

# Inclusion

## Living in localities: the factors influencing the social inclusion in neighborhoods of adults with intellectual disability. A systematic scoping review.

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**Title Page (blinded for peer review)**

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Intellectual Disability. A Systematic Scoping Review**

Authors' names and affiliations blinded for peer review

**Abstract**

Adults with intellectual disability (ID) are now more likely to live in ordinary localities. However, this does not always equate with engagement, leading to forming new relationships and a sense of connection. This systematic scoping review examined research on social inclusion in neighborhoods for adults with ID, synthesizing 94 peer-reviewed studies published between 2000 and 2020. The characteristics of neighborhoods that foster inclusion include: richness of opportunities in localities, public acceptance, positive neighboring, and multi-dimensional accessibility. Social inclusion in neighborhoods is complex, with a range of other influencing factors also identified. Recommendations for further research and implications for practice are discussed, to support individuals to actively engage locally and to enhance their informal social networks.

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People with intellectual disability (ID) have experienced a history of separation from mainstream society, especially those who live away from their family of origin in institutional care (Lemay, 2009). With an international trend to close residential institutions, adults with ID are more likely to live in ordinary localities. However, this does not always equate with engagement, leading to forming new relationships and having a sense of connection. Since the 1970s the process of closing institutions and developing locally based day and residential services has been a feature of the ID service context in the developed world, providing an impetus for applied research (Parmenter, 2004). Small scale services are found to afford a better quality of life (e.g., Kozma et al., 2009). However, whether the ethos of locally based services has changed is debatable (Lemay, 2009). Moving to staff supported services may involve loss of valued relationships for individuals, unless active support from family members or staff is in place to retain them. A study of the culture in underperforming group homes for adults with high support needs, found a gap between disability policy expressed in service objectives such as community participation and staff perceptions of the capacities of residents (Bigby et al., 2009). Understanding the preferences of people with ID for participation is key, along with the attitudes of supporting staff to creating opportunities for local engagement (Overmars-Marx et al., 2014). Services in the developed world have been described as being in transition to a more personalized model of support (e.g., McConkey & Keogh, 2016). Whatever the service type, however, the readiness of non-disabled people to engage with adults with ID living locally has been found to vary greatly. A global survey found that high levels of stigma towards people with ID persist, despite broad support for social inclusion (Scior et al., 2020). Reviewing public attitude studies revealed ambivalence towards adults with ID indicating that they are perceived by some non-disabled people as “highly undesirable for social interactions” (Scior, 2011, p.2178).

While recognizing attitudinal and environmental barriers, a guiding principle of the UN Convention on the Rights of People with Disabilities (UNCRPD, 2006) is full and effective participation and inclusion in society for all people with disabilities. Some governments that have ratified the

convention, have initiated new, or further developed their existing national strategic plans (Flynn, 2011). Some state disability strategies have identified participation linked with neighborhood engagement as objectives (e.g., Government of New Zealand, 2016; UK Valuing People Strategy 2009.). However, government strategies and legal instruments alone do not guarantee more socially included lives for individuals with ID. The question remains as to how these national disability strategies translate into strengthened neighborhoods, in which the social inclusion of adults with ID becomes the norm. Shifting from legal/ policy statements to positive results for adults with ID requires an in-depth understanding of the barriers and facilitators to their social inclusion in neighborhoods.

The existing review literature on what was most often titled social inclusion or community participation of adults with ID highlighted conceptual ambiguity (e.g., Amado et al., 2013; Bigby, 2012). The phrases social inclusion, community integration, community participation and social participation were used inconsistently across a range of empirical studies reviewed. Defining broader social inclusion, Cobigo et al. (2012) offer a somewhat more rounded view of the concept as:

a series of complex interactions between environmental factors and personal characteristics that provide opportunities to (1) access public goods and services, (2) experience valued and expected social roles of one's choosing based on his/ her age, gender, and culture, (3) be recognized as a competent individual and trusted to perform social roles in the community, and (4) belonging to a social network within which one receives and contributes support (p. 82).

Influenced by Cobigo et al. (2012) and drawing also on social geography literature (e.g., Corcoran, 2002; Gregory et al., 2009), the present study defines social inclusion in a neighborhood as focused on both identification with and connection to place, in addition to engagement with people that matter to an adult with ID, in the locality in which they live (Authors, 2021, blinded for peer review). The experience of neighborhood for a person with ID is not static. Based on individual preferences, it can be expected to develop with exposure to interactions and new experiences. Facilitation to engage in valued social roles (Lemay, 2006) and support to both maintain and broaden social networks

(Howarth et al., 2016) are understood as potential building blocks to social inclusion for adults with ID.

The prior review literature highlighted that social inclusion and having a range of interpersonal relationships are positive influences in the lives of adults with ID (e.g., Amado et al., 2013). However, physical presence alone outside of segregated spaces does not equate with engagement or forming new relationships. Bigby (2012) described participation as often restricted to the distinct social space of family, staff, and other people with ID. Further research was recommended to examine the factors that facilitate or impede social inclusion: neighborhood characteristics; the influence of adopting local social roles (e.g., volunteering) as a bridge to participation; and the influence of social policy (Overmars-Marx et al., 2014). The most recent broad literature review, while systematic, was limited to the years 1996 to 2006 (Verdonschot et al., 2009a; 2009b). Empirical studies identified focused mainly on what authors termed mild ID, pointing to a restricted evidence base in the body of literature for the decade reviewed. A broad state of science systematic review has not examined literature on this topic prior to 1996 and since 2006 (when the UNCRPD was published). Therefore, this systematic scoping review intended to deepen understanding of the scientific context and to synthesise core findings across a range of empirical studies and conceptual/theoretical papers. While the aim of the study was to examine the nature of research on social inclusion in neighborhoods for adults with ID, the specific questions examined were:

- What characteristics of neighborhoods are reported to facilitate people with ID to participate to their satisfaction?
- What other factors are reported to influence adults with ID in achieving social inclusion in their immediate neighborhoods?

### **Methodology**

This systematic scoping review aimed to achieve a comprehensive, replicable search of a body of literature that was large and heterogeneous (Levac et al., 2010; Geogh & Thomas, 2012). PRISMA scoping review guidelines (Tricco et al., 2018) were used to benchmark the methods.

