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Housing for People with Intellectual Disabilities: A Scoping Review

Logements pour personnes ayant une déficience intellectuelle : Un examen de la portée des écrits

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Abstract

People with intellectual disabilities (ID) continue to report unmet housing needs. The purpose of this scoping review was to explore the extent of research on housing for people with ID, and the complexities of people's housing experiences. A search yielded 44 studies conducted from 2009 to 2018, meeting the study inclusion criteria. The study findings were analyzed thematically, using an ecological systems framework, which examines the inter-relationships between individual experiences and their contexts, such as within families, organizations, communities and socio-political settings. Cross-study comparisons were conducted using qualitative matrices. Regarding housing types, the use of large institutions to house people with ID continues in most countries and countries are at various stages in the deinstitutionalization process. Supported housing was the most promising housing type related to positive outcomes; however, it is highly dependent on availability of affordable housing stock and individualized supports. Study findings show that people's experiences vary greatly and interact with differences in severity of disability, income levels, country of origin, and mental health. Across housing types, people report stigma and loneliness. This article highlights study findings alongside systems-level themes and identifies areas for further study.

Résumé

Les personnes ayant une déficience intellectuelle (DI) continuent d'exprimer des besoins de logement non comblés. L'objectif de cet examen de la portée des écrits est d'explorer l'étendue de la recherche concernant les types de logement pour personnes ayant une DI et les expériences des personnes y résidant. Cet examen a identifié 45 études menées entre 2009 et 2018 répondant aux critères d'inclusion de la présente étude. Les résultats de l'étude ont fait l'objet d'une analyse thématique prenant le système écologique comme cadre d'appui. Ce dernier examine l'interrelation entre les expériences individuelles et leurs contextes, notamment ceux des familles, des organisations, des communautés et socio-politiques. Des comparaisons ont été effectuées parmi les différentes études en utilisant des matrices de données qualitatives. Concernant les types de logement, la plupart des pays ont recours aux grandes institutions pour loger les personnes ayant une DI et en sont à diverses étapes du processus de dés institutionnalisation. Les logements supervisés représentent le type de logement le plus prometteur en lien à des effets positifs. Toutefois, cette modalité est influencée par la disponibilité et l'abordabilité du parc de logement ainsi que par l'individualisation du soutien par les dispensateurs de services. Les résultats de l'étude démontrent que l'expérience des personnes varie grandement et peut différer selon le niveau de sévérité de la déficience, le revenu, le pays d'origine et la santé mentale. À travers tous les types de logement, les personnes rapportent vivre de la stigmatisation et de la solitude. Cet article met en lumière des résultats d'études parallèlement à des thèmes systémiques et identifie des pistes pour de futures études.

Mots-clés : Logement, résidentiel, institutionnalisation, déficience intellectuelle, trouble du développement

Introduction

The global deinstitutionalization of people with intellectual disabilities (ID) has led to the growth of alternative housing options worldwide (Brown & Radford, 2015; Lakin & Stancliffe, 2007). Yet, people with ID report unmet needs for accommodation around the world (Bigby et al., 2011; Durbin et al., 2018; Soenen et al., 2015).

The challenge faced by researchers is to examine which housing models lead to the best outcomes while also shedding light on the challenges people with ID face simply finding an appropriate place to live (Bigby & Fyffe, 2009). The purpose of this scoping review was to explore the extent of research on housing for people with ID, and the complexities of people's housing experiences. While terms vary, "intellectual disability" is used for the purposes of this article, referring to the three aspects of such a diagnosis: 1) challenges with cognitive functioning; 2) challenges in adaptive behaviour; and 3) onset before the age of 18 years (APA, 2013).

Theoretical Framework

In order to highlight the complexities of housing for people with ID, studies were examined through the lens of Bronfenbrenner's ecological systems theory, which focuses on the

interrelationships between individuals and their contexts (Rosa & Tudge, 2013). Using this framework, when examining current research, personal characteristics, family dynamics, organizational elements, community factors, and socio-economic contexts were taken into consideration. A systems framework broadens the scope of recommendations to include contextual factors, such as funding considerations and organizational capacity. Systems considerations also prevent placing responsibility on individuals for their challenging housing situations and outcomes.

Previous Research

This review updates two previous reviews on housing for people with ID (Kozma et al., 2009; Mansell & Beadle-Brown, 2009). Previous reviews reported that dispersed, community-based housing was more beneficial to people with ID than either large institutions or clustered housing (Kozma et al., 2009; Mansell & Beadle-Brown, 2009). Clustered housing refers to more than one home or housing unit located in one area, segregated from the general population. Dispersed housing refers to housing that is typical of the general population and scattered throughout residential areas (Mansell & Beadle-Brown, 2009).

