Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model

Linda Gilmore* and Monica Cuskelly†
*Queensland University of Technology and †University of Queensland, Brisbane, Qld, Australia

Abstract Research with typically developing groups has identified loneliness as a significant predictor of a range of physical and mental health problems. This paper reviews research about loneliness in children and adults with intellectual disability. Although a considerable body of evidence has highlighted the difficulties individuals with intellectual disability have with friendships, there is a relative scarcity of research focused explicitly on loneliness. The available evidence suggests that up to half of persons with intellectual disability are chronically lonely, compared with around 15–30% of people in the general population. The cognitive, physical, and mental health problems already associated with intellectual disability are likely to be compounded by experiences of chronic loneliness. We argue that people with intellectual disability are highly vulnerable to loneliness and present a theoretical model of vulnerability that comprises three reciprocally influencing domains: social attitudes and expectations; opportunities and experiences; and skill deficits associated with intellectual disability. We propose that societal views that have traditionally devalued and stigmatized persons with intellectual disability limit their opportunities for experiencing social and emotional connectedness with others. Individual skill deficits in areas such as communication, self-regulation, and social understanding, as well as functional difficulties associated with intellectual disability, also potentially influence the opportunities and experiences of people with intellectual disability, both directly and via multiple layers of the social context. In turn, limited opportunities will entrench particular skill deficits and reinforce negative attitudes toward intellectual disability. The model proposed in this paper provides a starting point for developing a more sophisticated understanding of the experience of loneliness for individuals with intellectual disability.

Keywords: emotional isolation, friendship, intellectual disabilities, loneliness, social isolation

INTRODUCTION

In the general population, loneliness has been associated with a range of adverse life outcomes including physical and mental health problems and poor quality of life. There is now evidence that at least some of these deleterious outcomes result from, rather than merely co-occur with, loneliness (see e.g., Lente et al., 2012; Schinka, Van Dulmen, Bossarte, & Swahn, 2012). The links from loneliness to depression have been well documented (e.g., Aanes, Mittelmark, & Hetland, 2010; Qualter, Brown, Munn, & Rotenberg, 2010), with suicide being the most extreme outcome (Schinka et al., 2012). Other aspects of mental health, such as externalizing behavior and anxiety, have also been linked to loneliness in the general population (see Hawkley & Cacioppo, 2010).

There are also consequences for physical health. The underlying mechanisms are still not completely clear, but it seems that loneliness triggers an inflammatory response in the body that increases physical health risks, particularly for cardiovascular disease (Hawkley, Thisted, Masi, & Cacioppo, 2010). In a compelling example of the long-term implications of childhood loneliness, data from the Dunedin Longitudinal Study (Casp, Harrington, Moffitt, Milne, & Poulton, 2006) showed that cardiovascular disease risk was significantly elevated in a subgroup of the sample that had been socially isolated as children 20 years earlier. The association remained after controlling for other risk factors such as childhood weight, socioeconomic status, smoking, and stressful life events. The inescapable conclusion was that loneliness has persistent and cumulative adverse effects on adult health.

Lifestyle factors that have been linked to loneliness include smoking (DeWall & Pond, 2011) and alcohol abuse (Bonin, McCreary, & Sadava, 2000). Lonely people also engage in less physical activity (Newall, Chipperfield, Bailis, & Stewart, 2013), are more likely to be obese (Lauder, Mummery, Jones, & Caperchione, 2006) and, in later life, display greater cognitive decline (Wilson et al., 2007).

Individuals with intellectual disability have higher rates of mental health problems than those without intellectual disability, both during childhood (Einfeld, Ellis, & Emerson, 2011) and in adulthood (Bhaumik, Tyrer, & McGrother, 2008). Their physical health is substantially worse (O’Hara, McCarthy, & Bouras, 2010), their quality of life is consistently found to be poorer (Walsh et al., 2010), and many have difficulties with
following a healthy lifestyle (Jobling & Cuskelly, 2006). The scarcity of research about loneliness and intellectual disability means that the extent to which loneliness contributes to these outcomes is unknown. However, for individuals with intellectual disability whose life opportunities are already constrained to varying degrees by cognitive and health factors, further declines in functioning are of considerable concern, particularly if they result from preventable or modifiable factors. Mental health disorders such as depression and anxiety may be triggered or worsened by loneliness; physical health problems could be exacerbated; cognitive decline may intensify; and lifestyle choices (e.g., smoking, alcohol consumption, and reduced physical activity) could potentially compound all of these outcomes.

