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Understanding and Experiencing Ageing: The Perspectives of Older People with Intellectual Disabilities

Research Portfolio

Anna Whiteley

Doctorate in Clinical Psychology
University of Edinburgh

2015
D. Clin. Psychol. Declaration of own work

This sheet must be filled in (each box ticked to show that the condition has been met), signed and dated, and included with all assignments - work will not be marked unless this is done

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Title of work: Understanding and Experiencing Ageing: The Perspectives of Older People with Intellectual Disabilities

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Signature:                       Date: 28/08/15
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Thank you very much to my Clinical Supervisor Bruce Kidd who steered me along the way. A massive thank you to my Academic Supervisors Ethel Quayle and Ken MacMahon who went out of their way time and time again to give me help when I felt defeated. Your encouragement throughout has been most appreciated.

Lastly a huge thank you to my friends and family. It goes without saying that my partner Neil has been amazing in keeping me going with tea and hugs. He has been there for me at every turn. My Mum and Dad have been amazing in feeding me, giving me pep talks and putting up with me all this time. Everyone else – Helen, Nan, all my lovely friends everywhere who make a wonderful distraction – I really appreciate you being there for me.

*******************

Interviewer: Do you think it's important to ask [about ageing] then?

Participant: Well if it's a test, if you're studying old people, then maybe you should.

Interviewer: Okay, so you... sorry when you're studying older-, you think they should?

Participant: If you're studying, and you've got an assignment, then I think it's one of the things they need to learn, because it might be the only time the old folks have you know? (Participant 5)
Research portfolio abstract

Background: This thesis contains two elements: the first is a systematic review examining some of the determinants of quality of life for people with intellectual disability. Understanding these determinants can drive improvement at both individual and societal level. Yet there are a number of quality of life measures which might confound findings between studies. This systematic review sought to identify factors that influence quality of life using self-report on one measure developed for use with people with intellectual disability, the ‘Quality of Life Questionnaire’ (Schalock & Keith 1993).

The second element is an empirical study that aims to explore the lived experience of aging for older adults with intellectual disability. There are noted differences between people with and without disability as they grow older, for example in terms of health and social opportunity. Previous studies have not consistently sought the experience of the people with intellectual disability themselves, or have used participants not traditionally considered older adults. This study aims to address gaps and further our knowledge in the lived experience of getting older for older adults with intellectual disability.

Method: Within the systematic review a systematic search of relevant studies to 20th January 2015 was completed using a specified inclusion criteria, yielding 13 peer-reviewed journal articles. These were scored on 11-point purpose-designed quality criteria.

For the empirical study semi-structured interviews were completed with ten participants with intellectual disability (age range 60 – 74 years, five female) regarding their understanding of getting older and their experience of ageing. Nine transcribed interviews were analysed using interpretative phenomenological analysis.

Results: The systematic review found that living in a semi-independent environment or an urban setting, being employed, being involved in domestic and community
activities, receiving social support and possessing social skills and self-determination were factors that improved quality of life for people with intellectual disability.

Three major themes emerged from the empirical study data when participants discussed getting older: ‘Not changed by ageing’, ‘Thinking about the ageing process’ and ‘What happens when getting older’. Participants tended to feel that they were still the same due to continuation of the same activities and social support. They demonstrated confusion in the ageing process, considering the process ‘inevitable’ but insignificant, although also recognising some changes associated with the process. They discussed their views about what they considered happens when people get older, which tended to be stereotypical and often negative. However they also reflected on their own experiences and how they had changed.

Discussion: The methodological quality of the studies reviewed was found to be generally low due to a range of factors including study design, measurement of intellectual disability and reporting of sample demographics and results and therefore conclusions should be treated with caution. This highlights a need for further research with people with intellectual disability of a higher methodological quality.

The empirical study is discussed in reference to previous research and gerontological theories of ageing. The study highlighted that staff or family did not broadly discuss ageing with participants and their views often changed over the course of the interviews from more physical and negative aspects to how ageing impacted them. This research demonstrated older adults with intellectual disability do have opinions on ageing. Further exploration with people with intellectual disability on this topic is to be encouraged in the future to develop a more balanced view.
Self-reported quality of life using ‘The Quality of Life Questionnaire (QOL-Q)’ with people with intellectual disabilities: A systematic review

Abstract

Background: Understanding determinants of quality of life (QoL) for people with intellectual disabilities can drive improvement at both individual and societal level. There are several measures of QoL for this population, thus the influence of differing measures may confound findings between studies. This review sought to identify factors that influence QoL as measured by the Quality of Life Questionnaire (QOL-Q; Schalock & Keith 1993).

Methods: Relevant electronic databases were searched, supplemented by hand-searching. Studies were selected according to defined inclusion criteria, yielding 13 studies. Study quality was rated according to purpose-designed quality criteria.

Results: Living in a semi-independent environment or an urban setting, being employed, engagement in domestic and community activities, social support and self-determination were found to be factors that improve QoL. However, the methodological quality of reviewed studies was rated as generally low.

Conclusions: The QOL-Q was used across a broad range of settings, with independence, employment and self-determination found to be positive influences upon QoL for people with intellectual disabilities. Study quality was generally low due to study design, measurement of intellectual disability and reporting of sample demographics and results.

Word count: 7,333 (excluding figures and tables)
Introduction

Quality of life is a term in everyday use, yet is a complex phenomenon that can be difficult to define and assess (Verdugo et al. 2005). It has associations with related concepts of happiness and subjective well-being (Phillips 2006), but achieving a ‘good’ quality of life goes beyond meeting just basic needs. Instead, it encapsulates broader life enrichment and, critically, the perception of the individual (Rapley 2003). The World Health Organisation outlined several different aspects that may influence quality of life, including physical health, psychological state, level of independence, social relationships, personal beliefs and the environment around a person (WHO 1997). It has been asserted that quality of life is key to improving the circumstances of those at higher risk of social exclusion, such as people with intellectual disabilities (Schalock et al. 2002). It is considered a sensitizing notion, that is one that alerts us to what is important from the perspective of the individual (Gómez et al. 2013). It is a concept with far-ranging implications in diverse fields such as education, health care and social services.

Quality of life and people with intellectual disabilities

The normalisation movement of the 1970s (Wolfensberger 1972) and subsequent social role valorization (Wolfensberger 2000) are credited with instigating change in services for people with intellectual disabilities. These approaches developed in parallel with enquiries into long-stay hospitals regarding poor quality care and abusive treatment of people with intellectual disability in long-stay institutions (Victor 1997). These led to significant changes in the support of people with intellectual disabilities. There was a move toward deinstitutionalization, with greater community provision for people with intellectual disabilities (Chowdhury & Benson 2011), and a focus upon improving the quality of life for all. The publication of recent reviews into the use of quality of life measures with people with intellectual disabilities suggests ongoing interest in this area (e.g. Townsend-White et al. 2012; Li et al. 2013).
Evidence suggests that those with an intellectual disability score lower on measures of quality of life than for those without (Keith & Bonham 2005; Sabaz et al. 2001). Consideration of the concept of quality of life (and the different domains proposed to comprise it) can be a means of driving positive change in people’s lives, such as measuring and subsequently enhancing human rights for those with intellectual disability (Verdugo et al. 2012). The notion of quality of life also continues to have particular importance when considering the support provided to people with intellectual disabilities. Brown et al. (2009) outlined how quality of life can be applied to a range of systems such as overarching social policy (Gómez et al. 2013), or as an outcome measure for service evaluation, down to more specific interventions for individuals such as personalised support strategies (Claes et al. 2012). This is highlighted by publication of recent national-level publications aimed at improving quality of life for people with intellectual disability, including ‘The Keys to Life’ (Scottish Government 2013).

**The measurement of quality of life for people with intellectual disabilities**

There are a range of conceptual models that can be applied to people with intellectual disabilities that attempt to describe quality of life and provide a framework for assessment (Buntinx & Schalock 2010; Cummins 2002). Although it has been suggested that quality of life should be considered unique to each individual (Brown et al. 2013), a number of authors have found certain domains that are considered the summation of quality of life, giving measurable indicators (Hagerty et al. 2001; Verdugo et al. 2005; Schalock 2004). Hence, the consensus appears to be that quality of life is considered multi-dimensional (Buntinx & Schalock 2010).

Schalock et al. (2008) argued in favour of eight domains with associated quality of life indicators, with three higher-order factors overlaid across these (see Table 1 below), with studies supporting this conception across a number of cultures (Schalock et al. 2005).
**Table 1** Quality of life factors, domains and indicators (adapted from Schalock *et al.* 2008)

<table>
<thead>
<tr>
<th>Quality of life factor</th>
<th>Quality of life domains</th>
<th>Examples of quality of life indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
<td>Personal development</td>
<td>Education status, personal skills, adaptive behaviour</td>
</tr>
<tr>
<td></td>
<td>Self-determination</td>
<td>Choices/decisions, autonomy, personal control, personal goals</td>
</tr>
<tr>
<td>Social participation</td>
<td>Interpersonal relations</td>
<td>Social networks, friendships, social activities, interactions, relationships</td>
</tr>
<tr>
<td></td>
<td>Social inclusion</td>
<td>Community integration/participation, community roles, supports</td>
</tr>
<tr>
<td></td>
<td>Rights</td>
<td>Human and legal</td>
</tr>
<tr>
<td>Well-being</td>
<td>Emotional well-being</td>
<td>Safety &amp; security, positive experiences, contentment, self-concept, lack of stress</td>
</tr>
<tr>
<td></td>
<td>Physical well-being</td>
<td>Health &amp; nutrition status, recreation, leisure</td>
</tr>
<tr>
<td></td>
<td>Material well-being</td>
<td>Financial status, employment status, housing status, possessions</td>
</tr>
</tbody>
</table>

*Subjective and objective measures of quality of life in intellectual disability*

Felce and Perry (1996) recommended three broad dimensions that offer a framework with which to assess quality of life that can be applied to people with intellectual disabilities: objective life conditions (the objective description of the individual), subjective well-being (personal satisfaction derived from their aforementioned life conditions) and personal values and aspirations (the relative importance to the individual of the first two dimensions with regards to a given aspect of life). This implies that it is not possible to improve life satisfaction through external interventions, since the perception of the individual is the defining factor. While subjective measures are ‘authentic’, they cannot be easily confirmed. Instead, only an improvement in objective indicators is possible, such as income, living situation or the
size of an individual’s social network (Hatton & Ager 2002). There is however
general, but not complete agreement (Hatton & Ager 2002) that evaluation of quality
of life should include both subjective and objective measures (Verdugo et al. 2005; Cummins 1997; Hensel et al. 2002).

Concerns have been raised about attempting to assess an abstract concept such as the
quality of life of people with intellectual disability subjectively (Hatton & Ager 2002). This opinion was countered with the argument that the tools used to measure quality of life are the issue, rather than the individuals not being able to report their own views (Cummins 2002).

The use of proxy reports in quality of life for people with intellectual disability

There are two ways of achieving measures of quality of life; either through direct correspondence with the individual concerned, or through someone close to them, a ‘proxy’. Proxies are generally used when it is believed that participants may provide unreliable self-reporting, such as children, people with dementing conditions or people with severe intellectual disabilities (Rapley 2003). Several researchers have voiced concerns about the use of proxies as valid or accurate reporters of the individual concerned (McVilly et al. 2000; Rapley et al. 1998). Despite this, proxy reporting of quality of life continues to be regularly reported in research with people with intellectual disabilities (Beadle-Brown et al. 2009; Kraemer et al. 2003). Hartley and MacLean (2006) outlined difficulties associated with self-report measures with people with intellectual disability, specifically that participants need to understand what is being asked, to generate an answer without influence and to communicate it. This can be problematic for people with intellectual disability who often have limited verbal abilities (Rapley et al. 1998) and can acquiesce when providing a response (Perry & Felce 2002).

Adaptations can be made to improve the accessibility of quality of life measures for the intellectual disability population. The changes can include use of plain language, symbols and audio/video (Walmsley 2001). To make the research even more
emancipatory, the data collection can be completed by those with an intellectual disability (e.g. Keith & Bonham 2005; Perry & Felce 2004). Measures have also been produced to focus on those that have more significant intellectual disabilities. Petry et al. (2009) reported on the development of a quality of life questionnaire for people with profound multiple disabilities, for whom some aspects of current quality of life measures may be less relevant, such as wealth or status. More recently Gómez et al. (2015) attempted to operationalise quality of life using Schalock et al. (2002) eight domain model for people with severe intellectual disabilities, generating 118 items.

Debate continues on how closely proxy and self-reports correlate with one another. Schwartz and Rabinovitz (2003) reported highly significant correlations between participants with intellectual disability and staff or parents acting as a proxy on a life satisfaction measure. Perry and Felce (2002) however reported a lack of significant correlation with scores on a satisfaction measure. Reiter and Bendov (1996) outlined potential reasons for discrepancies, such as the proxy being more aware of the difficulties faced by those with intellectual disability in society, and consequently including this in their scoring. However using self-report demonstrates higher face validity and emphasises for participants the importance of finding out their views directly, again being led by the normalisation principle.

**Use of the Quality of Life Questionnaire (QOL-Q; Schalock & Keith 1993)**

A number of assessments have been specifically developed for use with people with intellectual disability (for reviews see Cummins 1997; Townsend-White et al. 2012; Li et al. 2013). This apparent choice presents a difficulty when attempting to understand the influence of different aspects of life on the quality of life of people with intellectual disabilities. The potential is then for disparate findings to either be ascribed to actual influences on quality of life, or discrepancies between the measures used, or, indeed a combination of both. Hence, there is considered a need to evaluate such aspects of life using a consistent measure. The Quality of Life Questionnaire (QOL-Q; Schalock & Keith 1993) is one of the most widely used measures in research, with studies spanning a number of years. It contains 40 items with a three-point scale
across four sub-scales: satisfaction, competence/productivity, empowerment/independence and social belonging/community integration. Respondents can therefore receive a score of between 40 and 120. Guidelines are provided on how to use the measure by proxy, if required, with the use of two proxy scorers.

A large international standardization sample with people of all levels of intellectual disability was used to evaluate the psychometric properties of QOL-Q (Schalock & Keith 1993). This was further evidenced by a factor analysis using a British sample (Rapley & Lobley 1995) and an Australian sample (Kober & Eggleton 2002). It has also been translated into a number of different languages to be used cross-culturally such as Spanish, Chinese and Portuguese (Cabello et al. 2005; Wong et al. 2011; Albuquerque 2012). The QOL-Q has been used in two studies for examining convergent correlations, and was found to correlate well with the Choice Questionnaire (Stancliffe & Parmenter 1999) but not with the Multifaceted Lifestyle Satisfaction Scale (Harner & Heal 1993). The QOL-Q has been used in varied research areas as diverse as mental health (Horovitz et al. 2014) and the influence of residential placement (Chou et al. 2011).