This current review expands the scope of the 2009 reviews by including all housing types studied within the timeframe of 2009 to 2018, identifying systems-level factors influencing findings (e.g., organizational characteristics, socio-economic contexts), and including qualitative and mixed methods studies.

The Present Research

The following research questions were examined:

1. What housing models for people with ID have been studied from 2009 to 2018?
2. What are the characteristics of these housing models and the results of their evaluations?
3. What are systems-level considerations influencing study findings?

Materials and Methods

The scoping review summarizes the breadth of evidence in a field (Arksey & O'Malley, 2005; Levac et al., 2010). The current review included the following steps: 1) Identify research question; 2) Outline search criteria and conduct search; 3) Select studies and refine search strategy iteratively; 4) Chart the data thematically; and 5) Summarize the results (Arksey & O'Malley, 2005; Levac et al., 2010).

Search and Inclusion Criteria

The following search terms were used: "intellectual disability," "developmental disability," "mental retardation," and "learning disability" AND "home," "hous*" and "residen*." Initial searches in *PsycINFO, PsycArticles*, and *Scopus* databases yielded 1,060 articles.

The titles and abstracts were scanned for the following inclusion criteria: dated 2009 to 2018, English language. and housing for people with ID was central. They also had to be qualitative, quantitative or mixed methods, peer-reviewed, academic studies. This initial scan yielded 94 articles, which were then read fully to assess them again for inclusion. A simple quality assessment process was also conducted: studies had to have an explicit focus and question, relevant method, a description of participants, and analyses and results. Following in-depth examination, 44 articles remained.

Analysis

Study characteristics, methods and findings were organized thematically in matrices. Separate matrices were developed to break down the findings by: 1) study characteristics and findings, 2) housing model, and 3) systems-level themes. Systems-level themes were organized by individual, family, organization, community, and macro levels, with sub-themes under each level (e.g., "choice" was under family, and "policy" was under organization). Data are presented in Table 1, which is a synthesized version of the matrices. Systems-level themes are presented throughout the results.

Results

Characteristics of Studies

Twenty-one of the 44 studies were quantitative, 21 were qualitative, and two were mixed methods. Twenty-eight (64%) compared two or more types of housing, 12 of which examined the move out of a large institution. The majority of studies were based in the United Kingdom and Australia. Ten additional countries were represented (see Table 1) as well as one study that included 14 European Union countries.

Study Findings

We examined housing for people with ID in large institutions, group homes, family homes and independent living models. Overall, independent, supported housing showed the most promising results related to positive outcomes. However, including studies with many different study methods (e.g., quantitative surveys, qualitative interviews and focus groups, observational studies), and examining their findings through systems-level considerations, revealed much variation within housing types, contradictions in definitions of housing types, and complex factors influencing people's housing experiences and outcomes.

Large Institutions

Residential Institutions for People with ID. Seventeen studies included large institutions for people with ID (McConkey et al., 2016; McKenzie et al., 2014). In addition to size (ranges of eight to 300 people), they were characterized by their distance from community, communal living spaces, regulated environments, and rigid routines (Kozma et al., 2009).

Table 1. Characteristics of Studies of Housing for People with ID (2009-2018)

Study	Sample	Housing Types	Method	Key Findings
QUANTITATIVE				
Bhaumik et al. (2012) United Kingdom	51 adults with ID and complex health needs, moving from large institution to community setting.	Residential institutions for people with ID; residential aged care; clustered group homes; dispersed group homes.	Longitudinal. Quality of life questionnaire.	Reported improvements in quality of life 6 months after re-location in community setting.
Chaplin et al. (2010) United Kingdom	750 adults with ID living with family (n = 375), in a group home (n = 280) or independently (n = 95).	Dispersed group homes; family homes; supported living.	Data collected at initial mental health service assessment.	Type of housing and mental health interact. Anxiety disorders 3X more prevalent for people living in family homes. Older adults more likely living in supported housing compared with other housing types.
Chou et al. (2011) Taiwan	26 adults with ID who moved from family home to community residence; 13 adults with ID who moved from an institution to a community residence.	Residential institutions for people with ID; dispersed group homes; family homes.	Longitudinal. Interviews with staff-person pair 5 times.	Reported increases in quality of life and family contact since moving into community. Those who moved from family homes had an increase in choice making. Group who moved from institutions had decreased maladaptive behaviour.
Ellis et al. (2013) United Kingdom	Support workers for 36 people with profound ID who were moved from institution to supported living.	Residential institutions for people with ID; inpatient health units; supported living.	Risk assessment tool completed by a support worker, assessing risks of deterioration in quality of life when moving out of an institution.	Low risk to quality of life levels in new housing arrangements. Risks included restricted choice, lack of individualized assessments, not gaining new skills, low community integration, and fewer social relationships.
Fahey et al. (2010) Ireland	29 people with ID living in "life-sharing communities," 64 adults with ID in group	Residential institutions for people with ID; village	Quantitative measures, mainly completed by a "coworker" in the residence.	Life-sharing communities were far from families. They encompassed a larger social

