Inclusion

Connecting Locally: Exploring Social Inclusion Experiences of Adults with Intellectual and Developmental Disabilities Through Mapping Their Neighborhoods.

--Manuscript Draft--

Manuscript Number:	INCLUSION-S-24-00036R2
Article Type:	Research Article
Keywords:	community participation; social inclusion; neighborhood; intellectual and developmental disabilities; case study
Corresponding Author:	Geraldine Margaret Boland, PhD UCD Dublin: University College Dublin Dublin, IRELAND
First Author:	Geraldine Margaret Boland, PhD
Order of Authors:	Geraldine Margaret Boland, PhD
	Eilin de Paor, MSc
	Suzanne Guerin, Ph.D
Manuscript Region of Origin:	IRELAND
Abstract:	This study explored how ten adults with intellectual and developmental disabilities understand and experience their neighborhoods. Using qualitative methods, their connections with people and places locally that are important to them were mapped. Most participants were known locally based mainly on their family membership. They had strong connections with places locally, including places that held important memories. Half had connections with local people (outside of family and staff). Neighborhoods that are rich in safe opportunities to participate were mainly found in rural towns. Facilitators and barriers to social inclusion are examined. An individualized service model best supports social inclusion in neighborhoods. The implications for social inclusion policy and practice regarding individualised planning are discussed, with recommendations for further research.

Connecting Locally: Exploring Social Inclusion Experiences of Adults with Intellectual and Developmental Disabilities Through Mapping Their Neighborhoods.

Manuscript INCLUSION-S-24-00036 Revision 2

Title: Connecting Locally: Exploring Social Inclusion Experiences of Adults with Intellectual and Developmental Disabilities Through Mapping Their Neighborhoods.

Abstract

This study explored how ten adults with intellectual and developmental disabilities understand and experience their neighborhoods. Using qualitative methods, their connections with people and places locally that are important to them were mapped. Most participants were known locally based mainly on their family membership. They had strong connections with places locally, including places that held important memories. Half had connections with local people (outside of family and staff). Neighborhoods that are rich in safe opportunities to participate were mainly found in rural towns. Facilitators and barriers to social inclusion are examined. An individualized service model best supports social inclusion in neighborhoods. The implications for social inclusion policy and practice regarding individualised planning are discussed, with recommendations for further research.

Introduction

The UN Convention on the Rights of People with Disabilities (2006, Article 19) calls for individuals to be supported to live independently and to be included in their community. Cross-culturally referenced indicators of quality of life based on the UNCRPD include social inclusion, interpersonal relations and self-determination as key domains (Lombardi et al., 2019). Adults with intellectual and developmental disabilities tend to live alone, with family or in individual/group accommodation with varying levels of staff support (Hewitt & Nye-Lengerman, 2019). They can face barriers to social and neighborhood inclusion (Authors, 2023). Many are not as connected with others without disability as they would like to be (Bigby et al., 2015). Many experience loneliness (McVilly et al., 2006), in particular older persons (Wormwald et al., 2019). The persistence of stigma towards people with intellectual disabilities

remains a global phenomenon despite broad support for social inclusion (Scior et al., 2020), with negative implicit public attitudes prevailing (Wilson & Scior, 2015). Public misperceptions and misinformation are common barriers to building satisfying relationships outside of family and segregated service circles (Amado et al., 2019). The impact of the Covid pandemic was significant for people with intellectual and developmental disabilities, with disruption to familiar services (Nygren & Lulinski, 2020) and a greater reliance on family members for support, including adult siblings (Redquest et al., 2021). While use of technology to remain connected to family and friends increased, many older adults with intellectual disabilities reported a restricted lifestyle regarding valued social inclusion activities (McCausland et al., 2021a).

Service providers for this population identify staff as key change agents in supporting participation (Bigby et al., 2009; McConkey & Collins, 2010), however, a national survey of service leaders found that most services did not have organizational policies in place to support social inclusion for individuals at a local level (Authors, 2022a). In order to develop clear policies to guide staff support actions, a clear understanding of what is meant by social inclusion is necessary. The act of engaging outside of a home environment for this population has been variously titled community integration, social participation, community participation and social inclusion. Reviewers identify community participation as an unclear (Amado et al., 2013; Bigby, 2012), contented concept (Clifford-Simplican, 2019). The present study adopted a definition of social inclusion at the level of neighborhood (Authors, 2021), derived from an examination of the prior literature (Authors, 2023). This definition built on prior conceptualizations, such as Simplican and colleagues' (2015) ecological model of social inclusion, spotlighting the interaction between interpersonal relationships and community participation. Other influences included the definition of social inclusion by Cobigo et al. (2012) embracing the complexity of interactions between personal characteristics and

environmental factors, linked to social roles. A central tenet of conceptualizations on social inclusion for this population is a shift from being physically present in public spaces to effective supports that foster relationships over time outside of family and service circles (Bigby and Weisel, 2019; Bogenschutz et al, 2024; Overmars-Marx, 2017). In addition to relationships, to capture participants' identification with and connections to places (if any) in a definition on social inclusion, social geography literature was considered. Kearns and Andrews (2009) conceptualize neighborhood as rooted in the immediate surroundings in which one's everyday life is lived. Place may be defined as: "a discrete if elastic area in which the settings for the constitution of social relations are located, and with which people can identify" (Agnew, 1993, p.263). We chose the definition of social inclusion below for the present study, as we intended to explore the connections (if any) of adults with intellectual and developmental disabilities to both people and places in their neighborhoods.

> Social inclusion in a neighborhood for individuals is defined as active engagement with people and places that matter to an adult with intellectual disability in the immediate locality in which they live, based on individual preferences. A distinction is made between the immediate neighborhood in which an individual's home is located and the wider locality which they engage in with or without support. This engagement may be achieved by being supported to become known by sight or by name in their neighborhood; engage in valued social roles; have equal access to public goods and services; and belong to a growing network of connections which may include family, mutually supportive neighbors, acquaintances, and friendships. The person can access flexible transport and paid support if needed to engage with people and places outside of home. The experience of being social included in their neighborhood for a person with intellectual or developmental disability is not static. With support to engage in convivial encounters/friendly exchanges, interactions and new experiences,

identification with and attachment to place, with a sense of belonging may develop for the individual (Authors, 2021).

Specialist services for people with intellectual and developmental disabilities often invest resources in a system of planning for individual care needs and personal goal achievement. While methods of individualized planning vary, review literature indicates that person-centred planning as a framework has positive outcomes for what authors describe as community involvement of adults with intellectual disabilities (Ratti et al., 2016). Person-centred planning includes what is variously termed as community involvement or enhanced participation as objectives (Ratti et al., 2016). However, when it comes to policy and practice, it can be unclear what is meant by the phrase 'the community' (Bigby, 2024). Some adults living in staff supported group homes have two neighborhoods that they value and wish to engage with, which adds complexity (Authors, 2022). An in-depth examination of how individuals with intellectual and developmental disabilities understand the concept of neighborhood is absent (Power & Bartlett, 2018). Further enquiry is needed to address the gap in understanding on how adults with intellectual and developmental disabilities themselves conceptualise their neighborhoods.

Review literature highlights strong research interest in social inclusion in developed countries for this population (e.g., Howarth et al., 2016; Overmars-Marx et al., 2014; Bigby, 2012). However, empirical enquiries on supporting social inclusion at the level of neighborhood are relatively recent (Authors, 2021; 2022b; Bredewold et al., 2016; 2020; Overmars-Marx et al., 2019; Power & Bartlett, 2018). A synthesis by Bigby and Wiesel (2019) examined the concept of encounter in public places between adults with intellectual disabilities and strangers, deepening understanding of the factors that enable or disrupt engagement. While a conceptual framework on social inclusion is available for this population (Simplican, 2015), a gap exists in comprehensively exploring how adults with intellectual and developmental disabilities in a

range of countries and cultural contexts experience their neighborhoods (Authors, 2023). Comprehensive individual mapping of their connections with both people and places where they live has not yet been reported in the literature.

This study aimed to build on the literature on conceptualisations of both social inclusion (Simplican, 2015) and encounter between people with and without disability (Bigby & Weisel, 2019). Creating maps of the people and places (if any) in their local area that adults with intellectual and developmental disabilities had connections with, was an objective. Exploring the value, if any, that they placed on these connections and the experiences of people living in a range of neighborhood types were also objectives.

The specific research questions were:

1) How do adults with intellectual and developmental disabilities understand and experience their neighborhoods?
2) Who are the people (outside of family and paid staff) and what are the places locally (if any) that they are connected to?