**Systematic review aims**

Continuing attempts to measure quality of life of people with intellectual disability has the potential to drive improvement for this population. Only through the measurement of quality of life can services be developed to enhance the quality of life of people with intellectual disability to that of the rest of the population (Schalock et al. 2002). However, Horovitz et al. (2014) noted ‘little is known’ about the variables that may affect the quality of life of individuals with intellectual disability, and that understanding of these would be beneficial to ‘highlight need’. Self-report of quality of life is sought to understand what is important from the perspective of the participants themselves.
In order to reduce the potential for variability of outcomes to be influenced by assessment method, the focus will be on research using the Quality of Life Questionnaire (Schalock & Keith 1993) only. This widely-used single measure of quality of life was designed to be used with people with intellectual disability, with studies addressing a number of potential influences on quality of life, including social, cultural and environmental. Further, this review will also explore the methodological quality of these studies. Therefore this review aims to identify factors that influence quality of life in people with intellectual disability, arising from self-report data using only one measure, the QOL-Q.
Method

Search strategy

The following electronic databases were searched for relevant literature: PsycINFO, Embase, MEDLINE and CINAHL. Google Scholar was also searched for any literature not identified through these databases. The following search terms were used: ‘intellectual developmental disorder*’ OR ‘intellectual disability*’ OR ‘learning disab*’ OR ‘mental retard*’ OR ‘down* syndrome’ or ‘intellectual impairment*’ or ‘mental deficienc*’ AND ‘quality of life’ OR ‘Quality of Life Questionnaire’ OR ‘QOL-Q’.

Articles were restricted within the databases to the adult population (age 18 years and above), in English language, and published from the year 1990 (when the initial QOL-Q was published) to 20th January 2015.

In addition, reference lists of articles that met inclusion criteria were searched, and journals from which articles met the inclusion criteria were found were hand-searched from the year 2000 to March 2015 (Education and Training in Mental Retardation and Developmental Disabilities, Research on Social Work Practice, Journal of Intellectual and Developmental Disabilities, Journal of Intellectual Disability Research, American Journal on Mental Retardation, Health Technology Assessment, Journal of Vocational Rehabilitation, Journal of Applied Research in Intellectual Disabilities). Articles that cited included studies were also reviewed. Contact was made with researchers within the area requesting knowledge of any further published studies, or unpublished data within retrieved studies, but no further relevant studies or data were identified by this method.

Inclusion and exclusion criteria

Articles were required to use the original English-language version of the QOL-Q with people with intellectual disability. Participants were adults aged 18 years old and
above and a majority of the data was to be from self-report, rather than proxy measured. All articles were published in peer-reviewed journals and in English.

Articles were excluded if they used a translated or adapted version of the QOL-Q, assessed family quality of life only, investigated the psychometric properties of the QOL-Q only, were a review (either systematic or narrative), used only informant reports of quality of life or were from conference abstracts or book chapters.

**Data extraction and analysis**

Article titles were reviewed initially to determine whether they met criteria for inclusion. Abstracts were then reviewed of the remaining articles. The full-texts of remaining articles were then reviewed to determine whether they met inclusion criteria (see Figure 1).

**Figure 1** Flow chart outlining literature search process
**Critical appraisal of studies**

In order to develop a set of formal criteria to review the quality of studies a number of published checklists were considered. These included the COSMIN checklist (Mokkink et al. 2012), SIGN methodology checklists (SIGN 2012), the STROBE statement (von Elm et al. 2007) and the CONSORT checklist (Schulz et al. 2010). However, a majority of widely-used published guidelines and checklists focus on randomised controlled trials or other intervention-based studies. As a majority of the research papers in this review were cross-sectional these checklists, unamended, were considered not to be appropriate.

Therefore, using the above checklists and guidelines to guide the important criteria in addition to the quality items domains and items outlined by Deeks et al. (2003), a new quality criteria was created. For this 11 specific criteria were considered important for this research area. Weighted values were used for four items considered to be of particular importance (method of assessment of IQ and functional skills, use of proxy reporting of quality of life and reporting of results). The scoring criteria are presented in Table 2.

Six of the 13 included studies (46.2%) were second rated, independently, in order to reduce the risk of subjective bias (SIGN 2014). There was a high level of agreement between raters (Kappa = 0.729, p<0.001). No rating was more than one point apart. Disagreements between the raters (on fourteen items) were resolved through discussion and full agreement was reached.
<table>
<thead>
<tr>
<th>Factor</th>
<th>2 (Good)</th>
<th>1 (Moderate)</th>
<th>0 (Poor)</th>
</tr>
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<tr>
<td><strong>Research Question</strong></td>
<td>Clearly defined with clear aims</td>
<td>Partially defined with partially clear aims</td>
<td>No clear question and/or no clear aims</td>
</tr>
<tr>
<td><strong>Inclusion and Exclusion Criteria</strong></td>
<td>Inclusion and exclusion criteria are fully stated</td>
<td>Inclusion and exclusion criteria are partially stated</td>
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</tr>
<tr>
<td><strong>Sample Representation of Population</strong></td>
<td>Random sample of geographical cohort</td>
<td>Convenience or volunteer sample</td>
<td>Unclear or not stated</td>
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<tr>
<td><strong>Measurement of IQ</strong></td>
<td>Standardised measure of IQ used e.g. WAIS-IV - 4</td>
<td>IQ inferred from unspecified measure - 2</td>
<td>IQ not stated (inc. level of ID only)</td>
</tr>
<tr>
<td><strong>Measurement of Adaptive Functioning</strong></td>
<td>Standardised measure of adaptive functioning e.g. ABAS, Vineland- 4</td>
<td>Adaptive functioning measured but with non-standardised measure or not stated what measure used - 2</td>
<td>Adaptive functioning not stated</td>
</tr>
<tr>
<td><strong>Sample Demographics</strong></td>
<td>Age, gender, SES, IQ and adaptive functioning reported</td>
<td>Age, gender, SES and level of ID reported</td>
<td>Three or less variables reported</td>
</tr>
<tr>
<td><strong>Informant Report</strong></td>
<td>All ratings self-report - 4</td>
<td>Informant-report ratings identified and differentiated in analysis - 2</td>
<td>Informant-report used, but unclear how these items have been differentiated in analysis.</td>
</tr>
<tr>
<td><strong>Missing Data</strong></td>
<td>Frequency stated and how handled</td>
<td>Missing data acknowledged, but unclear how has been handled</td>
<td>Unclear or not stated</td>
</tr>
<tr>
<td><strong>Justification for Statistical Analysis</strong></td>
<td>Power calculation completed and justification for statistical analysis provided</td>
<td>Justification for statistical analysis provided only</td>
<td>Unclear or not stated</td>
</tr>
<tr>
<td><strong>Reporting of Results</strong></td>
<td>Influence of gender, age range, SES and level of ID accounted for in analysis - 4</td>
<td>Influence of some demographics accounted for in analysis - 2</td>
<td>Influence of demographics not accounted for in analysis</td>
</tr>
<tr>
<td>Study Design</td>
<td>5</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>--------------</td>
<td>-----</td>
<td>---</td>
<td>-----</td>
</tr>
<tr>
<td>Longitudinal, within-subjects</td>
<td>Group comparison or regression analysis, matched for or included gender, age, SES and level of ID</td>
<td>Group comparison or regression analysis matched for or included three of four</td>
<td>Group comparison or regression analysis matched for or included two of four</td>
</tr>
</tbody>
</table>

Key: ID = intellectual disability, SES = socio-economic status, ABAS = Adaptive Behavior Assessment System, WAIS = Wechsler Adult Intelligence Scale
Table 3 Quality assessment of reviewed studies (weighted criteria indicated by *, where 4 = good, 2 = moderate, 0 = poor, otherwise 2 = good, 1 = moderate. For ‘study design’ scoring see specific scoring criteria, all Table 2)

<table>
<thead>
<tr>
<th>Study</th>
<th>Research question</th>
<th>Inclusion &amp; exclusion criteria</th>
<th>Sample rep. of population</th>
<th>Measure. of IQ*</th>
<th>Measure. of adaptive functioning*</th>
<th>Sample demographics</th>
<th>Informant report*</th>
<th>Missing data</th>
<th>Statistical analysis</th>
<th>Reporting of results*</th>
<th>Study design</th>
<th>Total (max. = 33)</th>
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<td>Schalock &amp; Genung, 1993</td>
<td>2</td>
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<td>0</td>
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<tr>
<td>Rapley &amp; Beyer, 1996</td>
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<td>0</td>
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<tr>
<td>Rapley &amp; Hopgood, 1997</td>
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<td>1</td>
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<td>0</td>
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<td>15</td>
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<td>1</td>
<td>0</td>
<td>4</td>
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<td>0</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
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<td>Study aim</td>
<td>Design of study &amp; statistical analysis used</td>
<td>% of measure by self-report</td>
<td>Key findings</td>
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| Schalock & Genung, 1993 (USA) | 85 participated but data analysed on 65 participants i.e. the two largest groups | Mean age 39.5 yrs (range = 33 – 74 yrs, SD = 10.4) 50.58% | To determine participants' current living and employment status, evaluate each person's QOL through interview and objective measure, and analyse the group's longer-term movement patterns | Cross-sectional Chi-square | 94.12% of original 85 participants | • Significant differences between group in intellectual disability service and non-service groups on Competency and Empowerment with the non-service group experiencing higher levels on both  
• No difference on other subscales |
| Rapley & Beyer, 1996 (UK)   | 14 participated but data collected for 12 participants for QOL-Q | Range only quoted = 23 – 82 yrs 14.29% | To complete a small-scale study assessing the potential value of direct measurement of QOL for service evaluation in addition to other objective measures. | Cross-sectional Correlation using the Spearman Rank Order Correlation coefficient | Not stated | • High Total score strongly inversely related to rates of 'no social activity'  
• Frequency of church going significantly correlated with Satisfaction and Competency.  
• Empowerment has a strong significant relationship with frequency of meeting friends.  
• High Social Belonging associated with high frequency of social activities and marginally with higher rates of 'clear social act' |
| Rapley & Hopgood, 1997 (Australia) | 35 participants | Mean age 32.97 yrs (range = 21 – 52 yrs, SD = 8.66) 38.24% | To analyse relationships between measures of key service outcomes, examine the level of variability in outcomes within community-based services, and assess service-users' subjective perceptions of community connectedness and inclusion. | Cross-sectional Completed univariate ANOVA and post-hoc comparisons (Bonferroni tests). Kruskall-Wallis or Wilcoxon test were used where there were violation of assumptions using Levene's Test | Not clear | • High correlation between measure of opportunity for domestic skills (IPDL) and Total Score, and Empowerment and Satisfaction.  
• These sub-scales were also significantly correlated with adaptive functioning measure (ABS Part 1)  
• Competence strongly correlated with IPDL and weakly correlated with measure of community involvement (ICI)  
• Sense of community (NSCI) inversely related to scores on Competence  
• Significant differences found by residence for Competence but not other subscales.  
• Total Score and Competence significantly higher in urban than rural locations. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Age range and gender (% female)</th>
<th>Study aim</th>
<th>Design of study &amp; statistical analysis used</th>
<th>% of measure by self-report</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| Rapley & Beyer, 1998  | 12 participants      | Range only given = 25 - 84 yrs  | Follow-up study from Rapley & Beyer (1996)                                | Longitudinal Repeated measures ANCOVA and one-tailed Wilcoxon matched pairs signed-rank tests               | 66.67%                      | • QOL-Q showed a significant difference between mean scores between T1 (baseline) and T2 (follow-up at 2 years) when adaptive behaviour levels were controlled for.  
  • Significant changes in Competency, Empowerment and Satisfaction were associated with increases in purposeful domestic activity (from ABS Part 1) and community-based activity (SNQ) |
| (UK)                  |                      | 16.67%                          |                                                                           |                                                                                                              |                             |                                                                                                                                             |
| Wehmeyer & Schwartz,  | 50 participants      | Mean age 36.22 (range = 20 – 69 yrs, SD = 10.92)  | To explore the contribution of self-determination to QOL and to empirically examine the relationships between self-determination and QOL | Cross-sectional Discriminant function analysis, ANOVA and one-tailed Pearson product-moment procedure         | 100%                        | • Significant difference between self-determination scores found between high quality of life and low quality of life groups.  
  • Self-determination scores significantly correlated with Total score, but choice availability (Life Choices Survey) did not significantly correlate with Total score. |
| 1998 (USA)            |                      | 52.00%                          |                                                                           |                                                                                                              |                             |                                                                                                                                             |
| Eggleton et al. 1999, | 56 invited and 50    | Mean age for in open employment group 27.8 yrs (SD = 6.5) and mean age for not in open employment 27.7 yrs (SD = 6.1) | To determine the impact of employment on the QOL for people with ID | Cross-sectional Wilcoxon-matched Pairs for matched-pairs samples and independent samples tested using Mann-Whitney test. Also assessed internal reliability of QOLQ using Cronbach alpha coefficient | 100%                        | • Those in employment report a significantly higher Total score, Satisfaction, Competence and Empowerment than those who were unemployed, attended a sheltered workshop or remained at home.  
  • There was a significant difference between those entered employment directly from home than those unemployed who remained at home for Total score, Satisfaction, Competence and Empowerment.  
  • Those who entered employment from a sheltered workshop experienced higher Total score, Competence and Empowerment than those who were unemployed and remained at a sheltered workshop.  
  • Those who were unemployed and attended a sheltered workshop reported significantly higher Total score and Competence than those who were unemployed and remained at home. |
<p>| (Australia)           | participated          | 36.00%                          |                                                                           |                                                                                                              |                             |                                                                                                                                             |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Age range and gender (% female)</th>
<th>Study aim</th>
<th>Design of study &amp; statistical analysis used</th>
<th>% of measure by self-report</th>
<th>Key findings</th>
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</table>
| Stancliffe & Keane, 2000 (Australia) | 97 assessed but 54 participants matched | Mean age for in semi-independent living 38.76 yrs (range 20.9 – 62.9 yrs, SD = 9.99) and for in group home 44.9 yrs (range 21.1 - 76.0 yrs, SD = 16.15) 42.59% | To contrast outcomes and costs for matched residents living in group homes or semi-independently | Cross-sectional Matched pairs t-tests and re-analysed Wilcoxon Test | 100% | • Significant higher Empowerment score for semi-independent living compared to group home  
• No difference between groups on other subscales |
| Cooper & Picton, 2000 (Australia) | 50 participants participated at initial data collection and 45 participants at follow-up | Mean age for in community residential unit 52.0 yrs (SD = 15.3) and in training centre 55.2 yrs (SD = 12.0) 47.50% | To examine the long-term effects (three years) of relocation on a sample of adults with ID who moved from a state residential institution to either small group homes (community residential units) or units within other institutions (training centres) | Longitudinal Repeated measures ANOVAs | Some questionnaires were completed by proxy | • A significant main effect of time was found for Total score i.e. an increase in quality of life for both groups |
| Lunsky & Benson, 2001 (USA & Canada) | 84 participants | Mean age = 38 yrs (range 20 – 65 yrs) 51.19% | To examine whether social support and social strain at T1 were differentially associated with QOL, depression and somatic symptoms at T2 (6 months) | Longitudinal Correlation matrix using Cronbach's alpha and hierarchical multiple regression analysis | 100% | • Social support, loneliness, depressive symptoms and somatic complaints were negatively correlated with Total score.  
• Social support accounted for significant variance in Total score above and beyond demographics. |
Table 4 Description of reviewed studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Age range and gender (% female)</th>
<th>Study aim</th>
<th>Design of study &amp; statistical analysis used</th>
<th>% of measure by self-report</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| Kober & Eggleton, 2005 (Australia) | 707 invited and 117 participated | Mean age 31 yrs 38.00% | To investigate the effect of different types of employment on QOL for people with ID | Cross-sectional Mann-Whitney U-Test after tested for normality and internal reliability using Cronbach's alpha | Not stated. | • Participants employed in open employment demonstrated statistically significantly higher Total score and Empowerment and Social Belonging.  
  • Participants with high work ability demonstrated statistically significant higher Total, Empowerment and Social Belonging than for those in sheltered employment. |
| Keith & Bonham, 2005 (USA)     | Not stated   | Not stated                       | To demonstrate the use of QOL data to influence policies and practices at the level of organisations and systems | Longitudinal Independent t-tests | Some questionnaires were completed by proxy | • Average score state-wide on all sub-scales were significantly higher for those without ID compared to those with ID. |
| Miller & Chan, 2008 (USA)     | 56 participants | Mean age 43.3 yrs (SD = 14.1) 44.60% | To explore the contributions of life skills (instrumental, interpersonal and leisure) and higher order predictors of social support, self-determination and productivity as predictors variables of life satisfaction in people with ID | Cross-sectional Correlation and hierarchical regression analysis | 100% | • Satisfaction correlated with interpersonal skills, social skills and Empowerment. Empowerment and Competence also correlated with instrumental skills.  
  • Full model accounted for 44% of variance.  
  • Basic skills variables contributed significantly to Satisfaction, with interpersonal skills predicting Satisfaction.  
  • Higher order predictors also contributed significantly to the variance in Satisfaction and are significantly related to Satisfaction when controlling for basic skills. |
| Tyrer et al., 2009 (UK & Australia) | 180 registered but 86 participated | Mean age 40.1 yrs 48.40% | To compare the effects of treatment of aggressive challenging behaviour in adults with ID using two medications and placebo on frequency of episodes of aggression | Randomised-controlled trial Mann-Whitney tests or Kruskal-Wallis tests, the Fisher Exact test and regression analysis | 100% | • No significant differences between groups |