As we will argue, it is likely that people with intellectual disability are highly vulnerable to loneliness. Our aims in this paper are to review the research evidence about friendships and loneliness in children and adults with intellectual disability and to develop a theoretical model that describes the risk factors and pathways that create an increased vulnerability for social and emotional isolation.

CHALLENGES IN UNDERSTANDING LONELINESS

Measurement Issues

Establishing a clear understanding of loneliness and intellectual disability is a difficult undertaking because of a number of issues related to the conceptualization and measurement of loneliness. In describing the construct, two interrelated features have been distinguished: social isolation and emotional isolation (Weiss, 1982). Those who feel they do not belong to a social group experience social isolation while those who feel they have no intimate, reciprocal relationships experience emotional isolation (Asher, Parkhurst, Hymel, & Williams, 1990; Hoza, Bukowski, & Beery, 2000).

Social connectedness can be determined, at least partially, by establishing the amount of time an individual spends with others or the number of friendships the person identifies. Such measures are insufficient to tap loneliness, however, because people may feel emotionally isolated and thus lonely even when surrounded by others; conversely, some may not feel lonely even if they have few social relationships. Measuring emotional isolation is a more difficult task, as it relies on self-reporting about one’s inner states. Individuals with intellectual disability have a tendency to be acquiescent (Carlin et al., 2008) and may have difficulty in responding to Likert-type scales (Hartley & MacLean, 2006). As a result, there are often concerns about the reliability of their responses to questionnaire measures (e.g., Cuskelly & Gordon, 2011). In order to tap into the personal perceptions of people with intellectual disability, some researchers have successfully employed a range of alternative or additional approaches, including semi-structured interviews (McVilly, Stanciliffe, Parmenter, & Burton-Smith, 2006a), pictorial scales (Watt, Johnson, & Virji-Babul, 2010), and sentence completion tasks (Dykens, Schwenk, Maxwell, & Myatt, 2007).

Another measurement issue relates to the developmental nature of friendship and loneliness. From research with typically developing children and adolescents, we know that understandings change with age and experience. Younger children view friends simply as playmates, whereas older children and adolescents recognize also the supportive and intimate nature of their role and are able to differentiate among different types of friends—some may be the repository of secrets, while others are called upon when one wants to dance and sing. Once children have been at primary school for a year or two, most have developed an understanding of loneliness that extends beyond the social dimension, recognizing the feelings of sadness that characterize emotional isolation (Chipuer, 2004; Liepins & Cline, 2011). For children and adults whose cognitive development is delayed or atypical, however, there is likely to be a mismatch between their understanding of the roles, demands, and benefits of friendship and that of their same-age peers. This means that different expectations and experiences may need to be considered when using self-report measures of loneliness in this population.

Developmental Aspects

Developmental aspects of friendships and loneliness are important in any model of vulnerability. The issues relate both to the developmental status of the individual and to the expectations and experiences of these individuals. Adolescence is a high-risk time for loneliness in the typically developing population (Franklin & Tranter, 2008), and some of the contributing factors (e.g., physical maturation and autonomy expectations; Laursen & Hartl, 2013) apply also to those with intellectual disability. In addition, social and environmental changes, such as those associated with the transition to high school, may mean fewer or more fragmented opportunities for social interactions as well as increased salience of the gap between the abilities of students with intellectual disability and their peers.

One of the most significant attainments of adulthood is the formation of one or more intimate, romantic relationships. Romantic relationships have both personal and social functions, and it is likely that many adults with intellectual disability hold the expectation that such a relationship will form part of their life. But stable intimate relationships are elusive for many people with intellectual disability. Marriages occur less frequently than in the general population, and individuals with severe intellectual disability rarely marry (Hall et al., 2005). The absence of an intimate relationship when such a relationship is desired will contribute to the experience of loneliness.

Older age is a time of increased loneliness in the general population (Victor & Yang, 2012). Not only are many adults with intellectual disability now living longer (Janicki, Dalton, Henderson, & Davidson, 1999) but also they tend to experience more risk factors for loneliness including grief and loss (Brickell & Munir, 2008), ill health (Paul & Ribeiro, 2009), and negative life events (Hulbert-Williams et al., 2014; Palgi, Shriya, Ben-Ezra, Shiovitz-Ezra, & Ayalon, 2012).

An important point to keep in mind is that intellectual disability is not a homogenous condition—individuals with intellectual disability may range in intellectual capacity from someone with only mild impairments in cognitive and adaptive skills who is able to live relatively independently, hold down a...
job, and interact effectively with others, to those who require support in all aspects of daily living, who have no ability to communicate with strangers, and whose likes and dislikes are established only through many years of close caring. The research evidence we discuss below comes almost exclusively from studies of children and adults who have mild or moderate, rather than severe or profound, levels of intellectual impairment, a lack that may reflect measurement difficulties or possibly a view that individuals with more severe intellectual disability are incapable of establishing meaningful friendships. (For an interesting discussion of profound intellectual disability and friendship, see Hughes, Redley, & Ring, 2011.)

