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ORIGINAL ARTICLE

Loneliness and how to counter it: People with intellectual disability share their experiences and ideas

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ABSTRACT

Background: People with intellectual disability are at higher risk of experiencing social isolation in their everyday lives, because of exclusionary practices, discriminatory social policies and structural exclusion. However, less is known about what people with intellectual disability themselves think about loneliness in their lives and what might alleviate it.

Method: In this inclusive research study, 17 people with intellectual disability participated in focus groups or individual interviews and talked about what makes them feel lonely and what helps them to feel included.

Results: Our findings indicate that the domains of interaction, participation, personal security and attitudes are areas of strong influence on people's experience of inclusion and exclusion and hold opportunities for positive change.

Conclusions: Change at systems and community levels is needed to ensure people with intellectual disability are included, have access to disability-ready places that respect their human rights, listen, recognise and include their strategies to alleviate loneliness.

KEYWORDS
Loneliness; social isolation; inclusion; participation; attitudes; rights

Growing evidence from research conducted with people with intellectual disability has indicated that they experience high rates of loneliness and social isolation and are at significantly increased risk when compared with people without intellectual disability (Emerson et al., 2021; Merrells et al., 2019). Studies of loneliness in the general population describe varying rates of loneliness in adults, in different countries and, often based on age (Emerson et al., 2021; Hawkley & Cacioppo, 2010; Macdonald et al., 2018; Victor & Yang, 2012). Around one in three (33%) of adults in Australia experienced loneliness between 2001 and 2009, which increased to 35–36% during the COVID-19 pandemic (AIHW, 2021). Emerson et al. (2021, p. 6) found that people with disability "should be considered to be at increased risk of exposure to loneliness and that this exposure may be an important mediator for their lower wellbeing." A recent study found 73% of people with an intellectual disability reported feelings of loneliness (Macdonald et al., 2018). While the high number highlights the extent of loneliness among people with intellectual disability, research into how and why they are lonely and what can be done to address loneliness is limited. The perspectives of people with intellectual disability of their experiences have not been widely canvased.

This study aimed to explore the perspectives, experiences, and priorities of people with intellectual disability around loneliness and how to prevent it. In this article, we explore the views and experiences expressed by people with intellectual disability from the study. Understanding what people think and how they feel about their lives can open new perspectives about addressing loneliness and supporting people to have happier and more fulfilling lives.

Research question

What do people with intellectual disability say about loneliness, particularly around what helps prevent it? What are the implications of their priorities and insights for policy and practice?

Background

Loneliness has many dimensions and is nested within the concepts and experiences of social isolation, social inclusion and wellbeing. It is a social and emotional concept and can be understood as "an emotional response to the fact that a person's need for connection to others is not satisfied" (Svendsen, 2017, p. 15). Loneliness is influenced by the quality of connections and

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engagements with others, and experienced when the discrepancy between the number and kind of interactions and connections we desire is not met by the number and quality of connections we experience (Petroutsou et al., 2018; Wigfield et al., 2020). Although loneliness and social isolation are intertwined, they are different concepts. Social isolation is more clearly defined around the objective lack of social contact or support (Poscia et al., 2018; Veazie et al., 2019). Perceived isolation is "tantamount to feeling unsafe" (Hawkley & Cacioppo, 2010, p. 220) and has direct implications for feeling lonely.

Experiences of loneliness are an affective dimension of interpersonal relationships and community participation, influenced by the conditions of social inclusion. A recent systematic study identified three factors that impact on and contribute to loneliness for people with intellectual disability; negative attitudes of the general community, limited opportunities for social interaction and the impacts of intellectual and behavioural impairment (Petroutsou et al., 2018, p. 653). These reciprocal factors influence opportunities for developing social networks, social engagement and encounters with others and form the basis for experiences of belonging and inclusion, or loneliness. A study with young people with intellectual disability (aged 18–24) focused on social inclusion in community and identified two themes. Participants in that study explained that they were "segregated and treated like an outcast in my community" and had "challenges in experiencing, initiating and maintaining peer friendships" (Merrells et al., 2019, p. 16).

There is a small literature grounded in the perspectives of people with intellectual disability about loneliness and what might alleviate it. The Building Bridges Inclusive Research Group (Mooney et al., 2019) completed research about their own experience of social isolation and found barriers to getting involved included transport, anxiety and fear, lack of choice and control and risks to personal safety. They recommended accessible information, increased support and advocacy and attention to community safety. McVilly et al. (2006) conducted interviews with people with intellectual disability about their experience of loneliness. They reported that people who felt most lonely had least reciprocity in their relationships with friends and felt the lack of a network of support that met their social and emotional needs.

Social inclusion sits counter to loneliness and has interpersonal relationships and community participation as central domains (Hawkley & Cacioppo, 2010; Olsen, 2018; Simplican, 2019; Simplican et al., 2015). It is a complex construct with both narrow and broad definitions and measures. Social inclusion can mean "access to activities, social roles and relationships with non-disability citizens" through to "being valued, trusted and competent" (Simplican, 2019, p. 117). Simplican (2019) draws on Amado et al, to suggest that measurement of social inclusion needs to include frequency, choice and intensity, to capture experience and preference in more depth.

