition, a measure of frequency of leisure engagement was found to be independently associated with POS score when all other factors were adjusted for.

When assessed by sub-scale, leisure engagement was found to be positively associated with social participation.

My third study assessed sensitivity to change of POS proxy and self-report data over a 12-month period. A key justification for the measurement of QoL, is the potential to use change in QoL to evaluate impact of services or interventions, yet no study has assessed sensitivity to change of POS or any other QoL measure for use with adults with intellectual disability. There was no evidence of sensitivity to change in the self-report data, but the likelihood of detecting change in proxy report data was fair ($P^\wedge = .77$). However, other data collected in the study suggested that participants experienced little change in the 12-month study period. For this, it was not possible to conclude whether data indicating POS was not responsive to change resulted from a limitation of the scale itself or the absence of change in the participants' lives during the 12-month study period. In the process of interpreting my findings I revisited some long-standing theoretical debates about the measurement of QoL and I expand on these below.

The final study comprised the first study in intellectual disability to explore the direct association between QoL and costs of access to health and social care. Results found no evidence of change in costs associated with service use over a 12-month period. Cross sectional analysis suggested that people with intellectual disability who experienced better QoL did not incur greater or fewer costs that those with poorer QoL, after adjusting for adaptive behaviour. I suggest that data which would provide greater insight into what influences QoL may not relate to the cost of staffing but rather the quality of staff to user interaction.

Implication of study findings

POS authors position the scale as a standardised measure of QoL which can be used to provide individuals and their support team with feedback about the difference quality improvement measures are making at the level of the person, as well as providing data from which to draw comparisons and gain insights about QoL across a sample population (Claes et al., 2008).

Since POS was developed in 2008 its psychometric properties have been investigated in many countries, and it has begun to be used as outcome measure in intervention studies. However, even though POS was originally written in English, the psychometric properties of the English language version of POS have never previously been tested. Although studies in Spain and Portugal have demonstrated evidence that POS conforms to the hypothesised 8-domain model of QoL, I was not able to replicate these findings with UK data. I was also unable to demonstrate evidence of sensitivity to change in the self-report measure, and my analysis of sensitivity to change in the proxy measure raised concerns over inter-interviewer reliability. Data presented suggest that more research is needed before we have confidence in the quality of information provided by POS. Crucially, interpretation of data presented has highlighted important gaps in knowledge about the nature of change in QoL in general. We do not know enough about the circumstances, or the length of time required before we see change in QoL. As such my studies raise doubts about the utility of QoL to be used as outcome measure. In the process of conducting my research I have found that the operationalisation of key principles and theories of the measurement of QoL result in practical impossibilities. These challenges help explain why a universally accepted measure of QoL has not yet been established for use with adults with intellectual disability. Therefore, after I have set out the next steps required to assess the psychometric properties of POS, I propose wider implications for research based on a reappraisal of the notion of QoL as a measurable construct.

Priorities for further research to assess psychometric properties of POS

Evidence in support of the validity of POS as a measure of QoL was presented in my second study. My analysis demonstrated that POS data varied as expected in relation to convergent and divergent factors. This suggests that POS scores are related to measures of other constructs which, on theoretical grounds, are expected to be close to the underlying construct of QoL which POS is designed to measure (Boateng, Neilands, et al., 2018).

Data did not support the construct validity of POS through Confirmatory Factor Analysis. I have provided detailed synopsis of the limitations of the data used in the CFA in chapter three, and it is plausible that the lack of fit stemmed from these limitations rather than inadequacy of the model itself. As I recommended in chapter three, replication with larger datasets is required. Evidence of good fit to the proposed model of QoL is required before POS can be recommended as outcome measure by which to evaluate impact.

However, even if further research demonstrates evidence in support of construct validity, there remain two essential properties of POS which need to be further assessed before the scale can be recommended for use as an outcome metric, these are, inter-interviewer reliability and sensitivity to change.

Inter-interviewer reliability

In chapter three I presented evidence to suggest that a high degree of variance in POS score is accounted for by the person conducting the interview. In chapter five I presented evidence that the magnitude of change between respondents who were allocated a new interviewer for their second interview was much greater than among those respondents who were interviewed by the same person. It is clear that reliability of POS data is attenuated by the influence of interviewer and further research is necessary to assess the degree to which scores vary dependent on the person conducting the interview.

There is no standardised method to establish interviewer calibration stipulated in the POS manual. When I observed interviewers at T1 of data collection, my record of participant response to items had excellent concordance with interviewer record of participant response (k = .87). However, this observation was a test of agreement between me and the interviewer in relation to what the participant response was. The test was not designed to assess whether two or more interviewers return the same responses irrespective of the flexibility allowed in administration of POS. It is generally accepted that measurement error can be introduced into a scale through inconsistent framing of questions and inconsistent item order (Diener et al., 2013). The flexibility allowed within administration of POS results in variation in both framing of questions and item order. The degree to which this flexibility introduces measurement error has never been tested. During the observations I noted variance in interviewer interpretation of meaning of scale items and response items. In response to the noted variance, I developed a user guide (see appendix J) and delivered refresher training to interviewers prior to data collection at T2. Interviewers anecdotally reported feeling more confident in the breadth of applicability of items, however my study was not designed to robustly test the degree of calibration between interviewers.

At a minimum, a small sample study (*n* ~ 40) is required whereby each participant is interviewed by at least two different interviewers a short time apart, to provide directly comparable data from which to assess inter-interviewer reliability (Boateng, Neilands, et al., 2018). Although previous studies have assessed inter-rater reliability of POS data with regards to respondent (e.g. self vs proxy) (Balboni et al., 2013; Carbo-Carrete et al., 2015; Claes, Vandevelde, et al., 2012; Simões, Santos, & Biscaia, 2016); there is no published record of research assessing inter-interviewer reliability of POS. Repeating interviews with the same participant does present a risk of introducing response bias, as it is possible that participation in the first interview could cause the participant to reflect on aspects of their live which may shift their response in the second interview (Blome & Augustin, 2015). However, as it currently stands the effect of the flexibility in POS administration on the reliability of results is completely untested, and a robust evaluation of interviewer affect is needed.

A recent study sought to increase accessibility of HrQoL scales for adults with intellectual disability not by allowing flexibility in administration, but by replacing the interviewer with a computerised survey which used audio and pictures to increase accessibility of the questions and response options (Walton et al., 2022). Although the study was conducted with a small sample (*n* = 41), participants were able to respond independently, and no participant skipped more than two questions. I recommend that the flexibility of interviewer-led POS interview is tested against a standardised computerised survey to investigate the assumption that flexibility of administration aids accessibility.

I also recommend that if POS is to be used at scale through engagement of many interviewers there is a need for interviewers to be routinely observed for quality assurance.

Sensitivity to change

My study assessed sensitivity to change in relation to the change in score relative to the variation among the sample (Tordrup et al., 2014). In addition, my study assessed sensitivity of change in POS score relative to changes in other measures expected to be related to QoL. Findings could not ascertain whether POS was not sensitive to change or whether, in fact, QoL had not changed in the 12-month period. This uncertainty has significant implications for further research into scale utility.

I discussed limitations to my data in chapter six and these include the relatively small sample size which restricted use of ROC analysis and the introduction of new interviewers at T2 which may have introduced additional variation in POS scores. I also only assessed sensitivity to change at the global QoL level and it may be that consideration of QoL as a composite measure masks variation at the domain level. It was clear from my findings that sensitivity to change differs dependent on whether data are collected via proxy or self-report and any future study will need to ensure recruitment of adequate sample size for each type of report. It would be possible to repeat my study with larger sample size, to ensure consistency of interviewer at both time points, and to assess sensitivity to change at domain and sub-scale level. However, findings from my study indicate there is also a need to incorporate experimental manipulation into the study design to increase the likelihood of change in QoL being experienced by participants within the study period. Experimental manipulation should ensure that change does take place, so that analysis is able to test that POS is responsive to that change.

Previous studies to estimate responsiveness in other scales have increased the probability that change occurs in the construct of interest in the duration of the study through ‘the application of a treatment of known and demonstrated efficacy in either observational studies or clinical trials’ (Revicki et al., 2006). It would be astute to follow similar methodology and use POS to measure QoL at multiple time points in a trial of an intervention with demonstrated efficacy in a primary outcome which is theoretically related to QoL. Data related to the primary outcome could then be used to categorise participants into those who had experienced positive change and those who had experienced negative or no change. Statistical methods such as calculation of Reliable Change Index (RCI) could be employed to estimate a clinical cut-off point (Jacobson & Truax, 1992). The cut-off point is the score that would need to be crossed following the intervention for QoL to be considered changed.

As it is recommended to assess responsiveness across multiple indices (Revicki et al., 2006) it would be beneficial to triangulate results from RCI with multiple anchors which are expected to be related to QoL. However, this requires selection of appropriate anchors which can used to verify change in factors expected to be related to QoL. As demonstrated in chapter five, data provided from the staff - reported GAC measure were not consistent with data related to other measures of change used in my study. There is a need to identify other measures which can be used as anchor. These would depend on the intervention under study but could include externally verifiable measures such as measures of community participation e.g. (Baker et al., 2021), leisure engagement e.g. (Hawkins et al., 1998) and breadth of social networks e.g. (Miller et al., 2023). My study did not employ participant-rated anchors of change and I recommend future research explores use of participant-rated anchors.

Anchor-based methods will be used to estimate Minimally Important Difference (MID) - the smallest change in treatment outcome that the participant identifies as important. As per methodology proposed in chapter five, changes in anchor measures can be used to categorise participants into those who had experienced change and those who hadn’t. Receiver Operating Curve analysis can then be conducted to plot the area under the curve and calculate the probability that any observed change in POS score is due to actual change in participant QoL. The MID is identified as the upper corner of the curve (Froud & Abel, 2014). Results from ROC analysis can be compared to other statistical methods to calculate MID based on change anchors such as Change Difference, Average Change and regression analysis (Mouelhi et al., 2020). It is also recommended that Delphi methods are used to engage professionals and participants in discussion of what constitutes reliable change in QoL.

This brief outline of approaches to assess responsiveness of POS to change in QoL provides direction but identifies some key gaps in knowledge which are broader in scope than assessment of POS. Specifically, this approach is dependent on employment of an intervention which is known to have significant and consistent impact on QoL of adults with intellectual disability, and on the collection of data related to anchor measures expected to provide independent verification of change in QoL.

Evidence in support of an intervention or exposure which has known and demonstrated impact on QoL of adults with intellectual disability is limited. There are practical approaches in provision of support for adults with intellectual disability which are theoretically linked to enhancements in QoL, for example Positive Behaviour Support (PBS). However, a systematic review of the outcomes of training staff in PBS concluded that there was no improvement in participant QoL across studies (MacDonald et al., 2018). A cluster randomised controlled trial of PBS conducted since the publication of the review did not use QoL as outcome measure and was also unable to find evidence of impact on related constructs such as community participation (Hassiotis et al., 2018). Authors note there were issues with fidelity to the intended programme within the trial, so this may go some way to explain the lack of impact on factors related to QoL.

Further research is also needed to identify valid and reliable anchor measures, especially those which are participant-rated. There is also a lack of evidence in relation to the duration of time which is required before evidence of change should be expected. I propose the following steps be taken to address these evidence gaps.

Systematic review of use of QoL as outcome measure

In the introduction and in chapter five I presented findings from published literature which suggest that when QoL is used as an outcome measure in RCTs, there is rarely significant impact reported, regardless of the measure used. This is a very interesting finding as it raises pertinent questions about the utility of QoL measurement to detect time sensitive change. However, this finding needs to be substantiated. I recommend as next step a systematic review of the use of QoL as outcome measure in trials involving adults with intellectual disability. The review will synthesise evidence in relation to impact of specific interventions or approaches on

QoL. The aim of the review is to identify which interventions or approaches have evidence of impact on QoL, and what period of time has been associated with significant change in QoL.

Outputs from the review will include identification of any QoL measurement tools which have demonstrated statistically significant change in response to an intervention. In addition, the review will identify any interventions or approaches which have demonstrated impact on QoL.

Development and testing of participant-rated anchor measures

My study aimed to use staff-reported global assessment of change (GAC) to categorise participants into those who had experienced positive change in QoL and those who hadn't. However, data collected through GAC did not correlate well with change on other measures of change I used in the study. In chapter six I discuss the potential sources of bias in the GAC measure and conclude its validity is uncertain.

An alternative approach could be to assess change in QoL through participant-rated anchor measures. Many studies have demonstrated significant difference between proxy and self-report measures (Claes, Vandevelde, et al., 2012; Cummins, 2002a), and it is feasible that a self-report anchor would provide more accurate assessment of change. Notwithstanding the discrepancy between self-report and proxy measures, there is still a tendency for researchers to use proxy measures by default on the basis that self-report from adults with intellectual disability is considered to be limited with regards validity and reliability (Shogren, Bonardi, et al., 2021). A systematic review to explore how MID was established in HrQoL measures found that out of the 36 studies which used a GAC measure, 30 of them were patient reported (Mouelhi et al., 2020). Yet, to my knowledge, no study has tested asking adults with intellectual disability to rate global change of their own QoL as an anchor by which to evaluate responsiveness of standardised QoL measures. I propose that participant reported GAC be tested.

A further approach to assess change from the perspective of the participant could be the use of Goal Attainment Scaling (Shogren, Dean, et al., 2021). Goal Attainment Scaling is a practice whereby participants are supported to identify goals at baseline and progress is then tracked towards those goals. It is plausible that the 8-domain QoL model could be used as the framework, from which participants are supported to set personally meaningful goals within each of the domains. These goals could be meaningful to both the individual and to the scope of the intervention. Follow up data could explore if POS score is responsive to progress towards QoL goals.

There are limitations to the use of Goal Attainment Scaling within trial conditions. To be valid and reliable indicators of change goals need to adhere to SMART principles (Specific, Measurable, Achievable, Relevant and Time Bound) and significant support may need to be provided to participants to set SMART goals. As such the setting of goals could in itself be seen as an intervention, and goal setting support in the intervention arm would need to match support provided in the control arm (Shogren, Dean, et al., 2021). However the setting of personalised meaningful goals fits within a framework of person-centred practice (Ratti et al., 2016). To varying degrees the setting of personal goals by the person in collaboration with their support team is already an integral component of personal care and support and could therefore be systematised within both arms of a trial. However, the use of Goal Attainment Scaling may also not be accessible across all levels of abilities and further research is needed to develop protocols for collaborative goal setting involving family, staff and the person.

Assessment of responsiveness to change of POS within trial conditions

If robust evidence is found of an intervention or approach which has impact on QoL, POS, and any other identified QoL measures which have demonstrated change could be used as outcome measures in a trial to evaluate that intervention or approach. Anchor measures derived from both participant self-report and externally verifiable indicators could be used to assess change. Results from the trial could then be used to assess responsiveness and calculate MID as per the methodology described above.

However, it is likely that strong evidence of an intervention which has a significant and consistent impact on QoL will not be found. The only intervention for which there is relatively consistent evidence base on the impact on QoLis deinstitutionalisation (Chowdhury & Benson, 2011; McCarron et al., 2019). For the most part people with intellectual disability do now live in communities so it is not feasible nor ethical to repeat this quasi-experiment. The design of a study appropriate to assess sensitivity to change of POS, or indeed of any scale designed to measure QoL of adults with intellectual disability is constrained by the circularity of missing data. There must be an evidence base which predicts that a sub sample of participants will experience change in QoL in the study period so that the sensitivity of the measurement scale to that change can be assessed. However, the strength of the evidence base of what predicts change in QoL is weak because little is known about the responsiveness of QoL scales or MID when used to measure QoL of adults with intellectual disability. This circularity of missing data raises important questions about the notion of QoL as measurable construct and I address these questions in the next section.

Critique of the notion of QoL as measurable construct

In the introduction I drew on the consensus report put forward by Schalock and colleagues which guide the operationalisation of QoL in the field of intellectual disability (Schalock et al., 2002). Schalock and colleagues' position QoL not just as a theoretical construct but as a tool to guide public policy. In the introduction, I depicted the operationalisation of QoL as a continuous feedback loop. In practice approaches such as person-centred planning provide a framework to centre aspirations to enhance QoL by ensuring support is tailored to a person's goals, and through working practices of staff which enable people to be actively involved in all aspects of their lives. The measurement of QoL enables the operationalisation of QoL in research and evaluation. Thus, support provision is evaluated based on its significance to a person's QoL, and QoL data are then used to inform and refine service design and staff practice (Claes et al., 2010). The intention to use QoL data for these purposes created substantial debate at the turn of the century concerning how to define the QoL construct and what approaches needed to be taken to capture the dynamics of the construct within a measurement tool (Cummins, 1997, 2001, 2002b; Felce, 1997; Felce & Perry, 1996; Hatton, 1998; Hatton & Ager, 2002; Perry & Felce, 1995). Consensus on these debates was reached in the report of an international panel of experts put together by Schalock and colleagues in 2002 (Schalock et al., 2002).

POS was designed in response to consensus recommendations (Claes et al., 2010) and yet data presented in my PhD suggest there are significant limitations to the validity and reliability of POS as a measure of QoL, at least when used with English data. In each chapter I have discussed why this might be in view of limitations of the present data. In addition, in the process of interpreting findings from my PhD I have had to revisit some of the longstanding debates concerning measurement of QoL of adults with intellectual disability. I propose that the specification of a scale to meet all the requirements as set out by the international panel of experts in 2002 (Schalock et al., 2002) results in a brief which is technically impossible.

The tenants of the consensus which result in these technical impossibilities can be summarised as the following. QoL is considered a multi-dimensional model and measurement must assess each domain. Domains should be measured both according to quality as understood by objective standards, and according to quality as understood by the individual (subjectively). Measurement should therefore be based on the individual’s perception wherever possible. However, as the importance of QoL applies to all people across the spectrum of intellectual abilities, any measurement scale must include provision to measure the QoL of people who do not have capacity to provide their own answers (Schalock et al., 2002). In trying to meet all these parameters, QoL scales attempt to measure everything at once, and in doing so fall short of the specificity required to provide meaningful insight into the impact of intervention or care provision on the lives of people with intellectual disability.

Over 20 years have passed since consensus was reached on how to measure QoL (Schalock et al., 2002), and there still does not exist a QoL measurement tool which meets all the requirements stipulated (Li et al., 2013; Townsend-White et al., 2012). There are inherent incompatibilities between the dynamic nature of the theoretical construct of QoL and the practicalities of measurement. I examine sources of these incompatibilities below.

The risk of imprecision in the broad scope of QoL measurement

Appraisal of QoL is dependent on individual values, preferences and experiences, yet the external measurement of QoL requires the rating of standardised items according to uniform criteria. Theoretically, QoL is said to comprise domains which are universal to everyone, but what equates to satisfaction within each of those domains is considered unique to the individual. For example, the importance of friendships is considered within the domain of interpersonal relationships in the 8-domain QoL model. But it is not immediately apparent how friendships should translate to an item on a standardised scale. One person may value how many meaningful friendships they have, whereas another may value how much time they have to spend with their friend(s). The need to assess indicators from an individual’s own perspective is the justification for using subjective measures (Cummins, 2002a). The real question is not how many or how much, but how satisfied a person is with their lot.

The idea that satisfaction is a truer measure of QoL has led many scholars to argue that subjective measures of QoL are the yardstick by which success should be measured (Cummins, 2002b). If we want to know how well a programme has performed, our primary source of enquiry should be to know how the person feels. However, as I discussed in detail in the introduction chapter satisfaction has been demonstrated to be a poor indicator of objective circumstances (Cummins, 2016; Perry & Felce, 2002). Measures of satisfaction have been shown to be relatively static across conditions and time suggesting they are unlikely to be responsive to change (Cummins, 2016; Diener et al., 2013).

It is for this reason that the collection of data in relation to objective circumstances of life, alongside measures of subjective well-being, is considered important for the assessment of QoL (Schalock et al., 2002). Objective data (e.g. quality of housing, frequency of access to leisure and community activities, size of social networks (Perry & Felce, 2002)) provide externally verifiable evidence that a person’s basic needs are being met and that they are being supported according to best practice guidelines in relation to what constitutes good support. But objective indicators do not measure QoL. As soon as an objective indicator is taken as evidence of QoL, the perception of the individual is overridden (Cummins, 2001). The individual’s values, preferences and desires, and the dynamic nature by which those values, preferences and desires may change over time or in relation to experience is reduced to a checkbox derived from normative behaviour (Shogren, Bonardi, et al., 2021). The sole use of objective indicators to measure QoL runs contrary to theoretical models of QoL which position the perception of the individual as the key indicator of QoL (Schalock et al., 2002). In addition, any proposal to measure QoL on exclusively objective measures is problematic as it excludes people with intellectual disability from appraisal of their own lives and conditions. Asking people how they feel about the services that are designed to support them enables people to have a voice in research, and in the design of services and policies which arise from research (Shogren, Bonardi, et al., 2021).

A different approach to collecting data to assess impact on QoL is to use a battery of scales which measure indicators within each domain of QoL. In chapter six, I summarised findings from literature which report outcomes from a battery of discrete measures of components of QoL rather than standardised measures of QoL e.g. (Beadle-Brown et al., 2021). These include (but are not limited to) measures of choice, social networks, community involvement, depression, activities of daily life, safety and physical health. These type of studies demonstrate that when social outcomes are measured by discrete outcomes it is clear that impact is not consistent across all outcomes – they do not all move in the same direction (Felce, 2017). It is improbable that a specific intervention would impact across all eight domains of QoL and the use of a composite score of QoL (e.g. total QoL) may undervalue the impact of an intervention on those outcomes it is designed to influence. On the contrary, the use of discrete measures enables evaluation based on measurement of outcomes for which there is theoretical basis to expect change as a result of a specific intervention or service (De Silva et al., 2014).

The need for outcomes to theoretically link to specific services or interventions applies even when the broad scope of adult residential care provision is considered. Person centred approaches have the potential to impact on every domain of a person’s life (Ratti et al., 2016), but there are many aspects of each domain which are outside of the sphere of influence of any residential service. For example, people may experience bereavement, relationship breakdown, job losses or sickness, all of which may impact their QoL, but which are not directly related to the care they receive from their residential provider. The choice to evaluate a service which has a broad scope (residential care) with a measure which is even broader in scope (QoL) has practical appeal but is limited with regards to the quality of information it provides.

There are clear arguments to evaluate programmes and monitor quality based on both objective and subjective measures. However, I argue that we should resist efforts to group these measures under the umbrella term of QoL. Data related to objective indicators provide insight from which to monitor service quality and to understand the impact of specific interventions on specific outcomes. Data related to subjective indicators provide insight into a person's well-being, satisfaction and fulfilment. These data have particular importance for evaluation of services or interventions which focus on mental health. Attempts to standardise measurement of all objective and subjective factors within one composite QoL scale mask the wealth of information within each factor.

Principles of inclusion and standardised measures

Proxy report data are often collected by default with regards to adults with intellectual disability (Shogren, Bonardi, et al., 2021) and the precedence placed on self-report response by POS authors is a key recommendation for use. In the introduction of this thesis, I put forward techniques to increase accessibility of self-report for adults with intellectual disability such as simplification of language, reduction of response options, inclusion of visual aids and involvement of communication partners (Kooijmans et al., 2022). I positioned POS as a scale which had been designed to incorporate all these techniques to increase accessibility. However, authors recognise that some people will not have capacity to self-report and the scale includes provision of a proxy report for use with anyone unable to provide their own answers. Inclusive approaches can be defined as enacting a simultaneous process of increasing inclusion whilst decreasing exclusion (Booth, 1999). POS authors position the use of proxy report as mechanism to ensure inclusion across diverse abilities, but data from previous studies has demonstrated significant differences in score when proxy data is compared to self-report for the same participant (Carbo-Carrete et al., 2015; Claes, Vandevelde, et al., 2012;

Simões, Santos, & Biscaia, 2016). It is questionable to argue that the provision of proxy report enables the inclusion of all people across abilities. Proxy report enables measurement across all abilities but in lieu of further efforts to increase accessibility, which could increase the proportion of people able to self-report.

POS is designed to be as accessible as possible within the parameters of a standardised measurement tool. Across some criteria principles of measurement have trumped principles of accessibility, for example at 48 items the length of the tool will result in reduced accessibility for some people (Bell et al., 2018; Fujiura, 2012). In addition, people with more severe intellectual disability may be able to answer yes/no questions, but these are not employed due to concerns that yes/no responses increase risk of recency bias and acquiescence (Kooijmans et al., 2022)

The evidence base for what constitutes principles of accessibility is drawn from studies which have almost exclusively been conducted among people with mild to moderate intellectual disability (Kooijmans et al., 2022). This is in part likely due to the ethical barriers which, though designed to protect vulnerable people, often result in the exclusion of people who do not have capacity to provide independent consent from research – even though recommendations from research may impact them (Kellett & Nind, 2014). What is known about principles of accessibility in relation to the inclusion of people with more severe intellectual disability is drawn from small studies and is largely anecdotal in nature (de Haas et al., 2022).

However, proponents of inclusive research argue that to include people with more severe intellectual disability researchers should not attempt to start by modifying existing models or tools (de Haas et al., 2022). Instead there is a need develop approaches that are capable of hearing meaning in new ways (de Haas et al., 2022). People with profound and multiple intellectual disability are likely to communicate in atypical ways such as through gestures, body languages, vocalisations, eye pointing and touch (Watson, 2016). Critical to these methods of communication is engagement of a trusted communication partner such as a member of family or staff team (Watson, 2016). POS authors advocate for the inclusion of communication partners within data collection, and suggest that people with intellectual disability should be present for proxy interviews and supported to contribute to responses as appropriate (Claes et al., 2008). Yet published psychometric evidence has only assessed the properties of self-report and proxy POS interviews as distinct from each other (Claes, Vandevelde, et al., 2012; Simões & Santos, 2016c). There has been no exploration of data integrity when reporting methods are combined.

Methods which have been designed to collect data in relation to the subjective well-being of people with profound and multiple intellectual disability tend to specify that data should be combined with data drawn from two or more proxies and data drawn from observation e.g. (Petry et al., 2010; Petry & Maes, 2006). Further targeted research is needed to understand the procedures necessary to meaningfully access subjective well-being of people who cannot self-report.

The prerequisite to measure QoL through a standardised scale, yet to employ efforts to ensure inclusion of people across all abilities results in methods which compromise principles of both standardisation and inclusion. A renewed focus on developing methods of measurement specific to communication capacity, with clear guidance for collaboration with communication partners may result in a more inclusive and rigorous process.

Rethinking the utility of the QoL construct within research and evaluation

Findings from this study and previous studies assessing measures of QoL suggest it may be time to abandon the search for a scale by which to measure QoL as outcome metric. QoL should instead be considered in relation to specific indicators (related to both objective conditions and participant's subjective experience) that specific services or interventions are targeting, in a similar way we evaluate other social constructs such as mental health. Mental health is a term which is widely used and has an established meaning, "Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community." (World Health Organization, 2001). But mental health is not a construct which is actively measured as a single (composite) construct. Instead, we measure symptoms of poor mental health (e.g. depression or anxiety) or we measure levels of functioning (e.g. strengths and difficulties).

Evaluation of approaches and interventions to support people with intellectual disability should be supported through development of detailed theory of change models. Theory of change models allow for multiple causal pathways and feedback loops and are therefore suitable for complex interventions (De Silva et al., 2014), such as those found within provision of adult social care. Theory of change models enable the empirical testing of underlying assumptions and pathways to change and are developed through synthesis of existing evidence and stakeholder consultation. Models require specification of not only the intended impact of an intervention but all the outcomes that will lead to that impact (De Silva et al., 2014). These outcomes should include objective measures of factors which are externally verifiable and sensitive to change. In addition, where mental health is an important component of the intervention (which it arguably will be for most interventions within the provision of care) measures designed to gage the subjective perception of the individual will be required.

I propose that efforts to measure QoL of individuals with intellectual disability should evolve into renewed areas of focus. One should be the application of intervention science to the evaluation of interventions and services. This would involve the development of sophisticated theory of change models which enable the impact of activities to be evaluated based on what they intended to achieve. Each Theory of Change will employ a specific battery of outcome measures and the use of statistical techniques like path analysis can be used to test mechanisms of change.

A further area of focus should be the development and testing of methods to measure subjective well-being for interventions which aim to impact mental health. Principles of inclusion should not be interpreted to mean the same method should be used across all abilities, but rather that methods and process should be developed to increase meaningful participation of people with diverse abilities.

Implications for practice

Data presented in this thesis does not support the use of POS data to assess group-level change. It should not therefore be used an outcome measure to evaluate impact of specific interventions. However, there could be great benefit in routinely providing space for adults with intellectual disability to reflect and provide their own answers with regards to QoL and the things that matter to them. Questions posed within POS centre the person’s strengths, preferences, routines and wishes, and POS may therefore be a useful tool to use at a practice level to describe a person’s individual experience. POS authors state the tool can provide feedback to the individual on their QoL and establish an expectation that change is possible (Claes et al., 2008). Thus, completion of POS can highlight areas where change is needed for that individual and reinforce notions of autonomy and self-determination for both participants and staff proxies. This may help to personalise the support that people receive and improve their engagement with the service. It may therefore be beneficial to use POS as an aid to person centred planning and to foster understanding of the person. However, my study was not designed to provide data to understand how useful POS is at practice level nor whether it is superior to other methods which aim to increase participant involvement in their personal development plans. Further investigation is needed at practice level to systematise the mechanism by which POS interviews feed into personal development plans, and to monitor the efficiency of this.

Because POS is not recommended for use as evaluation metric, it does not need to remain standardised. There is opportunity for the scale to be modified to best suit the need for which it is used. I advise any organisation considering using POS to monitor QoL of adults with intellectual disability to implement a Participant Action Research (PAR) framework to guide uptake of the measure (St. John et al., 2018). Although adults with intellectual disability were involved in initial development of POS, the tool was developed in 2008 and those involved in its development were from the Netherlands and Belgium (Claes et al., 2008). It would be beneficial for the English language version of POS to be reviewed by a panel of adults with intellectual disability in the UK to ensure that items have retained their relevancy over time and in a different cultural context.

Strengths and limitations of the PhD

I have discussed strengths and limitations of each study within their relevant chapters. In this section I discuss the strengths and limitations of the PhD as a whole.

The project constituted the first psychometric evaluation of POS as a measure of QoL in the UK. In addition, the project constituted the first assessment of sensitivity to change of any scale designed to measure QoL of adults with intellectual disability in the UK. A key strength of this project is in highlighting the importance of investigating sensitivity to change as a psychometric property prior to using any measurement scale as an outcome measure.

The studies reported in this thesis make a significant contribution to research into quality of life of adults with intellectual disability in the UK. Strengths of evidence presented are supported by the homogeneity of the sample with regard living arrangements as the majority were living in residential services. Studies of QoL involving adults with intellectual disability are often small in size and cross-sectional in nature. The inclusion of 80 adults across two time points is a relative strength of my research. In addition, the evaluation of sensitivity to change using both internal and external criteria adds important insight to the interpretation of findings. My analysis also features the first attempt to investigate the association between costs of access to health and social care and QoL as a global outcome.

Due to complexities of ethical approval processes many studies involving adults with intellectual disability restrict eligibility criteria to participants who have capacity to provide independent consent. My project built on the work of other researchers (Totsika, 2008) to ensure that all people with intellectual disability were eligible to participate in the study and that procedures aligned with the Mental Capacity Act. In addition, participant information was co-produced and tested with colleagues with intellectual disability at Mencap to try to increase accessibility of information provided. I believe this meant more people were able to provide independent consent than might otherwise have been. Accessibility of participant information for formal research is an under-researched area and my study highlights ways that the provision of study information can be done differently.

However, my PhD project does have some limitations. All my participants were recruited from services managed by Mencap, and I do not know how my results may have differed if people had been recruited from other providers. For all studies, participants were recruited through convenience sampling, so there may be bias in my sample which randomisation may have eliminated.

My PhD project was conducted from Sep 2020 to June 2024. During that time England was heavily affected by the COVID-19 pandemic. Most people who participated in my study lived in residential homes or supported living services, and many of them had comorbid conditions which increased their vulnerability to COVID-19. In the first year of my PhD, it was not possible for any non-essential visitor to visit people’s homes. This meant not only that I could not carry out recruitment and study activities, but also that Mencap was not able to conduct POS interviews as part of their regular service monitoring. The sample size included in my study is therefore much smaller than was originally planned, and this has had implications for the analysis which has been possible, and for the generalisability of findings.

Although people with intellectual disability were involved in the creation of study materials, I did not include the perspectives of people with intellectual disability in the interpretation of results of each study. In the process of writing this discussion and grounding my results back into the theoretical frameworks of the measurement of QoL, I am aware of the lack of voice of adults with intellectual disability. It would be of interest to hear the opinion of adults with intellectual disability on whether they think it is ever appropriate for another person to answer for them on questions of satisfaction or well-being and if so who, and under what circumstances.

Conclusion

Since POS was developed in 2008 its psychometric properties have been investigated in many countries, and it has begun to be used as outcome measure in intervention studies. Although studies in Spain and Portugal have demonstrated evidence that POS data conform to the hypothesised 8-domain model of QoL, I was not able to replicate these findings with UK data. I was also unable to demonstrate evidence of sensitivity to change in the self-report measure, and my analysis of sensitivity to change in the proxy measure raised concerns over inter-interviewer reliability. My studies suggests that more research is needed before we have confidence in the quality of information provided by POS. In addition, my studies have highlighted important gaps in knowledge about the nature of change in QoL in general.

The core principles of QoL measurement have created a set of requirements which make QoL measurement neither practical nor possible. QoL as a concept does not have the precision required to translate into an outcome metric which could be used to meaningfully evaluate services or monitor quality improvement. Proponents of the QoL model as a mode of evaluation have tried to increase precision of measurement by generating lengthy and time-consuming scales (e.g.

