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Social Inclusion in Group Homes: Determining Facilitators and Barriers to Inclusion for People with Intellectual Disabilities

Inclusion sociale dans les foyers de groupe : détermination des facilitateurs et des obstacles à l'inclusion pour les personnes ayant une déficience intellectuelle

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Abstract

Social inclusion is central to positive life experiences for those with and without intellectual disabilities (ID). Unfortunately, those with ID experience high levels of social isolation. As group homes, one of the most common forms of community living, aim to provide an equitable quality of life for adults with disabilities, significant responsibility of promoting social inclusion falls to them. The intention of this review is to identify the facilitators and barriers associated with social inclusion for people with ID living in group homes to develop an evaluation framework. Five databases were searched, and inclusion/exclusion criteria were used to narrow the results to 21 articles. Four main categories of barriers and facilitators to inclusion became apparent in the literature: (1) Home characteristics and social inclusion, (2) Staff characteristics and social inclusion, (3) Organizational/Leadership characteristics and social inclusion, and (4) Resident characteristics and social inclusion. While the findings from these articles have been divided into four broad categories, it is acknowledged the identified barriers and facilitators are varied and highlight the important role of the group home and surrounding communities in promoting social inclusion of their residents. This review also highlights a gap in current literature surrounding social inclusion for those with ID. Overall, more emphasis on understanding the various pathways to achieving social inclusion from group home residents with ID could contribute to the creation of effective policy and practices.

Résumé

L'inclusion sociale est au cœur des expériences de vie positives pour les personnes avec et sans déficience intellectuelle (DI). Malheureusement, les personnes avec une DI connaissent des niveaux élevés d'isolement social. Étant donné que les foyers de groupe sont l'une des options les plus courantes de vie dans la communauté et qu'ils visent à offrir une qualité de vie équitable aux adultes handicapés, ils ont une bonne part de responsabilité dans la promotion de l'inclusion sociale. Le but de cet examen est d'identifier les facilitateurs et les obstacles associés à l'inclusion sociale pour les personnes ayant une DI vivant dans des foyers de groupe afin d'élaborer un cadre d'évaluation. Cinq bases de données ont été consultées et des critères d'inclusion et d'exclusion ont été utilisés pour limiter les résultats à vingt-et-un articles. Quatre grandes catégories d'obstacles et de facilitateurs à l'inclusion sont apparues dans la littérature : (1) caractéristiques du foyer et inclusion sociale, (2) caractéristiques du personnel et inclusion sociale, (3) caractéristiques organisationnelles/de leadership et inclusion sociale, et (4) caractéristiques des résident·es et inclusion sociale. Bien que les résultats de ces articles aient été divisés en quatre grandes catégories, nous reconnaissons que les obstacles et les facilitateurs identifiés sont variés et soulignent le rôle important du foyer de groupe et des communautés environnantes dans la promotion de l'inclusion sociale de leurs résidents. Cet examen met également en évidence une lacune dans la littérature actuelle en matière d'inclusion sociale des personnes ayant une DI. Dans l'ensemble, mettre davantage l'accent sur la compréhension des diverses trajectoires menant à l'inclusion sociale pour les résident·es des foyers de groupe ayant une DI pourrait contribuer à l'élaboration de politiques et de pratiques efficaces.

Introduction

Medically speaking, an intellectual disability (ID) originates before 18 years of age, and affects physical, intellectual, and/or emotional development. However, the social model of disability moves beyond this definition and states the experience of disability, "…does not stem directly from [the body], but rather from [the] unwelcome reception in the world, in terms of how physical structures, institutional norms, and social attitudes exclude…" (Goering 2015, p.134). As such, having an ID can impact almost every aspect of one's life including independence, housing, healthcare, and relationships (Fresher-Samways et al. 2003). In recent history, there have been movements aimed at shifting the perception of persons with ID, these include deinstitutionalization and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Niles 2013). Adopted in 2006, the UNCRPD states those with ID are full

and equal members of society, the stated purpose being to "…promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (UN General Assembly 2006).

Following the social model of disability, inclusion for people with ID is found to be central to a person's life experience and aligns with specific articles outlined in the UN Convention; namely, *Article 19: Living independently and being included in the community* (Simplican et al. 2015). While it has been noted that one of the obstacles in achieving social inclusion is the lack of a clear definition, a review of the varying definitions suggest that it encompasses two domains that overlap and are mutually supportive; interpersonal relationships and community participation (2015). This review will define social inclusion as such. The concept of social inclusion, as understood for this review, also considers the various levels of factors affecting inclusion; these include individual characteristics, interpersonal networks, organizational care, community characteristics and socio-political factors (Overmars-Marx et al. 2014). Despite inclusion being a key component of the UNCRPD and the focus of studies investigating disabilities, people with ID are continuing to experience high levels of social isolation/exclusion in the forms of discrimination, avoidance and accessibility issues (Macdonald et al. 2018; Merrells, Buchanan & Waters 2019; Temple et al. 2019; Tilly 2019).

The onset of deinstitutionalization in developed nations and the increased need for community resources and housing resulted in the development of group homes for people with disabilities (Sealy & Whitehead 2004). For the purpose of this review, disability group homes were defined as accommodations for between three and ten people, where significant and extensive support is provided to the residents by paid support staff (Clement & Bigby 2010; Sandeep 2017). Typically, such homes aim to improve the life and inclusion of those living within

them. Though group homes, in some instances, have been negatively labelled as institution-like, these residential settings remain the most common form of community living for people with IDs (Spagnuolo 2016). As such, social inclusion within the group home environment must be promoted (Clement & Bigby 2010).