While there is little attention directly to the experience of loneliness, policies to activate the rights of people with intellectual disability and improve social inclusion have been in place since the 1980s, influenced by the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007; Wiesel & Bigby, 2014). More recently in Australia, these policies have been implemented through the goals of the National Disability Strategy (Commonwealth Government, 2011) and the recent Australia's Disability Strategy (Commonwealth Government, 2021). The NDS adopts principles of the UNCRPD, including for people with disability to have "full and effective participation and inclusion in society" (Commonwealth Government, 2011, p. 22). These policies remain aspirational for many people when it comes to meaningful social inclusion within their communities. People with intellectual disability remain among the most marginalised members of the population (Macdonald et al., 2018), and both scholars and activists highlight the need for improved social inclusion and ways to "promote happiness and wellbeing" (Simplican, 2019, p. 117).

Encounter, belonging and participation

Social and urban geography has generated a rich body of theory about social inclusion, and the concepts of encounter, belonging and participation, as factors that counter loneliness. Encounters are those daily engagements with the world, incidental meetings with others, particularly with strangers in close geographic proximity. Wiesel and Bigby (2014) argue that encounters facilitate experiences of social inclusion in those moments, and the intensity can be measured along a continuum of community presence through to community participation. In such encounters, people with intellectual disability and others have opportunities for engagement with each other that hold both possibility for recognition and the risk of failing to meet expectations (Wiesel et al., 2020). These are chances for people to be recognised or known and can produce moments of conviviality and hold potential for new relationships and belonging.

Belonging is a subjective construct, about being emplaced in context, place and relationships (Jansen-van Vuuren & Aldersey, 2020). Belonging is a sense of being "at home," belonging in and to place, and a form of "socio spatial inclusion" (Antonsich in Strnadová et al., 2018, p. 1092). For young people with intellectual disability, identities and belonging are conceived around the concepts of "who I am, people I know, places I go, and things I do," and the relationships they have in places and spaces (Robinson, Hill, et al., 2020, p. 58). Interpersonal relationships of reciprocity and respect are important aspects of belonging, underpinned by factors of wellbeing, including having a purpose, participation (Jansen-van Vuuren & Aldersey, 2020; Strnadová et al., 2018) and "having things to do" where you "feel a part of something" (Foley et al., 2012, p. 380).

Simplican (2019) also unpacks the concepts of belonging and participation. Participation is when people are able to take up opportunities and engage in social, economic and civic life, and move beyond encounters and community presence; "participating and being included is important because it makes people feel good" (2019, p. 117). Stigma, exclusion, and discrimination impact on participation and are common for people with intellectual disability, although research suggests attitudes are changing (Jansen-van Vuuren & Aldersey, 2020). People with intellectual disability "notice a sense of belonging, commitment and ability to make their own choices" when participation occurs (Byhlin & Käcker, 2018, p. 172). Further, participation in meaningful activities has shown to have a "significant positive impact on loneliness for people with intellectual disability" (Wilson et al., 2017, p. 847).

In framing loneliness through encounters, belonging and participation, it is important to address how we understand, and what we want or expect from community participation. Is loneliness a product of community that resists complexity and focuses on shared sameness and not diversity, justice and dignity?

Framework for analysing loneliness

Our focus was on the experiences of people with intellectual disability, and their ideas and advice about how to mitigate or prevent loneliness. To provide a context for this we have situated our analysis using the Wigfield et al. (2020) framework for understanding social isolation and loneliness. The framework identifies meaningful interactions as the fulcrum around which understanding of loneliness and social isolation builds. It looks closely at the distinction and overlap between these concepts and opens space to explore social relationships and meaning in interaction (Wigfield et al., 2020).

Wigfield et al. explain that engagement with others, in the "right kinds of societal conditions" is where people are more likely to experience meaningful interactions (2020, p. 6). These are encounters that support wellbeing and take place within four interconnected domains – interaction, participation, safety or security, and attitudes, influenced by individual markers, geography and key life events (Wigfield et al., 2020, p. 2). This framework of meaningful interactions across the domains and factors provides a useful perspective for recognising what impacts on and affects loneliness.

According to Wigfield et al, the *interaction* domain includes contacts or encounters with others that are not formal or organised. The *participation* domain is connected to having a voice and political representation, being involved in social, cultural and civic activities and having access to work. The *personal security* domain consists of feelings of security and safety. Feelings of perceived threat can reinforce negative social interactions and close the cycle of fear, which prevents interaction and participation and promotes loneliness. *Attitudes* determine our everyday lives and can determine if we are content to go into public space or not, and how we experience the interactions or engagements we have with others. For some, the "social stigma of disability" can impact on when or if a person might participate or interact with others (Wigfield et al., 2020, p. 16). The effect of each domain impacts on a person's opportunities for meaningful interactions.

