

Loneliness in People with Intellectual and Developmental Disorders (IDD) across the
Lifespan: a Systematic Review of Prevalence and Interventions.

Abstract

Background: The aim of the study was to conduct the first systematic review investigating the prevalence of loneliness in people with IDD and the interventions targeting loneliness.

Method: A search across five databases was conducted (May 2016 - June 2016). One reviewer (A. P.) selected the articles for inclusion and assessed their risk of bias using a standardised tool. The second reviewer (A. H.) examined the list of included/excluded articles and the ratings of the studies. **Results:** Five prevalence studies met the inclusion criteria and provided an average loneliness prevalence of 44.74%. Only one intervention study was included and it demonstrated that there was not any significant group difference for loneliness outcomes ($p = .21$). The majority of the studies had a weak quality rating.

Conclusion: The systematic review evidenced that loneliness is a common experience in people with IDD and there is a need to extend current research.

Keywords: loneliness, prevalence, interventions, intellectual developmental disabilities (IDD)

The term Intellectual Developmental Disabilities (IDD) refers to significant deficiencies in intellectual functioning and adaptive behaviours that originate before the age of 18 (Schalock et al., 2010). People with IDD have an IQ score below 70 and limited practical, conceptual, adaptive and social skills (Schalock et al., 2010). Various alternative terms have been developed internationally for describing the same condition, such as learning disabilities (LD), or developmental disabilities (DD) (MacRae et al., 2015). It has been estimated that approximately 1.04% of the general adult population have IDD (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011).

1. 1 Conceptualisation of Loneliness

Loneliness has been increasingly investigated in the field of mental health. In a recent review exploring concepts relevant to loneliness, loneliness was found to comprise three components (Wang et al., 2016). First, loneliness can be understood as a painful experience that arises when there is a discrepancy between an individual's expectations concerning relationships and his/her actual experience (McVilly, Stancliffe, Parmenter & Burton-Smith, 2006). Second, loneliness reflects the perception that one's emotional and social needs are not being met by the quantity and, especially, the quality of a social relationship (McVilly et al., 2006). Third, loneliness is multidimensional in nature consisting of both a social and an emotional dimension. The former arising when a person has difficulties with social integration and the latter when a person experiences a lack of meaningful and intimate social relationships (Weiss, 1973; Russell, Cutrona, Rose, & Yurko, 1984).

1.2 The Role of Loneliness in Mental Illness

Longitudinal research has identified loneliness as a vulnerability factor for mental health problems in the general population. For instance, Green et al.'s (1992) prospective study demonstrated that loneliness, low satisfaction with life and smoking were associated with an increased incidence of depression 3 years later in an elderly sample. In line with these

findings several longitudinal studies have evidenced that loneliness predicted symptoms of depression up to 10 years from the first assessment (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006; Hagerty & Williams, 1999; Heikkinen & Kauppinen, 2004; Jaremka et al., 2014; Qualter, Brown, Munn, & Rotenberg, 2010).

These findings are in line with previous research suggesting that loneliness might increase the risk for depression because it may be associated with inflammation (Hackett, Hamer, Endrighi, Brydon, & Steptoe, 2012; Jaremka et al., 2013), activation of the hypothalamic–pituitary–adrenal (HPA) axis (Cacioppo & Hawkley, 2003) (this was not the research conducted by these authors) and in the development of maladaptive cognitions (Qualter & Munn, 2005). Nevertheless, it is important to note that only one study examined the effect of loneliness on the incidence of depression, thus further prospective studies in this area are needed.

In people with IDD, loneliness may aggravate their pre-existing vulnerability towards mental health problems (O'Hara, McCarthy, & Bouras, 2010) and is associated with depressive symptoms (Heiman, 2001) and suicidal ideation (Lunsky, 2004; Merrick, Merrick, Lunsky, & Kandel, 2006). However, the number of studies exploring the relationship between loneliness and mental health problems in people with IDD is limited.

1.2 Prevalence of Loneliness in IDD

People with IDD have a greater risk of experiencing loneliness compared to the general population and have a limited social network that is mainly composed of other disability service users, staff and family members (Bigby & Knox, 2009; Lippold & Burns, 2009). Verdonschot, de Witte, Reichrath, Buntinx and Curfs (2009) found that individuals with IDD have an average of 3.1 people in their social network compared to 125 social network members observed in the general population (Hill & Dunbar, 2003). Research focusing explicitly on loneliness is limited but loneliness appears to be prevalent in people

with IDD (Gilmore & Cuskelly, 2014). Guralnick (2006) anticipated that the prevalence of loneliness might be very high in children, as 60%-65% reported facing problems with friendships. These estimations are higher compared to the 10.5% prevalence of loneliness in the general population (Beutel et al., 2017). Several studies have reported that individuals with IDD experienced more loneliness compared to their non-IDD counterparts (Heiman & Margalit, 1998; Luftig, 1988; Williams & Asher, 1992). More recently, Sheppard-Jones, Prout and Kleinert (2005) reported that adults with IDD felt less autonomous, more lonely, more afraid in their homes, and were less likely to have friends. However, they provided no information on how loneliness was defined and measured, indicating a lack of conceptual clarity and consistent measurement of loneliness.