While the definition and experiences of social inclusion for adults with IDs has been a focus of previous reviews and have highlighted broad enabling and disenabling factors to social inclusion (Simplican et al. 2015; Merrells, Buchanan & Waters 2018), to date, there is no scoping review of the literature on facilitators and barriers of social inclusion specifically within the group home context. In line with this finding, these previously conducted reviews have highlighted a need to look beyond broad enabling and disabling conditions behind social inclusion towards organizations and services to understand more context-specific characteristics and challenges in fostering social inclusion (Merrells et al. 2019; Simplican et al. 2015). Therefore, the intention of this review is to identify the facilitators and barriers associated with social inclusion for people with ID living in group home settings, as defined above. This specific inquiry into the barriers and facilitators of social inclusion in group homes could aid in creating a framework to evaluate social inclusion policies and practices.

Methods

This scoping review was conducted using the using the five-step framework outlined by Arksey & O'Malley (2005) and refined by Levac et al. (2010). Steps described in this framework include, (1) Identifying the research question, (2) Identifying relevant studies, (3) Study selection, (4) Charting the data, and (5) Collating, summarizing, and reporting results.

This review asked the question, *what are the barriers and facilitators to social inclusion for adults with intellectual disabilities living in group homes?* The electronic databases ProQuest: Sociological Collection, PubMed, PsychNET, PAIS and CINAHL were searched on March 1st, 2019 by entering the keywords (("intellectual disabilit*" OR "developmental disabilit*" OR "learning disabilit*" OR "mental retardation" OR "cognitive impairment") AND (inclusion OR participation OR relationship) AND ("group home" OR "support home" OR "residential home")). Keyword selection was determined with the help of the home university's librarian services.

A reference list of articles identified in the original search was generated. Once duplicates were removed, the search was refined using inclusion and exclusion criteria during title/abstract and full-text screening. The following inclusion criteria were applied: (1) the paper was published in English; (2) the paper was published in 2006 or later so it would capture the enactment of the UN convention on the rights of persons with disabilities such that the equal right of all persons with disabilities to live in the community with full inclusion and participation was recognized; (3) the paper explored the outcome of social inclusion and (4) the focus of the study was on people with ID living in group homes. On this basis, studies that focused on other residential settings (e.g. hospitals, family homes) were not included. Research involving participants below the age of 18 was excluded. Finally, to apply a form of quality control, only peer review journal articles were included. Once the final list of included articles was determined, each reference list was examined for possible additional inclusions.

To extract and chart the data from the potential studies, the following headings were used: citation; location of origin; study type; sampling; recruitment; sample size; setting description; type of ID; barriers to social inclusion; facilitators of social inclusion; and limitations. NVivo®, a data analysis software, was then used to collate and organize findings, extracted under "barriers to

social inclusion" and "facilitators of social inclusion", from the included studies. This data was clustered around similar and interrelated categories to present a narrative account of the existing literature.

A second reviewer followed the identical methodology, completing each stage of the article selection process, to ensure consistency and agreement in the analysis process. The two reviewers met to ensure consensus and involved another author when an agreement could not be reached.

Results

4.1 Overview of Studies

The process for the study selection can be followed in Figure 1. Database searches retrieved 672 articles in total, of which 56 were removed as duplicates. An additional 595 articles were excluded after employing the inclusion and exclusion criteria. After screening the reference lists of the included articles, an additional 7 full texts were screened. Ultimately, no additions were made to the original 21 articles included in the final review.
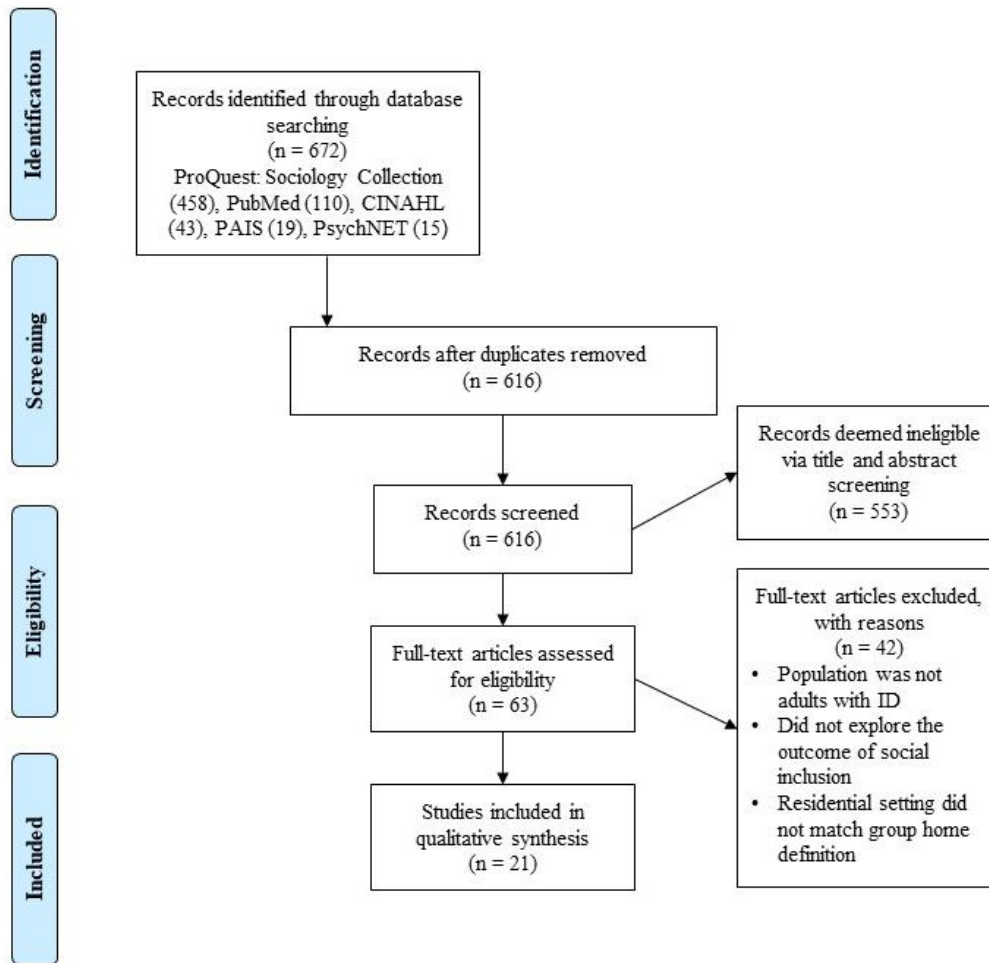
Figure 1: Flow diagram of articles included within the scoping review.

