

**ORIGINAL ARTICLE**

# Our Homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland

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**Accessible Summary**

- The Inclusive Research Network (IRN) is a group of researchers who do projects that matter to people with intellectual disabilities in Ireland.
- This paper is about a project we did to learn what it is like for people with intellectual disabilities in Ireland to move from one house to another.
- We talked to 35 people who moved house.
- Some people chose where to move but others had no choice.
- Feeling safe made them happier in their new home.
- One third of the people we spoke to had no choice about where they live and who they live with.
- Having these choices is their right under the United Nations Convention on the Rights of Persons with Disabilities.
- People with intellectual disabilities need supporters who listen and respect them.

**Abstract**

**Background:** Supporting people with intellectual disabilities to live well in communities they choose is deinstitutionalisation's central aim and endorsed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). This study focused on the experiences of people with intellectual disabilities in Ireland when moving home using an inclusive research approach.

**Method:** This inclusive research project employed a qualitative approach. Participants included 19 men and 16 women (total  $n = 35$ ) with ages ranging from 22 to 77 years. Structured interviews attended to the experience of moving home and the supports accessed during and after the transition to community living.

**Results:** Thematic analysis yielded four themes: "expressing choice" in the moving process; "feeling connected or isolated when moving"; "accessing supports during and after the move"; and finally, participants' reflections on "experiencing vulnerability and feeling safe" while resettling.

**Conclusions:** This is the first study about people with intellectual disabilities moving home to be collaboratively designed and completed by an inclusive research team. Although much is understood about the long-term benefits of engaging in meaningful choices about housing and supports, concerns remain about the extent to which the will and preferences of people with intellectual disabilities in Ireland are respected when moving home.



## 1 | INTRODUCTION

Supporting people with intellectual disabilities to live well in communities they choose is deinstitutionalisation's central aim (Mansell & Beadle-Brown, 2010; Verdugo, Navas, Gomez, & Schalock, 2012). The shift from congregated settings was catalysed by reports in the 1960s highlighting inadequate and abusive residential services (Kugel & Wolfensberger, 1969) and the Independent Living Movement (Snyder & Mitchell, 2006). Community-based housing became the destination for people with intellectual disabilities as asylums closed (Rothbard & Kuno, 2000). After decades of activism combined with international negotiations, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) was forged. Article 19 (United Nations, 2006) states that people with disabilities have the right to choose where to live and with whom.

Benefits of community-based housing for people with intellectual disabilities are well established. Systematic reviews by Chowdhury and Benson (2011) and Walsh et al. (2010) both concluded that people living in community-based accommodations experience greater self-determination, more opportunities for meaningful decision-making, enhanced personal development, greater community participation and more social inclusion than people who remain in congregated settings. In their metasynthesis of literature reviews, Mansell and Beadle-Brown (2010) concluded that community-based housing was linked to more positive outcomes than institutional living for people with intellectual disabilities. Despite the benefits of community living and the guidance in CRPD (United Nations, 2006) about accessibility, ensuring equal opportunities and respecting the choices of people with disabilities, services are slow to respond with new support options (Hendy & Barlow, 2012). Implementing change poses challenges to service providers, families and people with intellectual disabilities (Brown, Anand, Fung, Isaacs, & Baum, 2003; Jones & Gallus, 2016). Trusting relationships and effective communication among stakeholders are required for positive change management in disability services during the transition to community living (Clare et al., 2017; Schalock, Verdugo, Bonham, Fantova, & Loon, 2008). Others argue that the move away from congregated settings requires a local, individualised approach for people with intellectual disabilities and support staff combined with a much broader societal shift in recognising full citizenship of people with intellectual disabilities (Bigby & Fyffe, 2006).