1.3 Increased Vulnerability for Loneliness in IDD

The investigation of the underlying risk factors for the higher prevalence of loneliness in people with IDD is essential. Skill impairments arising from difficulties in communication, comprehension, perspective taking, and information processing are considered to be primary reasons for the increased susceptibility of loneliness in people with IDD (Gilmore & Cuskelly, 2014). Further deficits include behavioural regulation such as the ability to inhibit aggressive behaviours (Bellanti & Bierman, 2000). It is reported that up to 60% of adults with IDD exhibit aggression and around 20% have any challenging behaviours (Koritsas & Iacono, 2012; Lundqvist, 2013). In support to this, Tipton, Christensen and Blacher (2013) found that underdeveloped social skills and behavioural problems among people with IDD at age nine predicted a poorer friendship quality at age 13. Problems with self-regulation also affect the ability to occupy oneself creatively during time alone (Margalit, 2004). Difficulties with initiating self-directed activities can provide an explanation to Heiman's (2000) finding that many people with IDD spend free time alone and engage in passive activities.

Research on the role of contextual factors on loneliness suggests that living arrangements are not directly associated with loneliness (Duvdevany, 2008; Duvdevany & Arar, 2004; Felce et al., 2008; Perry et al., 2013; Stancliffe & Keane, 2000) but may have impact on other quality of life domains that may be related to loneliness. Semi-independent living is associated with greater self-determination, empowerment, and independence in community activity (Felce et al., 2008; Stancliffe & Keane, 2000). Moreover, Perry et al. (2013) argued that advantages of in-area placements included greater participation in community activities, social clubs, and more frequent visits with friends compared to out-of-area placements. Finally, research has shown that living in foster homes was related to greater involvement in leisure activities compared to group homes (Duvdevany, 2008; Duvdevany & Arar, 2004). Duvdevany (2008) suggested that the increased freedom and independence in foster homes accounted for greater motivation in being involved in leisure activities.

1.4 Combating Loneliness in IDD

A recent meta-analysis investigating the effectiveness of loneliness interventions across several populations identified four main strategies: improving social skills, enhancing social support, increasing opportunities for social contact and addressing deficits in social cognition (Masi, Chen, Hawkey, & Cacioppo, 2011). Across the four types of interventions the most effective was the one that aimed to improve maladaptive social cognition (Masi et al., 2011). Unfortunately, the meta-analysis did not involve studies with participants with IDD, therefore, no assumptions can be made about the effectiveness of these options for loneliness in this population.

The development of social network interventions is an emerging approach for people with IDD. In particular, Carter and Hughes (2005) reviewed the evidence for social network interventions among adolescents with IDD and their peers without IDD and found that

combining both social-skill and support-based interventions was the most promising way to promote social interactions. Furthermore, Broer, Nieboer, Strating, Michon and Bal (2011) developed the “social participation improvement project”, which aimed to widen the social networks of people receiving services for IDD or mental disorders. Participants reported feeling less lonely despite the social networks remaining the same. The researchers suggested that improvements in quality of relationships, community integration, and opportunities for talking about social needs could account for the reduction in loneliness (Broer et al., 2011). Nevertheless, the study did not report the number of participants with IDD thus reducing the generalisability of the results to all people with IDD.

The attempts at improving the social lives of people with IDD have been expanded by developing interventions that target the inclusive nature of the greater community. For example, Carlson (2000) aimed to support integration for people with IDD through a city neighborhood-based project specifically designed for facilitating community participation for all citizens. Similarly, Caitlin and Jacobson (2011) described community-wide initiatives to improve neighbourly inclusion instead of focusing explicitly on people with disabilities. However, these interventions require further evaluation in order to investigate their effectiveness in increasing social connectedness and combating loneliness.

