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The outcomes of individualized housing for people with disability and complex needs: a scoping review

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ABSTRACT

Purpose: Worldwide, disability systems are moving away from congregated living towards individualized models of housing. Individualized housing aims to provide choice regarding living arrangements and the option to live in houses in the community, just like people without disability. The purpose of this scoping review was to determine what is currently known about outcomes associated with individualized housing for adults with disability and complex needs.

Methods: Five databases were systematically searched to find studies that reported on outcomes associated with individualized housing for adults (aged 18–65 years) with disability and complex needs.

Results: Individualized housing was positively associated with human rights (i.e., self-determination, choice and autonomy) outcomes. Individualized housing also demonstrated favourable outcomes in regards to domestic tasks, social relationships, challenging behaviour and mood. However, outcomes regarding adaptive behaviour, self-care, scheduled activities and safety showed no difference, or less favourable results, when compared to group homes.

Conclusions: The literature indicates that individualized housing has favourable outcomes for people with disability, particularly for human rights. Quality formal and informal supports were identified as important for positive outcomes in individualized housing. Future research should use clear and consistent terminology and longitudinal research methods to investigate individualized housing outcomes for people with disability.

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KEYWORDS

Disability; complex needs; individualized housing; independent living; accommodation

► IMPLICATIONS FOR REHABILITATION

- Individualized housing models can foster self-determination, choice and autonomy for adults with disability and complex needs.
- Having alignment between paid and informal support is important for positive outcomes of individualized housing arrangements.
- A more substantial evidence base regarding individualized housing outcomes, in particular long-term outcomes, and outcomes for people with an acquired disability, is required.

Introduction

Residential environments are significant social determinants of health that play an important role in promoting quality of life [1–3]. Despite this, people with complex and significant disabilities (e.g., intellectual disability, brain injury, spinal injury, multiple sclerosis, cerebral palsy) have limited choice when it comes to housing and living arrangements [4–7]. Traditionally, government funded housing developed for people with disability has tended to be separate from the community and congregated with other people who have disability [7]. However, recent innovations and policy developments in the disability sector are now moving away from traditional congregated living settings and towards more individualized housing options [8,9]. Reflecting the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [10] principles, individualized housing aims to provide adults with disability (i.e., aged 18–65 years) choice regarding living arrangements, and the option to live in houses in the community just like people without disability. Given the recent policy

developments guiding housing to become individualized and the significant impact these reforms will have on the lives of people with disability¹, it is critical to understand the outcomes associated with individualized housing.

Complex needs refer to functional impairment which has a substantial impact on the person's independence in one or more activities in the domains of mobility, self-care, domestic life, or self-management [12]. The term complex needs is commonly used in the literature and policy to capture the breadth (i.e., multiple needs that are interrelated or interconnected) and depth of needs (i.e., profound, severe, serious or intense needs) of people with various disabilities [13]. People with complex needs may have to negotiate a number of different issues in their life and often lack access to suitable housing or meaningful daily activity [14].

Currently, a continuum of housing arrangements is available for people with disability and complex needs [6]. This continuum broadly consists of four main streams: institutions (large

residential centres, now predominantly closed), group homes (smaller residential centres with shared facilities and often shared support), living with parents beyond the age when people would usually leave (often living with ageing carers) and living in the community with support (i.e., individualized housing) [6]. Since the closure of institutions, group homes have become a dominant form of housing and support for adults with disability [15,16]. Although group homes aim to resemble suburban homes, in this model people with disability are often treated as service users or recipients of care who live according to staff routines, rosters and priorities [17]. Thus, similar to institutional care environments, group homes maintain large power imbalances between staff and residents, and service centred terminology is typically used to describe them [17]. Concerns about group homes have been raised due to the limited choice available to residents regarding with whom and where they live, as well as inadequate engagement and participation outcomes [18–20]. Research findings also suggest people living in group homes are vulnerable to abuse and neglect [21–25]. In recognition of the potential negative outcomes, international trends in living arrangements for people with disabilities are now moving away from group homes and towards more individualized housing options which aim to prioritise principles of self-determination and community inclusion [10; Article 19].

Individualized housing refers to housing options that are life stage appropriate, where people with disability have choice regarding where and with whom they live, the support they receive and their day to day activities [6]. An important goal of individualized housing is to support people's choice and control over decisions that affect their lives [26]. Such choices include smaller decisions about everyday living (e.g., sleep and wake times, meal content etc) through to more complex choices (e.g., type of support, who provides support, which community-based facilities to use or how to participate in the community) [27]. Therefore, as these living arrangements are modified depending on personal preferences and type of disability the way they are implemented can vary substantially from person to person [26]. Research has highlighted self-determination and autonomy as important contributing factors to quality of life, indicating that more individualized housing arrangements are likely to have beneficial outcomes [28]. Previous research comparing quality of life outcomes between group homes and individualized housing options has found mixed results [29,30]. While more individualized housing arrangements have been shown to have better outcomes on domains of choice, frequency, and range of recreational or community-based activities, group homes have yielded better outcomes in terms of safety, frequency of scheduled activities, health, and money management [29,30]. The outcomes associated with individualized housing options therefore remain unclear.

Although it is recognised that the specific needs of adults with acquired neurological disability differ from adults with developmental intellectual disability, people with both forms of disability experience functional impairments which create challenges in one or more of the mentioned domains [17]. Accordingly, people with acquired neurological disability and developmental intellectual disability have experienced similar housing options [17]. That is, institutions, group homes, living with biological families and more recently individualized housing [6]. It is therefore essential to understand the outcomes of individualized housing for people with both forms of disability.

As countries around the world have signed and ratified the UNCRPD, there is currently a strong international focus on the

provision of suitable, affordable housing for people with disability and on maintaining people's right to choose where they live [10].

Many governments have introduced individualized funding programs for people with disability [31]. In some jurisdictions specific funds dedicated to specialist disability housing are available [32]. For example, policy developments in Australia now allow some people with severe disability to access individualized funding for housing and therefore the potential to exercise choice between available housing options [33]. One purpose of individualized funding is to support people to move away from group homes or congregate settings into their own home, if that is their preference [20]. Accordingly, the number of people with disability who choose to live in individualized housing options is anticipated to increase [7]. Given these policy developments towards more individualized housing models, it is critical to understand the outcomes associated with individualized housing. Therefore, the primary aim of this scoping review was to determine what is known about outcomes of individualized housing for adults with disability and complex needs.