### **Search and Screening Strategy**

Examination of prior reviews on ID and/or social inclusion identified PsycINFO; Medline; ERIC; CINAHL; and Social Sciences Citation Index as the most used databases. Trial search strings were tested, using terms commonly used to describe both the population and the topic. A gap was identified for older studies, in particular those from North America, in which the term 'mental retardation' was used. This term was included in the search string to broaden the search. The terms: social inclusion, community integration, community participation and social participation were incorporated, with the intention that the review would be comprehensive. Databases were searched from inception (to ensure a comprehensive search) using the following search string: (disab\* OR retard\* OR handicap\*) AND (intellectual OR mental\* OR learning) AND (community OR neighbo\*rhood OR social OR local\*) AND (participat\* OR inclus\* OR integrat\* OR involve\* OR capital OR network\*). The database searches were conducted on June 1, 2017, with a follow-up search on February 2, 2020. The search was restricted to peer-reviewed studies published in English, to reflect the skills of the research team.

Empirical studies, systematic/literature reviews and theoretical/conceptual papers **were screened, focused on people with ID over 18 years of age.** The three-person review team completed a two-stage screening process: title and abstract screening and full text screening, following closely the stages detailed by Arskey and O'Malley (2005) and Levac et al. (2010). Covidence systematic review software ([www.covidence.org](http://www.covidence.org)) was used to support the process. The first and second authors screened title/abstract records without conferring. Disagreements were referred to the third author for review and differences were resolved through team discussions. Full text screening was completed using the same process. Reference lists of included papers were also searched by the first author for relevant papers, which were then screened using the same two-stage process.

### **Quality Appraisal**

The quality appraisal system for the review focused on five 'fatal flaws' in the methodological quality of studies (Dixon-Woods et al., 2006). For each included study, the following aspects were appraised: clarity of study objectives; appropriateness of research design; data display to support

interpretations; clear account of the process by which findings were produced; and an appropriate method of analysis.

### **Data Extraction and Analysis**

Data extraction was structured, using a template to record the key research design features of studies and core findings related to factors influencing the social inclusion in neighborhoods of adults with ID. The data extraction template was independently tested on sample papers by two members of the team ensuring reliable and comprehensive data extraction. Data analysis involved descriptive statistics tabulating key features of included papers. Thematic analysis (Braun & Clarke, 2006; 2017), including coding and a staged development and refinement of themes was completed on findings related to the specific review questions.

### **Credibility and Reliability Checks**

Credibility checks were completed to examine the reliability of the quality appraisal completed by the first author, the rigor of the data extraction process, and the credibility of themes interpreted through thematic analysis. An independent researcher completed an inter-rater reliability check on the quality appraisal of 10% of randomly selected studies included from full text screening. There was a 97.14% agreement between the researchers. The independent researcher also completed data extraction using the extraction template on the 10% random sample of included studies, with an overall score of 78.39%. Both researchers extracted the same core findings. However, discrepancies were noted in the level of detail extracted on study findings, with the first author tending towards a greater level of detail. The results of these checks indicated a good level of agreement and exceeded an acceptable agreement of 70% or above (Guerin & Hennessy, 2002).

## **Results**

The database searches yielded a total of 5250 records. With the removal of non-relevant records, 372 articles were eligible for full text screening. Reference list searches led to screening of a further 33 studies. After full text screening, the final number of included studies was 150, with 46

(30.66%) published pre 2000 and 104 (69.34%) published post 2000. Reasons for exclusion are summarized in Figure 1, with the most common being that the focus was not substantively on social inclusion in neighborhoods.

<Figure 1 near here>

The search strategy in this review aimed to be exhaustive, however, the volume of papers identified was challenging in terms of feasibility. An analysis of studies by year of publication indicated a noticeable pattern, whereby studies focused primarily on adults with ID transitioning to living outside institutions were mainly clustered in the period pre 2000 (e.g., Birenbaum & Re, 1979; Cummins et al., 1990). These studies centered primarily on community adjustment (e.g., McGrew et al., 1992) as opposed to in-depth enquiries into participation at a neighborhood level. Based on this pattern, a some-what pragmatic cut-off point of post 2000 was agreed on, with a final figure of 104 articles between January 1, 2000, and February 2, 2020, meeting the inclusion criteria (see supplemental material 2). Ten of these were literature review papers.

### **Quality Appraisal of Included Studies**

Sixty-three (97%) of the empirical papers met all quality appraisal criteria. Two papers (Martin, 2006; McClimens et al., 2009) met three or four out of five criteria. Removing these papers was considered, however, Dixon–Woods et al. (2006) highlight that the final judgement about inclusion rests on an assessment of relevance as well as on quality and so both papers were retained.

### **Overview of Included Studies**

Included studies (n=104, including empirical, conceptual/opinion and review articles) showed a steady research interest in the topics of what was most commonly titled social inclusion or community participation of adults with ID in the years 2000 to February 2020. The countries with the highest numbers of studies were Australia (n=28, 26.92%); the UK (n=26, 25%); the Netherlands (n=15, 14.42%); and USA (n=13, 12.5%). Other countries also demonstrating interest in the topic since year 2000 included Canada (n=7, 6.73%); Ireland (n=6, 5.77%); Israel (n=3, 2.88%); Germany (n=1, 0.96%); and New Zealand (n=1, 0.96%). There were some transnational studies (n=4, 3.84%). The type of

studies varied, with empirical studies (n=84) making up 80.77% of all included articles, broken down as qualitative (n=44, 42.31%), quantitative (n=28, 26.92%) and mixed methods (n=12, 11.54%). The remainder included theoretical/conceptual papers (n=10, 9.61%) and reviews (n=10, 9.61%) (six systematic reviews and four literature reviews).

### **Characteristics of Studies Included in Detailed Analysis**

The detailed analysis focused on 94 papers (excluding review papers). The characteristics of all 94 theoretical/conceptual (n=10) and empirical (n=84) studies are detailed in Supplementary Materials 1, with included studies highlighted in the reference list. Sample size/composition varied considerably, as did data collection methods. In empirical studies (n=84), primary participants included adults with ID; staff and service managers; family members and others. The other category comprised of disability professionals and policy stakeholders; neighbors of group home residents; community club leaders/volunteer mentors; community and arts organization leaders; public bus drivers; and members of a national online internet survey panel. Examining sample compositions highlighted that while adult-with-ID-only samples were the most common (n=53; 63.09%), mixed samples also featured (n=19; 22.62%). The latter varied in composition, with family members included in six mixed samples, and staff members included in 13. Family-only and staff-only samples were uncommon in the studies reviewed.