1.5 Aims and Objectives

The aim was to carry out a systematic review of the prevalence and management options for loneliness in people with IDD across the life span. In particular the objectives were:

1. To identify the extent to which youth and adults with IDD feel lonely
2. To identify whether interventions targeting loneliness in youth and adults with IDD are effective

2. Method

2.1. Eligibility Criteria

Participants. Studies were included if participants of any age were reported as having intellectual developmental disability, mental retardation, mental handicap, learning disability and mental disability either measured by means of a neuropsychological test or being recipients of specialist care. Concerning the term learning disability it was necessary to check if the samples were defined according to the correct criteria of IDD, as in the USA the term learning disability can be used to refer to dyslexia and other types of specific learning difficulties. Studies that involved participants with genetic conditions that always result in IDD as part of the phenotype (e.g. Down syndrome) were included. Studies involving participants with IDD and comorbidities were included if > 50% of the sample had an IDD or if a subgroup analysis for the IDD group was reported.

Interventions and comparators. Studies of interventions were eligible if they aimed to decrease loneliness in people with IDD. Specific inclusion criteria regarding the components, duration, delivery, format or setting of the intervention were not applied.

Outcomes. For objective 1 of the present systematic review, studies that reported a figure of the proportion of people with IDD who experienced loneliness at a given point in time (point prevalence) or during a specified period (period prevalence) were included. Loneliness prevalence was obtained through quantitative research methods. There were not any inclusion criteria on how loneliness prevalence was measured; single items, surveys and psychometrically validated scales either self or proxy reported were eligible. For objective 2 of this systematic review, the sole eligibility criterion was the report of loneliness as an outcome.

Study type.**Objective 1**

- (i) Observational studies with primary data on loneliness prevalence using cross-sectional, case-control, and cohort designs were eligible. Studies had to include more than 15 participants in order to ensure some degree of methodological quality.

Objective 2

- (ii) Quantitative studies collecting primary data were eligible. These included controlled and uncontrolled pre-post designs, randomised controlled-trials (RCTs), quasi-randomised controlled trials and case studies including single-subject research designs.

English language studies published in peer-reviewed journals were eligible. There was also a date restriction starting from studies published at 2000, as this period was associated with the closure of most NHS institutions housing people with IDD leading to the acceleration of community services (Emerson & Hatton, 1994). Given the differences in mental health service provision, the inclusion of studies before 2000 would not be representative of loneliness outcomes in studies conducted after 2000.

2.2. Search Strategy

Electronic databases including Web of Science, PsycINFO, PubMed, ERIC (proquest) and Embase were searched from May to June 2016, combining synonyms for: intellectual developmental disabilities, loneliness, prevalence, and intervention (see Appendix A for search terms, see Appendix B for the electronic search strategy). Both Medical Subject Headings (MeSH) terms and free text terms were applied for search terms in order to retrieve both broader and narrower terms of similar concepts. The reference lists of studies meeting the inclusion criteria were hand searched for any additional citations. Finally, Google Scholar was searched for identifying unpublished studies. Study authors and other experts of the field

were contacted to identify further studies or provide information on missing data.

2.3. Study Selection

Two reviewers completed the process of study selection. Initially, only one reviewer (A.P.) screened all the titles and abstracts of the studies against the predetermined eligibility criteria. Then full papers of potential relevant studies or studies for which relevance could not be assessed without accessing full text were obtained in order to assess the eligibility of the articles. Then a second reviewer (A.H.) examined an excel sheet depicting the authors, titles and the abstracts of the studies along with the comments of the first reviewer about their eligibility. Any discrepancies were resolved by discussion between the two reviewers.

2.4. Synthesis and Data Extraction

One reviewer (A.P.) initially completed the narrative synthesis and data extraction process with the second reviewer examining them. In particular, two structured data extractions forms were developed as the systematic review aimed to address two objectives. For the first objective, details of each eligible study including its first author (year, country), participants' characteristics, design, measurements, and findings regarding prevalence of loneliness and related outcomes were extracted. For the second objective, similar data were extracted with the addition of intervention information and findings related to intervention outcomes.

2.5. Quality Assessment

The studies of the systematic review were assessed using the Quality Assessment Tool for Quantitative Studies (EPHPP, 2009). The tool was used in order to assess the following criteria: (i) selection bias, (ii) study design, (iii) confounders, (iv) blinding of outcome assessors and participants, (v) data collection methods, (vi) withdrawals and drop-outs. The reviewer attributed one of the following ratings for each domain of criteria: strong, moderate or weak risk of bias. Then a final global rating was attributed for each study

depending on the ratings in the aforementioned six criteria. One reviewer (A.P.) completed the quality assessment of the studies and discussed the findings with the second reviewer (A.H.). Additional descriptive information was provided regarding the role of sample size, sampling or information bias and confounding variables for each study.