Methods

A scoping review method was considered most appropriate for the current study as this method is effective in answering broad questions where there is emerging evidence about a topic [34,35]. Reporting of the method and results was guided by The Prisma Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation [36]. The research question guiding the review was "What are the outcomes associated with individualized housing options for adults with disability and complex needs?" Three concepts informed the development of the key words that were used in the final search. The first concept described the population (i.e., persons with physical, sensory, or cognitive disability including intellectual/developmental, and neurological disorders with complex needs) the second concept reflected the setting of interest (i.e., individualized housing options or home-like settings) and the third concept reflected outcomes associated with living arrangements (i.e., quality of life, self-determination, community participation, cost). A search strategy based on these concepts was developed and adapted for each database with consultation from a research librarian (see online supplementary file for detailed search strategy). Literature searches were carried out in January 2019 for studies published over the past 20 years (since 1999). This period was chosen as most developed countries had undergone significant disability policy reforms resulting in the closure of institutions, and an emphasis on community-based living [37–39]. Databases searched were Medline, PsychINFO, CINAHL, Scopus and Embase (MeSH terms were added in MEDLINE, CINAHL, PsycINFO and Embase).

Following the initial inclusion criteria outlined in Table 1, a selection of 200 titles were blind screened by two reviewers (EGK and SO) which demonstrated 92% interrater agreement. At each stage of the review, conflicts were resolved through discussion. The remaining titles were independently screened by the two primary reviewers (EGK and SO). After title screening, the remaining abstracts were double blind reviewed by two reviewers (EGK and SO). Following abstract screening, the inclusion and exclusion criteria were tightened for full text screening (see Table 1). The exclusion criteria for study design required significant adjustment. In line with the primary aim of the review, seven additional study design criteria were developed to ensure that findings related to individualized housing outcomes for the relevant population. Specifically, if results of individualised housing outcomes for

Table 1. Exclusion criteria development.

| | Title/ Abstract screening | Full text screening |
|------------------|--|---|
| Time period | 1. Before 1999 | 1. Before 1999 |
| Publication type | 1. In language other than English 2. Grey literature, non peer-reviewed journals, theses, conference proceedings, unobtainable during review period 3. Articles with no extractable data: literature reviews, book chapters, commentary, editorial | 1. In language other than English 2. Grey literature, non peer-reviewed journals, theses, conference proceedings, unobtainable during review period 3. Articles with no extractable data: literature reviews, book chapters, commentary, editorial |
| Population | 1. Aged under 18 or over 65 years 2. Mild disability 3. Does not have complex needs or high support needs 4. Mental health without complex needs | 1. Aged under 18 or over 65 years 2. Mild disability 3. Does not have complex needs or high support needs 4. Mental health without complex needs 5. Does not provide adequate information to determine population characteristics |
| Setting | 1. Located in institutional or shared living facilities | 1. Located in institutional or shared living facilities 2. Does not specify participants are, or were, living in individualized housing 3. Doesn't define housing or living situation |
| Study design | 1. Individualized housing is an outcome | 1. Independent living is an outcome 2. Does not separate groups based on living situation throughout paper 3. Doesn't provide characteristics of people 4. If includes participants over or under 65 exclude if groups are not separated by age throughout study 5. If includes various disability levels exclude if groups are not separated based on disability level 6. If does not separate by disability level must have more than half meeting population criteria 7. If does not separate by age must have majority under 65 and over 18 8. If does not separate by housing must have more than half meeting housing criteria |

adults (18–65 years) who had complex needs living in individualized housing, were unable to be isolated, the article was excluded.

It was identified at this stage of the review that consistency of terminology was an issue across articles. Therefore, guiding terms which indicated housing status were used to determine whether an article was referring to an individualized home, or to a housing arrangement that was not relevant to the current review (i.e., group homes or institutions). The guiding terms reflected both descriptors (e.g., purpose-built apartment) and characteristics (e.g., tenancy rights, choice regarding where and who to live with) of housing arrangements. Additionally, some terms used in the literature were recognised as being ambiguous. Often these terms had various meanings across countries, the meaning of the term had changed over time, or the terms were used differently depending on personal interpretations. When these terms were used in the literature, additional information that indicated the article was referring to individualized housing was also required in order to be included in the review. Table 2 provides a summary of the guiding terms used to indicate housing type. Articles in which the population or housing arrangements were not described were excluded. All full text articles were double blind reviewed by two reviewers (EGK and SO). Any disagreements and uncertainties regarding the inclusion or exclusion of articles were discussed by the primary screening reviewers (EGK, and SO), with the input of two independent review authors (DW and JD). Articles that were identified as meeting the inclusion/exclusion criteria after full text screening were assessed by the review team (DW, EGK, JD and SO) for final agreement for inclusion.

In total, the literature search retrieved 31,657 articles. After removing duplicates, 19,581 titles were screened by two independent reviewers. Based on the eligibility criteria outlined 19,109 articles were excluded at title screening. Abstracts of the remaining articles were examined to determine eligibility, resulting in the exclusion of a further 209 articles and 263 articles remaining. Using the revised exclusion criteria, an additional 245 articles were excluded based on an in-depth assessment of the full text.

Upon full text screening, articles were excluded for the following reasons: 58 due to population; 66 due to setting, 70 due to study design; 41 due to publication type and 10 articles could not be accessed (refer to Table 1 for detailed exclusion reasons). Four additional articles were identified through forwards and backwards citation searches of the 263 articles that were included for full text screening. Data was extracted from the final 22 Articles [40–61]. The reporting of study selection was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [62] (see Figure 1).

Data extraction

For the 22 papers included in the review, the following data were extracted and recorded into various tables: authors, date of publication, country of research, details of participants (including type of disability, comorbidities and number of participants in different settings), study design, measures utilised, outcomes assessed in the research, and significant outcomes associated with individualized housing. Comparative data analyses were only extracted if comparisons were between individualized housing models and other forms of housing (i.e., group homes or congregated care settings). As previously discussed, the reviewed literature utilised a variety of terminology regarding individualized housing models. In order to stay true to the original meaning, data were extracted and reported using the primary sources language.

Results

Participant characteristics

The 22 identified studies shared a number of common characteristics. As can be seen in Table 2, of the studies included, 18 primarily recruited participants with intellectual disability, learning disability or “mental retardation”². One study focused on people primarily with spinal cord injury and two studies recruited participants with acquired brain injury. Participants comorbidities were

Table 2. Guiding terms used to indicate housing type.

| | Individualized | Other | Ambiguous |
|-----------------|---|---|--|
| Descriptors | Personalized housing, independent living, self-directed housing, housing, own home, unsegregated, purpose-built apartment | Group home, agency housing, temporary housing, accommodation, shared supported accommodation, short term accommodation, community-based residential services, segregated, group homes, institution, boarding house, hostel, nursing home, non-community based, family-model homes | Supervised living, semi-independent living, social housing, clustered housing, intentional community, community housing, assisted living, home share, small residential home, dispersed housing, parent or relatives' home |
| Characteristics | Choice, tenancy, home ownership, living like everyone else, living an ordinary life, age-appropriate | Placement, service users, clients, consumer, segregated, scheduled routine, isolated, temporary, isolated, segregated, house manager | Person-centred, individualized support, shared facilities, residents |

reported in 9 studies. As per the exclusion criteria, all studies reported on participants between 18–65 years, with most reporting on a population with a mean age of approximately 40 years. Most studies reported on samples that consisted of over 50% males [40,42,43,45–48,53,57,59–61] and two studies reported on a sample that was 100% male [49,50]. The number of participants included in the studies ranged from 6 to 8,892 people. The studies included in the review reported on a variety of respondents' perspectives (see Table 3 for summary). In accordance with the exclusion criteria, all studies reported on participants with moderate-severe disability.

