Journal of Housing and the Built Environment (2022) 37:2215–2235
https://doi.org/10.1007/s10901-022-09948-y

ARTICLE

Co-designing in Australia housing for people with intellectual disability: an integrative literature review

Richard Tucker[1] · **Patsie Frawley**[2] · **Mirjana Lozanovska**[1] · **Meredith Prain**[3]

Received: 7 April 2020 / Accepted: 18 March 2022 / Published online: 8 April 2022

Abstract

Background This paper provides an evidence base for practice in Australia from an integrative literature review of research on co-designing housing with people with an intellectual disability. The study asks: what methods and outcomes have been reported from including people with an intellectual disability in the co-design of their housing?

Method The integrative review framework described by Whitemore and Knafl (2005) was used to analyse the literature.

Results The literature searches yielded 16 articles after applying inclusion and exclusion criteria. Important gaps in the literature were found relating to: co-designing with people with an intellectual disability; the co-designing of housing with people with an intellectual disability; specific frameworks or benchmarks for co-designing with people with an intellectual disability; processes on use of proxies; and on design outcomes.

Conclusions Considerable work is required to explore and evaluate co-design processes in the design of housing with adults with intellectual disabilities, as well as how the outcomes of these processes are evaluated.

✉ Richard Tucker
richard.tucker@deakin.edu.au

Patsie Frawley
patsie.frawley@deakin.edu.au

Mirjana Lozanovska
mirjana.lozanovska@deakin.edu.au

Meredith Prain
meredith@meredithprain.com.au

[1] School of Architecture and Built Environment, Deakin University, Geelong Waterfront Campus, 3220 Geelong, Victoria, Australia

[2] School of Health & Social Development, Deakin University, Geelong Waterfront Campus, 3220 Geelong, Victoria, Australia

[3] Meredith Prain Deafblindness Consultancy, 3220 Victoria, Australia

1 Introduction

Article 19 of the United Nations Convention on the Rights of Persons with a Disability states that persons with disabilities should have "the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement" (United Nations, 2007, p. 12). However, "despite the overwhelming interest in housing design and quality practice within the housing and health sectors, there remains a general lack of robust research around housing design in disability and a lack of evidence relating to the design process" (Zeeman, Wright, & Hellyer, 2016, p. 764).

Adults with intellectual disabilities live in a broad range of housing with a broad range of supports depending on their level of independence, the involvement of family in their lives, and their age. A common form of supported housing is the group home where people with disabilities are co-residents in a house that likely will not have been designed for the people residing in it, and where the residents have had little input into the social or structural components of the house. Adults with intellectual disabilities typically have little involvement, if any, in decision-making regarding their living situation, including the design of their homes.

While co-design is increasingly common in the development of services and technologies to assist people with disabilities, there remains relatively limited information or examples of co-design of homes with people with an intellectual disability. This is likely due to a variety of factors including previous lack of funding and support (Wiesel et al., 2015), perception of capacity of people with intellectual disability and disability more broadly to be involved in the design process (Mackie, 2012; Pirinen & Verma, 2016), and a lack of models or guidelines for co-design with this population.

Multiple factors contribute to the challenges of co-design with people with an intellectual disability. Firstly, there are communication challenges inherent in undertaking co-design with people with an intellectual disability (Brereton, Sitbon, Abdullah, Vanderberg, & Koplick, 2015; Francis, Balbo, & Firth, 2009; Gaudion, Hall, Myerson, & Pellicano, 2015; Herriott, 2015; Lowe, Gaudion, McGinley, & Kew, 2014). Dawe (2007) highlights three further challenges in designing with this population: (1) they have widely varying abilities and needs; (2) they are represented by themselves as well as a network of caregivers; and (3) the co-design environment is less predictable and stable than the real-world context of the artefact being designed. As well as varying abilities and needs, Fudge Schormans et al. (2018) have shown that people with intellectual disabilities bring diverse and intersecting histories of disability, race, gender, ethnicity and class.