People with opportunities for social interactions are less likely to feel lonely, however, the quality and nature of the interactions is important, and *meaningful* interaction – that is a positive interaction, that is not only superficial, with someone who is valued, can reduce feelings of loneliness (Wigfield et al., 2020). Meaningful interactions and participation operate within a loop of influence, shaping and responding to a person's sense of inclusion and loneliness (see also Simplican et al., 2015). These are influenced by a person's sense of security and their own attitudes and those of others.

Overarching the domains are factors of individual markers and transitory life events. Individual markers are personal characteristics and circumstances, which include aspects of socio-economic security and geographic location and intersect with how we understand disability. In this analysis, rather than view disability as an individual marker, as noted in the framework (Wigfield et al., 2020, p. 29) or factor of identity, we consider the relational nature of engagements with others. We approach the other factor "transitory life events," noting that the events themselves and their impacts may be short lived or long-lasting (Figure 1).

Methods

This qualitative study followed methods of inclusive research practice, working with a community researcher with intellectual disability and an advisory group comprising people with intellectual disability who are active members of a self-advocacy group (Bigby & Frawley, 2010; Di Lorito et al., 2018). Tim Cahalan (TC), the community researcher, provided lived experience perspective when the study was being conceived and later when it was conducted. TC supported JI and SR in developing interview and focus group questions, facilitating group interviews, contributing to data analysis, and developing an easy read report.

The advisory group provided feedback through two workshops at the preliminary stages of the project about research design, and one workshop on data analysis following data collection. The advisory group also provided information about their own lives and wanted this to be included as research data. SR and JI presented the findings and the results at an in-person workshop to people involved with organisations supporting the research, prioritising self-advocates by publishing results first in an easy-read report.[1]

Participants

The study participants were recruited through a self-advocacy organisation of people with intellectual disability and their networks. Recruitment was at arms-length working through a partner organisation. JI presented information about the study at a self-advocacy information meeting and distributed flyers. The partner organisation also advertised on their website and in newsletter, with a snowball effect. Interested participants were asked to contact the partner organisation for more information if they were interested. Initial enthusiastic interest in participation waned following the sudden shutdown of [state] due to a COVID-19 outbreak. Adult participants comprised women ($n = 9$) and men ($n = 8$), living in a range of accommodation including group homes, alone with support, independently or with family. Participants ranged in age from their mid-twenties to seventy, all were from urban areas, and all but one from the same state in Australia. All were able to provide consent on their own behalf, and able to reflect without difficulty on their own experience with the help of plain English language and pictorial mapping methods. People's capacity to consent was confirmed by support people in the self-advocacy services who knew them well. The researchers followed principles of assent, watching closely for any indications that people were uncomfortable with lines of questioning or were ready to stop the interview. No participants or their supporters reported distress arising from the interview process.

Data collection

Data collection was conducted iteratively, relying on guidance and expertise from our co-researcher [name] throughout and the advisory group in the initial, mid-point and concluding stages. Following advisory group and community researcher guidance the focus for the study was on what supports people to feel included and to belong, and this was done purposefully to avoid dwelling too heavily on painful subjects. Their guidance also influenced how information was shared with participants, with an emphasis on presenting ideas using images and plain English.

Participants were invited to either an individual or small group interview, whichever they preferred. Four people took part in an individual interview (40–70 min). Ten people preferred small group interviews (80 and 90 min). Four people brought trusted support people with them, mostly to help with communication and confidence. Meetings were held at the meeting room of the organisations helping us with recruitment (a familiar and private space), two interviews were at research participants' homes, and one interview was conducted by phone. The partner organisation circulated Easy Read information and consent forms prior to the interviews. Participants completed consent forms at the interview, some with assistance from the partner organisation representative, and after any questions had been satisfactorily answered.

The study received Ethics Approval from Flinders University, HREC 2118. The researchers were careful not to cause or trigger emotional harm and the interview format was developed to ensure participants were engaged in positive aspects of being included as the interview concluded. This approach was refined and encouraged by the advisory group.

Data analysis

All interviews were audio-recorded transcribed (with consent) and deidentified for analysis, and each person assigned a pseudonym for reporting. The interviews were semi-structured with the focus and interests of the participants leading discussions. Pictorial mapping was used during the interviews (excluding the phone interview) to highlight main themes and ideas. Mapping supports participant engagement with research findings in real time and allows participants opportunities to review their ideas and correct any misinterpretation