Study	Sample	Housing Types	Method	Key Findings
	homes, 60 in campus residences.	communities; dispersed group homes.		network compared to other housing types and higher reciprocity in relationships. Life-sharing communities were also more supportive than group homes but had less choice. Less rigid than campus residences but greater choice.
Felce et al. (2011) United Kingdom	30 people with ID living independently, 142 in family homes, 559 in "staffed home".	Dispersed group homes; family homes; supported living.	Secondary analysis of four datasets.	Group homes had greater participation and variety of community activities than family homes. Group homes had as high a variety and frequency of activities as independent living.
Griffiths et al. (2015) Ontario, Canada	61 family members of people with ID, moved out of an institution into group homes.	Residential institutions for people with ID; dispersed group homes.	Completed a Family Survey.	90% were satisfied with group homes. 69% reported unexpected positive outcomes, in wellbeing, independence, socialization, self-care, activities, and health in the group homes.
Hatton et al. (2017) United Kingdom	263 people with ID and 1,785 people with borderline intellectual functioning, living with family. 21,446 people without ID.	Family homes.	Secondary data analysis - mental health, social determinants of health.	People with ID in family homes had greater risk of mental health problems than people without ID. Difference was attributed to poorer living conditions.
Hsieh et al. (2009) United States	330 people with severe and profound ID.	Residential aged care.	Longitudinal. Residential and social factors and mortality.	Higher environmental diversity and community integration were related to lower mortality, regardless of personal characteristics and type of residence.

Study	Sample	Housing Types	Method	Key Findings
Luijkx et al. (2013) Netherlands	1,785 parents of people with ID, living in residential settings.	Residential institutions for people with ID; dispersed group homes.	Quantitative questionnaire assessed daily care, housing, day services, leisure activities.	Average overall quality of support was 7.3/10. Number of visits per month were negatively related to parent ratings of quality of support (lower number of parent visits to their child in residential setting associated with lower parent ratings of quality of support in the setting).
Mansell et al. (2010) England, UK	201 public and private inpatient health units for people with ID. Representing 1,891 spaces total (1,492 public and 399 private).	Inpatient health units.	Quantitative survey - characteristics of inpatient health units.	All units had 100% occupancy. 5 had more people than spaces. 19% in public units and 6% in private had finished treatment but no plans to leave. 35% of units had a care plan for every patient.
Martinez-Leal et al. (2011) 14 EU Countries	1,269 people with ID or their proxy.	Residential institutions for people with ID; family homes.	In-person interview – health status.	Higher prevalence of health conditions in countries at early stages of deinstitutionalization. Higher density of people in institutions related to illnesses. Low levels of health promotion, medical checks, and higher obesity levels in family homes and independent settings. Sedentary lifestyles in residences.
McConkey et al. (2016) Ireland	29 moving from congregate to supported housing, 31 from congregate to group homes, 29 remained in congregate setting.	Residential institutions for people with ID; dispersed group homes, supported living.	Structured interviews – quality of life.	People who moved to group homes or supported living had better outcomes than those who stayed in congregate. People in supported living had better outcomes than those in

Study	Sample	Housing Types	Method	Key Findings
				group homes (control, choice, community engagement, relationships).
McConkey et al. (2013) Ireland	17,000 adults with ID in either congregate or community-based settings.	Residential institutions for people with ID; dispersed group homes.	Longitudinal (10 years – 1999-2009). Secondary analysis of Ireland's national dataset of people with ID.	Less than 15% moved from congregate to community-based settings over 10 years of study. New admissions to congregate were high in some areas. 45% increase of people in community-based settings over 10 years.
McKenzie et al. (2014) South Africa	37 managers of non-governmental residential facilities for people with ID in South Africa.	Residential institutions for people with ID; inpatient health units; clustered group homes; dispersed group homes.	In-person quantitative survey.	Challenges accessing funding. Focus on protection rather than rights. Isolation and lack of skill development in residential settings.
Perry et al. (2011) United Kingdom	19 people with ID with challenging behaviours, and their key workers.	Residential institutions for people with ID; dispersed group homes.	Longitudinal - quality of life and quality of care.	When they moved out of institutions into group homes (with their workers), attention from staff increased. No differences in staff responses to challenging behaviours. Decrease in aberrant and challenging behaviour. Increased family contact and independence.
Sines & Hogard (2012) United Kingdom	39 people with profound ID. Measures completed by formal caregivers and parents by proxy.	Residential institutions for people with ID; dispersed group homes; supported living.	Longitudinal - quality of life measures.	Improvement in overall quality of life on 7 domains, which was significant after 6 months of being in supported living accommodation. Care planning and autonomy and choice related to largest improvements.