Method

We chose a qualitative multiple case study design as best suited to the exploratory nature of this enquiry. The case study design aided us in examining contextual conditions in real world cases (Yin, 2018). Underpinning our study was the contructionist contention that it is together that we construct our social worlds and everything that is real for us arises out of some kind of communal relationship (Gergen, 2015). The multiple case study design matched the objectives of this study focused on participants' experiences and perspectives on social inclusion in their neighborhoods. Examining multiple cases permitted the identification of individual life circumstances, complex patterns and contextual factors (Yin, 2018) across both town and rural

neighborhood types. Developing both narrative accounts and maps as visual representations were incorporated, focusing on the people and places (if any) that individuals with intellectual and developmental disabilities had formed connections with locally. The study received ethical approval from [*Name of academic institution and reference number removed for peer review*]

Sample

Six women and four men with intellectual and developmental disabilities consented to participate in the study. Demographic details are summarized in Table 1. While the age range for the sample was 25 to 52 years, seven participants were in the age range 40 to 50 years. All ten participants had white Irish ethnicity. They had daily support needs of varying levels. Each person received either a day program or a residential service from a single service provider serving three rural counties in Ireland. Three individuals received ongoing specialist supports for behaviours that challenge. One person had epilepsy. No wheelchair user came forward for this study, however, two participants had mobility challenges and didn't walk long distances. All participants were single. Five had experienced loss of a parent in the three years prior to the study, with one having experienced the loss of both parents. Two people lived in staffed group homes, while eight lived with family members; four with widowed mothers and four either with the families of adult siblings or other extended family members. Seven had lived in the same neighborhood since childhood, with three having moved once to a new locality in their adult lives. One person had two neighborhoods, first the location of her group home and the second the area of her family home.

Insert Table 1 about here

Participant Recruitment

A short accessible video was used to advertise the study. The video was distributed to managers of all centres/ adults service hubs in three rural counties served by a single service provider.

Staff showed the video advert to either groups of adults in day service programs or individuals receiving residential services. The inclusion criteria were that participating adults (over 18 years) had an intellectual disability and resided in one of three rural counties served by this single service provider. There were no exclusion criteria. The sample was self-selecting. An easy read information leaflet and consent form were used in individual information meetings for potential participants with the first author.

Data Collection Process

Data were collected using: 1) photos taken by the research participant of places and people locally (later used as conversation prompts to support communication); 2) a sit-down qualitative interview; and 3) a walking interview (King & Woodroffe, 2017). A staff member (chosen by the participant) was asked to support each individual as a communication partner (Kent-Walsh & McNaughton, 2005) during data collection stages. Staff members were not research participants, rather they supported the process by helping with the technical aspects of taking photographs, prior to the first sit-down interview. They were available during interviews if the participant chose to call on them for support. They also helped the researcher to understand all names and references to the local area made by the participant. Data collection involved individual semi-structured qualitative interviews. Two types were utilized: first a sit-down interview, followed (one week later) by a walking interview (King & Woodroffe, 2017), with the objective of deepening understanding of lived experiences in particular places. Walking interviews offered naturalistic opportunities "to explore the ways in which life experiences are interwoven with the places in which people live and the meanings they have for their lives." (King & Woodroffe, 2017, p.19). Combining sit-down with walking interviews was intended to strengthen the research design, allowing participants with intellectual and developmental disabilities to show places, talk about their experiences and about people connected to the locations who were important to them. The audio recordings of sit-down

interviews (usually one hour long) were transcribed and anonymized. The lead researcher kept field notes of walking interviews (usually one to two hours) by immediately afterwards creating a detailed audio recording of any observations made. These recordings were also transcribed and anonymized.

Between the information/confirmation of consent meeting and the first interview (one-month interval), the participant, supported by their communication partner photographed locations that they felt connected to (e.g., favourite leisure facilities or commercial/ public services). Participants showed these photos to the researcher during the first interview as prompts and aids to conversation and communication. The photos remained the personal property of the participant. The walking interview followed one week later.

Interview Schedule and Observation Protocol

Both interview formats were tested prior to the launch of the study with two adults with intellectual disabilities (not participants in the sample), with refinements made to the questions and sequence of the sit-down interview schedule. The observation protocol for walking interviews was based on the definition of social inclusion in neighborhoods above (Authors, 2021), which the researchers adapted through team discussions into 12 distinct aspects of social inclusion at a local level (see Table 2). The testing of the walking interview observation protocol included observations on whether each the 12 aspects of social inclusion were present or not present. Following testing, the wording of the 12 statements were refined through team discussions and the option of each social inclusion aspect being partially present was added prior to the launch of the study. For example, one of the volunteer participants in the testing phase did not use public transport unaccompanied. He had reliable service provider transport to his service provider's day service hub and to his part-time job. He had three friends living in different locations between 1km and 10km from his rural home. He wanted to see his friends

at weekends but had no transport to visit two of them. Therefore, one of the 12 social inclusion aspects *Having reliable, flexible modes of transport to get to chosen locations or activities* was only partially present. The observation protocol also included the typology of encounters (Bigby & Weisel, 2019) in order to develop an understanding of the factors that enable or disrupt engagement for each individual. During walking interviews, the researcher observed interactions between participants and people without disabilities using "the three types of convivial encounter (shared identification; recognition; and becoming known); and three less inclusive types of encounter (exclusionary; in a distinct social space; and non-encounters)" (Bigby & Wiesel, 2019, p.42). The development of individual maps was also tested using Adobe Illustrator (Version 29.2.1).

(Insert Table 2 about here)

Data Analysis

Stage 1

Individual case analysis was completed followed by cross-case analysis (Stake, 2005; Yin, 2018). Data from interview transcripts and researcher field notes were analysed using qualitative inductive content analysis (Mayring, 2000; Hsieh & Shannon, 2005). Content analysis had the best fit for the research questions for the study, allowing the clusters of meaning to flow from the data. A detailed audit trail of how content analysis was operationalised is available at Table 3.

[Insert Table 3 about here]

Steps 1 to 6 of the data analysis were completed by the first author. A credibility check (Elliott et al., 1999) on the analysis was completed by the second author (an independent researcher, with no involvement in planning or conducting the data collection). This was intended to

enhance reflexivity and an interpretation that was thorough, nuanced, and insightful. The second researcher read the randomly chosen, deidentified transcripts of both interviews for two participants and the descriptors of the six clusters of meaning (see Results section) from the inductive content analysis. The researcher found that the cluster headings were clear, and the descriptors reflected the participants experiences. They suggested some edits to the cluster descriptors for clarity and minor transfers of points between clusters for consistency.

Stage 2

Individual anonymised case reports were drawn up which included the combined content analysis of both interviews, and the development of an individual neighborhood and wider locality map (see Figures 1 and 2) for each participant. Some participants verbally confirmed their connections with named people locally during interviews, while others demonstrated this through their photographs. During walking interviews there were naturalistic opportunities to gather data on connections outside of family and staff, if participants were greeted by name by locals. These connections were identified on each map using a smiley face emoji and the quote: "*I know them and they know me*" P4. (see Figures 1 and 2). Deductive content analysis was used to explore 12 aspects of social inclusion in neighborhoods, derived from the definition presented above. The deductive analysis of the 12 aspects of social inclusion was completed as a final step for each participant by the first author, based on the totality of the analysis of both interview transcripts, each individual case report and map.

Positionality

From study design through data collection, analysis and reporting, our team engaged in a reflexive process akin to the questions and research indicators proposed by Banks et al (2023): why; by whom, for whom; with whom; and who is affected by the benefits and costs of the qualitative study? Our team of researchers have both practitioner and academic backgrounds,

all with white Irish ethnicity. One team member had a career as an intellectual and developmental service provider leader prior to becoming an academic researcher, while another holds dual clinical services leadership and academic researcher roles. The third holds a full-time academic position. A strength of this study was that the research team were urban dwellers and had no personal or professional connections in the rural localities of the ten participants. We were not employees of the service provider hosting the research. We reflected that our experiences of social inclusion in neighborhoods as white, middle-class, able-bodied adults had the potential to introduce researcher subjectivity and bias to all stages of the enquiry. Using a range of data collection methods was intended to capture participants' unique lived experiences. Biases of interpretation were exposed and resolved through regular team discussions. This was particularly evident during data analysis stages. For example, while mapping of connections (if any) was an intended outcome of the study, we discussed the possibility that some adults with intellectual disabilities do not prioritise social inclusion/ participation in their lives. Others may wish to engage locally, however, have few or no connections outside of family and paid staff.

Reflecting on the potential benefits and costs of the study (Banks et al, 2023), our combined practitioner and academic experience was helpful in forging the research partnership with a service provider for people with intellectual disabilities and a mainstream local authority service organisation. The partnership secured research funding from an Irish Government Department fund dedicated to the national promotion and implementation of the UN Convention on the Rights of People with Disabilities (2006). The fund objective of removing barriers to community involvement for people with disabilities had a close alignment with our study objectives and research questions. As a team, we are committed to transfer of research knowledge (Authors, 2019) to a range of stakeholders. Dissemination of early findings through

an international webinar open to practitioners and researchers was completed to promote strategies that facilitate participation and reduce barriers to social inclusion for this population.