The aim of this review is to provide an overview of recent literature that addresses the co-design of housing with people with an intellectual disability. The question addressed here is: what methods and outcomes have been reported from studies including people with an intellectual disability in the co-design of their housing? By mapping the field of knowledge on co-design of homes with people with an intellectual disability, and identifying the main issues as well as possibilities, this paper provides relevant information for local policy makers and practitioners. These findings also provide potential exchange with the much more advanced policies on housing for people with physical disability. The findings in the review of the literature also uncover the international scale of this issue, especially with regards to a paucity of evidence-based research on housing co-design for that people with intellectual

disabilities, and therefore inform organisations such as the United Nations concerned with the rights of persons with a disability, especially an approach to improving the quality of their housing.

1.1 Understanding intellectual disability

People with an intellectual disability have a right under the Convention on the Rights of Persons with Disabilities (CRPD) to have choices about their housing. The CRPD applies to all people who are identified or self-identify as experiencing disability and does not categorise disability rights based on disability *type*. The CRPD takes a social model approach to disability that "…explains disability as a social construct through discrimination and oppression. Its focus is on society rather than the individual" (Degener, 2016, p. 3). Applying this model to the question of accessible housing for people with an intellectual disability, the difficulties people with an intellectual disability face that relate to their experiences of housing and home are due to the built and social environments of the houses/homes, not the impairment effects of intellectual disability.

The lived experience of intellectual disability cannot be defined purely by cognitive impairments assessed by intelligence tests: issues with memory, learning and knowledge retention, decision making and complex problem solving. When referring to intellectual disability in this paper, we are referring to a very broad lived experience that is mediated by the social and built environments that people interact in and with, and to what extent these environments have been adapted or designed to be universally accessible. It is not possible to say specifically or generally how much 'intellectual disability' defines housing needs. People with an intellectual disability are women, men, young, old, live in rural and metropolitan areas, are Lesbian, gay, bisexual, transgender, queer and intersex (LGBTIQ), may have multiple impairments and complex lived experiences of disability. The premise of this paper is 'people' with intellectual disabilities can and should, as defined by the CRPD, be involved in shaping and designing the houses and homes they will live in.

It is difficult to identify specific housing and housing design components that would address some key and shared issues faced by people with an intellectual disability in housing. Bertelli, Salvador-Carulla, Lassi, Zapella, et al. (2013) found that little research had been done to engage people with intellectual disabilities in shaping what is important to them in housing design. One Canadian study that did ask people what their needs were, reported the following components, "…affordable, comfortable, secure/safe environment, a space to get away from others, privacy, less noise, spacious, freedom to do what you want when you want, warmth, love, family, relaxing atmosphere, knowing that you have a place to go to, a place to think, a place where you can follow your hobbies" (Bertelli et al., 2013, p. 227). While these could be seen as broad and possibly abstract, Bertelli et al. (2013) more broadly identify that people with an intellectual disability have not had the opportunity to describe what these factors mean and look like for them in their homes. Co-design approaches could enable a more material indication of what some of these components could look like in a home matching the needs of people with intellectual disability.

1.2 Background: housing challenges for people with intellectual disability

In Australia, adults with intellectual disability commonly stay at home with parents until they reach middle age or beyond when, as a result of parental death or incapacity, they are normally transferred to some form of group home. The transition from familial surroundings results in disruption and even dislocation trauma. Ageing in place for people with intellectual disability is unlikely, with their new accommodation – shared with others who have related (although often quite different) complex needs and generally at least part government-funded – offering a very different environment to their old home. In the following passages, the wider Australian context will be summarised to elucidate the challenges facing people with an intellectual disability and their supporters, including parents and families searching for well-designed housing that meets the needs of family members with an intellectual disability. We will focus on two key challenges, lack of: (1), well-designed housing and integrated support models; and (2) participation of people with disability in the design of their housing.