Description: Figure 1 outlines the flow diagram of articles included within the scoping review. Database searches retrieved 672 articles in total, of which 56 were removed as duplicates. An additional 595 articles were excluded after employing the inclusion and exclusion criteria. This resulted in 21 articles included in the final review.

Data extracted for each included article are summarised in Table 1 (Appendix). In terms of

study location, 13 studies reported research carried out in Europe, three in Australia, four in North

America and one in Asia (see Figure 2). The literature was published at a steady rate, with at least

one article published each year from 2006-2018, excluding 2012, for an average of 1.62 papers

published each year (see Figure 3). In terms of data collection methods, nine studies conducted

interviews, six conducted questionnaires, five conducted focus groups, three conducted

ethnography/direct observation, one conducted a case-study, and another conducted an outcome

evaluation. Note that due to three studies employing mixed methodologies, the total number of
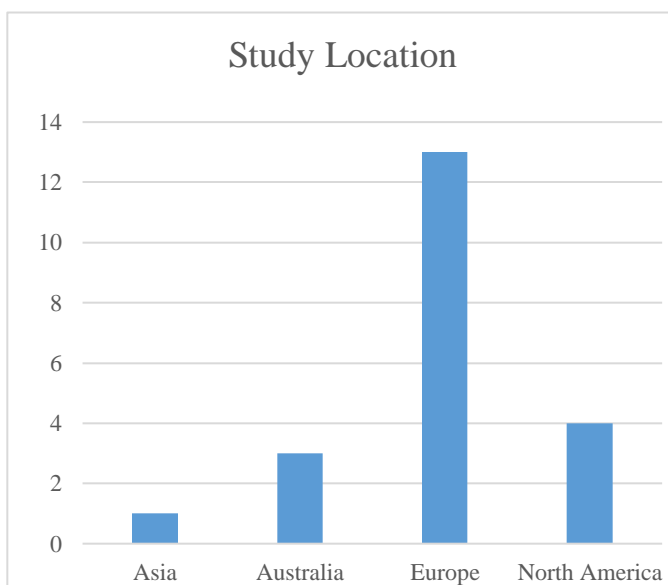
methods exceeds 21.

Figure 2: Location of Included Articles   *Figure 3: Publication Year of Included Articles*

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published each year.

Four main categories of barriers and facilitators to inclusion became apparent in the

literature: (1) Home characteristics and social inclusion, (2) Staff characteristics and social

inclusion, (3) Organizational/Leadership characteristics and social inclusion, and (4) Resident

characteristics and social inclusion.

4.2 Home & Community Characteristics and Social Inclusion

Typically, group homes supporting adults with disabilities are located within a residential

community and are managed by a non-profit organization or a private company. Hence, the social

inclusion of their residents can be affected by location of the group home, and the communities in

which they are located. The studies included under this category highlight both the facilitators and

barriers to social inclusion as they relate to the home's location and the surrounding community.

4.2.1 Location of Group Homes

Characteristics of group homes that affect access to community activities, facilities and hinder the

ability of residents to build and maintain relationships are identified as barriers to social inclusion

for those with ID (Abbott & McConkey 2006; Siska et al. 2018; Ouellette-Kuntz & Burge 2007).

Specifically, focus groups conducted with residents of group homes in the included studies

identified the location of the group home as a potential barrier to social inclusion. For group

homes located outside of the city centre, the increase in distance to community activities, facilities

had an effect on accessibility and cost of transportation within the community (Abbott &

McConkey 2006; Siska et al. 2018). Additionally, McConkey (2007) found that a group home

which is dispersed within a local community, rather than clustered with other group homes, could

be a predictor for residents experiencing higher levels of social inclusion, though not significant.