From 2008, when Ireland became a signatory, the CRPD has informed national policy, exemplified through the National Housing Strategy for People with Disabilities 2011–2016 and "Time to move on from congregated settings" (Health Services Executive, 2011). Both documents make explicit commitments to support people with intellectual disabilities to move into community-based accommodations. According to data from the National Intellectual Disability Database, most people with intellectual disabilities in Ireland live with relatives or in foster families; thus, with ageing parents and longer life expectancies in this population, there is significant projected need for community housing (Doyle, Hourigan, & Fanagan,

2017). Additionally, over 7,600 people still lived in residential centres in 2016, demonstrating only a 1.5% reduction from 2015 (Doyle et al., 2017). Thus, although the policy commitment to community living in Ireland is clear, implementation is protracted. Recent Irish housing statistics identify that only 16% of adults with intellectual disabilities live in community-based homes and as few as 8% living independently (Kelly & O'Donohoe, 2014). Although the intent of national policy in Ireland (Health Services Executive, 2011) was to close institutions where 10 or more people with disabilities reside in one unit or campus-based setting, an inadequate funding model, limited housing options and substantial challenges within service provider organisations responsible for providing housing constrained progress (Linehan et al., 2015; McConkey, Kelly, Craig, & Mannan, 2013; McConkey, Kelly, Mannan, & Craig, 2011; Mulvany, Barron, & McConkey, 2007).

Findings of multiple studies, including the in-depth statistical analyses of disability services across 19 states in the United States completed by Ticha et al. (2012), indicate that the structure of disability support services substantially shapes the real choices people with intellectual disabilities have about their lives. According to the narrative literature synthesis completed by Wehmeyer and Abery (2013), limited experience of choice when living in congregated settings impacts a person's self-determination. This claim is supported by Stancliffe et al. (2011) who reported that more than half of the 6,778 adults with intellectual disabilities across 26 states did not participate in decisions about where to live nor with whom. Likewise, in Ireland, the first wave of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) reported on many dimensions of participation by 753 adults with intellectual disabilities most of whom lived in residential settings and supported accommodations in community (McCarron et al., 2011). IDS-TILDA was not designed to include the experience of moving from one home to another. According to Bigby, Bould, and Beadle-Brown (2017) little is known about supported living from the perspectives of people with intellectual disabilities. None of the current published literature about moving homes cited used an inclusive research design where people with intellectual disabilities were integral members of research teams from project inception to dissemination. Inclusive research offers a collaborative alternative (Roberts, Greenhill, & Talbot, 2011) to traditional enquiry, one in which people with intellectual disabilities and academics create a shared account of a significant issue that can be used to catalyse change at individual and societal levels (Nind, 2008; Walmsley & Johnson, 2003). There are many current versions of inclusive research ranging from participatory to emancipatory (Strnadová, Walmsley, Johnson, & Cumming, 2016). Although there is a growing interest in using inclusive research, definitions and details of implementation are lacking in published literature (Nind & Vinha, 2012). Bigby, Frawley, and Ramcharan (2014) encourage inclusive research teams to explain how they worked together.

Thus, the purpose of this study was twofold. First, it was designed to explore the experiences of people with intellectual disabilities in Ireland when moving home focused on reasons for moving

and supports provided during the transition process. Secondly, the team aimed to use an inclusive research process thus making a novel methodological contribution to the literature.

## 2 | METHODS

The Inclusive Research Network (IRN) is a consortium that collaborates on projects that matter to people with intellectual disabilities in Ireland. The IRN is led by a steering group comprised of people with intellectual disabilities with support from the National Federation of Voluntary Bodies and academic researchers from University of Limerick and Trinity College Dublin. Reflecting on the analysis of inclusive research methodologies described by Bigby et al. (2014), in our early days over a decade ago, an advisory panel style was used; however, as the IRN evolved all decisions about project, design and direction are now made by self-advocates with guidance from academic supporters. This is evidenced by the way the topic of this project was agreed in 2012 through consensus-building. This was achieved in a full-day workshop where 25 people with intellectual disabilities initially worked in small groups to brainstorm topics of interest. They were supported by five personal assistants and two academics who wrote down all the ideas generated. The whole research team then looked for elements common across the lists compiled by small groups, organising ideas into bigger topics with subheadings. The academic supporter explained what makes a good research question using easy read text and photographs on powerpoint slides. As the day progressed, the research focus settled on this question: What was it like for people with intellectual disabilities to move from one place to another? There was a secondary, linked question: What support did people access before, during and after moving house? The IRN decided that doing individual structured qualitative interviews was best suited to the research question and aims given that this also enabled novice members of the research team to readily engage as interviewers in the data collection phase of the project. This individual approach ensured a confidential space for participants to share their stories.