RESEARCH ABOUT FRIENDSHIPS AND LONELINESS

A considerable body of evidence has highlighted the difficulties individuals with intellectual disability have in initiating, establishing, and maintaining friendships. As children, they participate in fewer social activities with friends and are reported by parents to have fewer reciprocal friendships than their typically developing peers (Solish, Perry, & Minnes, 2010). Adolescents with intellectual disability tend to spend more time alone (Buttiner & Tierney, 2005). Adults, too, are less socially engaged and their friends tend to be others with intellectual disability (Emerson & Hatton, 2008). Bigby and Knox (2009) found that the social relationships of older adults with intellectual disability were largely restricted to paid staff, family, and others with intellectual disability. Among those with profound levels of intellectual impairment, very few have regular contact with friends (Emerson & Hatton, 2008).

There is clear evidence that some adults with intellectual disability understand the characteristics of friends and friendship, including the centrality of communication, the need to keep some disclosures confidential, to forgive one another, and to provide assistance when asked (McVilly et al., 2006a; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b). There are also adults who have difficulty with the concept of friendship, identifying people with whom they spend a lot of time, such as care workers, as friends or claiming friendship with television personalities or characters (Jobling, Moni, & Nolan, 2000).

Chappell (1994) challenged the field to consider the focus of friendship research with those with disability. Often underlying this research was the philosophical approach of inclusion (termed “integration” in 1994), which led to an emphasis on friendships with nondisabled people and devalued friendships with others with disability. McVilly et al. (2006b) found that many individuals with intellectual disability felt that friendships, particularly best friendships, could occur only with another person with intellectual disability. Their reasoning included both the need for friends to be “equal” and also the rejection and dominance they experienced when mixing with others, an experience also recounted by participants in a study by Diez (2010).

There is a relative scarcity of research focused explicitly on loneliness, but consistent with findings from studies with other atypical groups, the evidence generally indicates that those with intellectual disability report higher levels of loneliness. Compared with around 15–30% of people in the general population (Heinrich & Gullone, 2006), it is estimated that up to half of those with intellectual disability are chronically lonely (Stancliffe et al., 2010). For children, Guralnick (2006) puts the estimate even higher, claiming that 60 to 65% have difficulties with friendships and consequent social isolation.

In an investigation that asked children with intellectual disability directly about their experience of loneliness, Williams and Asher (1992) found that 8- to 13-year-old boys with mild intellectual disability reported more loneliness than their typically developing peers, but that difference was not evident for girls. Luftig (1988) assessed loneliness in students who were attending mainstream schools and concluded that, in comparison with other students, they were significantlylonelier and more isolated. Although Heiman and Margalit (1998) found that younger children with intellectual disability were lonelier than their typically developing peers irrespective of whether they attended mainstream or special schools, the findings were different for adolescents. Those in special schools self-reported more loneliness and depression than those who were integrated in regular classrooms, and there were no differences in loneliness for the latter group compared with their typically developing classmates (Heiman, 2001). The mainstreamed students in this study may have acquired better social skills through modeling their typically developing peers or they may have experienced fewer friendship obstacles such as emotional dysregulation.

Findings from studies of adults with intellectual disability have suggested that the experience of loneliness is common. Almost half of the samples studied by Stancliffe and colleagues (Stancliffe et al., 2007; 2010) reported being lonely at least sometimes. A study of adults with Down syndrome found that 40% reported they were lonely all the time, and loneliness was significantly associated with depression (Ailey, Miller, Heller, & Smith, 2006). In addition, links of loneliness with suicidality have been established for adults with intellectual disability (Lunsky, 2004; Merrick, Merrick, Lunsky, & Kandel, 2006).