Results

Six clusters of meaning were identifiable from inductive content analysis: 1) connection to place and span of immediate neighborhood and wider locality; 2) influence of characteristics of neighborhoods/localities on connecting locally; 3) influence of individual characteristics as challenges to and drivers of connecting locally; 4) scaffolding to support or barriers/limits to social inclusion- role of family and service provider staff; 5) connections with friends, neighbors and acquaintances; and 6) social roles as focal points for social inclusion in neighborhoods.

Cluster 1a) Connection to Place

All participants had a strong connection to the place where they lived. One person had two neighborhoods, first the location of her group home and the second the area of her family home, which she visited regularly. All strongly identified with their family home place and maintaining this connection also facilitated their contact with extended family. One also had a strong connection to the family's holiday home and its locality. Regular visits to favourite shops, cafes, restaurants and services were manifestations of connection to place as illustrated by the following quotes:

"[Showing photo] *On Friday night, I get my treat right there in the chippers."*P4

"This is [Name of Charity Shop]. I buy DVDs and other things every Monday with my own money…. DVDs, some toys, that's all, and CDs"P6

All participants shopped locally, with the most frequented shop being their nearest small convenience supermarket. Some participants used their photo prompts to talk about local

landmarks or beauty spots that they liked. Two were from farming backgrounds and the family farm was important to them, with one helping out on the land.

"I really like it [Home/Farm]. We have hens, sheep and a dog." P2

"I do be on the bog [family peatland plot]. *I bring it home. I help to bring the turf* [fuel for fire] *home."* P3

All participants talked about places locally that held important memories for them.

"My church" was frequently mentioned, including by those who did not attend regularly. Some described important family events that had happened there, including funerals, anniversaries and siblings' weddings. Regular church goers showed the researcher their preferred pew that they sat in each Sunday with their family. Their family's grave in the local graveyard was mentioned by over half the sample, with some welcoming opportunities to visit during walking interviews.

[showing photo] *This is my Mum and my Dad's grave in* [Name of village]. *I like to visit, say 'Hello, I miss you so much*.'"P1

Two recently bereaved participants now live nearby their old family home, a place that held many memories for them.

'This is my house, where I used to live with Mam and Dad [deceased]… *There are lots of memories there'* P3

'My brother got married in that church and my sister got married in that church too.' P2

Town buildings held childhood memories (e.g., a childhood school), memories of deceased parents and connections with other relations, as exemplified by this exchange:

[Showing photo]*P5:This is the [Name of public building] – my Dad was a [job title] that used to work in here…. It's in [name of town], yeah. And then he retired. … When I was a little girl, I was inside there. I looked around.'*

Researcher: Do you walk past this at all?

P5: Yeah, all the time.…every day."

Cluster 1b: Connection to Place- Span of Immediate Neighborhood and Wider Locality

Analysis of participants' connections with people and places highlighted a difference between their immediate neighborhood and the wider locality that they engage with for commercial services, personal health services and leisure.

The experiences of those living in small towns (population <5000) varied depending on the location of their home. Those living within 1km of the main street had the option of walking either accompanied or independently (if able) to the places that were important in their lives (See Figure 1), for example:

P4: [Showing photo]*That's the square in* [Name of small town].

Interviewer*: So, do you walk up there?*

P4: I do, I'm independent now. I go down the town myself."

For other small-town dwellers, living over c.1km from the main street, a short car journey was required to access to the places and people important to them. For these participants their immediate neighborhoods spanned two to three kilometres from home. For three participants living in small towns, their walkable neighborhood (alone or accompanied) extended to the whole town, facilitating frequent encounters with neighbors, acquaintances, extended family, and retail/services staff (See Figure 1). For other participants living in large towns (population >5000), immediate neighborhoods were often a street in a housing estate, nearby small shops and a local park. Accessing their wider locality in the town for commercial services, personal health services and leisure necessitated family or service provider transport and being accompanied. It was common to access work, larger shops, services or leisure pursuits in the wider locality, i.e., the larger geographic span of the town. Some had strong connections and familiarity with other locations further afield, developed through vacations and/or visits to extended family.

[Figure 1 around here]

In contrast, for those living in rural townlands, (usually a detached property on a rural road 4-9kms from a nearest village or town), the span of their immediate neighborhoods varied. Most felt connections with the rural road they lived on. All rural dwellers needed transport and to be accompanied to access their immediate neighborhood. Rural participants' immediate neighborhoods usually included the nearest village that had a convenience supermarket/shop and some limited amenities, e.g., a church. For more remote rural dwellers, wider localities could consist of two to four villages and towns, with distances from their homes ranging from 2km to 20km (average 8.8km). Transport was essential for those living in rural townlands to access a range of public, commercial and leisure services in their wider localities. Participants use of services usually followed family patterns and was often dispersed between two to four nearest villages and towns, e.g., weekly supermarket shop in the nearest town, barber in nearest village (See Figure 2), for example:

"[Showing photo] *This is the bus stop where I wait for the bus to bring me to [Name of village]. Then my brother meets me and gives me a lift home" P7* [P7's rural home is 9km from this bus stop in his nearest town]

"P8: I do the shopping in [Name of shopping mall in town 14km from home]

Researcher: Yes. And what do you like to buy there?

P8: I buy clothes."

[Figure 2 around here]

Cluster 2: Influence of Characteristics of Neighborhoods/Localities on Connecting Locally

Living in a town provided most opportunities for shopping, leisure or work. Rural villages and townlands offered more limited social inclusion opportunities. The location of the family home influenced access to shops and public services. Living in or near a town, with amenities at a walkable distance from home facilitated some participants (who did not need to be accompanied) to be self-determinate and have independent access. For some not having a road to cross when walking from home to a nearby shop facilitated safe unaccompanied access.

Towns that had well-maintained footpaths and were walkable facilitated access to shops and services (e.g., bank, pharmacy, or doctor).

> *"P5: Sometimes I would go into [Name of small supermarket]. That's on the way home again.*
>
> *Researcher: That's also on the way home for you. And what do you buy in [Name of small supermarket]?*
>
> *P5: I get a drink or magazines and all that…. Yeah – it's not too far from my house."*

Some participants enjoyed a favourite leisure walk in a local park or by a river.

> *"It's lovely and quiet down here."* P3 [walking trail in nearest town 9km away from P3's rural home]

In rural areas, however, walking whether accompanied or alone on narrow country roads with high traffic volumes was unsafe. Participants with higher support needs living in either towns or rural areas did not leave home without being accompanied by a family/staff carer who provided transport for trips to the wider locality. Public transport availability and access facilitated social inclusion for two participants. The type of dwelling/property contributed to opportunities to meet neighbors. One town dweller living in a row of terraced houses, knew all their neighbors by name and had regular opportunities to greet them when walking to and from home (see Figure 1).

> *Interviewer: what do you like about living in [Name of town]?*
>
> *P4 "Just the people know me, and I know them when you're up and down in the shops and I stop and have a little chat, you know, like that."* P4

In contrast, rural participants lived in detached houses on plots with fencing and closed access gates, with neighbors living at more of a distance. While they may have recognized some neighbors' faces, natural opportunities for encounter were fewer, often just a wave when passing neighbors in cars on rural roads. Some towns had designated public outdoor social spaces that were well frequented (e.g., an outdoor seating area on a main street with high footfall, with nearby cafes, supermarket, restaurants and a pub) (see Figure 2). These communal public spaces allowed for opportunities to greet locals and have friendly exchanges. In rural

villages and townlands, encounters with acquaintances and strangers were less common and usually happened in a single local convenience grocery shop (with a combined post office) and/or a church (for those who attended regularly).

Cluster 3:-Influence of Individual Characteristics on Connecting Locally

Individual characteristics acted as a challenge to engaging locally for some and a driver for others who made connections more easily. While being able to get around independently was a facilitator of neighborhood participation, seven participants needed to be accompanied when away from home. For people who needed to be accompanied, opportunities were more limited as they were dependent on staff or family members availability. Most disliked being outdoors in wet or cold weather. Persistent fears deterred some participants from regularly walking in their immediate neighborhoods or wider localities, e.g., dogs/stray animals, traffic or meeting strangers, as the following quote exemplifies:

> *Researcher: "And do you walk on your own or do you like to have somebody with you?*
>
> *P2: I do like to have somebody with me. Because there are dogs around and the road is too busy up my way.*
>
> *Researcher: Dogs. Tell me about the dogs.*
>
> *P2: I am afraid of them."*

Solitary home-based leisure pursuits such as watching TV or online videos/games were preferred by some, as described by one participant:

> *"Researcher: The village where you live. What do you like about living there?*
>
> *P6: "I like it in my house….I watch the telly…. That's my home. I like watching television, listening to music and anything good on the internet... I got a [Brand name] TV."*

Due to issues relating to behaviours that challenge, two participants were closely supervised by staff or family members when outdoors. Age-related changes to mobility meant that some preferred not to walk long distances, needed to be accompanied or were fully reliant on service provider/family transport. Some expressed anxiety about new experiences. For the five participants who had experienced the loss of a parent, experiences varied. While living/home

circumstances had changed for some, all five continued to live in their neighborhoods. The continuity of engagement with familiar places and people that this provided was evident for most. However, one bereaved participant had withdrawn, but with the support of siblings and staff had slowly begun to re-engage with new experiences outside home.