A project handbook was prepared by the IRN steering group and academic supporters. This document explained how to complete all aspects of data collection, from inviting people to take part through to completing the interview and contained all supporting paperwork—information sheets, consent forms, interview questions. The IRN produced a video that demonstrated the full process from greeting the person, to going through the consent form, asking the questions and closing the interview. Two interview workshops were provided to IRN members. In total, twenty-six IRN researchers, along with 13 supporters, conducted interviews. Having a structured interview guide ensured that all members of the large research team gathered the same information from participants.

A structured interview guide was developed over 6-day long-team workshops convened over six months, then piloted and revised

twice to ensure it was readily understood by participants and the full IRN research team. The topics covered include where people lived in the past, where they lived at the time of the interview, how they moved to their new home, the supports they had to move and what they liked or did not like about their home. The final interview guide included 50 questions with a mixture of open and closed formats. The full interview guide can be viewed at [http://www.fedvol.ie/Reports\\_by\\_the\\_Inclusive\\_Research\\_Network/Default.2084.html](http://www.fedvol.ie/Reports_by_the_Inclusive_Research_Network/Default.2084.html) in the Our Homes Researcher Handbook (pages 61–75).

### 2.1 | Recruitment and participants

Ethics approval was obtained from Trinity College Dublin. Two subsequent ethics approvals were required from regional service provider organisations. IRN members shared easy read information about the project with people they knew from their local areas, including 11 different counties in Ireland. Potential participants were given at least one week to review the project details and the consent form. They were then asked by the researcher if they wanted to take part in an interview. If the person agreed to participate, the researcher and supporter went through the four-item consent quiz to ensure the person understood their rights (see pages 53–56 of Our Homes Researcher Handbook). Once all the participants' questions were answered, they signed the easy read consent form. After going through the consent process, 33/35 participants agreed to have their interview audio-recorded. The researchers took notes when a participant preferred not to be recorded. All recordings were delivered to the IRN secretary and then transcribed by supporters.

Recruitment began via IRN contacts, through information sessions in 11 service provider organisations, then by snowball sampling. Anyone over the age of 18 who identified as having an intellectual disability and who had experienced at least one move was eligible to take part. Once all IRN members had exhausted recruitment options in their local areas, data collection ended. The research team had an agreed protocol in place should any participant become upset during the interview; however, the interview teams reported back that people they spoke with were comfortable and talked openly about their story of moving house. Interviews ranged from 30 to 40 min and were completed by an IRN member and supporter as a team at a location chosen by the participant, typically in their home or day service space.

Given Ireland's small population, demographic information is aggregated to protect participant privacy. Participants included 19 men and 16 women (total  $n = 35$ ) from across 11 counties in Ireland. The average age was 47 with a range of 22 to 77 years. All participants were able to answer interview questions verbally or with support from someone who knew them well. Previous housing ranged from the family home ( $n = 14$ ), a large setting with 10 or more people ( $n = 17$ ), to group homes with less than 10 people ( $n = 13$ ). A few people lived with flatmates in the past ( $n = 2$ ) and two participants lived on their own previously or with a partner. The number of moves varied, with three people reporting a single move from the family home to their current accommodation and

**TABLE 1** Themes and related topics

Theme	Topics
Expressing Choice	Moving Where to live Who to live with
Feeling connected or isolated when moving	Connections before moving Connections after moving
Accessing supports during and after moving	Supports to Organise Move Types of Support Relationships with Supporters Qualities of supporters
Experiencing vulnerability and feeling safe	In relationships In new environment

one participant moving seven different times. Although the IRN worked for many months on the interview guide and asked extensive questions about what it was like for people to move house, in retrospect, we noted that participants were not asked how long they were settled in their current accommodation. Of the 29 people who disclosed home location, 14 lived in urban areas, 12 in small towns and three lived rurally. The most common housing type was a supported flat or house ( $n = 26$ ) with four people living in group homes and four participants moving in with a family member. Only one participant lived in a larger facility with more than 10 others.