Key: QOL = quality of life, ID = intellectual disability
Results

Characteristics of included studies

A total of 13 studies met criteria and were included in this review (see Table 4). Study sample sizes ranged from $n = 12$ to $n = 117$. Age range varied across the studies, between 21 years and 82 years, and the percentage of female participants ranged from 14.3% to 52.0%. A majority of the studies were cross-sectional ($n = 9$), four were longitudinal in design, with one of these being a randomised controlled trial.

The 13 included papers examined a number of areas that may contribute to quality of life for people with intellectual disabilities. Four studies investigated the impact of residence on quality of life (Rapley & Hopgood 1997; Stancliffe & Keane 2000; Cooper & Picton 2000; Wehmeyer & Schwartz 1998), two the impact of receiving service support (Schalock & Genung 1993; Keith & Bonham 2005), two investigated the contribution of employment (Eggleton et al. 1999; Kober & Eggleton 2005), two a range of perceived social factors that could influence quality of life including social support and frequency of stressful social interactions (Lunsky & Benson 2001; Miller & Chan 2008), two investigated the impact of activity participation (Rapley & Beyer 1996; Rapley & Beyer 1998) and one looked at the impact of medication on challenging behaviour, with quality of life being one outcome measure (Tyrer et al. 2009).

Two studies transformed the data from the original format laid out in the questionnaire (Schalock & Keith 1993): Cooper and Picton (2000) produced a single mean from all 40 items of between one and three, whilst Keith and Bonham (2005) converted the three-point scale of the QOL-Q to a ten-point scale. No evaluation of the psychometric properties of the amended questionnaire was reported in either study. All other studies utilised the QOL-Q in its original format. A variety of statistical analysis techniques were used across studies. Details of these are given in Table 4. Three studies (Cooper & Picton 2000; Lunsky & Benson 2001; Tyrer et al. 2009) reported only total scores for the QOL-Q, and one study (Miller & Chan 2008) used three of the subscales, whilst the remainder described outcomes for each subscale. Although only self-report data was sought, studies were included if they reported they used some proxy measures, or
were not clear in whether all data was self-report. This inclusive approach was taken due to the limited literature within this area.

**Overview of methodological quality of studies**

With regard to the quality of studies, none were regarded as reaching a high quality threshold (see Table 3). Tyrer *et al.* (2009) was rated as the highest quality study in the review (18/33 on quality assessment). Ten further studies scored between 11 and 17, with the remaining two studies scoring ten or less. It should also be noted that the reporting of demographic information was poor across all studies, with no study rated above zero on this criteria. This highlights the issue of generalisability of study outcomes, since the samples used were not well-defined.

The 13 studies will be reviewed according to the six main factors that they addressed, i.e. residential setting, service provision, employment, activity participation, social factors and other factors. However, some studies assessed a number of additional variables, which will also be discussed.

**Residential setting**

Four studies investigated the influence of residential setting on quality of life (Rapley & Hopgood 1997; Stancliffe & Keane 2000, Cooper & Picton 2000; Wehmeyer & Schwartz 1998). Cooper and Picton (2000) scored the highest of the four on the quality rating (see Table 3) despite some proxy reporting of quality of life. They investigated the effect of moving from large institutional care to one of two types of community-based residences (small group homes or units within other institutions, although these are poorly described). They reported that relocation led to a significant improvement in quality of life, with quality of life improvement a main effect of moving from a large institution, and differences not seen between either independent community living, or a smaller residential setting. A randomised sample from one large institution was selected and a breakdown of level of intellectual disability for the two groups was provided, but assessment of the level of intellectual disability was not described.
Stancliffe and Keane (2000) reported a significant difference on the Empowerment subscale only for those in semi-independent living (classified as having part-time staff) compared to those in a group home (classified as having full-time staff). They made attempts to control confounding variables by matching the two groups on variables including gender and age. They also used only self-report data.

Rapley and Hopgood (1997) investigated how rural and urban locations impact on quality of life. They found residing in an urban location was associated with a higher score on the Competence subscale and associated Total score. They used only a small convenience sample (n = 34) from five residences and were unclear whether all questionnaires completed were self-reported. They did however investigate the possible confounding effect of adaptive functioning on quality of life, where a weak correlation was found, although their measure of adaptive functioning was limited and was not used as a covariate in final analyses.

Wehmeyer and Schwartz (1998) investigated the impact of self-determination on quality of life in a specific residential setting of four-to-six person group homes using only self-reported data. They used discriminant analysis and found that higher quality of life was associated with participants being more self-determined. They provided descriptive statistics on the subscales but only used the Total score in the analysis. Participants were recruited from recommended group homes in one US state and IQ scores for participants were provided, but it was not explained how this was obtained. Wehmeyer and Schwartz (1998) divided their sample into high or low quality of life dependent on whether they were above or below the 50th percentile of their sample. They found no differences between the two groups based on IQ or age, but this did not appear to be as a result of specifically matching the groups. Consequently although Wehmeyer and Schwartz (1998) assessed more variables that other studies, there are still possible confounding variables and therefore the study is weak in its design.
Two studies assessed how quality of life was influenced by receiving a service specifically for people with intellectual disabilities (Schalock & Genung 1993; Keith & Bonham 2005), although Schalock and Genung (1993) did not provide sufficient information on what type of service they were evaluating. The research was particularly weak in this area (see Table 3). Schalock and Genung (1993) followed up participants 15 years after leaving a community-based training programme, although again they were not specific in the type of programme they were describing. They stated the use of some proxy reporting of quality of life. They reported that those no longer in receipt of services rated themselves significantly higher on the Competence and Empowerment subscales, compared to those who continued to receive services. However, this is likely to be a reflection of participants developing their skills, and therefore no longer requiring a service, rather than being in receipt of a service adversely affecting quality of life per se. Those no longer receiving a service also scored more highly on controlling their environment, arranging help from others and socializing and some aspects of adaptive functioning, based on other measures. Schalock and Genung (1993) was the only study to explicitly state the use of a standardized measure of IQ and also used a not widely known adaptive functioning measure but scored poorly on a majority of the quality criteria.

Despite scoring poorly in terms of assessed quality rating, Keith and Bonham (2005) did utilise a longitudinal design. They collected data from every adult in one US state who was in receipt of intellectual disability support services over three years. The results showed inconsistent changes across the four subscales, with a consistent increase only in Satisfaction but a decrease in Competence. However, the absence of control for potentially confounding variables makes it difficult to determine what factors contributed to these changes. Additionally, the Empowerment subscale scores were broken down depending on type of service provision; ‘assisted living’, ‘supported living’ or ‘in-home living’.
It should be noted that Keith and Bonham (2005) was the only study to include data from both people with and without intellectual disability, although the comparison group was much smaller. They found a significant difference between the two groups on all domains, with people without intellectual disability scoring more highly on all subscales. No statistical analysis was completed to understand whether the increase in quality of life for people with intellectual disability was statistically significant, and the authors also stated caution in interpretation between people with and without intellectual disability due to small sample size for the comparison group. The authors amended the QOL-Q response scale to a ten-item scale, making comparison with other studies more difficult. Overall it is difficult to conclude from the results of the study whether the provision of services to people with intellectual disability provides a consistent contribution to their quality of life.

**Employment**

Two studies investigated the influence of employment on quality of life (Eggleton *et al.* 1999; Kober & Eggleton 2005), with the former scoring marginally higher in terms of quality rating. Both studies used only self-reporting responses. Eggleton *et al.* (1999) reported those in employment demonstrated a higher quality of life in terms of Satisfaction, Competence, Empowerment and Total score compared to those who were unemployed. There were also positive findings for those who attended a sheltered workshop compared to those who were unemployed and remained at home. Eggleton *et al.* (1999) provided matched groups in terms of age, gender, educational background, job description and socio-economic status (SES). However they did not assess either IQ or adaptive functioning and so the method of determining intellectual disability is not clear. Eggleton *et al.* (1999) recruited from one employment agency leading to questionable representativeness of the sample, although a random sample was selected from within this.

Kober and Eggleton (2005) again demonstrated that those in employment reported a higher quality of life, finding that those employed scored more highly on the Empowerment and Social Belonging subscales and Total score compared to those in
sheltered employment. In particular those with ‘high work ability’ and in open employment reported a significantly higher quality of life compared to those with ‘high work ability’ but in sheltered employment. They reported no statistical differences between groups in terms of gender, but as a result of analysis rather than matching the groups. There was a significant difference of the groups in terms of age.

**Activity participation**

Three studies investigated how activity participation contributed to quality of life although none stated clearly if only self-reporting of data was used. Rapley and Beyer (1996) scored the lowest of the three in terms of quality (see Table 3). They investigated the effect of a range of activities on quality of life. They found a high Total score was inversely correlated with rates of no social activity and a significant correlation between frequency of attending church and Satisfaction and Competence subscales. High scores on Social Belonging correlated with higher frequencies of social activities over the past year and marginally with social interaction. Empowerment demonstrated a significant relationship with frequency of meeting friends. It was therefore suggested that observed and reported social activity contributed to a higher reported quality of life. They assessed adaptive functioning using part of a standardised measure and also assessed whether this was a confounder, although no significant correlations were found. This study, and the follow-up, used the fewest number of participants (n = 12).

Rapley and Beyer (1998) reported a two-year follow-up study of participants in the community following on from Rapley and Beyer (1996). Rapley and Beyer (1998) scored the highest of the three studies in terms of methodological quality, and reported a significant increase over time in terms of Satisfaction, Competence and Empowerment but not the Social Belonging subscale. They also assessed domestic activity, such as personal care, simple chores and engaging with staff and community engagement, such as the number of friends participants had and the type of activity they participated in. They noted small but non-significant findings in level of activity engagement and attributed the change in quality of life to them. However, participant
numbers were limited (n = 12 from one housing network) and again used one section of an adaptive functioning measure, which they used to assess confounding effects on quality of life, and participation in domestic and community activities.

Rapley and Hopgood (1997) found significant correlation with opportunities to participate in domestic activities and involvement in community activities and quality of life, particularly with Competence subscale but also with Empowerment and Satisfaction. With regards to local community involvement they also found a strong correlation with Competence and Total score.

**Social factors**

Two studies utilised regression analysis to investigate the effect of social factors on quality of life (Lunsky & Benson 2001; Miller & Chan 2008), with the former scoring marginally higher in terms of quality rating. Both also used only self-reporting of quality of life. Lunsky and Benson (2001) explored how perceived social support, loneliness at home and social strain were related to Total quality of life. Controlling for age and gender, they found perceived social support contributed significantly to variance in quality of life but social strain (frequency of stressful social situations) did not. In terms of limitations, there was a degree of selection of participants (participants were nominated by staff) and only a measure of vocabulary was taken (with the Peabody Picture Vocabulary Test), rather than any substantive measure of IQ or adaptive functioning. However, age and gender were considered as a potential confounding variable within their regression analysis.