1.3 Suitability of housing for people with intellectual disability

The 2011 Productivity Commission report on *Disability Care and Support*, which paved the way for the National Disability Insurance Scheme (NDIS) in Australia, reported that there were "15,700 people with disabilities in state managed supported accommodation" and that "waiting lists would add a further 25% to the population needing specialist disability accommodation" (Productivity-Commission, 2011, p. 759). While group homes are the most common example of specialist disability supported housing in Australia, at the time of the Productivity Commission report there were still 1903 people with disabilities living in large-scale congregate disability institutions in Australia. Research, in particular people with intellectual disabilities, highlighted unmet need, inadequate planning and support for housing as key social and disability policy issues (Bigby, 2010; Mercier & Picard, 2011; Wiesel et al., 2015). While housing 'type' is an important focus, design and co-design of housing by people with disabilities has had less attention than housing availability and models of support.

In the Western world, individualised design of housing has had less focus than individualised direction of the type and use of supports people receive. Often, funding for the housing aspect of a person's needs and funding for support are separate. The NDIS in Australia is a clear example of this approach evidenced through the Specialist Disability Accommodation (SDA) funding rules of this scheme. This funding is limited to people with "very high support needs who meet specific eligibility criteria" identified as a "small proportion of NDIS participants" (NDIA, 2019) that is estimated to be 6% of participants. The rules for SDA note that the funding is for "bricks and mortar" and is intended to "stimulate investment in the development of new high-quality dwellings for use by eligible NDIS participants. It does not refer to the support services, but instead to the homes in which these services are delivered" (NDIA, 2019). Design is referred to only in relation to five key categories: (1) basic, (2) improved liveability, (3) fully accessible, (4) robust, and (5) high physical support design. A sixth separate category 'innovative design' is referred to. While the funding rules are clear about these factors, there is no mention of 'co-design'.

1.4 Co-design in Australia with people with disability

Co-design emerged from the people-environment architectural experimentation of the 1970s. These early models were inspired by Hassan Fathy, *Architecture for the Poor: an experiment in rural Egypt* (Fathy, 1969), a key publication that influenced an entire generation of architects with a keen interest in people-environment relationships (See journal *Environment and Behaviour*). The work led by David Stea in the late 1960 and 1970 s at the University of California (Studer & Stea, 1966), along with cognitive-behavioural approaches to spatial cognition, overlapped with activist housing practices (Turner & Fichter, 1972) and precede the literature review at hand. This knowledge can be seen in current approaches including mapping, modelling, and cross-cultural creative exercises in ethnography (Blaut, Stea, Spencer, & Blades, 2003). Tailoring our search towards co-design of the housing of people with an intellectual disability has required boundaries to contemporary uses of the terminology of 'co-design' as its popularity and vastness extends across Information Technology (IT) (Uzzell, 2008) and ethnographic methods. In addition, practices and development of co-design processes within our research scope occur at various stages in community-oriented projects (early consultation to decision making) and are also used in municipalities-led projects keen to gain community consultation. The former is difficult to capture in scholarly research, and the latter can be criticised for their bureaucratic overlays (Graham & Leesam, 2017).

Much research, policy development and implementation in relation to housing has evolved in the broader populations with physical disability, but not in the particular population with intellectual disability, particularly adults with intellectual disability. Brian Kidd's campaign for accessible environments beginning as teaching programmes for Australian architects in 1977 resulted in the major disability standards for all Australian buildings (Standards Australian Committee AS 1428.1 Design for Access and Mobility). In 1984, Kidd pioneered person-centred design exemplified in his Aldersgate Village, reorienting the institutional character of aged care facilities towards homelike environments. Despite this valiant beginning, co-design has not evolved as a central design process amongst architects working with people with diverse needs (Lozanovska, 2005).

Two problems have arisen from this slow uptake of co-design amongst architects. Firstly, co-design processes have become split between the professions and de-linked from the architectural design process. This means that projects may engage with a co-design process, but this does not directly influence the development of the building. Secondly, those developing co-design processes are not necessarily informed about the architectural processes integral to developing the project. A project with adults with intellectual disability highlights the chief co-design challenge of including end users in the process. Central to this challenge are the difficulties around communication, especially due to the range and diversity of capacities of people with intellectual disability. To this end various forms of communication can be drawn upon. Some that have been used in the co-design repertoire – including visualisation, and playful modelling – may need adaptation or new methods developed for this particular group, like the scripting of scenarios.