## 2.2 | Analytical approach

Since many participant responses were fewer than 50 words, an excel spreadsheet was used for data management. Qualitative analysis was three-pronged. First, during two IRN workshops, each anonymised interview was summarised in easy read format by seven working groups comprised of 3–4 IRN members with one supporter per group. These two-page summaries were then distributed among groups to read over. Key points made across interviews were then discussed until agreement was reached about recurring ideas. These included what participants did or did not like about where they lived in the past and where they lived at the time of the interview; choices people had about moving; planning and support around the move. Secondly, responses to closed questions were tallied. Finally, content analysis based on the main ideas identified in the first stage of analysis was completed over 5 monthly team meetings, with an average attendance of 27 people, enabling the team to construct the preliminary research findings. The IRN wrote an easy read report, selected indicative quotes and incorporated pictures to illustrate the text. The easy read report for “Our Homes” is available at [https://www.fedvol.ie/Reports\\_by\\_the\\_Inclusive\\_Research\\_Network/Default.2084.html](https://www.fedvol.ie/Reports_by_the_Inclusive_Research_Network/Default.2084.html).

Translating the report into an academic paper involved a writing team lead by the first author, further engaging in the collaborative approach to inclusive research described by Bigby et al. (2014). The

IRN writing team comprised of three IRN members, two supporters and two academic researchers, who met twice to discuss central points to bring forward in the paper. Choices about which quotes to incorporate were also made by this working group. We met again to decide how to respond to peer reviews of the first manuscript. The authors further synthesised findings through this iterative writing process, thus moving beyond the initial content analysis and proceeding through all stages of thematic analysis (Patton, 2015).

## 3 | FINDINGS

Analysis across participant stories yielded four themes. First, moving home provided participants with a means to express choice. The second theme demonstrates the importance of support leading up to and following housing transition. The third key theme focuses on how socially connected or isolated people felt when moving. Finally, participants’ reflections on safety and vulnerability while moving are presented. Themes and key elements of each are outlined in Table 1.

### 3.1 | Expressing choice

Choice about moving was available to just over half of the people interviewed with 18 participants deciding to move. Another 11 had no choice with six not commenting. Choice related to moving house was expressed in different ways including the initial decision to move, home location, living space design and housemates. Thirteen participants moved within a year of making the decision, with two people moving within a few days if safety was an issue; yet, others described a wait that for some lasted decades. A person in her late 50s said, “(I waited) twenty years. I always wanted to live on my own.” The choice to move was described as an expression of autonomy. A man who moved into his own rented apartment said, “I had a choice to move out. I was speaking up for myself.” Similarly, a woman in her mid-20s noted, “I thought it was best for me to move out because I had to learn how to do things for myself and not rely on others to do

things for me." In stark contrast, another participant described moving into a shared apartment stating, "I was told I was moving. I had no choice." All 35 participants experienced a move; however, there was no clear pattern in who had a choice about moving and who did not.

Selecting where to live was another core choice. Being centrally located with access to amenities, transport and work was a priority. For example, one 30-year-old woman liked where she moved "because it's near bus routes, trains, shops, family and my training centre." Seven participants described their current home as better designed and more accessible than where they lived before. A 30-year-old woman explained her choice stating, "It's community supported independent living. We pay rent. It's a bigger apartment on the second floor. We both like living there. It also has wheelchair access." Having space for company was also important as noted by a 46-year-old man who said, "It is a two bed (house) so I can have people stay with me if I want. Will you come visit me?" The importance of having space to share with a housemate or with guests was reiterated across interviews.

Choice also arose in relation to housemates with 12 people opting to live alone. One man explained, "I prefer to live on my own... I didn't like some of the staff. And I didn't like living with the other group...I moved from there to a small apartment and I am happy there now." Another man in his mid-60s moved from large dormitory-style accommodation to a group home before finally moving into his own place. He commented, "I moved to the house I am in now and I love it. I can do what I like and have a house to myself. I love spending time on my own. I am my own boss and I don't have anyone to tell me what to do." Although many people enjoyed having their own place, 23 participants lived with others—of these only 10 chose their housemates.

### 3.2 | Feeling connected or isolated when moving

Whether living alone or with housemates, feeling socially connected was essential before and after moving. For many who had housemates in the past, their companionship was enjoyed. A woman aged 65 noted, "I liked the people" when she spoke about her previous home. Of the 14 people who previously lived with their families, nine recalled that time fondly. For example, a woman in her 20s enjoyed living with family "because I got all the support and if it wasn't for them I would not be able to live away from home." In contrast, a 62-year-old man, thinking back on his life in a group home, felt social situations were imposed on him stating, "I could not go out to town on my own; big groups went everywhere together." Still others felt isolated as described by a woman in her mid-40s who said "I was very lonely before I moved."