In empirical studies that included participants with ID the ages of adults ranged from 18 to 71 years. In just over a third of the studies (n=30; 35.71%), the mean age of adults with ID was not specified. A further 16.67% (n=14) were other studies with staff and family member participants, in which neither the age range nor mean ages of the adults they referred to were reported. In almost half of empirical studies (n=40; 47.62%) mean ages were reported. Participants with ID with mean ages between 40 and 59 years comprised 60% (n=24), with 5% (n=2) in the 60-69 age range, and none over 70 years. Adults between 18 and 39 years comprised 35% (n=14) of studies. Considering the heterogeneity of the samples, some authors offered a description of support needs, while other studies reported the levels of ID. Studies included individuals with mild (n=3; 3.57%), mild to moderate

(n=19; 21.62%) and severe or profound ID (n=12; 14.29%). All levels of ID were included in just over a third (n=29; 34.52%) of papers. However, 25% of studies (n=21) did not refer to ID classification levels, with these studies typically including a summary description of participants as a group and/or a listing of types of ID syndrome.

### **Themes identified on the characteristics of neighborhoods that facilitate participation**

Given the review questions on the characteristics of neighborhoods and other factors influencing participation, themes related to social inclusion in localities were identified. Sixty-seven (71.27%) papers had extractable data on the characteristics of neighborhoods/localities that facilitate people with ID to participate. Five interconnected themes were interpreted that addressed this question. Sample data extracts of findings from included studies related to these five themes are presented in Table 1.

<Table 1 near here>

#### ***Locations and Safe Neighborhoods Rich in Opportunities to Participate***

Safe neighborhoods, rich in opportunities to participate facilitated engagement, whereas impoverished areas, with limited leisure options, high unemployment, poor volunteering possibilities, few community facilities and/or crime impacting on personal safety (e.g., Hall, 2005), were presented as limiting participation. Small rural communities afforded some informal opportunities to connect, however, the range of social activities available to engage in may be narrow (e.g., Bates & Davies, 2004). Town and urban public spaces (e.g., shopping malls, supermarkets, parks) involved more fleeting or no interactions between people with and without ID (e.g., Wiesel & Bigby, 2014), which may limit opportunities for adults with ID to become known in their locality. However, the participation opportunities for work/leisure may be richer in towns and cities. A facet of this theme was that adults with ID appreciated living close to valued social network members. Proximity to local facilities and to a range of services was also important. Living in the area an individual with ID grew up in presented an advantage to being known, having long standing acquaintances with whom they had

convivial encounters (e.g., Overmars-Marx, 2019). Neighborhoods in which adults with ID reported they felt safe (day and night) to socialize and use local services, facilitated being out and about more, offering repeated encounters and opportunities to become known.

### ***Public Acceptance of Adults with ID***

Public acceptance was a factor influencing engagement in localities. Studies found both experiences of rejection/exclusion based on name calling or intimidation, and adults with ID being actively welcomed, with their differences understood by people in their locality. Also noted was ambivalence by neighbors about the presence of adults with ID based on bodily appearance or unusual vocalizations (e.g., Walker et al., 2014). This was represented as experiences by adults with ID of silent avoidance, disapproving stares, or being included but given special treatment (Merrells et al., 2019). The challenge of being understood, in person and over the phone presented a barrier to accessing services. As consumers of services (e.g., banking, shopping), interaction challenges led occasionally to service staff doubting the agency of an adult with ID to complete a transaction, with experience of impatience among other customers. Some adults experienced commercial/service staff addressing the person accompanying them rather than them directly (e.g., Strnadova et al., 2018). Arising from studies examining contact between adults with and without ID, authors discussed public recognition of the right of adults with ID to use public places and amenities in ways that may be perceived as different or departing from established norms (Wiesel & Bigby, 2014). Ease of interactions between adults with ID and people without disabilities through exchange of greetings was one representation of public acceptance (Overmars-Marx et al., 2019). However, for the general population, relying on conversation exchange alone appeared to limit social engagement with many adults with ID. Acceptance by non-family natural supporters was valued by adults with ID, including helpful public bus drivers, welcoming social club members, people offering lifts or directions and friendly, patient retail/waiting staff, who addressed them directly. However, some adults with ID were observed as choosing to converse within a closed group of other adults with ID in public places, leading to unknowingly excluding people without disabilities from engaging (Bredewold et al., 2019).

***Positive Neighboring Experiences***

Positive neighboring experiences with near neighbors were associated with societal or local norms. Examples included becoming known by exchanging greetings, being a familiar face at neighborhood events, respecting neighbors' boundaries/privacy through spontaneous contact without demands or obligations and being tolerant of occasional nuisances (e.g., van Alphen et al., 2010). Convivial encounters with strangers or acquaintances in public spaces were valued and supported by boundaries being respected (e.g., Wiesel et al., 2013) and both parties having the space and freedom to disengage (e.g., Bredewold, 2019). Making connections as a neighbor was grounded in repeated exposure to neighborhoods, and encounters were most often greetings or a short conversation (e.g., Overmars-Marx et al., 2019). Staff members working, but not residing in group homes were also perceived by people living locally to be neighbors and were expected to engage accordingly (e.g., van Alphen et al., 2010). Neighbors were reported to be reassured by staff presence to help the flow of interactions, particularly in encounters with adults with high support needs (e.g., van Alphen et al., 2012). Neighboring may be enhanced if links were forged through pivotal neighbors who organized get togethers. Within the context of this theme, the disruption of contact with immediate neighbors appeared to be related to a range of factors, including unfriendly or hostile neighbors (e.g., Power & Bartlett, 2019). Some neighbors may be unaware of people with ID living in their neighborhoods, others may see people as visible in shops and other amenities as a customer or employee. Commentary on the appearance of group residences (e.g., Overmars-Marx et al., 2017) suggested that if local norms were not considered, barriers to positive neighboring followed.