GENCAT (Verdugo et al., 2010), INICO-FEAPS (Gomez et al., 2015), POS (Claes et al., 2008)) . POS is not the longest of these scales, but the length of the scale (48 items) and the time it takes to administer (1-2 hours) require significant time investment from both the organisation collecting the data and the participant being interviewed. In addition, the specification of indicators to measure QoL domains, no matter how well researched, will always result in inherent contradiction to the premise that what constitutes value within each domain is dependent on the personal values and beliefs of the person whose quality of life is being assessed.

The importance of the concept of QoL in the operationalisation of person-centred support for people with intellectual disability is indisputable but I propose that it is time to abandon the notion of QoL as a measurable construct. Instead, we should move to evaluate interventions and service provision with discrete measures which are chosen based on hypothesised causal links between activities and outcomes. In many evaluations one of these outcomes will certainly be the measurement of subjective well-being and there is a need to expand thinking on inclusive practices that enable people across all abilities to provide their own answers wherever possible.

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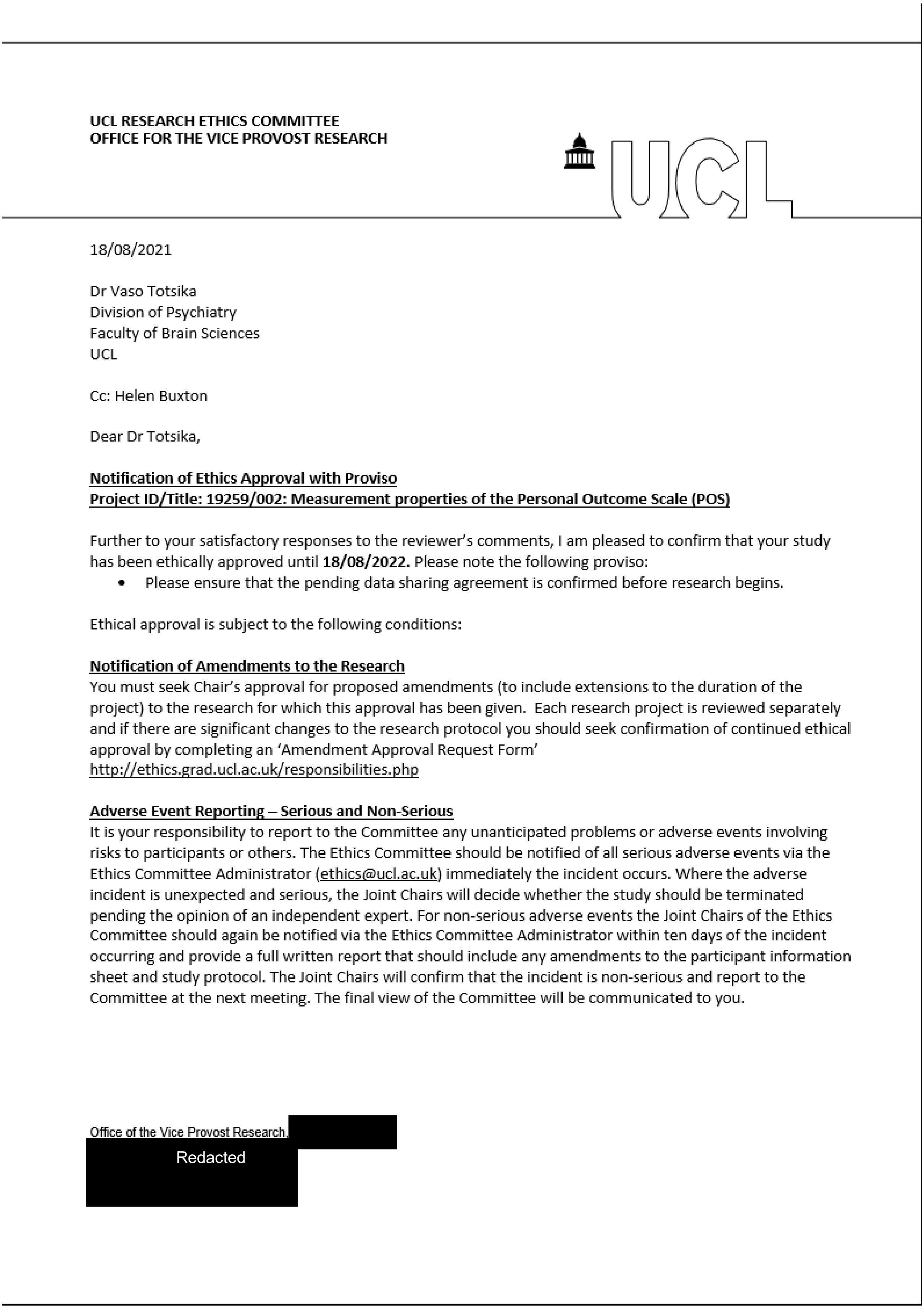
Chapter 8 Appendices

Appendix A: Ethical approval for analysis of secondary data



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

18/08/2021

Dr Vaso Totsika
Division of Psychiatry
Faculty of Brain Sciences
UCL

Cc: Helen Buxton

Dear Dr Totsika,

Notification of Ethics Approval with Proviso
Project ID/Title: 19259/002: Measurement properties of the Personal Outcome Scale (POS)

Further to your satisfactory responses to the reviewer's comments, I am pleased to confirm that your study has been ethically approved until **18/08/2022.** Please note the following proviso:

- Please ensure that the pending data sharing agreement is confirmed before research begins.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, Redacted

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: www.ucl.ac.uk/srs/governance-and-committees/research-governance
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

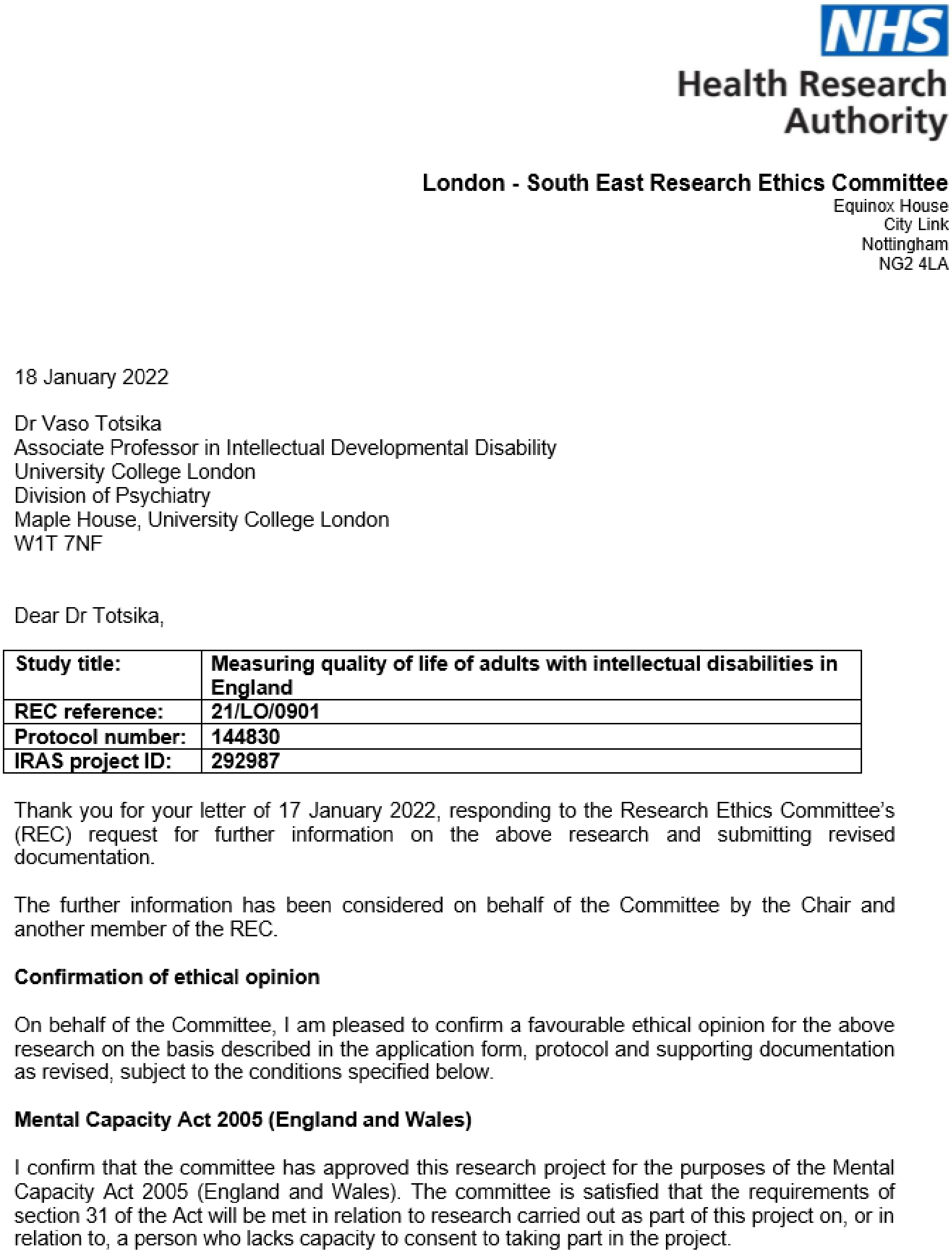
With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix B: Ethical approval for longitudinal study



NHS
Health Research
Authority

London - South East Research Ethics Committee
Equinox House
City Link
Nottingham
NG2 4LA

18 January 2022

Dr Vaso Totsika
Associate Professor in Intellectual Developmental Disability
University College London
Division of Psychiatry
Maple House, University College London
W1T 7NF

Dear Dr Totsika,

Study title:	**Measuring quality of life of adults with intellectual disabilities in England**
REC reference:	**21/LO/0901**
Protocol number:	**144830**
IRAS project ID:	**292987**

Thank you for your letter of 17 January 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and another member of the REC.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005 (England and Wales)

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005 (England and Wales). The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Relevance of the research to the impairing condition

The Committee agreed the research was connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

Justification for including adults lacking capacity to meet the research objectives

The Committee agreed the research could not be carried out as effectively if it was confined to participants able to give consent.

Arrangements for appointing consultees

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 135 of the Mental Capacity Act (Northern Ireland) 2016) to advise on whether participants lacking capacity should take part and on what their wishes and feelings would have likely to have been if they had capacity.

After discussion the Committee agreed that reasonable arrangements were in place for appointing consultees.

Balance between benefit and risk, burden and intrusion

The Committee agreed that the research has the potential to benefit participants lacking capacity without imposing a disproportionate burden on them.

Additional safeguards

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 137 of the Mental Capacity Act (Northern Ireland) 2016).

Information for consultees

The Committee was satisfied that the information to be provided to consultees about the proposed research was adequate to enable consultees to give informed advice about the participation of persons lacking capacity.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		01 August 2021
Letter from funder		29 May 2019
Non-validated questionnaire		
Other [Validated interview tool (Proxy report)]		
Other [Record of manager's advice related to potential participant capacity]	1	13 October 2021
Other [Instructions for interviewers]	1	13 October 2021
Other [Record of participant capacity assessment]	1	13 October 2021
Other [Personal consultee declaration]	1	13 October 2021
Other [Study information letter to personal consultee]	1	13 October 2021
Other [Study information to personal consultee]	1	13 October 2021
Other [Study information for nominated consultee]	1	13 October 2021
Other [Nominated consultee declaration]	1	13 October 2021
Other [Staff information sheet for proxy respondent]	1	13 October 2021
Other [Staff information sheet for survey respondent]	1	13 October 2021
Other [Study enrolment tracker]	1	09 July 2021
Other [Data to be provided from Mencap Data files]	1	21 July 2021
Other [CV PhD Student (Helen Buxton)]	1	27 August 2021
Other [GCP certificate (Helen Buxton)]	1	14 October 2021
Other [Risk Assessment]	1	26 August 2021
Other [G3_QOLID_Overview_Mencap_POS_App]		
Other [Pre-validation questions]		
Other [Response to REC]	1	13 January 2022
Participant consent form	1	13 October 2021
Participant information sheet (PIS)	3	10 January 2022
REC Application Form [SC_Form_25112021]		25 November 2021
Referee's report or other scientific critique report [UBELDTP letter]	1	23 January 2020
Research protocol or project proposal	3	10 January 2022
Summary CV for Chief Investigator (CI)		18 August 2021
Summary CV for supervisor (student research) [M. Gomes CV]		
Validated questionnaire [Self report]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 292987 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely,

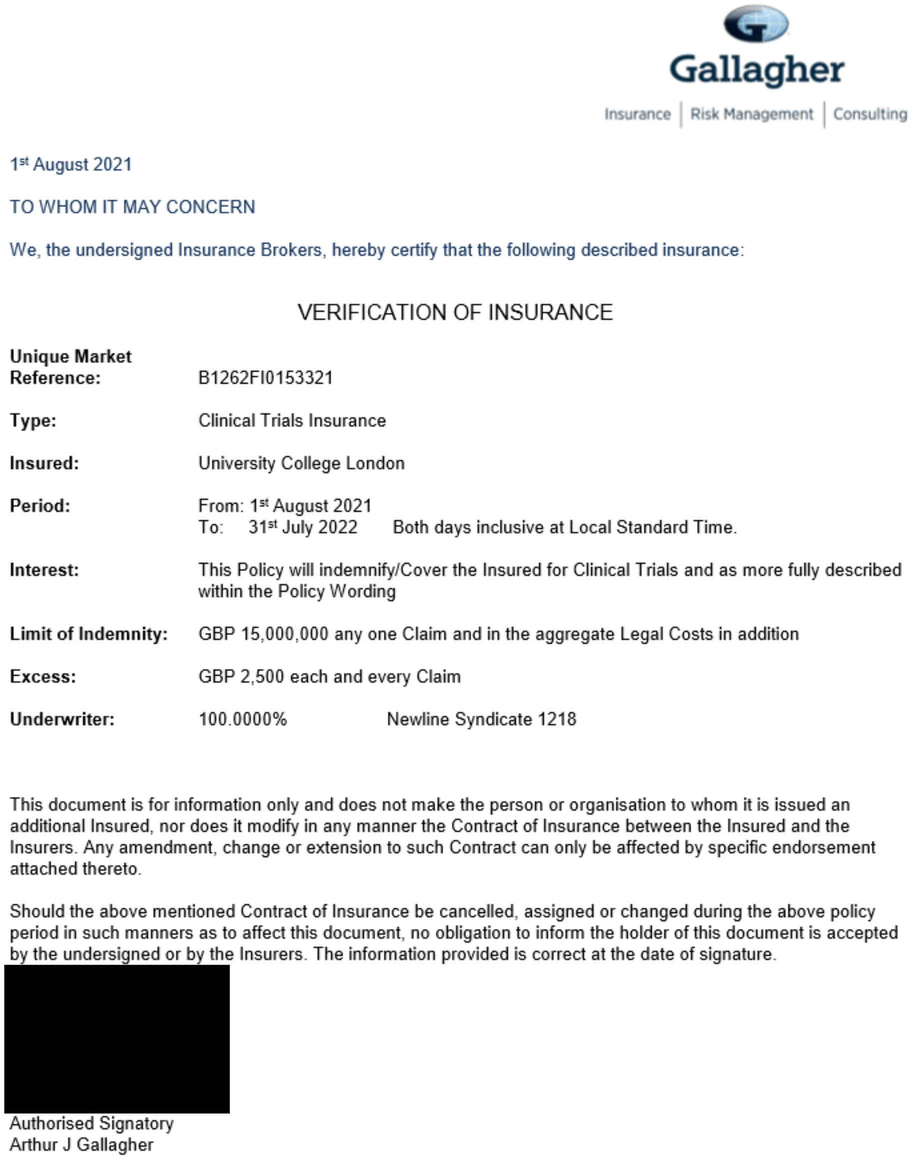
[redacted]

Ms Stephanie Cooper
Chair

Email: londonsoutheast.rec@hra.nhs.uk

Enclosures:	**After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval]**
Copy to:	Mr Pushpsen Joshi

Appendix C: UCL Joint research office sponsor insurance



Gallagher
Insurance | Risk Management | Consulting

1st August 2021

TO WHOM IT MAY CONCERN

We, the undersigned Insurance Brokers, hereby certify that the following described insurance:

VERIFICATION OF INSURANCE

Unique Market Reference:	B1262FI0153321	
Type:	Clinical Trials Insurance	
Insured:	University College London	
Period:	From: 1st August 2021 To: 31st July 2022 Both days inclusive at Local Standard Time.	
Interest:	This Policy will indemnify/Cover the Insured for Clinical Trials and as more fully described within the Policy Wording	
Limit of Indemnity:	GBP 15,000,000 any one Claim and in the aggregate Legal Costs in addition	
Excess:	GBP 2,500 each and every Claim	
Underwriter:	100.0000%	Newline Syndicate 1218

This document is for information only and does not make the person or organisation to whom it is issued an additional Insured, nor does it modify in any manner the Contract of Insurance between the Insured and the Insurers. Any amendment, change or extension to such Contract can only be affected by specific endorsement attached thereto.

Should the above mentioned Contract of Insurance be cancelled, assigned or changed during the above policy period in such manners as to affect this document, no obligation to inform the holder of this document is accepted by the undersigned or by the Insurers. The information provided is correct at the date of signature.

[redacted]

Authorised Signatory
Arthur J Gallagher

Appendix D: Risk Assessment

UCL
Risk Assessment

Summary

Reference: RA052095/1 **Sign-off Status:** Authorised

Date Created:	26/08/2021	**Confidential?**	No

Assessment Title: QOLID Risk Assessment for study to test measurement of Quality of Life of adults with intellectual disability in the UK

Assessment Outline: Risk assessment of proposed new study: QOLID: Measuring quality of life of adults with intellectual disabilities in the UK IRAS Project ID: 292987 The risk assessment is being carried out in advance of the study commencing. The study is being undertaken as part of a PhD project and study period is October 2021 - September 2023. The study is in partnership with the charity Mencap and all participants (n=150) will be drawn from people who Mencap holds a contract to provide at least 3 hours of support a week at home (supported living, registered care home, private home). All participants will be adults (over 18) with an intellectual disability; support need intensity will vary greatly between participants. Mencap's Director of Quality and Practice is the tertiary supervisor on this project and he is supportive of study activities. Mencap has assigned a project manager from among their staff to support study activities. The main aim of the study is to test the measurement properties of the Personal Outcome Scale (POS); a scale designed to measure quality of life of adults with intellectual disability. Participation is on the basis of voluntary informed consent. For potential participants who lack capacity to provide independent consent, the service manager at the home they live will initiate a consultation process with personal or nominated consultees (if no personal consultee available) to determine if the participant would likely wish to participate. Study activities will be 2x POS interviews with participants; 2 x online survey to be completed by nominated staff respondent. Data collection activities will take place 12 months a part. In addition data which Mencap holds about the person regarding their health and support needs and their daily activities will also be shared with the researchers. For participants who do not have capacity to provide their own answers to the POS interview, a member of staff will be nominated as proxy respondent to provide answers on their behalf. The POS interview can be done either face to face or remotely via MS Teams, though the preference is for it to be done face to face at the person's home. POS interviewers are members of Mencap staff who have been trained specifically in the informed consent process and interview technique. As they are Mencap staff they have also undergone CRB check and organizational training in safeguarding, GDPR and are practiced professionals in working with people with Intellectual disability. For a small number of interviews the interviewer will be the PhD student but as she also works for Mencap (since 2019) she has also undergone all relevant checks and training. Interviews take place at the participant's home in a space they choose, where they feel comfortable and are not worried about being overheard. Staff at the home will accommodate this as necessary, e.g. they may make some space in the office available, or ensure other residents understand not to disturb the interview whilst it is ongoing. The majority of participants will share their home with other people with intellectual disability, though some may live with family or friends in private homes. All participants, and other residents, will be used to there being a Mencap staff presence in their home, and the interviewer will most likely be at the home at the same time as other Mencap staff are present. The PhD student has been double vaccinated against Covid-19, as have the majority of interviewers and participants. However, all interviewers will take a rapid lateral flow test in the morning of the day they are planning to interview the person. They will also wear a mask when interviewing the participant (unless the participant requires them not to for communication needs). Interviewers will practice social distancing and regular hand sanitising. All staff at the service where the interview is due to take place will follow Mencap's procedure on regular staff testing and use of PPE and will inform the interviewer of any outbreaks at the service if they occur. These measures should minimise the risk of Covid infection to both participant and interviewer. However where participants are considered high risk due to underlying health conditions (either their own or of other household members); or if participants express anxiety or other reservations about having people visit them at home; then interviews will take place over MS Teams.

Area Responsible (for management of risks)

Division, School, Faculty, Institute:	Faculty of Brain Sciences
Department:	Division of Psychiatry
Group/Unit:	Epidemiology & Applied Clinical Research

Location of Risks Off-Site

Building:	Maple House
Area:	Ground and Above
Sub Area:	ALL Sub Areas

Further Location Information: The study will be managed by a PhD student in the faculty of Brain Science. Data collection will take place in services (supported living, residential care homes, private homes) where people with intellectual disability live.

Is this a GMM Class 1 Risk Assessment?:

UNITED KINGDOM

Assessment Start Date:	26/08/2021	**Review or End Date:**	26/08/2022

Relevant Attachments:

Description of attachments:

Location of non-electronic documents:

Assessor(s): Buxton, Helen R

Approver(s): VASO TOTSIKA

Signed Off: VASO TOTSIKA (07/09/2021 10:24)

PEOPLE AT RISK (from the Activities covered by this Risk Assessment)

CATEGORY
Employees
Disabled Persons

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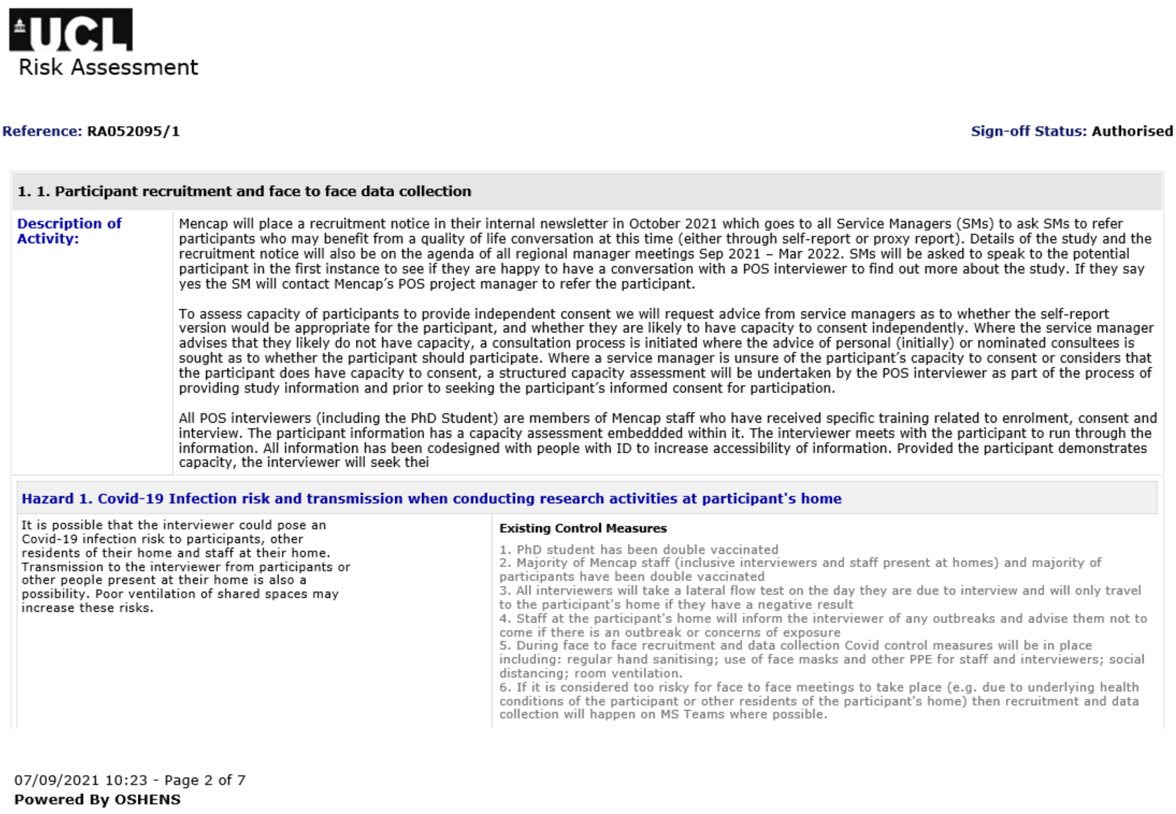


Risk Assessment

Reference: RA052095/1 **Sign-off Status:** Authorised

1. 1. Participant recruitment and face to face data collection

Description of Activity:

Mencap will place a recruitment notice in their internal newsletter in October 2021 which goes to all Service Managers (SMs) to ask SMs to refer participants who may benefit from a quality of life conversation at this time (either through self-report or proxy report). Details of the study and the recruitment notice will also be on the agenda of all regional manager meetings Sep 2021 – Mar 2022. SMs will be asked to speak to the potential participant in the first instance to see if they are happy to have a conversation with a POS interviewer to find out more about the study. If they say yes the SM will contact Mencap's POS project manager to refer the participant.

To assess capacity of participants to provide independent consent we will request advice from service managers as to whether the self-report version would be appropriate for the participant, and whether they are likely to have capacity to consent independently. Where the service manager advises that they likely do not have capacity, a consultation process is initiated where the advice of personal (initially) or nominated consultees is sought as to whether the participant should participate. Where a service manager is unsure of the participant's capacity to consent or considers that the participant does have capacity to consent, a structured capacity assessment will be undertaken by the POS interviewer as part of the process of providing study information and prior to seeking the participant's informed consent for participation.

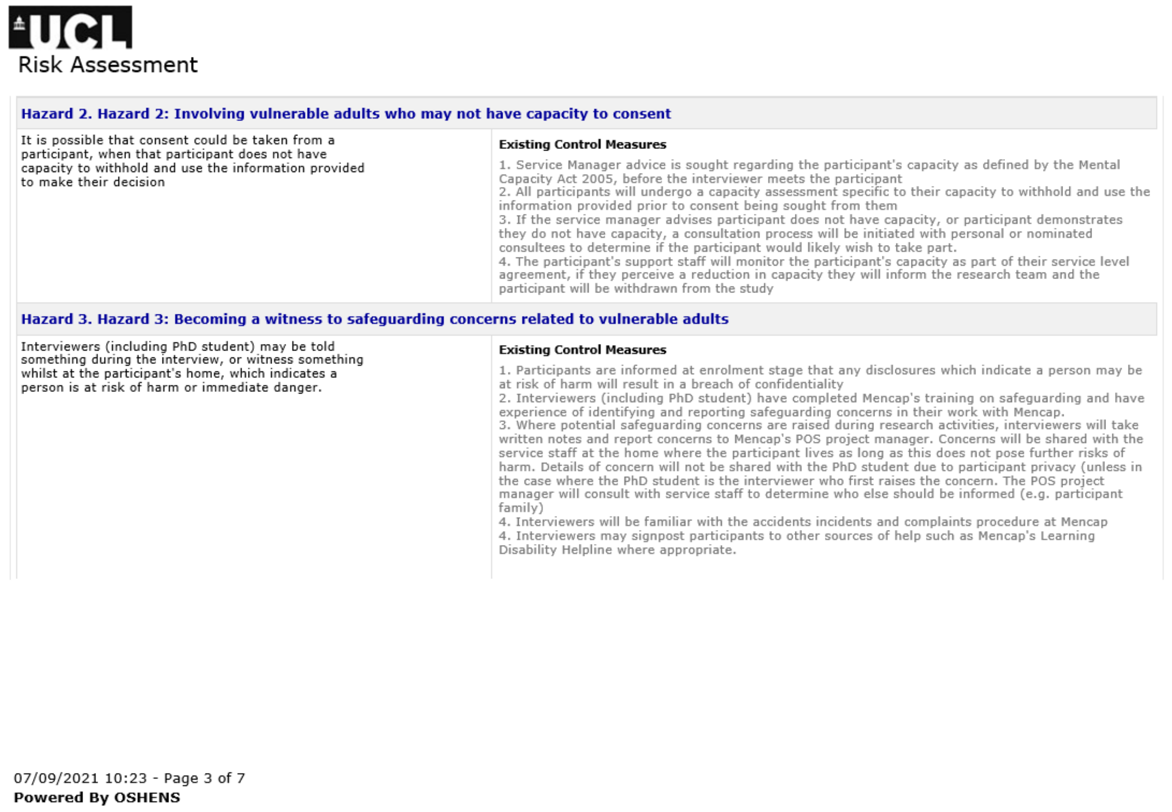
All POS interviewers (including the PhD Student) are members of Mencap staff who have received specific training related to enrolment, consent and interview. The participant information has a capacity assessment embeddded within it. The interviewer meets with the participant to run through the information. All information has been codesigned with people with ID to increase accessibility of information. Provided the participant demonstrates capacity, the interviewer will seek thei

Hazard 1. Covid-19 Infection risk and transmission when conducting research activities at participant's home

It is possible that the interviewer could pose an Covid-19 infection risk to participants, other residents of their home and staff at their home. Transmission to the interviewer from participants or other people present at their home is also a possibility. Poor ventilation of shared spaces may increase these risks.

Existing Control Measures

1. PhD student has been double vaccinated
2. Majority of Mencap staff (inclusive interviewers and staff present at homes) and majority of participants have been double vaccinated
3. All interviewers will take a lateral flow test on the day they are due to interview and will only travel to the participant's home if they have a negative result
4. Staff at the participant's home will inform the interviewer of any outbreaks and advise them not to come if there is an outbreak or concerns of exposure
5. During face to face recruitment and data collection Covid control measures will be in place including: regular hand sanitising; use of face masks and other PPE for staff and interviewers; social distancing; room ventilation.
6. If it is considered too risky for face to face meetings to take place (e.g. due to underlying health conditions of the participant or other residents of the participant's home) then recruitment and data collection will happen on MS Teams where possible.



Hazard 2. Hazard 2: Involving vulnerable adults who may not have capacity to consent

It is possible that consent could be taken from a participant, when that participant does not have capacity to withhold and use the information provided to make their decision

Existing Control Measures

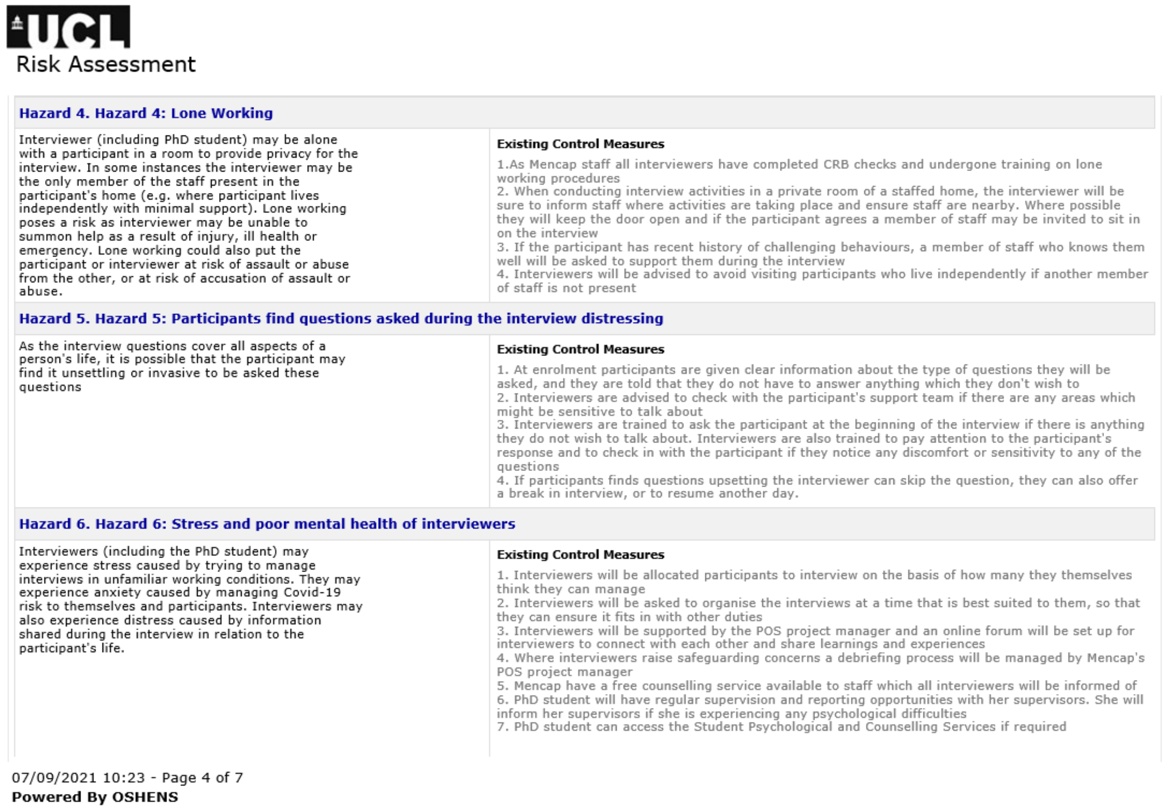
1. Service Manager advice is sought regarding the participant's capacity as defined by the Mental Capacity Act 2005, before the interviewer meets the participant
2. All participants will undergo a capacity assessment specific to their capacity to withhold and use the information provided prior to consent being sought from them
3. If the service manager advises participant does not have capacity, or participant demonstrates they do not have capacity, a consultation process will be initiated with personal or nominated consultees to determine if the participant would likely wish to take part.
4. The participant's support staff will monitor the participant's capacity as part of their service level agreement, if they perceive a reduction in capacity they will inform the research team and the participant will be withdrawn from the study

Hazard 3. Hazard 3: Becoming a witness to safeguarding concerns related to vulnerable adults

Interviewers (including PhD student) may be told something during the interview, or witness something whilst at the participant's home, which indicates a person is at risk of harm or immediate danger.