3. Results

3.1 Study Selection

The search resulted in 730 studies (after duplicates removal) whose titles and abstracts were screened. A flow diagram showing the study selection process is demonstrated in Figure 1. A significant proportion of studies were excluded at the abstract screening stage, as they did not meet the inclusion criteria of the review (see Figure 1). This left 58 studies that were identified as potentially relevant for inclusion based on their abstracts. Hand searching of references identified two additional papers leaving in total 60 papers that were considered for full text review. Of the retrieved full texts 54 studies were excluded. Six studies were selected for inclusion in the final review.

3.2 Study Characteristics

The five prevalence studies and one intervention study included in the review are presented in Table 1 and Table 2 respectively.

3.3 Included Studies

Dates of publication and country of study. The six studies were published between 2006-2015. One study was conducted in the Netherlands (Lehmann, Bos, Rijken, Cardol, Peters, & Curfs, 2013) and Australia (Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015) and the other four studies were conducted in the USA (Ailey et al., 2006; Stancliffe, Lakin, Doljanac, Byun, Taub, & Chiri, 2007; Stancliffe, Lakin, Taub, Chiri, & Byun, 2009; Stancliffe, Larson, Auerbach, Engler, Taub, & Lakin, 2010).

Age and gender. Only an adult population was included in the studies with a mean

age of 49.86 years; range 42.55 (Stancliffe et al., 2010) to 55.60 (Stancliffe et al., 2015). The gender distributions favored male participants in 5 of the 6 studies (Stancliffe et al., 2007; Stancliffe et al., 2009; Stancliffe et al., 2010; Stancliffe et al., 2015; Lehmann et al., 2013).

Number of participants per study. There was significant variation in the sample size included from 7,996 participants (Stancliffe et al., 2010) to 100 participants (Ailey et al., 2006). The overall sample across the 6 studies was 11,685.

Diagnosis of IDD. In two of the 6 studies all participants had an IDD, whilst in the remaining four the greatest majority had an IDD (97.1% in Stancliffe et al., 2007; 97.5% in Stancliffe et al., 2009; 95.9% in Stancliffe et al., 2010; 69% in Stancliffe et al., 2015). One study also included participants with a diagnosis of Down syndrome (Ailey et al., 2006). Where reported, the majority of participants had a mild level of IDD with the most common co-existing condition being mental illness.

Study design. All of the prevalence studies were cross-sectional designs providing an estimation of the point prevalence of loneliness. The intervention study was a matched intervention and control group with pre-test and post-test assessments.

3.4 Quality Ratings of Studies

The quality rating of each study is demonstrated in Table 3. Two of the prevalence studies (Ailey et al., 2006; Lehmann et al., 2013) and the intervention study (Stancliffe et al., 2015) received a weak quality rating (i.e. two or more weak component ratings) while the other three prevalence studies received a moderate quality rating (i.e. only one weak component rating). In particular, all of the studies were rated weak in study design and moderate in blinding assessors and participants to outcomes. One study was rated weak in selection bias as the participants were self-selected (Stancliffe et al., 2015). In the rest of the studies participants were randomly selected but there was no report of the percentage of participants who refused to participate or randomisation processes. One study was rated

weak in reporting the number and reasons of drop-out/withdrawals as it did not provide the relevant information (Lehmann et al., 2013). One study was rated weak in data collection methods due to the absence of reporting the reliability and validity of the instruments (Lehmann et al., 2013). Two studies were rated weak for controlling confounders (Ailey et al., 2006; Lehmann et al., 2013) whereas the rest of the studies were rated moderate.

3.5 Findings for Prevalence of Loneliness and Related Outcomes in People with IDD

Prevalence of loneliness. The mean loneliness prevalence in people with IDD across all five studies was 44.74%. The lowest loneliness prevalence was 38% and the highest was 50.2% (Stancliffe et al., 2007). In one study that sampled solely participants with Down Syndrome the prevalence of loneliness was 40% (Ailey et al., 2006).

Prevalence of related outcomes. Other prevalence outcomes identified across the included studies were: 40% of participants felt that they wanted more friends or had no friends (Ailey et al., 2006), 32% of participants had high depression scores on the CDI-S screening measure (Ailey et al., 2006), 83.2% (Stancliffe et al., 2009) and 85% of people felt happy (Lehmann et al., 2013), 88.6% liked where they live (Stancliffe et al., 2009), 72% and 83% of people felt satisfied with life (Lehmann et al., 2013), 20.2% felt afraid at home and 20.7% felt afraid in the neighbourhood (Stancliffe et al., 2009). All of the prevalence outcomes were obtained through self-report measurements.