An additional study conducted by McConkey and colleagues (2016) further supports the negative

impact of clustered homes within a community; mainly that attending community services as part

of the same organization as the home, versus services through other organizations, does not

promote community engagement. Not only do those living within the group home find location to

be an important consideration for social inclusion, community members also suggested living

arrangements dispersed within a community promoted the greatest inclusion opportunities for

adults with ID (Ouellette-Kuntz & Burge 2007).

4.2.2 The Surrounding Community

A number of the included studies explore the role of neighbours in the social inclusion of group

home residents. Neighbouring contact between those with ID and those without ID was positive

but, in many cases, could only be described as friendly recognition. The lack of 'community'

between those with and without ID was postulated to be due to the perception of neighbours that

residents do not need help, will invade their privacy, and cannot have a conversation (Overmars-

Marx et al. 2018; Overmars-Marx et al. 2017; Ouellette-Kuntz & Burge 2007). Beyond the lack of

relationships built between neighbours with and without ID, one participant from an included

study mentioned the unattractive physical environment of group homes was not particularly

welcoming to neighbours and stated that, "the building is like a fortress" (Overs-Marx et al. 2017,

p.7).

Overall, as Dijker et al. (2011) found, the perceptions and attitudes of neighbours can

either promote or inhibit social inclusion of residents in group homes. To facilitate the social

inclusion of those with ID, neighbours with and without ID should move beyond any "prejudiced

or stigmatising tendencies" and work to interact around mutual needs (Dijker 2011, p.893)

Other studies reveal the importance of coordination with other local community services

supporting those with disabilities. A lack of coordination and support with these community

services was highlighted as a barrier to social inclusion. (Siska et al. 2018; Shipton & Lashewicz

2017). With a lack of support between community services and the group home, the system of

services for these individuals was compartmentalized, reducing the opportunity to access services

that could promote inclusion.

Thus, based on information from the studies reviewed, suggested factors affecting the

social inclusion of adults with ID residing in group homes include the location of the group home

(urban vs. rural), dispersion of group homes within the community, the perception and attitudes of

community members, and the availability and relationship with community services.

4.3 Staff Characteristics and Social Inclusion

Due to the barriers of communication and consent processes for group home residents with ID, a

large proportion of the included studies have disability support staff as participants. As such,

several findings concerning the connection of group home staff and social inclusion are presented.

The studies included under this category highlight both facilitators and barriers to social inclusion

as they relate to the direct support staff within group homes.

A comprehensive understanding of the definition and application of social inclusion

practices is required for staff to adequately facilitate both interpersonal relationships and

community participations. Findings from ethnographic research conducted by Clement & Bigby

(2009) to evaluate the goal of 'inclusion' suggest most group home staff did not attach a working

definition to social inclusion. This led to the prioritization of activities that were not meaningful to

the residents (2009). Even for those who were trained and shown ways to encourage participation

and relationships for residents, most group home staff had a 'wait-and-see' attitude toward their

role in incorporating the promotion of social inclusion in their daily tasks (Overmars-Marx,

Thomese &Meininger 2017). Considering that group home staff responsibilities cover a range of

activities, their priority and ability to enable community activities and encounters affected social

inclusion of their clients; this was postulated to be due to availability of staff and opportunities for

one-on-one support (Abbott & McConkey 2006; McConkey & Collins 2010; Overmars-Marx, Thomese & Meininger 2017). From an additional study, staff participants that gave greater personal priority to promoting social inclusion might be more likely to encourage residents to take part in community activities and accompany residents to social venues within the community; activities geared towards community participation and development of social relationships (Iriarte et al. 2016). In addition to prioritization and understanding of social inclusion, some of the included studies explored the importance of social-inclusion related actions. For example, the importance of staff encouragement was found to assist in the promotion of social engagement and inclusion (Finlay et al. 2008). Social inclusion goals were reached when direct support staff attitudes and actions toward residents included empowerment and independence. Staff participants of these studies also felt that maintaining a person-centred approach on both the individual and group level was fundamental to facilitate these social inclusion goals (Kahlin, Khellberg & Hagberg 2015). As such, staff actions that contradicted this empowerment and independence; i.e., imposing restrictions on residents' choices; could be barriers to social inclusion (Abbott & McConkey 2006).

Several studies reveal the importance of staff training and competence levels in achieving the goal of social inclusion. One article shows the importance of support workers having the knowledge and skills to encourage security and freedom for those living in the group homes (Shipton & Lashewicz 2017). Data collected from focus groups in the included studies highlighted common issues affecting the social relationships and community involvement is staff issues surrounding training and supervision (Holburn et al. 2008). Considering most residents of group homes required formal support, training support workers to provide reliable services was a possible facilitator of meaningful goals, such as social inclusion (Buys et al. 2008). Informants

also mentioned a lack of appropriate training and counselling. Some staff members had received

training on neighbourhood social inclusion. However, staff in one study mentioned that the

knowledge received had mostly been forgotten, as it was not part of any routine training (Overs-

Marx et al. 2018).

Thus, potential facilitators to social inclusion is the understanding and prioritization of

social inclusion responsibilities, staff attitudes supporting empowerment and independence, and

direct support staff training and supervision.

4.4 Organizational/Leadership Characteristics and Social Inclusion
Looking beyond the direct support staff within group home organizations, the reviewed studies

highlight the importance of strong organizational leadership as a factor promoting social

inclusion. Given that some of the responsibility for training of disability support workers falls to

the employers, leadership staff equipped to provide appropriate and effective training and

resources could promote the emphasis of social inclusion tasks. Strong leadership would not only

lead to good training but also to consistent implementation of program models such as *Active*

Support.