Existing Control Measures

1. Participants are informed at enrolment stage that any disclosures which indicate a person may be at risk of harm will result in a breach of confidentiality
2. Interviewers (including PhD student) have completed Mencap's training on safeguarding and have experience of identifying and reporting safeguarding concerns in their work with Mencap.
3. Where potential safeguarding concerns are raised during research activities, interviewers will take written notes and report concerns to Mencap's POS project manager. Concerns will be shared with the service staff at the home where the participant lives as long as this does not pose further risks of harm. Details of concern will not be shared with the PhD student due to participant privacy (unless in the case where the PhD student is the interviewer who first raises the concern. The POS project manager will consult with service staff to determine who else should be informed (e.g. participant family)
4. Interviewers will be familiar with the accidents incidents and complaints procedure at Mencap
4. Interviewers may signpost participants to other sources of help such as Mencap's Learning Disability Helpline where appropriate.



UCL

Risk Assessment

Hazard 4. Hazard 4: Lone Working

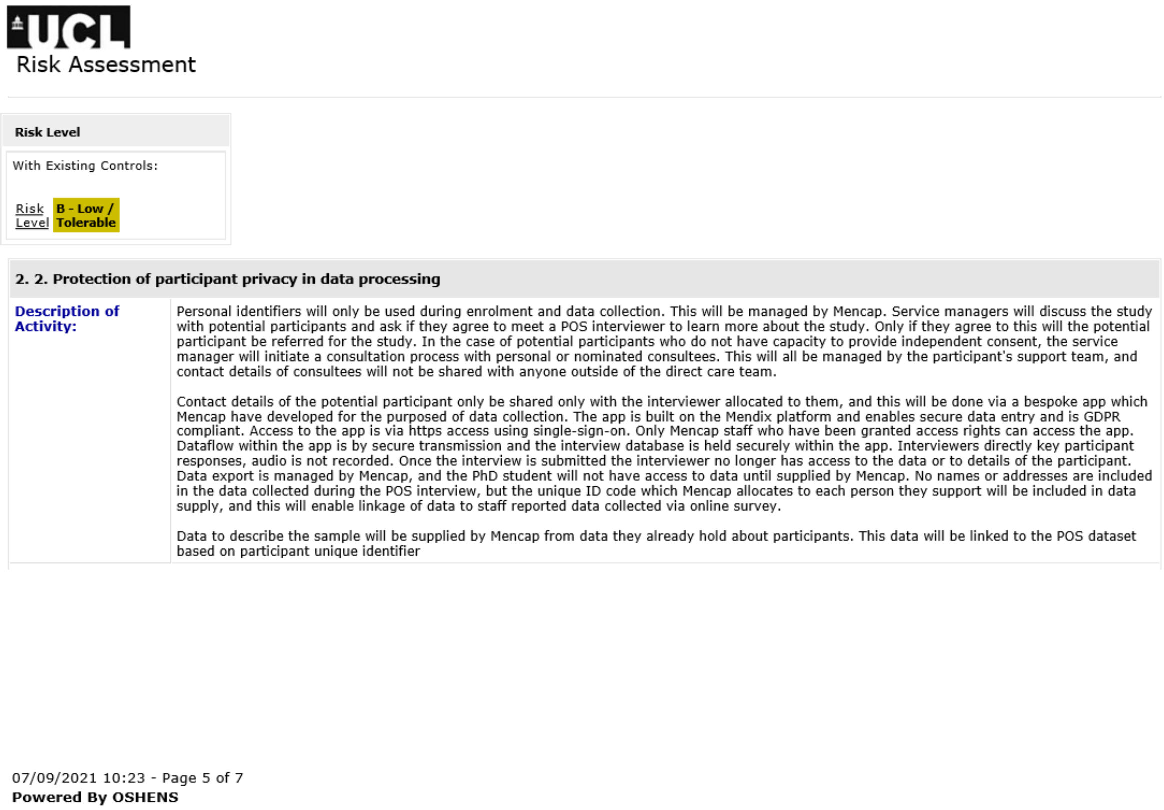
Interviewer (including PhD student) may be alone with a participant in a room to provide privacy for the interview. In some instances the interviewer may be the only member of the staff present in the participant's home (e.g. where participant lives independently with minimal support). Lone working poses a risk as interviewer may be unable to summon help as a result of injury, ill health or emergency. Lone working could also put the participant or interviewer at risk of assault or abuse from the other, or at risk of accusation of assault or abuse.	**Existing Control Measures** 1.As Mencap staff all interviewers have completed CRB checks and undergone training on lone working procedures 2. When conducting interview activities in a private room of a staffed home, the interviewer will be sure to inform staff where activities are taking place and ensure staff are nearby. Where possible they will keep the door open and if the participant agrees a member of staff may be invited to sit in on the interview 3. If the participant has recent history of challenging behaviours, a member of staff who knows them well will be asked to support them during the interview 4. Interviewers will be advised to avoid visiting participants who live independently if another member of staff is not present

Hazard 5. Hazard 5: Participants find questions asked during the interview distressing

As the interview questions cover all aspects of a person's life, it is possible that the participant may find it unsettling or invasive to be asked these questions	**Existing Control Measures** 1. At enrolment participants are given clear information about the type of questions they will be asked, and they are told that they do not have to answer anything which they don't wish to 2. Interviewers are advised to check with the participant's support team if there are any areas which might be sensitive to talk about 3. Interviewers are trained to ask the participant at the beginning of the interview if there is anything they do not wish to talk about. Interviewers are also trained to pay attention to the participant's response and to check in with the participant if they notice any discomfort or sensitivity to any of the questions 4. If participants finds questions upsetting the interviewer can skip the question, they can also offer a break in interview, or to resume another day.

Hazard 6. Hazard 6: Stress and poor mental health of interviewers

Interviewers (including the PhD student) may experience stress caused by trying to manage interviews in unfamiliar working conditions. They may experience anxiety caused by managing Covid-19 risk to themselves and participants. Interviewers may also experience distress caused by information shared during the interview in relation to the participant's life.	**Existing Control Measures** 1. Interviewers will be allocated participants to interview on the basis of how many they themselves think they can manage 2. Interviewers will be asked to organise the interviews at a time that is best suited to them, so that they can ensure it fits in with other duties 3. Interviewers will be supported by the POS project manager and an online forum will be set up for interviewers to connect with each other and share learnings and experiences 4. Where interviewers raise safeguarding concerns a debriefing process will be managed by Mencap's POS project manager 5. Mencap have a free counselling service available to staff which all interviewers will be informed of 6. PhD student will have regular supervision and reporting opportunities with her supervisors. She will inform her supervisors if she is experiencing any psychological difficulties 7. PhD student can access the Student Psychological and Counselling Services if required



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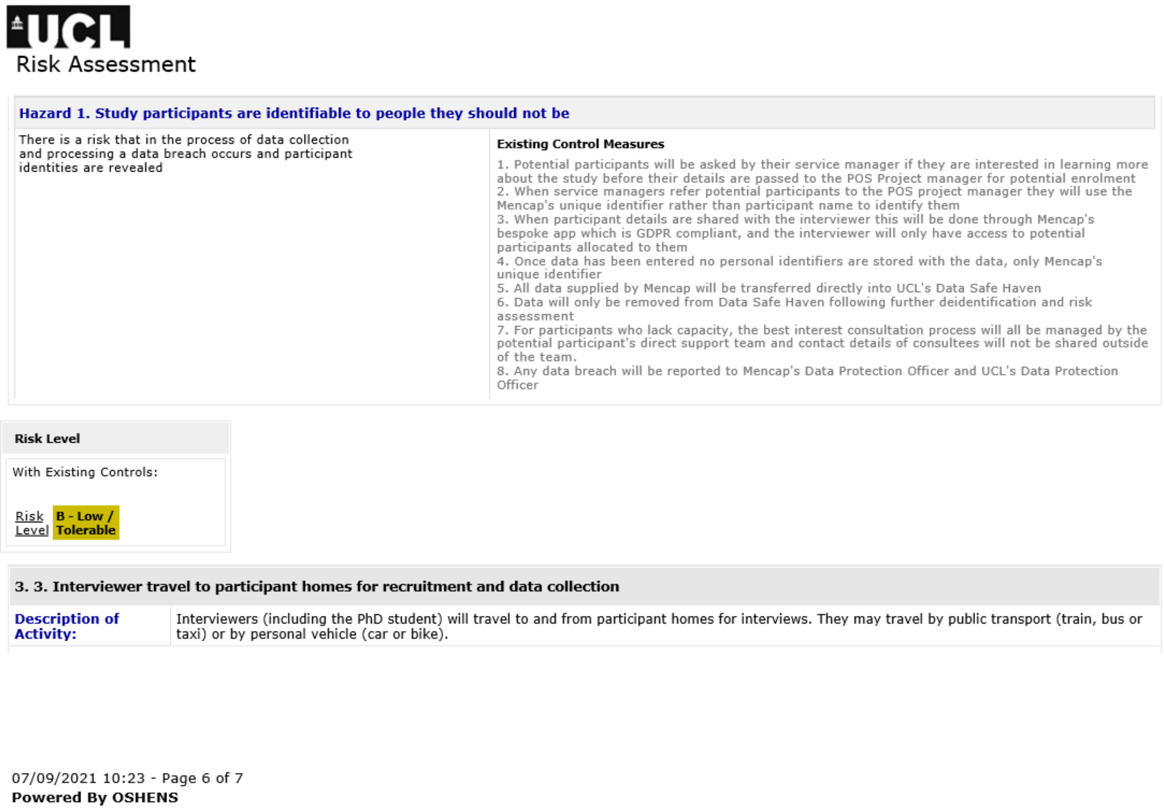
Risk Assessment

Risk Level
With Existing Controls: Risk Level **B - Low / Tolerable**

2. 2. Protection of participant privacy in data processing

Description of Activity:	Personal identifiers will only be used during enrolment and data collection. This will be managed by Mencap. Service managers will discuss the study with potential participants and ask if they agree to meet a POS interviewer to learn more about the study. Only if they agree to this will the potential participant be referred for the study. In the case of potential participants who do not have capacity to provide independent consent, the service manager will initiate a consultation process with personal or nominated consultees. This will all be managed by the participant's support team, and contact details of consultees will not be shared with anyone outside of the direct care team. Contact details of the potential participant only be shared only with the interviewer allocated to them, and this will be done via a bespoke app which Mencap have developed for the purposed of data collection. The app is built on the Mendix platform and enables secure data entry and is GDPR compliant. Access to the app is via https access using single-sign-on. Only Mencap staff who have been granted access rights can access the app. Dataflow within the app is by secure transmission and the interview database is held securely within the app. Interviewers directly key participant responses, audio is not recorded. Once the interview is submitted the interviewer no longer has access to the data or to details of the participant. Data export is managed by Mencap, and the PhD student will not have access to data until supplied by Mencap. No names or addresses are included in the data collected during the POS interview, but the unique ID code which Mencap allocates to each person they support will be included in data supply, and this will enable linkage of data to staff reported data collected via online survey. Data to describe the sample will be supplied by Mencap from data they already hold about participants. This data will be linked to the POS dataset based on participant unique identifier



UCL

Risk Assessment

Hazard 1. Study participants are identifiable to people they should not be

There is a risk that in the process of data collection and processing a data breach occurs and participant identities are revealed	**Existing Control Measures** 1. Potential participants will be asked by their service manager if they are interested in learning more about the study before their details are passed to the POS Project manager for potential enrolment 2. When service managers refer potential participants to the POS project manager they will use the Mencap's unique identifier rather than participant name to identify them 3. When participant details are shared with the interviewer this will be done through Mencap's bespoke app which is GDPR compliant, and the interviewer will only have access to potential participants allocated to them 4. Once data has been entered no personal identifiers are stored with the data, only Mencap's unique identifier 5. All data supplied by Mencap will be transferred directly into UCL's Data Safe Haven 6. Data will only be removed from Data Safe Haven following further deidentification and risk assessment 7. For participants who lack capacity, the best interest consultation process will all be managed by the potential participant's direct support team and contact details of consultees will not be shared outside of the team. 8. Any data breach will be reported to Mencap's Data Protection Officer and UCL's Data Protection Officer

Risk Level

With Existing Controls:

Risk Level	**B - Low / Tolerable**

3. 3. Interviewer travel to participant homes for recruitment and data collection

Description of Activity:	Interviewers (including the PhD student) will travel to and from participant homes for interviews. They may travel by public transport (train, bus or taxi) or by personal vehicle (car or bike).

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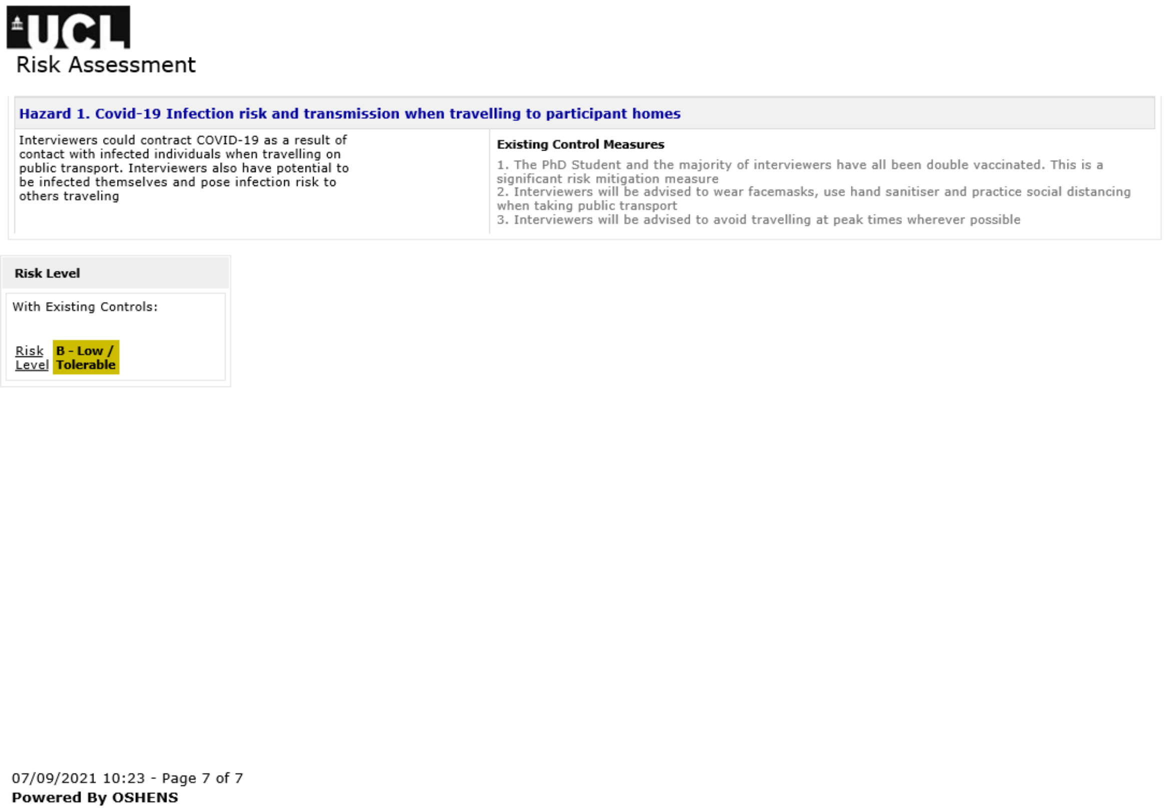

UCL

Risk Assessment

Hazard 1. Covid-19 Infection risk and transmission when travelling to participant homes

Interviewers could contract COVID-19 as a result of contact with infected individuals when travelling on public transport. Interviewers also have potential to be infected themselves and pose infection risk to others traveling	**Existing Control Measures** 1. The PhD Student and the majority of interviewers have all been double vaccinated. This is a significant risk mitigation measure 2. Interviewers will be advised to wear facemasks, use hand sanitiser and practice social distancing when taking public transport 3. Interviewers will be advised to avoid travelling at peak times wherever possible

Risk Level

With Existing Controls:

Risk Level	**B - Low / Tolerable**

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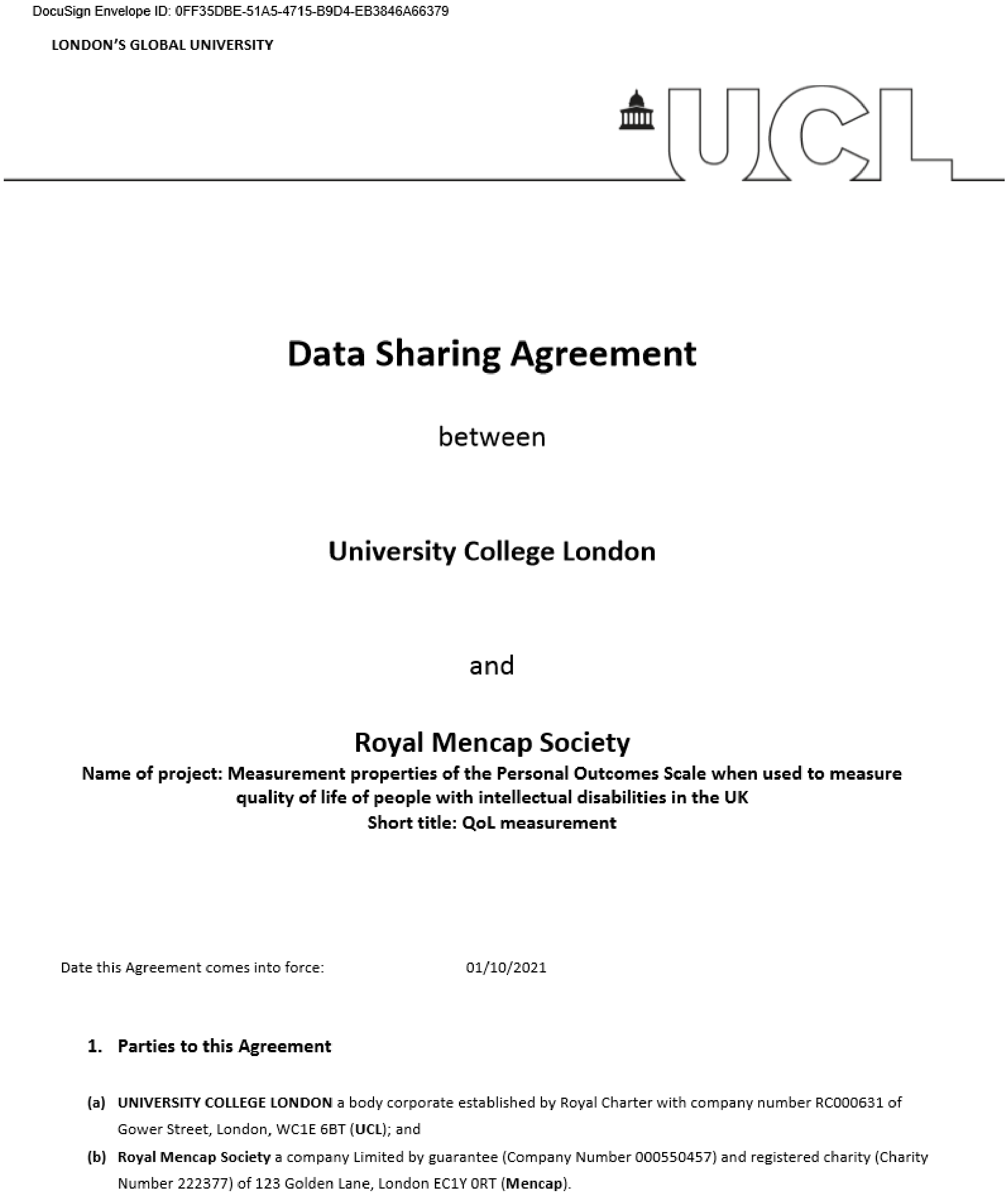
Appendix E: Data sharing agreements



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LONDON'S GLOBAL UNIVERSITY

UCL

Data Sharing Agreement

between

University College London

and

Royal Mencap Society

Name of project: Measurement properties of the Personal Outcomes Scale when used to measure quality of life of people with intellectual disabilities in the UK

Short title: QoL measurement

Date this Agreement comes into force: 01/10/2021

1. Parties to this Agreement

(a) **UNIVERSITY COLLEGE LONDON** a body corporate established by Royal Charter with company number RC000631 of Gower Street, London, WC1E 6BT (**UCL**); and

(b) **Royal Mencap Society** a company Limited by guarantee (Company Number 000550457) and registered charity (Charity Number 222377) of 123 Golden Lane, London EC1Y 0RT (**Mencap**).

2. Purpose

(a) This Agreement establishes the terms and conditions under which the parties will share personal data in connection with the with the QoL measurement project. The QoL measurement project and data flow are detailed in appendix one

(b) Data to be shared under the terms of this agreement are detailed in appendix two.

(c) Data to be collected by the PhD student from Mencap staff respondents are detailed in appendix three

(d) The parties shall share the personal data described in 2(a) above only in accordance with the terms of this Agreement.

3. Term and termination

(a) This Agreement shall commence on the date set out at the beginning of it and shall continue until 31/03/2024 unless terminated earlier in accordance with its terms.

(b) Either party may terminate this Agreement with immediate effect by giving written notice to the other party if that other party commits a material breach of any term of this Agreement which breach is irremediable or (if such breach is remediable) fails to remedy that breach within a period of 30 days after being notified in writing to do so;

(c) Clause 3 (Term and termination) and Clause 4 (Data protection) shall survive the termination or expiry of this Agreement, as shall any other Clause which, by its nature, is intended to survive termination or expiry.

(d) Termination or expiry of this Agreement shall not affect any rights, remedies, obligations or liabilities of the parties that have accrued up to the date of termination or expiry, including the right to claim damages in respect of any breach of the Agreement which existed at or before the date of termination or expiry.

4. Data protection

(a) In this Clause, the following terms have the following meanings:

(i) **Controller** means a person which, alone or jointly with others, determines the purposes and means of the Processing of Personal Data;

(ii) **Data Protection Laws** means all applicable statutes and regulations in any jurisdiction pertaining to the processing of Personal Data, including but not limited to the privacy and security of Personal Data;

(iii) **Data Subject** means the individual to whom the Personal Data relates;

(iv) **Personal Data** means any information relating to an identified or identifiable living individual;

(v) **Processing** means any operation or set of operations which is performed on Personal Data or on sets of Personal Data, whether or not by automated means, and Process, Processes and Processed shall be construed accordingly; and

(vi) **Personal Data Breach** means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, Personal Data transmitted, stored or otherwise processed.

(b) The parties acknowledge and agree that where a party Processes Personal Data under or in connection with this Agreement it alone determines the purposes and means of such processing as a Controller.

(c) In respect of the Personal Data a party Processes under or in connection with this Agreement, the party shall:

(i) comply at all times with its obligations under the Data Protection Laws;

(ii) notify the other party without undue delay after becoming aware of a Personal Data Breach; and

(iii) assist and co-operate fully with the other party to enable the other party to comply with their obligations under Data Protection Law, including but not limited to in respect of keeping Personal Data secure, dealing with Personal Data Breaches, complying with the rights of Data Subjects and carrying out data protection impact assessments.

(d) The parties shall work together to ensure that each of them is able to Process the Personal Data it Processes under or in connection with this Agreement for the purposes contemplated by this Agreement lawfully, fairly and in a transparent manner and in compliance with the Data Protection Laws. This shall include but not be limited to entering into such other written agreements as may be required from time to time to enable each party to comply with the Data Protection Laws.

5. Miscellaneous

(a) No variation of this Agreement shall be effective unless it is in writing and signed by the parties (or their authorised representatives).

(b) A failure or delay by a party to exercise any right or remedy provided under this Agreement or by law shall not constitute a waiver of that or any other right or remedy, nor shall it prevent or restrict any further exercise of that or any other right or remedy. No single or partial exercise of any right or remedy provided under this agreement or by law shall prevent or restrict the further exercise of that or any other right or remedy.

(c) If any provision or part-provision of this Agreement is or becomes invalid, illegal or unenforceable, it shall be deemed modified to the minimum extent necessary to make it valid, legal and enforceable. If such modification is not possible, the relevant provision or part-provision shall be deemed deleted. Any modification to or deletion of a provision or part-provision under this Clause shall not affect the validity and enforceability of the rest of this Agreement.

(d) This Agreement constitutes the entire agreement between the parties and supersedes and extinguishes all previous agreements, promises, assurances, warranties, representations and understandings between them, whether written or oral, relating to its subject matter.

(e) Each party agrees that it shall have no remedies in respect of any statement, representation, assurance or warranty (whether made innocently or negligently) that is not set out in this Agreement.

(f) Nothing in this Agreement is intended to, or shall be deemed to, establish any partnership or joint venture between any of the parties, constitute any party the agent of another party, or authorise any party to make or enter into any commitments for or on behalf of any other party.

(g) This Agreement does not give rise to any rights under the Contracts (Rights of Third Parties) Act 1999 to enforce any term of this Agreement.

(h) This Agreement may be executed in any number of counterparts, each of which when executed shall constitute a duplicate original, but all the counterparts shall together constitute the one Agreement.

(i) This Agreement and any dispute or claim (including non-contractual disputes or claims) arising out of or in connection with it or its subject matter or formation shall be governed by and construed in accordance with English law.

(j) Each party irrevocably agrees that the courts of England and Wales shall have exclusive jurisdiction to settle any dispute or claim (including non-contractual disputes or claims) arising out of or in connection with this Agreement or its subject matter or formation.

Signed for and on behalf of **University College London**

[redacted]

Name (print): Skye Van de Vorst

Job title: Head of Research Contracts - SLMS

Date: 18 October 2021

Signed for and on behalf of **Royal Mencap Society**

[redacted]

Name (print): Zac Taylor

Job title: Director of Quality and Practice

Date: 14/10/2021

APPENDIX ONE – DESCRIPTION OF STUDY AND DATA FLOW

Description of study

This study will assess the psychometric properties of the Personal Outcome Scale (POS); a scale designed to measure QoL of adults with intellectual disability (ID). Data will be collected from adults with ID in the UK in order to assess validity (how well does POS measure Qol); reliability (is the measurement of QoL free from error) and responsiveness (the ability of POS to detect change in QoL over time). The study will also explore association of change in QoL with health and social care service use and cost. This will be the first assessment of POS' psychometric properties in the UK and is the first study to examine responsiveness of POS. Findings will benefit ID service providers and researchers by contributing to the evidence base on ways to measure QoL of people with ID, and how to interpret scores.

The study is being completed as part of a PhD project, and the PhD student is co-funded by the European Social Research Committee (UBEL-DTP) and the charity Mencap.

The study will include the analysis of a) data collected by Mencap prior to the start of the study commencing; and b) data collected in pursuit of study aims. Data collected prior to the start of the PhD was collected as part of the service level agreement between Mencap and the participant and data collection methods were not reviewed by an external ethical review board. However participants have been informed that data will be shared for research purposes, but only when robustly anonymised. The use of this data for secondary analysis in this study has since been reviewed and approved by UCL ethics board Project ID: 19259/002. This data will be shared as soon as this contract is signed by both parties.

Data collected in pursuit of study aims is collected following review by a HRA social care REC (approval pending); and is collected on the basis of voluntary informed consent (or best interest assessment where participants lack capacity to provide independent consent). Names, addresses and other personal identifiers will not be present in data which is accessible to UCL, but the unique participant ID will be retained in the dataset. This is to enable analysis to compare participant data over two time points. The sharing of this data is dependent upon favourable review from an HRA social care REC.

Description of data flow

Data flow is depicted in figure one.

a) Data collected prior to study commencing

The supplied dataset will consist of all unique POS interviews conducted between 01 Jan 2018 and 31 March 2020 with participants in England with whom Mencap holds a contract to provide personal care. When supplying report of other data only staff report should be supplied. In cases where there are two staff reports per participant only one should be supplied. Appendix two details the dataset which will be supplied by Mencap.

Mencap will ensure anonymization and encryption prior to sharing. Sharing of the data will be done using UCL's Drop Box system, and a one time pass code and claim ID will be generated to access the file. Please note UCL Drop Box is not the same as the commercial Dropbox product. More information about UCL Drop Box can be found here.

On receipt, data will be stored in Filestore@UCL S: drive, and will only be accessible by the PhD student and her supervisors.

b) Data collected in pursuit of study aims

Use of personal identifiers during data collection

Enrolment for the study will be managed by Mencap. Personal identifiers (names and addresses) will be used in the process of enrolment, consent and arranging interviews, but these identifiers will not be present in data transferred to UCL. All consent records will be securely retained by Mencap. The enrolment process will be tracked centrally by Mencap on their One Drive and the PhD student will have access to this tracker. Personal identifiers within the enrolment tracker are Mencap's unique ID for the participant and the names of staff responding to the proxy report and the staff survey.

POS data collection will be managed through an app which Mencap have developed specifically to manage data for this project. Access to the app is via https access using single-sign-on. Interviewers have access to personal identifiers (name, service location) of only the participants assigned to them to interview. Dataflow within the app is by secure transmission and the interview database is held securely within the app. Data export is managed by the Data Quality Officer at Mencap, and the PhD student will not have access to POS data until supplied by Mencap.

Interviewers are members of Mencap staff trained as POS interviewers. The PhD student will also act as interviewer and will conduct approximately 25 of the 150 interviews. She will have access to the personal identifiers of those participants for the interviews she conducts via Mencap's app up to the point that the interview data is submitted.

Data will also be collected through an online staff survey. The name and email of the member of staff respondent will be shared with the PhD student via secure transfer. The PhD student will email the person the study information sheet and a link to the online survey. The online survey will be pre-populated with the unique ID of the participant but this will be the only data which could be linked back to the participant's identity. Staff will receive online surveys to complete via REDcap and all responses will be stored in the Data Safe Haven.

Data transfer

Data will be supplied to the PhD Student at UCL via secure transfer and stored in the Data Safe Haven. All POS data supplied will be pseudonymised with Mencap's unique ID but no other personal identifiers. All qualitative comments collected during the interview will be excluded from the data supply as they are not relevant to study objectives.

Following secure transfer the PhD student will use the unique identifier in the 2 datasets to link them. The unique identifier will be retained in the data set to enable longitudinal data analysis, and to ensure that though pseudonymised the participant could be identifiable should they later wish to exercise any of their rights under GDPR. The dataset will be retained for at least 10 years in accordance with UCL policy.
Once the data is linked the PhD student will make a copy of the dataset and anonymise the data: by reviewing the risk of indirect identification and by replacing Mencap's unique ID with a study specific code. Once robustly anonymised the PhD student can then move the dataset to her S drive for analysis.
Prior to secure transfer the data custodian will be Mencap's Data Quality Officer. Once the data has been transferred to UCL's data safe haven the data custodian will be the PhD student.