A huge gap in the literature and research is how the co-design process and its outcomes are transferred over to the development of the architectural project. Displacing the co-design process from the architectural process creates a new problem. It is unclear who will collate the design ideas and how, which further undermines the architects' capacities to

synthesise ideas into spatial parameters and a deeper interpretation of the outcomes. Additionally, the housing issue may vary depending on the current situation and the aspirational options of the person and/or the family of the person with intellectual disability. Would the housing required be individual and sited on private property, or is the challenge to develop innovative models of housing that can have the attributes of 'home' and yet be organised on site as spatially collective models? New models for housing for people with intellectual disabilities require research and practices of co-design that integrates the architectural process (Gaudion et al., 2015) and development to work through the challenges towards actual manifestation of homes.

2 Method

The integrative review framework described by Whittemore and Knafl (2005) was used because it allows for the inclusion of diverse data sources in order to provide a comprehensive and holistic understanding of the topic being researched.

Literature Search.

From August to October 2018, databases were selected to be searched for compressive coverage across the disciplines of architecture, design, medical science, nursing, and allied health and social sciences: Avery Index, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Medline (all via EBSCOhost), Cochrane Library, Scopus, Web of Science, and Google Scholar. Additionally, two journals were hand searched: (1) Codesign: International Journal of CoCreation in Design and the Arts, and (2) the Journal of Architectural Education.

Combinations of key terms were used to search and identify the relevant articles, and included:

- "hous*" OR "home" OR "supported living" OR "assisted living"..

AND.

- "codesign" OR "co-design" OR "coproduction" OR "co-production" OR "cocreation" OR "co-creation" OR "participatory design" OR "co-design process" OR "codesign process"..

AND.

- "intellectual disab*" OR "developmental disab*" OR "cognitive disab*" OR "learning disab*" OR "learning diffic*" OR "mental retardation"..

2.1 Inclusion criteria and selection process

Studies were included if they:

- included people with an intellectual disability;

- explored the process of co-design;
- were published between 2000 and September 2018 (including online ahead of print); and were.
- written in English.

Studies were excluded if they:

- focused only on children;
- were conference abstracts; and.
- did not include co-design process.

Initially, one of the inclusion criteria was a focus on housing. However, when it became apparent that there were extremely few articles with a focus on all three key areas of interest – co-design, adults with an intellectual disability, and housing design – inclusion criteria were broadened. When reviewing those articles found in the initial searches, articles were included if two of the areas of interest were discussed. Articles with an emphasis on service provision within the home without looking at the design of the physical structure of the home were also included.

Next, additional references were identified by searching the reference lists and citations of relevant papers. "Grey literature" such as project reports found through Internet searching was also included.