Health condition or diagnosis

Findings regarding participants health condition(s) in more individualized housing options were mixed. Multiple studies found no difference in the presence of psychiatric disorders or the presence of autism spectrum disorder across living conditions (i.e., supported living, personalized arrangements, own home, group homes and institutions) [42,51,58]. Conversely, Felce et al. [44] found people living independently were less likely to have the triad of impairments indicative of autism than people living in family or group homes. Additionally, Ticha et al. [58] found people with disability living in their own home were less likely to have a profound intellectual disability, mobility limitations, a vision impairment or a hearing impairment, compared to people living in large institutional settings (16+ residents). McConkey et al. [51] reported that people with a history of epilepsy were less commonly provided the opportunity to live in personalized arrangements, and tended to be placed in group homes. One study reported that a significantly higher proportion of people with spinal cord injury lived in their own home, rather than in nursing homes or homeless shelters [47]. Results from three studies that sought matched samples suggest that people with disability and complex needs can live in individualized settings (i.e., supported living, semi-independent living or community residences) when provided the opportunity [40,57,60].

Study characteristics

An overview of the characteristics, outcomes assessed and main findings of the studies included in the review is provided in Table 4. Of the studies included, 3 used a qualitative methodology, 18 were quantitative and 1 utilised a mixed methods design. The studies originated from a variety of countries, with 7 from the USA, 3 from Australia, 3 from the United Kingdom, 3 from Ireland, 2 from Canada, 1 from Finland, 1 from Wales, 1 from Columbia and 1 from The Netherlands.

Findings

The primary aim of this review was to identify the outcomes of individualized housing for adults with disability. To identify the quantitatively assessed outcomes, the measures utilized in the quantitative and mixed methods studies were mapped onto the International Classification of Functioning, Disability and Health (ICF) [12]. As can be seen in Table 5, the most commonly used outcome measures focused on the person's activities and participation (e.g., relationships and resident choice) and environmental context (e.g., support and safety). Quantitative and qualitative findings are reported using the domains of ICF framework in the following section.

Body function

Quantitative findings. According to the ICF, mental functions are a subcomponent of body functions. The quantitative research included in the current review investigated global mental functions, such as challenging behaviour (any behaviour that causes significant distress or danger to themselves or others), and specific mental functions such as emotional functioning (any mental functions related to the feeling and affective components of the mind) [12]. Marlow and Walker [39] found participants challenging behaviour decreased following a move from group homes into individual flats and that these changes were maintained after six months. Additionally, Felce et al. [44] found that people living independently were less likely to have challenging behaviour than people living in family or group homes. Emerson et al. [42] found no difference in challenging behaviour across living conditions, which included group homes, institutions and the participants own home. However, results of Emerson et al. [42] may be influenced by a cohort effect as participants included people who had experienced institutional living. In regards to emotional functioning, Marlow and Walker [49] found that people's mood increased one month after they moved from group homes into individualized flats and that these changes were maintained after six months. Valk-Kleibeuker et al. [59] found that mood did not change for participants in their study until 18 months post traumatic brain injury (TBI), after which it significantly improved. Similarly, discharge destination after TBI was a significant predictor of mood. Patients who were directly discharged home had better mood scores over a three-year period compared to patients who were treated in an inpatient rehabilitation centre or nursing home [59]. Taken together, these findings indicate that individualized housing options have favourable outcomes for challenging behaviour and mood.

Qualitative findings. Within the domain of body function, the qualitative research focussed predominantly on emotional function. Personalised residential settings were reported to enhance