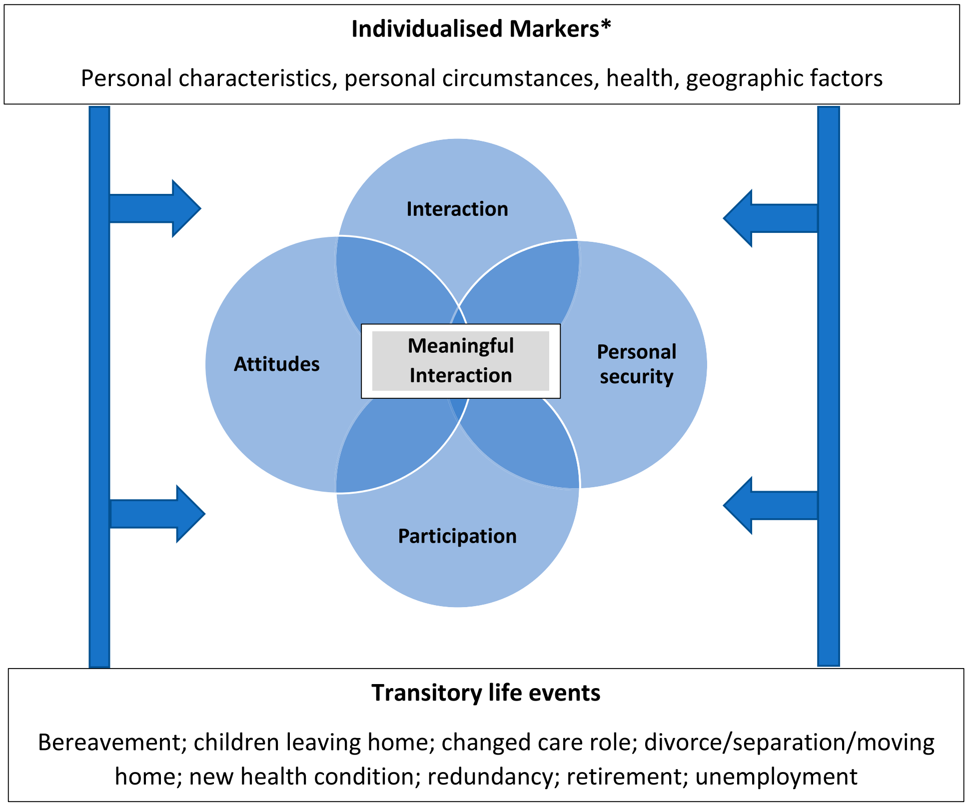

Figure 1. Framework for understanding the nature and experience of meaningful interaction (Wigfield et al., 2020).

(Impellizzeri et al., 2017). Mapping included both images and text with participants' preference for images, and the use of representative images for concepts (Näykki & Järvelä, 2008).

Transcripts were thematically coded in a descriptive coding structure confirmed by members of the research team, SR, JI and TC, who had all taken part in the fieldwork. JI analysed the data following the codes and themes discussed using the software program QSR NVivo 12. Iterative categorisation, a systematic technique for transparently managing qualitative data, was employed as this had been used effectively in previous inclusive research (Neale, 2016; Robinson, Graham, et al., 2020). We applied the descriptive themes from the first round of coding to the core constructs of the Wigfield et al. (2020) framework to each research question in turn to build up a shared understanding of participants' experiences filtered through feelings, action, attitudes, relationships and values. A reflective diary kept by JI was also used to inform analysis and team discussions. Following preliminary analysis by the research team, the initial findings in Easy Read format were presented to the advisory group in a workshop for discussion and feedback. Discussing these with the advisory group and community researcher helped us to identify particular priority areas and identify findings that resonated strongly with people's lived experience.

Findings

The collective insights of participants identified that many people had shared experiences and priorities about how they support themselves and adjust to experiences of loneliness, and how other people in the community and organisations might support them to feel welcomed, respected and included. They explained the barriers and facilitators of inclusion, exclusion and loneliness, and their views made visible systemic structures and attitudes that contribute to these experiences. These findings are presented under the organising themes of interaction, participation, personal security and attitudes, and are aligned with the Wigfield et al. (2020) meaningful interaction framework domains.

Interaction

Positive interactions are shown to contribute to wellbeing, occur in place and in conditions of trust and mutuality, where the potential reward of such encounters is one of conviviality (see also Wiesel et al., 2020).

Interactions determine a person's social connection with others, and these vary from in-person encounters to those by email, phone or social media, and also occur in public space.

Feeling unheard, devalued and disrespected

Almost all people in this study told us that, although some of their interactions with others were positive, many were not. Many participants described experiences and examples of times when they felt lonely as a result of being disrespected, excluded, or overlooked. Often, this loneliness was about feeling unheard and unrecognised as a person of value. Jenny described how she found it difficult to go to places where people did not know her, as strangers rarely had the patience to listen to her or took the time to understand her speech or ideas. Peter explained interactions where he felt excluded, and how this affected his confidence:

> Being put down and told I'm not good enough or when my speech all stutters everywhere and nothing comes out right.

Countering loneliness through interaction – encounter and equality

Quite a number of people explained they experienced inclusion through casual encounters on the street, in the shops or the café and through long-term friendships and relationships. Many people described how these encounters were important to their sense of belonging and community. These were things like being recognised at a local café, where people knew their name or their drink order, being a member of the local RSL club, or being respected by fellow gym members for progressing after an injury. Doug said that in his local area:

> There's a coffee shop round the corner. They know my name and the reason I support there is sometimes they employ people with disabilities in that shop.