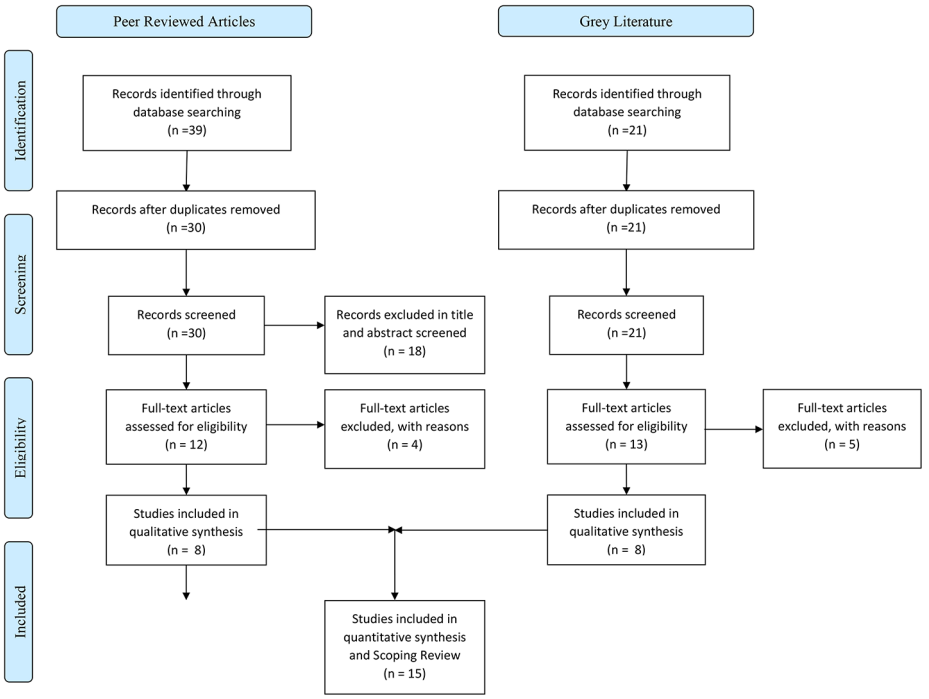

Fig. 1 Study flow diagram

Table 1 Summary of studies

Article	Type	Population	Co-design process	Outcomes
Lowe et al., (2014) #1	Co-design project description	Adults with autism	Literature review, design ethnography, participatory observation, co-design workshops, interviews, visual probes & mapping tools, involvement of family & staff, assessment tools	Distilled information to 4 design themes: 1. growth & development 2. triggers 3. robustness 4. support tools Observed & reported positive changes in staff & participants with autism
Herriott (2015) #2	Co-design project description	Adults with ID with complex communication needs	Proxies, co-design workshops, interviews with family & staff, ethnographic processes (e.g. observations & gathering quantitative data from proxies), use of prototypes	Increased interaction with partners of participants Change in staff behaviour Continual evaluation through triangulation.
Lazar et al. (20) #3	Co-design project description (technology)	People with Down syndrome	Literature review, focus groups, design workshops with participants & caregivers, use of prototypes, inclusion of experts in design team (dietician)	Conceptual design of app completed
Papoulias (20) #4	Investigation of use of visual participatory methods	People with communication impairments	Visual participatory methods (photographs & video as data), photo elicitation, photovoice	While visual participatory methods have merits, need to determine kinds of expertise needed to attend to such engagements & how to work collectively to facilitate methods & ethics that are able to receive—& do justice to—what can remain unsayable.
Francis (2009) #5	investigation of the potential to develop guidelines for co-design techniques for people with autism	People with autism	Video recording & review, self-photography, think aloud (described by Atwood (1998), role play	Guidelines developed
Pirinen, & Verna (2016) #6	Co-design project description	People with ID	Empathic tools, empathic process (unspecified), observation, visual elicitation methods (unspecified), interviews with parents & staff, observation of participants undertaking daily activities.	Guiding themes for co-design 3 concepts developed
Brereton et al. (2015) #7	Co-design project descriptions with emphasis on key process (technology)	People with cognitive & sensory impairments	Literature review, collaborative-design, action research, ethnographically-inspired exploration of user experience, iteration proxies, development of prototypes, observation of participants	Designs used in different create ways through iteration & appropriation "Design after design" process.

Table 1 (continued)

Article	Type	Population	Co-design process	Outcomes
Gaudion et al. (20) #8	Co-design project description	Adults with autism	Sensory activities, mirroring interests, making & doing activities, participatory observation, shadowing, mapping interests, mapping sensory preferences, artworks-I-like booklets, online survey artwork selection activity, artwork evaluation, storyboarding, co-creation workshops, ready-steady-make, interviews	Evaluating design process. Prioritisation of designer's empathic understanding. Design outcomes – (1) created a new garden, (2) adapted an existing object (a bubble-blowing vacuum cleaner), & (3) added artworks into the home
Br& (2010) #9	Co-design project description	Adults with autism	Literature review, interviews, observation, development of expert reference group	Design themes & guidelines
Myerson & Lee (2011) #10	Opinion piece with case studies	Not specified (inclusive of people with disability)	3 case studies to highlight co-design methods	Designing for: • consumer focus groups, observations, interviews, prototype building/testing, • 'rapid design ethnography', • Creating 'personas' working with 'extreme users' • use of 'empathy tools' Designing with: • user forums & workshops, making of 'pseudodocumentaries', & 'cultural probes'
Dawe (2007) #11	Co-design project description	People with cognitive disabilities	Ethnographic methods: interviews, participatory design activities, technology probes, observation, diary study	Implications outlined for: • future design outlined • technology interface • socio-technical environment • design methodology
Graham (2017) #12	Co-design project description	People with a learning disability or physical disabilities	Client design panel, involvement of family & friends (process not described), involvement of local government & local community groups	Lists: • design features & reports increased independence of residents • learnings regarding design process
Huddle (2016) #13	Project to increase co-design in service provision	People with disability	Scoping of current knowledge & issues in disability sector, co-design workshops for service providers, follow up with service providers, reflection on learnings	Suggestions to consider when introducing co-design to service provision in the disability sector.
Fudge Schormans, Wilton & Marquis, (2018) #14	Co-research project	Self-advocates with ID	Individual interviews, city research journeys, GIS mapping, photography, drama-based workshops, documentary film-making as a tool for dissemination, self-advocacy & activism	New relationship Development of new skills People with ID disseminating results through presentations & documentary Reflection upon involving people with ID in co-research