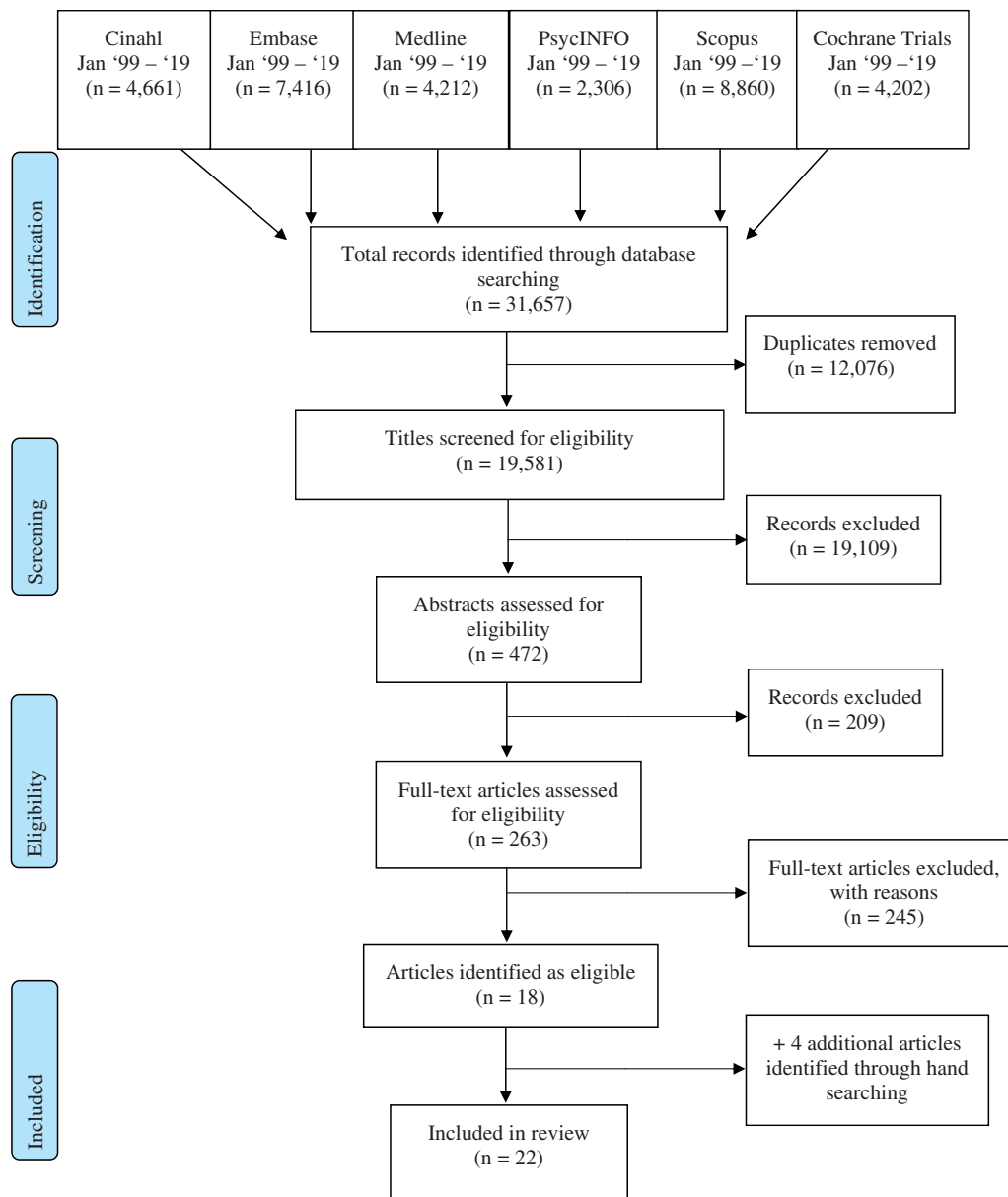


Figure 1. PRISMA flow diagram.

general wellbeing due to an enhanced lifestyle that offered growth and development [41]. The importance of emotional and behavioural self-control was also highlighted in the qualitative literature as factors that contributed to the success of independent living in the community [41,50].

Activities and participation

Quantitative findings. Quantitative findings regarding activities and participation, including adaptive behaviour, varied between living conditions. Adaptive behaviour is the collection of conceptual, social, and practical skills learned by people to enable them to function in their everyday lives [12]. Outcomes regarding adaptive behaviour, as well as general tasks and demands, commonly showed no differences between individualized housing options (i.e., supported living, independent living and independent flats) and group homes [40,44,49,56,58]. Similarly, findings for self-care showed no difference for people in supported living or independent flats and group homes [42,49]. However, residents living semi-independently or independently, participated in significantly more

domestic tasks, such as household cleaning, cooking, shopping and related tasks, compared to people living in family and staffed homes [44,57].

Mixed results were also evident for interpersonal interactions and relationship outcomes. A handful of studies found that living in group homes was associated with more scheduled social and community activity [42,44] and more frequent community connections [56] when compared to independent living, supported living or living in an independent home or apartment. One study found that people in supported living arrangements (including living alone, in a home-share or with formal support arrangements) had low levels of friendship activities, and that residential setting was an important determinant of the form and content of activities with friends [43]. In contrast, it was commonly reported that people living in personalized arrangements experienced more social relationships and interactions with friends, including inviting friends or relatives over for meals and giving and receiving help from neighbours compared to residents in group homes [51–55]. Further, supported living residents had more access to social

Table 3. Participant characteristics.

| Author | Primary disability | Comorbidities | Individualized housing | Comparison setting | Respondent(s) |
|--------------------------|--|---|---|---|---|
| Bigby et al. [39] | Intellectual disability | An average of 6 additional health conditions such problems with weight, joint and muscle pain, hearing, dental/oral and hygiene, mental health and physical impairments | Supported living* N = 29 | Group homes N = 29 | Participant Staff member |
| Cocks et al. [40] | Intellectual disability | Cerebral Palsy, mental illness, Prader-Willi syndrome, epilepsy | Supported living* N = 5 | Host family N = 1 | Participant Staff member |
| Emerson et al. [41] | Mental retardation | Autism, mental health and high health needs | Supported living* N = 63 | Small (1 to 3 residents) and large group homes (4 to 6 residents) N = 207 | Participant Close other Participant Staff member |
| Emerson and McVilly [42] | Intellectual disability | Not reported | Home owners, people with tenancy, small residential homes* N = 942 | Larger homes (4+ residents), nursing homes, NHS provision, adult placement N = 417 | Participant Staff member |
| Felce et al. [43] | Intellectual disability | Triad of impairments characteristic of autism spectrum disorder | Living independently N = 30 | Family homes, staffed homes N = 701 | Not reported |
| Friedman [44] | Intellectual and developmental disability | Not reported | Own home* N = 284 | Provider owned group homes, state-operated group homes, intermediate care facilities, family home, other (e.g., nursing home, foster care) N = 1,057 | Participant |
| Gardner and Carran [45] | Mental Retardation, Cerebral palsy, Autism, Seizure, Hearing, Vision, Mobility, Physical, Traumatic Brain Injury, Mentally Ill | Not reported | Living independently, supported living arrangements N = 708 | Supervised living arrangements, foster families, natural families N = 2305 | Participant |
| Ho et al. [46] | Spinal cord injury, Diabetes, Amputation, Fractured leg or hip, Stroke, Arthritis (hip or ankle), Brain injury & Others | Not reported | Private residences N = 8 | Homeless shelters, nursing homes N = 20 | Participant |
| Houseworth et al. [47] | Intellectual disability | Not reported | Living independently (home or apartment) (Total N = 15,248) | Parents or relatives' home, foster or host home, agency (1-3 residents), agency (4-6 residents), agency (7-16 residents), agency (16+ residents) (Total N = 15,248) | Participant Staff member |
| Marlow and Walker [48] | Intellectual disability | Autism, Epilepsy, wheelchair users, down syndrome, visual impairment | New-build individual flats* N = 6 | Pre-move data N = 6 | Close other Staff member |
| McCull et al. [49] | Acquired brain injury | Not reported | Own apartments* N = 3 | Family members, significant others, service providers N = 17 | Participant Close other Staff member Participant Staff member |
| McConkey et al. [50] | Intellectual Disability & Mental health problems | Not reported | Personalized arrangements* N = 72 | Group homes, congregated settings, family carers N = 84 | Participant Staff member |
| McConkey et al. [51] | Intellectual disability | Epilepsy, medical conditions affecting daily life, autism, feeling down/ depressed | Personalized arrangements (living alone or with a friend)* N = 29 | Group homes, congregated settings N = 60 | Participant |

(continued)

Table 3. Continued.