A known program to promote participation, create support plans, and monitor quality of

life was identified as a factor affecting social inclusion for residents with ID. *Active Support* is

designed to ensure those receiving support are engaged and fully involved in their lives. A few

studies discuss the use of this program in promoting inclusion. One study concluded that *Active*

Support has the potential to promote community inclusion but did not find success in the

implementation when evaluated (Chou et al. 2011). Without differences found between the

comparative groups, and stated limitations, the researchers determined the need for further follow-

up studies (2011). A similar study conducted to evaluate the use of *Active Support* found using

practice leadership as a means to focus staff attention, produced a significant difference in the

success of the program (Beadle-Brown et al. 2014). While this study produced encouraging

findings, a few limitations were presented and therefore, it was also concluded that further

research is needed (2014). A larger study conducted in Australia exploring the role of *Active*

Support in engaging residents in meaningful activities and relationships found that the

implementation of this program was not consistent across agencies which could account for the

limited findings associated with the effects of *Active Support* (Mansell, Beadle-Brown & Bigby

2013).

While these studies did not find conclusive evidence for the role of *Active Support* in

social inclusion, the findings suggest that given the recommended implementation of the program

is achieved by leadership staff, there is a possibility for it to facilitate social inclusion for residents

of group homes. The leadership abilities of the managing staff were therefore also found as a

factor affecting social inclusion in this context.

4.5 Resident Characteristics and Social Inclusion

Some studies discuss specific facilitators of social inclusion based on the personal behaviour of

those with ID living in group homes. While these facilitators are not connected, it highlights the

important role of involving individuals with ID in promoting their own social inclusion. In

general, it was found that individuals with ID who stand up for themselves and advocate for their

participation in community and relationships are more likely to experience positive community

living (Siska et al. 2018). A further study, while mentioning significant limitations, provides

evidence to suggest there is a relationship between participation in physical activity and social

inclusion (Blick et al. 2015). As such, while not thoroughly evidenced, it is important to consider choices of the individuals with ID themselves as facilitators for social inclusion.

Overall, this scoping review identified 21 peer-reviewed studies that explore social inclusion within disability group homes. The review presented here suggests there are various characteristics of these group homes that either facilitate or create barriers to social inclusion for the residents living within them. Although many adults with ID live in group homes and the evidence identifies social inclusion as central to their life experience, there is an insufficient amount of research conducted on the topic (Clement & Bigby 2010). While the findings from these articles have been divided into four broad categories, it is acknowledged the identified barriers and facilitators are varied and highlight the important role of the group home and surrounding communities in promoting social inclusion of their residents. Figure 4 summarizes the list of those characteristics that may affect the social inclusion experiences of adults with ID living in group homes found in this review.
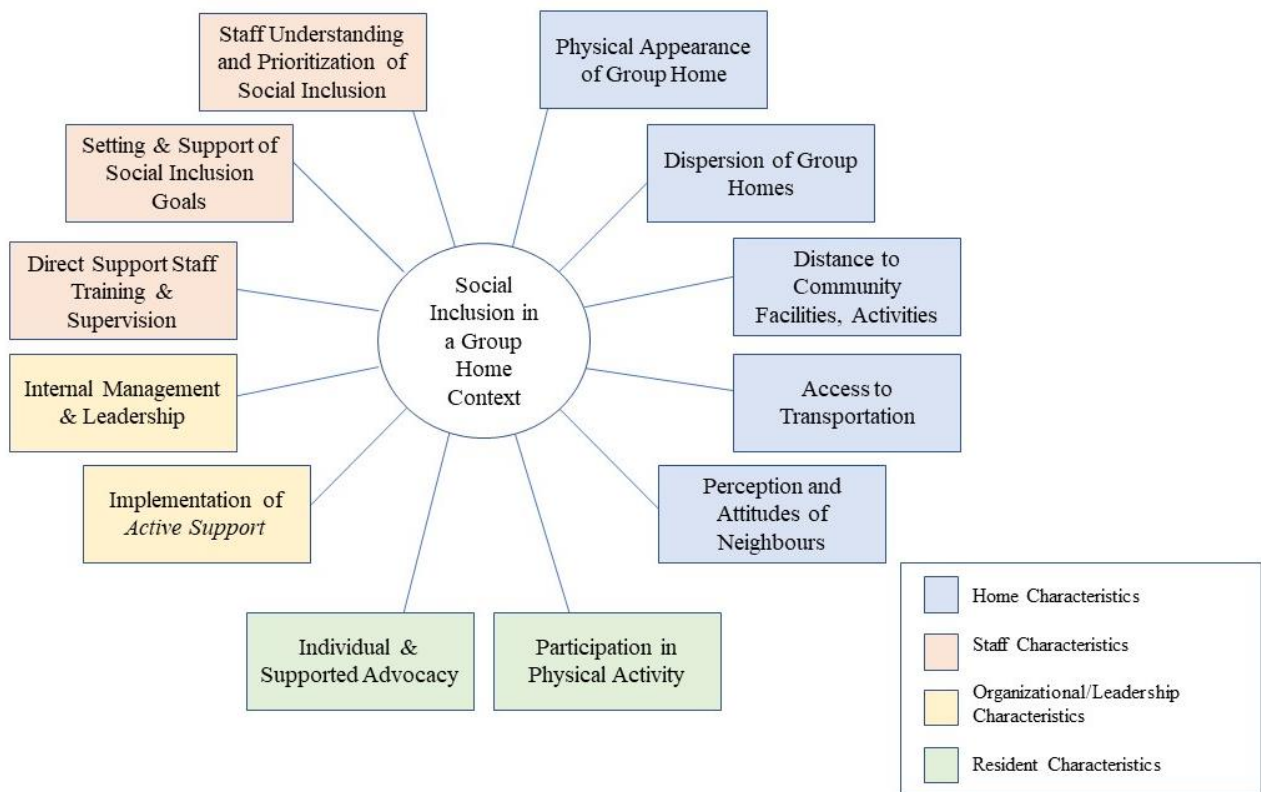
Figure 4: A categorized summary of the characteristics affecting the social inclusion of adults with intellectual disabilities living within group homes