***Accessibility of Buildings, Information, and Adaptation of Activities to Suit Adults with ID***

This theme had multiple dimensions. Lack of access to buildings, open spaces and community events for wheelchair users and adults with sensory impairments blocked participation. Mainstream services (e.g., those for older people) were found to be ill-equipped to meet the needs of adults with ID (Ager et al., 2001). Accessible services and activities also hinged on accessible technology, access to

social media, application forms, appointment letters and information (e.g., signage, maps, and bulletins about local activities). At the level of citizen participation, accessible voting materials, technical instructions and individual assistance from service providers promoted engagement (Agran et al., 2015; 2016). Inclusive and accessible cultural and sporting activities with a declared philosophy of equal access and opportunities were seen to enable participation, and encompassed activities specifically aimed at breaking down barriers between people with and without disability (e.g., Fujimoto et al., 2014). A facet of this theme was practical deterrents for adults with ID to going outdoors, such as adverse weather and snow-blocked/damaged footpaths (e.g., Heffron et al., 2018).

### ***Flexible Transport Options***

Transport options that supported participation included service provider vans, family cars, and taxis. More opportunities for encounters and becoming known were noted for adults with ID who walked without needing to be accompanied (Overmars-Marx et al., 2019), were cyclists, and/or public transport users. Concessionary travel passes were valued by public transport users. Replacing lost or stolen bus passes, however, involved cost and being housebound until it arrived, while changes to public transport routes were confusing (Mooney et al., 2019). The prohibitive cost of taxis, with added tariffs for wheelchair access was a potential disincentive to participate. Dependency on staff and family members for transport placed limits on neighborhood engagement (e.g., Welsby & Horsfall, 2011). Advance travel planning and flexibility were keys to success, however, in some contexts transport for adults with ID was inaccessible, inflexible, and unavailable at short notice.

### **Themes Identified on the Other Factors that Influence Social Inclusion in Neighborhoods**

Following from characteristics of neighborhoods, this review posed the question, what are the other factors that influence social inclusion in neighborhoods for adults with ID? Eighty-six (91.49%) papers had extractable data on this question. Thematic analysis generated a total of five interconnected themes that served to answer this question. Sample data extracts of findings from included studies related to these themes are presented in Table 2.

<Table 2 about here>

### ***Where and With Whom an Adult with ID Lives***

Place of residence was identified as underpinning opportunities for social inclusion in neighborhoods. Large care residences, whether locally based or in campus settings (set apart from neighborhoods) were considered a type of closed community that takes care of itself (e.g., van Alphen et al., 2010) and were seen as least likely to facilitate engagement or reciprocity in the locality (e.g., McConkey et al., 2007). Staff-led group outings to public places were the norm for larger residences, a practice considered a barrier to neighboring, as it created a distinct social space with limited or no interactions with adults without ID. A supported living model (e.g., living alone, or with a partner/friend) appeared more likely to lead to participation in the life of a neighborhood (e.g., McConkey et al., 2007). Unsupported however, these living arrangements could lead to loneliness and isolation. Living with family members (including foster family) and in small group homes was described as having the potential for independent participation, with supports for engagement (e.g., McConkey et al., 2005). Individualized supports that facilitated participation were essential to maintain engagement, especially as people aged and their circumstances changed.

### ***Individual Characteristics Acting as Both a Challenge to and a Driver of Participation***

This theme identified individual characteristics as both a challenge to and a driver towards engagement. Adults with high support needs and/or older adults were less likely to experience social inclusion in their neighborhoods. Studies found that individuals with ID who needed to be accompanied outside of home and/or older adults without dedicated individualized supports, were less likely to engage in neighborhood leisure activities. Poor physical and mental health were individual characteristics described as affecting consistent participation. Persistent fears related to being outdoors and anxiety about new social experiences also affected engagement (e.g., Mooney et al., 2019). Knowledge, skills and personal qualities also served as drivers towards or challenges to social inclusion. Examples included communication skills, ability to form relationships/friendships, recognize personal boundaries of others, navigate societal norms and the expectations of others and

ability to plan a social life (e.g., Renwick et al., 2019). A range of experiences was discernible in the literature, with self-determination and control evident for some (including some who disliked the disability label) and the partial/full reliance on staff or family members for others. An aspect of control was having the financial means to engage in leisure activities and agency over one's own money (e.g., Heffron et al., 2018). Another aspect of this theme was the personal motivation of an individual with ID as a push towards being included as an equal in **their** locality (e.g., Martin, 2006). In contrast, some adults with ID may have personal preferences or scarce time which narrowed their opportunities for engagement outside of dedicated service spaces (Overmars-Marx et al., 2019).

### ***The Role of Informal Social Networks***

Social networks enabling social inclusion in neighborhoods was also identified as a theme. In tandem, neighborhood participation had the potential to enhance the existing social networks of adults with ID. Informal social networks included neighbors, acquaintances, friends, and family members. Social networks of adults with ID were described as small and dense, with a reliance on family members and staff (Forrester-Jones et al., 2006). Their maintenance through contact and reciprocity was noted, presenting a challenge to some adults with ID. This theme also captured a focus on friendships, with friendship for adults with ID often restricted to other adults with ID. However, adults breaking out of the distinct social space of family, staff and others with ID also featured, becoming known, and forming acquaintances with non-disabled adults (e.g., Wiesel & Bigby, 2016). Family support and friendships with peers were evident as conduits to engaging in a locality. Having no friends to go out with limited involvement, while having a supportive family who understood the importance of participation was generally considered a critical enabling factor (Buys et al., 2012). Conversely, family attitudes to both real and perceived risks of abuse, accident or harm had the potential to hamper the neighborhood social inclusion of their relatives with ID (e.g., Venema et al., 2016). Adults with ID being taught not to talk to strangers, limited the possibility of encounters (e.g., Wilton et al., 2018). Some family members struggled to believe that participation in a locality was a realistic goal for their relative, holding a fixed view of their choice and decision-making capacities.

Some family members had limited time and energy, or described themselves as not that sociable, therefore, were challenged to facilitate interactions outside the family (Walker et al., 2014). Moreover, where there was a history of over dependence on family, teaching of life skills into adulthood may have been delayed (Buys et al., 2012). Family control of an individual's welfare payment featured for some. A facet of this theme was the potential for social capital to emerge from social networks, with family and friends helping to access housing, employment, and identification of local groups to join.