Study	Sample	Housing Types	Method	Key Findings
Soenen et al. (2015) Netherlands	36 young adults with mild to borderline ID. 20 with externalizing behaviour problems and 16 with internalizing behaviour problems.	Dispersed group homes; supported living.	Measures of functioning and support, examining employment and housing support needs.	Overall lack of individualized support in housing arrangements. While 15% with externalising behaviours were recommended for group homes, 75% were in a group home (mismatch between recommended arrangement and actual arrangement). 40% were dissatisfied with their accommodation.
Stancliffe et al. (2011) United States	6778 adults with ID	Residential institutions for people with ID; inpatient health units; dispersed group homes; supported living.	Quantitative analysis of National Core Indicators database. Analyzed choice of where to live and who to live with by residence type and severity level of ID.	44.6% chose or provided input around where to live. 40.6% chose who to live with. Less severe ID related to more choice. Institutional settings related to less choice.
Van Straaten et al. (2017) Netherlands	513 people who were homeless.	Supported living.	Longitudinal. Self-reported care needs.	97% preferred supported housing. People with an ID had care needs for longer than people without ID.
Woodman et al. (2014) United States	303 adults with ID over 10 years (study 1) and 75 adults with Down Syndrome over 20 years (subsample, study 2).	Residential aged care; dispersed group homes; family homes; supported living.	Longitudinal.	People in supported living had higher adaptive behavior levels than others in the sample. People in family homes or group homes had higher adaptive behaviour than those in nursing homes/hospitals. People in family homes had better health than those in group homes. Health decline was greater in nursing homes/hospital compared to other settings. People with lower family income were

Study	Sample	Housing Types	Method	Key Findings
				more likely to move over the 10 years.
MIXED METHODS				
Hutchings & Chaplin (2017) United States	90 older adults with ID (50 years +). 20 direct care staff of group homes.	Dispersed group homes; supported living.	Qualitative interviews, participant observations and quantitative ratings around functional ability.	Lack of accommodating individual differences in group homes was reported. Descriptions of group home as a "pseudo home" - related to multiple moves, feeling of living with strangers, lack of ownership, and staff changes.
Weeks et al. (2009) Canada	33 older parents of people with ID.	Residential aged care; dispersed group homes.	Mixed methods. Qualitative interviews and in-depth quantitative interviews.	Parents preferred "small option homes" and retirement homes that provide care to both older parents and adult children. And not "lumping all adults with disabilities together."
QUALITATIVE				
Bigby et al. (2017) Australia	34 people with mild ID who moved from group homes to supported living in past 5 years.	Clustered group homes; dispersed group homes; supported living.	7 focus groups and 6 individual interviews.	People in supported living described greater choice and control of everyday life in supported living; independence and increased activity; loneliness; not being in control of formal supports or finances.
Bigby et al. (2011) Australia	59 family members, group home supervisors and program managers, for 17 older adults with ID in group homes, 6 of which were moved to residential aged care.	Residential aged care; dispersed group homes.	Longitudinal.	Decisions to move to aged care were made quickly, triggered by acute health episodes. Decisions were made by staff rather than people with ID and families.