Description: Figure 4 provides a categorized summary of the specific characteristics affecting the social inclusion of adults with intellectual disabilities living within group homes. Under 'Home Characteristics' is physical appearance of group homes, dispersion of group homes, distance to community facilities/activities, access to transportation and perception and attitudes of neighbours. Under 'Staff Characteristics' is staff understanding and prioritization of social inclusion, setting & support of social inclusion goals and direct support staff training & supervision. Under 'Organizational/Leadership Characteristics' is internal management & leadership and implementation of Active Support. Under 'Resident Characteristics' is individual & supported advocacy and participation in physical activity.

Discussion

Current research measuring the extent people with ID experience social inclusion reveals the need

to better understand the practices supporting social inclusion (Bigby 2012b). Limitations in

previous reviews surrounding social inclusion for adults with ID noted the need for

conceptualized indicators for social inclusion that can give direction to specific programs,

contexts and services (Bigby 2012a, Simplican et al. 2015).

As defined by a review seeking to provide a working definition for social inclusion, there

are various pathways and levels of factors to consider. These include, (1) the individual level, (2)

the interpersonal level, (3) the organizational level, (4) the community level, and (5) the socio-

political level (Simplican et al., 2015). This review seeks to list the factors that have been

identified in previous literature as barriers or facilitators to social inclusion specifically within

group homes. It should be kept in mind that there may be additional factors affecting the social

inclusion of adults living within these homes that are not specific to the group home context. By

exploring barriers and facilitators that are specific to the context of group homes, a focused and

relevant list of factors to consider can be presented to group homes supporting adults with ID. As

such, by providing this synthesis and summary of the existing information, this review seeks to

consolidate and move beyond the previous reviews highlighting broad enabling and disabling

factors affecting social inclusion for adults with ID. This discussion sorts the found barriers and

facilitators to social inclusion in group homes into the various pathways in an attempt to identify

recommendations for group homes and gaps that should be addressed.

1.1 Individual Pathway to Social Inclusion in Group Homes

One highlighted individual level facilitator to social inclusion is the means and motivation to self-

advocate for personal social inclusion (Siska et al. 2018). While the activity choices and personal

advocacy of residents within the group home are presented as individual factors to consider in the

pathway to social inclusion, research also highlights the importance of management and staff

supported self-promotion; involving people with ID in decision making and collaboration

surrounding inclusion domains (2018). For those requiring assistance to self-advocate (skills

and/or confidence), group home support staff should attempt to create an equal partnership with the resident when setting social inclusion goals. (Flynn 2010). An earlier study found that even when advocacy groups for persons with ID are in place, the decisions made and their consequences should not be in isolation and all people with ID should be represented (Hall 2005). Group home residents and those working within them should strive to develop spaces for empowerment and support to decide on community participation activities and the development/sustaining of relationships.

5.2 Interpersonal Pathway to Social Inclusion in Group Homes

A majority of the studies find group home staff to be an integral factor affecting social inclusion of residents, including their relationships with the residents and social inclusion responsibilities. Two facilitators to social inclusion are found, (1) direct support staff understanding and prioritization in achieving social inclusion goals for the residents, and (2) direct support staff attitudes of empowerment and independence. As such, direct support staff should work to understand the personal social inclusion goals of the residents they are supporting since they play such a powerful role in enabling residents with ID to participate in the community and maintain relationships (McConkey & Collins 2010).

5.3 Organizational Pathway to Social Inclusion in Group Homes

Beyond the relationships with direct support staff, some other characteristics of group homes are identified as organizational barriers or facilitators to social inclusion. There include, (1) the leadership of internal management, (2) training opportunities developed and presented to staff, and (3) implementation of certain programs, such as *Active Support.* The managing organization's leadership team should strive to train support staff in a way that highlights the importance of social inclusion and its incorporation into everyday life. As noted in previous studies, disability

support staff are generally inexperienced in promoting inclusion domains (i.e., community

participation, interpersonal relationships); therefore, the necessary knowledge and skills must be

gained through the training process (Cummins 2016; Rodenburg, McWhirter & Papadopoulos

under review). Internal management practices such as supervision, team meetings and coaching,

as well as seeking external support are suggested to significantly improve the residential service's

ability to support people with ID (Windley & Chapman 2010). As such, group homes should

strive to increase the frequency of training support provided by the managing organization. Even

beyond knowledge and skills, the existing literature finds support staff enjoy their work more

when they were able to facilitate good life experiences for those they support. It is recommended

group homes make the effort to train and support staff using a framework that not only addresses

fundamental care, but also relationship care (2010).