Miller and Chan (2008) investigated how adaptive functioning and social support impacted on quality of life, although this was represented by the Satisfaction subscale. They found interpersonal skills, part of the adaptive functioning predictors set, contributed significantly to the variance. The ‘higher order’ predictor of perceived social support also contributed significantly to the variance beyond this. Additionally Empowerment and Competence were part of the ‘higher order predictors’. However it was only one of two studies which completed a power calculation.
Other factors – influence of medication

Although outwith a general social intervention, one study was retrieved that incorporated the QOL-Q within a trial of two medications and a placebo control on challenging behaviour (Tyrer et al. 2009). The study was included within this review as it met inclusion criteria, and the use of a quality of life tool within a study of medication to reduce challenging behaviour was felt to be of value. The study was rated as the highest of the 13 studies in terms of methodological quality (see Table 3). The study included people with all levels of intellectual disability. They found no differences between the three groups either at baseline or at four weeks into the study on Total score. The study used a geographical sample, although participants were recruited from specific treatment sites. They included a comprehensive overview of inclusion and exclusion criteria, used only self-report data and a power calculation. However they reported only level of intellectual disability with no assessment of IQ or adaptive functioning.

Association of subscales of QOL-Q with specific factors

It should be noted that the different factors described above improved overall quality of life, a significant positive effect was associated with particular subscales of the QOL-Q for some of these factors (see Table 5).
Table 5  Factors associated with having a positive effect on each of the four subscales of the QOL-Q

<table>
<thead>
<tr>
<th>Subscale of QOL-Q</th>
<th>Positive Influencing Factors</th>
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<tr>
<td>Empowerment</td>
<td>Semi-independent living&lt;br&gt;No longer receiving support from a specific intellectual disability service&lt;br&gt;Employment&lt;br&gt;Domestic activity and community engagement</td>
</tr>
<tr>
<td>Competence</td>
<td>Urban living&lt;br&gt;No longer receiving support from a specific intellectual disability service&lt;br&gt;Employment (either in open employment or sheltered workshop)&lt;br&gt;Domestic activity and community engagement such as church attendance</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Employment&lt;br&gt;Domestic activity and community engagement including church attendance</td>
</tr>
<tr>
<td>Social Belonging</td>
<td>Employment&lt;br&gt;Social activity</td>
</tr>
</tbody>
</table>
Discussion

This review has considered the influence of several factors (residential setting, service provision, employment, social factors, activity participation, use of medication for challenging behaviour and self-determination) on quality of life for people with intellectual disability. There are a multitude of measures of quality of life; therefore, to avoid the influence of different measurement tools on outcomes, only studies that utilised the Quality of Life Questionnaire (QOL-Q) were chosen for review.

Summary of study outcomes

From the articles reviewed, evidence suggests that higher overall quality of life is associated with aspects of a person’s accommodation: living in semi-independent living compared to a group home (Stancliffe & Keane 2000), living in an urban rather than a rural environment (Rapley & Hopgood 1997) and living in the community, as opposed to institutional care (Cooper & Picton 2000). Increased self-determination was also associated with higher quality of life (Wehmeyer & Schwartz 1998).

In terms of service provision, quality of life was higher for those who no longer received a service (Schalock & Genung 1993), although it is not clear what service is being provided. This implies that the benefit the positive impact on quality of life is through being more independent and therefore not requiring support through a paid service.

Employment had a positive impact on quality of life (Kober & Eggleton 2005), with involvement in a sheltered workshop also a positive influence, in comparison to unemployment (Eggleton et al. 1999). Therefore being employed contributed to higher levels of quality of life, with working in a sheltered workshop coming second to contributing to quality of life, with unemployment contributing the least to improving quality of life.
Greater levels of domestic activity and community involvement were positively associated with higher quality of life (Rapley & Hopgood 1997; Rapley & Beyer 1998), as was social activity (Rapley & Beyer 1996). Provision of perceived social support and better interpersonal skills predicted higher quality of life (Lunsky & Benson 2001; Miller & Chan 2008). Lastly whether taking active medication or a placebo did not have any impact on quality of life for people with intellectual disability and challenging behaviour (Tyrer et al. 2009).

It is interesting to note that ‘The Keys to Life’ (Scottish Government 2013) makes a number of recommendations in areas described in this systematic review. This document outlines the ten year strategy of the Scottish Government for people with intellectual disability, specifically with a focus on improving quality of life. In the most part it has an emphasis on health, particularly around health inequality with the intellectual disability population. However it is acknowledged how this can be linked to other factors that impact on quality of life such as lack of employment and social isolation. The strategy is comprehensive and covers areas described in this systematic review, for example the importance of self-determination, encouraging independent living and the importance of relationships to people with intellectual disability.

Although the scope of the review was limited, intentionally, it was evident that there is a lack of high-quality, methodologically sound research in this area. The majority of the studies reviewed were cross-sectional, which has implications in terms of the confidence it is possible to place in conclusions that have been drawn. In addition, the use of convenience samples in the majority of studies further limits the generalisability of outcomes. A further limitation across all studies is the absence of either a priori or post hoc power calculations, with many studies using relatively low sample sizes. A relatively broad range of factors that could influence quality of life have been investigated using the QOL-Q, however each factor is supported by a small number of studies. Therefore caution should be used when drawing conclusions from this literature base.
Another particular issue is the limited evidence of potentially confounding variables (such as level of intellectual and functional abilities) being measured robustly and included within analysis. Without the consideration of such variables, there is a risk that findings will be influenced by these, rather than the factors that are identified by authors, such as living circumstances, as being the main variables under consideration. This is perhaps a reflection of the complexity of quality of life, particularly for people with intellectual disabilities, where there is the potential for multiple influences.

**Summary of study quality**

This review specifically included only those studies that used the QOL-Q, which led to inclusion of studies of varying quality. The mean total quality rating score of all studies was 13.23 out of a possible maximum 33, suggesting that overall the studies were of poor methodological quality. The study of the highest quality rating was Tyrer *et al.* (2009) which was the only RCT. Only three studies out of the 13 reviewed studies were longitudinal in design and therefore this limits the confidence that can be placed on the overall results.

It is of note that all of the studies reviewed scored zero on the criteria regarding provision of sample demographic information. This introduces risk of bias and limits the overall quality of the studies in terms of generalisability. This also had implications in terms of the reporting and interpreting results of the studies.

In general, studies were limited in their assessment and consideration of level of intellectual disability within statistical analysis, with only one study reported using a standardised measure of IQ (Schalock & Genung 1993). Although five studies used a standardised measure of adaptive functioning, this was often limited in scope such as using one part or not controlling for them as a confounding variable (See Table 2). Use of self-report of quality of life was sought yet only seven of the studies reviewed explicitly reported using only self-report, whilst the remaining six studies were either unclear or used proxy-report but did not differentiate this in the analysis.
Limitations of using the QOL-Q

The QOL-Q has been used widely in research across different settings and has been specifically validated for using with people with all level of intellectual disability. It was designed to be used as a self-report measure and covers 40 different quality of life indicators. Consistency reliability, test-retest reliability, inter-rater reliability are all reported for this measure, whilst there is also evidence for its factor structure and content validity. Research has previously demonstrated the benefits of using a three-point likert scale, as used in the QOL-Q (Fang et al. 2011).

It is acknowledged that, in their systematic reviews of quality of life measures for people with intellectual disabilities, Li et al. (2013) and Townsend-White et al. (2012) concluded that the QOL-Q performed adequately in terms of psychometric properties relative to other measures. It covers only four of the eight widely-agreed domains of quality of life. Out of the commonly agreed eight quality of life measures the QOL-Q does not explicitly assess interpersonal relations, material well-being, physical well-being and rights. However, the measure was designed on the assumption that quality of life cannot be determined from objective measures and the omitted domains are potentially more objective in nature. To be used as a self-report measure, participants need to be verbally able, which can potentially exclude some people with intellectual disabilities, although this is the case for all self-report measures.

Limitations of this systematic review

This review focused on a single measure of quality of life and excluded translations of the measure from its original, English version due to possible culture-specific variations in findings (e.g. Verdugo et al. 2005). Excluding translated version allow for researchers to ensure that the same concept is reliably being understood. However with this there is the risk of language bias, and not determining whether the factors that influence quality of life are universal. Verdugo et al. (2005) indicate there are processes to follow to ensure that translated versions are close to the original version as possible. Research has been completed using translated versions of the QOL-Q
It is also a limitation of this review that ‘grey’ literature was not included. Grey literature is of lower quality due to not being derived from peer-reviewed academic literature. It is noted that some grey literature would not have sufficient information required for evaluation in this review. However some grey literature, such as doctoral theses, are assessed by academic staff and consequently are subject to some level of scrutiny in terms of study design outcomes. Therefore future research should consider the use of grey literature.

Although it was initially hoped that it would be possible to consider only self-reported quality of life, this was not possible due to the lack of clarity in published research regarding when quality of life was reported by proxy or by individuals themselves. It is recommended that study authors make this explicit, and consider discrete analyses of self-report and proxy data.

The absence of well-controlled research was notable, both in terms of the confounding variable that are accounted for, and also with respect to study design. This leads to difficulties in drawing definitive conclusions in this area. However the quality criteria used in this review may have complicated the assessment of study quality. Weighting was given to items related to the research question i.e. those that would contribute to understanding how intellectual disability was assessed in the study, whether informant or self-reporting of quality of life was used and the reporting of results of the study. This was to determine whether the results were of acceptable quality. Although weighting these certain items was useful for this review, this practice can skew how the studies perform in terms of comparing study quality. These items are not related to determining risk of bias in study design, which is of significant importance. Including a total score for each study again allows readers to understand how each study compares in terms of items pertinent to the research question. However the weighting of certain items skews the total score, with some studies scoring highly according to the quality criteria yet in terms of study design and risk of bias, they are
of poor quality. It is important to take these points into consideration when viewing the quality assessment of reviewed studies (Table 3).

Clinical implications and future directions of research

‘The Keys to Life’ (Scottish Government 2013) outlines the importance of improving quality of life for people with intellectual disability. It is generally accepted that quality of life is lower for people with, than without, intellectual disability (Keith & Bonham 2005; Sabaz et al. 2001). This review highlights changes that can be made to the lives of people with intellectual disability that will improve quality of life, but there is still a need for substantive research to clarify potential influences of individual factors such as level of disability.

Although there are a selection of quality of life measures that can be used with people with intellectual disability, there is criticism that person-specific indicators of quality of life, which would indicate what is important to that individual, and patient-generated indicators for people with or without intellectual disability are still not available at this time and therefore evaluation of policies continue to be assessed using these more common indicators (Brown et al. 2013). This situation could be improved through the development of individualised measures of quality of life, generated by the person who is being assessed (examples of patient-generated quality of life indexes include Ruta et al. (1999) and Kyle et al. (2013).

The research, using a consistent measure of quality of life, reviewed in this systematic review suggests that living in the community, in semi-independent living and in an urban location can have a positive impact on quality of life. It also suggested that no longer receiving a service is associated with a higher quality of life, most likely through correlation with improvement of circumstances and therefore no longer needing that service. Employment is associated with a higher quality of life. Domestic and community activity can contribute to higher quality of life, as can social support and social skills. Lastly self-determination is also associated with higher quality of life for people with intellectual disabilities. Yet, at present, the quality of research is variable, with the risk of bias in these findings. Further consideration of confounding
factors such as intellectual and adaptive abilities, and studies with controlled, longitudinal designs would help to understand better what contributes to better quality of life for people with intellectual disability.
References


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Subjective judgements of quality of life: A comparison study between people with intellectual disability and those without disability. *Journal of Intellectual Disability Research* 46 (2), 95-107


The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research* 49 (Part 10), 799-805


The effect of different types of employment on quality of life. *Journal of Intellectual Disability Research* 49 (Part 10), 756-760

Quality of life for young adults with mental retardation during transition. *Mental Retardation* 41 (4), 250-262


Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: A systematic review. *Journal of Developmental and Physical Disabilities* 25, 253-270

Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research* 45 (Part 2), 106-114


Predictors of life satisfaction in individuals with intellectual disabilities. *Journal of Intellectual Disability Research* 52 (12), 1039-1047

The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of Life Research* 19 (4), 539-549


Abstract

Background: Adults with intellectual disability are living longer. The experience of ageing for the intellectual disability population may be different from that of the non-intellectual disability population. This study identifies and seeks to address gaps in our understanding of the lived experience of ageing for adults with intellectual disability.

Methods: Semi-structured interviews were completed with ten participants (age range 60 – 74 years, five female) with intellectual disability living in the community. Nine transcriptions were analysed using interpretative phenomenological analysis.

Results: Three major themes emerged from the data: ‘Not changed by ageing’, ‘Thinking about the ageing process’ and ‘What happens when people get older’.

Discussion: Participants struggled to talk about ageing which in part appeared to reflect that there had been little opportunity to do so before the research. They did not describe themselves as feeling older and emphasised that they were still involved in the same activities as they always had been. When ageing was referred to it was with respect to others although this changed over the course of the interviews. Discussion of ageing is encouraged in the future.

Word count: 10,260 (excluding figures and tables)
Introduction

People with intellectual disabilities are living longer, with disparities in life expectancy between those with and without intellectual disabilities gradually reducing (e.g. Hilgenkamp et al. 2011). At present, there are estimated to be around 26,000 adults in Scotland with an intellectual disability, with over 10% of this population being over the age of 65 years (Scottish Government 2013; Scottish Consortium for Learning Disability 2013). It is expected that those over the age of 60 with intellectual disability will increase threefold over the next two decades (Janicki 2010). Research has suggested that the desires and needs of people both with and without intellectual disability are similar (e.g. Buys et al. 2008). However the context in which many people with intellectual disabilities live can be different from the rest of the population. People with an intellectual disability have, in general, poorer physical health, smaller social networks and a greater prevalence of mental health difficulties (Lehmann et al. 2013).

As the population of older people with intellectual disabilities has grown, interest in understanding ageing from their perspective has also increased (e.g. Burke et al. 2014). An early paper by Erickson et al. (1989) studied participants with an intellectual disability and their perceptions of ageing. The study demonstrated concerns about anticipated changes (physical health, work- and social-related changes, depression and death), rather than the participant’s experience of getting older. Other researchers have looked at different aspects of the transition into older age, such as experience of service use (Bigby & Knox 2009), perspectives about the future (Hole et al. 2013), or gender-related issues, specifically older women with intellectual disability (Dew et al. 2006; David et al. 2015; Strnadová et al. 2015).