Table 1 (continued)

Article	Type	Population	Co-design process	Outcomes
Robertson et al. (2008) #15	Co-research project	People with ID	Observations (all researchers made observations of a variety of homes, & the behaviour of the co-researcher with a disability was observed & reflected upon), interviews with staff working in the homes.	Guidelines / questions to evaluate homeliness of a home for people with an intellectual disability. Reflections upon involving people with ID in co-research.
Karban et al. (2013) #16	Co-research project	Adults with mental health or learning disabilities.	social inclusion questionnaire, one-to-one qualitative interviews with residents, family, support staff, service managers & senior managers, small groups of participants used photography, art & creative writing.	Widespread satisfaction with new homes. More time needed for research & transition by both residents & staff Increased independence of residents.

The database searches yielded 39 results, 9 of which were duplicates. The 30 articles were reviewed with relation to the study's inclusion / exclusion criteria, leaving 8 articles for analysis. Iterative searches of reference lists of included articles, author searches and internet searches for "grey literature" yielded a further 8 references, making a total of 16 for review (Fig. 1), from 15 different sources (journals or organisations).

2.2 Data evaluation

As the current integrative review used a diverse sampling frame across empirical, non-empirical, and theoretical sources, an approach to evaluating quality, as described in Whitemore and Knafl (2005), was applied. The authenticity, methodological quality, informational value, and representativeness of the data sources was evaluated by the authors using a two-point scale of low or high for each feature.

2.3 Data Analysis

Information was extracted on population involved, co-design process and outcomes as well as any reference to the concept of co-design and key discussion points. Data display matrices were developed to show the coded data from each report by category and were iteratively compared.

3 Results

The following is a summary of the results in terms of article type, population included, co-design processes and outcomes (see Table 1 summary).

3.1 Article type

Nine of the 16 papers reported on co-design projects, three on co-research projects, two reviewed specific co-design processes, one was a perspective on co-design, and one was a report of a project to facilitate others to implement co-design projects.

Ten were from peer reviewed journals, four were project reports (two on organisation websites, one in a newsletter, and one online), one was a PhD dissertation, and one was a conference presentation.

3.2 Population

All articles included or were relevant to people with an intellectual disability, but only four had intellectual disability alone as the sole population involved in the project. Four focused on people with autism, one focused on people with Down syndrome, six focused on people with an intellectual disability as well as people with other disabilities, and one focused on co-designing with people generally including people with disabilities.

3.3 Co-design processes

3.3.1 Literature Review

Five of the articles reported undertaking a literature review to either gain a greater understanding of the population being designed with (see for example (Lowe et al., 2014)), or to review any previous similar design projects with this population (see for example (Lazar et al., 2018). While all papers incorporate relevant literature only five had clearly undertaken a thorough review of the literature to support the design process.