| Author | Primary disability | Comorbidities | Individualized housing | Comparison setting | Respondent(s) |
|-----------------------------|---|---|--|--|---|
| McConkey et al. [52] | Intellectual disability & mental health problems | Not reported | Personalized arrangements (living alone or with a friend of their choosing) * N = 58 Living in an apartment* N = 12 | Group homes, congregated settings or family carers N = 75 | Participant |
| Salovita and Aberg [53] | Learning disability | Not reported | Living in an apartment* N = 12 | Group homes, institution N = 42 | Participant |
| Sheth et al. [54] | Physical Disability, Psychiatric Disability, Chronic Health Condition, Blindness or Vision Loss, Cognitive Disability, Speech/ Communication Difficulties, Deaf or Hearing Loss | Respondents could choose more than one disability category | Apartment/condominium/private home/townhouse, public housing, residential group homes (<6 residents), other N= 150 | Nursing home, institute for mental disease/ immediate care facility, residential group home (6 + residents), state-operated institution, assisted living N = 150 | Participant |
| Stainton et al. [55] | Intellectual Disability, Autism, Other Conditions | An average of 2 additional diagnoses such as autism, mental illness, communication disorders, physical disability or hearing or vision impairment | Independent home or apartment, agency-owned apartment N = 104 | Group home, long-term care or extended care facility, at home with family members, living in "other" type of setting N = 710 | Close other |
| Standliffe and Keane [56] | Intellectual disability | Cerebral palsy, chronic health problem, deafness, epilepsy, psychiatric and other conditions | Semi-independent living* N = 27 | Group homes N = 27 | Participant Close other |
| Ticha et al. [57] | Intellectual disability | Mobility limitations and other hearing impairments, mental health diagnosis or taking psychotropic medications, autism | Own home N = 1221 | Natural family, host family, Agency 1-3ppl, Agency 4-6 ppl, Agency 7-15 ppl, Agency 16 + ppl N = 7671 | Participant Close other |
| Valk-Kleibeuker et al. [58] | Traumatic brain injury | Not reported | Home N = 45 | Rehabilitation centre, nursing home N = 53 | Participant Family member Staff member Participant |
| Wehmeyer and Bolding [59] | Mental retardation | Not reported | Community-based group* N = 91 | Community-based congregate group, noncommunity-based congregate group N = 182 | Participant |
| Wehmeyer and Bolding [60] | Intellectual disability | Not reported | Community-based group* N = 31 | Community-based congregate group, noncommunity-based congregate group N = 31 | Participant |

*Includes definition of individualized housing.



Table 4. Study characteristics and outcomes.

| Author, Year, Country | Study design, method | Outcomes | Main findings |
|--|--|--|---|
| Bigby et al. [39] Australia, 2018 | Mixed Methods, matched sample Survey, semi-structured interviews | <ul style="list-style-type: none"> • Quality of Life • Support and participation | Compared to group homes, supported living residents had significantly more access to social clubs and was significantly cheaper |
| Cocks et al. [40] Australia 2016 | Qualitative, consensus-seeking process Semi-structured interview | <ul style="list-style-type: none"> • N/A | Successful approaches to individual supported living are diverse, formal and informal support environments are important factors |
| Emerson et al. [41] United Kingdom, 2001 | Quantitative, cross-sectional Questionnaire, structured interviews | <ul style="list-style-type: none"> • Setting procedures • 'Institutional features' • Leisure and community-based activities • Social networks and support • Choice and control over key aspects of life • Risk of accidents, injuries, abuse and exploitation • Residential support • Community involvement • Friendship activities | People living in supported living arrangements reported greater choice, more community-based activities, fewer scheduled activities, were more likely to have their home vandalized and were considered at greater risk of exploitation when compared with small group homes; no significant differences between living settings in service costs |
| Emerson and McVilly [42] United Kingdom, 2004 | Quantitative, cross-sectional Secondary analysis of merged data sets | <ul style="list-style-type: none"> • Residential support • Community involvement • Friendship activities | Supported accommodation residents experienced low levels of friendship activities, residential setting is a more significant determinant of the form and content of friendship activities than participant characteristics |
| Felce et al. [43] Wales, 2011 | Quantitative, cross-sectional Secondary analysis of four merged datasets | <ul style="list-style-type: none"> • Participant's involvement in domestic activities • Variety and frequency of participants' social and community activities • Personal Outcomes | People living independently participated in significantly more domestic activities compared to people in family and staffed homes |
| Friedman. [44] USA, 2019 | Quantitative, cross-sectional Secondary analysis of survey data | <ul style="list-style-type: none"> • Personal Outcomes | Controlling for impairment level, participants living in their own homes had significantly higher levels of choice and community participation compared to group homes and institutional settings. |
| Gardner and Carran [45] Columbia, 2005 | Quantitative, cross-sectional Secondary analysis of state collected data | <ul style="list-style-type: none"> • Personal Outcomes | Independent living had a significantly greater percentage of personal outcomes than supported living and living with natural families; natural support systems are important for personal safety and freedom from abuse and neglect |
| Ho et al. [46] USA, 2007 | Qualitative, semi-structured focus group discussion | <ul style="list-style-type: none"> • N/A | Participants living in inaccessible apartments or houses worried about their ability to maintain daily living and social activities; participants perceived barrier-free housing to be a pre-requisite for independent living and for ensuring basic health and wellbeing |
| Houseworth, Stancliffe and Tichá [47] USA, 2018 | Quantitative, cross-sectional Secondary analysis of state collected data | <ul style="list-style-type: none"> • Support-related and everyday choice | High levels of support-related choice and everyday choice were significantly associated with living in an independent home or apartment |
| Marlow and Walker, [48] United Kingdom, 2015 | Quantitative, repeated measures, natural experiment Structured interview | <ul style="list-style-type: none"> • Quality of life • Emotional well-being • Living skills • Interactions • Staff and carers opinions • N/A | Following the move to supported living, tenant's mood increased and challenging behaviour decreased; changes were maintained after 6 months; time spent in activities outside house was low (inferential statistics not reported) |
| McCull et al. [49] Canada, 1999 | Qualitative, consensus-seeking process | <ul style="list-style-type: none"> • N/A | Common factors that contributed to successful transitions to independent living included support from family and programme personnel; staying away from drugs and alcohol; availability of structured daily activities, financial management and emotion and behaviour self-control |
| McConkey et al. [50] Ireland, 2016 | Quantitative, natural experiment Structured interview | <ul style="list-style-type: none"> • Ratings of Change • Choice and Control • Daily Activity • Relationships • Staff Costs | People living in personalized arrangements reported greater choice, control, community engagement and personal relationships as well as lower average staff costs when compared to people living in group homes and congregated settings |

(continued)

Table 4. Continued.