Theories of ageing

We are ageing throughout our lives, however the latter period of our lives has been the subject of a number of specific theories. In particular there are a number of theories
about how to successfully age, as opposed to ‘normal ageing’, in addition to what successful ageing means to both researchers and the general population.

Rowe and Kahn (1987) discussed ‘usual’ and ‘successful’ ageing, as distinct from pathological ageing. They described successful ageing as containing three components: low probability of disease and disease-related disability, high cognitive and physical functional capacity and active engagement with life (Rowe and Kahn 1997). Jorm et al. (1998) described similar ideas of successful ageing consisting of absence of disability, high cognitive skills, good self-rated health and living within the community. However a recent systematic review regarding ‘successful ageing’ noted there continues to be no universal operationalization of the term (Cosco et al. 2014). In this review physical aspects such as physical functioning (92.4%) were found to be the most frequent construct within models, followed by engagement constructs such as social engagement (49.5%), well-being constructs such as life satisfaction (48.6%), personal resources such as resilience (25.7%) and extrinsic factors such as finances (5.7%). This demonstrates it to be a heterogeneous area which is further complicated by the difference of view between researchers and older adults themselves. Phelan et al. (2004) indicated that older adults considered successful ageing to be more multidimensional whilst Strawbridge et al. (2002) found that 50.3% of older adult participants considered themselves to be ageing successfully, whilst only 18.8% of participants were classified as ageing successfully according to Rowe and Kahn’s criteria. This highlights a need for a more universally agreed definition, although as indicated there is significant individual variation.

These frameworks of successful ageing are problematic for the intellectual disability population, as Jorm et al. (1998) indicate that that factors associated with successful ageing include absence of disability, high cognitive skill and living in the community. There is no research on successful ageing with people with intellectual disability to date.

Despite a lack of applicability to the intellectual disability population in terms of certain theories of successful ageing, more recent models of how to successfully age
are more applicable. Baltes and Baltes (1990) suggested the model of selective optimisation with compensation, which can be applied at any age, but is of particular benefit in older age. This strategy comes can be applied when behavioural capacity is reduced to below a standard needed for continued adequate functioning. The first aspect, selection, refers to an increasing restriction to life domains that are of high priority to the individual, and therefore can be the choice of the individual. For example this might be a certain hobby or interest. The second aspect, optimisation, determines that individuals engage in behaviours that modify the environment to provide more desirable outcomes in the face of changes experienced. This might mean reducing distractions and spending more time on practice. Compensation emerges from a restriction in the adaptive potential of the individual. It can include physical or psychological aids.

In addition to investigating what can contribute to successful ageing, it is important to consider how to assess these concepts. Ken Laidlaw and colleagues have created a questionnaire, the Attitudes to Ageing Questionnaire, to determine how older adults understand this period (Laidlaw et al. 2007). Arguing that ageing is more likely a process than a state, this measure encapsulates three different aspects of ageing; psychosocial loss, physical change and psychosocial growth. A recent Mokken Scaling Analysis (Shenkin et al. 2014) using the questionnaire indicated what is considered more important to 802 older adults. Three scales were created from items of the measure; the first related to ‘vitality’, where they endorsed more easily physical loss, but psychosocial loss less so. The second scale was regarding ‘legacy’, which is related to a hierarchy of endorsement from feeling a sense of making a difference during their lifetime to a feeling of passing things on. Lastly a scale of ‘exclusion’ emerged with regards to a hierarchy related to endorsement of a general concern of loneliness to specific expressions of exclusion through lack of involvement or friends.

Laura Cartensen and colleagues (Cartensen et al. 1999) developed Socioemotional Selectivity Theory (SST) to describe how priority of social goals, depending on the perceived time left. This can apply to older adults, but also to anyone with perceived lack of time left to live. When this occurs preferences for social partners changes from
those that are more socially distant but might contribute to longer-term goal achievement, such as knowledge provision which could be useful in the future, to those that are more short-term in nature, such as emotional satisfaction. When short-term, more present-orientated goals are considered, the selection of social partners also changes. It is noted that more meaningful emotional exchanges are found with close social partners, these are preferred over more peripheral partners.

Therefore older adults may tend to prefer those that offer more emotional satisfaction. In addition to who they select, this theory also influence in other areas such as social network composition and cognitive processing (Löckenhoff & Cartensen 2004). Specifically in line with SST, older adults tend to categorize their world along more emotionally salient dimension and in particular with focus on more positive emotional material (Löckenhoff & Cartensen 2004). These adaptations are likely to improve the lives of older adults through improving subjective satisfaction.

The impact of intellectual disability on ageing

Growing older and moving into later life is typically a time of change and transition. This can include moving from a work-based lifestyle to that of retirement, the change of family focus with the introduction of grandchildren, and changes or deterioration in physical, sensory and cognitive functioning (Smith et al. 2002). Despite increased similarities in life expectancy, experience of older age is likely to be different for those with an intellectual disability. It has also been suggested that there are specific challenges facing people with intellectual disability in older age such as frailty occurring earlier and limited support systems (Evenhuis et al. 2012; Doka & Lavin 2003; Ward 2012).

In non-intellectual disability populations marriage is considered a protective factor in ageing (Zhu & Gu 2010). In terms of social support, older adults with intellectual disability are at a disadvantage with often being unmarried or without a partner (Doka & Lanvin 2003), resulting in less potential support from a spouse or adult children. This may mean that older adults with an intellectual disability remain tied to the wider
family or paid support systems more so than the general population. Those in this situation can be exposed to a decreasing social network as elderly parents die (Bigby 2008). Those living in the community may have few friendships with those who are not co-residents, staff or family (Emerson & Hatton 1996). More critically, age is negatively associated with size of network (Robertson et al. 2001), which may be the result of lack of transportation or the required social and communicative skills needed to maintain friendships. Loneliness has been reported to be an issue for older adults with intellectual disability and has been associated with living with family as opposed to residential accommodation (O Rourke et al. 2004).

Despite these findings, O Rourke et al. (2004) indicated that the majority (almost 70%) of their sample of 92 older people with intellectual disability were happy with where they were living, whether in residential or group or with family. However this was influenced by the attitudes of staff, and level of available activities and social contact. Qualitative research by Bigby (1997) with older adults with intellectual disability, who had left home after the age of 40 years, also reported a more optimistic outlook on this time of life. Participants identified opportunities for learning new skills, such as using public transport or cooking, or participation in new social activities as positives.

*Retirement and implications*

The effect of retirement for the intellectual disability population has been extensively explored. This may not just be retirement from paid employment, but from voluntary services or day centres. Lysaght et al. (2009) noted that employment for people with intellectual disability is a source of empowerment, meaningful social role and personal success. Judge et al. (2010) investigated views of retirement, utilising interpretative phenomenological analysis, through interviews of participants leaving day centres. Five major themes were identified: the importance of remaining active after retirement; how the day centre had become a ‘social hub’; confusion around the transition; that continuity of the current situation was desired; and lastly the importance of independence.
Retirement may not only mean a loss of social networks, but also a change in routine. Despite older adults with intellectual disability reporting that they want to remain active (Buys et al. 2008; Judge et al. 2010), Rogers et al. (1998) reported a lack of self-determination about when to retire and in the pursuit of leisure activities for older adults with intellectual disability, and that retirement can be a time of ‘boredom and loss’. Respondents who were more satisfied with retirement activities tended to be involved in community-based activities.

**Existing research on the experience of ageing**

The use of questionnaires or proxy reports in much of the existing research does not allow for fully exploring the lived experience of participants in detail (e.g. Thompson 2002; Salvatori et al. 2003). Salvatori et al. (2003) found differences in the responses between people with intellectual disability and their proxies, such as the emphasis on future concerns for family but not for the participants themselves. This highlighted the need to consult with the people with intellectual disability directly, rather than to rely only on proxy reports.

Prior research into different aspects of ageing for people with intellectual disability has been completed across the globe. As has been noted, there are distinct areas where the experiences of ageing for people with and without intellectual disabilities may differ. At present there is, however, little research on the specific experience of ageing, but more recently there have been two qualitative studies from Sweden and Ireland (Kåhlin et al. 2015; Burke et al. 2014).

Kåhlin et al. (2015) investigated the views of a wide age range (aged 48 – 71 years) of people with mild to moderate intellectual disabilities living in group accommodation. Two overarching themes were uncovered in the research interviews: ‘ageing as a process of change’ and ‘existential aspects of ageing’. Ageing was considered a time of change ‘physically, psychologically and intellectually’, with an associated adaptation of participation in activities. However, it was also viewed as something ‘inevitable’ that the shared experience of ageing could bridge the gap between older
people with intellectual disability and the rest of the population. Participants explained that, having reduced skills, they would all need increased support, which was also the case for other older people in general. While Lifshitz (2002) suggests that social identity theory (Tajfel 1978) separates younger and older generations, it could be theorised that older people with intellectual disability identify more with the general older adult population.

There are however shortcomings associated with this study. All participants were drawn from group accommodation from two areas in Sweden, which is likely to limit the generalisation of their experiences. Only half the participants considered themselves as ‘old’, arising from for example through experiencing pain or being a mother and grandmother. It was not stated whether this correlated with chronological age. It was of note that interviewees tended to refer to significant others when considering the ageing process, and when taken the wide age range of participants into account, ageing may have been an important consideration for some more than others.

In the Irish study, Burke et al. (2014) interviewed a large number of participants (n = 367) from a random sample of all levels of intellectual disability and a wide age range (41 – 90 years). They used seven closed questions and five open questions regarding ageing. The majority of participants considered themselves to be young to middle-aged, which might challenge that this study was about the experience of getting older. This has consequences for whether participants were speaking from their own experience, or as Kåhlin et al. (2015) suggest, from a more general position. Both Kåhlin et al. (2015) and Burke et al. (2014) reported that getting older was generally felt to be a time of improvement or continuation of current functioning. In Burke et al. (2014) 77% of participants indicated positive aspects of growing older, such as wisdom, an increase in social activities or fulfilment. However they most frequently associated getting older with physical changes and voiced concerns about these physical changes including illness, loss of independence and death.

Burke et al.’s (2014) sample included participants aged as little as 41 years old, which may not correspond to an ageing population and therefore makes it difficult to draw
conclusions from this study. Additionally Burke et al. (2014) did not explore the participant’s experience of aging in depth, but instead explored their perceptions of ageing through a mixture of closed and open questions. These two studies illustrate the complexity of what ageing might mean for older people with an intellectual disability, and the challenges of researching this area.

**Study aim**

This study will focus on an older group of people (> 60 years) than have participated in previous studies. This age range is more in keeping with general norms of what society considers to be an ‘older’ age group (Dodd 2008). Studying this group may allow participants to discuss their experiences, rather than their expectations, of ageing.

To date, existing research completed with older adults with intellectual disability has tended to focus on specific life transitions. It has been shown that there has been a somewhat mixed picture of how respondents view ageing. Given that the proportion of older people with intellectual disabilities is increasing, and there are unique issues for this population, it would seem timely to explore the experiences of ageing as a phenomenon in older people with intellectual disabilities.

This study will utilise qualitative methods, to allow for the richness of data needed to understand the views of the participants. Research has demonstrated that qualitative methods can be used effectively to understand the experiences of people with intellectual disabilities (Anslow 2013; Davidson et al. 2013; MacMahon et al. 2014). The overall research question seeks to address how older people with intellectual disability understand the process of aging, and how they describe their own experiences. The research will be conducted with individuals directly rather than via proxy reporting.
Method

Design

A qualitative research approach was used to allow detailed exploration of how people with an intellectual disability understand and make sense of the experience of ageing. The chosen approach was Interpretative Phenomenological Analysis (IPA: Smith et al. 2009). IPA is known for being accessible, flexible and applicable (Larkin et al. 2006), and is increasingly used in research with people with intellectual disability. IPA is generally used at the idiographic level, concentrating on particular individuals as they deal with specific events in their lives (Larkin et al. 2006). The stance of the participant being an expert of his or her own experience is encouraged. It is not descriptive but interpretative of the expressions gathered, putting them in a wider social, cultural and theoretical context (Larkin et al. 2006). As it is not considered possible to gain direct access to the participant’s world, it is acknowledged that the results of the research will emerge from the researcher’s view in addition to the interaction between researcher and participant (Willig 2006).

There are different qualitative methodologies available to the researcher, for example grounded theory, which IPA is often compared to. Typically using a larger sample than IPA (Smith et al. 2009) grounded theory is used to further theory generation (Willig 2006). In particular it is argued that grounded theory is used to study social processes but is less adept at exploring the individual experience at a phenomenological level (Willig 2006). IPA does not attempt to test any pre-determined hypotheses and is particularly useful in more novel areas of research (Smith & Osborn 2003), using ‘micro-analysis’ of lived experience (Smith et al. 2009) and therefore was thought to be more appropriate for this study.

Procedure

Ethical approval was received through the Integrated Research Application System (IRAS) and the School of Health in Social Science, University of Edinburgh. The research was in the first instance undertaken in collaboration with a Specialist Learning
Disability Service in the West of Scotland, with all identified participants known to be service-users. Therefore it followed that these participants would have a significant intellectual disability and would not be assessed for this as part of the research. Due to a lack of potential participants meeting the inclusion criteria and known to the service, recruitment was subsequently widened to non-NHS organisations, such as Activity and Resource Centres and support agencies.

Participants were required to have sufficient expressive language skills to be able to provide the rich detail required for analysis by IPA. Participants between the ages of 60 and 75 years were sought to allow for real-life experience of ageing to be discussed. They were also to be ambulant, living within the community, and their first language was to be English. People who were actively being treated by the team at time of research were excluded to avoid confusion about the role of the researcher. Participants with Down’s Syndrome, who are at higher risk of having dementia by this age, were excluded from the study. Additionally anyone with a diagnosis of dementia or autism, were terminally ill, were registered blind or deaf or considered by the team as unable to give consent were also excluded.