Some individuals were shy of strangers and/or challenged to recall names of neighbors. Some did not readily initiate conversations or spoke particularly loudly, softly or indistinctly, meaning that others had some difficulty understanding them. For example, one person was observed as keen to initiate conversations with people in a park and retail staff in a familiar local shop, however, their loud voice and indistinct speech startled strangers. For two participants, outdoor noise and stimulation were difficult to tolerate, as exemplified by the following extract from researcher field notes:

> *"As the walking interview finished, I saw P6 walking out, accompanied by a staff member to the local shop. He had a loose dark sweatshirt (hoodie) on, with his face and head partially covered by the hood. I observed that he was attempting to cover his ears with his hands and seemed bothered by the traffic noise as they waited to cross the road. It would be challenging for anyone to make eye contact with P6 as he was looking at the ground. He chose not to look at or engage in conversation with any stranger or the accompanying staff member who was walking close by."*

While some individual characteristics were observed as posing challenges to connecting locally, others evidently proved to be driving factors. Being able to communicate with others facilitated making local connections. Some participants struck up conversations easily with people, both strangers and those they knew, for example:

> *"I walk in the door [local library] and say 'good morning', something like that. I have a card and I look around and say 'I'm going to look around and take some books.'"* P4

Being well orientated around their neighborhood and going for regular local walks was advantageous for making new and renewing existing connections. For four participants who were well-known in the small towns they had lived in since childhood, being greeted frequently and stopping for conversations with acquaintances was the norm. Some enjoyed light-hearted

engagement with neighbors, acquaintances and familiar retail staff. One participant who was a dog owner knew other dog owners living nearby. One person's speech was not always easily understood, but their smile, eye contact and light-hearted engagement facilitated frequent convivial encounters with locals. Some participants used mobile phones, video call technologies and social media (e.g., Facebook) to stay connected with friends and family. For one participant however, solitary technology use was associated with behaviours that challenge, so was not a straightforward support to making connections.

Cluster 4a: Scaffolding to Support or Barriers/Limits to Social Inclusion- Role of Family

In this sample, all bar one participant had strong connections with their family of origin. The seven who had lived in the same locality since childhood continued to live with family members. Some were facilitated to remain living at home by supports provided by adult siblings, extended family or single elderly parents. Three had experienced loss of both parents and now lived with adult siblings' families. While some participants had moved house in the previous three years, they continued living in their familiar wider locality.

"My brother's house is across the road from me. He lives there with his wife and my three nephews. I am very close." P1

Eight participants were known by locals in their immediate neighborhoods based on their family membership. This was strongest for those living in small towns and in rural villages/townlands. Another individual living in a group home had frequent full weekend visits to her family home, retaining strong familial ties and a connection to her second rural neighborhood. Families provided individualized support as scaffolding for social inclusion, in practical ways e.g. transport, being a companion/carer, finding employment or supporting them to use services (e.g., banking) as these quotes illustrates:

> [Showing photo] *"Sometimes we go in there [local café] for our breakfast in the morning, if we walk downtown to do our shopping like that. …Well, it's only myself and my Mum, it's our treat like." P4*

> *Researcher: How did you get that job?*

P4:"My mum knows [Name of store manager] *and we do our shopping there over the years."P4*.

In addition to parental support, nine participants had involved siblings offering a range of practical supports with shopping, socializing and availing of services in their local area.

[Showing photo]: *"This is the pub I go to with my brother." P10*

Some participants had large extended families, with some living in the same county and siblings living abroad. Some families organized vacations, returning to favourite holiday locations. During pandemic restrictions, use of video calls was popular. Some also used social media, independently or with support to remain connected to remain connected to extended family members, though the norm for participants was to browse rather than to create their own posts.

"P5: *I didn't really have Facebook before, so it was my Mum suggested I use Facebook, so I can Facebook anyone.*

Researcher: And who do you stay in touch with using Facebook?

P5: My brother in Australia, he'd be one of them anyway. My friends as well. …. I have a good few friends in it now…Sometimes my Mum and me would be on Skype…you know, because my family are in different places."P5

There was one instance of family-imposed restrictions to a participant's outside-home activities. This appeared to be due to safety concerns regarding a health condition. Two families were fully in charge of participants' welfare payments, which restricted their relative's self-determination regarding spending money.

[Showing photo of Post Office] "I don't collect money [disability allowance] *at the post office, but Ma does." P6*

Others were facilitated by family to manage their own money, by being accompanied when completing transactions in a local bank as illustrated in this quote:

"P5 [Showing photo]: *This is the [Name of bank]*

Researcher: Do you go into the [Name of bank]?

P5: I do. Mum goes in with me."

Researcher: And what brings you in there, why do you go in there?

> *P5: Sometimes they want me to sign things, as in cheques or anything like that. Or maybe I could get money out as well, the cash machine. So, that's where I keep allowances and money and things like that."*

Some were facilitated to use a credit card that they could tap for everyday purchases instead of using cash. This was particularly suited on one individual whose hand tremor made it difficult to handle cash.

Cluster 4b: Scaffolding to Support or Barriers/Limits to Social Inclusion- Role of Service Provider Staff

Service provider staff provided a range of supports for engaging locally, both on a one-to-one and group activity basis. Some participants received individualized support to connect with public and commercial services, including their favourite local shops and leisure amenities. Staff intentionally supported residents of group homes to connect with immediate neighbors and maximise their use of local amenities. For those who did not readily initiate conversations with strangers, some were introduced by accompanying staff to retail workers. For some this led to being greeted by name in shops and services that they visited regularly. For individuals with behaviours that challenge, locations/activities with low footfall were often chosen, as a bridge to the individual slowly developing skills of engaging with strangers. Three participants had changing needs affecting their ability to interact with others (i.e., health issues and/or declining memory). Having once been engaged independently, they were now supported by accompanying staff to maintain their involvement in valued activities in their local area. Two participants remained in touch with former group home staff as valued acquaintances.

Service provider pandemic restrictions were still remembered by participants. They had been experienced as impactful, in particular by participants who lived in group homes who could not shop or socialize locally during the pandemic, depending on staff-led home-based online social and educational activities.

> *"Covid was bad, very bad ….I had to stay in my room for 10 weeks…no I mean 10 days…I had to isolate… It wasn't nice. P2*

For the eight participants living with families, staff support was available through attendance at congregate intellectual and developmental disabilities day services. One participant was supported by staff to engage in activities (e.g., light meal preparation) within their own home. Some received support from staff to find and maintain part-time employment. Participants commented on staff support and some availed of bespoke online courses provided by their service provider, for example:

> *"I done the [service provider name] computer class." P1*

> *"I have a best keyworker to help me sort all this* [new job] *out."P4.*

> *P1: "I like going to the cinema with my friend. The staff help us."*
> *Interviewer: How often do you go?*
> *P1: "About once a year."*

Participants engaged in leisure opportunities that were mainly staff-facilitated providing for groups of adults with intellectual and developmental disabilities (e.g., daytime swimming or bowling or evening discos). These activities were re-instated following pandemic restrictions and were included in the participants' weekly schedules. Some participants had received one-to-one staff support to go for a leisure walk around their local town, offering opportunities for greeting locals and forming acquaintances. For some, these supports were specific to the period of pandemic restrictions and were no longer available once staff-supported group leisure activities were re-instated. Walking interviews revealed scope for some new social inclusion opportunities not previously identified (e.g., one person wished to visit the local library and another with a strong interest in farming expressed a wish to get more involved). Four people enjoyed the task of taking photographs for the research study and expressed a wish to now complete a photography course. *"I love all this. I love to do it…. I am going to get a book for my photos. I want to do a course for photographs." P4.*

Cluster 5- Connections with Friends, Neighbors and Acquaintances.

This cluster captures a range of participants' lived experiences of connections with friends, neighbors and acquaintances (outside of family and paid staff). All bar two participants had peer friendships, commenting that they did not get to see their friends as much as they wished. Some participants appeared passive in their approach to making arrangements with friends. Others had paused meeting friends one-to-one during the pandemic and were slow to reactivate these arrangements, for example: *"I haven't seen him* [friend] *for a good while now…Sometimes somebody might ask me to go out, have lunch, something like that."P5*

With the full reopening of day services, they now had more opportunity to meet friends mostly during daytime hours.