Almost all participants had clear messages about how to prevent loneliness and improve inclusion. To counter their experiences of negative interactions, many participants talked about the importance of being treated equally. For them, this centred on respect, equality, and human rights, seeing the person and not the disability and valuing all people across the community. Many people said that it was important people without disability made opportunities and time to listen, and they wanted to see other people facilitate community inclusion experiences – that the effort should not be always their responsibility.

Participation

Participation is how we engage with the world, how we are heard and take part in community and society.

Participation, people and places

In our study, every participant described places where they felt at ease and included, and also those places where they definitely felt excluded. Many participants explained that being familiar with the people in those places often influenced whether they felt they could participate. Going somewhere new or meeting new people, who may express ableist or discriminatory attitudes toward people with intellectual disability, made interactions difficult, impacted on their confidence, and made participation a challenge.

Many people highlighted that the key factors that alleviated loneliness were being able to do things with other people, being invited to events and celebrations, going out, and participating in things they wanted and liked to do. These things were interwoven – for example, Toby explained that it is good to have someone to talk to, to be with other people and have a lot of fun. Many participants talked about having some control over their lives and several described a passion, making art, drawing, writing and studying, making cards, volunteering or having a hobby.

People described developing relationships and friendships through participation. For many people, developing and maintaining friendships required a level of support from others, often family, support staff or organisations. Positive, helpful and encouraging support workers and collegial or friendly homes impacted on participation in activities and interests, self-advocacy and for some people, in work. Many people described friendships formed over time and through participation in a shared activity, such as being in the same gym class.

> … just built up a friendship over years of, you know, I used to have lunch in the canteen, you know, on your half hour for lunch and I'd go into the pool from the gym. I'd meet people out in the gym and then I'd meet the ladies from the exercise class out at the pool and so you built up a bit of a friendship with them and they included you in their social groups and that sort of thing. (Peter)

Alice explained group activities provided opportunities for meaningful interactions that helped her feel included and part of something and introduced her to new things.

> Alice: Well, … I've been involved in that. And a friend has got me involved in with the Lion's

> charity … She's got me involved in everything now, so it's great.
>
> JI: And do you like that?
>
> Alice: Love it, love it. We've been like together ever since.
>
> JI: What do you love about it?
>
> Alice: Well, the fact that I've been introduced to new areas, events, by a friend and I think that's great, it's something that's never happened to me before, it's terrific.

Access to information and the right support

Participation often required access to the right supports, and relationships with support workers were frequently the gateway to taking part. Several participants with mobility or communication issues described how workers' attitudes, capability and capacity determined their participation. Support workers who acted in ways that showed they had the person's rights at the centre of their decisions and actions were talked about as examples of positive and "good" support. "Good" support actively facilitated participation "and made you happy" (Jasmine). This was illustrated in the many ways that people described their participation in activities they enjoyed, such as Jim attending self-advocacy meetings, Peter doing ocean swims, Alice going to the pool, and Jasmine going bowling.

All the participants in this study described how good support made participation in group activities possible. Many of these activities were disability-specific and some were based on interests, exercise, craft, choir, and volunteering. For some participants, asking for help to participate was hard and finding the right place to go was also important.

> So, finding the right type of community that I want to be involved with, that's the big picture I am aiming for that. (Darren)

The impact good support made to participation was illustrated by Jim's experiences. He described the difference between one support worker who always "wrote in his book" (daybook/diary) and made sure he could attend activities he wanted to go to, and others who often prevented his participation despite being planned:

> Yeah, all the times when I go … with other staff there's, "No, you can't go there." (Jim)

Like many other people with intellectual disability, Jim experienced barriers to participation through system structures that prevented him from taking part, unhelpful support worker attitudes and when information was not presented in ways that he could understand.

For those many people without good support, participation and relationships suffered or could not be developed to the extent that people wished. For people living in shared or group accommodation, sometimes friendships required ongoing support to be maintained. Anna talked about how a close relationship faltered when her friend, who she had lived with for some time, moved house. For them, meeting up was complicated and outings relied on other people, support workers or family members, to arrange and often fell through. Anna found it "hard." When we spoke, she had given up on that friendship and focused on keeping up with people online, using TikTok or other social media.

Anna also talked about feeling a loss when her close support worker moved jobs and was no longer part of her support team. She had felt confident to do new things with that support worker, but her confidence fell, and she was now limiting her activities.

Self-advocacy

Several participants in this study were involved in self-advocacy groups and they talked about a shared sense of purpose from their participation. They described how the interactions and relationships formed in the groups helped them to feel included and they felt they were contributing to their community. Frank had been involved with self-advocacy for a long time, and said he was "part of the family now, part of the furniture … I partly grew up there." Frank had a long-term friendship with one of the other members.