### ***Staff and Services Providing Individualized Supports as Scaffolding for Social Inclusion***

Individualised staff support as scaffolding for social inclusion in a locality was another theme evident in the literature reviewed. Scaffolding was understood to be the structured approaches helpful to adults with ID to form connections in their own right. Individualized service approaches facilitated ongoing participation, with personal goal setting implemented consistently by staff enhancing participation over time (e.g., McConkey & Collins, 2010a). The value of staff roles in maintaining and enhancing informal social networks was also stressed. Other scaffolding components were innovative service models that included personalized budgets and strategies to bridge connections outside traditional service structures, away from specialist sites such as sheltered workshops. Some group-based ID services were limited in fostering interactions with peers without disability, with a tendency by some staff to organize segregated group activities in mainstream settings, under a banner of community inclusion (e.g., Wiesel & Bigby, 2016). A pattern of peers and friends with ID made in service settings not contacted outside service hours also featured. Within this context, staff attitudes, beliefs and work practices were evident as both powerful enablers and potential blocks to social inclusion in neighborhoods (e.g., McConkey & Collins, 2010b). Staff led local social gatherings featured, intended to create opportunities for neighbors to meet group home residents. Staff availability to address neighbors' concerns and offer helpful information about their neighbors with ID raised issues of protecting individual confidentiality. In some studies staff debated whether adults with high support needs could realistically participate in their local area (e.g., Bigby et

al., 2009). Staff turnover, limits to staff skills, knowledge, competence, and available time also hampered local engagement, as did concerns about safety risks. Another facet of this theme was the influence of government policy as scaffolding. Promoting inclusive societal structures twinned with the service provider role in securing commitment to social inclusion in neighborhoods (Power, 2013). However, the benefits trap as a barrier to employment, cutbacks to services, labor intensive accountability systems, service safety policies/curfew rules and scarcity of dedicated resources to mobilize individualized approaches, were also identified as barriers (Simplican et al., 2015).

### ***Social Roles as Focal Points for Social Inclusion in Neighborhoods***

This theme highlighted the importance of valued roles as stepping-stones to engagement for adults with ID. Employment, supported volunteering and education offered opportunities for forming relationships. However, being acquainted with fellow employees did not appear to extend into contact outside the workplace, and some adults faced workplace discrimination (Strnadova et al., 2001). The social role of church or club memberships also received attention in the literature (e.g., Carter et al., 2015). Segregated leisure and sports clubs were found to support the development of social skills and valued friendships with peers. However, they were critiqued as absorbing available time and resources, leaving less time for developing naturally occurring acquaintances and friendships within the locality. Places with very strict norms of behaviour or highly competitive activities were found to be more exclusionary towards people with ID (Wiesel & Bigby, 2016). Self-advocacy groups were potential catalysts for broader social inclusion, with the potential to lead to friendships, volunteering and/or paid work (e.g., Frawley & Bigby, 2015). Underpinning this theme was the value of common interests (e.g., dog walking) as opportunities for convivial encounters or an integrating shared activity as a focal point for successful engagement with peers without disabilities (e.g., Bould et al., 2018). Repeated visits to the same venue, shopping area (Wilton et al., 2018), or social group led to opportunities to extend their social network through becoming known (Overmars-Marx et al., 2019). Joining in a shared, non-competitive activity (Chng et al., 2013) appeared to create the conditions in which convivial encounters and/or personal connections could occur (Wiesel & Bigby, 2016).

### Discussion

This systematic scoping review aimed to establish the nature of literature on social inclusion in neighborhoods of adults with ID, identifying facilitating factors, including the characteristics of neighborhoods. Research interest in the topic has been steady in developed countries, however, only one transnational empirical study was traced (Power, 2013). Literature over close to two decades, is strong on qualitative research designs, with over half the empirical studies using these methods, a third using quantitative methods and a relatively small number of twelve using mixed methods. While a number of studies included adults with ID, there was a pattern of examining participation or social networks in the context of community involvement, without defining the precise meaning of the term community. A small number of studies towards the end of the period reviewed had begun to consider social inclusion in neighborhoods from the perspectives of adults with ID (Overmars-Marx et al., 2019) and their place-based experiences of inclusion and exclusion (Power & Bartlett, 2018a; 2018b). The current review established a gap in comprehensively exploring how individuals with ID in a range of countries and cultural contexts experience their neighborhoods. For example, comprehensive mapping of individuals' interactions with both people and places in their immediate neighborhoods has not yet been reported on in peer-reviewed literature.

Safe neighborhoods rich in opportunities for participation and the importance of positive neighboring experiences are perhaps important for all citizens engaging in their locality. However, poor accessibility presents significant barriers for adults with ID. The theme of multi-dimensional accessibility (Fugimoto et al., 2014) offers insights into barriers that block adults with ID from information on/entry into mainstream services, associations, and clubs. The availability of flexible and accessible transport also featured as a theme in the present review, in line with prior reviews (e.g., Overmars-Marx et al., 2014; Verdonschot et al., 2009b). Public acceptance as a characteristic of welcoming neighborhoods was also found in prior reviews, with Overmars-Marx et al., (2014) and Verdonschot et al., (2009b) identifying that local people being hostile or welcoming as an environmental factor influenced participation of adults with ID. Positive neighboring as a theme is

relatively new in the review literature as a factor that facilitates social inclusion, with some authors recommending further research on characteristics of neighborhoods (Overmars-Marx et al., 2014) and the attitudes and experiences of what are titled community members (Amado et al., 2013). The present review synthesized studies that examined the attitudes of neighbors without disability (e.g., van Alphen et al., 2010; 2012; Overmars-Marx et al., 2018) and the interactions between people with ID with their neighbors (e.g., Dijker et al., 2011). Positive neighboring was grounded in individuals with ID being visible, becoming known by sight and by name through having repeated exposure to short interactions with neighbors. The finding that support staff working but not residing in group homes are also perceived as neighbors and are expected to behave accordingly, adds a dimension to the understanding of how connections may be forged locally. However, positive neighboring is also fostered by adults with ID becoming known for their valued contribution locally.