For one person, friends made through paid employment had moved on and arrangements to socialize outside of work with new colleagues were no longer made. There were particular challenges in making and maintaining friendships for participants living in rural areas. One rural dweller had made friends living in other counties through family connections. However, due to death of a parent, support to sustain these connections was gone and the friendships had lapsed. Another rural dweller had a friend living within 4km, however, could not arrange to meet up without service provider or family transport. Whether living in towns or in rural areas, meeting up one-to-one with friends in the evening time, at weekends and during day service closure periods was challenging for most. This was due to either lack of transport and/or lack of staff/family carers to accompany those who needed it.

Town dwellers experienced frequent convivial encounters with strangers and acquaintances, and this was most likely if participants had lived in the town since childhood. Encounters with strangers and acquaintances in rural areas were less, and for some were linked to church attendance or meeting up at a local club. Changes to neighborhoods were commented on by some participants, with valued neighbors or friends having moved away. Being known by sight

or by name by local acquaintances was common in this sample. Two participants knew at least one shop staff member by name in every retail outlet they used within their small towns and had regular friendly exchanges.

> *Researcher: What do you like about living in [Name of town]?*
>
> *P4: "Just the people know me, and I know them. When you're up and down in the shops and I stop and have a little chat, you know, like that. … I walk down myself, do a little bit of shopping for Mum"(P4, small town dweller).*

Some immediate neighbors engaged with participants, others did not. Neighbors of those living in group homes were experienced by participants as displaying mixed reactions to them, with some exchanging in greetings and short conversations when passing outdoors. Some knew participants by name, but others appeared distant and were experienced as avoiding contact.

> *Researcher: Can you tell me about your neighbors? Do you know any names of neighbors?*
>
> *P5: Not really – some of them moved away. Sometimes you see them coming in and out."*

Two participants chose not to engage with people outside of family and service provider staff and did not have peer friendships. All participants were known by sight by some local people to greater or lesser degrees. However, participants who avoided eye contact and chose not to engage were observed as moving within their neighborhoods or wider localities without convivial encounters.

Six types of interactions from strangers were observed as participants walked in their immediate neighborhoods: 1) a friendly greeting that may or may not have been responded to by the participant; 2) the participant initiating a greeting that was responded to directly by a stranger or acquaintance; 3) locals hearing, but not understanding a participant's greeting/conversation and seeking clarification from an accompanying staff member; 4) locals staring at the participant, followed by an averted gaze and moving past; 5) people expressing impatience (e.g., eye rolling) if the participant's pace was slow; and 6) strangers looking down and not engaging (e.g., looking at mobile phone). The exclusionary encounters were observed

in the main for the participants who avoided eye contact and whose pattern was not to engage with anyone outside of family and familiar staff.

Extract 1 from researcher walking around interview notes:

"P9 brought her family dog along on a lead to the walking around interview. She met a man with a dog whom she did not know in the middle of her local village. As the dogs greeted each other, the stranger entered into conversation with her on the topic of dogs. P9 responded by smiling and admired the stranger's dog. The man asked: "How old is your dog?" P9 hesitated and there was silence. When she didn't answer, the keyworker intervened and guessed the age. The stranger then began talking to the keyworker and made no more eye contact with P9."

Extract 2 from researcher walking around interview notes:

"P7 was waiting at a narrow pedestrian crossing in a town he walks around regularly, with his keyworker, and I. We were joined by a man. He first stared at P6 and didn't engage, turning his back to him. Next, he initiated a conversation with the key worker and I, with a short exchange about the weather. Then nodding his head towards P7, he said, 'Ye have your work cut out for ye today.' The lights changed and we all crossed the road and went separate ways. What I interpreted from this remark was that he recognized that P7 had a disability, he assumed that we were his carers, and held an opinion that P7 was hard work."

Cluster 6: - Social Roles as Focal Points for Social Inclusion in Neighborhoods

Five participants had part-time work ranging from 2 to 9 hours (average 5.4) per week. The social role of employee was generally a facilitator of making connections locally. Jobs included kitchen assistant (restaurant) and office assistant. While shared tea-breaks with colleagues were valued by participants, socializing did not extend outside of work hours. Some employee roles offered more opportunities than others to become known and to develop new acquaintances. Two participants living in small towns walked to their jobs stacking shelves in busy small convenience supermarkets. Both were visible as uniformed employees on the shop floor, were known by name and had multiple interactions with both customers and colleagues.

[P10 showing two photos related to his part-time work in a local convenience supermarket]: Photo 1- *"This is my boss- I really like her, she's good to me."* [Photo 2 of two men]*: "I work with them. [*Man's name 1*] is very funny. [*Man's name 2*] has jokes, he makes me laugh. He lives in [*name of nearby townland*]"P10*

In contrast, another participant had short hours working as a cleaner in a mostly empty building and interacted mainly with the accompanying service provider job coach. Employment was being actively pursued as a goal for another participant, however, the options were narrowed due to issues regarding behaviours that challenge and the need for an environment that would

have low stimulation. Two participants had lost their jobs, and another lost a valued volunteer role as a result of changes made during the Covid pandemic, as explained by one participant:

> "P4 [Showing photo]. *This is the kids place* [kindergarten]. *Before Covid, I used to help out there, two mornings.*
>
> *Researcher: Were you a volunteer or was it a job?*
>
> *P4: I didn't get paid. I wanted to do it… I did cleaning and some playing with the kids.*
>
> *Researcher: And what happened when Covid came along?*
>
> *P4: It all crashed down. I couldn't go back there anymore."*

None of the participants had a current volunteer role. One had been offered the opportunity to explore this in the past and had declined. No participant was a student in a mainstream education course or short term-class. Some attended specialized leisure clubs for adults with intellectual and developmental disabilities. Being a member of a mainstream club or organisation was present for five people, with the most common being church member. With evening transport provided by family members, one participant and her friend were members of a local knitting circle in a rural area. Another had joined a daytime gym and two had joined Men's/ Women's sheds.

> *"Researcher: And why did you decide to go to the women's shed?*
>
> *P5: Its one way to meet people and get to know them."*

Deductive analysis using the 12 aspects of local social inclusion derived from the definition presented above is presented in Table 2. Results indicate that the strongest aspects present for this sample were: being known by sight or by name in their neighborhoods, and a strong sense of connection to places locally. All ten participants engaged in local shopping to varying degrees, and seven also accessed some personal, business or public services in their local area. While all had some transport available from a combination of service provider staff and family members, for half this was not enough to enable them to see their friends as often as they would wish.

Discussion

This study explored how adults with intellectual and developmental disabilities experience their neighborhoods. Those living in towns, rural villages and remote rural areas have strong connections with place in their neighborhoods and for some with their wider localities. Connections with both places and people (outside of immediate family) were strongest for those living in vibrant towns, with a range of shops, public services, amenities, clubs and leisure options. While the mapping of connections with both people and places locally reveals a distinction between the person's immediate neighborhood and their wider locality, individual experiences vary considerably. Review literature has detailed a range of facilitators and barriers to social inclusion for this population (Amado et al., 2013; Authors, 2023; Bigby, 2012; Overmars-Mark et al, 2014). In this Irish study, neighborhoods that are rich in safe opportunities to participate were mainly found in rural towns. Barriers were evident for participants living in rural areas, the most common being limited local amenities, fewer people and social activities to engage with and the lack of flexible transport to participate in a wider locality or to make arrangements to meet up one-to -one with friends outside of day service hours. Review literature highlights individual factors that strongly influence participation (Bigby, 2012; Authors, 2023; Overmars-Marx et al., 2014), and those featured in this study included: how the person communicates, their level of support need, mental and physical health, mobility and whether or not the person needs to be accompanied. This may be attributable in part to the median age of the sample (45.5 years), with some evidence of changes to health status and increasing support needs. Results of the present study highlight individual personal preferences on all aspects of social inclusion as key to the extent to which individuals chose to engage with people outside of their home environment. Some actively sought new acquaintances, while others preferred limited or no engagement with people outside the circle of family and service provider staff members.

The type of interactions that were observed between participants and strangers in a town and rural context are examples the conceptualisation of encounter by Bigby et al. (2019). Convivial encounters (shared identification, recognition and becoming known) (Bigby et al., 2019) were observed in both towns and rural villages in this study. Non-encounters with strangers were observed for all participants and were to be expected on busy thoroughfares. However, exclusionary encounters with strangers in town and village streets and parks were also observed, in particular for participants with behaviours that challenge. Avoiding or excluding individuals has been linked to many factors such as bodily appearance, unusual vocalisations, misinformation about intellectual and developmental disabilities and/or public concerns about unpredictable behaviour (Walker et al., 2014). These may have been contributory factors underlying the exclusionary encounters observed in this study.