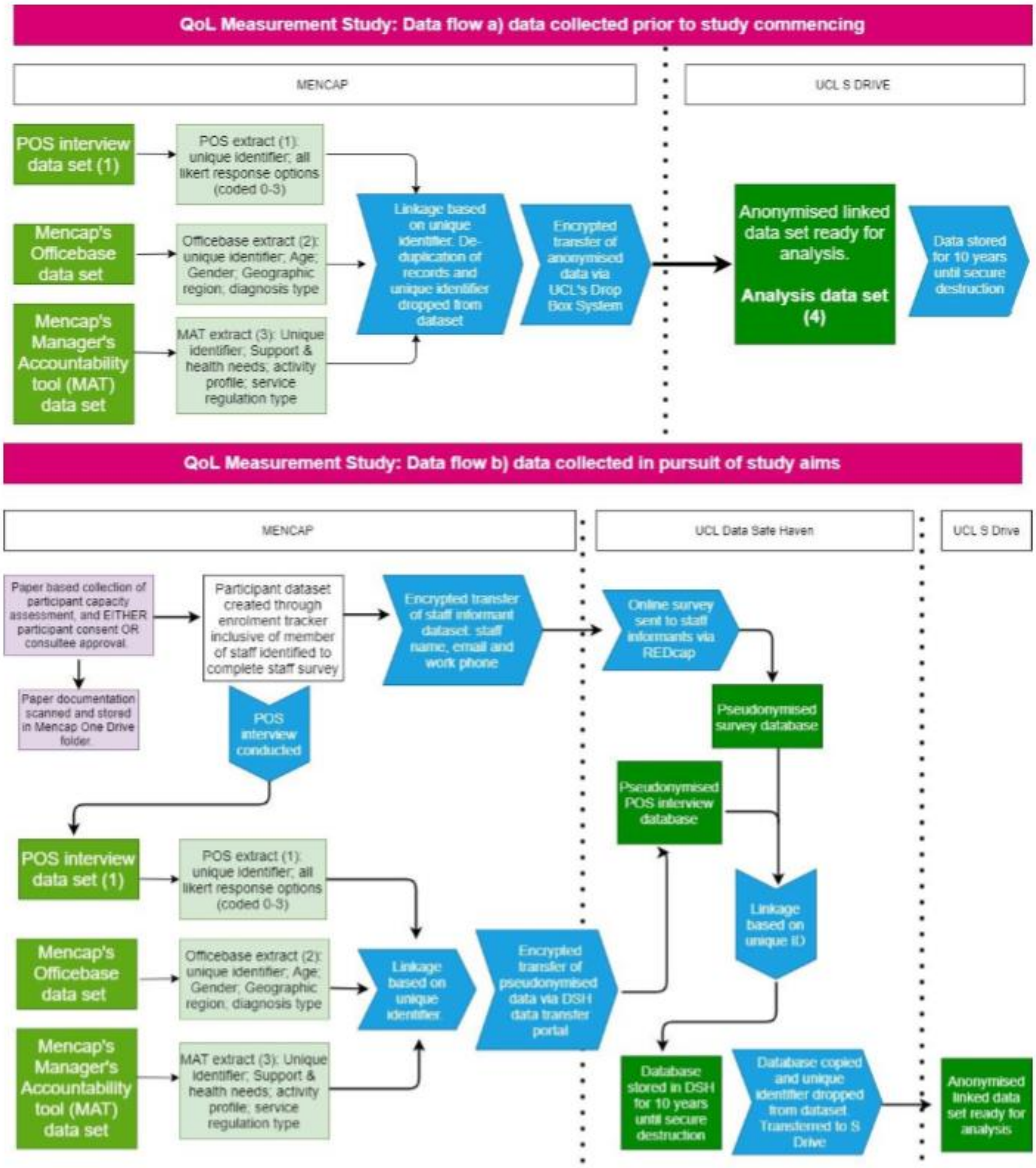
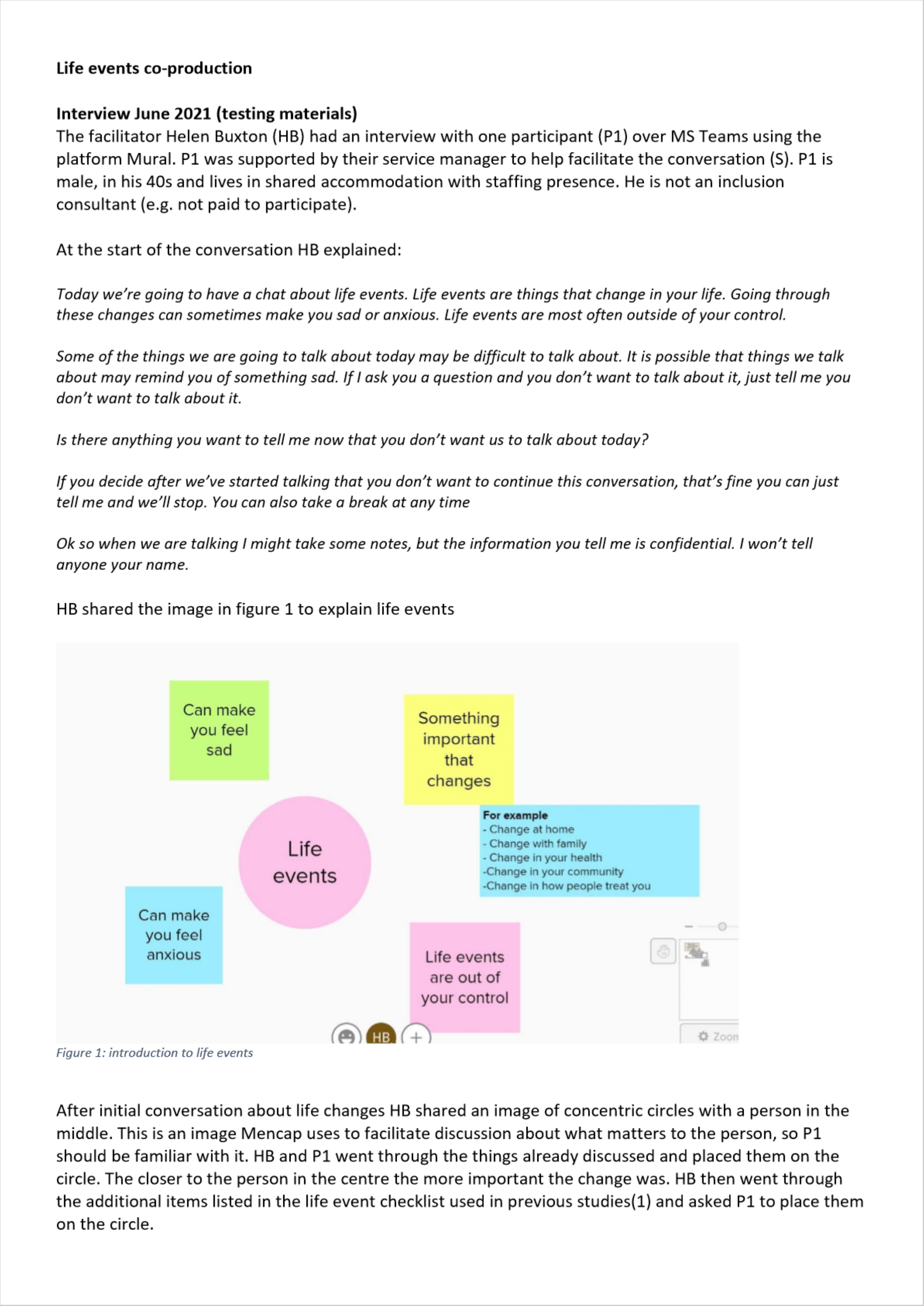


Figure 1: Data flow diagran

Appendix F: Summary report from co-production workshops



Life events co-production

Interview June 2021 (testing materials)
The facilitator Helen Buxton (HB) had an interview with one participant (P1) over MS Teams using the platform Mural. P1 was supported by their service manager to help facilitate the conversation (S). P1 is male, in his 40s and lives in shared accommodation with staffing presence. He is not an inclusion consultant (e.g. not paid to participate).

At the start of the conversation HB explained:

Today we're going to have a chat about life events. Life events are things that change in your life. Going through these changes can sometimes make you sad or anxious. Life events are most often outside of your control.

Some of the things we are going to talk about today may be difficult to talk about. It is possible that things we talk about may remind you of something sad. If I ask you a question and you don't want to talk about it, just tell me you don't want to talk about it.

Is there anything you want to tell me now that you don't want us to talk about today?

If you decide after we've started talking that you don't want to continue this conversation, that's fine you can just tell me and we'll stop. You can also take a break at any time

Ok so when we are talking I might take some notes, but the information you tell me is confidential. I won't tell anyone your name.

HB shared the image in figure 1 to explain life events

Figure 1: introduction to life events

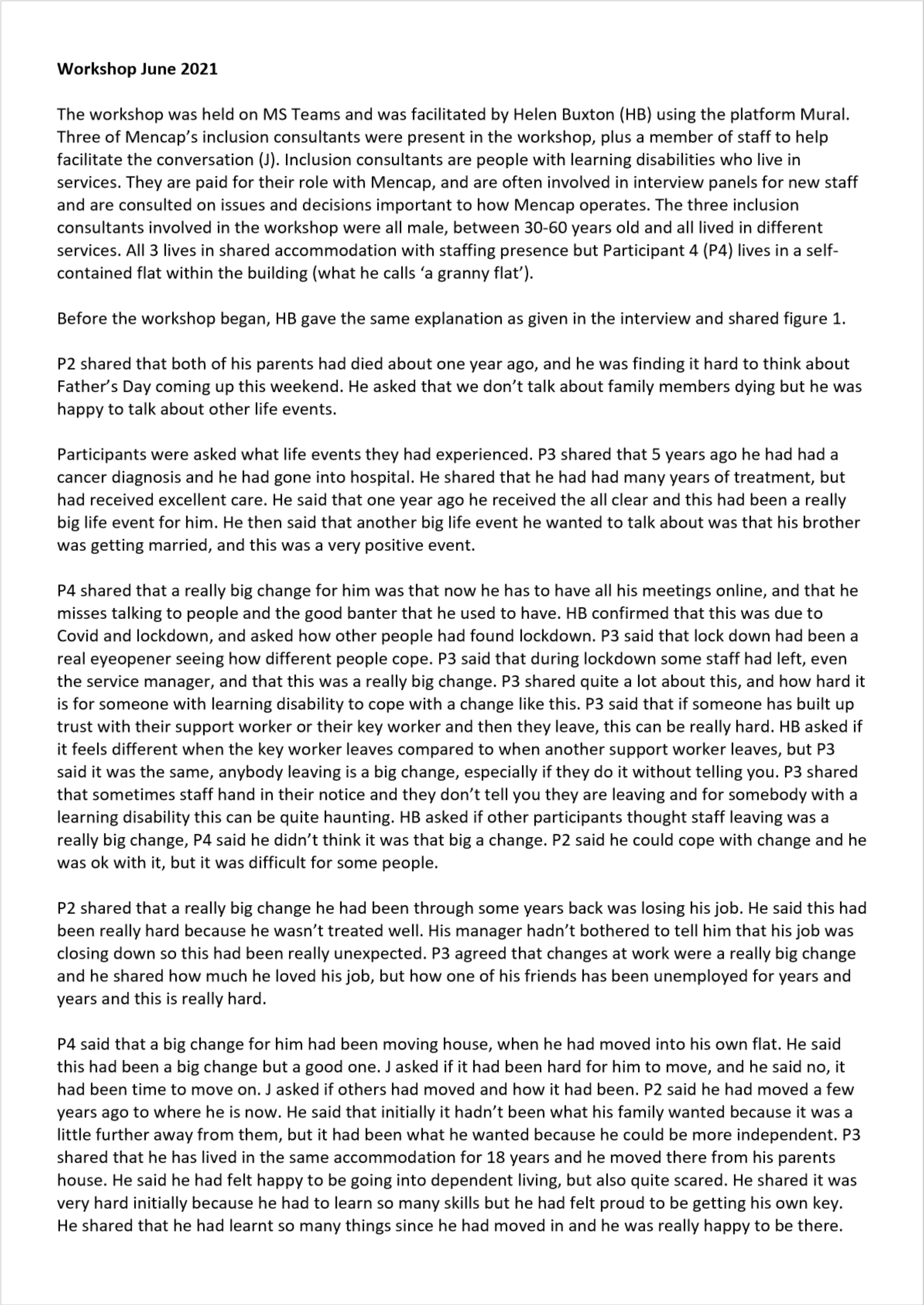
After initial conversation about life changes HB shared an image of concentric circles with a person in the middle. This is an image Mencap uses to facilitate discussion about what matters to the person, so P1 should be familiar with it. HB and P1 went through the things already discussed and placed them on the circle. The closer to the person in the centre the more important the change was. HB then went through the additional items listed in the life event checklist used in previous studies(1) and asked P1 to place them on the circle.

Figure 2: Circle of change from interview with P1

The co-produced circle of change in shown in figure 2. Although this was a good visual aid to further discussion about change I don't think it was effective in answering research questions about which changes were most important for P1. I think instead the changes in the inner circles are the changes which P1 has experience of, whereas the changes on the outer edges are changes he personally has not experienced. For this reason I will not use this visual aid in the workshop.

Key changes which P1 raised were that his brother has not been able to visit him during lockdown and that this has been a very difficult change for him. In the last month he has been on holiday with his brother and this was a very important event for him.

P1 also shared that his diabetes got worse last year, so he has had to make really big changes to his diet this year, and that has been difficult. He is proud though that he has made good progress in taking care of his health. P1 said that he had volunteered some years before and it was a big change when this had stopped.



Workshop June 2021

The workshop was held on MS Teams and was facilitated by Helen Buxton (HB) using the platform Mural. Three of Mencap's inclusion consultants were present in the workshop, plus a member of staff to help facilitate the conversation (J). Inclusion consultants are people with learning disabilities who live in services. They are paid for their role with Mencap, and are often involved in interview panels for new staff and are consulted on issues and decisions important to how Mencap operates. The three inclusion consultants involved in the workshop were all male, between 30-60 years old and all lived in different services. All 3 lives in shared accommodation with staffing presence but Participant 4 (P4) lives in a self-contained flat within the building (what he calls 'a granny flat').

Before the workshop began, HB gave the same explanation as given in the interview and shared figure 1.

P2 shared that both of his parents had died about one year ago, and he was finding it hard to think about Father's Day coming up this weekend. He asked that we don't talk about family members dying but he was happy to talk about other life events.

Participants were asked what life events they had experienced. P3 shared that 5 years ago he had had a cancer diagnosis and he had gone into hospital. He shared that he had had many years of treatment, but had received excellent care. He said that one year ago he received the all clear and this had been a really big life event for him. He then said that another big life event he wanted to talk about was that his brother was getting married, and this was a very positive event.

P4 shared that a really big change for him was that now he has to have all his meetings online, and that he misses talking to people and the good banter that he used to have. HB confirmed that this was due to Covid and lockdown, and asked how other people had found lockdown. P3 said that lock down had been a real eyeopener seeing how different people cope. P3 said that during lockdown some staff had left, even the service manager, and that this was a really big change. P3 shared quite a lot about this, and how hard it is for someone with learning disability to cope with a change like this. P3 said that if someone has built up trust with their support worker or their key worker and then they leave, this can be really hard. HB asked if it feels different when the key worker leaves compared to when another support worker leaves, but P3 said it was the same, anybody leaving is a big change, especially if they do it without telling you. P3 shared that sometimes staff hand in their notice and they don't tell you they are leaving and for somebody with a learning disability this can be quite haunting. HB asked if other participants thought staff leaving was a really big change, P4 said he didn't think it was that big a change. P2 said he could cope with change and he was ok with it, but it was difficult for some people.

P2 shared that a really big change he had been through some years back was losing his job. He said this had been really hard because he wasn't treated well. His manager hadn't bothered to tell him that his job was closing down so this had been really unexpected. P3 agreed that changes at work were a really big change and he shared how much he loved his job, but how one of his friends has been unemployed for years and years and this is really hard.

P4 said that a big change for him had been moving house, when he had moved into his own flat. He said this had been a big change but a good one. J asked if it had been hard for him to move, and he said no, it had been time to move on. J asked if others had moved and how it had been. P2 said he had moved a few years ago to where he is now. He said that initially it hadn't been what his family wanted because it was a little further away from them, but it had been what he wanted because he could be more independent. P3 shared that he has lived in the same accommodation for 18 years and he moved there from his parents house. He said he had felt happy to be going into dependent living, but also quite scared. He shared it was very hard initially because he had to learn so many skills but he had felt proud to be getting his own key. He shared that he had learnt so many things since he had moved in and he was really happy to be there.

HB shared the mural screen again, this time with the visual scale of smaller change to really big change. One by one she went through the life events discussed in the group and asked where on the scale they should be. It was very difficult for participants to choose where to put the items on the scale as they felt they should all be classed as really big changes. HB therefore repurposed the visual exercise as a tool just to aid further discussion rather than a ranking exercise.

The full list of life events discussed in the session are shown in figure 3 (N.B. items relating to family members getting sick or dying were added after the session due to P2's request not to discuss these in the session).

In addition to items already discussed P4 raised a couple of items related to his role at Mencap (shown in yellow). P4 also raised that the rules about holidays should change because to go on holiday he needed two members of staff to accompany him, and this currently wasn't possible with the staff rota. P3 then added that changed to the staff planner were quite a big deal, and sometimes staff on duty would be different from the staff mentioned on the planner. P2 said he wanted to include relationships because he had been in a relationship with someone and it had ended and this was a very difficult change for him.

Finally we talked about staying in hospital, everyone had had a time where they had to stay overnight in hospital. They all said they had been treated well, but it had been difficult. P4 said that there was a time when he had to regularly visit hospital, take lots of medication and have a lot of visits with the nurse. In recent years though he is much more in control of his health, and this means he takes less medication and has a lot less visits to the nurse.

HB asked if people had experience of having anything stolen from them, but this did not lead to any further discussion. HB asked if having a new person come to live at their home was a significant change, but none of the participants felt that this was a big change. Participants then started talking about how important it is to know how your family members are doing. P3 said that he likes to know how his brother is getting on and it feels good to him when he knows good things are happening for his brother. The other participants agreed that it is really important to know how people are getting on.

Mencap's new values

Mencap going digital

Lockdown

Any staff member leaving home

Change to staff planner

Changes to Holiday

Moving house

Learning independent living skills

Loosing your job

Relationship breakdown

Having a serious sickness (Cancer)

Staying in hospital

Improvement to health

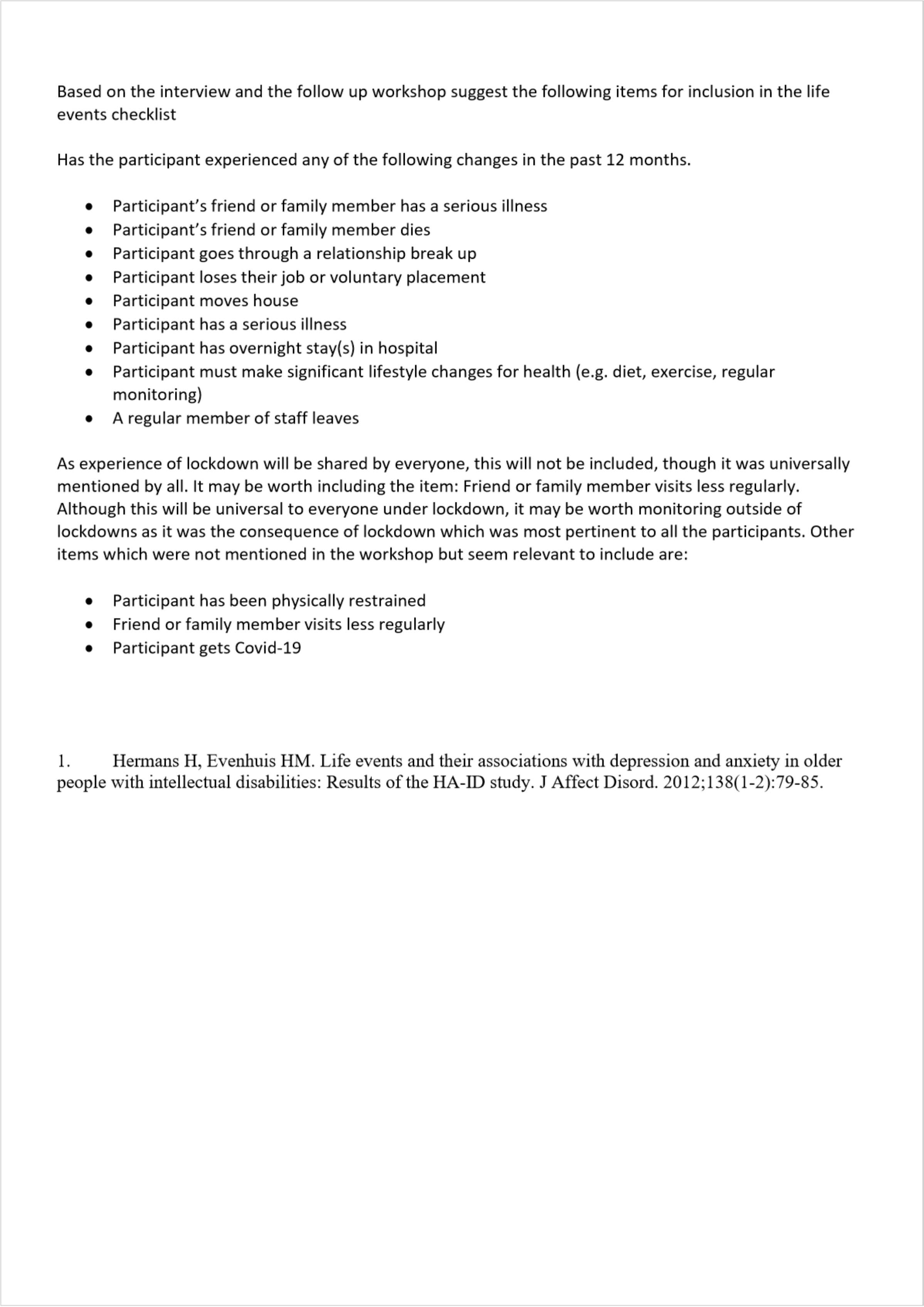
Changes in health/ monitoring

Friend or Family member dies

Friend or Family member gets sick

Figure 3:list of life events discussed in session

Summary



Based on the interview and the follow up workshop suggest the following items for inclusion in the life events checklist

Has the participant experienced any of the following changes in the past 12 months.

- Participant's friend or family member has a serious illness
- Participant's friend or family member dies
- Participant goes through a relationship break up
- Participant loses their job or voluntary placement
- Participant moves house
- Participant has a serious illness
- Participant has overnight stay(s) in hospital
- Participant must make significant lifestyle changes for health (e.g. diet, exercise, regular monitoring)
- A regular member of staff leaves

As experience of lockdown will be shared by everyone, this will not be included, though it was universally mentioned by all. It may be worth including the item: Friend or family member visits less regularly. Although this will be universal to everyone under lockdown, it may be worth monitoring outside of lockdowns as it was the consequence of lockdown which was most pertinent to all the participants. Other items which were not mentioned in the workshop but seem relevant to include are:

- Participant has been physically restrained
- Friend or family member visits less regularly
- Participant gets Covid-19

1. Hermans H, Evenhuis HM. Life events and their associations with depression and anxiety in older people with intellectual disabilities: Results of the HA-ID study. J Affect Disord. 2012;138(1-2):79-85.

Appendix G: Participant enrolment, information and consent documentation

List of participant enrolment, information and consent documents

Document name	**Document version**	**Document date**
A1: Recruitment notice in Mencap's Manager's newsletter	1	13/10/2021
A2: Manager's advice on participant capacity	1	13/10/2021
B2: Participant information and capacity assessment PowerPoint	2	10/01/2022
B3: Capacity to consent assessment	1	13/10/2021
B4: Consent form	1	13/10/2021
C1: Personal Consultee letter	1	13/10/2021
C2: Personal consultee information sheet	1	13/10/2021
C3: Personal consultee declaration	1	13/10/2021
D2: Nominated consultee information sheet	1	13/10/2021
D3: Nominated consultee declaration	1	13/10/2021

A1: Study recruitment notice placed in Mencap’s Manager’s newsletter

Project title: Measuring quality of life of people with learning disabilities in England

Date: 13 Oct 2021

Version: 1

IRAS ID
292987

Could someone you support take part in a research study about Quality of Life?

We are looking for participants to take part in an important research study to understand more about how to measure quality of life of people with learning disability.

The study is a PhD project being undertaken by Helen Buxton at University College London (UCL) and it is in partnership with Mencap. Mencap currently uses the Personal Outcome Scale (POS) to measure quality of life and Helen’s study will test how accurately POS measures quality of life.

Mencap has found the POS conversation can be really valuable to people, their families and their support teams, because it helps us to focus on what matters most to the person. Everyone who takes part will receive a report from the conversation. This can help staff teams develop outcomes for the person. Contact pos@mencap.org.uk to let us know if someone you support could take part.

POS data will be used by Mencap and shared with Helen Buxton at UCL for her research. The study will also ask staff to provide some additional information on the person with learning disability (health, services used, type of support received) via an online survey. Data will be collected twice, 12 months apart.

We are keen to include people with different degrees of support intensity and/or any other need or from any background.

If you think someone you support would like to take part in this study, please contact [redacted]to let us know. If you would like to know more about the study and activities, please get in contact with whom and we will be very happy to have a chat about this.

A2: Record of advice from Service Manager

In relation to capacity of potential participant to provide independent consent and self-report

Project title: Measuring quality of life of people with learning disabilities in England

Date: 13/10/21

Version: 1

IRAS ID
292987

Participant identification number
____

Date completed
____

Name of Service Manager completing this form
____

What we need from you

We would like to involve someone you support in a research study. The research study is being conducted by researchers at UCL in partnership with Mencap. We would like to have a quality-of-life conversation with the participant, or with a member of staff who knows them well and can answer on their behalf. We will have the Quality-of-life conversation twice, 12 months apart. Quality of Life data will be used by Mencap and shared with Helen Buxton at UCL for her research. The study will also ask staff to provide some additional information on the person with learning disability (health, services used, type of support received) via an online survey. Data will be collected twice, 12 months apart.

The person’s name, address or other identifying details won’t be shared with UCL.

Participation is voluntary and we will seek the potential participant’s consent to take part in the study. However, we want to ask your advice on how best to involve this potential participant.

Before you answer the questions below, please have a look at the participant information sheet which we have also sent you. This is the information we will go through with the potential participant when we invite them to take part in the study. We would like your advice on whether you think the potential participant will have capacity to use this information to make their own independent decision about taking part.

Please read the participant information sheet and answer the questions below

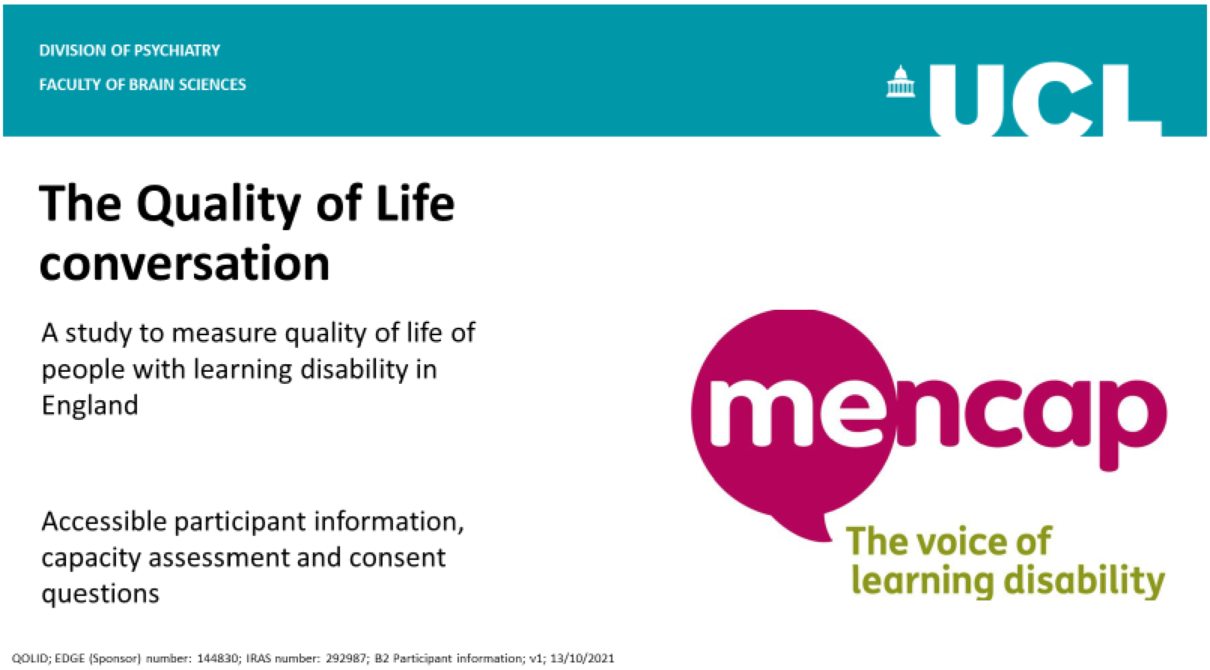
1. In your opinion, will the potential participant be able to *comprehend and retain* information from the participant information sheet?
   Yes/ No / Not sure
2. In your opinion, will the potential participant be able to *weigh or use* the information to decide whether to consent to the study or not?
   Yes/ No / Not sure

If you answered yes or not sure in any of these 2 questions, we will assess the capacity of the person to consent to the study when we meet them. We enclosed this process for your information – see document B2.

If you have answered no to any of these questions, then we will initiate a consultation process to assess if it is the potential participant's best interest to take part in this research study.

Please return this for by email to [redacted]

B2: Participant information and capacity assessment



DIVISION OF PSYCHIATRY
FACULTY OF BRAIN SCIENCES

UCL

The Quality of Life conversation

A study to measure quality of life of people with learning disability in England

Accessible participant information, capacity assessment and consent questions

mencap
The voice of learning disability

QOLID; EDGE (Sponsor) number: 144830; IRAS number: 292987; B2 Participant information; v1; 13/10/2021

UCL

You are invited to take part in a research study.

This study is happening because we want to understand how to measure quality of life of people with learning disabilities in England.

This information will help you decide if you want to take part.

You can ask any questions.

Who is organising the study?

The research is organised by Helen Buxton at University College London.

The study is in partnership with Mencap.

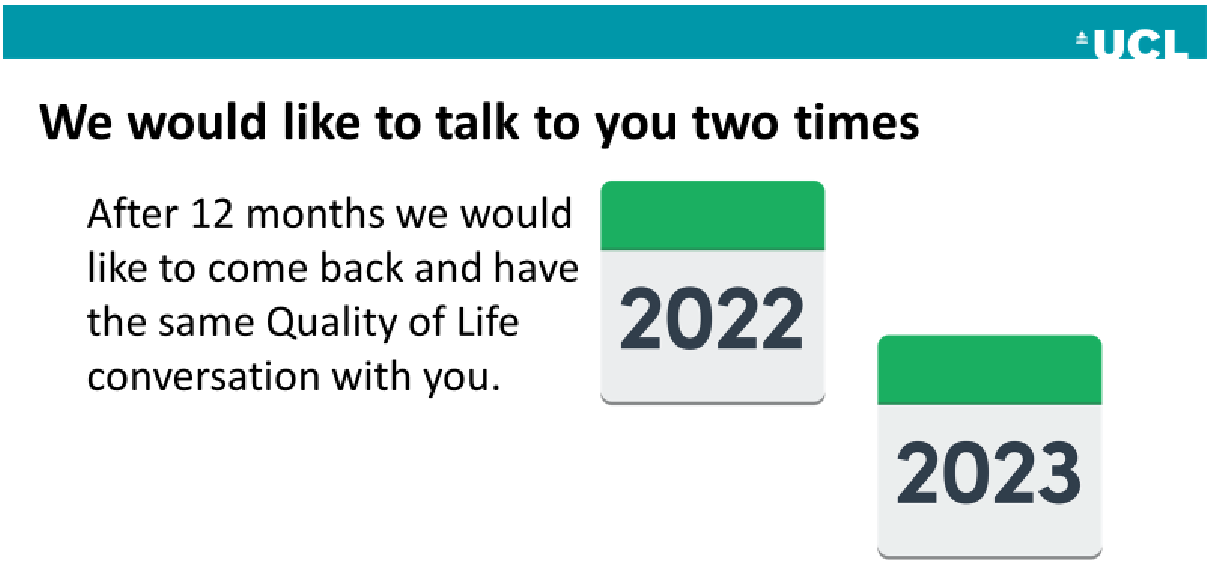
What you will be doing if you take part

We would like to have a conversation about your Quality of Life.

We will talk about the things that are most important to you.

The talk will take between one and two hours.

We do not have to do it all at once.



We would like to talk to you two times

After 12 months we would like to come back and have the same Quality of Life conversation with you.

2022

2023

What information will we collect about you?

- Your age and gender
- The things you need support with
- Your health
- Activities that you do
- Services you used this year

We will ask Mencap to tell us these things about you.

Why take part?

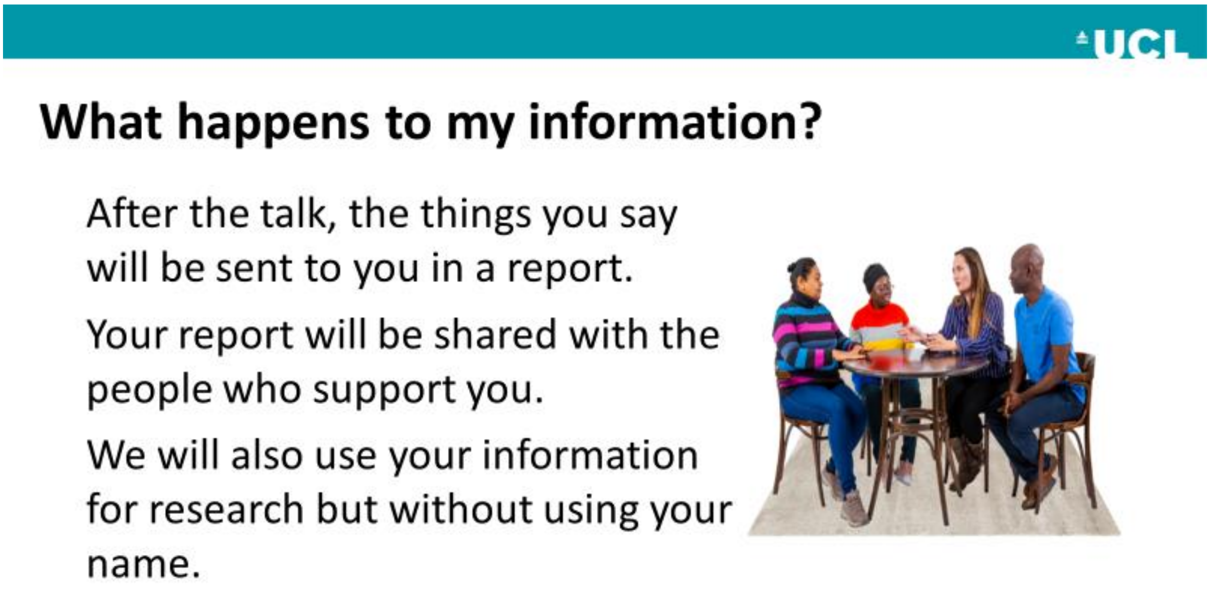
The research will help us to understand more about how to measure quality of life for people with learning disability.

What are the possible risks to taking part?

You could find some questions upsetting. If you feel uncomfortable or upset then please let me know.

You do not have to answer anything you do not want to.

You can stop at any time.