The present review also asked: what are the other factors reported to influence the social inclusion of adults with ID in their neighborhoods? The value of a social role based on a shared interest/activity appeared to positively impact on engagement in mainstream encounters in urban settings. A cluster of Australian studies reported the testing of an intervention in which volunteer mentors supported adults with ID to join leisure clubs on an equal footing. These papers offer a clear conceptual framework and best practice recommendations to service providers on supporting social inclusion (Bigby et al., 2014; Craig & Bigby 2015; Wilson et al., 2010; 2013). Findings indicated that public ambivalence can be overcome through targeted public education, focused on individuals not groups of adults with ID. There is scope for further larger scale public awareness interventions that may serve to counter persistent stigma experienced by this population (Scior et al., 2020), building foundations for safe neighborhoods that are rich in opportunities for engagement. In their review of 13 intervention studies, Bigby et al. (2018) examine mainly Australian and other related studies, finding promising approaches which have the potential for larger scale replication and examination of outcomes. Given the dearth of transnational studies on social inclusion identified by the present

review, there is scope for replication of studies in which social roles are supported, to examine social inclusion in a range of cultural contexts. The current review indicates that being employed did not generally lead to leisure or social engagement outside the workplace. However, the workplace factors underpinning this have not been comprehensively examined.

A supported living model: either living alone, with a partner or friend in an ordinary neighborhood, was the living arrangement that was likely to lead to most opportunities for participation in the life of a neighborhood. This confirms findings of prior reviews, some of which also included small group homes as having a positive effect on social inclusion (e.g., Amado et al., 2013). The theme of individual characteristics as both a challenge to and a driver of participation is a finding that also reflects prior reviews (e.g., Bigby, 2012). In the last state of science review, empirical studies were found to focus mainly on adults with mild ID (Verdonschot et al., 2009a). The present review noted wide-ranging levels of ID in the samples of included studies, with a finding that adults with high support needs faced greater challenges in engaging locally, including being understood, ability to form relationships/friendships, recognize personal boundaries of others, navigate societal norms and the expectations of others. This reflects the finding of a prior review that being a neighbor involves adults with ID learning particular skills (Overmars-Marx et al., 2014).

The influence of social networks as a factor supporting or detracting from social inclusion at a local level is noted in some prior reviews as little researched (e.g., Amado et al., 2013). Consideration of the family context as both an enabler and a potential barrier to social inclusion of adults with ID is a theme identified in the present review, however, the small range of studies with family only samples suggest scope for further research. Understanding service providers and staff as part of the scaffolding that supports individuals to be socially included in their neighborhood, the current review confirmed the findings of both Bigby (2012) and Howarth et al. (2016). These prior reviews focused on interventions found that person-centered planning improved social inclusion, including for people with behaviour labelled as challenging (Bigby, 2012). Howarth et al. (2016) found evidence from intervention studies that social skills acquisition programs and increasing the frequency of target

inclusion activities produced positive results. The current review further highlighted the knowledge and skills required by staff to develop plans that lead to enhanced participation. Based on the 10 themes identified, comprehensive staff education is recommended, including modules such as the barriers and facilitators to social inclusion in neighborhoods, focused person-centered planning, investigating neighborhood resources and opportunities, and supporting individuals to potentially build connections with neighbors. However, staff education without change at the organizational level is likely to be limited in effectiveness. Making policy aspirations a reality was a challenge to staff in some included studies in this review (e.g., Bigby et al. 2009; McConkey & Collins, 2010b). Developing reflective process evaluations of service provider systems to identify unintended service obstacles is thus proposed as a possible way forward. While there has been some research activity on the role of direct support staff, examination of the role of service leaders in fostering social inclusion is uncommon in this body of literature and is an avenue for future research.

### **Strengths and Limitations**

This systematic scoping review was founded on a comprehensive search strategy. Given the problems of nomenclature identified in prior reviews, careful attention was given to the testing of the search string. However, semantic ambiguity and conflation of terms in the disability literature on this topic is a limitation. The multiple possible meanings for the use of the term 'community' in a range of cultural contexts in included studies is acknowledged. This scoping review intended to be comprehensive, with its inclusion criteria grounded in the definition of social inclusion by Cobigo et al. (2012), assuring that all included studies focused on contexts outside the parameters of segregated services. Studies that were not peer-reviewed were excluded leading to the possibility of publication bias. Hand searching of the reference lists of included studies was successful in sourcing studies not identified through database searches. The three-person multi-disciplinary research team with a combination of practitioner in ID and academic backgrounds was a distinct strength. The team completed a two-stage independent screening process, with the intention of minimizing bias and ensuring that the inclusion/exclusion criteria were rigorously adhered to. Quality appraisal was

completed on all studies that passed initial screening. Further efforts were made to minimize bias by carrying out independent credibility and inter-rater reliability checks on data extraction, quality appraisal and data analysis. However, the review was limited by its restriction to articles published only in the English language, the choice to exclude review papers from the extraction process, and the later pragmatic choice to limit the analysis to papers published after 2000. Studies eligible for screening were conducted in developed countries: Australia/New Zealand, Europe, and North America, in which the development of community-based services for adults with ID was well established. While it has been possible to draw conclusions for the developed world, this may be understood as a narrow base from which to draw global conclusions. On balance, the strengths of this review outweigh its limitations and moderate confidence can be placed in the recommendations for research and practice identified from the analysis of included studies.

### **Recommendations for Research and Practice Implications**

The findings from this review indicate a number of areas for further research and consideration in practice. Further research is recommended to explore how adults with ID conceptualize and experience their neighborhoods. In addition, given the dearth of studies focused exclusively on family members, further research is recommended to explore how parents and adult siblings of individuals with ID may facilitate or hamper their relative's social inclusion in their neighborhood. The importance of structured support is underlined to support friendships and maintain a social life (Wilson et al., 2017). International replication studies are recommended to test the findings on the value of a social role to neighborhood participation, based on a shared common interest/activity. Specifically, further examination of the education of volunteer mentors to facilitate adults to join mainstream clubs is recommended. Testing the findings of studies in this area in a range of countries and geographical locations, including town, village and remote rural areas is recommended.