In discussing loneliness, many participants' advice was that feelings of loneliness and being excluded can be alleviated through activating their rights. They found that knowing and advocating for their rights had been a positive experience and helped them to have a purpose – which led to meaningful interactions with a range of people, with and without disability. Darren suggested that knowledge of human rights should be extended across the community, so that everyone knew people with disability have rights and that this would improve community inclusion. Annika spoke about the importance of education:

> We are teaching people their rights and people – they've got a right to say no, and they've got a right to go to another company [for NDIS services] … Because I can speak out if they can't talk for themselves, I can speak out for them.

Many participants were generous with their ideas of how to support each other and others experiencing loneliness. Many talked about how they could take responsibility for those who felt lonely and suggested they would use their own support networks to help. Annika was quick to recommend that if others needed help, they would do well to contact her support coordinator, who she relied on. Alice talked about places where you could get helpful information and offered to pass that on. Many people suggested they would make time to listen to the person and ask what they could do to help. Julie explained it is important people understand they can speak up and that helps.

> Speak up for your rights and you got rights to say something, and you got rights, you don't have to do anything, you just tell them. (Julie)

Personal security

Personal security and safety are when a person feels safe, can go about their lives, and are at ease to participate in activities at home and outside home in public.

Feeling safe and secure

The behaviour and attitudes of other people toward people with intellectual disability had a strong impact on many participants and everyday negative interactions on participants' sense of personal security was striking. Participants talked at length about things other people in the general community did and said, which left them feeling excluded and lonely. They described being laughed at, bullied, ignored, overlooked, put down, and treated as less valued than others.

The effects of this pervasive lack of welcome and disrespect were described powerfully by Don, when he talked about how he feels when he wants to engage with the wider world:

> When you try and mix with other people, you always step carefully. At my old place, I've been cracked across the jaw for saying hello to somebody they don't want to know me because of my disability. … I go and say hello to her and [she] puts me down … people out there, if you are not the same as them, you don't say hello to anybody, they don't want to know you, then they ring up the cops.

Loneliness, abuse and neglect

The long tail of historical abuse was also evident in the ways that some of the older participants in this study navigated their personal relationships and how they felt about stepping outside of their immediate circles. Julie, an older participant, described how her sense of personal safety was compromised in the place where she lived thirty years ago due to abuse. Her account of this time remained clear in her memory, as she talked about being hit by another resident, abused and locked into a small room by staff. These experiences left her fearful and needing time and support to establish trust. Her memories of negative support in two different group homes illustrate how history affects people's experiences and determines the kinds of supports people need to feel safe:

> Julie: Well in [previous housing] they wouldn't let me go out, they let the other group go, they said I had to stay in by myself and I felt lonely … there was no night staff coming around.

By contrast, Julie described how the support workers in her current accommodation facilitate her many activities, are concerned for her personal safety, provide a sense of security and ensure she had the transport and supports she needs. Julie also talked about the close relationships she had with people she lived with. Julie's positive experience of building trusting relationships with her housemates and support staff helped her to feel safe. Other people expressed similar sentiments, saying support must be based on trust and respect, it needs to be flexible, and responsive to people's will and preference.

Personal relationships and personal security

In considering what helped to mitigate a sense of loneliness and a stronger sense of personal security, participants described important personal relationships and friendships. Several people talked about how friendships build over time, are valued, create a sense of belonging and a deep-seated sense of security (see Frank and Julie above).

People told us said that having someone to talk to, a person who you trust and who treats you well are important factors in alleviating loneliness. Some people said they had no one to talk to or no one who would listen to them. Peter explained that trust and respect are also critical to support worker relationships, (having "good support") to ensure people felt safe at home and also able to participate in the world.

> Even in your own home, trust is very much an important part. You might be in your [house], they might have ducked up to your bedroom or something, you don't know what they're doing. (Peter)

Several participants were in committed relationships and said that this stopped them from being lonely. Some participants did not have family or did not see their family, and those with family had mixed experiences. For ethical reasons, there was limited conversation about interaction and relationships with family members and its effects on loneliness to minimise the risk of distress to those people with difficult or no family relationships.

Jane's experience illustrated the connection between family relationships, personal security and participation. Due to outside factors, Jane's living situation changed, which led to her feeling lonely lacking control over her daily decisions. When Jane's mother moved into aged care, her siblings stepped in to support her, however, her brother's fear for her safety and her sibling's approach to support was quite restrictive. Where previously Jane travelled independently and was involved in a range of community activities, she was no longer allowed to and she lost any opportunity to meet people or go out.

> No as I just said – not allowed to leave … But when I used to work, yeah, used to have heaps of friends. (Jane)

Attitudes

Attitudes are both those we hold and have toward others and those we perceive others display or hold toward us. Attitudes strongly influence and shape the other domains of the framework, interactions, participation and personal security.