Study	Sample	Housing Types	Method	Key Findings
Cocks et al. (2016) Australia	50 people with ID.	Supported living.	Synthesis of 50 "evaluations" of supported living arrangements.	Wide variations in findings mainly due to formal and informal support and management. Supported living appropriate for high support needs.
Cocks & Boaden (2011) Australia	16 adults with ID and 18 key informants (parents, service providers, policy makers).	Supported living.	Case studies over 2 years, 1 focus group with adults with ID, written surveys with key informants.	Nine themes related to supported living arrangements: assumptions of high expectations of people with ID, leadership is needed from someone involved to make the arrangement successful, a sense of ownership, one person at a time (not grouping people together), planning, control, support, thriving, social inclusion.
Drake (2014) Australia	7 boarding house residents, 3 who had left a boarding house, 27 staff, 3 boarding house proprietors .	Licensed boarding houses.	Semi-structured and unstructured interviews, policy analysis, analytic notes.	Boarding houses lacked rights, privacy, self-determination, choice, financial security, and community participation.
Grey et al. (2015) Wales, UK	9 families of people with mild to profound ID.	Family homes.	Qualitative interviews.	Reasons for seeking housing: parents' aging, and people with ID's desires for independence. Housing system prioritizes crisis. Lack of housing stock. Inappropriate housing offers.
Hole et al. (2015) British Columbia, Canada	22 people with ID, 33 home share providers, 13 family members.	Home sharing.	Qualitative interviews - factors that contribute to quality home sharing.	Key factors in home sharing success: good match, proactive planning, effective supports, relational dynamics,

Study	Sample	Housing Types	Method	Key Findings
				flexibility. There was a lack of housing choice.
Iriarte et al. (2016) Ireland	32 staff and 16 people with ID who moved from congregate setting.	Clustered group homes; dispersed group homes; supported living.	Qualitative interviews - role of support staff in moving people from institution to community.	Some didn't want to move out of the congregate setting. Support staff provided similar support in supported living and dispersed group home settings but more individualized than clustered group homes.
Isaacson et al. (2014) Australia	Two young adults with ID moving from family homes into supported living.	Family homes; supported living.	Qualitative case study. Family interviews, document review, observations.	Transition period was stressful for parents. Social isolation was a major issue. Parents expressed unmet need building social network.
Jecker-Parvex & Breitenbach (2012) Romandy, Switzerland	11 elderly parents, 5 siblings, 5 older adults with ID, and one husband.	Family homes.	22 semi-directive interviews - characteristics of family units caring for an adult child with an ID.	Family often did not want to change living arrangement. Need for community-based services and home care. Adults with ID wanted to live independently, on their own or sharing with peers.
Johnson & Bagatell (2017) United States	7 people with severe to profound ID and 8 group home staff members.	Dispersed group homes.	Ethnographic, participant observation, and document analysis.	Lack of opportunity to choose activities. Challenges individualizing support. Emphasis on routine. Reports of stereotypes of adults with ID's capabilities.
Kilroy et al. (2015) Ireland	Key workers of 8 people with severe ID, serving as proxy participants.	Clustered group homes; dispersed group homes.	Qualitative interviews - quality of life moving from clustered to dispersed group homes.	When they moved to dispersed group homes, reported improvements in: emotional wellbeing, health, privacy, freedom, material wellbeing, independence, choice, social opportunities.

Study	Sample	Housing Types	Method	Key Findings
				Lack of community integration.
Nasser et al. (2017) Israel	18 parents of people with ID, ranging from 2-26 years of age.	Residential institutions for people with ID.	Qualitative interviews - process of residential placement within socio-political context of the Palestinian minority in Israel.	Initial resistance to placement then resignation. Cumulative support challenges (e.g., poverty). Relief and guilt following placement.
Owen et al. (2015) Ontario, Canada	10 family members of people with ID moving from large institution to community group home, 10 planners, 20 staff.	Residential institutions for people with ID; dispersed group homes.	Focus groups and qualitative interviews - process of deinstitutionalization.	Transition was rushed, little time for personalized planning. Limited housing availability.
Randell & Cumella (2009) United Kingdom	15 people with ID living in a village community.	Village communities.	Ethnographic. Unstructured interviews and participant observation.	People described their experiences living in village communities as having: active lives; diverse roles; social networks; a sense of community; absence of overt subordination; and a lack of space.
Reindl et al. (2016) Netherlands	17 parents, 15 people with ID, 3 staff members (N=35).	Dispersed group homes.	Semi-structured, in-depth interviews - outcomes of parent-initiated shared housing.	Living schemes (dispersed group homes) were more enabling than institutions. Led to “steps towards” self-advocacy and autonomy.
Shaw et al. (2011) Australia	15 people with ID and 10 family members who care for adults with ID	Residential institutions for people with ID; residential aged care; dispersed group homes; family homes; supported living.	Phenomenological. Focus groups and interviews. Housing and support preferences.	Concerned with parents’ health. Preference for large group settings in the community, living close to peers (with ID). Saw aging sector as good fit but parents said inappropriate option.
Sheerin et al. (2015)	9 people with mild to moderate ID and 2 relatives.	Clustered group homes; dispersed group homes.	Qualitative interviews - exploring the experiences of	The moves to dispersed group homes led to increased