The inclusion and exclusion criteria were tailored to provide a relatively homogeneous sample as recommended by Smith et al. (2009). To reduce the likelihood of recruiting participants who were unable to fully take part in the research, the Community Learning Disability Nurses (CLDN) were consulted to identify potential participants who met the inclusion criteria. As a result, 12 potential participants were identified and eight agreed to take part in the research. A further two participants were suggested by non-NHS managers and selected through this method. One interview was later excluded (Participant 9) due to concerns that the participant did not understand the questions. Smith et al. (2009) recommend a total of between four and eight interviews for doctorate level research using IPA.
Table 1 Characteristics of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age at interview</th>
<th>Gender</th>
<th>Support received</th>
<th>Single or married</th>
<th>Setting</th>
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<td>Lives with mother</td>
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<tr>
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<td>Yes</td>
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<td>Lives on own</td>
</tr>
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<td>Lives with wife</td>
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<tr>
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<td>Yes</td>
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<td>Lives with wife</td>
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<tr>
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<td>74</td>
<td>Female</td>
<td>Yes</td>
<td>Single</td>
<td>Lives on own</td>
</tr>
</tbody>
</table>

Pre-interview and interview process

A face-to-face semi-structured interview format was used to provide a reasonably standard set of interview questions whilst being flexible. An interview schedule was designed, in collaboration with a Speech and Language Therapist and another Clinical Psychologist working in intellectual disability. Questions were informed by earlier research (Kåhlin et al. 2015) and considered adaptations suggested in other research (see Appendix 3). This included making questions shorter and simplified and focusing on current issues and concerns (Salvatori et al. 2003). A pilot of the interview schedule was completed at a local Activity and Resource Centre with two participants within the required age range, where their opinion of the materials was sought.

Potential participants were approached by the relevant CLDN or support worker for recruitment to avoid any undue influence by the researcher. Participants were given a copy of the accessible information sheet and completed the consent form to demonstrate understanding of their involvement (see Appendices 1 and 2). Assistance was given in filling in the form if required but not with answering the questions. A week’s ‘cooling off period’ was given before the participant was contacted by the researcher to see if they were still interested in participating. A time was organised to meet before the research interview to build rapport and to answer any queries. A second meeting was organised for the research interview.
On all but one occasion the interview was completed at the home of the participant, with one completed at the office of the researcher. Attempts were made to put the participant at ease by initially discussing familiar topics. Each interview was recorded with two digital audio recorders and lasted between 39 and 76 minutes. On one occasion the participant’s wife was present, otherwise participants were interviewed alone.

**Analysis**

Each interview was fully transcribed by the researcher and then analysed using IPA. Analysis was supported by Dedoose online data analysis software (http://www.dedoose.com/). Smith *et al.* (2009) outline the analysis procedure in detail and the following stages were followed. The first step was to read and then re-read one transcript at a time. In the second step initial notes were made about the data, looking at the meaning of what was said and the language used. The third step involved looking for emergent themes that reflected what was said in the transcript and the notes about it, in addition to the researcher’s interpretation. After this connections were sought across emergent themes. These processes were then repeated for each case in isolation, allowing the transcript of each participant to be given full attention. The last step involved looking for patterns across participants. It was important throughout to emphasise interpretation of the participant's perception. The final product of the analysis illustrates the major themes and underlying sub-themes with extracts from interviews as examples of each. To ensure the quality of IPA was maintained, the guide laid out in Smith (2011) was used, considerations included a clear focus, using strong data, leaving sufficient space for each theme, including both convergence and divergence from themes. The principles of Yardley to evaluate validity (2000; 2008) were followed, considering sensitivity to context, commitment and rigour, transparency and coherence and impact and importance of the research.

**Epistemological position of researcher**

It is important to be mindful of the researcher’s own epistemological view of knowledge as this will shape the process and understanding of the research.
Epistemology is a philosophical paradigm concerned with the theory of knowledge and learning about the world. The epistemological perspective of positivism indicates that information from and about the world can be directly and accurately described. As a result the goal of research from a positivist stance is the production of objective and measurable knowledge, without any influence from the researcher (Willig 2004). Consequently this epistemological branch is more suited to quantitative research questions, although this stance suggests that phenomena researched using IPA is a direct representation of the experience of the individual.

The epistemological stance of constructivism is closer to the viewpoint of this researcher. This is dependent on the context of the knowledge and therefore there can be multiple knowledges rather than one real representation. Social constructivism suggests that the social interactions and the language used can contribute to the different understandings of the same phenomena. This idea that there is no one reality of the situation that can be directly accessed and that multiple understandings of the same phenomena lends itself well to qualitative research, in that it gives a reason to ask different individuals their experience of the same phenomena.

Quality in research study

Quality in the research was sought through initially selecting an appropriate study design and qualitative approach based on the research question. IPA was used on this basis, primarily due to the experiential aspect of the research question, the desire to look at the phenomena in detail and the lack of research in this area to date. The researcher of the study completed all interviews with the same interview schedule to increase reliability. A reflective log was also completed to assist with analysis of the interview schedules. Findings emerging from the data were regularly discussed with supervisors on the study, in addition to the above guide by Smith (2011) to improve quality in the analysis. Feedback from the NHS team was also sought when presenting the findings to them (see Discussion for exploration of views emerging from this).
Results

The following three themes were identified in the analysis of the data: ‘Not changed by ageing’, ‘Thinking about the ageing process’ and ‘What happens when getting older’. These themes address the research question and demonstrate experiences of this sample of adults with intellectual disability as older adults and their experience of ageing, and are evidenced by the use of excerpts from anonymised data. These themes suggest views that are at times contradictory, with respondents distancing themselves from what they think of as an older adult, but also recognising that they have changed over time and that some of these changes are associated with ageing.

**Theme 1: Not changed by ageing**

*Figure 1 Theme 1: Not changed by ageing*

There was a strong indication that participants considered themselves to be fundamentally the same as they had always been, whilst acknowledging that they were older. Although some had noticed aspects of change in themselves in more recent years, most notably Participants 1 and 6, the majority of these changes were related to their physical state or their daily activities. This sense that life was the same could be influenced by a lack of transition markers that other people navigate, such as retirement.

*I think I'm just... still the same* (Participant 2)
Some of the participants had previously been in employment and two demonstrated the continued importance of their work role as part of their identity and outlook rather than what stage of life they were in, even if they were no longer working. Like a job, recreational activities gave a sense of purpose and structure to participants’ weeks. Participants openly discussed current routine or leisure activities and some mentioned additional activities that they hoped to take up in future, although they tended to focus on the here-and-now. When discussing these points, participants were optimistic and almost never mentioned age as a reason for stopping any activities, or considered that age could be a barrier to continuing with, or starting, new activities:

‘I: What do you think is a good thing about getting older?

P: I can do anything.

I: You can do anything?

P: I can do the laundry, I can do the fish and chips, make supper.’ (Participant 4)

‘I: And what would you like to do in the future?-

P: Find myself a wee job.’ (Participant 7)

This suggests participants had limited insight or consideration at this time in their life into how they might be affected by ageing in the future, or that they discounted the possible limitations brought about by age.

Participants within this study often lacked a wide social network, and this was highlighted by the significant role family and staff had played, and continued to play, in their lives. This ongoing support came mostly from paid services and was central for helping with everyday tasks as well as social support. All but one of the participants received support, which may be seen as different from many adults where a more typical experience is a transition to receiving support only in older age, or where infirmity makes this necessary. This difference is likely to have influenced participants’ perceptions of ageing: they expressed how they were used to having staff around them and, for example, seemed unfazed by changes brought about by someone new coming to work with them.
For a majority of participants family was described as an essential part of their daily life. Family provided ongoing sources of interest, such as evidenced with Participant 3, who was keen to discuss a recent family-related event at length:

‘I: Ah. And -

P: And I've got a great-niece now!’ (Participant 3)

Having a great-niece was clearly important, but there was no reflection on her being ‘great’, which might have been taken as an indication of time passing and Participant 3 getting older.

Over half of the participants (five of nine) were quite explicit that they did not see themselves as an older adult, in spite of identifying changes that could be associated with moving into later life. When changes were discussed they often seemed transient or coincidental, such as feeling tired more frequently, rather than generating a consistent sense of becoming an older adult. This may have been related to how participants see other older adults. Participants talked of themselves in comparison to their perception of what being old was like, and this was different to how they saw themselves. Older adults might be described for example as being ‘crabbit’ (‘irritable’; Participant 5), or as Participant 10 suggested:

‘It’s different for the old folk, they like company, I’m the other way around’ (Participant 10)

Other participants emphasised their continued mobility, almost with a sense of pride, which seemed to set them apart from other people they identified as older adults. An example of this was discussed in relation to health and being old (Participant 5):

‘And, cos I'm young, it didnae hurt my leg... in two or three days and I was better. But if it was an old man can come in and fallen, he would have been sent for an ambulance and taken to hospital ken... So I’m feeling more healthy than the old people’ (Participant 5)

Being an older adult appeared undesirable for most participants, and they were keen to distance themselves from being seen as one. Even those who did consider
themselves older tended to describe older adults in negative and stereotypical terms. Participant 7 indicated that it was necessary to dye your hair to avoid looking older, whilst Participant 4 associated being an older adult with not working. As he was keen to continue to work this meant that being an older adult was incompatible with how he saw himself:

‘She's [his sister, who has retired] packed it in but I'm no, I'm still working! She's getting old now.’ (Participant 4)

Consequently the accounts of participants made reference to experiences that led them to conclude that they were the same as they had always been. When they acknowledged changes associated with ageing these tended to be negative and described what was happening to other people. This may have reflected a desire by participants to not think of themselves as getting older and further reinforced the idea that they were still the same as they always had been. The nature of having an intellectual disability may contribute to this theme. Thinking in more concrete ways and focussing on how they feel in the present moment typified what was said. There was much less evidence of more abstract thinking about how they might change in the future, or how the changes they see associated with ageing will happen to them.

**Theme 2: Thinking about the ageing process**

*Figure 2* Theme 2: Thinking about the ageing process
Both within and across interviews, many participants struggled with how they made sense of what ageing is in relation to them as opposed to other people. Of interest, a majority of the participants (seven of nine) explained that they had not thought about to any extent before the research interviews, or discussed with others, the process of ageing. Ageing was known to occur but was seen as nothing special by some, and did not generally appear to be considered as a significant influence on their lives. It is possible that this could be perpetuated by family and staff not seeing the need, or giving a space to, discussing ageing. It was not clear from the interviews whether this may be due to concerns about upsetting participants, or a belief that they would not understand or be interested.

While most participants acknowledged that they were getting older, this was in a limited way and generally without reference to changes or necessary adaptations to their life in the future. Living in the present may not be unique to this group of participants and it may reflect the views of the general population about when one needs to consider the beneficial effects of, for example, moving closer to family or getting additional support. What was present in the interviews with participants was a lack of urgency about the need to think of the possible consequences of ageing. This was expressed by Participant 10:

'Oh, I don’t think about my age you ken. Like a birthday, it’s just another year older…’

(Participant 10)

Participant 10 indicated significant discomfort in considering herself as getting older despite suggesting the inevitability of ageing and what this might mean for her. She was explicit in wanting to prevent ageing through keeping her ‘mind active’.

Participants strongly emphasised that they were not able to change getting older and therefore did not consider it further, and for some participants there was recognition of the inevitability of ageing being the same for everyone. This was one aspect where participants saw themselves the same as other people, regardless of the presence of an intellectual disability. However, all participants appeared to struggle with the concept of ageing and what it meant. Participant 2, in talking about getting older, seemed at times confused in her account. For example, she initially described how an increase in
the level of support offered to her was as a result of becoming older, but later suggested that she had received support for a long time, without any reference to the intensity of this changing. This suggested the difficulty of being able to attribute changing needs to ongoing disability or the changes associated with ageing. At times participants were explicit in saying that they were unable to explain what getting older meant to them. Others were able to say that they felt different to their younger days, but were unable to say in what way, or how they might expect to feel:

‘Bound to tell on you when you’re older, and that’s all I can say ken... Otherwise I’m no sure’ (Participant 8)

The lack of clarity about the ageing process for some participants, and therefore how they may change, may also have implications for how they think about the future. Participant 5 displayed an awareness that his situation could change in the future but felt unsure about planning for the future potentially for this reason. Participant 7, one of the participants who was married and helped to care for his wife, was different in this regard in wanting to plan for both of their futures, to ensure that she would be cared for, and demonstrated some understanding that things will change.

Participants also tended to struggle to articulate what other people of the same age might think about ageing. This might suggest that participants could be unsure of the concept and find it difficult to think how other people conceptualise ageing. Some considered the process of ageing to be more visible at some times than others which is likely to be similar to those without intellectual disability. They were able to indicate examples which they associated with ageing, and these examples tended to have negative connotations. Participant 7 noted the increased use of his inhaler and related this to ageing but otherwise did not consider himself to be moving into older age. Participant 1 was reminded of being older when she went to sleep at night, due to feeling more tired than she had previously. Participant 1 was the only interviewee who saw the process of ageing as a positive as it brought her closer to her family.

For some of the participants these changes were often complicated by other pre-existing health-related factors, such as diabetes, and as a result participants appeared confused by these changes and whether they might be attributed to ageing. For
example, two participants noted that having mobility difficulties was nothing new, and therefore downplayed the impact that getting older might have. Participant 4 was quite clear that he did not feel older, yet commented on a few occasions how activities that he had always done now left him tired.

When asked directly about when people begin to get older, some participants commented that they started to feel older in their sixties, whereas it was unclear for a few of the participants when they thought moving into older age ‘starts’. Some participants considered the only marker of old age to be a chronological age, which was always beyond the age that they were now, reinforcing the impression that they did not see themselves as old. In some cases ageing was described as happening just before death, and it was unclear whether this reflected what they had been told by other people, or to more direct experience. For Participant 1, her thoughts of getting older were related to her father who had passed away and for Participant 7 this appeared to reflect what had been told to him as part of his religious upbringing:

‘Somebody told me...when you get older you die, and you come back to life. No...’ (Participant 7)

Some of the participants were uneasy about this association between ageing and death. They did not however voice concerns about the implications of, for example, the death of family members and how this in turn would reduce their social network. Participant 8, who discussed being lonely, was the only participant who voiced concern about family members passing away, suggesting he realised the significant impact it would have.

The process of ageing was confusing for a majority of the participants, leaving them unsure of what it involves, particularly the possible breadth of experience it can encapsulate. Some felt it to be inevitable or insignificant, whilst others felt that it is only really noticeable at certain times.
Theme 3: What happens when getting older

Figure 3 Theme 3: What happens when getting older

All participants had some experience of other people who were older; either family, friends or people they associated with at their day centre or residence. Along with more usual stereotypes, these relationships tended to be the reference point for their initial understanding of getting older. While participants were unclear about their own process of ageing, they appeared generally more readily able to recognise physical changes that occurred when other people became older. Physical changes noted by participants included wrinkles or grey hair. Ideas about ageing in others was not restricted to physical appearance but included distinct examples of what older people did. These were wide ranging, from Participant 5 suggesting that older adults had second homes to more stereotypical views of older adults playing dominoes and going to bingo. These were not activities that the participants themselves were involved in, nor was buying a second home probably an option for a majority of them. This again contributed to the sense that people with intellectual disability may tend to think of ageing in others rather than themselves.