INTELLECTUAL DISABILITY AND VULNERABILITY FOR LONELINESS

Three reciprocally influencing domains contribute to the increased vulnerability to loneliness experienced by those with intellectual disability: features of the social world in which they live, their experiences (or lack thereof), and characteristics associated with intellectual disability. Our model reflects the bio-psycho-social model of disability and includes some characteristics (described below) that we believe are inherent to intellectual disability. Figure 1 shows the hypothesized pathways of influence. Social attitudes and expectations are arguably the most influential aspect of this model, with opportunities and experiences being next most important. We propose that societal views that have traditionally devalued and stigmatized those with intellectual disability (Wolfensberger, 2000) limit their opportunities for experiencing social and emotional connectedness with others. Individual skill deficits in areas such as communication, self-regulation, and social understanding, as well as functional difficulties associated with intellectual disability, also have the potential to influence the opportunities and experiences of people with intellectual disability, both directly and via
The model explicitly acknowledges the connection between attitudes and skill deficits through the limited opportunities and negative experiences afforded to those with intellectual disability. It also postulates a direct link between skill deficits and attitudes. Those who differ from the majority in any substantive way are very likely to be marginalized and accorded fewer opportunities within society (Wolfensberger, 2000).

Social Attitudes and Expectations

While society has become more inclusive over the past few decades, intellectual disability remains a stigmatizing characteristic (Scior, Potts, & Furnham, 2013). The general population holds substantial reservations about interacting with this group and some believe that segregated settings, such as special schools, are the most appropriate (see Scior, 2011). Segregation, while a consequence of the negative attitudes of the community, also feeds back into attitudes. If the general population has little opportunity to engage with people with intellectual disability in regular schools, workplaces, and community settings, they are more likely to be seen as different, deviant, and unpredictable, thus reinforcing negative societal attitudes. In a meta-analysis of 515 studies of intergroup prejudice, Pettigrew and Tropp (2006) showed the value of contact in breaking down negative attitudes. The importance of contact has also been established in breaking down prejudice (Krajewski & Flaherty, 2000; McManus, Feyes, & Saucier, 2011).

Opportunities and Experiences

Wolfensberger’s (1998; 2000) theory of social role valorization provides a framework for understanding the impact of contexts on the opportunities provided to individuals with intellectual disability. The (lack of) value attributed to those with intellectual disability means that they are more likely to be placed in special schools or separate classes, segregated in special residential settings, and employed in sheltered workshops, if at all. Thus, the experiences of many individuals with intellectual disability fall along a spectrum from reduced opportunity for social engagement to outright rejection. Their social network may be restricted to others with intellectual disability, precluding important modeling opportunities. Difficulties with establishing and maintaining friendships may be a consequence of their devalued status as well as their difficulty in behaving in ways that are congruent with peer expectations (Guralnick, 2006).

There is no doubt that the contexts in which individuals with intellectual disability live, learn, and work have the potential to impact on their capacity for developing social networks and participating in mainstream activities, particularly beyond the school or work settings. For many individuals with intellectual disability, leisure activities are undertaken with paid “friends” (Jobling et al., 2000) and meaningful engagement with others in the community is rare (Gilmore, Campbell, Shochet, & Roberts, 2013; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Because of low rates of employment and poor wages, adults with intellectual disability generally have limited financial resources that restrict their ability to access recreational settings where they might establish friendships. They are also likely to be dependent on others for transport to social venues and they often have little autonomy about the nature and timing of social encounters (Jobling & Cuskelly, 2002).

Those with intellectual disability experience more negative life events, some of which may increase vulnerability to loneliness. In particular, individuals with intellectual disability experience more personal loss (e.g., through high turnover of staff in support organizations). In addition, there is evidence that they experience more complicated grief than others (Brickell & Munir, 2008). These negative experiences, in turn, may impact on mental health, itself a barrier to relationships (as discussed below).

Characteristics of Intellectual Disability

Associated with intellectual disability are a range of characteristics that make individuals more vulnerable to chronic loneliness. Social relationships can be compromised by difficulties in areas such as communication, perspective-taking, social information processing, attention, and self-regulation. Some genetic syndromes are characterized by atypical social phenotypes, such as hypersociability in Williams syndrome (Jarvinen, Korenberg, & Bellugi, 2013) and social withdrawal in Fragile X (Cornish et al., 2005). Difficulties with social relationships may stem from brain-based differences but the social environment, if one of rejection, potentially acts to canalize or exacerbate them.

Some individuals with intellectual disability have difficulty regulating their own behavior and inhibiting aggressive responses (van Nieuwenhuijzen, Orobitg de Castro, & van Aken, 2009), thus increasing the likelihood that they will be excluded or rejected by their peers (Bellanti & Bierman, 2000). In typically developing children, externalizing behavior has been linked via
peer rejection to loneliness (Pederson, Vitaro, Barker, & Borge, 2007). The predictive importance of externalizing behavior was demonstrated in a longitudinal study of children with development disabilities (Howell, Hauser-Cram, & Kersh, 2007). Children with fewer problem behaviors at age 3 had lower levels of loneliness at age 10.