Factors associated with loneliness prevalence. Various variables were examined in order to explore their effect on loneliness. Initially, Ailey et al. (2006) investigated the association between loneliness and the experience of depression and found that they were positively associated. Similarly, Stancliffe et al. (2009) observed that across a number of *personal characteristics* only having a psychiatric diagnosis was positively associated with experiencing greater loneliness. Moreover, Stancliffe et al. (2007) found that an additional *personal characteristic* that was inversely associated with loneliness was age, as age

increased, loneliness decreased. Consistently, Lehmann et al. (2013) showed that age was a significant negative predictor of loneliness. However, Stancliffe et al. (2010) demonstrated that age as well as use of aided Augmentative and Alternative Communication were not related to loneliness.

Concerning *living arrangement* variables, it was found that being recipients of either Home and Community Based Services (HCBS) or Intermediate Care Facility Services (ICF/MR) and the choice of where to live, did not have an effect upon loneliness. Living in a large residence setting (7 + residents) was associated with greater loneliness, and the choice of living companions as well as living with family was related with less loneliness (Stancliffe et al., 2007; Stancliffe et al., 2009). However, the finding that a larger residential setting was a positive predictor of loneliness was not replicated in Stancliffe et al.'s (2010) study.

Furthermore, having *social contact* with friends and family was found to be associated with less loneliness (Stancliffe et al., 2007; Stancliffe et al., 2010). Two out of the three *social climate* variables, including being afraid at home and neighbourhood, were associated with greater loneliness, whereas liking where you live, was related to less loneliness (Stancliffe et al., 2007; Stancliffe et al., 2010). Finally, among variables related to *personal resources* it was demonstrated that social satisfaction, having a partner, having children and living independently were not predictors of loneliness whereas better physical health was a negative predictor of loneliness (Lehmann et al., 2013).

3.6 Interventions for Loneliness in People with IDD

Intervention. Stancliffe et al. (2015) developed an intervention that aimed to enable older people with IDD to reduce attendance at work/day program by one day per week in order to join a community group. Existing members of the community groups who did not have IDD were trained to provide support and guidance to people with IDD facilitating their participation in the activities of the group.

Control group. The work hours remained the same and there was not any attendance to community groups.

3.7 Findings for Interventions with Loneliness

Loneliness. Stancliffe et al.'s (2015) study involved two measures of loneliness: the UCLA Loneliness Scale (UCLALS) and the Modified Worker Loneliness Questionnaire (MWLQ) that assesses loneliness and social satisfaction. There was not a significant group-difference in self-reported loneliness in response to both of the loneliness measurements. However, the intervention participants ($M = 11.43$, $SD = 0.95$) were significantly more socially satisfied at post-test than the comparison group ($M = 10.17$, $SD = 1.90$) ($p < .001$).

4. Discussion

4.1 Summary of Findings

This was the first systematic review aiming to provide a broad overview of research on loneliness in people with IDD, to estimate the prevalence of loneliness and to evaluate the effectiveness of loneliness interventions. Five prevalence studies including adult populations were retrieved and demonstrated that loneliness is a widespread problem in people with IDD. Specifically, an average loneliness prevalence of 44.74% was estimated across a total sample of 11,685 adults with IDD. Concerning management options for loneliness, only one study was retrieved aiming to reduce loneliness through facilitating community group participation for older adults with IDD (Stancliffe et al., 2015). Through a matched intervention and comparison group design, it demonstrated that participants were more socially satisfied relative to the comparison group. Nevertheless, it was found that the intervention was not effective in reducing feelings of loneliness, highlighting the fact that combating loneliness is a challenging process that requires more comprehensive efforts.

4.2 Limitations of Included Research Studies

The quality assessment of the studies showed that there were no strong quality studies. Most of the prevalence studies had large samples reporting demographic information, but there was an overrepresentation of males and a restriction to mild/moderate IDD populations of USA, Netherlands and Australia preventing broader generalisations. As a related matter, the researchers of the studies did not refer to the operational definition of IDD, the means of diagnosis and how well participants meet the criteria for IDD. Another important limitation of the prevalence studies was that the majority of them did not provide a definition and some general conceptual information regarding loneliness. Additionally, the prevalence of loneliness across all studies was obtained through a single question (Lehmann et al., 2013; Stancliffe et al., 2007; 2009; 2010) and a single loneliness-item of the Children's

Depression Inventory Short Form (CDI-S) instead of validated loneliness scales, highlighting the lack of a conceptual framework for loneliness. Another limitation of using single-items that explicitly ask about loneliness is that they might result in underreporting, as lonely people carry a social stigma making it harder to express feelings of loneliness (Lau & Green, 1992). Given the absence of longitudinal experimental research it is also hard to establish causation between loneliness and the factors found to be associated with it across the prevalence studies. An important limitation of the intervention study was that it was based on a matched controlled design and was not randomised, which increases the risk of selection bias. Finally, most of the research has been conducted by a specific research group (Stancliffe et al. 2007; 2009; 2010; 2015), thus, there is a need of additional independent research groups to replicate the findings in order to be considered empirically supported (Chambless & Hollon, 1998).