No participant in the present study held a volunteer role and there was no evidence of any appreciating the value of how volunteering can spotlight one's contribution to a local community (Hall, 2017). There is scope for further research on whether volunteer social roles that are not intended as a bridge to employment can contribute to the social inclusion of adults with intellectual and developmental disabilities.

Wilton et al. (2018) found that in an urban Canadian context, repeated shopping experiences provided potential for individuals with intellectual disabilities to have moments of recognition and social connection with retail and service staff. This finding was also salient in the rural Irish context of the present study, with many of the participants known by name and developing acquaintances with retail and service staff. This was strongest for those who walked around their neighborhood regularly, frequented the same cafes and shops, were known by family membership, had extended family living in the same county, had a local job in a retail shop and/or lived within 1km of the main street of the small towns where they had grown up. It was weakest for those with additional social, communication or behavioural challenges.

Interpersonal relationships as a quality-of-life domain have been linked to the UNCRPD emphasis on maintaining contact with family and developing friendships (Lombardi et al., 2019). However, the present study revealed how having a large and growing set of acquaintances close to where you live can also contribute to quality of life, even if those acquaintances do not lead to fuller friendships. In workplace settings, socializing with colleagues outside of work was not the norm in the present study, however, forming acquaintances with work colleagues and enjoying their company during work hours was valued. If the set of acquaintances also includes neighbors, public, commercial and/or retail services staff, the potential for natural support for individuals with intellectual and developmental disabilities may be fostered.

Service provider staff support for social inclusion of participants in this study at the time of data collection, was in a state of transition from pandemic restrictions back towards a previous norm. This norm largely involved staff-supported group leisure activities using mainstream venues. Group leisure activities may have limitations regarding persons with intellectual and developmental disabilities becoming known as individuals locally. Todd (2000) identifies the role of supervising staff in this context as that of tour guides, with responsibility to steer the experience of the group of people with disabilities who may be perceived as visitors to community spaces. Bredewold et al. (2020) found that a group with disabilities socializing in a public space may be perceived as a closed group, leaving little room or opportunities for others to engage. It is notable that during the pandemic, an experience of one-to-one staffing support was that it had the potential to allow for the possibility of convivial encounters, making neighborhood acquaintances and becoming known as an individual. Based on the findings of the present study, the reinstatement of on-to-one staff support for individuals to walk around and engage in their locality is recommended.

Results of the present study indicate that choices to engage or not with people outside of family or staff members is influenced by changing life circumstances, for example, a close family bereavement. Dodd et al. (2008) found that one third of bereaved adults with intellectual disability experience complicated grief symptoms following the death of a parent. The varying practices related to planning for transitions following parental death is described by some as a time bomb (Anderson-Kittow et al., 2022). Without planning, the present study identifies that adults with intellectual and developmental disabilities face the potential of a quadruple loss of parent, family home, local social network and connection to place. This highlights the importance of adults with intellectual and developmental disabilities being supported to maintain control and independence with individual preferences central to planning ahead. Brown (2023) highlights uniquely personal factors that hold importance for individuals with intellectual and developmental disabilities as needing more focus in quality-of-life frameworks. Personal factors identified in the present study include individual connection with places that are familiar and hold memories, alongside maintaining links with acquaintances and the local social network that forms part of an adult's life story. Bereaved participants in this study had been supported in the main by adult siblings and their extended families to continue to live in their locality, even though some were no longer living in their original family homes. The continuity provided by transitioning to a new living arrangement in a known locality that one has grown up in has policy implications for supporting aging in place whenever possible. It is recommended that planning ahead resources (Anderson-Kittow et al, 2024) be introduced to older adults and their families, with a view to a partnership approach by service providers.

Strengths and Limitations

The research questions were exploratory in nature, framed from the extensive prior literature on the topic. The study design was found to be effective. Participants reported that they enjoyed taking photographs which were later useful in supporting their communication and

conversation in a face-to-face research interview. Content analysis of the data was applied with consistency and checking credibility with an independent researcher added a level of trustworthiness to the analysis process. Cross case analysis led to identification of six clusters of meaning. While this synthesis served to maintain confidentiality on individual cases, there may be limits to reporting on unique individual experiences of neighborhoods. Creating individual maps was a strength of this study. A limitation was that budget restrictions did not allow the researcher to return to get feedback from each of the ten participants on their maps. Walking around interviews with detailed observation notes, offered an alternative method for participants to highlight what was important to them and a valuable opportunity for observing their interactions with locals. However, exploring the perspectives local people on these interactions was outside the scope of this study, and would be a valuable future enquiry to deepen understanding on how best to support social inclusion. This study was intentionally focused on the experiences of adults with intellectual and developmental disabilities. Service provider support staff were not interviewed. While some participants commented on the support for social inclusion that they had received from staff, examining the service provider interventions that underpinned these individuals engaging locally was outside the scope of the present study. A prior study had examined service providers' interventions on social inclusion in Ireland (Authors, 2022b), however, the present study raises questions about how or whether the pandemic period has altered available services and supports. Has there been any lasting impact of the restrictions and alterations on practice during these years? Exploring the perspectives of family members was also outside the scope of this study. However, the role of adult siblings in supporting social inclusion is examined elsewhere with recommendations for practice and further research (Authors, 2021). The sample size (n=10) was small, with limits to the diversity of perspectives and range of experiences captured in the study. Further studies are recommended focussing on more diverse samples, including individuals from a range

ethnic/ cultural backgrounds. Participants who were wheelchair users did not come forward for this study and further research on the impact of both physical and intellectual/developmental disability on individuals' experiences of engaging locally is recommended.

Implications for Practice and Recommendations Further Research

For those who wish to continue to live with family in the area where they grew up, social inclusion at the level of neighborhood is best supported by a combination of family members and staff focused on one individual at a time. For those living in staff-supported accommodation, making connections with people and places in a new area takes time, with a focus on supporting each person to become known in their own right. Staff education on the concept of encounter and their role in fostering social inclusion is recommended (e.g., Living with Disability Research Centre, La Trobe University course on social inclusion). Service provider-led education for family members (including adult siblings) on the common barriers and facilitators of social inclusion is also recommended. Educating families on how best to support convivial encounters may build on the range of practical ways in which they are already supporting their relatives' local social inclusion.

Person-centred planning has potential to support the social inclusion of adults with intellectual disabilities (McCausland et al, 2021). The process of involving individuals in mapping the people and places that they connect with in their immediate neighborhood and wider locality is recommended as an addition to person-centred planning processes. Use of photographs as conversation prompts and learning about each individual through walking around together are recommended as strategies Mapping offers insight into what is valued by each individual and their preferred level of engagement with people and places locally. In the months leading up to an annual person-centred planning meeting, an exploration is recommended of an individual's connections with people and places through photograph taking and walking around the

neighborhood, using the 12 aspects of social inclusion (Table 2) as a starting point. The central questions for this process include: 1) Who are the people (if any) living or working locally (outside of family and paid staff) that matter to the individual? 2) Which are the places locally (if any) that matter most to the person? 3) Are there places that the person can access independently, and which are the places that the person needs support from family/staff to access? 4) What are the facilitators and barriers (if any) to engaging locally as experienced by this individual with intellectual and developmental disability? Involving participants in creating the visual map of their neighborhood and wider locality is recommended. If repeated, perhaps annually, this process may have the potential to track changes, including whether an individual's social network is expanding or contracting over time.

Conclusion

Adults with intellectual and developmental disabilities who have remained living in the area that they grew up in have a sense of connection to place and are known by sight or by name in rural towns and villages. The distinction between a person's immediate neighborhood and wider locality is important, as reliable transport is required to access chosen locations beyond what is walkable or accessible by wheelchair from home. Rural towns provide a range of safe opportunities to participate, with barriers to social inclusion evident for remote rural dwellers. Without the necessary supports, people with intellectual and developmental disabilities are challenged to maintain connections with others outside of family and staff and have limited access to local amenities, commercial or public services, local volunteering or employment. Mapping connections with people and places locally has the potential to contribute to person centred planning. Staff and family education on facilitating social inclusion opportunities in everyday life is recommended. Future planning that supports aging in place is crucial in order that bereaved adults with intellectual and developmental disabilities may maintain their valued connections with people and places in their familiar locality.

References

Agnew, J. (1993). Representing space: Space, scale and culture in social science. In J. Duncan, & D. Ley, (Eds.), *Place, culture and representation* (pp. 251-271). Routledge.

Amado A., Stancliffe R., McCarron, M., McCallion, P., (2013) Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities* 51(5): 360–375. https://doi.org/10.1352/1934-9556-51.5.360

Amado, A., Van Ness, J., Hall-Lande, J., Dosch-Brown, R., (2019), Friendship, love, and fun: social inclusion and relationships. In Hewitt, A. S., & Nye-Lengerman, K. M. (Eds.). *Community living and participation for people with intellectual and developmental disabilities*. American Association on Intellectual and Developmental Disabilities.