Problem behaviors are likely to continue into adulthood (Totsika & Hastings, 2009) and to have a cascading effect, limiting opportunities to observe and practice appropriate social skills, and in turn impeding the establishment and maintenance of friendships. There is evidence to suggest that up to 60% of adults with intellectual disability have problem behaviors such as aggression, and around 20% display very challenging behaviors such as self-injury and sexual inappropriateness (Koritsas & Iacono, 2012; Lundqvist, 2013). Challenging behaviors are likely to restrict social relationships and community inclusion. For those with more severe intellectual disability, challenging behaviors occur with a prevalence as high as 80% (Poppes, van der Putten, & Vlaskamp, 2010) and often precipitate segregation (Perry et al., 2013). The estimated 20 to 30% of individuals with intellectual disability who have comorbid autism spectrum disorder (Bryson, Bradley, Thompson, & Wainwright, 2008; Saemundsen et al., 2010) display more social deficits and higher rates of challenging behavior, and consequently experience greater social exclusion.

Sometimes seen as an inherent part of intellectual disability (Whitman, 1990), problems with self-regulation are relevant not only with respect to behavioral regulation. An important self-regulatory skill that protects against loneliness is the ability to occupy oneself productively during time alone (Margalit, 2004). Individuals with intellectual disability are likely to have more difficulty with self-regulatory skills, such as initiating and sustaining self-directed activities (Kasari & Freeman, 2001). As a result, many may spend solitary time engaged in passive pastimes such as sleeping or watching television (Heiman, 2000), unless they are given sufficient opportunities to develop the capacity for self-regulating their time alone.

As indicated at the beginning of this section, contextual attitudes and expectations, opportunities and experiences, and individual characteristics are likely to interact and to reciprocally influence one another. As one example: The social rejection experienced by those with intellectual disability leads to segregation, which reduces opportunities for modeling and enhancing social skills; inadequate social skills combined with emotional dysregulation may lead to aggressive behaviors that result in peer rejection and even fewer opportunities to develop effective social skills; inaccessibility to peer networks may encourage directive parenting that restricts the development of self-regulatory skills. Aggression, poor self-regulation, and parental over-involvement will all contribute to the social stigma associated with intellectual disability and to devaluing of the individual.

FUTURE DIRECTIONS FOR RESEARCH AND PRACTICE

The scarcity of research on the topic of loneliness in those with intellectual disability is at least partly the product of difficulties with robust measurement of internal states in this population, and it will prove difficult for the field to progress until this problem is overcome. Research is likely to be best served by a developmental perspective that takes account of levels of cognitive functioning along with recognition of the nontypical social experiences of many individuals with intellectual disability. We need to identify the experience of loneliness (and also of friendship) in those with intellectual disability across the life span to understand the consequences of loneliness for these individuals and to identify the contributors to loneliness. The model proposed here provides a starting point with respect to this last task.

Interventions around issues of social connectedness are almost always focused on the skills deficits identified in persons with intellectual disability, although there are some notable exceptions where programs have been developed in an attempt to foster friendships between community members and persons with an intellectual disability (see e.g., Fish, Rabidoux, Ober, & Graff, 2006). Unfortunately, while this may be the area in which change is most easily accomplished, it is unlikely to be effective in altering the quality of life of those with intellectual disability unless there are also changes in the opportunities made available for them to participate in the social life of the community. For some individuals with intellectual disability, no skills-based intervention will be sufficient to develop appropriate interpersonal skills. Without change in the value accorded to those with intellectual disability—irrespective of ability level—then opportunities for friendship and emotional closeness will be curtailed.

CONCLUSIONS

Despite a considerable body of research about loneliness and its correlates and consequences in the general population, studies of children, adolescents, or adults with intellectual disability are relatively infrequent. Generalizing from research with nondisabled groups is likely to be risky, given the possibility that people with intellectual disability may understand, experience, and interpret loneliness somewhat differently. In addition, the correlates, mediators, or pathways of loneliness may differ. Nevertheless, it is clear that loneliness is important, that people with intellectual disability are almost certainly lonelier than those in the general population, and that the cognitive, physical, and mental health problems already associated with intellectual disability are likely to be compounded by experiences of chronic loneliness.

Research is imperative for establishing a more sophisticated understanding of loneliness and intellectual disability. This understanding will better equip us to foster social connectedness for people with intellectual disability and to prevent the adverse outcomes that are associated with chronic loneliness, thus enhancing their social and emotional well-being and quality of life. As Wolfensberger (2000) pointed out, personal relationships are the key to quality of life for people with intellectual disability.

REFERENCES