Study	Sample	Housing Types	Method	Key Findings
Ireland			adults with ID who moved from residential settings (clustered) to dispersed group homes.	happiness, space, privacy, independence, money management. Also, loneliness and insecurity (related to safety), and low community integration.
Shipton & Lashewicz (2017) Alberta, Canada	2 people with ID and/or mental disorders, 23 family members, and 29 paid caregivers.	Dispersed group homes.	9 focus groups - quality of care.	Social inclusion and self-determination related to residents feeling understood and experiencing security and freedom.
Webber et al. (2014) Australia	9 family members and 10 staff of 10 older adults with ID who moved from group homes to residential care for older adults.	Residential aged care; dispersed group homes.	Qualitative interviews with parents and staff – health and social inclusion.	Positive health outcomes in residential care for older adults but social isolation. Staff did not have skills to include people with ID in community in residential care settings.
Witso & Kittelsaa (2018) Norway	11 professionals supporting people in their homes and 5 people with ID.	Clustered group homes.	4 focus groups, 5 participant observations.	Dilemmas around supporting self-determination (lack of time and resources). Challenges knowing when to support choice (e.g. nutrition, lifestyle). Isolation was reported. People want to be treated as individuals but are often treated as a group.

Higher numbers of people living in a residence were related to an increase in illnesses, sedentary lifestyles, isolation, and lack of skill development (Martinez-Leal et al., 2011; McKenzie et al., 2014). People who moved from large institutions to group homes or supported living had better outcomes related to daily activity, choice, control, relationships, well-being, and quality of care (McConkey et al., 2016; Sines & Hogard, 2012; Stancliffe et al., 2011). Perry et al. (2011) and Chou et al. (2011) reported decreases in challenging behaviours when people moved from large institutions to dispersed group homes.

Other Large Residences. In addition to institutions for people with ID, six studies (14%) examined mainstream seniors' residences, four (9%) included inpatient health institutions, and one (2%) examined the use of boarding houses by people with ID (Drake, 2014; Ellis et al., 2013; Mansell et al., 2010; McKenzie et al., 2014; Shaw et al., 2014; Webber et al., 2014). These mainstream institutions tended to be unsuitable for people with ID, and were related to poor outcomes, such as social isolation, lack of privacy, and no care plans (Drake, 2014; Mansell et al., 2010; McKenzie et al., 2014; Shaw et al., 2011; Webber et al., 2014).

Systems Theme 1: ***Severity and complexity of disability are related to limited housing options.*** At the individual level, people with higher support needs, such as medical fragility, severe and profound ID, and challenging behaviours, were more likely to be placed in large institutions and clustered group homes (McConkey et al., 2013; Woodman et al., 2014). This exclusion from other housing models was largely due to stigma about people's capabilities and lack of funding (Bigby & Fyffe, 2009; Cocks & Boaden, 2011; Ellis et al., 2013; McConkey et al., 2016).

Systems Theme 2: ***Internationally, people with ID continue to live in large institutions.*** Some governments in the studies were just beginning the process of closing down large institutions (Chou et al., 2011; McConkey et al., 2013; McKenzie et al., 2014). Also, housing a subgroup of people with ID in large institutions continued in most countries. Continued institutionalization was sometimes related to countries with economic instability and systemic racism (McKenzie et al., 2014; Nasser et al., 2017).

Group Housing

Clustered Group Homes. Seven studies included a clustered group home model (16%). People with ID who moved out of clustered homes into dispersed housing reported improvements in emotional well-being, health, privacy, freedom, independence, choice, and social opportunities (Kilroy et al., 2015; Sheerin et al., 2015). On the contrary, one study reported that such a move led to loneliness and lack of community integration (Sheerin et al., 2015).

Village Communities. In addition to clustered group homes, "village communities" were another type of clustered housing examined in two studies (4%) (Fahey et al., 2010; Randell & Cumella, 2009). These were different from clustered group homes in that support was provided by volunteers who lived communally with people with mild to moderate ID (Mansell & Beadle-Brown, 2009).

Overall, people with ID in village communities reported having diverse roles, large social networks, and a sense of community (Fahey et al., 2010; Randell & Cumella, 2009). In Fahey et al.'s (2010) study, people in village communities had less rigid routines and more daily choice

than clustered group homes. At the same time, they had less choice than people in dispersed group homes and about the same routine structures (Fahey et al., 2010).