Anderson-Kittow, R. J., Keagan-Bull, R., Giles, J., & Tuffrey-Wijne, I. (2023). 'There's a timebomb': Planning for parental death and transitions in care for older people with intellectual disabilities and their families. *Journal of Applied Research in Intellectual Disabilities,* e13174. https://doi. org/10.1111/jar.1317

Anderson-Kittow R, Keagan-Bull R, Giles J, Tuffrey-Wijne I. Co-designing resources to support older people with intellectual disabilities and their families plan for parental death and transitions in care. *Health Expect*. 2024; 27:e14000. doi/:10.1111/hex.14000

Banks, J., González, T., Mueller, C., Pacheco, M., Scott, L. A., & Trainor, A. A. (2023). Reflexive Quality Criteria: Questions and Indicators for Purpose-Driven Special Education Qualitative Research. *Exceptional Children*, *89*(4), 449-466. https://doi.org/10.1177/00144029231168106

Bigby, C. (2012). Social inclusion and people with intellectual disability and challenging behaviour. A systematic review. *Journal of Intellectual and Developmental Disability*, 37(4), 360-374. https://doi.org/10.3109/13668250.2012.721878

Bigby, C., (2024). Supporting Community Participation, in Bigby, C. & Hough, A., (Eds), *Disability Practice, Safeguarding Quality Service Delivery*, Palgrave- Macmillan, pp.59 -78. https://doi.org/10.1007/978-981-99-6143-6_4

Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research, 53*(4), 363-376. https://doi.org/10.1111/j.1365-2788.2009.01154.x

Bigby, C., & Wiesel, I. (2015). Mediating community participation: Practice of support workers in initiating, facilitating or disrupting encounters between people with and without intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 28(4), 307-318. https://doi.org/10.1111/jar.12140

Bigby, C. & Wiesel, I., (2019). Using the concept of encounter to further the social inclusion of people with intellectual disabilities: what has been learned? *Research and Practice in Intellectual and Developmental Disabilities*, 6(1), 39-51. https://doi.org/10.1080/23297018.2018.1528174

Bogenschutz, M., Johnson, K. R., Hall, S., Lineberry, S., Rand, J., Rossetti, Z., Shikarpurya, S., & Ticha, R. (2024). An Equity-Based Research Agenda to Promote Social Inclusion and Belonging for People With IDD. *Intellectual and developmental disabilities*, *62*(3), 186–199. https://doi.org/10.1352/1934-9556-62.3.186

Bredewold, F., Haarsma, A., Tonkens, E., & Jager, M. (2020). Convivial encounters: Conditions for the urban social inclusion of people with intellectual and psychiatric disabilities. *Urban Studies*. https://doi.org/10.1177/0042098019869838

Bredewold, F., Tonkens, E., & Trappenburg, M. (2016). Urban encounters limited: The importance of built-in boundaries in contacts between people with intellectual or psychiatric disabilities and their neighbors. *Urban Studies, 53*(16), 3371-3387. https://doi.org/10.1177/0042098015616895

Brown, I. (2024). The importance of personal factors in assessing quality of life. J*ournal of Policy and Practice in Intellectual Disabilities*, *21*(2), e12502. jppi.12502

Cobigo, V., Ouellette-Kuntz, H., Lysaght, R. & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2), 75-84. http://stigmaj.org/article/view/45

Clifford-Simplican, S. (2019) Theorising community participation: successful concept or empty buzzword? *Research and Practice in Intellectual and Developmental Disabilities* 6(2): 116–124. https://doi.org/10.1080/23297018.2018.1503938

Living with Disability Research Centre, (n.d.) *Supporting Inclusion: What does it mean to a person with intellectual disabilities?* La Trobe University, Melbourne. Retrieved July 9, 2024, from https://www.latrobe.edu.au/lids/resources

Dodd P., Guerin S., McEvoy J., Buckley S., Tyrrell J. & Hillery J. (2008) A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research* 52, 415–25.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215-229. https://doi.org/10.1348/014466599162782

Gergen, K. J. (2015). *An invitation to social construction* (3rd ed.). SAGE Publications, London.

Hall, S. A. (2017). Community involvement of young adults with intellectual disabilities: Their experiences and perspectives on inclusion. *Journal of Applied Research in Intellectual Disabilities,* 30(5), 859–871. https://doi.org/ 10.1111/jar.12276

Hewitt, A. S., & Nye-Lengerman, K. M. (Eds.). (2019) *Community living and participation for people with intellectual and developmental disabilities*. American Association on Intellectual and Developmental Disabilities. https://www.aaidd.org/publications/bookstore-home

Howarth, S., Morris, D., Newlin, M., & Webber, M. (2016). Health and social care interventions which promote social participation for adults with learning disabilities: A review. *British Journal of Learning Disabilities, 44*(1), 3-15.

https://doi.org/10.1111/bld.12100

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. https://doi.org/10.1177/1049732305276687

Kearns, R., & Andrews, G., (2009). Geographies of wellbeing. In S. Smith, R. Pain, S. A. Marston & J.P. Jones III, *The sage handbook of social geographies* (pp.309-328). SAGE Publications.

Kent-Walsh, J. & McNaughton, D. (2005). Communication partner instruction in AAC: Present practices and future directions. *Augmentative and Alternative Communication*, 21(3), 195-204. https://doi.org/10.1080/07434610400006646

King A.C., & Woodroffe J. (2017) Walking Interviews. In Liamputtong P. (Ed.) *Handbook of research methods in health social sciences*. Springer. https://doi.org/10.1007/978-981-10-2779-6_28-1

Lombardi, M., Vandenbussche, H., Claes, C., Schalock, R. L., De Maeyer, J., & Vandevelde, S. (2019). The concept of quality of life as framework for implementing the UNCRPD. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(3), 180-190. https://doi.org/10.1111/jppi.12279

Mayring, P. (2000). Qualitative content analysis. *Forum: Qualitative Social Research*, *1*(2), http://dx.doi.org/10.17169/fqs-1.2.1089

McCausland, D., Luus, R., McCallion, P., Murphy, E., and McCarron, M. (2021a) The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland. *Journal of Intellectual Disability Research*, 65: 879– 889. https://doi.org/10.1111/jir.12862

McCausland, D., Murphy, E., McCarron, M., & McCallion, P. (2021). The potential for person-centred planning to support the community participation of adults with an intellectual disability. *Journal of Intellectual Disabilities*, https://doi.org/10.1177/17446295211022125

McConkey, R. & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54(8), 691- 700. https://doi.org/10.1111/j.1365-2788.2010.01295.x

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). 'I get by with a little help from my friends': Adults with intellectual disability discuss loneliness. *Journal of Applied Research in Intellectual Disabilities*, *19*(2), 191-203.

Nygren, M.A. & Lulinski, A. (2020). *State of the Science on COVID-19 and People with IDD* [Research brief]. American Association on Intellectual and Developmental Disabilities. https://www.aaidd.org/docs/default-source/publication/state-of-the-science-on-covid-19-and-people-with-idd---dec-2020.pdf?sfvrsn=25893421_4

Overmars-Marx, T., Thomese, F., Verdonschot, M., & Meininger, H. (2014). Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability and Society*, 29(2), 255–274. https://doi.org/10.1080/09687599.2013.800469

Overmars-Marx, T., Thomése, F., & Meininger, H. (2017). Social inclusion in the neighbourhood and the professional role identity of group home staff members: Views and experiences of staff regarding neighbourhood social inclusion of people with intellectual disabilities. *Society, Health & Vulnerability*, *8*(1). https://doi.org/10.1080/20021518.2017.1395676

Overmars-Marx, T., Thomése, F., & Meininger, H. (2019). Neighborhood social inclusion from the perspective of people with intellectual disabilities: Relevant themes identified with the use of photovoice. *Journal of Applied Research in Intellectual Disabilities*, 32(1), 82-93. https://doi.org/10.1111/jar.12511

Power, A., & Bartlett, R. (2018). 'I shouldn't be living there because I am a sponger': Negotiating everyday geographies by people with learning disabilities. *Disability & Society*, *33*(4), 562-578. https://doi.org/10.1080/09687599.2018.1436039

Ratti, V., Hassiotis, A., Crabtree, J., Deb, S., Gallagher, P., & Unwin, G. (2016). The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, *57*, 63-84. https://doi.org/10.1016/j.ridd.2016.06.015

Redquest, B. K., Tint, A., Ries, H., and Lunsky, Y. (2021) Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 65: 1– 10. https://doi.org/10.1111/jir.12793.

Simplican, S. C., Leader, G., Kosciulek, J. & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, *38*, 18-29. https://doi.org/10.1016/j.ridd.2014.10.00

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2020), Intellectual disability stigma and initiatives to challenge it and promote inclusion around the globe. *Journal of Policy and Practice in Intellectual Disabilities*, 17(2),165- 175. https://doi.org/10.1111/jppi.12330

Stake, R. E. (2005). *Multiple case study analysis*. Guilford Press.