Although many participants recalled their earlier housing arrangements warmly, 29 out of 35 said their current housing was better. They were able to have more company, spend more time with friends and easily visit shops and restaurants. Others enjoyed connecting with people in their community. A man in his early 40s appreciated his current home "because I am getting to know the neighbours." Yet, there were a few people who regretted moving.

One woman who lived with her sisters before moving to a group home commented, "I did want to move... and now I want to move back again, back to my own house." Regardless of their housing situation, feeling well connected while also having desired time alone was a crucial balance for participants throughout the housing transition.

### 3.3 | Accessing supports during and after the move

Many participants described a gradual move. For example, a 30-year-old explained, "We did courses on independent living, budgeting money learning about fire safety, setting alarms and spent one night to see how we got on." Support for skill acquisition to live independently was discussed by many participants. Another woman in her mid-20s said, "I got more experience of doing my own washing and cooking. I had my own key to come and go." The moving process varied across participants—with some people given little assistance, while others accessed ongoing support. For example, a man in his mid-40s said his paid supporter "wrote a letter to the Council saying that I could live alone. That was the only help I got." In contrast, a participant in his late 40s noted, "I started looking at houses in a neighbourly village up the road from me. And I approached a service provider organisation to purchase the house." Parents and siblings helped with the move for some, while paid supporters contributed to the transition for other participants.

All participants had at least one supporter they could rely upon with a few people naming up to five including family members and paid staff. Nineteen people said they chose their supporters. For example, one person stated, "Yes I did (choose my supporter). I interviewed them." Service provider organisations chose supporters for other participants. One person was not aware she could choose her supporter stating, "Is it possible to choose your own support?" Whether or not they were involved in hiring supporters, participants valued staff during and after moving. A 30-year-old explained, "(Staff) helped me understand about living independently. If I am in difficulty I can phone them for help." Having consistent, trusted supporters who were readily available to answer questions simplified moving.

Participants accessed different types of support once they settled into their current home. Support for household chores was appreciated with cooking and cleaning commonly cited. One participant explained that supporters, "help me with cleaning and sometimes cooking. At weekends they call asking if I want to call up to the girls and they bring me up." Transportation was an essential role for supporters, providing participants with access to local amenities, recreational activities and social events. Managing household finances was a core area for support. One person in his 50s said, "They help me with my money situations and any bills I get stuck on." Personal care and support in everyday tasks was also valued. A 30-year-old explained, "They help me through all my day to day appointments, shopping and answer my questions." Just knowing someone would check in was highly rated. One participant noted, "They come around to visit to check on me and ask if everything is grand." Half of the participants described accessing supporters daily; however, a

few participants did not require paid supporters. A 25-year-old explained, "I go to work on my own. I can go food shopping on my own." Another person believed that more support was needed to live well in the community stating, "I have good support but (I need) more hours to do the things I want to do." Thus, types of and access to support were pivotal to a positive move.

Most participants spoke well of supporters ( $n = 33$ ), with one participant stating, "We are very happy to have him... He's brilliant." Yet, there were two instances where staff were described as obstructive, with one participant commenting that paid supporters "definitely boss me around telling what me what to do... It's my own business where I want to go." Despite some dissatisfaction, overall participants commented on supporters being attuned to their needs.

Participants prioritised specific traits in supporters. Being trustworthy, reliable, friendly and having a good sense of humour were qualities participants commonly sought in supporters. A 32-year-old explained, "I'm looking for humour, friendly (person) and advice when making decisions." Someone who could provide practical assistance was crucial. A person in his late 40s said, "someone that will help with tidying and managing the house... (and) agree to do what I need doing." Being good listeners, respectful, punctual, agreeable and organised were important characteristics in supporters. One participant summed up effectively stating, "They should be kind to me and have respect for me and be nice to me." This emphasis on matching type of support and qualities exhibited by paid staff to the person's preference was consistent across interviews.

### 3.4 | Experiencing vulnerability and feeling safe

Although there were many positive recollections of past housing, participants described complex situations where they felt vulnerable. A woman in her 60s offered an example when a past landlord did not respect her privacy. "One morning (the landlady) went out and gave the key to the house to a man to mix concrete in my kitchen—that is no lie." Several participants mistrusted past landlords, demonstrated by another woman in her mid-60s.