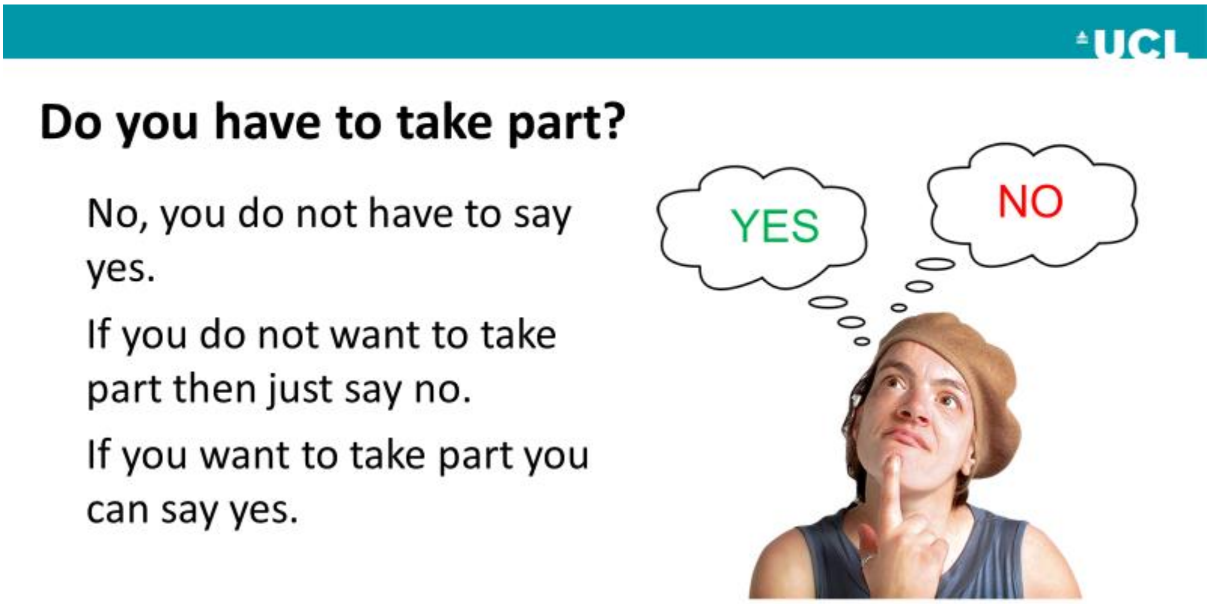


What happens to my information?

After the talk, the things you say will be sent to you in a report.

Your report will be shared with the people who support you.

We will also use your information for research but without using your name.



Do you have to take part?

No, you do not have to say yes.

If you do not want to take part then just say no.

If you want to take part you can say yes.

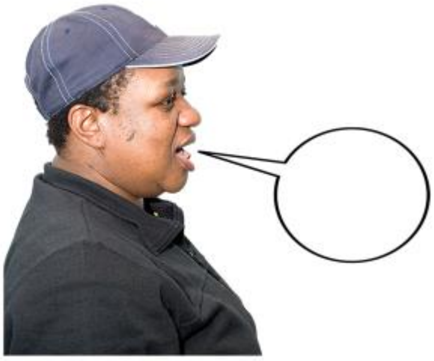
What if you change your mind?

If you say yes but then you change your mind that's OK.

Just tell me no later on.

You do not have to tell me why. Nobody will mind.

Your turn!



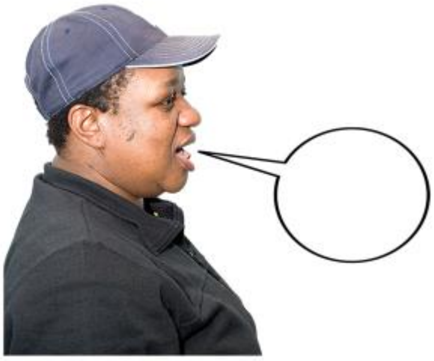
Can you tell me..

What things are we going to talk about?

C1

UCL

Your turn!



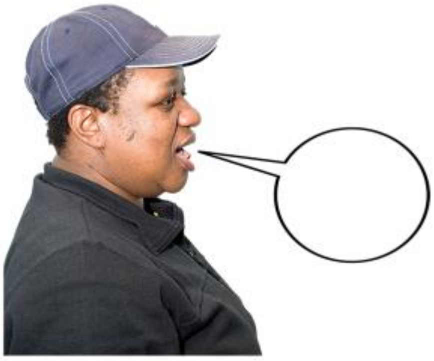
Can you tell me..

How many times do we want to speak to you?

C2

UCL

Your turn!

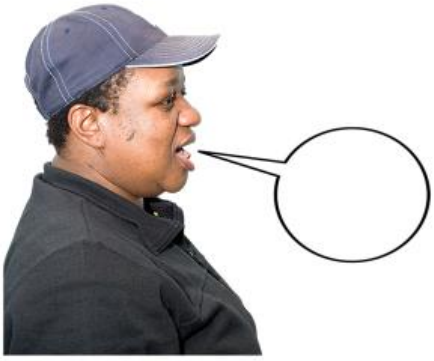


Can you tell me..

Are there any risks to taking part?

C3

Your turn!



Can you tell me..

What will you do if you change your mind about taking part?

C4

Where does the conversation happen?

You will be in your home. I might visit you or we might speak through video link.

If we use video link, you will not be recorded.

Will it be difficult?

If you find it hard to answer the questions then I will try to help you understand.

If you prefer, somebody you know can stay with you to help you answer.

How we keep your information safe

We will keep your information in a safe place. Your name will not be shared with the researchers. No one will be able to identify you from your answers.

We will keep study information for at least 10 years.

The information may be used for more research.

What will happen to the results from the research?

The researcher will use the results in her PhD project.

She will write a paper and publish it in an academic journal.

Results will also be shared at meetings with people who do work which has an impact on people with learning disability.

An easy read paper will be created to share results with people with learning disabilities

When we share the results your name will not be used. Mencap will protect your privacy.

What if there is a problem?

If you feel worried about anything to do with the research you can ask questions.

There are people you can contact if something worries you. Your support team can help you to contact these people.

If you change your mind

If you decide you do not want your information to be used you can ask for it to be deleted.

You just need to tell a member of staff and they can let the researchers know.

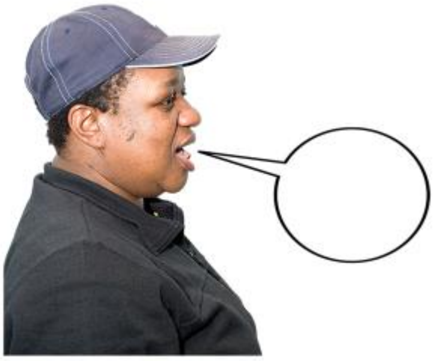
Your rights

This study has been reviewed the XX Social Care Research Ethics Committee.

Contact the XX Social Care Research Ethics Committee

You can read more about your rights by reading Mencap’s latest Privacy Policy: https://www.mencap.org.uk/our-privacy-policy

Your turn!



Do you have any questions for me?

Do you agree?

	YES	NO
1: The interviewer has explained to me why this study is happening.		
2: I have been able to ask all the questions I want. I have had the time to decide if I want to take part in this study.		
3: I understand that taking part is voluntary. I know I can stop taking part at any point.		
4. I understand I can change my mind.		
5: I agree to take part in a conversation about my Quality of Life.		
6: I agree that researchers will ask Mencap other information about me (my health, my activities, the services I use).		
7: I understand that the researcher will not identify me by name.		
8: I understand my information may be used for other research in the future		

Thank you for listening

Who to contact if there is a problem

At Mencap:	At University College London:
The Project Manager Ellen Kennedy: [redacted]	**The Researcher** Helen Buxton [redacted]
The Data Protection Officer [redacted]	**The Data Protection Officer** [redacted]

B3: Assessment of participant's capacity to provide voluntary informed consent

Project title: Measuring quality of life of people with learning disabilities in England

V1: 13/10/2021

IRAS ID	292987
Participant identification number	___________________
Name of interviewer	___________________
Date completed	___________________

Instructions for use:

This process has been developed in consultation with members of Mencap's staff who have a learning disability.

- Open the PowerPoint B2 and share your screen with the participant.
- Begin going through the information with the participant
- There are 4 slides (slides 12-15) with the title 'Your Turn!'
- The 'Your Turn!' questions are designed to assess the participant's capacity to retain and use the information provided.
- Read the question to the participant exactly as it is written on the slide. and use this form to mark their answer

C1 (slide 12)

Information provided: We are going to have a conversation about your quality of life.

We will talk about the things that are most important to you. (Slide 4)

- Your turn! Can you tell me… What things are we going to talk about? (Score 1 if the participant gives similar answer to information provided in slide 4 (e.g., quality of life, the things that are important to me). Score 0 if answer is irrelevant or too vague, e.g., 'me') ☐

C2 (slide 13)

Information provided: We would like to talk to you two times. After 12 months we would like to come back and have the same Quality of Life conversation with you. (Slide 5)

- Your turn! Can you tell me… How many times do we want to speak to you? (Score 1 if the participant gives similar answer to information provided in slide 5 (e.g. 2 times). Score 0 if answer is irrelevant or too vague) ☐

C3 (slide 14)

Information provided: You could find some questions upsetting. If you feel uncomfortable or upset, then please let me know. You do not have to answer anything you do not want to. You can stop at any time. (Slide 8)

- Your turn! Can you tell me … What are the risks to taking part?
  (Score 1 if the participant gives similar answer to information provided on slide 8 (e.g. questions may be upsetting). Score 0 if answer is irrelevant or too vague) ☐

C4 (Slide 15)

Information provided: If you say yes but then you change your mind that's OK. Just tell me no later on. You do not have to tell me why. No one will mind. (Slide 11)

- Your turn! Can you tell me … What will you do if you change your mind? (Score 1) if the participant gives similar answer to information provided (e.g. tell you no). Score 0 if answer is irrelevant or too vague) ☐

Overall Scoring

- If the participant scores 0 to any of the questions C1-C4 then it is concluded they do not have the capacity to consent to this study. We will contact the service manager at the service where the participant lives to start a best interest assessment with a personal consultee

- If the participant scores 1 for each question it is concluded they do have capacity to consent to this study. Please complete the consent process with the participant

- Please email this form to [redacted]

B4: Participant Consent form

Study title: Measuring quality of life of people with learning disabilities in England

IRAS ID
292987

Participant identification number ____________________

Name of interviewer seeking consent ____________________

Date completed ____________________

Consent sought face to face or via MS Teams. F2F / MS Teams

When seeking consent face to face a printed version of this form should be completed with the participant. If the participant is not able to sign or mark the form themselves, a member of staff should witness the consent process and sign this form to indicate the person has given verbal consent.

If the interviewer is seeking consent via MS Teams, they should use the record function on MS Teams to record the participant's answers to the consent questions.

	YES	**NO**
1: The interviewer has explained to me why this study is happening.		
2: I have been able to ask all the questions I want. I have had the time to decide if I want to take part in this study.		
3: I understand that taking part is voluntary. I know I can stop taking part at any point.		
4: I understand I can change my mind		
5: I agree to take part in a conversation about my Quality of Life		
6: I agree that researchers will ask Mencap other information about me (my health, my activities, the services I use).		
7: I understand that the researcher will not identify me by name.		
8: I understand my information may be used for other research in the future		

Continued overleaf

If consent sought face to face, please ask the participant or a witness to sign below.:

Name of Participant	Date	Signature

Name of Witness (if participant is not able to sign the form themselves)	Date	Signature

---

Notes for Mencap administration

If the participant does not consent to take part in the study, but they do consent to have the POS interview as part of Mencap's service delivery, on the understanding that their information will not be shared outside of Mencap, then please put a tick in the box ☐

C2: Personal Consultee letter

C2: Information for personal consultee to support discussions about whether it's in a person's best interests to participate in this study when they lack capacity to consent themselves.

Project title: Measuring Quality of Life of Adults with Intellectual Disabilities in England

Date: 13 October 2021
V1 IRAS ID: 292987

Why are you being contacted?

Your friend or family member has been invited to participate in a study but does not have capacity to provide informed consent independently. We would like to invite you to decide if participation in this study is in your friend or family member's best interest. This information sheet tells you what the study is about, why we would like to include the participant and what we would like you to consider.

The research is organised by Helen Buxton at University College London. The study is in partnership with Mencap. The research is funded by the Economic Social Research Council and Mencap.

What is the project about?

We want to understand how best to measure the quality of life of people with learning disabilities in the UK. One measure of Quality of Life is called the Personal Outcomes Scale. It is completed during an interview with a person with a learning disability. When a person cannot provide information for themselves, the interview is with a member of staff who knows them well.

We will measure Quality of Life twice, 12 months apart. We will look at quality of life data to determine if the Personal Outcomes Scale works well to capture people's experiences. We will also collect additional information about the person, so we can see how this additional information relates to scores on the Personal Outcomes Scale. Additional information will be about people's skills, health, the service they used and activities they do. This information will come from staff who know the person well, and Mencap datafiles.

What happens during the study?

An interview is arranged with the person with learning disability or a member of staff who knows them well if the person is not able to answer the questions themselves. The interview takes place over Microsoft Teams or face to face, depending on Covid restrictions and preferences. The interview lasts 1-2 hours. Sometimes a longer interview may be broken into two meetings to complete the Personal Outcomes Scale. The interviewer will be a member of staff from Mencap.

For the additional data, a member of staff is asked to complete a survey which takes approximately 45 minutes to complete. Staff provide information on the person's living arrangements, doctor and other health appointments, any other support they receive from services, health and mental health, skills and what they do during the day, and their perception of the person's quality of life.

Why is this research important?

There is a great need to develop measures of Quality of Life that work well for all people a learning disability. The Personal Outcomes Scale is promising, but research is needed to establish if the measure works well for people in the UK.

Measuring quality of life for people with a learning disability is important for 2 reasons: (1) we can measure quality of life for people without learning disability, and we should be able to do the same for people with a learning disability. (2) We need to be able to measure how the services supporting people with a learning disability improve their quality of life.

It is important to include all people with learning disability, including those who may not have capacity to consent, because information about them could contribute towards our understanding of how to measure quality of life for all.

What are the possible benefits of taking part in the study?

Mencap will create a personalised report from the data which will be shared with the participant's support team. This report may help the participant and their support team understand more about the things which matter to the participant. The research generated from this study will also help to understand more about how to measure quality of life of people with learning disabilities.

What are the possible risks of taking part in the study?

There is a small risk that the participant could find it upsetting or uncomfortable to know that questions are being asked about them. If the participant gives any indication that they do not wish the questions to be asked about them, we will exclude them from the study.

The answers given by the respondent are confidential. But if the respondent shares something which makes the interviewer worried that the participant or someone else might be in danger of harm, we might have to pass this information on to relevant authorities.

What happens to the data from this study

Mencap will look at the Personal Outcomes Scale data to understand what is important to this person and how they can help them achieve their goals. After the interview, each participant will receive an individual report from the conversation which will be shared with the participant's support team and can be used to help inform their personal development plan.

Mencap will share the Personal Outcomes Scale data with the UCL researcher who will evaluate how well this scale measures quality of life, alongside the additional data collected. Mencap will not pass on the name of the person to protect their anonymity. All data will be stored according to GDPR guidelines.

The research will not identify individual participants. The researcher will write about the findings in her PhD (an academic document), and in articles that can be widely distributed.

Research data will be kept securely at UCL, and only authorised researchers will have access to the data.

Mencap may use the Personal Outcome Scale data for further research and to help evaluate services.

The project has been approved by (named) Research Ethics Committee. The project has been designed to be safe for all participants and not to cause any undue distress. To make sure this is the case the researchers need advice from someone who knows the participant well.

What we would like you to consider:

We are asking you to consider the information provided above and let us know if you think that participation in the research is in your friend or family member's best interests.

When thinking about the wishes and interests of your friend or family member, it is important that you should set aside any of your own views about the project.

Participation in the research is voluntary. If you advise that your friend or family member may not wish to take part, or if they express any wish not to take part, they will be withdrawn from the study. This will not affect in any way the care they receive from Mencap or any other service or affect their legal rights.

What we would like you to do:

Please complete the attached form and send this back to Ellen Kennedy at Mencap using the stamped addressed envelope. Use the form to indicate if you think your friend or family member would like to take part or not. If you feel there is someone else who would be better placed to be consulted on this matter, then please suggest who we should approach.

Please return the form within 2 weeks. If we do not hear from you, we will try to ring you. If no communication is possible, we will assume that you do feel able to provide an opinion on this occasion and we will instead consult with staff members who know your friend of family member well.

How your information will be kept confidential:

Information about you (name, address and telephone number) and information that you disclose about your friend or family member is held by Mencap. Mencap will let the researcher know what response you provide when you return your form. Mencap will not share your name, address or telephone number with the researcher. However, if you request to discuss further before making a decision, Mencap will share your contact details with the researcher (or you can contact the researcher directly –see below).

If you wish to find out more about the project:
If you want to ask a question about anything to do with the research, please contact the researcher at University College London: Helen Buxton:
[redacted]

If you prefer to speak to someone at Mencap you can contact the project manager in the Quality Team Ellen Kennedy: [redacted]

If you have any questions about the way Mencap is using your information, please email Mencap's data protection officer at: [redacted]

You can read more about your rights by reading Mencap's latest Privacy Policy: https://www.mencap.org.uk/our-privacy-policy

C3: Personal consultee declaration

Project title: Measuring Quality of Life of Adults with Intellectual Disabilities in England

V1: 13/10/21

IRAS ID: *292987*   Participant code:

1. I think that my friend or family member would likely NOT wish to take part	I agree with this statement Signed ………………………………. Date …………………….
2. I think that my friend or family member would not be interested in taking part	I agree with this statement Signed ………………………………. Date …………………….
3. I cannot provide an opinion on this occasion. I think that another person is better placed to act as a consultee	I agree with this statement, and I enclose contact details below Signed ………………………………. Date …………………….

If you think another person is better placed to act as a consultee, please provide the name and contact details of that person. If you do not have any suggestions, please leave blank.

____

____

____

____

Thank you for completing the form. Please send in the enclosed stamped addressed envelope to Ellen Kennedy at Mencap

D2: Information for nominated consultee

D2: Information for nominated consultee to support discussions about whether it's in a person's best interests to participate in this study when they lack capacity to consent themselves.

Date: 13/10/21

V1 IRAS ID: *292987*

Why are you being contacted?

You support a person with a learning disability who has been invited to participate in a study but does not have capacity to provide informed consent independently. We would like to invite you to decide if participation in this study is in the participant's best interest. This information sheet tells you what the study is about, why we would like to include the participant and what we would like you to consider.

The research is organised by Helen Buxton at University College London. The study is in partnership with Mencap. The research is funded by the Economic Social Research Council and Mencap.

What is the study about?

We want to understand how best to measure the quality of life of people with learning disabilities in the UK. One measure of Quality of Life is called the Personal Outcomes Scale. It is completed during an interview with a person with a learning disability. When a person cannot provide information for themselves, the interview is with someone who knows them well and can provide information about their Quality of Life.

The study will measure Quality of Life twice, 12 months apart. We will look at quality of life data to determine if the Personal Outcomes Scale works well to capture people's experiences. We will also collect additional information about the person, so we can see how this additional information relates to scores on the Personal Outcomes Scale. Additional information will be about people's skills, circumstances, and health. This information will come from staff who know the person well, or Mencap datafiles.

What happens during the study?

An interview is arranged with the person with learning disability or a member of staff who knows them well if the person is not able to answer the questions themselves. The interview takes place over Microsoft Teams or face to face, depending on COVID restrictions and preferences. The interview lasts 1-2 hours. Sometimes a longer interview may be broken into two meetings to complete the Personal

Outcomes Scale. The interviewer will be either the researcher (Helen Buxton) or a member of staff from Mencap.

For the additional data, a member of staff is asked to complete a survey which takes approximately 45 minutes to complete. Staff provide information on the person's living arrangements, doctor and other health appointments, any other support they receive from services, health and mental health, skills and what they do during the day, and their perception of the person's quality of life.

Why is this research important?

There is a great need to develop measures of Quality of Life that work well for all people a learning disability. The Personal Outcomes Scale is promising, but research is needed to establish if the measure works well for people in the UK.

Measuring quality of life for people with a learning disability is important for 2 reasons: (1) we can measure quality of life for people without learning disability, and we should be able to do the same for people with a learning disability. (2) We need to be able to measure how the services supporting people with a learning disability improve their quality of life.

It is important to include all people with learning disability, including those who may not have capacity to consent, because information about them could contribute towards our understanding of how to measure quality of life for all.

What are the possible benefits of taking part in the study?

Mencap will create a personalised report from the data which will be shared with the participant's support team. This report may help the participant and their support team understand more about the things which matter to the participant. The research generated from this study will also help to understand more about how to measure quality of life of people with learning disabilities.

What are the possible risks of taking part in the study?

There is a small risk that the participant could find it upsetting or uncomfortable to know that questions are being asked about them. If the participant gives any indication that they do not wish the questions to be asked about them, we will exclude them from the study.

The answers given by the respondent are confidential. But if the respondent shares something which makes the interviewer worried that the participant or someone else might be in danger of harm, we might have to pass this information on to relevant authorities.

What happens to the data from this study

Mencap will look at the Personal Outcomes Scale data to understand what is important to this person and how they can help them achieve their goals. After the interview, each participant will receive an individual report from the conversation which will be shared with the participant's support team and can be used to help inform their personal development plan.

Mencap will share the Personal Outcomes Scale data with the UCL researcher who will evaluate how well this scale measures quality of life, alongside the additional data collected. Mencap will not pass on the name of the person to protect their anonymity. All data will be stored according to GDPR guidelines.

The researcher will do analyses which will not identify individual participants. The researcher will write about the findings in her PhD (an academic document), and in reports that will be written with the help of Mencap staff with a learning disability so findings can be widely distributed.

Research data will be kept securely at UCL, and only authorised researchers will have access to the data.

Mencap may use the Personal Outcome Scale data for further research and to help evaluate services.

The project has been approved by (named) Research Ethics Committee. The project has been designed to be safe for all participants and not to cause any undue distress. To make sure this is the case the researchers need advice from someone who has known the participant for some time.

What we would like you to consider:

We are asking you to consider the information provided above and let us know if you think that participation in the research is in the person's best interests.

When thinking about the wishes and interests of the prospective participant, it is important that you should set aside any of your own views about the project.

Participation in the project is voluntary. If you advise that the participant may not wish to take part, or if they express any wish not to take part, the participant will be withdrawn from the study. This will not affect in any way they care they receive from Mencap or any other service or affect their legal rights.

What we would like you to do:

Please complete the attached form and send this back to [redacted] Use the form to indicate if you think the prospective participant would like to take part or not. If you feel there is someone else who would be better placed to be consulted on this matter, then please suggest who we should approach.

Please return the form within 2 weeks. If we do not hear from you, we will follow up by email or phone.

How your information will be kept confidential:

Information about you (name, address and telephone number) is held by Mencap. When you complete the form Mencap will share your answer with the researcher.

If you wish to find out more about the project:
If you want to ask a question about anything to do with the research, please contact the researcher at University College London: Helen Buxton: [redacted]

If you prefer to speak to someone at Mencap you can contact the project manager in the Quality Team Ellen Kennedy: [redacted]

If you have any questions about the way Mencap is using your information, please email Mencap's data protection officer at: [redacted]

You can read more about your rights by reading Mencap's latest Privacy Policy: https://www.mencap.org.uk/our-privacy-policy

D3: Invitation to act as a nominated consultee

Project title: Measuring Quality of Life of Adults with Intellectual Disabilities in the UK

V1 IRAS ID: *292987*

Participant code: Date completed:

1. I think that the participant would likely NOT wish to take part	I agree with this statement Signed ……………………………… Date ……………………
2. I think that the participant would not be interested in taking part	I agree with this statement Signed ……………………………… Date ……………………
3. I cannot provide an opinion on this occasion. I think that another person is better placed to act as a consultee	I agree with this statement, and I enclose contact details below Signed ……………………………… Date ……………………

If you think another person is better placed to act as a consultee, please provide the name and contact details of that person. If you have no suggestions, please leave blank.

____

____

____

____

Thank you for completing the form. Please return the form to [redacted]

<END OF PARTICIPANT INFORMATION AND ENROLMENT DOCUMENTATION>

Appendix H: Data collection forms

Personal Outcome Scale – Self report

The Quality-of-Life Conversation
G1: Personal Outcome Scale Self Report interview tool
Project title: Measuring quality of life of people with learning disabilities in England

Date: 13/10/21

Version: 1

IRAS ID: 292987

N.B. data to be entered via an app, not paper data collection

A1: Interviewer ID

____

A2: Participant unique ID

____

A3: Does the person completing the interview deliver direct support? Yes/ No

A4: Does the person completing the interview directly support the participant? Yes/No

A5: What role does the interviewer have?

Service Manager

Assistant Service Manger

Key Worker

Support Worker

Quality team member

Other. Please specify __________________

A6: Date of interview

____

A7: Is this interview being conducted remotely? Yes/No

Learning

		3	2	1	0
L1	Are you able to feed yourself, stand up and sit down, use the toilet and get dressed by yourself?	Generally independent	Assistance needed for	Can't do on my own	No answer given

			some things		
L2	Are you able to prepare meals, clean the house, take your medication and go out by yourself?	Generally independent	Assistance needed for some things	Can't do on my own	No answer given
L3	Are you learning to do new things? (this might be taking a course, or something that you are doing as part of your development plan)	Yes, many new things	Some new things	Few if any	No answer given
L4	Are you able to demonstrate the skills you have and the things that you can do?	Yes, all the time	Some of the time	Rarely or never	No answer given
L5	Do you have access to the information that you are interested in. For example, being able to find out what's on TV or what's happening in your area	Yes, all the time	Some of the time	Rarely or never	No answer given
L6	Do you use a computer, mobile phone or tablet	Yes, all the time	Some of the time	Rarely or never	No answer given

L7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

L1	L2	L3	L4	L5	L6

1.2.2 Choices

C1	Do you get given choices about what you want to wear, to eat, and where you would like to go?	Always	Sometimes	Rarely or never	No answer given
C2	When you are given choices do you decide for yourself which choice to take?	Always	Sometimes	Rarely or never	No answer given
C3	When someone asks you to do something, can you say no?	Always	Sometimes	Rarely or never	No answer given
C4	Do people respect your decisions?	Always	Sometimes	Rarely or never	No answer given
C5	Do you have control over how you spend at least some of your money?	A lot of control	Some control	Very little or no control	No answer given
C6	Do you get to express your opinion or what you prefer to do, wear, go, and eat	Always	Sometimes	Rarely or never	No answer given

C7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

C1	C2	C3	C4	C5	C6

1.2.3 Friends and family

F1	Do you have people you think of as friends (not including paid staff)	Yes	More or less	No	No answer given
F2	How often do you participate in social activities like eating with friends, going to parties or meeting friends in town?	Often	Some of the time	Rarely or never	No answer given
F3	How often do you communicate or spend time with your family either in person, by phone or email?	Often	Some of the time	Rarely or never	No answer given
F4	How often do you communicate or spend time with your friends either in person, by phone or email?	Often	Some of the time	Rarely or never	No answer given
F5	Do you feel that you are important to your family?	Yes	More or less	No	No answer given
F6	Do you have a support network - people you can go to for advice and help?	Yes	More or less	No	No answer given

F7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

F1	F2	F3	F4	F5	F6

1.2.4 Social Inclusion

S1	Do you talk to people who live or work near to you?	Often	Sometimes	Rarely or never	No answer given
S2	How many people in the area do you know by name?	Many (5+)	Some (2 – 4)	Few (1-0)	No answer given
S3	Do you use shops and services near where you live? (e.g. café, shops, hairdressers, pub, bank, cinema, religious worship, public transport, gym or sports centre)	Often (daily)	Some of the time (1-2 times a week)	Rarely or never	No answer given
S4	Do you do things for other people when they need your help?	Often	Sometimes	Rarely or never	No answer given
S5	Do people from your community help you with things (including visiting you, taking you places or doing things with you)?	Often	Sometimes	Rarely or never	No answer given
S6	Do you go to any local clubs, groups or community centres near where you live?	Often	Sometimes	Rarely or never	No answer given

S7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

S1	S2	S3	S4	S5	S6

1.2.5 Rights

R1	Do you have a place in your own home where you can be by yourself?	Yes	More or less	No	No answer given
R2	Can you go out of your home and come back in whenever you want?	Yes	Depends	No	No answer given
R3	Can you have a pet if you want one?	Yes	Depends	No	No answer given
R4	Can you have a girlfriend or boyfriend if you want?	Yes	Depends	No	No answer given
R5	Are you allowed to be together as much as you want with your partner/ girlfriend/boyfriend? (Score yes if there is no partner)	Yes	Depends	No	No answer given
R6	Have you ever voted in recent elections?	Yes, every time you could	Yes, some of the time	No, never	No answer given

R7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

R1	R2	R3	R4	R5	R6

1.2.6 Happiness

Hap1	Do you feel safe and secure in your daily environment?	Very safe	Somewhat safe	Not safe	No answer given
Hap2	Do you feel successful in the things that you do?	Yes	More or less	No	No answer given
Hap3	How frequently do you express love, fondness or affection towards others?	All the time	Some of the time	Rarely or never	No answer given
Hap4	Are you a happy person?	Most of the time	Some of the time	Rarely or never	No answer given
Hap5	Are you satisfied with how things are going for you? (in general)	Definitely yes	With some things	Not at all	No answer given
Hap6	Do you trust the people who are important to you?	Yes	More or less	No	No answer given

Hap7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

Hap1	Hap2	Hap3	Hap4	Hap5	Hap6

1.2.7 Health

He1	In general, how healthy do you feel?	Very healthy	Okay	Sick or ill	No answer given
He2	How often do you exercise, play games, or are active (e.g. fitness, cycling, walking, swimming or football)?	Every day	A few times a week	Rarely or never	No answer given
He3	Do you get the right amount of rest and relaxation for you?	Yes	More or less	No	No answer given
He4	Is your diet varied and balanced?	Yes, all the time	Some of the time	Rarely or never	No answer given
He5	Are you ever in pain or uncomfortable? (not just today, but generally)	No	Some of the time	Yes, all of the time	No answer given
He6	How do you feel when you wake up in the morning?	Well rested	A little tired	Very tired	No answer given

He7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

He1	He2	He3	He4	He5	He6

1.2.8 Money

M1	Do you have enough money to pay for what you really need? (for example food and bills)	Yes	More or less	No	No answer given
M2	Do you have enough money so you can save some of it?	Yes, most of the time	Some of the time	No	No answer given
M3	Do you own things that are important to you? (e.g. your own pictures or photos, TV, mobile phone)	Yes, many things	Some things	Very few things	No answer given
M4	Do you have a paid job?	Yes (regular hours)	Sometimes (irregular hours)	No	No answer given
M5	Can you lock your door and keep your things safe at home?	Yes, all the time	Yes, some of the time	No	No answer given

M6	Do you have enough money to make choices (for example what to wear and what to buy?)	Yes, for most things	For some things	No	No answer given

M7: If any of the above questions were answered with help from someone other than the person being interviewed (e.g. support worker or family member) please tick which questions (tick all that apply)

M1	M2	M3	M4	M5	M6

X1: Were any communications aids/ systems used during this interview? (please describe)

END OF INTERVIEW

Personal Outcome Scale – proxy report

The Quality of Life Conversation

G2: Personal Outcome Scale Proxy Report interview tool
Project title: Measuring quality of life of people with learning disabilities in England

Date: 13/10/2021
Version: 1
IRAS ID: 292987

N.B. data to be entered via an app, not paper data collection

A1: Interviewer ID

____

A2: Participant unique ID

____

A3: Does the person completing the interview deliver direct support? Yes/ No
A4: Does the person completing the interview directly support the participant? Yes/No
A5: What role does the interviewer have?

- Service Manager
- Assistant Service Manger
- Key Worker
- Support Worker
- Quality team member
- Other. Please specify __________________

A5a: What is the relationship of the person being interviewed to the participant?