| Author, Year, Country | Study design, method | Outcomes | Main findings |
|--|--|--|---|
| McConkey et al. [51] Ireland, 2018 | Quantitative, natural experiment Structured interview | <ul style="list-style-type: none"> • Support needs • Wellbeing • Staff rating | People who moved into personalized living arrangements from congregated settings reported significant improvement in well-being; mean well-being scores were significantly higher for persons with higher support needs. |
| McConkey et al. [52] Ireland 2019 | Quantitative, natural experiment Structured interviews | <ul style="list-style-type: none"> • Social relationships at two time points | People who moved to personalized arrangements had more social relationships compared to those who remained in group settings; changes were maintained after 24 months; one in five persons increased their social relationships due to moving to personalized arrangements. |
| Salovita and Aberg [53] Finland, 2000 | Quantitative, cross-sectional Structured interviews | <ul style="list-style-type: none"> • Self Determination | People who were living in single apartments reported significantly higher levels of self-determination compared to people in group homes and hospital wards; level of disability did not explain differences in self-determination between housing types. |
| Sheth et al. [54] USA, 2019 | Quantitative, cross-sectional Questionnaire | <ul style="list-style-type: none"> • Quality of Life | People who lived in community settings reported significantly higher satisfaction, personal safety, service access, and community integration and inclusion compared to people living in institutional settings. |
| Stainton et al. [55] Canada, 2011 | Quantitative, cross-sectional Questionnaire | <ul style="list-style-type: none"> • Information and planning • Access to and delivery of supports • Choice and control • Community connections • Satisfaction with services • Overall perception of outcomes • Loneliness • Safety • Quality of life • Community living • Staff support • Service costs • Every day and support-related choice | People who living in independent and family homes settings reported significantly greater choice and control in regards to staff compared to group homes and family model homes; group homes and family model homes showed significantly better outcomes on all other measures |
| Stancilffe and Keane [56] Australia, 2000 | Quantitative, matched sample Structured interview Questionnaire Administrative data | <ul style="list-style-type: none"> • People living in semi-independent arrangements reported significantly more frequent and independent use of community facilities, greater participation in domestic tasks, greater empowerment, less social dissatisfaction; and lower per person expenditure compared to people living in group homes • Controlling for personal characteristics, individuals living in their own home had significantly more support-related choices than people living in any other residential arrangement | People living in semi-independent arrangements reported significantly more frequent and independent use of community facilities, greater participation in domestic tasks, greater empowerment, less social dissatisfaction; and lower per person expenditure compared to people living in group homes |
| Ticha et al. [57] USA, 2012 | Quantitative, state collected data Structured interviews | <ul style="list-style-type: none"> • Emotional status • Physical and cognitive functioning | Patients discharged from rehabilitation centres or nursing homes. Mood improved 18 months after Traumatic Brain Injury when motor and cognitive outcomes stabilized |
| Valk-Kleibeuker et al. [58] The Netherlands, 2014 | Quantitative, longitudinal Structured interviews Questionnaire, | <ul style="list-style-type: none"> • Self-Determination • Autonomy in Self and Family Care • Life and daily choices • Satisfaction across employment domains • Self-Determination • Autonomy in Self and Family Care • Life and daily choices | People who lived in community-based settings reported significantly more self-determination, autonomy and life choices than people who lived in more restrictive settings (e.g., group homes, nursing homes) |
| Wehmyer and Bolding [59] USA, 1999 | Quantitative, matched sample Questionnaire | <ul style="list-style-type: none"> • People who moved to community-based settings from more restrictive settings (e.g., group homes, nursing homes) experienced significant increases in self-determination, autonomous functioning and life choices | People who moved to community-based settings from more restrictive settings (e.g., group homes, nursing homes) experienced significant increases in self-determination, autonomous functioning and life choices |
| Wehmyer and Bolding [60] USA, 2001 | Quantitative, within-subjects Questionnaire | | |

Table 5. Quantitatively assessed outcomes mapped onto the international classification of functioning, disability and health.

| Component | Domain | Measures used | Studies reporting use | | |
|---|--|---|--------------------------------------|---|------------|
| Body functions | <i>Mental functions</i> | Aberrant Behaviour Checklist | [41,43] | | |
| | | Challenging Behaviour Interview | [48] | | |
| | | Learning Disability Casemix Scale | [42] | | |
| | | Adaptive Behaviour Scale Part I (ABS) | [39,41,43] | | |
| | | Adaptive Behaviour Assessment Scale (ABAS) | [48] | | |
| | | Inventory for Client and Agency Planning (ICAP) | [56] | | |
| | | National Core Indicators Consumer Survey (NCI-ACS) | [57] | | |
| | <i>Temperament and Personality</i> | Functional Assessment Measure | [58] | | |
| | | Mood, Interest and Pleasure Questionnaire | [48] | | |
| | | Wimbledon Self-Report Scale (WSRS) | [58] | | |
| | | Activities and participation | <i>General Tasks and Demands</i> | Adaptive Behaviour Scale Part I (ABS) | [39,41,43] |
| | | | | Adaptive Behaviour Assessment Scale (ABAS) | [48] |
| | | | | Inventory for Client and Agency Planning (ICAP) | [56] |
| | | | <i>Self-care</i> | Selected items from the Health Survey for England 1993 and the Tameside and Glossop Health Needs Survey | [41] |
| Weight and Medications | [48] | | | | |
| <i>Domestic life</i> | Functional Independence Measure | | [58] | | |
| | Index of Participation in Domestic life (IPDL) | | [43] | | |
| <i>Interpersonal Interactions and Relationships</i> | The Index of Participation in Daily Living | | [39] | | |
| | Index of Community Involvement | | [39–42] | | |
| | Loneliness Questionnaire | | [56] | | |
| | Index of Community Integration (ICI) | | [43] | | |
| | Hourly Observations of Interactions | | [48] | | |
| | Personal Outcomes Measure (my community, my relationships) | | [44] | | |
| | <i>Major life areas</i> | | Quality of Life Survey | [54] | |
| | | Lifestyle Satisfaction Scale - Job Satisfaction Subscale | [59] | | |
| | | Quality of Life Questionnaire (QOL-Q) | [56] | | |
| | | Life Experiences Checklist | [48] | | |
| <i>Human rights</i> | 25-item Personal Outcome Measure | [45] | | | |
| | Well-being Measure | [51] | | | |
| | Personal Outcomes Measure (my goals) | [44] | | | |
| | Self Determination Scale | [53] | | | |
| | Arc's Self Determination Scale: Adult Version | [59,60] | | | |
| | Autonomous Functioning Checklist: Self-Report Version | [59,60] | | | |
| | Life Choices Survey | [59,60] | | | |
| | The Choice Scale | [41] | | | |
| | National Core Indicators Adult Consumer Survey (NCI-ACS) | [47,57] | | | |
| | Personal Outcomes Measure (my human security, my choices) | [44] | | | |
| Environmental factors | <i>Natural environment and human-made changes to environment</i> | Quality of Life Survey | [54] | | |
| | | Architectural Features Scale | [41] | | |
| | <i>Support and relationships</i> | Residential Services Setting Questionnaire | [41] | | |
| | | People We Support Questionnaire | [39] | | |
| | | Social Capital Questionnaire | [39] | | |
| | | Social Network Map | [41] | | |
| | | Service and support section of The Survey of Family Members of People with Disability Who Are Receiving Services from Community Living British Columbia | [55] | | |
| | | The Risks Scale | [41] | | |
| | | Quality of Life Survey | [54] | | |
| | <i>Services, systems and policies</i> | Group Home Management Interview | [41] | | |
| | | Residential Services Working Practices Scale | [41] | | |
| | | Safety Questionnaire (developed by authors) | [56] | | |
| | | Support needs (13 items developed by authors) | [50,51] | | |
| | Body structures | | Observed Secondary Health Conditions | [39] | |