The landlady... didn't give me any heating. She was nicking stuff from me. When I went out to work in the morning she came into my apartment. I had no privacy... so I had to get the press (cupboard) locked. She would take my toilet roll... then my gas cylinder was missing. One morning I went to dry my hair—no hairdryer! She took it without asking.

Interpersonal relationships were a source of dissatisfaction when participants reflected on places they lived before. Tension with housemates or staff, and abusive situations were described. A woman in her late 70s explained.

We didn't like (that place) because there was a (staff person) there. He... had a stick down in the bathroom.... with a hook on the top of it. He had done it

(struck) one (housemate)... The Garda found out... and it stopped.

Feeling vulnerable extended beyond bullying and abuse. People spoke about unsafe environments where heating was inadequate, fire regulations were not adhered to and where it was not safe to walk. One woman explained, "The roads were too dangerous where I was before. There were no footpaths. You cannot go anywhere. You could get knocked down." Yet for many, moving house offered greater security and freedom. A man in his early 40s commented, "It is better because it is walking distance from my work. I don't have to ring anyone to collect me. I can come and go as I like." Greater self-determination combined with freedom from bullying was also conveyed by a man in his mid-50s who said, "I can put my feet up watching telly, no one to annoy me, or call me names." Feeling safe enabled people to enjoy their home and connect with others, aptly described by a woman in her mid-60s whose new home was "much better because you don't have to lock in stuff. You have great comfort. We can look after our own heating... I was on my own (before) and I have company now." For most participants, moving to their new home contributed to feeling safer which in turn prompted greater community participation and enhanced social connections.

## 4 | DISCUSSION

The connections between the findings of this study, current Irish and international literature will now be considered in relation to expressing choice, accessing supports and balancing safety with positive risk-taking when people with intellectual disabilities move home.

### 4.1 | Expressing choice in moving home

Choice around moving house was expressed in different ways including deciding to move, home location, living space design and housemates. Self-determination has been a central concept in research involving people with intellectual disabilities for many years. Wehmeyer and Abery (2013) argued effectively that self-determination flourishes when people have more opportunities to make meaningful choices. Yet, only half of participants in the IRN study were involved in decisions about moving home and housemates. A clear relationship between housing type and perception of choice was identified when Ticha et al., (2012) analysed data from 6,179 Americans from the National Core Indicators Project. Specifically, people with moderate intellectual disability living either in their own home or in accommodation with three or fewer residents managed by service providers had greatest reported daily living choices, whereas the same population in congregated settings of 16 or more people experienced the fewest (Ticha et al., 2012). Another analysis using data from the National Core Indicators project found that people with severe or profound intellectual disability from across 26 states rarely had housing choices (Stancliffe et al., 2011). Even though all

participants in the current study were able to speak for themselves, many still had no choice about where to live, raising concerns about the extent to which living arrangements are personalised in Ireland. A person-centred approach is linked to greater choice among people with intellectual disabilities (McConkey & Collins, 2010). When McConkey, Keogh, Bunting, Garcia Iriarte, and Flatman Watson (2016) compared outcomes of people with intellectual disability who moved from congregated settings to group homes ( $n = 31$ ) with those who transitioned into homes using an individualised approach ( $n = 29$ ) in the Republic of Ireland, those who lived in personalised accommodation experienced greater choice and independence.

Freedom and exerting personal control across multiple life domains was strong among people in supported living among 34 people with intellectual disabilities in an Australian qualitative study (Bigby et al., 2017). Like Bigby et al. (2017) the IRN findings indicated some participants struggled to assert autonomy when support staff or family restricted choices. In their comparison of people with intellectual disabilities living alone versus those in residential care, Bond and Hurst (2010) found a clear preference for living alone given the greater experience of freedom, space and privacy. When people with intellectual disabilities did not decide where to live and with whom, there was heightened risk of loneliness, dissatisfaction with housing and reduced happiness (Ticha et al., 2012). Thus, choices about moving home can have lasting health and quality of life consequences. Based on findings of the current project, IRN members emphasised that people with intellectual disabilities have the right to make decisions about moving home, who to live with—or to live alone—and be supported to live where they choose.

Although research about choices of people with intellectual disabilities exists around living arrangements, housemates and supports, little is documented about home design and location. Participants in the current study prioritised location, accessible design and space for guests. This intersection between people and preferred living spaces thus warrants further investigation from the perspectives of people with intellectual disabilities.