Todd, S. (2000), Working in the public and private domains: staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research*, 44: 600-620. https://doi.org/10.1046/j.1365-2788.2000.00281.x

Yin, R.K., (2018) *Case study research and applications: design and methods* (6th ed.). SAGE Publications

United Nations Convention on the Rights of Persons with Disabilities, December 13, 2006, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

Walker, E. M., Crawford, F., & Leonard, H. (2014). Community participation: conversations with parent-carers of young women with rett syndrome. *Journal of Intellectual and Developmental Disability*, 39(3), 243-252. https://doi.org/10.3109/13668250.2014.909919

Wilson M.C. & Scior K. (2015) Implicit attitudes towards people with intellectual disabilities: their relationship with explicit attitudes, social distance, emotions and contact. *PLoS ONE 10*(9): e0137902. https://doi.org/10.1371/journal.pone.0137902

Wilson, N. J., Bigby, C., Stancliffe, R. J., Balandin, S., Craig, D. & Anderson, K. (2013). Mentors' experiences of using the active mentoring model to support older adults with intellectual disability to participate in community groups. *Journal of Intellectual and Developmental Disability, 38(*4), 344-355. https://doi.org/10.3109/13668250.2013.837155

Wilton, R., Fudge Schormans, A., & Marquis, N. (2018). Shopping, social inclusion and the urban geographies of people with intellectual disability. *Social and Cultural Geography*, *19*(2), 230–252. https://doi.org/10.1080/14649365.2016.1274773

Wormald, AD., McCallion, P., McCarron, M. (2019) The antecedents of loneliness in older people with an intellectual disability. *Research in Developmental Disabilities 85*, 116–130. https://doi.org/10.1016/j.ridd.2018.11.009

Table 1
Sample Characteristics (n=10)

Age range	25 to 52 years Mean: 42.6 (median- 45.5)
Gender identity	Male: n=4 ; Female: n=6
Neighborhood types	Large town*: n=2 Small town**: n=3 Rural village: n=2 Remote rural road: n=3

*One person living in a group home visited their family home regularly and had connections with two neighborhoods and two localities
**Small town- population of <5,000; Large town population of > 10,000. Census Ireland, 2016

Table 2

Aspects of Participants' Mixed Experiences of Social Inclusion in Neighborhoods (n=10)

Social inclusion in neighborhoods*- 12 aspects	Present	Partially present	Not Present
Being known by sight or by your name in a locality	8	2	0
Having reliable, flexible modes of transport to get to chosen locations or activities.	5	5	0
Having the choice to engage in voluntary work	0	1	9
Having family and/or friends living in the locality that you see as often as you want.	3	5	2
Having a sense of connection to places locally	10	0	0
Having a sense of connection/ belonging with people (not relatives) who live locally	5	2	3
Engaging in leisure activities in the locality	7	3	1
Being a member of local organizations (e.g. church group, club member)	5	2	3
Knowing what's happening in the area	0	4	6
Doing some of your shopping in your neighborhood	10	0	0
Accessing some personal business (e.g., banking, post office, hairdresser/barber) and health services locally (e.g., G.P., dentist) or library.	7	3	0
Other aspects of social inclusion in locality (e.g., employment or mainstream education courses)	5	0	5

*12 aspects derived from a definition of social inclusion in neighborhoods (Authors, 2021).

Table 3

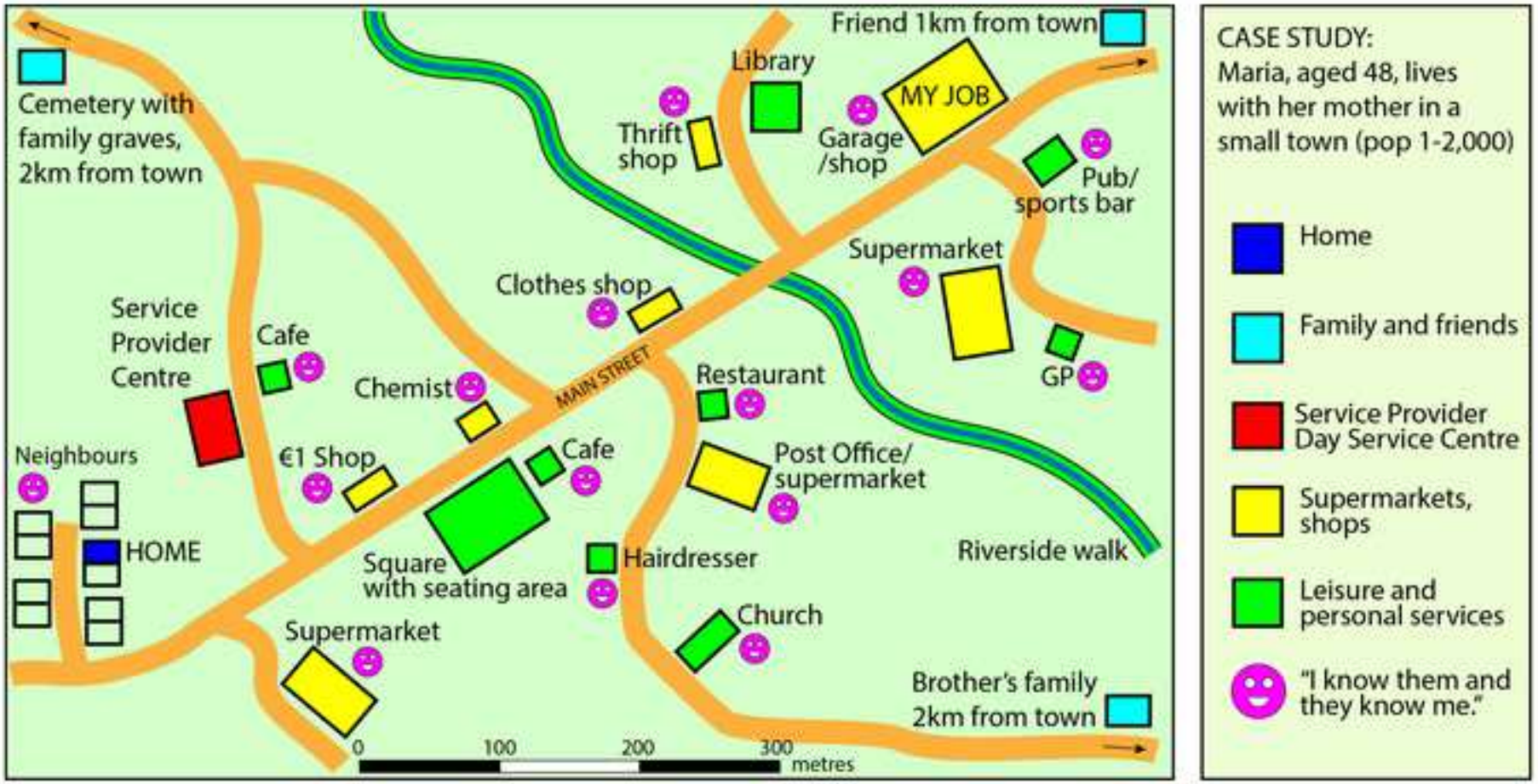
Steps in Operationalising Inductive Content Analysis

	Sequence of content analysis steps	Process of implementation for the qualitative survey data
Step 1	Reading all data repeatedly to achieve immersion and obtain a sense of the whole	Interview transcripts and detailed notes from the walking interviews for the 10 participants were read and re-read
Step 2	Coding of 'key thoughts or concepts' from the text data extracts	Codes were generated from the data extracts
Step 3	Sorting of codes into categories/ clusters. Refining and labelling of six categories/ clusters	Codes were first sorted alphabetically. Grouping of codes into clusters was completed with provisional titles identified
Step 4	Clarifying links or relationships between categories/ clusters.	Mapping of clusters/categories was completed
Step 5	Developing summary descriptors for each category/cluster.	Summary descriptors for the six clusters were developed by first author
Step 6	Identifying exemplars for codes and categories/clusters from the data.	Illustrative examples of data extracts (quotes) were identified for each category/cluster.
Step 7	Credibility checks*	A credibility check was completed by an independent researcher.
Step 8	Reporting	Journal article drafted reporting results

Note. Content analysis adapted from Mayring, P. (2000). Qualitative content analysis. *Forum: Qualitative Social Research, 1*(2) and Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. Copyright Sage journals. Credibility check* from Elliott, R., Fischer, C.T. and Rennie, D.L. (1999), Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology,* 38: 215-229. Copyright The British Psychological Society).

Figure

Click here to access/download;Figure;Figure 1 INCLUSION-S-24-00036 Revision 1.jpg



Figure

Click here to access/download;Figure;Figure 2 INCLUSION-S-24-00036 Revision 1.jpg