During the course of the interviews it was noted that there was an increased reflection by participants of changes in themselves, often in terms of changes in fitness. Participant 7 explained:
‘When I’m coming up the hill, I’m knackered. I tell you’ (Participant 7)

In addition, several participants described feeling noticeably different to when they were younger and that this was not simply a question of physical change. Participant 6 described himself as quieter as he was getting older, whilst Participant 8 noticed a considerable change in how he reacts to events around him:

‘... I used to be mad on Rangers ken... er, I used to take it serious. But now I’m getting older [interviewer], it doesn’t bother me as much if they get beat’ (Participant 8)

It is of note however, that two participants (Participants 5 and 8), put such changes seen in themselves down to medication rather than ageing. In addition to feeling different, a few participants reported spending their time differently. Participant 3 described how she used to attend the local activity and resource centre but no longer does:

‘I suppose it's cos it's for younger people’ (Participant 3)

This in itself is of interest in that she had judged herself to be no longer age-appropriate for the centre. Participant 6 reported a wide range of changes experienced as he got older, largely in comparison to when he was working as a farmer and also due to changes in his health. This was associated with feelings of frustration:

‘...It’s a physical thing... it’s a thing you can’t help with and that’s it’ (Participant 6)

All participants had noticed some changes as they were getting older, but some specifically saw ageing as a time of decline in themselves. Participant 6 was particularly negative in his experience of ageing. He was also the only participant who explicitly described a decline in his memory functioning and how this impacted on his life. Participant’s views may have been influenced by not discussing ageing with others and being exposed to wider views. Most of the other participants were able to take a more balanced view. For example Participant 1 saw opportunity in improving her cooking in the future as she grows older, whilst also describing a more general decline in ageing. In this quote she describes how she sees older adults:

‘Slumped and not very good with walking... Not really good dressed’ (Participant 1)
This was echoed by Participant 2, however both participants had close older family members, and this may have influenced their thoughts. Participant 5 also described in detail the fragility of older adults, later stating how his opinion had been shaped by a friend’s experience:

‘Boys, boys when they fall, in the snow they end up with skinned knees and that. But if an old couple were to fall it would be worse, he would be sent to hospital to get him fixed up ken’ (Participant 5)

Two participants had experienced falls, a common concern in older adults, and were keen to avoid this through looking after themselves. More widely, some participants were aware that older age may be a time of needing to be looked after, but importantly did not relate this to themselves. However some had noticed an increase in the support they received associated with getting older and this need was considered to be a restriction on their independence.

There were occasions where participants discussed seeing few differences between themselves and older adults who were known to them. This was different to their sense of difference to more generic older adults. Receiving a pension, a universal occurrence that everyone experiences, was described:

‘I'm 64 the now, I'm 65 and my pension comes up’ (Participant 4)

The mention of pensions was not generally presented as something positive, more that it was a reminder that they were ageing. It was noted that Participant 3 mentioned her moving from the activity and resource centre immediately after her brother’s retirement, suggesting she saw her departure as a form of retirement. There was awareness of the importance of work to others and how adjustment is needed in older age after retirement. Only Participant 4, who continues to work, voiced concern about what would happen afterwards.

Not all participants had an entirely negative view of ageing and it appeared that participants were typically enjoying life. Although participants often described changes associated with ageing in negative terms for them and other older adults, the overall impact of ageing on their life was inconsequential or positive. Most
participants tended not to dwell on the negatives in their own experience of aging and some were taking advantage of this stage of their life. For example Participant 4 was going to the local pub more frequently whilst Participant 6, who previously worked, reported having the opportunity to go to the Grand National which he had always wanted to go to.
Discussion

This study contributes to a growing body of research exploring the lived experience of older adults with an intellectual disability (Jenkins 2002; Judge et al. 2010; Kåhlin et al. 2015; Burke et al. 2014). The three themes that emerged from the study data outline what a majority of the research participants discussed when considering the experience of ageing. Importantly, for all participants these discussions were occurring for the first time. For this population of older adults with intellectual disability, ageing, typically a transitional time for many people, is a time where they have not changed, a process that can be confusing and at times can have largely negative connotations.

The first theme suggested that participants considered themselves as the same they have always been and did not initially identify themselves as older adults when discussing aspects of their lives. They did not on the whole feel older, which is understandable given the lack of consistent transitional markers and the stability of their day to day lives in terms of the people around them and the activities they are involved in. It is also understandable that participants wanted to distance themselves from considering themselves as an older adult due to the negative connotations they initially associated with ageing. With the caveat that their samples included a wider age range of participants, the first theme of this study generally supports the findings of Kåhlin et al. (2015) and Burke et al. (2014). The participants of the current study were from a narrower, older age range than Kåhlin et al. (2015) and Burke et al. (2014) and more in keeping with what is typically considered older age. Despite being older, the majority of participants still voiced similar sentiments of not feeling old. Some participants of the current study however could be described as being in the lower range of what could be considered old age and so may not be expected to feel significantly different to someone in middle age.

One point of difference is that participants with Kåhlin et al. (2015) felt ‘ageless’ when feeling physically able. Although there was less explicit expression of this idea in the current study, participants did note that it was often physical changes that reminded them of getting older. The participants of the current study were generally keen for
their activities to continue into the future. This was similar to the findings of Buys et al. (2008) who described older adults with an intellectual disability wanting to ‘keep on keeping-on’. They saw little reason associated with ageing for this not to happen, which may demonstrate the concrete perspective of remaining in the here-and-now, associated with people with intellectual disability. In addition to this, people with intellectual disability have until relatively recently been less integrated with the community and may not be exposed to possible beliefs of their peers without intellectual disability about activities they should be involved in.

The second theme regarded the process of ageing; the way in which participants discussed ageing demonstrated their confusion around the process. All participants stated they had not discussed ageing before which is likely to have contributed to lack of clarity in discussions on this topic. Ageing was not considered significant to many participants, which may have in turn led participants to not consider the consequences of ageing in significant depth. Participants tended to describe the process of ageing as inevitable for everyone, much as in Kåhlin et al. (2015). However unlike Kåhlin et al. (2015), participants did not report feeling increasingly similar to other older adults without intellectual disability as they aged, as support needs become more similar. Putting the participants of the current study into the wider societal context, they could be considered one of the last generations who have not experienced community inclusion from birth. Their view of only sometimes feeling similar to other older adults could demonstrate a lack of integration with the rest of the community. They demonstrated this through struggling to explain how other older adults experience ageing.

Whilst some participants considered ageing to occur around a certain chronological age range, some participants were also unclear about when ageing occurs. This led to the idea that ageing is less of a process and more of a state that occurs before death, contrary to what Shenkin et al. (2014) suggested. Participants’ lack of understanding of the ageing process suggests that they may lack the opportunity to explore what ageing means, not only in physical and practical terms, but also in existential terms. However the overall feeling was that despite participants being unclear about the
process of ageing, the majority did not seem unduly concerned. Most of the participants, like many people with intellectual disability, had not experienced typical transition reference points. This, along with participant’s longstanding co-morbid conditions, could explain their confusion. Ageing was often not at the forefront of participant’s minds, although it could be argued that this is the case for a majority of the population.

The third theme was associated with what happens when getting older; the changes associated with ageing noted by participants tended to be clearer in relation to others, and they generally focussed on stereotypes or negative aspects of ageing, such as physical deterioration. Participants initially noted these changes in relation to others, but there was a gradual trend towards noticing changes in themselves too. Previous research has also found that stereotypes of old age strongly influences people with intellectual disability, with older adults being seen as ‘helpless and useless’ (Liftshitz 2002). It has been suggested that, beginning in childhood, stereotypes are reinforced by repeated exposure over time, and then consequentially correspond with self-stereotypes as the individual grows older (Levy 2003).

There was overlap between the second and third theme in terms of understanding what ageing contributes and what other health conditions contributes to their experiences. Despite the cause, participants were able to note some changes that occurred over time in comparison to when they were younger. Whereas in previous research both positive and negative aspects of getting older were described by participants, this dichotomy was present to a lesser degree in this study. The participants in Kåhlin et al. (2015) described positive aspects of ageing, whilst Judge et al. (2010) described older age as potentially a time of growth and increased activity. However it should not be lost that participants of this study highlighted continued positives in their lives.

It is interesting to consider these themes in light of theories of successful ageing, as discussed previously. In terms of the theory of selection, optimisation and compensation (Baltes & Baltes 1990) there was some expression by participants that they had on the whole made significant changes to the focus of their goals as a result...
of ageing. Participant 7 appeared to be adapting his goals in relation to supporting his wife as a result of her increasing needs and his changing abilities. Some of the participants described reducing their activities but more as a result of the influence of others, such as Participant 1 visiting the day centre less frequently or Participant 4 attending activities less due to staff not being available. In terms of optimisation, participants described completing activities that are familiar to them, and wanting to maintain these, which does not require the learning of new skills. In terms of compensation, participants were already used to receiving assistance from family and paid staff to complete daily activities.

Socio-emotional selectivity theory (Cartensen et al. 1999) has been described to be more important in times where perceived time available is decreasing. As described, people with intellectual disability are now living as long as those without intellectual disability, and therefore this population of 60 to 74 year olds are not considered the oldest old of an ageing cohort. Older adults with intellectual disability have generally had to rely more on family throughout their lives for social support (Bigby 2004) and have not always had the opportunity to enjoy social relationships with a wider circle. However previous research by Judge et al. (2010) noted how friendships built up through attending day centres remained important for their cohort. Only one participant in the current study (Participant 6) had a child and only two participants (Participants 6 and 7) were married. It is therefore difficult to determine whether socioemotional selectivity theory applies to the population studied in the current study. However it is considered that the cohort of older adults with intellectual disability interviewed for the current study are living in a time of change, where community inclusion and experiencing a wider social circle is the norm.

Laidlaw and colleagues have acknowledged the importance of wisdom to older adults, yet wisdom was not raised by any of the participants in the interviews. This may have been in part a result of not being explicitly asked about wisdom and participants not considering ageing before, and therefore not considering more fully both the positive and negative aspects of ageing. Related to this there was, on the whole, a lack of consideration about what participants would like in the future beyond their current
experiences. This does not detract from their day to day lives, but rather indicates other possible avenues for discussion in the future, especially with the knowledge that family will not always be there for them.

**Strengths of research**

This research gave the opportunity to a purposive sample of older adults with intellectual disability to discuss their experience of ageing. Participants were able to fully engage in this study using a qualitative method and discuss their experiences. The study contributes to a growing area of research with older adults with intellectual disability. Previous research has used participants of a wide age range, where it is questionable that the experience of ageing can be fully explored. This study took particular care to explore the ageing experience with those who had had the opportunity to experience it, even if their experience was that ageing is less of a transition than for the rest of the older adult population.

The research highlighted the need to explore this more with this population as it has been scarcely discussed. As more adults with intellectual disability are reaching older age, consideration should be given to this.

**Limitations of research**

There are limitations associated with this research. The sample, following guidance by Smith *et al.* (2009) was small and purposive. It was specifically sought primarily from an NHS service and one non-NHS support organisation. Although this increased the homogeneity of the population, this excluded the opportunity to access the lived experiences of other individuals who have not sought external support during their lives. The ability to generalise from the results is limited, but the research contributes to a larger body of research understanding the experience of ageing in older adults with an intellectual disability.
Research with people with an intellectual disability required some extra consideration to ensure high level of quality. As described in previous research (e.g. Walmsley 2001; Beail & Williams 2014) adaptations are possible to ensure the interview process is understood. Researchers may need to work harder to understand the lived experience of participants who may have limited communication abilities compared to other IPA studies completed with other populations. For example as in this study gaining interpretation from much shorter responses. It may have been beneficial to complete a second interview with participants (Hall 2013), but due to time limitations this was not possible.

Previous research has also highlighted the importance of including people with intellectual disability in the entire research process, including development of questions and completion of data collection. Beail and Williams (2014) and Hall (2013) indicate importance of involving people with intellectual disabilities in a meaningful way for both researchers and participants that is not tokenistic. Due to time constraints this was not possible but should be strongly considered in terms of the participants being experts of their own experiences. Related to this is that the level of intellectual disability of participants was predicted mild to moderate, which is typical of research in this area. However to improve inclusivity, all levels of intellectual disability should be involved in research. Jenkins (2010) attempted this and further consideration should be given to involve those less verbally able.

The age range of participants was wider than anticipated, however only through completion of the research did it become apparent that even in the age range of 60 – 74 years, participants did not see themselves as older and therefore struggled at times to describe their experience of ageing. Lifshiftz (2002) reports a relationship between the age of participants and understanding of ageing, suggesting that older adults need to experience ageing on their terms to be able to discuss it.
**Practice considerations**

The present cohort of participants experienced some interactions with older adults without an intellectual disability, such as at the day centre where both people with and without an intellectual disability attended. More interaction between these groups could have a positive effect on the understanding of ageing and any fears about what the future might hold for them. Although normalization has encouraged integration of people with intellectual disability into the community, this needs to be felt through the lifespan.

This study demonstrates that older adults with intellectual disability do have views on their experience of ageing and the population described not having previously considered what ageing means. This highlights a need for discussions to be had with people with intellectual disability to explore their ideas and understanding of ageing. Feedback arising from this research has suggested that discussing the ageing process with older adults with intellectual disability could be unfair or upsetting, and that it is better for the population to be unaware of the ageing process. However this perpetuates the view that people with intellectual disability should be protected from information that is applicable to them. This goes against more recent principles of normalisation, that important information should be provided to the relevant population in an accessible way. Not discussing ageing also perpetuates the idea that the ageing process is only a negative and that decline is ‘inevitable’.

It is known that there are positive aspects associated with ageing, such as an increase in well-being from middle-age (Blanchflower & Oswald 2004). Previous research with the non-intellectual disability population has demonstrated the possessing positive attitudes to ageing is associated with better functional health (Levy *et al.* 2002). It is therefore suggested that open and balanced conversations with people with intellectual disability would be beneficial.

Some consideration may need to be given as to who should be engaging with older adults on this topic. As demonstrated by this study, not all older adults with intellectual
disability are in contact with NHS services. It might be appropriate for any family members or professionals who are comfortable discussing the issue with this population, and who the individual feels able to discuss it with. Centrally produced information could contribute to unbiased information that does not lean excessively on stereotypes.