## 4.2 | Accessing supports

In the current study, support was pivotal for participants and ranged from assisting with household chores, providing transportation, managing finances among other daily life tasks. Findings from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) indicated that people with intellectual disabilities living in residential settings rarely engaged in activities commonly completed by people living in the community including cooking, grocery shopping and managing finances (King et al., 2016). The attention to skills needed for living independently presents across international literature. For example, Bond and Hurst (2010) noted that many people they interviewed in the UK still felt a need to prove themselves although they lived in the community with minimal supports. A number of people in the IRN study also spoke about participating in training about how to live independently before moving. Although this strategy may have some merit, it is crucial

that service providers and policymakers recognise that people with intellectual disabilities do not need to earn the right to live in the community that right is already self-evident (United Nations, 2006). Rather than asking what skills the person must acquire, the question could instead be focused on what personalised supports are needed to immediately move to community-based homes.

Although seemingly intuitive, people need to get on well with their supporters. Participants in the Bigby et al., (2017) qualitative study effectively described supporter characteristics comparable to those highlighted in the IRN project—being good at listening, having no personal agenda and holding positive aspirations for the person to live in the community. Similarly, in their cultural analysis of better group homes in Australia, Bigby and Beadle-Brown (2016) described the importance of personalised supports demonstrated through responsive, respectful relationships that naturally incorporated fun. Like the nine participant stories presented by Bond and Hurst (2010), people in the IRN study described both formal (paid) and informal (typically family) supports and were largely satisfied with support received. Thirty-three people in the current study reported positive relationships with supporters; however, like Australian participants in (Bigby et al., 2017), a few felt disenfranchised by supporters. Living well in the community requires responsive, high-quality support services (Mansell & Beadle-Brown, 2010). To that end, involving people with intellectual disabilities in the hiring process for support staff could enable individual preferences to be addressed while simultaneously setting the tone for the support relationship.

The shift in service delivery models when moving from congregated to community settings requires a reorientation of support (Stainton, Brown, Crawford, Hole, & Charles, 2011). Providing ongoing training for facilitating personalised, active supports was advised in well-structured narrative reviews (Amado, Stancliffe, McCarron, & McCallion, 2013), in position statements by influential scholars (Mansell & Beadle-Brown, 2010), and in comparative analyses across groups living in different accommodation models (McConkey et al., 2016). Equally, Qian, Ticha, and Stancliffe (2017) emphasised the importance of strong leadership, buy-in from stakeholders and staff retention to successful implementation of active supports. Thus, the relationship between people with intellectual disabilities and supporters, guided by active support principles (Felce, Jones, & Lowe, 2000; Mansell, Elliott, & Beadle-Brown, 2002), coupled with strong, person-centred leadership within organisations form a stable framework for positive transitions from family homes, group homes and congregated settings to community accommodations.

## 4.3 | Balancing safety and vulnerability when moving home

Participants in the IRN study optimally engaged in preferred activities when they felt safe at home, in transit and more broadly in the community. The desire to feel safe resonates with the quality of life framework proposed by Schalock et al (2002) and aligns with the CRPD as demonstrated by Verdugo et al., (2012). In contrast to the UK participants in the Bond and Hurst (2010) qualitative study,



no one interviewed by the IRN lived in high crime areas nor spoke of disputes with neighbours; however, several felt their privacy was violated by landlords. Some felt unsafe on footpaths and road crossings but did not raise the issue of avoiding going out after dark as those in Bigby et al., (2017) noted, perhaps because few people in the current study accessed evening activities. Like most participants in IDS-TILDA (McCarron et al., 2011), people in the IRN study primarily relied on supporters rather than using public transit to move through their communities. In contrast, Bond and Hurst (2010) reported positive risk-taking in relation to transportation among some participants—where people made informed choices about walking routes and when to ask for transport support. Being able to get around in one's community is an enabler for social and civic participation (World Health Organisation, 2007). Based on these findings, it is recommended that an individualised safety and well-being checklist be documented when planning a move—one that includes usual expectations around fire safety and accessibility but also addresses how the neighbourhood feels at various times of day and night, routes to accessing public transit and the landlord's respect for privacy when entering the property. This aligns with the supported approach to choices proposed by Stancliffe et al (2011) and to the Irish Assisted Decision-Making Act (2015), enabling people to identify and manage risks in relation to housing options.