4.3 Limitations and Strengths of the Systematic Review

A key limitation of systematic reviews is that they provide findings that are as reliable as the studies included (Murad et al., 2014). Consequently, the conclusions of this systematic review are limited by the low quality of the original studies. Moreover, given the limited research on this topic in the field of IDD wide inclusion criteria were developed in order to obtain collectively as many studies as possible. For example, there were not any exclusion criteria regarding the means of diagnosis, the age of participants, and the type of study designs, weakening the extent to which the findings between studies can be compared and synthesized. Moreover, restricting the language to English-only publications increased the risk for language bias.

Although the processes of study selection and quality appraisal were standardised they were based on the subjective judgments of the two reviewers. Having more than two reviewers who independently assess the studies would have been more effective in reducing

error and subjectivity. It should also be noted that the reviewers were not blinded to journal name, author, and institution. However, evidence suggests that it is a time-consuming process that its value in reducing bias is still unclear (Centre for Reviews and Dissemination, 2009).

Strengths of the review were the development of predefined eligibility criteria based on the PICOS acronym (Participants, Interventions, Comparisons, Outcomes, Study Type) (Higgins & Green, 2011), a detailed display of how papers were identified, and a thorough quality assessment of the studies using a standardised instrument. Such procedures improve the transparency and the reproducibility of the systematic review.

4.4 Findings of the Systematic Review in Relation to Previous Research

The higher loneliness prevalence in people with IDD compared to the 10.5% loneliness prevalence observed in the general population (Beutel et al., 2017) is consistent with previous research (Williams & Asher, 1992; Heiman & Margalit, 1998; Luftig, 1988; Sheppard-Jones et al., 2005). This finding supports the notion that various reciprocal factors related to (i) the cognitive and behavioural impairments of people with IDD (ii) the negative attitudes of the general population and (iii) the limited opportunities for social interaction, contribute to the increased susceptibility towards loneliness in people with IDD (Gilmore & Cuskelly, 2014).

A high proportion of participants also felt that they were not satisfied with their social life and were experiencing depressive symptoms, demonstrating the co-occurrence of loneliness along with other poor quality of life outcomes and mental health problems. With respect to the prevalence of other well-being issues, the finding that the majority of participants reported high levels of life satisfaction and happiness was unexpected, as previous research has demonstrated that loneliness is inversely correlated with these variables (Schultz & Moore, 1988; Schumaker, Shea, Monfries, & Groth-Marnat, 1993). The researchers suggested that this could reflect the occurrence of psychological homeostatic

mechanisms that maintain the average life satisfaction independently of other emotional variables (Cummins 1995, 2005; Lehmann et al., 2013). Thus, future research needs to expand our understanding of the coping styles involved in life satisfaction and loneliness.

The review found that only two studies supported that older age was marginally associated with less loneliness; those studies had the higher mean of middle age (44.53 in Stancliffe et al., 2007; 46.73 in Lehmann et al., 2013). A meta-analysis with the general population demonstrated that loneliness has a U-shaped relationship with age across middle and late adulthood; loneliness will decrease in middle age (mean age < 60 years) and rise in very old age (mean age > 80 years) (Pinquart & Sorensen, 2001). One possible explanation for the reduction of loneliness in the middle age is that adults have developed a stable network and have learned to adapt their emotional needs to the available opportunities (Ryff, 1989; Tornstam, 1992). Similar explanations can be applied to the findings of the review suggesting that people with IDD closer to middle age are less likely to feel lonely. Future research involving subgroup analyses of the effect of age on loneliness is necessary in order to support the U-shaped relationship in an IDD population.

Another personal characteristic that was positively associated with loneliness was psychiatric diagnoses. This finding is consistent with previous research in people with IDD showing that loneliness is associated with symptoms of depression (Heiman, 2001). Similar results have been obtained from longitudinal prospective studies in the general population supporting that loneliness increases the risk of depression (Green et al., 1992). The finding that loneliness was marginally associated with poor physical health highlights the fact that both physical and mental health problems are interrelated with feelings of loneliness in people with IDD. Research has indicated that changes in inflammation and the HPA axis could constitute a common pathway by which loneliness increases the risk for physical (Adam, Hawkley, Kudielka, & Cacioppo, 2006) and mental health problems (Hackett et al.,

2012; Jaremka et al., 2013).