Based on the importance of individual factors as both facilitators and barriers identified in this literature, further targeted research on promoting social inclusion in neighborhoods including through formal intervention and support, is recommended. For example, this review identified that being an employee, a social role of value to adults with ID, was not generally associated with supporting leisure or social engagement outside of the workplace. The workplace or other factors underpinning this have not been comprehensively examined. In addition, individual characteristics such as older age or level of need have not been comprehensively examined. Individualized approaches based on person-centered planning may serve as appropriate starting points for further intervention-based research.

This review also highlighted some evidence that geographic location may be influencing inclusion; for example, encounters with strangers for adults with ID were found to be more frequent in a country town than a metropolitan suburb in Victoria State, Australia (Wiesel & Bigby, 2014). Choice of geographic location in which to purchase or rent individualized or small group accommodation for adults with ID was a key contributor to offering safe neighborhoods, which could be rich in opportunities for participation. A comprehensive neighborhood location assessment based on this review's findings is recommended. This assessment tool for service providers should ideally be completed prior to purchasing or renting accommodation for either individuals with ID living alone, with friends or partners or in small group homes. Therefore, examining the impact of geographic location (urban, sub-urban, town, village and remote rural) on the opportunities for neighborhood engagement for adults with ID is proposed. While acknowledging that a range of factors influence choice and decision-making about where adults with ID live **including affordability**, the impact of being located close to or removed from valued unpaid social network members on building connections locally is recommended for in-depth enquiry.

Further research examining the role of service providers in supporting neighborhood participation is recommended. Based on the themes identified in this review, education of staff and service managers is recommended, focused on their role in facilitating social inclusion in neighborhoods of individuals with ID. Developing reflective process evaluations of service provider

systems to identify and address unintended service obstacles to neighborhood engagement may support services to develop more effective ways to promote inclusion for people with ID.

Finally, this review identified variation in the level of reporting of sample demographics by some, with gaps noted in the necessary detail to support replication. Comprehensive reporting of both sample and context is recommended for future empirical studies on this topic.

## **Conclusion**

Overall, this review suggests a consistent interest over close to two decades on the broad topic of adults with ID engaging outside their homes. However, social inclusion in neighborhoods as a specific focus of enquiry is relatively recent. Despite the inconsistencies in definition, international researchers conclude that social inclusion in a locality matters in the lives of adults with ID. The literature is moderately strong in its examination of the supporting role of staff, however, weak on studies with family only samples. In a climate of scarce resources, evidence-based practice resulting in high quality services is an imperative. The role of service leaders in supporting policy and practice on social inclusion in localities has not been extensively researched. This review has synthesized findings on the characteristics of neighborhoods and a range of factors that facilitate adults with ID to participate. At a practice level, the potential exists to lead to enhanced individualized plans that facilitate adults with ID to broaden their social networks and enhance participation over time in their neighborhoods, based on individual preferences. Article 19 of the UNCRPD underscores the importance of inclusion of all people with disabilities as equal citizens and the prevention of segregation and isolation. If this is to be operationalized for all adults with ID, regardless of age or level of support needs, a sustained focus on social inclusion in neighborhoods in research and practice is called for. The impact of national restrictions related to the global pandemic starting in 2020 reflects an international context in which many adults with ID were shielding at home, with concerns among service providers about their increasing isolation (e.g., Hughes & Anderson, 2020). Many experienced disruption to valued daily routines, connecting with people and places locally (e.g., Embregts et al.,

2020). However, the future directions for research and practice arising from this review remain positive in a post-pandemic context, given the importance of adults with ID restoring existing or forging new connections locally.

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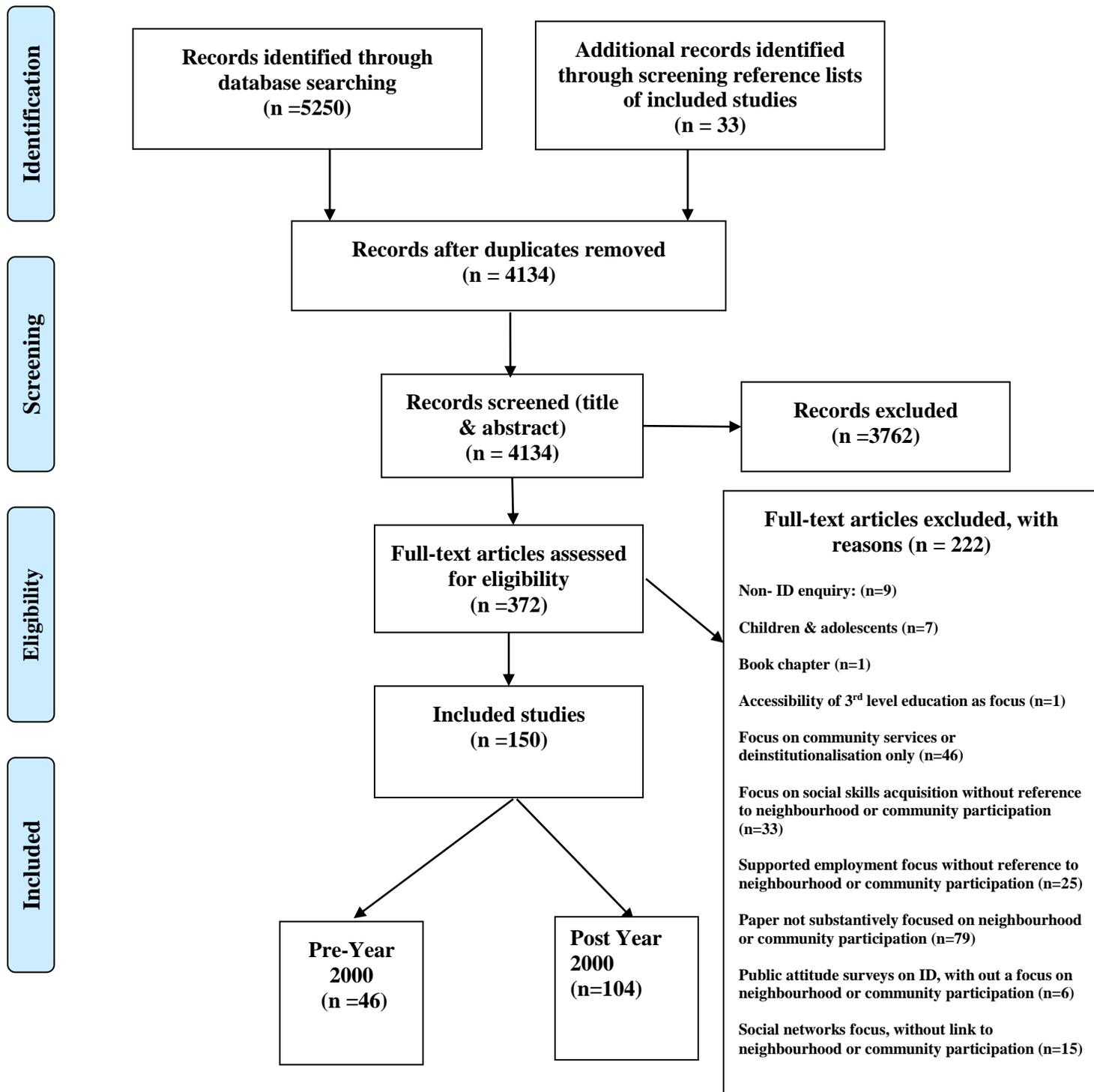
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Figure 1