Participants in the IRN study felt less lonely in their current compared to their previous homes, yet for some this feeling persisted. Similarly, half of the participants in IDS-TILDA reported feeling lonely at times (McCarron et al., 2011). Bigby et al (2017) raised loneliness as an ongoing concern among people with intellectual disabilities living in the community. As a few participants in the current study pointed out, moving from a family home into community housing can be experienced as a significant social loss. Based on IDS-TILDA data, McCausland, McCallion, Cleary, and McCarron (2016) reported that people living in community-based housing had more contact with their families than those living in congregated settings; however, most had limited contact with family or friends compared to older Irish adults without intellectual disability. The connection between choice and loneliness is noteworthy; specifically, people who decided who to live with were less lonely than those who did not (Stancliffe, Lakin, Taub, Chiri, & Byun, 2009). Yet, many participants in the current study had no choice about where to live or with whom, thus concern about loneliness is justified. Service providers are encouraged to consider not only the right of persons with disabilities to choose where they live and with whom (United Nations, 2006), but also the protective influence of engaging in meaningful choices when moving home.

The challenge of establishing community connections after moving from congregated settings negatively impacts quality of life, demonstrated in Chowdhury and Benson (2011) literature synthesis. We might therefore question Dunbar's (2015) argument that recreating segregated housing is the way forward, given the risks of loneliness and exploitation among this population. In contrast,

Hall (2010) endorsed self-authored spaces where people with intellectual disabilities set the parameters for participation. These social networks are thus nested within larger communities where people feel at ease connecting with others. Becoming embedded in a new community takes enormous effort, yet findings from the current study indicate that 83% of participants preferred their new home. Amado et al. (2013) suggested that proactively addressing discrimination via community-wide disability arts initiatives can mitigate the risk of loneliness while simultaneously facilitating greater belonging among people with intellectual disabilities.

#### 4.4 | Limitations

Reflecting on limitations of this study is timely. Twenty-six people with intellectual disabilities and 13 supporters were involved in data collection. This number enabled access to a broader pool of participants than would have been possible with a smaller research team; however, it also created challenges regarding consistency in the data collection process. These concerns were partially addressed by using a structured interview guide and engaging in five sessions where all members of the research team were able to practise doing interviews with guidance from the academic supporters. The responses of participants at times reflected the terminology typically employed by service providers in relation to concepts like "choice" and "community" and "home." Deeper engagement with how these concepts are understood by people with intellectual disabilities is warranted in future research. Although the IRN is a diverse team, we acknowledge that it is difficult to critique our own work. To address this issue, in early 2018, connections were established with inclusive research teams internationally to enable peer review of key documents like interview guides and easy read reports. The snowball sample recruitment strategy limits the transferability of findings given that all the people interviewed were known to IRN members. This could have created a sample that inadvertently excluded people with particular experiences. On reflection, we realised that no participants used alternative forms of communication. In future, the IRN aims to include people who use non-traditional communication, particularly since Ticha et al. (2012) noted that this group rarely participate in decision-making about their own lives. In the process of co-designing, implementing, analysing and writing up our findings, the IRN recognised that we need to carefully attend to how our own views shape what we ask people and the story we ultimately tell. Thus, as a team, we are committed to documenting and critiquing how we work together to enhance the trustworthiness of our work.

#### 5 | CONCLUSION

This inclusive research study explored the accounts of adults with intellectual disabilities as they reflected on moving from one place to another, typically from residential institutions or group homes into more individualised accommodation in the Republic of Ireland. This is the first study of its kind to be co-designed and completed



by an inclusive research team. Collaboration between IRN members, supporters and academics enabled unique connections to be made between the rights of people with intellectual disabilities to express their choices in relation to housing and access to appropriate support, while feeling secure and socially connected within their new community. The findings demonstrate that significant problems can occur in the translation of national policies, where rights and community living are prioritised, to the practice of supporting people with intellectual disabilities to make decisions about their living arrangements. Although much is understood about the long-term benefits of engaging in meaningful choices about housing and support, concerns remain about the extent to which the will and preferences of people with intellectual disabilities in Ireland are respected when moving home.

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