Regarding living arrangements, it was found that smaller residence settings, living with family, and choice of living companions were associated with less loneliness. Consistent with these findings, previous research has shown that smaller residence settings characterized by greater autonomy and freedom of choice were associated with greater social satisfaction in people with IDD (Felce et al., 2008; Stancliffe & Keane, 2000). Moreover, the studies of the systematic review displayed that a general satisfaction with living arrangements along with reduced feelings of fear in one's home and neighbourhood counteracted feelings of loneliness. Although the studies did not examine what factors were related to feelings of fear, previous research suggests that being afraid of other residents is a serious and common problem in the lives of people with IDD (Hewitt, Larson, & Lakin, 2000; Whaite, Stancliffe, & Keane, 1999). Feelings of fear may be related to the experience of incompatibility with other people, triggering loneliness (Margalit, Tur-Kaspa, & Most, 1999; Stancliffe et al., 2007).

This suggestion can provide further explanation of the inconsistent findings regarding the effect of residence size on loneliness, with two studies finding a significant association (Stancliffe et al., 2007; 2009) whereas another showing no association (Stancliffe et al., 2010). It could be implied that instead of the residential size per se having an effect on loneliness, it could be other factors related to this. For instance, in settings with a larger number of residents there is a greater risk of conflict, or less attention by care providers, or less privacy for the development of intimate relationships. Future research exploring these variables is necessary in order to understand the association between loneliness and residence settings.

The review found that social contact with friends and family was associated with lower levels of loneliness. This supports the notion that a richer social life reduces experiences of loneliness (Duvdevany & Arar, 2004; Hawkley, Browne, & Cacioppo, 2005; Peplau & Perlman, 1982). The lack of a significant effect of social satisfaction, life satisfaction and having children or partner on loneliness was an unexpected finding, as relationships that nurture, provide a sense of security, and satisfaction are considered necessary for fulfilling inherent social needs (Weiss, 1973; Russell et al., 1984). One possible explanation for this may be that social and life satisfaction reflected a stable trait that is influenced by individual temperament instead of an emotional state (Stancliffe et al., 2010). It can also be argued that having children or partner per se does not have an impact on loneliness but it is the nature of relationships with these family members that are important. For instance, Asselt-Goverts, Embregts and Hendriks (2015) found that one of the most valued elements of a relationship with family members in people with DD is affection. Sullivan, Bowden, McKenzie and Quayle (2016) added that feeling valued, accepted, and independent is necessary for the maintenance of close relationships. Thus, the exploration of the nature of relationships with close network members could have yielded significant results.

Finally, Stancliffe et al. (2015) suggested that the ineffectiveness of their intervention in reducing loneliness could be attributed to the absence of components targeting the development of social relationships outside of the community groups. Thus, the social connections of participants were restricted to the community integrative settings. Based on previous research it can be proposed that interventions are more likely to be effective if they are multicomponent. For instance, Carter and Hughes (2005) found that the effectiveness of social network interventions was optimised when both social-skill and support-based components were combined. Similarly, Broer et al., (2011) suggested that the holistic nature of their approach targeting the quality of social and emotional relationships as well as

community integration could account for the effectiveness of their social network intervention.

4.5 Implications for Future Research

Future research should examine the prevalence of loneliness in children and adolescents in order to identify any differences across various age groups. The prevalence of loneliness should also be compared across different cultures and countries (Lehmann et al., 2013). Moreover, as most of the research has been conducted with people with mild to moderate IDD there is a heightened need for future studies to include people with severe to profound IDD. Given the conceptual issues concerning loneliness, it is necessary for future researchers to develop a clear conceptual framework for loneliness and to include loneliness scales. Such work has been initiated by Wang et al. (2016). In this regard, it will be informative to include validated measurements that differentiate between the emotional and social dimension of loneliness (i.e. De Jon Gierveld & Van Tilburg, 2010).

Although the studies of the review explored the effect of several factors on prevalence of loneliness, there is a need to extend research to investigate additional factors such as important life events (Lehmann et al., 2013), quality of relationships with family members and professionals (Hermsen, Embregts, Hendriks, & Frielink, 2014), social media (Amado, Stancliffe, McCarron, & McCallion, 2013) and the experience of stigma and discrimination. Moreover, in an attempt to understand the role of loneliness in mental illness it will be informative to develop longitudinal prospective studies with loneliness as a predictor of future incidents of psychiatric disorders. Randomised controlled trials (RCTs) of intervention studies are also necessary for investigating the causal relation between loneliness and psychopathology. For example, if RCTs demonstrate that loneliness interventions are effective in improving mental health problems then there is considerable evidence to suggest that loneliness constitutes a causal mechanism for the development of mental illness.