5.4 Community Pathway to Social Inclusion in Group Homes

Factors pertaining to the community in which the group home is located are also identified as

barriers or facilitators to social inclusion: (1) rurality of urbanity of the community, (2)

availability of local support services/activities and, (3) perception and attitude of neighbours.

Overall, this review shows the strong role the surrounding community can play in the inclusion

and acceptance of people with ID. A number of studies focus on the physical integration of people

with disabilities, though others mention the importance of social integration, especially as it

relates to relationships within one's personal community (Cummins & Lau 2003). The findings

from this review specifically highlight the importance of perceptions and attitudes of neighbours

without ID. Though not the sole responsibility of group homes, it has been suggested that offering

a mediating role between neighbours with and without ID could encourage more direct and

improved contact (Dijker et al. 2011). This recommendation offers a transition into the found

benefits of group home staff being able to vary their roles and responsibilities as they relate to promoting social inclusion.

5.5 Socio-political Pathway to Social Inclusion in Group Homes

Since the focus of the included studies was in the context of group homes, the presentation of larger societal factors that might affect the social inclusion of residents with ID was limited. However, it is found that the location and dispersion of group homes can either enable or disenable efforts for inclusion. Considering the varying factors that might shape the location of group homes (e.g. zoning, economics, community perception), it is clear a co-ordinated approach across various sectors is critical to achieve optimal conditions concerning the distance to community services and dispersion within the community (Siska et al. 2018). Though the research is scant in this area, involving people with disabilities in these decisions has been suggested as a way to generate supportive policy systems (2018). Participation of people with disabilities in political life on an equal basis with others is also stated in the Convention on the Rights of Persons with Disabilities (Article 29). The United Nations Development Program notes this is a, "a vital aspect of combatting exclusion…and to leaving no-one behind" (Mar Dieye 2019). As such, it is recommended group homes and local municipalities involve people with disabilities in the decision-making process on policies that will directly affect the community/home they live in.

Research in the area of social inclusion seldom looks at all pathways to reaching this outcome (Simplican et al. 2015). When presented together, the included studies of this review do highlight barriers and facilitators to inclusion across the individual, interpersonal, organizational, community, and societal level, however the majority of research currently surrounding the topic of social inclusion within disability group homes focuses on the operational nature and function of these homes. Management, support staff, and the structure of the group homes are identified as a

few of the key factors affecting the inclusion for residents with ID, disproportionately focusing on the interpersonal, organizational and community level pathways to social inclusion. While some of the presented studies touch upon policies and personal advocacy, there is a major gap in the research as it pertains to the identification of individual-level and socio-political barriers and facilitators to social inclusion for people with ID living in group homes. Hence, future research should not only confirm or refute the previously highlighted facilitators and barriers to social inclusion but should look beyond.

An additional noted gap in the collected literature was found in the participants of the studies. It has been emphasized in previous literature that there is a lack of individuals with ID sharing their experiences of social inclusion or the aspects that promote or inhibit it (Merrells, Buchanan & Waters 2017). While approximately half of the 21 included articles included some insight from adults with intellectual disability, there are still a number of studies that use the input of others to present and understand the experience of those with ID. It is known that views and input from those with lived experience can provide the most valuable information for contributing to policies and programs for those with disabilities (McDonald, Kidney & Patka 2013). As such, emphasis on the importance of amplifying the voices of those with ID is once again presented here as an area for future research.

Overall, the pathway to social inclusion for an adult with ID living within a group home should be guided by supportive factors beyond staff, organizations and communities. Group homes and researchers should first prioritize the voices of residents when determining how to promote social inclusion. By creating a space that de-centres the voices of service provider knowledge, we can better understand the voices and experiences of those whose social inclusion we are hoping to promote (Ashby 2011). In order to enhance the inclusion of adults with ID living

in our communities, we should also locate and evaluate the policies that exist to support group homes in this mission. We need to ask, *How/do policies support the facilitators to inclusion and mitigate the barriers to inclusion?* Once various pathways to achieving social inclusion are identified, more powerful facilitators can be put in place to assist group homes for those who have been historically underserved.

Limitations

Not withstanding those stated within each paper that was reviewed, limitations of this review need to be considered when interpreting the results. In line with the methods of conducting a scoping review, it should be highlighted that the quality of evidence was not formally appraised, and the relative weight of evidence is not presented (Arskey & O'Malley 2005). Though a thorough search was conducted within five databases it must be noted there could be additional articles with findings contributing to the results presented as no grey literature search was conducted and only peer-reviewed texts were included. Additionally, as the articles included were primarily of qualitative nature, the potential for increased bias due to multiple levels of interpretation should be considered (Evans & Pearson 2001).

Conclusion

Social inclusion is emphasized as central to life experience for those with and without ID. It consists of both participation and engagement and the fostering of roles and relationships within the community. As group homes aim to provide an equitable quality of life for adults with disabilities, significant responsibility of promoting social inclusion falls to them. This review finds and lists certain characteristics of group homes and surrounding communities that can either facilitate or create barriers for social inclusion. For group homes to be successful in the promotion

of social inclusion, participation from the managing organization, community members, group home staff and residents with ID is recommended.