Attitudes about disability and loneliness

Participants described how their own attitudes had positive impacts on feeling included and allaying loneliness, but also, as in the findings above, how the attitudes of others shaped their experience, supported them to feel included or made it obvious that they were left out. There were diverse views. Don talked about his identity as a disabled man, and how he often felt misunderstood:

> People don't really understand – we can't turn off our disabilities at all. We live it on a daily basis. Some people, they go to work from nine to five, then they turn off. We can't turn off. We take every day as it comes, and how we work it out around our disability. (Don)

Darren described his approach and philosophy around disability and the importance of education for the broader community, about disability. He explained:

> Now, I believe that if you've got a disability, then within reason, within your realistic ambitions and stuff you can do it. You can put your mind to it by having the right support and you can change your life. But there are a lot of people that don't think like that. They think that they're the underdog and so it's very important to educate the community to start with. (Darren)

The attitudes of others – support workers, family and organisations

People frequently mentioned struggles around (dis)respect, in both informal and formal contexts. In several examples, participants talked about staff entering their rooms without knocking, and not respecting their privacy or autonomy. Participants' discussions around negative interactions as a result of some support workers' attitudes shone a light on how some systems that were set up to support people with disability, in practice, did the opposite.

Jim said when he was on the phone staff often asked who he was talking to and what they were talking about, something he found was "just rude." Several people felt that their disability had been "used against them," recently and in the past. Jasmine explained she had "felt used" for promotional material by her school to illustrate their values and mission statements, which she felt they did not apply in practice when it came to meeting her support needs. Toby said his girlfriend's support staff were disrespectful. He explained that they prevented Toby and his girlfriend from doing things together and turned their dates into group activities by bringing along other people without prior arrangement or agreement. For Lidia, lack of clear communication meant she was often late for things she wanted to do. Kylie discussed how accessible taxis don't arrive on time and she is left outside waiting to get home from events. People emphasised that it was hard to get staff to be concerned about these problems in their lives.

> And they don't listen to what you're saying to them. That really, really pisses me off [with support] workers – when there's an [issue] and you are trying to tell them what you want and they don't know, they don't listen to you. (Annika)

Darren explained that support worker attitudes and good support had an impact on people with intellectual disability and on how they felt.

> … it's like it's a job for some people. Like they just go in and do their job, they get their money every week and that's all that matters to them. Then you get the other type of people that really put in a lot of effort and do it because they're passionate about it. So, more people need to be, in the disability sector, passionate about what they – and also be responsible for all their lives to help them. Yes, and through that you might find a few changes. (Darren)

The impacts of the attitudes of others: family, organisations, and other people, which can promote a sense of belonging or increase loneliness, were discussed frequently and with passion. While National Disability Insurance Scheme (NDIS) expectations of people with intellectual disability included being part of the broader community, Don's experiences had showed him that this was not so easy in places where he was not known. He said he had friends in the disability community because he felt treated with value here:

> … but it's hard when you've got a disability trying to make friends, they [people with disability] treat you as equal person, right when you go to meet them treated as equals, but it's hard trying to get the community – the community out there – people always put you down, because you're not the same as everybody else. And in the area, like with the NDIS [expectation that you will go to new places] … it's hard.

Attitudes, structures and organisations

One clear message around support for people to feel included and not lonely, was attitudes embedded in how organisations are structured and carry out their work. This finding identifies the issues people with intellectual disability experience when participating and being in the world. Importantly participants noted that "disability ready" places are critical to alleviating loneliness for people with intellectual disability.

Disability-ready means the organisation is equipped to support the inclusion of people with intellectual disability to participate in work, have their rights respected, have access to information, and are listened to. Disability-ready places are the responsibility and obligation of organisations, service providers, and government departments, and the people who work and use them. It also means staff have capacity and skill to ensure human rights are upheld and the needs and wishes of people with intellectual disability are central to any support.

People told us they thought organisations could do better to improve communication, particularly in how they listen to people with intellectual disability. They told us that organisations could do more outreach into the community and let people know what they could access and what they could do; and have a flexible approach when working with people with intellectual disability.

Discussion

According to Wigfield et al. (2020), a lack of meaningful interactions is at the core of loneliness and social isolation. Analysis of our findings using the framework of meaningful interactions points to evidence of both individual and community wide actions and approaches that may support people with intellectual disability and alleviate their experiences of loneliness. At the same time, the findings made evident systemic factors that perpetuated exclusion and loneliness and participants described disabling barriers to participation that are the effect of attitudes and structural barriers reflected in the literature (Gilmore & Cuskelly, 2014; Macdonald et al., 2018; Petroutsou et al., 2018).

People with intellectual disability were clear about what helped them to feel included and the kinds of attitudes, interactions, and places that impacted on them and made them feel lonely. They had advice the broader community can learn from, and things they might do to support people with intellectual disability to feel included and improve their sense of belonging. Their views were consistent with the limited literature that focuses on the views of people with intellectual disability about what supports their sense of belonging and inclusion (Foley et al., 2012). But people also talked about a pervasive sense of loneliness, a lack of meaningful interactions that occurred across the domains, which were embedded in community attitudes. Reflecting the literature, the attitudes of others toward people with intellectual disability almost always played a part, positive or negative, in their encounters, and shaped their experiences and opportunities (Bigby & Wiesel, 2015; Gilmore & Cuskelly, 2014; Hastings, 2010).