- Member of direct support team
- Assistant service manager
- Service manager
- Other

A6: Date of interview

____

A7: Is this interview being conducted remotely? Yes/No

Learning

		3	2	1	0
L1	Is the person able to feed them self, stand up and sit down, use the toilet and get dressed by themselves?	Generally independent	Assistance needed for some things	Can't do on my own	No answer given
L2	Is the person able to prepare meals, clean the house, take their medication and go out by themselves?	Generally independent	Assistance needed for some things	Can't do on my own	No answer given
L3	Is the person learning to do new things? (this might be taking a course, or something that they are doing as part of their development plan)	Yes, many new things	Some new things	Few if any	No answer given

L4	Is the person able to demonstrate the skills they have and the things they can do?	Yes, all the time	Some of the time	Rarely or never	No answer given
L5	Does the person have access to the information that they are interested in. For example being able to find out what's on TV or what's happening in their area	Yes, all the time	Some of the time	Rarely or never	No answer given
L6	Does the person use a computer, mobile phone or tablet	Yes, all the time	Some of the time	Rarely or never	No answer given

L7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

L1	L2	L3	L4	L5	L6

Choices

C1	Does the person choose what they want to wear, to eat, and where they would like to go?	Always	Sometimes	Rarely or never	No answer given
C2	When the person is given choices do they decide for themselves which choice to take?	Always	Sometimes	Rarely or never	No answer given
C3	When someone asks the person to do something, can they say no?	Always	Sometimes	Rarely or never	No answer given
C4	Do you think the person's decisions are respected by the people around them?	Always	Sometimes	Rarely or never	No answer given
C5	Does the person have control over how they spend at least some of their money?	A lot of control	Some control	Very little or no control	No answer given
C6	Does the person get to express their opinion on the things they want e.g. what they prefer to do, wear, go, and eat	Always	Sometimes	Rarely or never	No answer given

C7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

C1	C2	C3	C4	C5	C6

Friends and family

F1	Does the person have people they think of as friends (not including paid staff)	Yes	More or less	No	No answer given
F2	How often does the person participate in social activities like eating with	Often	Some of the time	Rarely or never	No answer given

	friends, going to parties or meeting friends in town?				
F3	How often does the person communicate or spend time with their family either in person, by phone or email?	Often	Some of the time	Rarely or never	No answer given
F4	How often does the person communicate or spend time with their friends either in person, by phone or email?	Often	Some of the time	Rarely or never	No answer given
F5	Do you think that the person is important to their family?	Yes	More or less	No	No answer given
F6	Does the person have a support network - people they can go to for advice and help?	Yes	More or less	No	No answer given

F7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

F1	F2	F3	F4	F5	F6

Social Inclusion

S1	Does the person talk to people who live or work near to them?	Often	Sometimes	Rarely or never	No answer given
S2	Does the person know many people in the area by name?	Many (5+)	Some (2 – 4)	Few (1-0)	No answer given
S3	Does the person use shops and services near where they live? (e.g. café, shops, hairdressers, pub, bank, cinema, religious worship, public transport, gym or sports centre)	Often (daily)	Some of the time (1-2 times a week)	Rarely or never	No answer given
S4	Does the person do things for other people when they need their help?	Often	Sometimes	Rarely or never	No answer given
S5	Do people from the person's community help them with things (including visiting them, taking them places or doing things with them)?	Often	Sometimes	Rarely or never	No answer given
S6	Does the person go to any local clubs, groups or community centres near where they live?	Often	Sometimes	Rarely or never	No answer given

S7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

S1	S2	S3	S4	S5	S6

Rights

R1	Does the person have a place in their home where they can be by themselves?	Yes	More or less	No	No answer given
R2	Can the person go out of their home and come back in whenever they want?	Yes	Depends	No	No answer given
R3	Can the person have a pet if they want one?	Yes	Depends	No	No answer given
R4	Can the person have a girlfriend or boyfriend if they want?	Yes	Depends	No	No answer given
R5	Is the person allowed to be together as much as they want with their partner/ girlfriend/boyfriend? (Score yes if there is no partner)	Yes	Depends	No	No answer given
R6	Has the person ever voted in elections?	Yes, every time you could	Yes, some of the time	No, never	No answer given

R7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

R1	R2	R3	R4	R5	R6

Happiness

Hap1	Do you think the person's daily environment is safe and secure?	Very safe	Somewhat safe	Not safe	No answer given
Hap2	Do you think the person feels successful in the things that they do?	Yes	More or less	No	No answer given
Hap3	How frequently does the person show express love, fondness or affection towards others?	All the time	Some of the time	Rarely or never	No answer given
Hap4	How often does the person show signs of happiness?	Most of the time	Some of the time	Rarely or never	No answer given
Hap5	Do you think the person feels satisfied with how things are going for them? (in general)	Definitely yes	With some things	Not at all	No answer given
Hap6	Do you think the person trusts the people who are important to them?	Yes	More or less	No	No answer given

Hap7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

Hap1	Hap2	Hap3	Hap4	Hap5	Hap6

Health

He1	In general, how healthy do you think the person is?	Very healthy	Okay	Sick or ill	No answer given
He2	How often does the person exercise, play games, or be active (e.g. fitness, cycling, walking, swimming or football)?	Every day	A few times a week	Rarely or never	No answer given
He3	Do you think the person gets the right amount of rest and relaxation for them?	Yes	More or less	No	No answer given
He4	Does the person have a varied and balanced diet?	Yes, all the time	Some of the time	Rarely or never	No answer given
He5	Is the person ever in pain or uncomfortable? (not just today, but generally)	No	Some of the time	Yes, all of the time	No answer given
He6	How do you think the person feels when they wake up in the morning?	Well rested	A little tired	Very tired	No answer given

He7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

He1	He2	He3	He4	He5	He6

Money

M1	Does the person have enough money to pay for what they really need? (for example food and bills)	Yes	More or less	No	No answer given
M2	Does the person have access to savings if they need additional things?	Yes, most of the time	Some of the time	No	No answer given
M3	Does the person own things that are important to them? (e.g. their own pictures or photos, TV, mobile phone)	Yes, many things	Some things	Very few things	No answer given
M4	Does the person have a paid job?	Yes (regular hours)	Sometimes (irregular hours)	No	No answer given
M5	Can the person lock their door and keep their things safe at home?	Yes, all the time	Yes, some of the time	No	No answer given
M6	Does the person have enough money to make choices about what they spend their money on (for example what to wear and what to buy?)	Yes, for most things	For some things	No	No answer given

M7: If any of the above questions were answered with help from the participant please tick which questions (tick all that apply)

M1	M2	M3	M4	M5	M6

X1: Were any communications aids/ systems used during this interview? (please describe)

Online survey

This form to be completed by a member of staff who has worked with the person for at least 3 months and knows them well. (N.B. data collection through REDCap)

V1: 13/10/21
IRAS ID: 292987

Office base number of the person with learning disability this survey is about ______________

Section 1: About you (the person completing the form)

1. What is your role?
   - Service Manager
   - Assistant Service Manger
   - Key Worker
   - Support Worker
   - Quality team member
   - Other. Please specify ________________
2. How long have you known the person? Years__________ Months __________
3. In an average week how many hours do you typically spend with the person?

Section 2: Information about the person with intellectual disability this survey is about

4. What is the person’s age (years) ____________
5. What is the person’s gender?
   - Male
   - Female
   - Non-binary
   - Other/ Prefer not to say
6. Choose one option that best describes the person’s ethnic group or background

A White

- English / Welsh / Scottish / Northern Irish / British
- Irish
- Gypsy or Irish Traveller
- Another white background

B Mixed / multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Another Mixed/ multiple ethnic background

C Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Another Asian background

D Black / African / Caribbean / Black British

- African

- Caribbean
- Another Black / African / Caribbean background

E Other Ethnic Group

- Arab
- Latin American
- Another ethnic group
- Prefer not to say

7. What is the person’s relationship status?

- Single, never married
- Single, divorced or widowed
- In a relationship/married but living in separate houses
- In a relationship/married but living in separate rooms in the same house
- In a relationship/ married and cohabiting

8. What is the person’s employment status?

- In education
- In part-time paid employment
- In full-time paid employment
- Volunteers part-time
- Volunteers full-time
- Unable to work due to disability
- Unemployed and seeking work
- Retired

The person’s home

9. What type of area does the person live in?

- City
- Large town
- Small town
- Village

10. Which best describes the home where the person lives?

- A home where the person lives alone or with a partner
- A home where the person lives alone or with a partner but in a building/ complex where other people with learning disability live
- A home where the person lives alone or with a partner but in a building/ complex with communal areas shared by other people with learning disability
- A home shared with other people with learning or physical disability

<IF home shared with others> How many people does the person share their home with?

11. Which category of accommodation does the person live in ?

- Residential care home
- Supported living
- Specialised supported housing

12. What staffing pattern most accurately describes the staff situation at the person’s home?

- 24-hour active staff presence (staff awake at night)
- Staff present during waking hours and sleep in presence at night
- Staffed during the day, not overnight
- Daily visiting staff
- Visiting staff less than once a day

<Skip 13-17 if visiting staff less than once a day>

13. How many staff are usually on duty during the morning?

14. How many staff are usually on duty during the afternoon?
15. How many staff are usually on duty during the evening?
16. How many staff are usually on duty during the at night?
17. Are the night-time staff:

- Waking
- sleeping-in
- on call
- No cover provided

The person's support package

18. Is Mencap the sole provider for the person's care and support at home?

Yes/ no/ don't know

19. How many hours per week of 1:1 support is the person contracted to receive?
20. How many hours per week of shared support is the person contracted to receive?
21. In reality in an average week how many hours of 1:1 support does the person receive?

Section 3: Skills that the person has

Hatton, C., et al. (2001). "The adaptive behavior scale-residential and community (part I): towards the development of a short form." Research in Developmental Disabilities **22**(4): 273-288.

General instructions:

When completing the form, please observe the following general rules:

1. When answering these questions think about the last 6 months.
2. Items that specify "with help" or "with assistance" for completion of the task refer to direct physical assistance.
3. Give credit for an item even if verbal prompting or reminding is needed to complete the task, unless the item definitely states "without prompting" or "without reminder".
4. If the question asks about an action you have never seen the person do, please give them credit if you believe this is something they could do.

Part 1: Ranking questions

Please tick the highest ranked activity which you believe the person could usually manage independently.

1. Use of table utensils: Select the top action which you think the person can usually manage independently	
Person uses knife for cutting or spreading	6
Person feeds self neatly with spoon and fork (or appropriate alternative utensil, e.g. chopsticks)	5
Person feeds self, causing considerable spilling with spoon and fork (or appropriate alternate utensil, e.g. chopsticks)	4
Person feeds self with spoon – neatly	3
Person feeds self with spoon – considerable spilling	2
Person feeds self with fingers	1
Person does not feed self or must be fed	0

2. Ordering food	
Person orders complete meals in restaurants	3
Person orders simple meals like hamburgers or hot dogs	2
Person orders simple items e.g. soft drinks, ice cream, donuts	1
Person does not order food for themselves	0

3. Cleanliness

Person prepares and completes bathing unaided	6
Person washes and dries themself completely without prompting or helping	5
Person washes and dries reasonably well with prompting	4
Person washes and dries self with help	3
Person attempts to soap and wash self	2
Person cooperates when being washed and dried by others	1
Person does not attempt to wash or dry self	0

4. Dressing and undressing

Person completely dresses self	5
Person dresses themself only when verbally prompted to do so	4
Person dresses themself by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping, Velcro) them with help	3
Person dresses themself with help in pulling or putting on most clothes and fastening them	2
Person cooperates when being dressed by extending arms and legs	1
Person must be dressed completely	0

5. Safety at Residential Facility or Home

Person asks whether an unfamiliar object is safe to touch or consume	3
Person is careful about danger of electrical outlets and sockets	2
Person is careful about danger of hot foods and beverages, or hot dishes or pans	1
Person is not careful about possible danger	0

6. Money handling and budgeting:

Person takes complete care of their own money	4
Person counts out change correctly but does not use banking facilities	3
Person can count coins, up to one pound	2
Person uses money but does not count out change correctly	1
Person does not use money	0

7. Purchasing:

Person buys own clothing	4
Person buys own clothing accessories	3
Person makes minor purchases without help (candy, soft drinks, etc.)	2
Person does shopping with slight supervision	1
Person doesn’t shop	0

8. Expression:

Person sometimes uses complex sentences containing “because”, “but”, etc.	3
Person asks questions using words such as “why”, “how”, “what”, etc.	2
Person speaks in simple sentences	1
Person speaks in single word or short phrases only or is nonverbal	0

9. Verbal comprehension: Tick the top action which you think the person can usually manage independently

Person understands complex instructions involving a decision, “if ___, do this, but if not, do ___.”	4
Person understands instructions involving a series of steps, e.g. “First do ___, then do ___.”	3
Person answers simple questions such as “What is your name?” or “What are you doing?”	2
Person responds correctly to simple phrases, e.g. “stop”, “sit down”, “come here “	1
Person is unable to understand even very simple verbal communications	0

10. Numbers: Tick the top action which you think the person can usually manage independently

Person can perform division and multiplication	6
Person can do simple addition and subtraction	5
Person can count ten or more objects	4
Person mechanically counts to ten	3
Person can count two objects by saying “one… two”	2
Person can discriminate between “one” and “many” or “a lot”	1
Person has no understanding of numbers	0

11. Food preparation: Tick the top action which you think the person can usually manage independently

Person can use microwave correctly to prepare a meal	4
Person can prepare an adequate complete meal (may use canned or frozen food)	3
Person can mix and cook simple food, e.g. fried eggs, makes pancakes, cooks TV dinners, etc.	2
Person can prepare simple food requiring no mixing or cooking, e.g. sandwiches, cold cereal, etc	1
Person does not prepare food at all	0

12. Leisure time: Tick the top action which you think the person can usually manage independently

Person can organize leisure time activities on a fairly complex level, e.g. going on a fishing trip, arranging to play billiards, scheduling time to do computer games, etc.	4
Person has active interest in a hobby, e.g. painting, embroidery, collecting stamps, coins, baseball cards, etc.	3
Person participates in organized leisure time activity when arranged from him or her	2
Person engages in leisure activity on a simple level, e.g. watching TV, listening to the radio, etc.	1
Person is unable to arrange leisure time activity, even of the simplest nature	0

13. Responsibility: Tick the top action which you think the person can usually manage independently

Person is very conscientious and assumes much responsibility – makes a special effort; assigned activities are always performed	3
Person is usually dependable – makes an effort to carry out responsibilities; one can be reasonably certain that assigned activities will be performed	2
Person is unreliable – makes little effort to carry out responsibilities; one is uncertain that the assigned activities will be performed	1
Person is not given responsibilities; is unable to carry out responsibilities at all	0

14. Personal responsibility: Tick the top action which you think the person can usually manage independently

Person usually maintains self-control	3
Person understands concept of being on time	2
Person seeks and accepts help on instructions	1
Person reports (to teachers, supervisor, etc.) if there is a problem	0

Part 2: Yes/ No Questions

Under each question there are a list of actions. Please indicate yes or no to show whether the person does these actions independently. If the person requires some reminding or prompting before they do the action, please still indicate yes.

15. Toilet use	**Yes**	**No**
Person lowers pants at toilet without help	1	
Person sits on toilet seat without help	1	
Person uses toilet tissue appropriately	1	
Person flushes toilet after use	1	
Person puts on clothes without help	1	
Person washes hands without help	1	
16. Walking and running	**Yes**	**No**
Person can walk alone	1	
Person can walk up and down stairs alone	1	
Person can walk downstairs by alternating feet	1	
Person can run without often falling	1	
Person can hop, skip or jump	1	

17. Care of clothing	**Yes**	**No**
Person wipes and cleans shoes when needed	1	
Person puts clothes in drawer, chest or cupboard	1	
Person hangs up clothes without prompting	1	
Person calls attention to missing buttons and holes and/or repairs clothing	1	

18. Shoes	**Yes**	**No**
Person puts on shoes correctly without assistance	1	
Person ties shoes correctly without assistance	1	
Person unties shoes correctly without assistance	1	
Person removes shoes without assistance	1	
Person attaches or detaches Velcro on shoes	1	

19. Miscellaneous independent functioning	**Yes**	**No**
Person has ordinary control of appetite, eats moderately	1	

Person knows postage rates, buys stamps from post office	1	
Person looks after personal health, e.g. changes wet clothing	1	
Person deals with simple injuries, e.g. cuts, burns	1	
Person knows how and where to obtain and doctor's or dentist's help	1	
Person knows own address	1	

20. General domestic activity	**Yes**	**No**
Person washes dishes well	1	
Person makes bed neatly	1	
Person helps with household chores	1	
Person does household chores routinely	1	
Person can load and use dishwasher correctly	1	
Person can use small, electric kitchen appliances correctly	1	

21. Passivity	**Yes**	**No**
Person needs constant encouragement to complete task	1	
Person has to be made to do things	1	
Person has no ambition	1	
Person seems to have no interest in things	1	
Person finishes task last because of wasted time	1	
Person is unnecessarily dependent on others for help	1	
Person's movement is slow and sluggish yes/ no	1	

22. Persistence	**Yes**	**No**
Person cannot organize task	1	
Person becomes easily discouraged	1	
Person fails to carry out tasks	1	
Person jumps from one activity to another	1	
Person needs constant encouragement to complete task	1	

23. Consideration for others	**Yes**	**No**
Person shows interest in the affairs of others	1	
Person takes care of others' belongings	1	
Person directs or manages the affairs of others when needed	1	
Person shows consideration for others' feelings	1	
Person shows interest in the affairs of others	1	

24. Awareness of others	**Yes**	**No**
Person recognizes own family	1	
Person recognizes people other than family	1	
Person has information about others, e.g. job, address, relation to self	1	
Person knows the names of people close to him or her, e.g. classmates, neighbours	1	
Person knows the names of people not regularly encountered	1	

Section 4: Person's life in general

Thinking back to how the person's quality of life was 12 months ago, how would you say their quality of life is today?

Greatly improved	Slightly improved	About the same	Slightly deteriorated	Greatly deteriorated

Question amended from Braun, T., et al. (2021). "Responsiveness and interpretability of commonly used outcome assessments of mobility capacity in older hospital patients with cognitive spectrum disorders." Health and Quality of Life Outcomes 19(1).

Brief quality of life scale

The following questions will give us an overall view of how the person is getting on. Please think about the last **two months** of the person's life. Read each statement and state how much you agree or disagree with the statement.

		Strongly disagree 1	Disagree 2	Neither agree nor disagree 3	Agree 4	Strongly agree 5
1.	The person has lots of chances to express personal choices on a daily basis.	1	2	3	4	5
2.	The person gets on well with people they live with.	1	2	3	4	5
2a	Not applicable (person lives alone)					
3.	The person is willing to try new tasks or activities.	1	2	3	4	5
4	The person has the chance to interact with people they do not live with at least weekly.	1	2	3	4	5
5.	The person gets on well with other adults such as friends and co-workers.	1	2	3	4	5
6.	The person has good access to local places they enjoy visiting at least weekly.	1	2	3	4	5
7.	The person gets on well with family members.	1	2	3	4	5
7a.	Not applicable (person has no known family members).					
8.	The person has good chances to participate in leisure pursuits of their own choice at least weekly.	1	2	3	4	5

Section 5: The depression screen

Westlake, F., et al. (2021). "The role of behaviour problems in screening for mental ill-health in adults with intellectual disability." The European Journal of Psychiatry **35**(2): 122-125.

The following questions help to monitor any signs of depression in the person. Please think about how the person's behaviour in the **last four weeks.** For each item, decide whether the behaviour is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behaviour is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

Do not spend too much time on each item – your first reaction is usually the right one.

		0	1	2	3
1	Listless, sluggish, inactive				
2	Seeks isolation from others				
3	Preoccupied				
4	Irritable and complains				
5	Fixed facial expression (different from usual)				
6	Uncooperative				
7	Depressed mood				
8	Isolates self				
9	Sits or stands in one position for a long time				
10	Cries over minor annoyances				
11	Mood changes quickly				
12	Unresponsive to structured activities (does not react)				
13	Difficult to reach				
14	Pays no attention when spoken to				

Section 6: Challenging Behaviour

Rojahn, J., et al. (2012). "The Behavior Problems Inventory-Short Form for individuals with intellectual disabilities: Part I: development and provisional clinical reference data." Journal of intellectual disability Research **56**(5): 527-545.

Thinking about the last **two months**, please indicate if you are aware that the person has performed any of the following behaviours. If you are not aware that the person has performed the behaviour, please indicate 'never/ no problem' and move to the next behaviour. If you are aware that the person has performed the behaviour, please indicate the frequency of the behaviour and the severity of the behaviour. Please read the description for what counts as a mild, moderate or severe challenge. The final section asks for frequency of stereotyped or repetitive behaviour.

never/ no problem	**Average frequency of occurrence**				**Severity of the behaviour**		
	Monthly	**Weekly**	**Daily**	**Hourly**	**mild**	**moderate**	**severe**

Self-injurious behaviour
***Behaviour causes damage to person's own body - i.e. damage has either already occurred or it must be expected if the behaviour continues. Behaviour occur repeatedly in the same way over and over again, and they are characteristic to that person*.**
Mild challenge: Behaviour occurs but does not inflict significant damage on other people (e.g temporary reddening of the skin, very light bruising)
Moderate challenge: Behaviour may inflict moderate damage on the individual (e.g. moderate bruising, scratching through the skin, repeatedly picking scabs)
Severe challenge: Behaviour may inflict moderate to severe damage on the individual (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required

1	Self-biting								
2	Head hitting								
3	Body hitting (except for the head) with own hand or with any other body part								
4	Self-scratching								
5	Pica (ingesting non-food items)								
6	Inserting objects in nose, ears, anus etc								
7	Hair pulling (tearing out patches of hair)								
8	Teeth grinding (evidence of ground teeth)								

Aggressive behaviours
Aggressive or destructive behaviours are deliberate overt attacks directed towards other individuals or property
Mild challenge: Behaviour occurs but does not inflict significant damage on other people (e.g. temporary reddening of the skin, very light bruising) or disruption or mild damage to property (e.g. objects thrown, furniture ripped, doors slammed, meals spoilt etc.)
Moderate challenge: Behaviour may inflict moderate damage on other people (e.g. moderate bruising, scratching through the skin, repeatedly picking scabs, moderate damage to property)
Severe challenge: Behaviour may inflict moderate or severe damage on other people (e.g. biting through the skin, eye gouging, fracturing bones) minor or major medical intervention required, significant damage to property)

9	Hitting others								
10	Kicking others								
11	Pushing others								
12	Biting others								
13	Grabbing and pulling others								
14	Scratching others								
15	Pinching others								
16	Verbally abusive with others								
17	Destroying things (e.g. rips clothes, throws chairs, smashes tables)								

18	Bullying - being mean or cruel (e.g grabbing toys or food from others)								
Stereotyped behaviour ***Behaviours look unusual or strange. They are voluntary acts that occur repeatedly in the same way over and over again and they are characteristic for that person. They do not cause physical damage***									
19	Rocking, repetitive body movements								
20	Sniffing objects, own body								
21	Waving or shaking arms								
22	Manipulating (e.g. twirling, spinning) objects								
23	Repetitive hand and/ or finger movements								
24	Yelling or screaming								
25	Pacing, jumping, bouncing, running								
26	Rubbing self								
27	Gazing at hands or objects								
28	Unusual body postures								
29	Clapping hands								
30	Grimacing								

Section 7: Significant life events

Has the participant experienced any of the following events in the past 12 months?

- A friend or family member has a serious illness
- A friend or family member dies
- A relationship breaks up
- Loss of job or voluntary placement
- Moves house
- Serious illness
- Overnight stay(s) in hospital
- Significant lifestyle changes for health (e.g. diet, exercise, regular monitoring)
- A regular member of staff leaves
- Participant has been physically restrained
- Gets Covid-19
- Friend or family member stops visiting (or visits much less frequently)

Section 8: Person’s time use

1. On the **last weekday you were working with the person**, how much time do you estimate the person spent doing the following activities?

	Did not do	< 30 mins	30 mins – 2 hours	>2 hrs
Work or volunteering				
Exercise				
Spending face to face time with family and friends				
Spending time communicating digitally with family and friends				
Arts and crafts activities				
Other hobbies				
Watching television, (or using streaming services like Netflix) or gaming				
Housework or DIY				
Being outside their home (including on a balcony or in the garden)				

2. In the past 7 days, how many days has the person:	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
not left the house or garden?								
Been outside the house for 15 minutes or more (including on a balcony or in the garden)								
Had face to face contact with another person for 15 minutes or more (including someone they live with)								
Had a phone or video call with another person for 15 minutes or more								

Items amended from: Bu, F., et al. (2020). Time-use and mental health during the COVID-19 pandemic: a panel analysis of 55,204 adults followed across 11 weeks of lockdown in the UK, Cold Spring Harbor Laboratory.

Section 9: Day activities

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

1. Thinking about the last **6 months** how often has the person participated in any of the following activities?

Service	Participated (Yes/ No)	Provider sector (1= health; 2 = LA; 3 = Voluntary org; 4 = Private)	How often does the person normally go? (Every day/ couple of times a week/ once a week/ a couple of times a

			month/ once a month/ less than once a month)
Day centre			
Sheltered work			
Voluntary work			
Adult education			
Drop-in centre			
Social club			
Recreation (e.g. swimming horse riding – specify)			
One to one activities (Specify)			
Other activities (specify)			

2. How does the participant usually travel to day activities?
   - Transport provided by the place where the person lives
   - Transport provided by the day activity organisation
   - Public transport
   - Taxi
   - Personal transport
   - Other (please specify)

3. Does a paid member of staff usually accompany the service user to day activities? Yes/ No
4. In the past six months, has the person used respite care services? Yes/No

   4.1 <IF 4= YES> what type of respite care did the person access?
   - Residential care
   - Alternative family-based respite
   - Holiday scheme

   4.2 <IF 4= YES> In the past six months, how many days has the person spent in the respite care services?

Section 10: Informal care

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

1. Does the person receive support from an unpaid carer (parent, other relative, partner, friend etc.)?
   - Yes from a single unpaid carer
   - Yes from an unpaid carer and their partner
   - Yes from an unpaid carer and others
   - No

   1.1 <IF 1 does not = No> Thinking of a typical week, how many hours does the unpaid carer provide support to the person?

   1.2 <IF 1 does not = No> Has the carer given up or cut down on paid work to provide support to the person?
   - Yes/ No/ Don't know

Section 11: Community based health and care services

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

Thinking about the last 6 months, please complete the information for each service type

Service	**Did the person use this service? (yes/ no)**	**Where did the person access the service?** **1= clinic/surgery;** **2 = day centre;** **3 = home**	**Provider:** **1= public;** **2 = Private;** **3 = voluntary**	**How many times has the person used this service in the last 6 months?**
GP				
Community/ district nurse				
Community Psychiatric nurse				
Learning disability nurse				
Community psychiatrist				
Psychologist				
Care manager/ social worker				
occupational therapist				
Art/ drama/ music therapist				
Alternative therapist (e.g. reflexologist)				
Counsellor/ advocate				
Physiotherapist				
Dentist				
Speech therapist				
Home care worker				
Community Mental Health team member				
Health care assistant				
Social work assistant				
Optician				
Audiologist				
Chiropodist				
Employment services/ job centre				
Other (specify)				

Section 12: Hospital based services

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

Thinking about the last six months, please complete the information for any hospital-based services

	Tick if yes	**No. of admissions in last 6 months**	**Total no. of nights in hospital**
Overnight inpatient stay			
Psychiatric intensive care ward			
Acute psychiatric ward			

Psychiatric rehabilitation ward			
General medical elective/ planned inpatient administration			
General medical non-elective/ unplanned inpatient administration			
General medical intensive care/ high dependency unit			

A&E	**Tick if yes**	**No. of contacts in last 6 months**
Physical health (admitted to hospital)		
Physical health (not admitted)		
Mental health (admitted to hospital)		
Mental health (not admitted to hospital)		

Outpatient appointments	**Tick if yes**	**No. of contacts in last 6 months**
Psychiatric outpatient appointment		
Day patient procedure/ test		
General medical outpatient appointment		

Section 13: Medication

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

1. Is the person taking any medication at the moment?
Yes/ no

Name of medication	Regular medication or PRN (as needed)?	Dose	Frequency	In the last 6 months, how many weeks has the person been taking this medication?

Section 14: Criminal justice services

Amended from CSRI used in Willner, P., et al. (2011). "Anger management for people with mild to moderate learning disabilities: Study protocol for a multi-centre cluster randomized controlled trial of a manualized intervention delivered by day-service staff." Trials **12**(1): 36.

1. Over the past six months has the person been in contact with police (Contact = interview or a stay of some hours, but not overnight)
    - Yes
    - No
2. Over the past six months has the person spent the night in a police cell or prison?
    - Yes
    - No

2.1 <IF 2= YES> How many nights have they spent in a police cell?
2.2 <IF 2= YES>How many nights have they spent in a prison cell?
2.3 <IF 2= YES>How many learning disability or psychiatric assessments have they had whilst in custody?

3 Over the last six months how many criminal or court appearances has the person had?
Criminal Court __________
Civil Court __________

<END OF SURVEY>

Appendix I: Mencap/UCL POS interviewer user guide

Project title: Measuring quality of life of people with learning disabilities in England

Date: 17/01/23
Version: 1
IRAS ID: 292987

Purpose of this guide:

The team interviewing for the Mencap/UCL study have all received POS training and are experienced interviewers. This guide acts to refresh interviewers on the main aspects of the POS approach and provides clarifications for the meanings of each of the POS questions. This guide has been written based on information provided by the original POS authors, observations of POS interviews and discussions with Mencap POS interviewers and Mencap staff.

Approach to interviewing:

We want the POS interview to feel like a conversation. Our aim is to make the questions relevant to the person, so it is easier for them to understand. In practice this means:

- You can ask the questions in any order,
- You can respond to the things the person wants to talk about and reference things you know about the person, or that they share with you to help the questions make sense to the person.
- You don't have to use the exact language of the questions, so long as you understand the meaning of the questions, you can use language which will help the person understand.

Although you can phrase the question in the way which works best for the person you must ask the person to clarify which option they want to pick E.g.

"… so, you've said people listen to your decisions and take them seriously – do you think people always listen to your decisions, or sometimes listen?"

Initially it might feel clumsy, but it does work without disrupting the conversation. You can see this in action by watching our POS demonstration video (insert link).

All the points in this guide apply to both self-report and report of other versions of the POS. You may find that you stick closer to the written order and wording of questions when you're interviewing a member of staff, but you can also

Remember:

The POS is not about fixing things, you are not there to create an action plan or make suggestions. Your role is to listen and try to walk alongside the person to gain insight into their quality of life and the things that matter to them. This can feel quite different from day-to-day roles, but sometimes our fixes are based on our assumptions. We may learn more simply by listening and allowing someone the space to communicate. It also gives the person the chance to express themselves and their needs in a way they may not encounter day to day.

If there are things which come up in the interview which you think could be ‘fixed’, you have the opportunity to make note of this in the narrative comments (most likely under ‘start’).

Although you are not here to fix, you still have safeguarding responsibilities and if the person discloses anything which worries you, you should let them know that you have a responsibility to pass that information on and ask any questions you need to gain further information. Please follow normal safeguarding procedures.

Starting the interview:

The beginning of the interview is an opportunity to put the person at ease and build some rapport. Feel free to go off script and just have a chat as you would normally when meeting a person you support. Everyone will have had a POS interview before, but please remind them at the start:

- The conversation will take about one hour. You can take breaks at any point.
- If there’s any question you don’t want to answer just let me know and we’ll skip it
- After the conversation we will create a report for you which will be shared with your team. Are you happy for people in your support team to have the report?
- The information will also be shared with a university for a study about quality of life.

Beginning questions:

To start the conversation, you might like to ask questions like:

- Is there anything you’d like to start with?
- Is there anything you’d like me to know?

Or for report of other:

- Is there any part of their life you’d like to talk about first?

Or you might start by picking up on something the person’s said when you’ve been chatting to them. E.g.

“You’ve been showing me your brilliant drawings, do you go to a club to do those? How often you do you go to that club? And are there any other clubs you go to?”

How this guide can help you

Reaching a shared understanding of the POS questions

We have added clarifications to all the POS questions to help you understand what each question is asking and to be sure which response to choose. These clarifications are based on information provided by the original POS authors, observations of Mencap POS interviews and discussions with Mencap staff.

These clarifications will help you be sure you have the same understanding of each question as all other Mencap POS interviewers, and this will mean as much as possible we are all using the interview questions to measure the same thing.

Modelling the POS approach

A key aspect of the POS is that is feels like a conversation and the questions are relevant to the person. We have added examples of how you can phrase the questions as part of a conversation next to each question. All these phrases are direct quotes from observed interviews, so they are things that interviewers already say. We don't want you to repeat these phrases in every interview, but they are examples to model how to use the POS approach to help you feel more confident about turning the questions into a conversation

Finding out more for the POS report

The POS report is an immediate outcome from the interview for the person and their support team. Much of the information for the report comes from the conversation, rather than just asking the questions. I've included examples of additional questions in each section. You don't need to ask all these questions; they are just examples of some of the ways to open up the conversation and find out more.

Clarification on POS questions

Learning questions

<table>
<tr><td>L1: Are you able to feed yourself, stand up and sit down, use the toilet and get dressed by yourself?</td><td>• Generally independent
• Assistance needed for some things
• Can't do on my own</td></tr>
<tr><td colspan="2">Clarification: Generally independent is only selected if the person can do all the listed things with no support. If help is needed for any part of any of the items (e.g. if participant can get dressed but needs help tying their shoelaces) then select ‘assistance needed for some things’. If the amount of support a person need is more than 50% of the total effort needed for any of the tasks then select ‘can’t do on my own’</td></tr>
<tr><td colspan="2">Examples of how to phrase the question in a conversation
• I can see you’ve got your comfy wheelchair – can you move around at all or are you always in your wheelchair? Can you move your wheelchair yourself?
• When you got up this morning did you have a shower? And did you do that yourself? Did you turn the shower on? Did you wash your hair? Did you get changed or did Mel help you?</td></tr>
</table>

<table>
<tr><td>L2: Are you able to prepare meals, clean the house, take your medication and go out by yourself?</td><td>• Generally independent
• Assistance needed for some things
• Can't do on my own</td></tr>
<tr><td colspan="2">Clarification: It should be unusual for our participants to score generally independent on this question. E.g. even if person can use hob and cooker but needs reminders about timings and to be careful around the heat this would be ‘assistance needed for some things’. If assistance needed is more than 50% of total effort for any of the task than select ‘can’t do on my own’.</td></tr>
<tr><td colspan="2">• This morning, did you take any medication? Did you remember yourself or did the staff give that to you?
• I can see it’s very clean in here, do you do that or do staff help you? Which bits do you do? Do you do the hoovering? Do you clean the surfaces?</td></tr>
</table>

<table>
<tr><td>L3: Are you learning to do new things? (this might be taking a course, or something that you are doing as part of your development plan)</td><td>• Yes, many new things
• Some new things
• Few if any</td></tr>
<tr><td colspan="2">Clarification: At Mencap we don’t want this question to only refer to formal courses. We want to include other things a person might be learning. For example: helping in the house, being more independent, knowing the way to the supermarket, getting used to a routine etc.</td></tr>
<tr><td colspan="2">• Are you learning anything new at home?
• So it sounds like you’re doing lots in the kitchen – are those new skills for you?</td></tr>
</table>

<table>
<tr><td>L4: Are you able to demonstrate the skills you have and the things that you can do?</td><td>• Yes, all the time
• Some of the time
• Rarely or never</td></tr>
<tr><td colspan="2">Clarification: This question is not about hobbies – hobbies are explored under happiness in the question about feeling successful - this question is trying to understand whether people feel like they are receiving the hotel model of care (even if accidentally). E.g. is the support they receive stopping them from doing things for themselves?</td></tr>
<tr><td colspan="2">• So you’ve told me about your support team, is there anything they do for you which you want to do yourself? What are those things?</td></tr>
</table>

• Do you do as much as possible by yourself? • Thinking about the things you've told me you're really good at - do you get to do that a lot?