This research was completed with a small sample of older adults with intellectual disability, yet it is not a heterogeneous population. Further research should be completed with older people with intellectual disability to compare experiences, particularly the oldest older adults (typically referred to as 85+ years). In addition to further research being completed with the population of older adults it is also a burgeoning area determining why these conversations are not currently being had. At present it is unclear whether this is because it is considered unnecessary, upsetting or uninteresting for example.

There is also a distinct lack of research on what people with intellectual disability consider ‘successful ageing’. As this population have a higher frequency of multimorbidity (Hermans & Evenhuis 2014) and often do not experience some of the important transitions that the rest of the population experience, such as a career and creating a family, what does to age successfully to this population mean? If this is understood then it may be facilitated.

In conclusion this study has sought the attitudes of older adults with intellectual disability with regards to their experience of ageing. Three themes emerged with regards to what ageing means to them: ‘not change by ageing’, ‘thinking about the ageing process’ and ‘what happens in getting older’. There was a change in how ageing was perceived in that whereas physical and negative aspects were originally the focus, broader aspects were later considered. The study also demonstrates there is a real need to discuss this topic with this population in more detail, to open up the understanding of ageing to the possibility of more balanced and positive aspects.
References


Dodd K. (2008) Transition to old age—what can we do to aid the process? *Advances in Mental Health and Learning Disabilities* 2(3), 7-12


Hall S. A. (2013) Including people with intellectual disabilities in qualitative research. *Journal of Ethnographic & Qualitative Research* 7, 128-142


Thompson D. (2002) “Well, we've all got to get old haven't we?” Reflections of older people with intellectual disabilities on aging and change. *Journal of Gerontological Social Work* 37(3-4), 7-23


Research portfolio references


Thompson, D. (2002). “Well, we've all got to get old haven't we?” Reflections of older people with intellectual disabilities on aging and change. *Journal of Gerontological Social Work*, 37(3-4), 7-23.


Appendix 1

Information sheet for research

Title of research: What do people with a learning disability understand about the experience of ageing?

Name of researcher: Anna Whiteley

My name is Anna and I am training to be a Clinical Psychologist with the University of Edinburgh and NHS Dumfries and Galloway. I need to complete a research project as part of my work.

I would like you to take part in my research. Please take some time to read this information sheet about it. You do not need to make a decision now about taking part. Please discuss it with others.

You can ask the Community Nurse or me if you have any questions.
The research

I want to speak to older people with a learning disability. I am interested to hear how you feel about getting older.

I would like to talk about:

- what you think about getting older
- what is good about getting old
- what might be bad about getting old
- if you have any worries about getting older

This is important because people with a learning disability in Scotland have not been asked this before. This could help make services better in the future.

Why me?
One of the Community Nurses from the Learning Disability Team who knows you thought you might want to take part.

Who do I want to talk to?
I want to talk to people with a learning disability who are between 60 and 75 years old.

You should be able to tell me what you are thinking.
If you are being seen by the Learning Disability Team you cannot take part in the research.

If you have a diagnosis of dementia then you cannot take part.

**What does it involve?**
It is **up to you** if you want to take part.

If you want to take part in the research, then you should complete the **consent form**. This will show you have understood what the research is about. You will then have 1 week to think about whether you really want to take part.

If you want to take part, then the Community Nurse will give me your name and address.

**Before we meet – if you want to take part**

- After 1 week I will arrange to meet you to get to know you.
- We will agree on where to meet.
- If you are happy to carry on, we will arrange another meeting.

**When we meet**
- This meeting will last about an hour.
- It will be recorded so I get all the details.
- We will discuss different topics on what you think about getting older.
• You can ask any questions you have.

• You can stop taking part in the research at any time. This will not stop you from getting help from services.
• I will not tell anyone your name so no one will know what you said.
• All your information will be kept locked away safely.

**After we meet**
• After we meet what you said will be put together with what others have said. This will be looked at in detail.
• You doctor will be told we met but not what you said.
• The findings will be put in a report. You can be given a copy of the findings.

**Benefits of taking part**
• You will be able to give your views about getting older.
• It could help with making services in Dumfries and Galloway better.

**Risks of taking part**
• The questions you will be asked are not meant to be upsetting, but you might get upset.
• If you do we can stop and take a break.
• If you are still upset and need to talk to someone in Clinical Psychology this can be arranged.
Any questions?

My phone number is: 01387 244495

My address is:
Mental Health Directorate
Cree West
Crichton Hall, Crichton Royal Hospital
Bankend Road
Dumfries, DG1 4TG

Do you have any problems with the research?

If you have worries about the research you can speak to me.

If you are still unhappy you can speak to:

Bruce Kidd who is my boss on:
01387 244 244
Appendix 2

Consent form for research

Title of research: What do people with a learning disability understand about the experience of ageing?

Name of researcher: Anna Whiteley

This is to check you have understood the information given to you about the research. If you want to take part in the research you need to fill in this form.

Please

I have read the information sheet

I have had enough time to talk to others about it

I have been able to ask any questions

My questions have been answered

It is okay for Anna to contact me

It is okay for my doctor to be told I am taking part
What is the research about?

............................................................................................
............................................................................................
............................................................................................

Is it up to you whether you take part? Yes / No
Can you stop taking part at any time? Yes / No
Do you understand what is good about taking part? Yes / No
Do you understand what might be bad about taking part? Yes / No
Do you want to take part in the research? Yes / No

Name of participant:

Signature of participant:

Date:

I will get in touch with you in one week to check you are happy to take part.

My phone number: 01387 244495
Appendix 3

Interview schedule

Thank you for agreeing to meet me today. We will be talking about how you feel about getting older. I will be asking you different questions on this topic. I want you to tell me what you think in as much detail as possible. I might have to check with you sometimes whether I have understood you correctly or ask you for an example. Just do the best you can to answer any question. Do you have any questions?

Remember that you can ask to stop this meeting at any time if you want a break or you want to finish. That is okay. If you tell me anything that might worry me, such as that you might hurt yourself or someone else, I will need to tell a member of the team. Does that make sense?

- Start with questions around current activities to reduce any anxiety e.g. what have you been doing today/this week? What do you like to do? Where do you live? Who do you live with? Do you like it?

- Now I am going to ask you about getting older. What does getting older mean to you?
  - What does it look like?
  - What does it feel like?
  - What do older people do?

- Do you feel old?

- What are some of the good things about getting older?

- What are some of the bad things about getting older?

- What helps with growing older?

- Do you feel different to when you were younger e.g. thirty years ago?

- Do you think about the future?
  - What would you like to do?
  - Where would you like to live?
  - Do you have any worries about the future?

Thank you again for taking the time to talk to me today. Is there anything else you want to mention? Do you have any questions?

When I finish speaking to all the participants for this research study I will look at what everybody has said and write a report. Do you want to know the results when I have finished this? [Give details if needed i.e. that it will involve meeting all participants as a group, and that the results will also be written in an accessible leaflet that can be sent out to them].

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Appendix 4

Ms Anna Whitely
Cree West, Crichton Hall
Bankend Road
Dumfries
DG1 4TG

Date: 18th August 2014
Our ref 14/DGY/035
Study title: WHAT DO OLDER PEOPLE WITH I.D. UNDERSTAND ABOUT THE PROCESS AND EXPERIENCE OF AGEING

Dear Ms Whitely

Thank you for sending me details of your study with a request for management approval. I can confirm that the study review team has reviewed the documentation and on this basis I am pleased to inform you that your study has management approval for commencement within NHS Dumfries and Galloway..

It is a condition of this approval that everyone involved in this study abides by the guidelines/protocols laid down by this Health Board in respect of confidentiality and Research Governance. It is your responsibility to ensure you are familiar with these; please do not hesitate to seek advice if you are unsure. (Copies of Research Governance Framework document available via the website www.sehd.scot.nhs.uk/cso and then use the publications link).

We also note that it is the sponsor’s responsibility to ensure that appropriate training is in place for all local investigators. It is important that all research must be carried out in compliance with the Research Governance Framework for Health and Community Care and the new EU Clinical Trials Directive (for clinical trials involving investigational medicinal products).

As part of the Health Board’s responsibilities under Research Governance we will be monitoring studies at least on an annual basis. It is therefore important that all records in connection with the study are kept up to date and available for review. We are also required to inform you that details of your study will be entered onto our R&D database. As custodian of the information collated during this research project, you are responsible for ensuring the security of all personal information collected, in line with NHS Scotland IT Security Policies, until the destruction of this data.
If your study is adopted by UKCRN into a portfolio then please advise this department of recruitment figures by adding accrual data to that database on a monthly basis.

Please notify the R&D office immediately you become aware of any serious adverse events associated with this research.

You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary. I understand that performance of this study will not infringe on NHS Dumfries and Galloway’s ability to deliver our usual level of service.

May I take this opportunity to wish you every success with your project. Please do not hesitate to seek help and advice from the R&D Support Unit (ext 33164 and 33165) if there is anything which you feel you would like assistance with. I look forward to hearing about your work as it progresses and would appreciate a short annual report and a final report when the study is complete.

Yours Sincerely,

J.R. Lawrence
R&D Director

Cc
Appendix 5

**RE: Caldicott Guardian approval required?**

You replied on 03/04/2014 08:46.

Cameron Angus (NHS DUMFRIES & GALLOWAY)
Sent: 03 April 2014 07:18
To: Whiteley Anna (NHS DUMFRIES & GALLOWAY)

Good Morning,

This sounds straight-forward from my point of view. The patients are freely consenting to the process, and although you describe them as having intellectual difficulty, I presume that they have capacity? If that is the case then I would be happy for you to go ahead With best wishes for your study

Angus Cameron

**From:** Whiteley Anna (NHS DUMFRIES & GALLOWAY)
**Sent:** 02 April 2014 16:50
**To:** Cameron Angus (NHS DUMFRIES & GALLOWAY)
**Subject:** Caldicott Guardian approval required?

Hello,

I am a second year Clinical Psychology trainee currently attempting to submit my IRAS form to NHS ethics. Whilst in the process of submitting my documents to university (University of Edinburgh) I realised I was unsure whether I need to gain Caldicott Guardian approval for my project. My project is qualitative, involving semi-structured interviews with a maximum of ten participants selected from the NHS Specialist Learning Disability Team. The topic is around older adults with intellectual disability and their experience of ageing. Based on my inclusion and exclusion criteria the Community Nurses of the team will suggest and then meet with potential participants in the first instance and then meet them to explain the project in detail and gain their informed consent if they agree. I will not have access to their clinical notes, but once the participants have agreed to take part, their name, age (not date of birth) and address will be passed onto me so I can contact them to set up the interviews. My Clinical Supervisor is Bruce Kidd, Consultant Clinical and Forensic Psychologist, and my Academic Supervisor is Ethel Quayle at Edinburgh.

Do you need further information? I am more than happy to provide anything you might need to make a decision.

Thank you for your help,
Appendix 6

Miss Anna Whiteley
Trainee Clinical Psychologist
NHS Dumfries and Galloway
Mental Health Directorate, Cree West
Crichton Hall, Crichton Royal Hospital
Bankend Road, Dumfries
DG1 4TG

Dear Miss Whiteley

Study title: What do older people with intellectual disability understand about the process and experience of ageing?

REC reference: 14/LO/1145
Protocol number: N/A
IRAS project ID: 142167

The Proportionate Review Sub-committee of the NRES Committee London - Brent reviewed the above application on 18 August 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Ms Julie Kidd, nrescommittee.london-brent@nhs.net.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.
You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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 approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 8 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blayett ([catherine.blayett@nhs.net](mailto:catherine.blayett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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).

Ethical review of research sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Approved documents

The documents reviewed and approved were:

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<th>Date</th>
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<td>GP/consultant information sheets or letters [Letter to GP]</td>
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<td>27 January 2014</td>
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<td>Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flow chart for research project]</td>
<td>Version 1.1</td>
<td>01 February 2014</td>
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Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

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.

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
The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service 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/

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/.

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

14/LO/1145 Please quote this number on all correspondence.

Yours sincerely

PP

Dr John Keen
Chair
Email: nrescommittee.london-brent@nhs.net

Enclosures: List of names and professions of members who took part in the review

“After ethical review – guidance for researchers”

Copy to: Professor Charlotte Clarke
Dr Gwen Baxter, NHS
Miss Anna Whiteley, NHS Dumfries and Galloway
Appendix 7

NHS

Health Research Authority

NRES Committee London - Brent
60 London Road
Skelton House
London
SE1 8LU
Tel: 02079722571

26 August 2014
Miss Anna Whiteley
Trainee Clinical Psychologist
NHS Dumfries and Galloway
Mental Health Directorate, Cree West
Crichton Hall, Crichton Royal Hospital
Bankend Road, Dumfries
DG1 4TG

Dear Miss Whiteley

Study title: What do older people with intellectual disability understand about the process and experience of ageing?
REC reference: 14/LO/1146
Protocol number: N/A
Amendment number: Amendment number 1, 11/8/14
Amendment date: 11 August 2014
IRAS project ID: 142167

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents
The documents reviewed and approved at the meeting were:

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<tr>
<td>Participant information sheet (PIS)</td>
<td>1.3</td>
<td>11 August 2014</td>
</tr>
</tbody>
</table>
Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

14/LO/1145: Please quote this number on all correspondence

Yours sincerely

[Signature]

Dr John Keen
Chair

E-mail: nrescommittee.london-brent@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr. Gwen Baxter, NHS
          Professor Charlotte Clarke
Appendix 8

Journal of Applied Research in Intellectual Disabilities

© John Wiley & Sons Ltd

Edited By: Chris Hatton and Peter Langdon

Impact Factor: 1.137

ISI Journal Citation Reports © Ranking: 2014: 31/55 (Psychology Educational); 38/70 (Rehabilitation (Social Science))

Online ISSN: 1468-3148

Author Guidelines

Crosscheck
The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

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

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

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

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

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

2.1 Authorship and Acknowledgements

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

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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

2.2 Ethical Approvals

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

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

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

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).
The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: [www.clinicaltrials.org](http://www.clinicaltrials.org), [www.isrctn.org](http://www.isrctn.org). The clinical trial registration number and name of the trial register will then be published with the paper.

### 2.4 Conflict of Interest and Source of Funding

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

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

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

**Source of Funding:** Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

### 2.5 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

### 2.6 Copyright Assignment

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

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4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http://mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on ‘create an account’. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

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

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

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.
4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

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

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

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

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

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

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**Main Text:** All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

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