Additionally, conducting RCTs with large samples and long-term follow-ups is of vital importance for evaluating interventions targeting loneliness. Finally, qualitative research should also be conducted to obtain information about the various aspects of the social lives of people with IDD (e.g. emotional value of intimate relationships) and also explore the views of family members, friends and the general community about what works to reduce loneliness.

4.6 Implications for Practice

The review found that poor physical and mental health was associated with greater loneliness, indicating that treatments for comorbid psychiatric or physical problems in people with IDD should also include elements that improve their social lives. Additionally, living arrangements should be considered when exploring loneliness and individuals should be provided with greater choice and self-determination. Greater independence can be achieved if carers move from a caring to a supportive role that encourages people with IDD to fulfill their wishes and needs (Abbott & McConkey, 2006). Finally, it is important for people with IDD to live in a safe environment with compatible residents that enables them to have frequent contact with family and friends.

The lack of effective interventions in reducing loneliness demonstrates that current therapeutic approaches need to be developed on the basis of a theoretical framework about the roots of loneliness in people with IDD. For instance, given the inherent skill impairments of people with IDD it is necessary to develop therapeutic components that aim to improve their social competence through leisure activities (Duvdevany & Arar, 2004), social-skill interventions related to the development of relationships and practical-skill training (e.g. adequate transportation) (Abbott & McConkey, 2006). Moreover, adding Cognitive Behavioural Therapy-based interventions to therapeutic practices could be a promising future implication as Masi et al.'s (2011) meta-analysis evidenced that interventions addressing

maladaptive social cognition were the most promising. The initiative to incorporate diverse therapeutic components in loneliness interventions should take place along with efforts to create inclusive community environments that will nurture social relationships. Thus, there is a need to continue and expand the work of Carlson (2000) and Caitlin and Jacobson (2011) in developing community-wide projects.

4.7 Conclusion

People with IDD have an increased vulnerability to experiencing loneliness, and it is associated with depression. Given that this systematic review is limited by the low quality of the studies, future research needs to focus on the longitudinal relationship between loneliness and symptoms of mental illness, and on interventions to tackle loneliness.

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Appendix A

Search Terms

Search Terms in Relation to Intellectual Disabilities and Truncated Variants

Intellectual disability

intellectual* disab*

intellectual* disorder*

intellectual* impair*

Mental retardation

mental* retard*

mental* challenged

mental* handicap*

mental* impair*

mental* deficien*

Learning disability

learning disab*

learning disorder*

learning impair*

Developmental disability

development* disab*

development* disorder*

development* impair*

subaverage intelligence

Search Terms in Relation to Loneliness

Loneliness

Lonely

Social isolat*

Search Terms in Relation to Prevalence of Loneliness and Intervention

Prevalence*

Questionnaire*

Survey*

Measure*

Intervention*

Therap*

Treatment*

Rehabilitation*

Appendix B

Electronic search strategy

PsychInfo

Limit: "2000-Current" AND English

("Intellectual* Disab* ".mp. OR exp "Intellectual Developmental Disorder"/ OR "Intellectual* Disorder* ".mp. OR "Intellectual* Impair* ".mp OR "Mental* Retard* ".mp. OR "Mental* Challenged ".mp. OR "Mental* Handicap* ".mp. OR "Mental* Impair* ".mp. OR "Mental Deficien* " OR exp "Learning Disabilities"/ OR "Learning Disab* ".mp. OR exp "Learning Disorders" OR "Learning Disorder* ".mp. OR "Learning Impair* ".mp. OR "Development* Disab* " OR exp "Developmental Disabilities OR "Development* Disorder* ".mp. OR "Development* Impair* ".mp. OR "Subaverage Intelligence.mp.") **AND** (Loneliness.mp. OR exp Loneliness OR Lonely.mp. OR exp "Social Isolation" OR "Social Isolation.mp. OR "Social Isolat* ") **AND** (Prevalence*.mp. OR exp Questionnaires OR Questionnaire*.mp. OR Survey*.mp./ OR exp Surveys/ OR Intervention*.mp. OR exp Intervention OR Therap*.mp OR Treatment*.mp. OR exp Treatment/ OR Rehabilitation*.mp. OR exp Rehabilitation OR Measure* OR exp Quantitative Methods)

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Conflict of Interest

None known