L5: Do you have access to the information that you are interested in. For example, being able to find out what's on TV or what's happening in your area	• Yes, all the time • Some of the time • Rarely or never
Clarification: This isn't just about TV, but any information a person needs access to. If the person says that they ask staff, you can follow up with 'and do staff always have the information you need?'	
• If you wanted to go to a new place how would you know what bus to catch? • How would you know what's on at the cinema? • If you wanted to find out what was on TV would you need someone to help you? • How do you find out when Heartbeat is on?	

L6: Do you use a computer, mobile phone or tablet	• Yes, all the time • Some of the time • Rarely or never
Clarification: Question is about use not just possession**.** If person says they have a mobile phone, ask if they use it.	

Example questions Mencap interviewers are asking to add more narrative information to the report:

- Would you like to go to college?
- Is there anything you would like to learn?
- Is there anything you need help with at the moment that you'd like to do by yourself?
- What do you like to watch on TV?
- Is there anything she'd like to start learning
- Would you like a tablet?

Choices Questions

C1: Do you get given choices about what you want to wear, to eat, and where you would like to go?	• Always • Sometimes • Rarely or never
Clarification: Can feel like C1, C2 and C6 are asking the same thing. C1 is asking do people give you options about what you would like?	
• You've got a lovely top on – did you choose to put that on today? • What did you have for breakfast? Who chose that? Do you always get to choose yourself? Did you ask for toast or were you given toast? • If you want to go out this afternoon, can you just go or do you need to plan it in? • When you go to the pub who chooses what drink you have?	

C2: When you are given choices do you decide for yourself which choice to take?	• Always • Sometimes • Rarely or never
Clarification: This is an extension of C1, we are trying to understand if the person actively engages in making choices, or if they are more passive in day-to-day decisions	
• If someone said to you, do you want to go to Sainsbury's, Asda or Tesco – do you choose which one? • Do you always choose for yourself, or do you sometimes ask people to choose for you? • Do you think he chooses what he wants, or do you think he picks things to please others?	

C3: When someone asks you to do something, can you say no?	• Always • Sometimes • Rarely or never
Clarification: We are interested in how comfortable a person feels going against the wishes of someone else. To make this concrete you can ask them something you think likely they do not wish to do. And if they demonstrate they can say no, then ask if they can say no always, only sometimes or rarely	
• Can I take your TV home with me, would you say that's ok? • Can we sit outside? Even though it's cold? Is that OK?	

C4: Do people listen to your decisions and take them seriously?	• Always • Sometimes • Rarely or never
Clarification: Often interviewers rephrase respect to listen. You can also ask: do people take your decisions seriously?	
• Do you feel like people listen when you say no? Does Sam listen to what you want to do? Does everyone else listen to what you want? • Do the people around you listen to you? Do they follow what you've chosen? • If he didn't want to do something, would anyone make him do it?	

C5: Do you have control over how you spend at least some of your money?	• A lot of control • Some control • Very little or no control

Clarification: This question isn't asking about all of a person's finances – just that they feel they have some control. So this may be demonstrated by having a weekly budget, a money tin, or some other example of personal choice around what a person spends their money on.
• Who's in charge of your money? Do you get to be in charge of any of it? Do you feel like you have any control of your money? • Do you have a money tin? Do you get to choose what you want to spend your money on? • Do you ever have to spend your money on things you don't want to spend it on? • When he goes out does he always have money with him to buy things if he wants to?

C6: Do you get to express your opinion or what you prefer to do, wear, go, and eat	• Always • Sometimes • Rarely or never
Clarification: This question goes beyond C1 & C2 and relates to if a person is able to make their wishes known to people. For example it's not just picking choices from a set meal plan but being able to make it known I'd like fish on Wednesday.	
• Do you get to chose where you go when you go out? Do you ask to go to certain places? • In the morning, do you tell John what you want to wear that day? • Do you tell people what you like before they ask?	

Example questions Mencap interviewers are asking to add more narrative information to the report

- Is there anywhere else that you'd like to go?
- What makes it hard to say no?

Friends and Family

F1: Do you have people you think of as friends (not including paid staff)	Yes More or less No

Clarification: If the person says that their housemates are their friends then you can include them in the count.

- F1 & F4 often asked together Can you tell me about your friends? Who are they? How often do you see them? Do you talk to them often?
- I can see some lovely photos behind you, who's in those photos?

F2: How often do you participate in social activities like eating with friends, going to parties or meeting friends in town?	Often Some of the time Rarely or never

Clarification: often = at least once a week. Similar to F1, activities done just with staff shouldn't be counted here, but activities with housemates can be.

- What sort of places do you go to when you go out together?
- When you go out – do you go out by yourself, with friends or with staff?

F3: How often do you communicate or spend time with your family either in person, by phone or email?	Often Some of the time Rarely or never

Clarification: follow up the question with: is that as much as you would like? If they say yes choose often.

- Can you tell me about your family – what are their names? How often do you see them?

F4: How often do you communicate or spend time with your friends either in person, by phone or email?	Often Some of the time Rarely or never

Clarification: follow up the question with: is that as much as you would like? If they say yes choose often.

F5: Do you feel that you are important to your family?	Yes More or less No

Clarification: This question can feel difficult to ask, but it is best to keep it straightforward.

F6: Do you have a support network - people you can go to for advice and help?	Yes More or less No

Clarification: a lot of people will respond yes and then say they would go to staff. This is fine, staff can count as the support network as long as the person considers them people they would be comfortable reaching out to.

- If you wanted to have a chat with someone who would you have a chat with?
- If you need support or help – do you feel like you have people you can talk to? Who do you speak to if you don't want to speak to staff?
- If you had a worry or you were upset? Who would you talk to?

Example questions Mencap interviewers are asking to add more narrative information to the report:

- Would you like more friends? Are you happy with how often you see them. Would you like to see them more?
- Do you think he’s happy not having friends, or do you think he’d like that?
- Would you like to see your family more?
- Sounds like something you’d like to do more? Would that be right to say?

Social inclusion

<table>
<tr><td>S1: Do you talk to people who live or work near to you?</td><td>• Often
• Sometimes
• Rarely or never</td></tr>
<tr><td colspan="2">**Clarification:** These are not people who live or work in the house, but anyone the person may say hello, wave or respond to. E.g. shop keepers, bus drivers, neighbours. Sometimes it can be ex staff who they see when out and about – this is fine as long as not current staff. Often is likely every time they go out, sometimes is now and then</td></tr>
<tr><td colspan="2">• It sounds like you have lots of people in the community that you know as well as your friends?
• You’ve told me about lots of people you know – the bus drivers, the people who live nearby you – do you talk to those people a lot?</td></tr>
</table>

<table>
<tr><td>S2: How many people in the area do you know by name?</td><td>• Many (5+)
• Some (2-4)
• Few (1-0)</td></tr>
<tr><td colspan="2">• Do you know the neighbours? Can you tell me their names?
• What’s the name of your bus driver</td></tr>
</table>

<table>
<tr><td>S3: Do you use shops and services near where you live? (E.g. café, shops, hairdressers, pub, bank, cinema, religious worship, public transport, gym or sports centre)</td><td>• Often (daily)
• Some of the time (1-2 times a week)
• Rarely or never</td></tr>
<tr><td colspan="2">• Where are you going today? Where’s your hairdressers? What else is in the town? Do you go to cafes? Do you get on the bus? Do you go to town every day?</td></tr>
</table>

<table>
<tr><td>S4: Do you do things for other people when they need your help?</td><td>• Often
• Sometimes
• Rarely or never</td></tr>
<tr><td colspan="2">**Clarification:** this question is asking if people would for others of their own freewill – it is not about doing something they are told to do (e.g. help staff with the hoovering) or something they have to do as part of their everyday life. Generally, if they are helping staff it probably doesn’t count, but if they are helping housemates it might. Ask the person – would you say that you do that often, or just sometimes?</td></tr>
<tr><td colspan="2">• Do you think if someone dropped something in front of him, he’d pick it up?
• You know this morning when you were helping the lady outside with the colouring in – do you do that often?
• Do you make people in the house drinks – do you make Nigel drinks?</td></tr>
</table>

<table>
<tr><td>S5: Do people from your community help you with things (including visiting you, taking you places or doing things with you)?</td><td>• Often
• Sometimes
• Rarely or never</td></tr>
<tr><td colspan="2">**Clarification:** This is asking if people from community help altruistically – so it is not e.g. the chiropodist coming to visit. It is also not friends or family coming. Most likely would be a volunteer. Often would be a regular fixed appointment, e.g. volunteer comes every two weeks, sometimes is more as and when opportunity arises</td></tr>
<tr><td colspan="2">• Is there anyone from the community like a volunteer who comes here?
• What about people out and about – like the bus drivers - do they help you?</td></tr>
</table>

S6: Do you go to any local clubs, groups or community centres near where you live?	• Often • Sometimes • Rarely or never
Clarification: this can be anything from day centre, discos, adult education etc. Often would be at least once a week, sometimes at least once a month, and rarely or never	

Example questions Mencap interviewers are asking to add more narrative information to the report:

- Would you like to go to any clubs? Would you like to do more things in the evening or in the daytime?
- What do you like to do in the daytime
- What is it that makes you not like going out so much?
- Where are the places you like going? What do you like to drink at the pub
- Would you like to go to clubs more often?

Rights

R1: Do you have a place in your own home where you can be by yourself?	• Yes • More or less • No
Clarification: Yes, means that nobody walks into the person's room without knocking first, more or less if there are times that people may come in and out of the room.	
• When you're in your room does anyone come in? Do they knock first? • Do you have any listening devices in your room?	

R2: Can you go out of your home and come back in whenever you want?	• Yes • Depends • No
Clarification: If the person cannot go out without support, they could still answer yes to this question as long as the support is flexible so they could change the time they wish to go. If they can only go out when someone is scheduled to be available this would be depends,	
• Can you go out by yourself? Are there ever times that you want to go out but there's nobody to go with you?	

R3: Can you have a pet if you want one?	• Yes • Depends • No
Clarification: We know a lot a people won't be able to have a pet because of tenancy agreements, but if this is the case just say no and comment in notes	
• Do you have a pet? Would you like one? But if you wanted one, would anyone try to stop you?	

R4: Can you have a boyfriend/ girlfriend /partner if you want?	• Yes • Depends • No
Clarification: This question can be difficult because some people will just say they don't want one. The question is would anyone try to stop you if you wanted one.	
• Do you have a gf/bf/partner? Would you like one? But if you wanted one, would anyone try to stop you? • If you did want to have one do you think the people around you would be ok with that?	

R5: Are you allowed to be together as much as you want with your partner/? (Score yes if there is no partner)	• Yes • Depends • No
• How often do you see them? And is that enough for you?	

R6: Have you ever voted in recent elections?	• Yes, every time you could • Yes, some of the time • No, never
• Would you like to vote? Would you like more information on this?	

Emotional wellbeing (happiness)

Hap1: Do you feel safe and secure in your daily environment?	• Very safe • Somewhat safe • Not safe
Clarification: this is not just the person's home but their neighbourhood too	
• When you go out and about in Southampton do you feel safe? Would you say you feel very safe or sometime safe?	

Hap2: Do you feel successful in the things that you do?	• Yes • More or less • No
Clarification: this is a good place to ask about hobbies, but it can also be about things the person does as part of their day – like chopping veg. if the person can name several things they feel good at select yes.	
• Successful – is when you think you do things really well, and you feel good about the things you do • Successful is when you feel proud • You were telling me earlier about something you achieved, and that made you feel proud. Do you feel like you're good at things? Do you feel like you achieve things • Can you tell me about your hobbies, do you feel like you're good at them?	

Hap3: How frequently do you express love, fondness or affection towards others?	• All the time • Some of the time • Rarely or never
Clarification: best to make this concrete by asking specifically about a person – e.g. do you show the staff you care about them? How do you do that? Do you do that all the time, or some of the time?	
• how do you show your sister that you love her? • Talking about the people you care about – do you get to show them you love them? How do you do that? Do you ever give them a cuddle? Do you like giving people cuddles and things like that	

Hap4: Are you a happy person?	• Most of the time • Some of the time • Rarely or never
Clarification: This question is about mood – so does the person experience happy moments. The question is subjective so ask the person to classify whether they are happy most of the time or some of the time	
• Are you a happy person? Would you say you're happy most of the time, or some of the time?	

Hap5: Are you satisfied with how things are going for you? (In general)	• Definitely yes • With some things • Not at all
Clarification: If someone is not satisfied there will things that worry them or frustrate them, so you can ask about worries to check this.	
• Satisfied is like feeling like everything's ok, and that everything's going ok for you. Would you say you're satisfied? • Is there anything that worries you? Or anything that you wish was different? • You feel like you doing good with your life? Is there anything that could make it better?	

Hap6: Do you trust the people who are important to you?	• Yes • More or less • No
Clarification: This can be staff, family, friends – anyone who the person considers to be important to them.	
• If you trust somebody, it means you know them, and they will do things that make you feel safe. So, do you trust your support workers? Do you trust your family? • If mum says she's going to book your hydrotherapy, do you believe she's going to do it? If your sister says she's going to visit on Friday, do you think she's going to come?	

Example questions Mencap interviewers are asking to add more narrative information to the report:

- What makes you feel safe?
- What could make you feel more safe?
- What makes him feel sad? / Or happy?
- What makes you feel happy?
- Is there anything we could do to make you happier more often?
- Is there anything that worries you?
- Is there anything that makes you feel unhappy – what sort of things make you feel a bit sad
- If you feel a bit sad, what do you do?
- What makes you trust them?

Health

He1: In general, how healthy do you feel?	• Very healthy • Okay • Sick or ill
Clarification: This question is asking about how the person feels about their health – so it is their opinion which is most important	
• Do you think you're healthy? Is there anything that worries you about your health? • Have you been sick at all recently? • When you think about your health, how you feel in your body and mind, do you think you're very healthy, ok or sick?	

He2: How often do you exercise, play games, or are active (e.g. fitness, cycling, walking, swimming or football)?	• Every day • A few times a week • Rarely or never
Clarification: If response is at least once a week pick the middle category rather than rarely or never. This can be any kind of activeness – doesn't have to be formal exercise. So, walking up and down the stairs could count	
• Do you do any exercises? Do you move about at home? • Do you go out for walks? Is that every day?	

He3: Do you get the right amount of rest and relaxation for you?	• Yes • More or less • No
Clarification: This question could be also be no if the person is getting too much rest – if they would like to be doing more.	
• If you want to have a rest in the day, can you do that? • Do you have enough to do in the day?	

He4: Is your diet varied and balanced?	• Yes, all the time • Some of the time • Rarely or never
Clarification: Making sure the person has variety in their food	
• We've spoken about your favourite foods – do you eat some fruit and vegetables as well • Do you have something different to eat on different days?	

He5: Are you ever in pain or uncomfortable? (Not just today, but generally)	• No • Some of the time • Yes, all of the time
Clarification: Make sure the person has the option to say (in their opinion) if they are in pain some of the time or all of the time	
• Is there anything that hurts you? Do you have any pain?	

He6: How do you feel when you wake up in the morning?	• Well rested • A little tired • Very tired
Clarification: This is about how the person's feels – It can be helpful to ask about what time the person sleeps and gets up, but ultimately, it's about how they feel	

- Do you feel like you sleep well – when you wake up do you feel wide awake or are you still tired?
- When you wake up in the morning do you wake up like me, really tired, or ready to face the day
- What time do you go to bed? Do you go straight to sleep, or does it take a while? And do you ever wake up in the night? So, what does it feel like when you wake up?

Example questions Mencap interviewers are asking to add more narrative information to the report:

- Do you think he'd like to eat more widely, or do you think he's happy with what he has?
- Why do you think you feel tired in the morning?
- Is that enough for you, or would you like to do it more?
- Do you sleep ok? What time do you wake up? What time did you wake up this morning? Do you feel tired? Or did you feel like you had a good night's sleep?

Money (material well-being)

M1: Do you have enough money to pay for what you really need? (e.g. food and bills)	• Yes • More or less • No
• Do you get a weekly budget? And is that enough for the things you need? Do you always spend it? Is there anything you need, and you can't buy because you don't have enough? • Have you always got enough in your tin to pay for the things you really need?	

M2: Do you have enough money so you can save some of it?	• Yes, most of the time • Some of the time • No
Clarification: Sometime the person may not be aware if they are saving money – asking if they have enough money to get bigger things is one way to assess this.	
• Do you have money in the bank saved up for big things? • If you wanted to get a new DVD, have you got money to do that? • Do you have to contact the funder if he needs something – do they ever say no? • Have you got money to buy big things? Like a bed?	

M3: Do you own things that are important to you? (e.g. Your own pictures or photos, TV, mobile phone)	• Yes, many things • Some things • Very few things
• Can you tell me about the things in your room? • I see you've got some lovely pictures here, what other things do you have that are important to you?	

M4: Do you have a paid job?	• Yes (regular hours) • Sometimes (irregular hours) • No
Clarification: Must be a paid job, not voluntary	

M5: Can you lock your door and keep your things safe at home?	• Yes, all the time • Yes, some of the time • No
Clarification: Some people may not have capacity to use locks, but this question is asking if the person feels like their belongings are safe.	
• You know your colouring books and your pens – do you keep them in your bedroom? Are they safe in there? • Do you have a TV in your room? Do you keep the door locked? Is it safe?	

M6: Do you have enough money to make choices (for example what to wear and what to buy?)	• Yes, for most things • For most things • No
Clarification: This question goes further than M1 as it is asking not just about the things a person needs but also the things that they want.	
• Do you have enough money to do the things you want to do? Like your hydrotherapy, and going bowling, and doing the things you like?	

- Is there anything you wish you had but you don't have the money for?

Example questions Mencap interviewers are asking to add more narrative information to the report:

- Where do you get your money from? Do you draw it out of a machine? Do you use a card? Where does it go when it comes home?
- Who's in control of your money?

Ending the interview

Make sure you go back over the questions at the end of the interview and check you have asked them all. If there are any questions which the person found difficult to answer you may wish to ask these again at the end of the interview. If there are questions the person has said they do not wish to answer that is fine – but please ask them if it's ok if you ask a member of staff to complete that question instead (and then follow up.

When it comes to the end of the interview it is good to give the person the opportunity to add

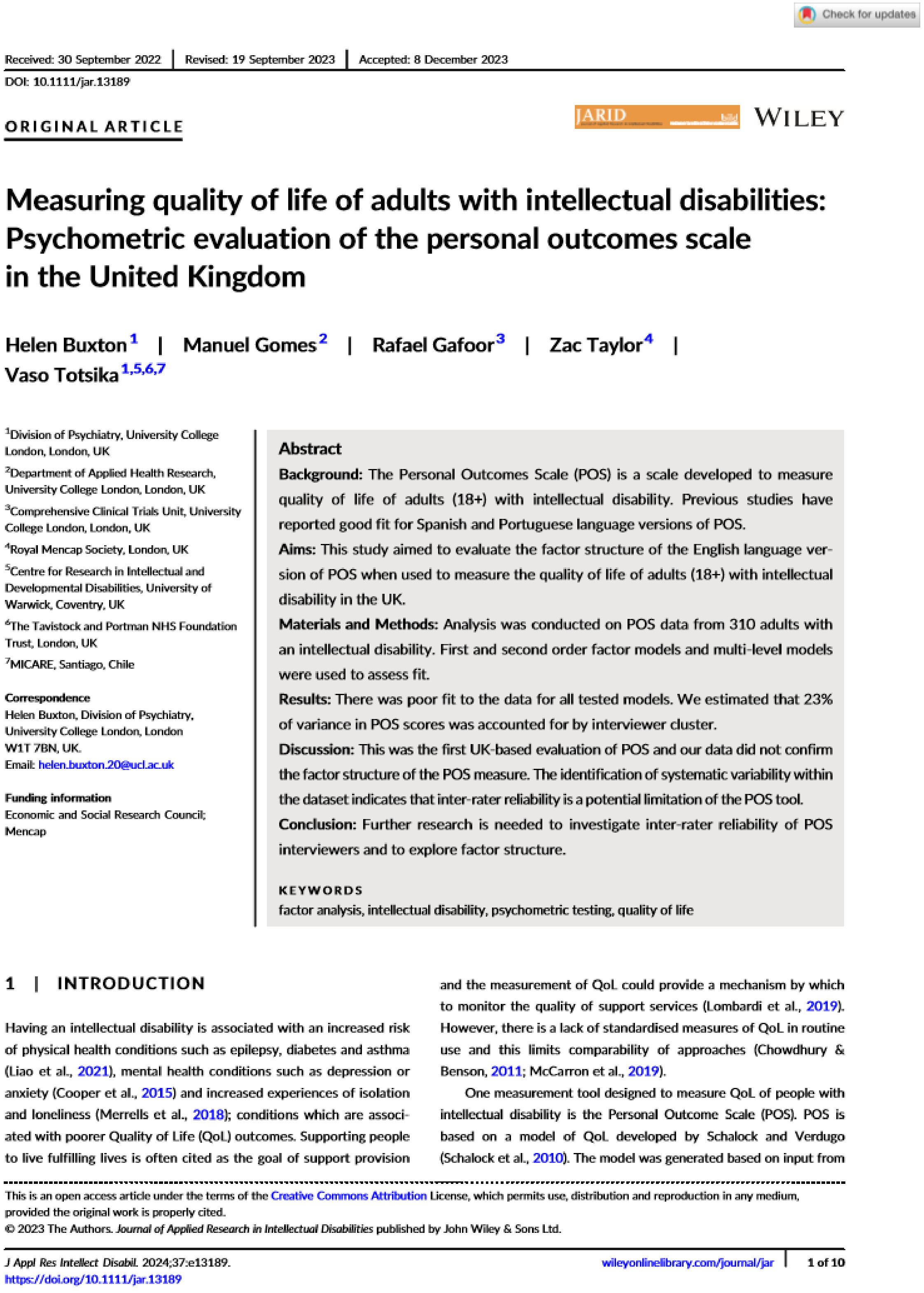
- Is there anything I haven't asked you about that you think is really important to know about
- Finish off – is there anything else you'd like to talk about?
- Is there anything you'd like me to tell (name of staff) about?
- Remember I said I was going to write a report – who would you like me to send it to?

And of course, remember to thank the person for their time and for sharing as much as they have with you.

<END OF POS INTERVIEWER USER GUIDE>

Appendix J: Dissemination

Peer reviewed publications



Received: 30 September 2022 | Revised: 19 September 2023 | Accepted: 8 December 2023
DOI: 10.1111/jar.13189

ORIGINAL ARTICLE

JARID WILEY

Measuring quality of life of adults with intellectual disabilities: Psychometric evaluation of the personal outcomes scale in the United Kingdom

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Funding information
Economic and Social Research Council; Mencap

Abstract

Background: The Personal Outcomes Scale (POS) is a scale developed to measure quality of life of adults (18+) with intellectual disability. Previous studies have reported good fit for Spanish and Portuguese language versions of POS.

Aims: This study aimed to evaluate the factor structure of the English language version of POS when used to measure the quality of life of adults (18+) with intellectual disability in the UK.

Materials and Methods: Analysis was conducted on POS data from 310 adults with an intellectual disability. First and second order factor models and multi-level models were used to assess fit.

Results: There was poor fit to the data for all tested models. We estimated that 23% of variance in POS scores was accounted for by interviewer cluster.

Discussion: This was the first UK-based evaluation of POS and our data did not confirm the factor structure of the POS measure. The identification of systematic variability within the dataset indicates that inter-rater reliability is a potential limitation of the POS tool.

Conclusion: Further research is needed to investigate inter-rater reliability of POS interviewers and to explore factor structure.

KEYWORDS
factor analysis, intellectual disability, psychometric testing, quality of life

1 | INTRODUCTION

Having an intellectual disability is associated with an increased risk of physical health conditions such as epilepsy, diabetes and asthma (Liao et al., 2021), mental health conditions such as depression or anxiety (Cooper et al., 2015) and increased experiences of isolation and loneliness (Merrells et al., 2018); conditions which are associated with poorer Quality of Life (QoL) outcomes. Supporting people to live fulfilling lives is often cited as the goal of support provision and the measurement of QoL could provide a mechanism by which to monitor the quality of support services (Lombardi et al., 2019). However, there is a lack of standardised measures of QoL in routine use and this limits comparability of approaches (Chowdhury & Benson, 2011; McCarron et al., 2019).

One measurement tool designed to measure QoL of people with intellectual disability is the Personal Outcome Scale (POS). POS is based on a model of QoL developed by Schalock and Verdugo (Schalock et al., 2010). The model was generated based on input from focus groups, personal interviews and published literature and has been validated in cross cultural studies involving approximately 2000 participants (Jenaro et al., 2005; Schalock et al., 2005; Wang et al., 2010). The model positions QoL as relational—it is not as crude as the tally of things a person possesses or has achieved (i.e., their position in life), but it is the relationship between this position and the person's expectation of what they should have (Cummins, 2005; Welham et al., 2001). This example illustrates why the measurement of QoL must take account of both objective criteria of a person's life as well as subjective criteria – how a person feels about their life (Cummins, 2005). The Schalock and Verdugo model considers QoL as multi-dimensional – comprised of eight core domains, all of which must be taken into consideration to understand a person's QoL (Schalock et al., 2010). The domains are personal development, self-determination, interpersonal relationships, social inclusion, rights, and emotional, physical, and material well-being. There is some evidence that the eight domains of QoL in this model can be aggregated into three higher order domains: independence (personal development and self-determination), social participation (interpersonal relationships, social inclusion and rights) and wellbeing (physical, mental and material wellbeing), and that this hierarchical structure may be more universally applicable across different cultural contexts than the 8-domain model (Wang et al., 2010).

POS was developed in 2008 in Belgium through consultation and pilot testing with people with intellectual disability, family members, direct support staff and experts (van Loon et al., 2010). Unlike some other scales (e.g., The Personal Wellbeing Index (Cummins et al., 2010); POS is designed to ensure inclusion of all people regardless of severity of communication and capacity needs. To achieve this, first interviewers are trained to use a semi-structured approach to administration, which enables interviewers to adjust language and context to the participant's capacity needs (Claes et al., 2008). Second, a proxy version of the tool was developed to enable collection of response from staff or family member where participants do not have capacity to self-report. Studies investigating inter-respondent reliability between self-report and proxy report have demonstrated moderate to high correlation (0.42–0.82) across the eight QoL domains, with subjective well-being consistently demonstrating the weakest correlation across studies. Proxies tend to score participants' QoL lower than participants would themselves (Carbo-Carrete et al., 2015; Claes et al., 2012; Simoes et al., 2015). These findings are aligned with previous research across a range of QoL measurement scales, especially in subjective domains (Cummins, 2002; Perry & Felce, 2002).

A POS manual and training process were also developed which stipulated that POS interviewers be trained over 2 days to ensure standardised interpretation of items and administration (Claes et al., 2008). A biproduct of the semi-structured approach is the generation of substantial qualitative data for each participant, which organisations can use to inform individualised support strategies (van Loon et al., 2010). The measure is currently in use in research and practice in 12 countries: the majority in Europe, but also including Taiwan, Japan, and USA (S. Santos, personal communication 07 Nov 2021).

Although POS authors conducted research into the psychometric properties of POS at the time of development, they did not conduct factor analysis (Claes et al., 2008). Factor analysis is a statistical technique to evaluate how well observed data support the conceptual model a scale proposes to measure (Brown, 2015). Factor analysis assessment conducted in Spain ($N = 529$) demonstrated strong support for an eight-factor structure and adequate support for a hierarchical 8 + 3 factor structure (Carbo-Carrete et al., 2015). Another analysis with a larger sample ($n = 1264$) conducted in Portugal (Simoes et al., 2015) found that eight of the 48 items from the POS failed to load adequately and were therefore dropped from analysis on the basis that the removed items did not adequately discriminate from those retained.

When analysis was repeated with the remaining 40 items both the eight-domain model and the hierarchical 8 + 3 factor structure were found to have adequate fit as estimated through small Root Mean Square Error of Approximation ($\text{RMSEA} \le 0.55$) and large Normed Fit Indices ($\text{NFI} \ge 0.97$) and Relative Fit Indices ($\text{RFI} \ge 0.95$) (Simoes et al., 2015). However, the eight-domain model showed higher absolute and incremental goodness-of-fit indices, compared to the hierarchical model. (Simoes et al., 2015). Statistics indicating good fit are defined as $\text{RMSEA} < 0.05$; $\text{CFI} > 0.9$; $\text{TLI} > 0.9$ (Brown, 2015). Both these studies have confirmed that the factor structure of POS is the same regardless of the informant (Carbo-Carrete et al., 2015; Simoes et al., 2016), which supports combining self-report and proxy data for the purposes of future factor analyses.

The factor structure of POS as used in the English language has yet to be established. The differences in factor analysis findings for POS scales in Portuguese and Spanish versions demonstrate the importance of conducting factor analyses when POS is used in new settings. These studies have also not investigated the evidence for reporting POS scores as one global QoL score across all the domains or items (e.g., either a first order single factor, or a second-order factor resultant from the eight first order factors).

The present study aimed to address these two gaps in the evidence, drawing on existing POS data collected as part of regular service provision by the UK charity Mencap (http://www.mencap.org.uk). The first objective of this study was to test the factor structure of the 48-item POS with data from people with intellectual disability living in the UK. We also intended to replicate the factor analyses conducted in Portugal with a reduced version of POS (40-items) (Simoes et al., 2016) to examine whether this would provide a better fit. All configurations were tested by combining data from self-report and proxy report responses.

2 | METHODS

2.1 | Design

POS data were collected during interviews with adults recognised by adult social care services as having an intellectual disability; and were conducted as part of routine service provision. The sample is therefore comprised of people who were selected according to service

TABLE 1 Participant demographic characteristics and interview administration ($n = 310$).

			POS score	
	n	(%)	Mean	SD
Age (years)				
(18–35)	22	(7.10)	112.32	(14.43)
(36–50)	95	(30.65)	114.32	(11.22)
(51–70)	129	(41.61)	110.71	(12.95)
(70+)	29	(9.35)	106.00	(11.70)
Missing	35	(11.29)	119.63	(8.05)
Gender				
Female	94	(30.32)	112.81	(11.94)
Male	121	(39.03)	110.68	(12.86)
Missing	95	(30.65)	114.51	(11.99)
Location				
London and Southeast and East Anglia	113	(36.45)	112.62	(12.25)
Wales, Southwest, and Midlands	101	(32.58)	112.05	(12.37)
Yorkshire and North of England	65	(20.97)	109.06	(12.97)
Northern Ireland	28	(9.03)	121.21	(7.55)
Missing	3	(0.97)	116	(4.58)
Year of interview				
2018	86	(27.74)	112.73	(12.04)
2019	115	(37.10)	112.53	(11.67)
2020	77	(24.84)	112.06	(14.27)
2021	31	(10.00)	112.68	(11.61)
Missing	1	(0.32)	–	–
Interview conducted before start of COVID-19 national lockdowns in the UK (March 2020)				
Post-March 2020	34	(10.97)	113.21	(11.24)
Pre-March 2020	275	(88.71)	112.39	(12.56)
Missing	1	(0.32)	–	–
Type of report				
Self-report	236	(76.13)	115.86	(10.32)
Proxy report	74	(23.87)	101.78	(12.39)

provider convenience. Demographic data were made available from service registers. A total of 350 interviews were conducted between Aug 2018 and Dec 2022 inclusive. Of these, 250 were self-report interviews and 100 were proxy report. Of the 350 interviews, 35 were repeat interviews (on the same person) and for five the proxy respondent was a family member as opposed to a staff member. These 40 interviews were excluded from analysis and thus the POS data set is comprised of 310 unique participants.

2.2 | Participants

All participants were adults (18+) with intellectual disability for whom Mencap provides personal care and support. Participants lived either in supported living, residential care services or in their family home. Mencap involvement varied from a 24-hr staff presence to staff who visit once or twice a week, as required by the participant's support needs. Mencap provided additional data to help describe participants. These included gender, age, geographic location, and date of interview.

There was a relatively large proportion of missing data relating to gender of participants ($n = 95$; 30.65%). Where gender was known there was a higher proportion of male participants ($n = 121$; 39.03%) than female ($n = 94$; 30.32%). The median age of participants was 53 years (Inter Quartile Range (IQR) 42–62 years) and participants were drawn from across England and Wales; the highest concentration (36.45%) being from around London, Southeast and East Anglia. Participant characteristics are displayed in Table 1.

As shown in Table 1, most interviews were conducted in the first 2 years of data collection (2018–2019: 64.84%), while 88.71% of interviews were conducted prior to the start of the UK COVID-19 lockdowns. Just 3/4 of interviews were self-report, and as found in previous studies mean proxy scores were about 15 points lower than those for self-report scores (Carbo-Carrete et al., 2015; Claes et al., 2012; Simoes et al., 2015).

2.3 | Measures

The POS contains 48 items which are rated on a 3-point Likert scale; though the response options are specific to each item (Claes et al., 2008). For example: "Do you talk to people who live or work near to you?" provides the response options: "Often," "Sometimes," "Rarely or never"; whereas "In general, how healthy do you feel?" provides response options: "Very healthy," "Okay," "Sick" or "Ill." Items and response options for both self-report and proxy versions are very similar and intended to measure the same constructs.

All interviews were conducted by members of Mencap staff who had completed standardised training. Staff self-selected to be POS interviewers as a professional development opportunity. Training was delivered by Mencap staff who had qualified at POS 'master trainer' level and POS 'co-trainer' level. Qualification to training roles is dependent on conducting at least 20 POS interviews and having been observed by a master trainer for three of these. Inter-rater reliability was not estimated as part of the training process.