People in this study identified two key factors – having a purpose and feeling valued and respected – that helped them avoid feeling lonely and provided a sense of belonging and inclusion. Alongside this, the priorities of the study participants were for the wider community to change, to be more friendly and welcoming, and recognise and respect people with intellectual disability as equals. This too resonates with findings that have identified the disabling structures of inaccessible and unresponsive social services, housing, and work as pathways to loneliness (Macdonald et al., 2018; Merrells et al., 2019).

The findings illustrated that opportunities for people with disability to experience meaningful interactions and participation were impacted by other people's attitudes and behaviours and organisations; systems and structures. Participation was often facilitated or prevented by support workers, family or others who were in a position to either enhance or detract from the quality of the experience considerably, as noted in related literature (Bigby & Wiesel, 2015: Gilmore & Cuskelly, 2014; Mason et al., 2013). Where obstacles were placed in the way, either due to concern for the person's safety (in the case of family members) or more commonly because of systems with rigid rules, participation was diluted and diminished. For example, Don's and Jenny's descriptions of other people's impatience and ableist attitudes increased their sense of loneliness. Unlike many people without disability, people with intellectual disability were often rendered powerless through the behaviours of others toward them and the structures imposed on their rights, often within systems that have ostensibly been established to support them. This is consistent with research in violence and abuse prevention, which points to the increased risks for people with intellectual disability when their agency and authority is diminished (Fyson & Patterson, 2020; Robinson, 2018).

The Wigfield et al. framework takes an individualised approach to identifying the characteristics and circumstances that shape a person's life, considering disability a factor along with others such as geography, employment, health, and financial security. We argue here for a more discursive view of disability that accounts for compounding and multiple effects of interaction with a complex environment, responding to the findings of our study, which demonstrate the multidimensional understanding people hold of themselves and their experiences. Rather than a label, for the purposes of understanding concepts such as loneliness an accounting of disability needs to hold space for sometimes contested questions of disability and identity, different approaches to disability and impairment (e.g., for self-identification, for funding, and for service provision), and the long tail of different models of disability (Shakespeare, 2014). An intersectional view considers the complexity of lived experience, dependent on many of the individual markers identified in the model, such as "age, class, culture, Indigenous status, intersex status, race, religion, sexuality, and so on, in addition to gender and disabilities" (Dyson et al., 2017, p. 6). This helps to see disability more productively *in dynamic engagement with* the systems in operation across the domains, rather than separate to them.

Applying an intersectional lens illustrates more clearly the structural barriers to participation and interactions, and effects of attitudes and personal safety experienced by people with intellectual disability in this study. It highlights aspects of gender, ability, and race within structural and functional social conditions. Other markers from the framework, such as personal circumstances, employment status, locality, access to transport, education, accommodation, are useful in understanding loneliness. This helps to understand why holding agency, authority and capacity to change personal circumstances around loneliness is such a longstanding and pervasive problem for people with intellectual disability.

Many life events described by participants in our study were transformative, and while the event itself may have been brief, there were lasting effects. Such changes disrupted several people's autonomy and engagement with the world. Their capacity to participate was restricted by the actions of others. For example, Anna and Darren described events that had long-lasting impacts on their friendships and feelings of inclusion. They had little or no power over these events, which led to a loss of friendship, capacity to do something they enjoyed or take part in things they liked. Such events produced unwelcome changes in the course of their lives, and to feelings of loneliness and being excluded. This deepens and extends the way "transitory life events" are applied in the Wigfield et al. model (2020).

Conclusion

This small study has shared the rich insights of people with intellectual disability about loneliness, and some of their ideas for improving it. The experiences of loneliness discussed in this study indicate that there is work to be done across the community to ensure people with intellectual disability are included, have access to disability-ready places that respect their human rights, listen carefully and recognise and include their vision for alleviating loneliness. Our findings indicate that the domains of interaction, participation, personal security and attitudes are areas of strong influence on people's experience of inclusion and exclusion and hold opportunities for future positive change. However, the strong influence of other people on the capacity of people with intellectual disability to exercise agency and authority is poorly considered in this framework, resulting in a thinness around the impact of systemic and structural impacts on a group of people who are heavily circumscribed by the actions of people working within systems.

Further research with people with intellectual disability that carefully explores loneliness and how to alleviate it is needed – particularly to better understand these experiences from the perspectives of people in different positions, such as young people, people living in rural areas, and people with diverse gender identities. However, we close with a caution from our advisors and participants that people do not want to dwell on this painful problem, they want to resolve it.

Note

1. What Helps you feel included; People with intellectual disability talking about loneliness and feeling included https://www.ourvoicesa.org.au/application/files/8416/2786/9113/What_helps_Easy_Read.pdf accessed 9

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