Dispersed Group Homes. Dispersed group homes tend to be owned by service providers, house a small number of people with ID (up to eight), and provide paid support staff, usually full-time (Mansell & Beadle-Brown, 2009). Twenty-eight studies (64%) included dispersed group homes. Ten were studies of people moving from large institutions. This move led to improvements in well-being, independence, socialization, self-care, challenging behaviour, privacy, health, and family contact (Chou et al., 2011; Griffiths et al., 2015; Kilroy et al., 2015; Perry et al., 2011; Sheerin et al., 2015; Sines & Hogard, 2012; Woodman et al., 2014). Families were satisfied with staff, location, and medical support (Griffiths et al., 2015). However, other research suggested that dispersed group homes lacked choice of support providers and who to live with, as well as a lack of a sense of belonging and community integration (Bigby et al., 2017; Hutchings & Chaplin, 2017; Johnson & Bagatell, 2017; Kilroy et al., 2015; Perry et al., 2011; Sheerin et al., 2015; Stancliffe et al., 2011).

Systems Theme 3*: People make housing choices within the context of community.* Researchers described people's housing preferences in light of their social relationships and desires for community integration. Shaw et al.'s (2011) study was comprised of people with ID who had become friends in a supported employment program together. They expressed a desire to live together in a congregate setting. People's satisfaction with village communities was linked to their large social networks and lack of subordinate staff-person relationships, while people were concerned that they would lack a social network in supported living arrangements (Bigby et al., 2017; Fahey et al., 2010; Isaacson et al., 2014; Randell & Cumella, 2009).

Systems Theme 4*: Organizational policies impact choice.* There was high variation in group home models, depending on organizational approach and resources. In Bhaumik et al.'s (2012) study, people with ID lived in a complex of flats together in a clustered setting. Yet, they owned or rented their own accommodation and controlled their support and who they lived with. In contrast, Kilroy et al.'s (2015) clustered group homes had high numbers of people in each home grouped together on a campus. Support was provided by the same agency and kitchens and bedrooms were locked during the day.

Family Homes

Ten studies (23%) documented the experiences of people with ID living with their relatives in their family homes. Four of the studies focused on people with ID moving away from their family homes into a more formal arrangement (Chou et al., 2011; Grey et al., 2015; Isaacson et al., 2014; Woodman et al., 2014).

Reasons people moved out of family homes were related to aging parents as well as desires for independence (Grey et al., 2015; Jecker-Parvex & Breitenbach, 2012). One study showed that people in family homes had lower levels of medical checks, slower adaptive behaviour development, and higher levels of obesity, compared to people in group homes (Martinez-Leal et al., 2011). However, in Woodman et al.'s (2014) study, people with ID living with family had better health over a 10-year period compared to people living in dispersed group homes. Moving out of family homes and into a group home was related to increased choice making, greater

participation in daily activities, and greater variety and frequency of social and community activities (Chou et al., 2011; Felce et al., 2011).

Systems Theme 5*: Parents and people with ID expressed differences in housing choices.* In Shaw et al.'s (2011) study, people with ID wanted to live in the aging sector with their peers while their parents felt such arrangements were not suitable for their adult children's needs. In Reindl et al.'s (2016) study, parents and people with ID had different ideas of what supported living should look like. And, in Chou et al.'s (2011) study, 40% of people who had moved out of their family homes, moved back within two years, based on decisions made by family or staff (not people with ID themselves). These findings highlight a complexity that families face when navigating choice of housing for people with ID.

Independent Living

Supported Living. In supported living arrangements, a person with ID rents or owns a home of their choosing, and they live with whomever they choose. Staff support is provided by an agency of their choosing and is separate from the housing provider. In this model, the person with ID has the same housing rights as the general population (Cocks & Boaden, 2011; Cumella & Heslam, 2013; Mansell & Beadle-Brown, 2009; McConkey et al., 2016).

Eighteen studies (41%) included supported living as a housing model for people with ID. Five of them documented moves into supported living arrangements, from large institutions, group homes, or family homes. As a result of these moves, researchers reported increased independence and choice, community engagement, and personal relationships, as well as improved well-being, and quality and location of housing. On the other hand, people also reported loneliness and a lack of social networks (Bigby et al., 2017; Isaacson et al., 2014). Regarding choice, almost all people (97%) in Van Straaten et al.'s (2017) study of people with ID who were homeless, preferred supported living compared to other housing models.

Home Sharing. In home sharing arrangements people with ID share a home with another person (unrelated) who is paid to provide support as needed (Hole et al., 2015). Hole et al. (2015) reported key factors related to good quality home sharing experiences: proactive planning, a good match, effective supports, and flexibility.