clubs [40], personalized living residents engaged in more fitness activities (e.g., sports or group fitness classes) and were more likely to be attending education or training courses [53], and semi-independent residents more frequently visited community places without paid support compared to group home residents [57]. One study investigated social relationships in different living arrangements and found that people who had moved to personalized living settings reported a significant increase in social relationships and more social relationships overall than group home

residents, and these differences were maintained over 24 months [51]. Two recent studies found that people who lived in their own homes, experienced significantly greater community integration and inclusion compared to group homes or institutional settings [45,55].

Outcomes regarding major life areas and human rights unanimously favoured more individualized housing options [42,45,46,48,49,52,54,55,57,58,60,61]. Specific areas investigated included job satisfaction [60], personal outcomes (e.g., affiliation,

identity, goal attainment) [46], quality of life [49,57] and well-being [52]. Studies that investigated levels of choice, autonomy and self-determination all favoured individualized housing options (i.e., supported living, community living, own home), compared to group-home settings [42,45,48,54,55,58,60,61].

Qualitative findings. Similar activity and participation outcomes identified in the quantitative studies were also found in qualitative literature. Cocks et al. [41] reported that people in supported living arrangements participated in a range of household activities including domestic duties, as well as social and community activities. Common barriers to achieving positive outcomes when living in private residences identified in the qualitative literature were social inclusion or the availability of meaningful occupation options [47,50] and financial management or money problems [47,50]. Outcomes regarding major life areas and human rights identified in the reviewed qualitative literature were similar to outcomes found in the quantitative literature. Specifically, increased autonomy and privacy were identified as common outcomes of living in supported living, private residences and apartments [41,47,50].

Environmental factors

Quantitative findings. In regards to the physical environment, Emerson et al. [42] found that significantly more supported living residents reported home-like settings (e.g., architectural features) when compared to large group home residents. Findings regarding support and relationships were mixed. One study found no difference in support when comparing supported living residents' experiences and group home residents' experiences [40], whereas Stainton et al. [56] found that residents in group homes reported significantly greater access to, delivery of, and assistance arranging, support compared to residents in independent living arrangements. In contrast, Emerson et al. [42] reported that a significantly higher proportion of supported living residents reported desirable support characteristics, such as support and housing being provided by different agencies. Additionally, Sheth et al. [55] found that people who lived in their own homes had significantly better experiences with personal care and were more likely to have access to the bathroom and medication when needed compared to people who lived in institutional settings. Outcomes relating to services, systems and policies were also inconsistent between studies. Although supported living residents reported higher staffing ratios as well as better internal procedures for allocating staff support based on individual needs, they were significantly less likely to have a key worker or an Individual Habilitation Plan (i.e., support plan), and staff were less likely supported in regards to assessment and teaching compared to group homes [42]. Additionally, one study found no differences in safety between living conditions [57], whereas Emerson et al. [42] reported that supported living residents were more likely to have their home vandalized and were considered at greater risk of exploitation. Of the studies that investigated differences in cost outcomes, one found no difference in service costs [42] and two found that semi-independent and supported living housing options had significantly lower support costs than group homes [42,57].

Qualitative findings. The qualitative literature also recognised the diversity of living arrangements that can be successful for people with disability [41,50]. Formal and informal support environments were identified as being critical for the success of living in individual apartments and supported living arrangements [41,50], as well

as living in environments that are suitable for individuals' physical, support or health needs [41,47,50].

Body structures

Quantitative findings. Findings regarding body structures in the reviewed quantitative literature indicate that individualized housing is suitable for people with high support needs. McConkey et al. [42] found that people living in personalised arrangements had improved well-being scores after moving from group homes, and that these changes were significantly higher for persons with higher support needs. Similarly, McConkey et al. [51] found that on average although residents in group homes had the highest support needs, people with high support needs were also accommodated in personalised settings. One study found that for residents in supported living, significant or chronic health conditions were associated with poorer quality of life outcomes, indicating that greater health support is required for this cohort [40].

Qualitative findings. Findings in the qualitative literature regarding body structures were similar to those reported in the quantitative literature. Specifically, Cocks et al. [41] reported that all people with a disability, no matter how high and/or complex their needs, can live in a personalised residential setting if it is sufficiently flexible and resourced.

Discussion

This scoping review has documented the outcomes associated with individualized housing for people with disability and complex needs as reported in the peer-reviewed literature. Individualized housing arrangements consistently demonstrated favourable human rights outcomes, specifically for self-determination, choice and autonomy [42,45,46,48,49,52,54,55,57,58,60,61]. Individualized housing options also demonstrated favourable outcomes in regards to social relationships [51–53], challenging behaviour [42,44,49], mood [49,59] and participation in domestic tasks [44,57]. These findings align with previous research that has highlighted the benefits of individualized housing regarding self-determination, functional skills improvement, meaningful social interaction and psychological wellbeing [29,63–67]. In contrast, outcomes regarding adaptive behaviour, self-care, scheduled activities and safety showed no difference, or less favourable results, when compared to group homes [40,42,44,46,56,57]. The reviewed literature also demonstrated the importance of formal and informal supports for the success of individualized living arrangements [40,41,47,50,56]. There were many significant gaps in the research, including an absence of systematic and comprehensive evidence of the outcomes associated with individualized housing, particularly for people with acquired disability and complex needs.

The reviewed literature identified some important factors that contributed to the outcomes of individualized housing arrangements. It was commonly found that having a mix of paid support and informal support through relationships and friendships was beneficial for people living in individualised housing arrangements [41,46,49,50,56]. Importantly, a good working relationship (e.g., frequent communication and involvement from both parties) between formal and informal supports was highlighted as contributing to the success of individualised housing [41,50]. This finding is consistent with previous research that has highlighted the importance of support [26,68,69], and reflects the UNCRPD emphasis on the provision of appropriate support. Notable barriers to positive outcomes in individualized housing included

having limited finances [48,50], money management [41], vulnerability to substance abuse [41] and being unable to access transportation [47,55]. The primary aim of the current review was to identify outcomes associated with individualised housing and in doing so, some important barriers and facilitators for the success of these arrangements have been identified. Further investigation regarding what specific features of individualized housing arrangements benefit or hinder the outcomes of people with disability is required.