2.4 | Analysis

2.4.1 | Confirmatory factor analysis of POS

The original eight factor 48-item POS scale was tested using Confirmatory Factor Analysis (CFA). Alternative configurations were tested using the 48 items including 8 + 3 higher order domains: 8 + 1 higher order and one global QoL factor. A reduced 40-item scale, based on findings published in a previous study (Simoes et al., 2016) was also tested using CFA.

Sample size is an important consideration for CFA, however the minimum sample required is inversely related to the model degrees of freedom *(d)* (MacCallum et al., 1996). All the models tested have large *d* due to the relatively large number of items in the POS scale (48), suggesting we can be confident that the sample is adequate to assess model fit. Factorability of the correlation matrix was further tested through Bartlett's test of sphericity and the Kaiser–Meyer–Olkin (KMO) test of sampling adequacy. Factor analysis is dependent on a p-value ≥0.05 for Bartlett's test, and KMO values ≥0.08.

Model fit was assessed using the RMSEA and its 90% Confidence Interval (CI). Values ≤0.05 were considered close fit (Hu & Bentler, 1999). The Comparative Fit Index (CFI) and the Tucker Lewis fit Index (TLI) were calculated; with values ≥0.95 considered good fit (Hu & Bentler, 1999). The Standardised Root Mean Square Residual (SRMR) was also considered, with values ≤0.08 considered good fit (Brown, 2015). Chi-square test results are also reported to assess the fit between the hypothesised model and the data – where the null hypothesis represents perfect fit.

2.4.2 | Understanding reasons for observed fit

Descriptive statistics, including response proportions for each item and inter-item correlations were generated and inspected for evidence of problematic items (Sexton et al., 2013). As data are ordinal, polychoric correlations were calculated. To extract components from the data measured variables must be sufficiently intercorrelated, and the majority of correlations should exceed 0.3 (Hair et al., 2014).

Due to the semi-structured nature of administration of POS, and the large number of interviewers involved in data collection, we hypothesised that a large proportion of variance in the data set was influenced by between-interviewer variability. There are a number of ways interviewers could have introduced error into the data—this could be at participant selection, for example, in the way that they made contact and gained cooperation from participants, or it could be measurement error introduced in the way that interviewers deliver questions (West & Blom, 2017).

To explore interviewer-specific effect Multi-Level Models (MLM) with interviewer ID as random intercepts were conducted. Based on complete case analysis 36 interviewers conducted a median of 2 interviews each (IQR 1–3). However, the number of interviews ranged from 1 to 26. Only four interviewers conducted more than 10 interviews.

MLM allow the variance to be partitioned into two levels—POS scores were regressed on demographics (age, gender, and geographic location) and interview administration (year and type of interview) while random intercepts at level 2 (interviewer ID) allowed for clustering at that level. We initially estimated an unadjusted model and computed the Intra-class Correlation coefficient (ICC)—the proportion of variability in the total QoL score that exists between interviewers. Participant level demographic variables (age, gender, and geographic region) were then added, followed by process variables (year of interview, pre/post start of Covid-19 lockdowns, self, or proxy report) to explore if the interviewer effect was attenuated by any of these variables. Model significance was tested through the serial likelihood ratio test, which if statistically significant ($p < 0.05$), indicated that the covariate-adjusted model is a better fit to the data than the unadjusted model (where only the interviewer-specific random effect was included).

2.4.3 | Missing data

The STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) diagram illustrates the patient selection process in Figure 1. There were 310 unique interviews available for analysis—236 interviews were self-report and 74 were proxy report. Two hundred and seventy of the interviews (87.10%) had complete data for all POS items. The greatest amount of missing data per participant was nine items but this was for only one participant. Data is missing for items if the participant chose not to answer a specific question, the answer is unknown or due to input error. As the proportion of observations with missing data was relatively small and visual inspection revealed no systematic missing data pattern or predictors of missingness, complete case analysis (n = 270) was conducted for CFA.

MLM analysis required data on interviewer ID and participant demographics. Sixty-four interviews were missing data on interviewer ID, all of which were conducted prior to February 2020 when Mencap was using a less robust form of data capture (MS Forms). Data are missing through user error (leaving field blank, entering their name inconsistently e.g., just first name or initials). Because interviewer ID was used to define the higher-level group in MLM, those interviews with data missing on interviewer ID were excluded from analysis. Data were taken from Mencap service registers to provide demographic information to participant observations. However, variables are not mandatory fields on Mencap's databases and inconsistent use resulted in missing data. A further 70 observations were missing data on at least one of the following variables: interviewer ID, gender, age, or geographic location. Multilevel analysis therefore comprises a reduced sample of 136 observations across 36 interviewers. This analysis assumed that, conditional on both individual characteristics and interviewer ID being present, the data were missing completely at random.

2.5 | Implementation

MPlus (version 8) was used for all factor analyses (Muthén & Muthén, 2017). For CFA the Weighted Least-Squares Mean and

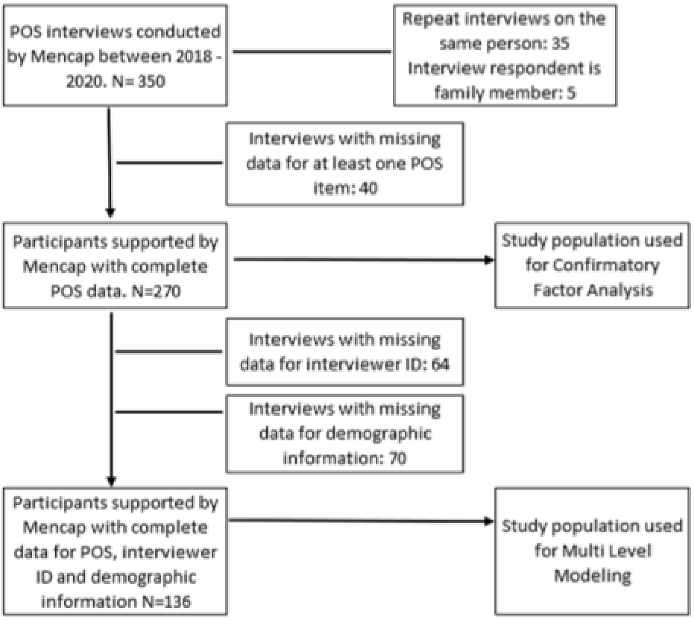

FIGURE 1 STrengthening the Reporting of OBservational studies in Epidemiology diagram: Illustrating selection of samples used for study analyses.

TABLE 2 Fit statistics for POS (n = 270).

Model	Chi square (p)	CFI	TLI	RMSEA (90% CI)	SRMR
8 factor, 48 items	1967.13 (<0.001)	0.750	0.732	0.057 (0.053–0.060)	0.121
8 + 3 factor 48 items	2088.96 (<0.001)	0.722	0.706	0.059 (0.056–0.063)	0.127
8 + 1 factor 48 items	2072.00 (<0.001)	0.727	0.713	0.059 (0.055–0.063)	0.128
1 factor 48 items	2362.26 (<0.001)	0.650	0.063	0.066 (0.063–0.070)	0.137
8 factor 40 items[a]	1357.56 (<0.001)	0.740	0.715	0.058 (0.053–0.063)	0.115

Abbreviations: CFI, Comparative Fit Index; POS, Personal Outcomes Scale; RMSEA, Root Mean Square Error of Approximation; SRMR, Standardised Root Mean Square Residual; TLI, Tucker Lewis fit Index.
[a]Model includes 40 items retained following CFA with POS data in a previous study (Simoes et al., 2016).

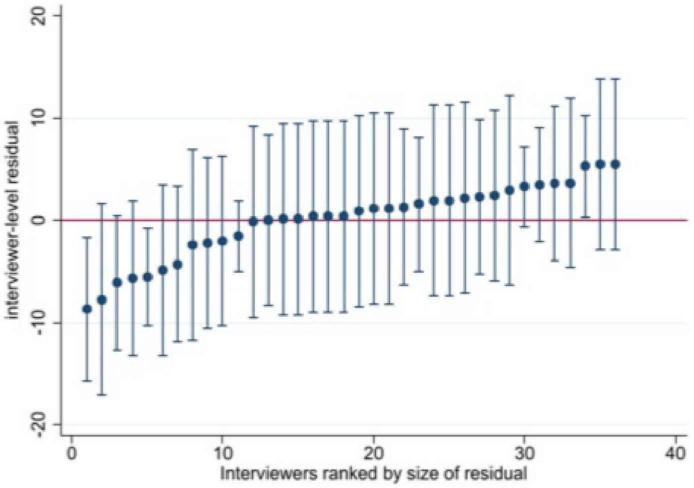

FIGURE 2 Caterpillar plot: Visualising variation between interviewer ($n = 136$).

TABLE 3 Summary comparison of multi-level models ($n = 136$).

Terms	Interim model 1 (demographics) coefficient (95% CI)	Interim model 2 (process) coefficient (95% CI)	Final model coefficient (95% CI)
Fixed effects			
Average POS score	121.11 (113.99–128.23)	106.56 (100.89–112.23)	105.10 (101.27–108.93)
Gender			
Female	1		
Male	−3.46 (−6.91 to 0.15)		
Age	−0.09 (−0.21 to 0.03)		
Location			
London & S. E	1		
Wales, S.W. & Central	−2.87 (−7.72 to 1.98)		
North of England	−4.38 (−10.02 to 1.24)		
Year			
2018		1	
2019		−2.01 (−6.85 to 2.82)	
2020		0.32 (−5.8 to 6.44)	
2021		−2.48 (−8.75 to 3.79)	
Report type			
Proxy		1	1
Self-report		10.06 (6.23–13.88)	10.51 (6.81–14.21)
Random effects			
Interviewer level—variance	25.72 (8.99–73.53)	22.22 (6.68–73.91)	22.90 (7.29–71.97)
Residual variance	86.16 (65.95–112.57)	72.59 (55.01–95.79)	73.21 (55.63–96.35)
Intraclass coefficient	0.230 (0.087–0.484)	0.234 (0.076–0.534)	0.238 (0.082–0.524)
Likelihood ratio test	chi2 = 6.37	chi2 = 29.31	
p-Value	0.173	<0.001	<0.001

Variance-adjusted (WLSMV) estimator was used to account for the categorical nature of the items (Bandalos, 2014; Muthén & Muthén, 2017). Stata v17 (StataCorp, 2019) was used to describe the data and for multi-level modelling.

As the study was a secondary analysis of routinely collected service data, POS interview data and demographic information were linked by the data owners (Mencap) prior to sharing an anonymised database with the research team. Ethical approval for the current study was provided by UCL research ethics committee (Project ID: 19259/002).

3 | RESULTS

3.1 | Results of confirmatory factor analyses

Results from the CFA to test the theoretical QoL measurement models are displayed in Table 2. Fit indices indicated poor fit to the data for all possible factor structures of the 48-item scale. Items were then reduced to 40 to replicate previous CFA from Portugal (Simoes et al., 2016). However, fit did not improve with the 40-item POS data.

3.2 | Investigating observed model fit

3.2.1 | Suitability of data for factor analysis

Although statistical test results indicated that data were suitable for factor analysis (p value: Bartlett's test <0.001; KMO: 0.812), examination of the polychoric correlation matrix for POS data found insufficient intercorrelations. Only 44.22% of all possible between item correlations reached the minimum expected cut off 0.3, and a further 30.02% of possible values returned negative correlations.

3.2.2 | Factors accounting for variance in POS scores

Examination of correlation matrices by interviewer indicated that there was variance in between-item correlation dependent on person who had conducted the interview.

To explore this further we conducted analysis on only the data which was complete across all demographic and process variables. Predicted POS score for the 136 observations when clustered by the 36 interviewers was 113.51 (95% CI 110.76–116.25). The variability in random intercepts for interviewers is illustrated by caterpillar plot (Figure 2). The wide confidence intervals displayed are likely a result of small numbers of interviews per interviewer, nonetheless the plot depicts variation among interviewer cluster means. Unexplained interviewer level variance was calculated at 30.44 (95% CI 10.82–85.68) and unexplained residual variance at 88.93 (95% CI 67.83–116.60). The ICC statistic indicated that the proportion of total variance that is accounted for by clustering at the interviewer level was 25.50% (95% CI 0.099–0.516).

Models were rerun inclusive of participant characteristics and interview administration variables (see Table 3). None of the participant characteristics was found to be significantly associated with POS score, but type of report (self or proxy) did demonstrate association. The ICC coefficient for the model with type of report included at participant level further supports the finding that a large proportion of total variance in POS score is accounted for by interviewer cluster (ICC: 0.2383 95% CI 0.0817–0.5239).

4 | DISCUSSION

This study aimed to explore how well POS data from a sample of people with intellectual disability living in the UK fit the conceptual model of QoL which the scale is intended to measure. Fit indices indicated poor fit to the data for all tested models. Factor analyses of UK POS data did not support an 8-domain QoL model, an 8 + 3, 1, or an 8 + 1 domain QoL model. These findings do not replicate previous evidence published from research groups in Spain and Portugal which demonstrated acceptable fit for both the 8-domain QoL model and the 8 + 3 domain models (Carbo-Carrete et al., 2015; Simoes et al., 2016). Potentially this could be explained by differences in participant characteristics. In both previous studies the majority of participants lived in their family home and had mild to moderate intellectual disabilities—in Portugal a criterion for inclusion was verbal capacity to answer the self-report measure (Simoes et al., 2016). The majority of participants in our sample lived in supported accommodation and data were not available to categorise participants by intellectual disability level. We do know that the UK sample included people with severe intellectual disability, and verbal capacity was not considered a prerequisite for self-report. Where appropriate, people were supported to self-report through the engagement of communication aids and communication partners. UK data have therefore been collected from people with greater variability of severity of intellectual disability than those included in previous studies. Further analysis of the data collected in Spain examined the effect of severity of intellectual disability on individual item functioning and found that the scores of a significant number of items were affected by severity (Carbo-Carrete et al., 2019). Authors suggest this indicates the need for broader discussion of the adequacy of definitions of QoL dimensions and indicators for the whole spectrum of people with intellectual disability. The poor fit found in our study may reflect in some part the question of adequacy of POS indicators when used to measure QoL of people with severe intellectual disability, but further research is required to explore this.

In our study the lack of a clear factor structure was explained mathematically by weak inter-item correlation (Hair et al., 2014). We hypothesised that this variability in item correlation may have resulted from interviewer bias – systematic error introduced through the interviewer's gathering of selective data or their influence over the participant's response (Jager et al., 2020). Multi-level models were fitted to examine the effect of interviewer and our results indicated that 23.83% of variance in POS score was accounted for by interviewer cluster.

Bias in the sample could have been introduced at selection as participants were selected according to organisation and interviewer convenience (West & Blom, 2017). (e.g., interviewers may have been more likely to approach participants at services where they already held a relationship with either staff or participants). In addition measurement error may have been introduced during the interview as interviewers are trained to apply context which is meaningful to the participant to items to aid understanding (Claes et al., 2008), and any slight variation in interviewer style or technique (e.g., being suggestive or hasty); in attitude of the interviewer; or in interviewer interpretation of items could introduce variability.

A review of the literature on interviewer effect (Schaeffer et al., 2010) found that survey questions which were attitudinal, sensitive, ambiguous, complex or open-ended were more likely to introduce variable interviewer effects. POS questions are not open-ended but some could be classed as sensitive (e.g., do you think you are important to your family?); ambiguous (e.g., Are you able to demonstrate the skills that you have and the things that you can do?) or complex (e.g., Could you have a partner if you wanted one?). These types of questions may provide more opportunity for probing or using a more conversational format to deliver questions (West & Blom, 2017). Although previous studies have shown that these techniques tend to have a positive effect on response quality (West & Blom, 2017) the dynamic between interviewer and interviewee may result in higher likelihood of acquiesce bias (e.g., through leading questions) or recall bias (e.g., through excessive probing) (Bergen & Labonté, 2020). In addition, previous studies have found that interviewer demographics such as gender, age and race are related to response quality (West & Blom, 2017). In our study data related to interviewer demographics is not available to examine this further.

Increased interview standardisation has been shown to reduce interviewer effect (Jager et al., 2020), however the flexibility of scale administration is a key property to recommend POS for use with people with intellectual disability. POS authors have specified that interviewers be trained to administer the scale as a conversation, sensitive to the communication needs and styles of the person being interviewed, and ordering the questions aligned with the natural flow of conversation (Claes et al., 2008). A conventional measurement scale with fixed order and wording of items would result in the unnecessary exclusion of many people from self-report due to varying communication and comprehension needs. Theoretically, QoL must include consideration of a person's subjective experience, which pragmatically means that wherever possible the person whose QoL is being measured should be the one to rate themselves against given criteria (Schalock et al., 2010). Therefore, efforts to increase standardisation of the scale itself to reduce interviewer bias could be counterproductive by introducing selection bias into the sample.

Measures which use a semi structured interview process to assess a quantitative metric have been shown to have good reliability (e.g., Ford et al., 2018; Lobbestael et al., 2011), therefore the flexibility allowed in POS administration should not automatically be assumed to be a challenge to reliability. However. to our knowledge no study has formally examined inter-rater reliability of POS interviewer. POS data collection in both the Portuguese and Spanish studies used large numbers of interviewers and although interviewers were trained in POS administration, these studies do not report methods to ensure calibration of interviewers (Carbo-Carrete et al., 2015; Simoes et al., 2016). We were not able to estimate inter-rater reliability. However, the estimated size of the proportion of variance accounted for by interviewer clustering suggests that a significant proportion of the variability introduced into POS scores was attributable to the interviewer. Further research is needed to explore the inter-rater reliability of the measure.

Anecdotally, flexibility in the administration results in high acceptability of the measure by support staff and participants (Mencap, personal communication, May 2022). Potentially, this flexibility is further enhanced by Mencap's employment of direct support staff as interviewers. Direct support staff are highly skilled and experienced in adjusting their communication style and tactic knowledge to the needs of the people they support (Barken & Armstrong, 2018). Authors note from observing POS interviews that interviewers clarify and avoid bias by applying context from previous questions to further explore a response. As a qualitative interview technique this demonstrates expertise (Lavee & Itzchakov, 2021), but for the purposes of extracting a quantitative score from the interview, it is dependent on interviewers sharing exact interpretation of each of the questions and response options. The questions used in the POS scale are intended to be broad enough to apply to multiple contexts, for example, the question "Are you learning to do new things?" could refer to formal courses undertaken at college, or to tasks around the home done with one-to-one support, such as chopping vegetables. Interviewers must share awareness of the broad applicability of these items, in order to prompt interviewees further. Any slight variation in interviewer interpretation could introduce extra variability into the measure, and this may explain some of the variation seen in the results of this study.

5 | LIMITATIONS

This study analysed data collected in the context of regular service provision by a single provider. As such, participants were recruited according to convenience, and this could have introduced selection bias into the sample. In addition, as data were only collected by one provider, we cannot say how the inclusion of participants from different providers may have influenced results. Results may not be widely generalisable.

A high degree of missing data was observed for participant demographic information, while other important participant descriptors (e.g., verbal communication skills and level of intellectual disability severity) were not available. It is therefore not possible to understand how differences between respondents interact with the psychometric properties of POS. For example, the standard deviation in POS score is much lower among participants in Northern Ireland, but we cannot explore this difference further due to the scarcity of demographic information available. The large proportion of missing demographic data resulted in reductions in the sample size available as we restricted cases according to criteria of available demographic data. In addition, the sparsity of observations per cluster resulted in less precise estimates. Although our results were not able to demonstrate a statistically significant association between POS score and gender, age, or geographic location we would caution that this is likely the result of inadequate sample for the complexity of analysis.

Our results suggest that interviewer effect is compounding variability in the data already present due to the multi-item nature of the questionnaire, but we cannot conclude that other factors, such as severity of intellectual disability are not also a source of score variability. Further research is required to explore these factors.

6 | RECOMMENDATIONS

Our study findings highlight the need to establish better scoring consistency among interviewers prior to administration of the POS. During POS interviewer training, further emphasis should be placed on calibration between interviewers of interpretation of response options. Strong inter-rater reliability may need to be established prior to interviewing people. Aligned with methodology used in a previous study (Ford et al., 2018), interviewers could be asked to watch and independently assess recorded demonstration interviews until all interviewers reach ≥80% agreement with expert ratings. Following calibration of interviewers formal assessment of inter-rater reliability should be conducted through duplicate interviewing of the same participant (Gisev et al., 2013). The lack of studies assessing inter-rater reliability across any of the existing POS literature may be due to not wishing to overburden participant time. However, our study highlights that the flexibility in administration of the scale may undermine the validity of the POS and warrants investigation.

AUTHOR CONTRIBUTIONS

Vaso Totsika and Helen Buxton designed the study with contributions from Manuel Gomes and Rafael Gafoor. Helen Buxton cleaned and managed the data and performed formal data analysis with support from Vaso Totsika. Helen Buxton drafted the manuscript. Rafael Gafoor and Manuel Gomes provided oversight for the statistical analyses. All authors reviewed and edited the subsequent drafts and approved the final version of the manuscript.

ACKNOWLEDGEMENTS

We would like to thank the people who participated in this study without benefit to themselves as well as the staff of participating Mencap services. Special thanks go to the following individuals at Mencap for their support to coordinate data management and supply: Ellen Kennedy, Alice Leuenberger and Owen Bowden. All views expressed in this manuscript are those of the authors and do not necessarily reflect those of the funding bodies or affiliated organisations.

FUNDING INFORMATION

This study was co-funded by the Economic Social Research Council and Royal Mencap Society as part of a ESRC Studentship at the UCL, Bloomsbury and East London Doctoral Training Partnership (UBEL DTP). The funders played no role in the study design, analysis, or interpretation of data or in the writing of the manuscript.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

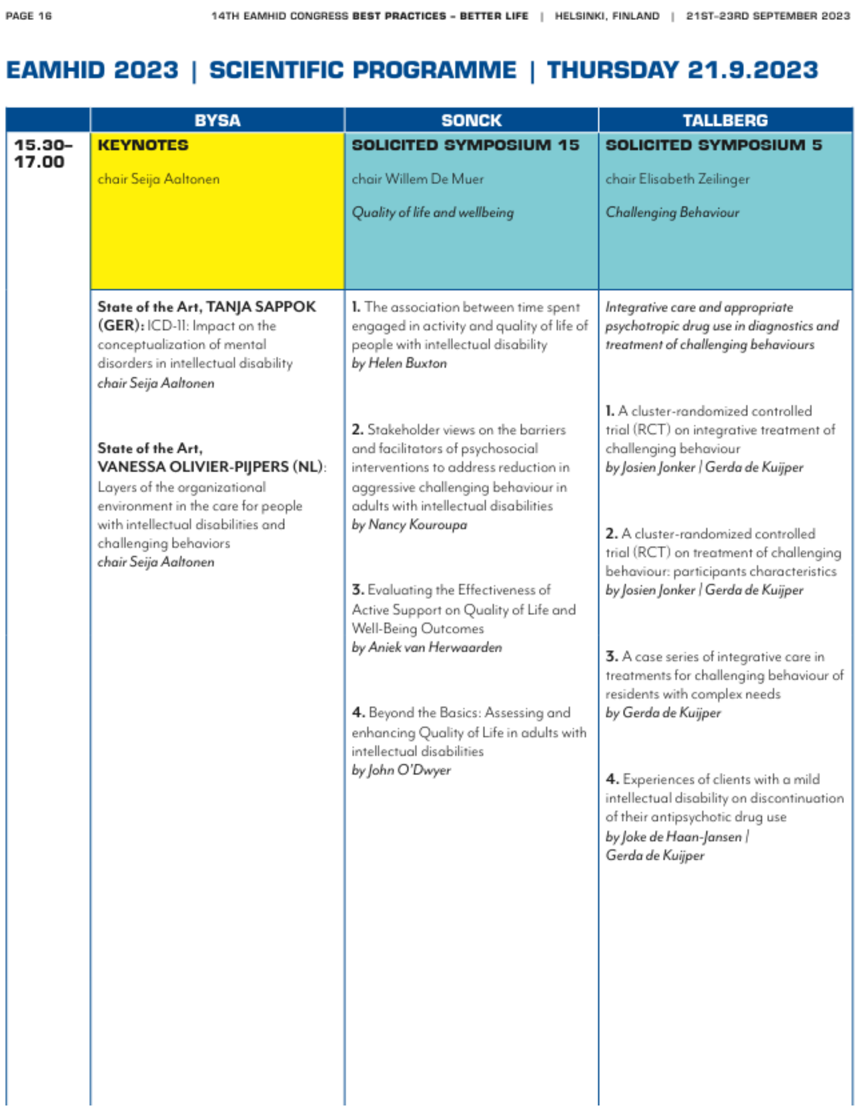
Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Buxton, H., Gomes, M., Gafoor, R., Taylor, Z., & Totsika, V. (2024). Measuring quality of life of adults with intellectual disabilities: Psychometric evaluation of the personal outcomes scale in the United Kingdom. *Journal of Applied Research in Intellectual Disabilities*, *37*(2), e13189. https://doi.org/10.1111/jar.13189

Oral presentation at EAHMID conference

Title: The association between time spent engaged in activity and quality of life of people with intellectual disability

Oral presentation at 14th European Association for Mental Health in Intellectual Disability 2023



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14TH EAMHID CONGRESS **BEST PRACTICES – BETTER LIFE** | HELSINKI, FINLAND | 21ST–23RD SEPTEMBER 2023

EAMHID 2023 | SCIENTIFIC PROGRAMME | THURSDAY 21.9.2023

	BYSA	SONCK	TALLBERG
15.30–17.00	**KEYNOTES** chair Seija Aaltonen	**SOLICITED SYMPOSIUM 15** chair Willem De Muer *Quality of life and wellbeing*	**SOLICITED SYMPOSIUM 5** chair Elisabeth Zeilinger *Challenging Behaviour*
	State of the Art, TANJA SAPPOK (GER): ICD-11: Impact on the conceptualization of mental disorders in intellectual disability *chair Seija Aaltonen* **State of the Art, VANESSA OLIVIER-PIJPERS (NL):** Layers of the organizational environment in the care for people with intellectual disabilities and challenging behaviors *chair Seija Aaltonen*	**1.** The association between time spent engaged in activity and quality of life of people with intellectual disability *by Helen Buxton* **2.** Stakeholder views on the barriers and facilitators of psychosocial interventions to address reduction in aggressive challenging behaviour in adults with intellectual disabilities *by Nancy Kouroupa* **3.** Evaluating the Effectiveness of Active Support on Quality of Life and Well-Being Outcomes *by Aniek van Herwaarden* **4.** Beyond the Basics: Assessing and enhancing Quality of Life in adults with intellectual disabilities *by John O'Dwyer*	*Integrative care and appropriate psychotropic drug use in diagnostics and treatment of challenging behaviours* **1.** A cluster-randomized controlled trial (RCT) on integrative treatment of challenging behaviour *by Josien Jonker | Gerda de Kuijper* **2.** A cluster-randomized controlled trial (RCT) on treatment of challenging behaviour: participants characteristics *by Josien Jonker | Gerda de Kuijper* **3.** A case series of integrative care in treatments for challenging behaviour of residents with complex needs *by Gerda de Kuijper* **4.** Experiences of clients with a mild intellectual disability on discontinuation of their antipsychotic drug use *by Joke de Haan-Jansen | Gerda de Kuijper*

Poster presentation at the Seatle Club Conference

Title: Time Spent engaged in leisure activities and quality of life of people with intellectual disability in England

Poster presented at the Seatle Club Conference, Birmingham University December 2023

Time spent engaged in leisure activities and quality of life of people with intellectual disabilities in England

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Introduction

Research supports an association between living in the community and improvements in quality of life of people with intellectual disabilities. Less is known about modifiable aspects of community living which could enhance quality of life.

Factors found to be associated with variance in quality of life of people with intellectual disability in previous studies

Positive association with Quality of life

- Person lives in community
- High self-determination/autonomy
- Person has a job or voluntary position
- Strong 'natural' support network (family/friends)
- Good self-rated health
- Person engages in daytime activities
- **Enjoys variety of social and leisure activities**

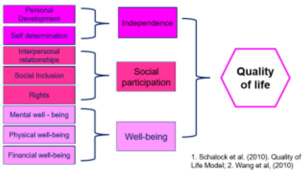
Negative association with Quality of life

- Severity of intellectual disability
- Anxiety/ depression
- Lack of access to required healthcare or specialised services
- If survey completed by proxy

There is good evidence from the general population that engagement in leisure is associated with gains in subjective well-being. Evidence gathered during the period of national lockdowns suggested that these gains were retained when leisure activities were restricted to people's homes or nearby surroundings. People with intellectual disability often face barriers to accessing formal leisure facilities and providers.

What is Quality of life?

- Multi-dimensional
- Combines both subjective and objective conditions of life



1. Schalock et al. (2010). Quality of Life Model; 2. Wang et al, (2010)

Research Question

What is the association between time spent engaged in accessible leisure activities and quality of life, after controlling for other factors known to be associated with quality of life?

Methods

All data collected Feb-Oct 2022. Quality of life data were collected via face-to-face interview with participant or by phone interview with staff respondent if participant did not have capacity to provide their own answers. Online survey completed by staff respondent captured data on demographics, adaptive behaviour, engagement in leisure, and an alternative objective measure of quality of life.

Key measurement variables

- Short Adaptive Behaviour Scale (SABS)
- Activity engagement score
- Quality of life: Personal Outcome Scale (POS)
- Quality of life: Brief objective measure (BQoL)

Cross sectional design used univariable analysis to identify factors to include in a multivariable regression analysis.

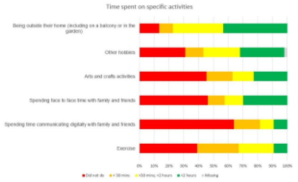
n = 100
Adults with intellectual disability

- 47% Male; 50% female
- Mean age: 55.97 years (SD 14.10)
- 14% live in residential care homes; 84% supported living facilities
- 14% have a job or voluntary position
- Broad range of support needs (mean score 55.8, SD 26.97 (sample range 2 – 101)

Results

Activity engagement of people with intellectual disability in our sample

Score was calculated by asking respondents to estimate amount of time spent on a set of leisure activities on the last weekday. Profile of activity engagement across the sample is shown in the figure



Unadjusted association of participant characteristics with quality of life score

- Significant association found between activity engagement and quality of life score as measured by POS.
- As expected from literature significant association also found between severity of intellectual disability, type of report, type of accommodation and having a job or voluntary position.

Factor	Coefficient	95% Confidence interval	P value
Participant is female (ref= male)	3.15	-2.33, 8.62	0.257
Participant age	-0.11	-0.31, 0.09	0.294
Participant shares their home with others (ref = participant lives alone)	-4.81	-12.17, 2.54	0.197
Participant lives in supported living (ref = residential care home)	9.61	2.00, 17.22	0.014
Participant has job / voluntary role (ref =does not)	14.19	6.9, 21.47	<0.001
Proxy report (ref = self report)	-9.16	-14.58, -3.74	0.001
Lower severity of intellectual disability	0.27	0.18, 0.36	<0.001
Higher activity engagement score	**1.22**	**0.58, 1.86**	**<0.001**

Multivariable analysis:

	QoL Outcome variable Coefficient (95% Confidence interval) p value			
	POS	**POS Independence**	**POS Social Participation**	**POS Well-being**
Activity Engagement Score	**0.96 (0.34, 1.57)** **p = 0.003**	**0.12 (-0.05, 0.29)** **p = 0.159**	**0.67 (0.33, 1.01)** **p <0.001**	**0.17 (-0.07, 0.4)** **p = 0.167**
Covariates				
Adaptive Behaviour Skills (SABS score)	0.17 (0.05, 0.29) p = 0.007	0.11 (0.07, 0.14) p <0.001	0.2 (-0.05, 0.09) p = 0.556	0.04 (-0.01, 0.09) p = 0.074
Type of report: Proxy (ref = self-report)	0.65 (-5.43, 6.73) p = 0.833	0.38 (-1.33, 2.09) p = 0.656	-1.23 (-4.59, 2.14) p = 0.471	1.49 (-0.86, 3.84) p = 0.211
Type of accommodation: Supported housing (ref = residential care home)	7.73 (1.05, 14.41) p = 0.024	2.8 (0.92, 4.68) p = 0.004	2.46 (-1.24, 6.16) p = 0.190	2.47 (-0.11, 5.05) p = 0.061
Participant has a job or voluntary position (ref = does not)	8.92 (1.58, 16.25) p = 0.018	1.88 (0.18, 3.94) p = 0.074	4.12 (0.04, 8.18) p = 0.048	2.93 (0.09, 5.76) p = 0.043

Sensitivity analysis	Activity engagement	SABS score	Type of report	Type of accom.	Job/ voluntary
Brief QoL	0.58 (0.34, 0.82) p <0.001	0.26 (-0.02, 0.07) p = 0.286	-0.81 (-3.19, 1.57) p = 0.502	1.53 (-1.08, 4.14) p = 0.246	-0.43 (-3.29, 2.44) p = 0.767

Discussion and conclusion

Findings support the hypothesis that increased engagement in leisure activities is associated with a positive impact on quality of life. When POS sub-domains were modelled as outcomes, data suggested that increases in social participation may be what drives these gains in overall quality of life.

The association between engagement in leisure and quality of life was also found when quality of life was measured using objective indicators only. Our findings suggest that the investing staff time and resources in supporting people to take part in activities could have significant benefits to quality of life

! Although we found significant association the magnitude of effect is small, and we do not know if this constitutes an important change for participants. To date, no research has looked at sensitivity to change of POS scores

! The participant group includes people with a wide range of support needs further research is necessary to understand how support need and activity engagement interact with quality of life.

! There is some crossover between indicators used to measure activity engagement and indicators used to measure Quality of life, so our outcome and exposure measurements may not be truly independent

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<END OF APPENDICES>