Systems Theme 6*: Housing availability depends on policy and funding frameworks.* While supported living shows promising results, it is dependent on housing availability, and funding frameworks (Cocks et al., 2016; Isaacson et al., 2014; Sheerin et al., 2015). In Nasser et al.'s (2017) study in Israel, government funding limited people's housing options to either family homes or large institutions. In contrast, Irish and Australian governments have supported the development of supported housing models in their countries, leading to an increase in this choice of housing (Cocks et al., 2016; Isaacson et al., 2014; Sheerin et al., 2015).

Discussion

Examining studies of housing for people with ID through an ecological systems framework showed that individual housing experiences interact with complex systems-level factors. This review showed that it is too simplistic to draw conclusions about individual outcomes by housing

type. Throughout this review, challenges around housing were not solely based on individuals and families but were influenced by systemic and structural contexts. People with ID were interacting with these systems, which were shaping their experiences, opportunities, and housing outcomes (Ruppar et al., 2017). Across all housing types, people with ID reported social exclusion, and a lack of community integration and support networks, indicating broader issues of stigma and discrimination facing people with ID (Brown & Radford, 2015; Jackson, 2011; Sheerin et al., 2015).

Individual differences in severity of disability, mental health, challenging behaviours, and income levels, greatly impact housing experiences. People with the highest care needs are often the most marginalized, have the least choice of housing, and live in the most restrictive, outdated and unstable housing arrangements (Bigby & Fyffe, 2009; Jackson, 2011).

The literature has a clear rights-based lens, framing studies around the rights for people to choose where to live and who to live with (Cocks et al., 2016). However, researchers observed policies and funding frameworks at various levels of government that constrict choice. Housing models, particularly those that were independent, dispersed, and in the community (e.g., supported housing), were a preferred choice for many, but were limited by lack of affordable housing units (Parker & Fisher, 2010).

Recommendations

In the studies in this review, the various housing models were not consistently defined. Study findings were sometimes contradictory, such as reports that moving into independent housing improved social opportunities and well-being but also increased loneliness and exclusion. These contradictions, while somewhat typical of housing experiences of marginalized groups, could be clarified with the development of consistent terms and definitions for housing models. Such clarification would improve comparability of findings in this body of literature.

The studies of people with ID living in family homes had the least consistent and comparable findings, such as in areas of health outcomes and choice of living arrangements. Family homes perhaps show the highest levels of complexities around choice, interdependence, and individualized formal support (Bigby & Fyffe, 2009). Further research is recommended on support needs of people with ID living in family homes.

It is also recommended that research addresses gaps around the experiences of people with ID who are homeless, people who are aging, and home sharing arrangements. While homelessness was a theme in our review, we identified the need for further study in this area (Drake, 2014; Van Straaten et al., 2017). Aging was identified as a reason to move out of family homes, and the aging sector was examined as an institutional housing option; however, more research is needed on housing for people with ID who are aging. Finally, only one study in the review included a shared housing model (Hole et al., 2015). No studies were found on shared home ownership.

Conclusion

This review covered the breadth of recent research on housing for people with ID, while also highlighting the complexities of people's experiences navigating this housing. Without continuous, concerted efforts and resources poured into improving the housing situation of

people with ID, many will continue to live in unsuitable arrangements, regardless of housing type (Bigby & Fyffe, 2009).

Key Messages from this Article

People with Disabilities. You have the right to choose where to live and who to live with.

Professionals. Across all housing types, people's well-being depends on availability of daily choices, flexibility of routines, and their social networks. People with ID face stigma and discrimination and may need others to help them advocate for community integration.

Policymakers. Housing policy and funding frameworks can promote choice and individualization of supports within any housing type. There is a need for increased affordable housing stock for supported housing, and formal supports that complement informal care provided in family homes.

Messages clés de l'article

Personnes ayant une incapacité : Vous avez le droit de choisir où et avec qui vous souhaitez vivre.

Professionnels : À travers tous les types de logement, le bien-être des personnes dépend de la disponibilité de choix quotidiens, de la flexibilité des routines et de leur réseau social. Les personnes ayant une déficience intellectuelle font face à de la stigmatisation ainsi qu'à de la discrimination et pourraient avoir besoin des autres pour les aider à revendiquer une intégration dans la communauté.

Décideurs : Les politiques et subventions en matière de logement peuvent promouvoir le choix et l'individualisation du soutien dans tous les types de logement. Il y a un besoin d'accroitre l'abordabilité du parc de logement pour les résidences supervisées ainsi que le soutien formel pour complémenter les soins informels prodigués au sein des résidences familiales.

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