**Table 1***Characteristics of Neighborhoods that Facilitate Participation - Sample Quotes*

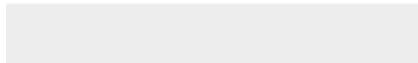
Theme title	No. of included studies with data extracts related to this theme	Sample quotes/data extracts from included papers
Locations and safe neighborhoods rich in opportunities to participate.	<b>(n=26)</b>	“Involvement in the community also meant using community resources, including access to facilities and venues, as well as mainstream services such as doctors or dentists. ‘It’s good living near the town centre, for the shops, schools, church and my GP. I can go down-town to walk my dog and meet my friends and play pool.’ ... Other participants felt there was a dearth of activities open to them. ‘There aren’t enough activities for us to get involved in. I wish there were more voluntary work opportunities. In a smaller town I feel I could go out on my own – I’d know the area. I wish there were more social venues close to my home’” (Abbott & McConkey, 2006, p.280).
Public acceptance of adults with ID	<b>(n=46)</b>	“Despite the warmth and friendliness of most group members [ <i>of leisure clubs approached with a request for an adult with ID to join</i> ], there were some people who were uncomfortable or unwilling to have close contact with the person with intellectual disability (p.22). ...Several groups approached as part of the process of locating a community group for participants expressed reluctance and did not become part of the study’ (Craig & Bigby, 2015, p.23).
Positive neighboring experiences	<b>(n=23)</b>	“Ten participants told stories about their contacts with neighbours. Apart from the friendship with a neighbour mentioned above, contact with neighbours was limited to greeting or having a small chat. Two participants from town B attended a barbecue where they met neighbours but both mentioned that these contacts did not continue after the barbecue. One participant from town A also mentioned contact through a barbecue meeting. Another participant—living independently—from town A met her neighbours during joint activities in the apartment building. “On Wednesdays, there is a gym activity and on Mondays we drink coffee together. If there is a communal activity, we have contact and when we meet, we say hi. We don’t visit each other, but I don’t feel the need to.” (Participant R from town A)” (Overmars-Marx et al., 2019, p.6).
Accessibility of buildings, information, and adaptation of activities to suit adults with ID	<b>(n=17)</b>	“Multidimensional access. A variety of communication channels may include information communication technology (e.g. websites, teletypewriter), brochures, posters, and word of mouth). Further, community sports organizations modify rules to assist people with disabilities to play sports with people without disabilities. Modified communal activities ensure that people with disabilities can interact with people without disabilities in an informal setting” (Fujimoto et al., 2014, p.528).
Flexible transport options	<b>(n= 16)</b>	“Transportation was identified the most by the young adults with ID. Without appropriate transportation options, it was difficult for them to see friends and participate in activities.” (Hall, S., 2009, p.34)

**Table 2***Other Factors that Influence Neighborhood Participation*

Theme title	No. of included studies with data extracts related to this theme	Sample quotes from included papers
Where an adult lives and with whom is key to neighborhood participation	<b>(n= 24)</b>	“This study confirms that the type of accommodation option available to people with an ID has an influence on the extent of their social inclusion as measured by contacts with other persons and use of community amenities. Overall, people in either form of supported living schemes tended to have greater levels of social inclusion than did those in small group homes or residential homes, with participants from campus- style settings having the lowest levels of social inclusion” (McConkey et al., 2007, p.215).
Individual factors both challenge and drive participation.	<b>(n= 58)</b>	“With respect to social contacts, older adults with ID (aged 50 years and over) had less social contacts with family and friends and had less leisure activities compared with younger people with ID (p.9).....The results of the present study imply that the severity of ID play an important role on the community participation in people with ID” [Dusseljee et al., 2011, p.14).
Social networks have a role in enabling neighborhood participation	<b>(n=45)</b>	“Family and extended family members were found to play a crucial role in facilitating independent living arrangements that promote autonomy, the maintenance of practical skills, community participation, and the pursuit of interests in line with individuals’ preferences, as well as providing those living in group homes with ongoing opportunities. However, a number of interviewees identified primary caregivers in childhood as having been overprotective, thereby setting trajectories of dependence” (Buys et al., 2012, p.62).
Staff and service providers- individualised supports as scaffolding for participation in a locality.	<b>(n= 40)</b>	“The change in confidence level of staff supporting people with I/DD to choose an activity in the community in which they would like to participate did increase after the intervention [ <i>staff education</i> ] but was not a significant change. One potential reason for this insignificant change may be due to larger funding and attitudinal barriers to supporting full participation choice and control within agencies; participants [ <i>staff</i> ] might value increased choice but were not able to effectively realize it occurring within their community agencies” (Zakrajsek et al., 2014, p.159).
Social roles as focal points for local participation.	<b>(n=41)</b>	“Many of the young adults with intellectual disability volunteered on a regular basis. Daniel volunteered at a nursing home and at a thrift store established by his service provider. ... Kara also volunteered at a nursing home where she was expected to ‘bring people to chapel and back to their rooms’. In the past, Jessie had volunteered at an animal shelter.... Yesenia supervised children with disabilities at their social group each week (p.864) ...Having a leadership position as a volunteer created a valued social role for the adults with intellectual disability (Lemay, 2006). They were proud of their roles and passionate about what they accomplished “(Hall, S., 2017, p.867).



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