This review has highlighted a gap in current research available surrounding social inclusion for those with ID; specifically, in the context of group homes. Overall, more emphasis on understanding the various pathways to achieving social inclusion of group home residents with ID could contribute to the creation of effective policy and practices. By further exploring the lived experiences of adults with ID, the role of support staff, and group home/external policies, we can develop a greater understanding into the strategies needed to address the increased experiences of social isolation for adults with ID living in group homes.

Table 1: Characteristics of the Included Studies

Study	Location	Sample	Method	N	Results
Abbott & McConkey (2006)	Ireland	Individuals with ID	Focus Groups	68	Facilitators of and barriers to social inclusion fell under four categories: personal ability and skills, staff and management, the community & the home/scheme
Beadle-Brown et al. (2014)	UK	Direct support staff on behalf of individuals with ID	Questionnaire	899	When staff are supporting people using active support, better engagement and social interaction outcomes are experienced. Management quality is an important factor in promoting the use of active support.
Blick et al. (2015)	USA	Individuals with ID	Interviews	788	Data indicates that persons who reported exercising often also routinely engage in inclusive tasks within their communities
Buys et al. (2008)	Australia	Individuals with ID, service providers, informal network members	Case Studies	16	Factors promoting community participation and interpersonal relationships include maintaining contact with friends, reliable support/companionship, a daily routine of engaging in meaningful activities, and individualized planning
Chou et al. (2011)	Taiwan	Individuals with ID	Evaluation	49	The Active Support intervention was effective in in increasing engagement, choice making and adaptive behaviour, depression decreased. The intervention did not improve community inclusion.
Clement & Bigby (2009)	Australia	Individuals with ID and direct support staff	Ethnography	5+	Staff attitudes and understanding of 'inclusion' lead to the fostering of community presence rather than participation. Changes in task priority and staff understanding needs to change to support community participation
Dijker et al. (2011)	Netherlands	Neighbours of individuals with ID	Interviews	30	Severity of disability and group home size influenced social acceptance. Social integration can occur when relationships between neighbours with and without ID are based on mutual needs.
Finlay et al. (2008)	Scotland	Individuals with ID and direct support staff	Ethnography	14	Staff interactions with clients through 'games' promote non-instrumental social interactions contributing to goals of social inclusion

Holburn et al. (2007)	USA	Individuals with ID, family, direct support staff, service managers	Focus Groups	119	Three themes emerged surrounding QoL of individuals with ID in group homes: staff issues, training/supervision & program/activities
Iriarte et al. (2016)	Ireland	Individuals with ID and direct support staff	Interviews	32	Staff recognized their role in developing skills to support community inclusion. This study highlighted the need for further training for both staff and individuals with ID to foster inclusion
Kahlin, Kjellberg & Hagberg (2015)	Sweden	Direct support staff of individuals with ID	Interviews	15	Person-centred approaches, peers and staff are found to be important for improving individuals with ID's participation and interaction. Low social contacts, staff habits, and lack of funding/organizational resources are found to inhibit.
Mansell, Beadle-Brown & Bigby (2013)	Australia	Individuals with ID, staff, managers	Questionnaire, Direct Observation	151+	Although active support was adopted, various factors affected quality of implementation and individuals with ID were not realizing their highest level of engagement
McConkey (2007)	Ireland	Direct support workers of individuals with ID	Questionnaire	260	With social inclusion as the outcome, the predictor variables were scores on competence (social), the type of accommodation, gender and age of the person, as well as the managing organization.
McConkey & Collins (2010)	Ireland	Individuals with ID	Interviews	130	Findings confirm that personal goal planning can promote greater social inclusion across all forms of accommodation. Staff, family, and friends are important in helping to attain these goals
McConkey & Collins (2010)	Ireland	Direct support staff of individuals with ID	Questionnaire	245	Managing organizations may need to give more emphasis to social inclusion and provide the leadership, training and resources to facilitate support staff to assess and adjust their priorities.
McConkey et al. (2016)	Ireland	Individuals with ID	Interviews	89	Few opportunities to invite friends to the home served as a barrier to relationships. Personalized supports for individuals promote participation and relationships.
Ouellette-Kuntz & Burge (2007)	Canada	General public	Questionnaire	680	The general public stated insufficient community services, level of disability, unwelcoming attitudes, and negative media portrayals and barriers to community integration

Overmars-Marx, Pepping & Thomese (2018)	Netherlands	Neighbours of group homes	Interviews	29 neighbours, 26 households	Neighbours and group home staff feelings/assumptions, and the social role of people with ID are important aspects of social inclusion
Overmars-Marx, Thomese & Meininger (2017)	Netherlands	Staff from group homes	Focus Groups	72	Staff attitudes, time, and physical appearance of group homes were found to affect social inclusion. Staff team management is highlighted as an area of focus
Siska et al. (2018)	Europe	Knowledgeable informants	Interviews	84	Three themes were identified surrounding barriers to social inclusion; policy and politics, social care and support systems & attitudes, awareness and advocacy. Facilitators include coordination, and involvement of individuals with ID in decision making
Shipton & Lashewicz (2017)	Canada	Individuals with ID and their family/direct support staff	Secondary analysis of 9 focus groups	52	Two main themes that facilitate social inclusion: being understood and experiencing security and freedom in living environment

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