3.3.2 Involvement of family and / or staff

All articles that reported on a co-design project included the perspectives of family members and /or staff in some way including ‘inclusion’ in co-design workshops with and without participants (e.g. Lazar et al., 2018; Lowe et al., 2014), inclusion in survey (e.g. (Francis et al., 2009)), in interaction with participants for designers to observe (e.g. (Herriott, 2015; Lowe et al., 2014)), or as proxies which will be discussed separately further below.

3.3.3 Inclusion of designer

All but one of the co-design projects reviewed included one or multiple contributors from a design background.

3.3.4 Inclusion of additional expertise

Three projects included professionals with specific knowledge and experience relevant to the project. Lazar et al. (2018) included input from a dietician, Francis et al. (2009) included input from psychologists and other health professionals with a knowledge of autism, and

Brand and Gheerawo (2010) included a researcher in the project reference group with a knowledge of autism.

3.3.5 Use of proxies

Two studies in particular, Brereton et al. (2015) and Herriott (2015) used family members as proxies as a key element of the co-design process. Other studies, while not using the term 'proxy', sought perspectives of family and staff to inform the design as discussed above.

3.3.6 Interviews

Nine projects reported using one-to-one interviews with people with disabilities or their family and / or support staff. It is not always clear whether these were conducted in the home or somewhere else. It is also not always clear whether participants alone, participants together with family members, or family members and / or staff alone were interviewed.

3.3.7 Ethnographic methods

Any project that involved observation and interaction with residents within their home was classified as using 'ethnographic methods'. Seven of the articles reviewed employed ethnographic methods, though only three explicitly stated this as the method used. Myerson and Lee (2011) also list 'rapid design ethnography' as a method of 'designing for all'. Dawe (2007), and Herriott (2015) were the only authors to employ additional quantitative components to recording ethnographic data.

3.3.8 Visual participatory methods

Visual participatory methods were used or reviewed in six of the articles, this overarching method encapsulates multiple methods including response to photographs, taking and reviewing photographs and videos, drawing, and writing.

3.3.9 Use of formal assessment tools

Only Lowe et al. (2014) reported the use of specific assessment tools to assist in gaining a deeper knowledge of the participants in the design process.

3.3.10 10 use of prototypes

Four of the studies used prototypes, three for technologies (Brereton et al., 2015; Dawe, 2007; Lazar et al., 2018) and one for facilitators of participant interaction (Herriott, 2015).

Empathy tools.

Three projects explicitly reported the use of empathy tools in the co-design process.

3.4 Outcomes of co-design

3.4.1 Guidelines, design themes and suggestions

Ten of the articles included co-design guidelines, themes or key suggestions for co-design with people with an intellectual disability.

3.4.2 Change in perspective and behaviour of participants and support people

Five articles noted positive change in behaviour of the participants with an intellectual disability and four articles noted positive changes in perspectives and behaviours of support people, with seven articles reporting a positive change in one group, or the other, or both.

3.4.3 Specific design features or concept designs

Of the ten articles reviewed that outlined co-design projects, three described specific design features resulting from the project, and three resulted in conceptual designs.

Most reports tended to focus on the design process rather than design outcomes.

4 Discussion

Here, findings are synthesised under eight themes which, following a discussion of the terminology, are grouped into two categories:

1. Methods of including people with an intellectual disability in the co-design of their housing: (1) co-design process, (2) communication challenges, (3) involvement of support people, (4) use of prototypes, and (5) the inclusion of a professional designer.

2. Outcomes reported from including people with an intellectual disability in the co-design of their housing: (1) managing competing demands, (2) research evaluation, and (3) research outcomes.

4.1 Terminology

Perhaps due to the challenges of genuinely co-designing *with* people with intellectual disabilities, a variety of terms are used to describe the collective processes used in the projects reported. These include ‘person centred design led approach’ (Lowe et al., 2014), participatory approach (Gaudion et al., 2015) and ‘social co-design’ (Herriott, 2015). Co-design processes used in other settings – for example ‘experience-based co-design’ used in health care settings – and central to Papoulias’s (2018) review of visual participatory methods, are also relevant to co-design of housing.