Two studies found that outcomes of people living in individualized housing changed over time. Marlow and Walker [49] found that tenants' mood improved following the move from group homes into individualized flats and that these changes were maintained after six months. Additionally, Valk-Klebeuker et al. [59] investigated the course of mood and its determinants over a three-year period following TBI. It was found that patients who were directly discharged home had better mood scores over time compared to patients who were treated in an inpatient rehabilitation centre or nursing home. Interestingly, mood did not change until 18 months post TBI, after which it significantly improved. One study found that people who moved to personalized arrangements had more social relationships compared to people who remained in group settings and that these changes were maintained after 24 months [53]. These findings indicate that living in individualized housing is likely to have ongoing and changing effects on health and wellbeing, particularly when people are adjusting to their new way of life. However, of the studies included in the review, just three studies reported follow-up outcomes. Thus, future research should endeavor to further investigate how the experiences, outcomes and needs of this population change over time by conducting longitudinal follow-up studies. This information would be valuable for the development of effective and sensitive policy initiatives that aim to support and transition people to more individualized housing options.

A number of important research gaps have been identified through this scoping review. The lack of detailed descriptions regarding housing arrangements created a significant challenge in identifying relevant studies, summarizing the research findings, and drawing conclusions regarding the outcomes associated with housing models. Previous literature reviews on specialist housing models have found similar results regarding housing descriptions [66,70–73]. Terms used within the field to describe housing (e.g., independent living, assisted living, supported housing) do not have a commonly understood meaning. Although authors or experts in one jurisdiction may know what is meant by a given term, the same meaning may not be shared by others [72]. Providing clear and detailed descriptions of housing arrangements is crucial in ensuring accuracy in the interpretation and application of research findings to inform policy and practice [66,70–73]. It is important for future research to clearly describe housing arrangements by explicitly stating the specific living arrangements they are referring to (see Friedman [45] for example).

Another major gap concerns the absence of comprehensive evidence on the outcomes for people with acquired disability and complex needs in regards to individualized housing. The majority of studies included in the review investigated outcomes specifically for people with intellectual disability. Although this research can provide valuable insights regarding housing outcomes, the nature and degree of functional limitations experienced by people with other forms of disability such as an acquired neurological disorder (e.g., brain injury, spinal cord injury, progressive neurological disorders) are different to those encountered by people

with intellectual disability [74]. Unfortunately, the severity of physical limitations was only reported in a handful of studies [40,46,48,49,58], so substantial conclusions cannot be drawn regarding the appropriateness of individualized housing for people with significant physical limitations. Previous research has documented the different employment outcomes [75] and support needs [67] for people with physical impairments or acquired neurological disabilities compared to people with intellectual disability. It is therefore likely that living in individualized housing will be associated with unique outcomes for people with different types of disabilities. It is important for future research to investigate outcomes of individualized housing for people with various types of disability (e.g., acquired and progressive neurological disorders) to develop a more comprehensive understanding of what makes individualized housing options successful, as well as what barriers exist, for different cohorts.

Lastly, between studies included in the review, a range of assessment tools and study designs were used to assess a variety of participant outcomes. The diversity of measures utilized between studies posed a challenge when comparing and contrasting research findings, and likely contributed to some of the mixed findings found in the current review. Additionally, multiple studies relied on administrative data [57], convenience data [43–45], population data [42,46,48,58] or unvalidated measures [49,51,52,57]. Future research should aim to use standardized outcome measures so that findings can be more easily validated, accumulated and compared. In terms of study design, most studies included in the current review utilised observational or non-randomized experimental designs. Therefore, none of the studies could conclude that the housing model caused changes in participant outcomes. So that we can consider directionality, and outcomes of housing models can be adequately compared, future research should endeavour to recruit random samples and when possible utilise quasi-experimental interventions, pretest-posttest designs, randomised controlled trial or single case experimental study designs.

Findings from the current review suggest that support arrangements are not adequate in some individualized housing options, and as a result may be impairing the outcomes of people with disability [40,41,47,50]. Previous research investigating similar housing models has also highlighted the importance of well-structured support models that consist of paid support as well as family, friends and community members [26,67,76]. In Australia, the Specialist Disability Accommodation (SDA) program was developed to encourage investment and growth in individualized housing options for people with disability [77]. With the introduction of the SDA, it is anticipated that a substantial increase of people with disability will choose to live in individualized housing options [77]. It is therefore crucial that policy is refined to be sensitive to both formal and informal support arrangements for people with disability.

A rigorous scoping review methodology using established methods was conducted to map the existing literature of the outcomes associated with individualized housing for adults with disability and complex needs. Although scoping reviews are not designed to give weight to studies' findings based on quality assessment, it is valuable to note the diversity in the quality of studies included in the review, which must be considered when interpreting the findings in the current review. Additionally, in order to comprehensively capture outcomes of individualized living, literature spanning over the past 20 years was included in the review. Therefore, it should be considered that some of the included articles utilise data from a cohort that experienced

traditional institutional living arrangements. It is also noteworthy that studies that investigated body structures tended to include older adults (>40 years) as participants [40–42,51]. Therefore, findings indicating that poorer body function outcomes are associated with congregate care may be confounded with issues related to aging. The possibility that all relevant articles may not have been captured through the search strategy is a risk of any systematic or scoping review. Although our search was quite comprehensive, there is still the possibility that we may not have captured all available studies.

Overall, this review has highlighted the potential of individualized housing options to offer improved self-determination, choice and autonomy for people with disability and complex needs. A good working relationship between formal and informal supports was identified as being important for the success of individualised housing arrangements. It is important for future research to clearly describe the housing arrangements they are investigating and use rigorous research methods to effectively inform practice and policy. There is still a considerable need to build a more substantial evidence base regarding individualized housing outcomes, in particular for people with an acquired disability, as well as the long-term outcomes of individualized housing. Policy developments should focus on ensuring effective formal and informal support arrangements are in place for people with disability who choose to live in individualized housing options.

Notes

1. The current article will use person-first language consistent with the UNCRPD, and as recommended by International Language Guidelines on Disability [11].
2. To ensure accuracy in reporting, this scoping review uses the original terminology of the articles we have reviewed. However, it is important to note that while "mental retardation" was a historically accepted term, the presently accepted nomenclature is "intellectual disability" or "learning disability".

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