There is also considerable overlap in terminology when describing co-design processes. For example, Dawe (2007) uses the term ‘meta-design’, while Brereton et al. (2015) use the term ‘design after design’ to describe the need for the design process to be iterative and for use of the design to evolve through the process of using it. Similarly, some authors explicitly state they have used ‘ethnographic methods’ (e.g. Dawe, 2007; Herriott, 2015), while others describe co-design methods consistent with ethnographic methods such as interview and

observation within the home e.g. (Gaudion et al., 2015; Robertson, Frawley, & Bigby, 2008) without explicitly using the term 'ethnographic methods'.

4.2 Methods of inclusion

4.2.1 Co-design process

A majority of the co-design processes described fall under Myerson and Lee's (2011) category of tools for designing *for*, as opposed to designing *with* (co-design), e.g. interviews, observation, ethnographic methods, and cultural probes. Certainly, Gaudion et al. (2015) acknowledge that their project is not "co-design in the traditional sense," yet given the complexities and challenges inherent in co-designing with people with intellectual disabilities outlined earlier, it is evident that new frameworks and benchmarks are required for co-design with this group.

4.2.2 Communication challenges

Communication can be a challenge for many people with an intellectual disability and is an area that necessitates adaptations be made to co-design processes to make them inclusive, which vary from other co-design processes where communication is not an issue. Also, the nature of the co-design process or processes will vary depending on the communication capacity of the individual and how well the communication environment is adapted to enable people with an intellectual disability to be involved in the co-design process. In some instances, proxies may need to be used to interpret and provide input for people with an intellectual disability.

Not mentioned in any of the articles is a process around how to decide when and why to use proxies.

Visual participatory methods, such as photo-elicitation and PhotoVoice, are both useful and necessary as a means of sharing and eliciting information with people with intellectual disabilities. Francis et al. (2009) and Papoulias (2018) examine in detail the benefits and challenges of using visual participatory methods. Papoulias (2018) argues for visual approaches to be robust enough to sit alongside more dominant, orthodox ways of eliciting information. To do this it is suggested that attention to training is required when employing and analysing visual information, and reflection is needed upon how very different types of data are brought together in multi-disciplinary contexts (Papoulias, 2018). Further work is required that examines the efficacy of using visual participatory methods. Moreover, methods used need to be explicitly stated when documenting the co-design process.

Also related to communication challenges is the use of empathy tools. While it was only explicitly stated that empathy tools were used in three of the projects, it is likely that most others used an empathic approach to greater or lesser extents, due to the need to better understand the perspective of someone who may not be able to express this verbally. Only Sutton-Long et al. (2016) document the empathy tools used (*Listening Channels* and *Empathy/Experience Maps*), whilst other reviewed studies did not clearly explain this aspect of the process. None evaluated the effectiveness or outcomes of using empathy tools in any formal way, however Gaudion et al. (2015, p. 64) states "priority should be placed upon the

designer's empathic understanding, as this proved to be the most important design method of all."

4.2.3 Involvement of support people

Every paper that involved projects with people with an intellectual disability involved family members, support staff, service providers, and in some instances service managers. Several authors note the importance of including family and service providers in the co-design process e.g. (Dawe, 2007; Graham & Leesam, 2017). People who know the person with a disability well are uniquely placed to provide information about the individual's preferences and abilities having seen them operate in many contexts over many years, and can provide information designers would not otherwise have access to.

All the studies reviewed clearly recognised the limitations of this being the sole source of information (that their perspective is not that of the participant), as all projects used additional co-design processes to achieve the end outcome.

It is worth noting that involving people who support the person with an intellectual disability in the co-design process not only informed the design, but in some instances positively changed perspectives and behaviours of these support people (e.g. Brereton et al., 2015; Lowe et al., 2014). For instance, in the Lowe study of housing design, sensory preferences and garden design at a centre delivering outdoor learning (2014), support staff claimed increased understanding about the people they supported and greater motivation for and engagement in providing structured, people-centred activities.

4.2.4 Use of prototypes

While some of the projects reviewed used prototypes, it is important to note that most of these were for the development of technology – or in Herriott's (2015) study for interaction facilitators for the communication partner without a disability to use. In terms of prototypes and housing design, Lowe et al. (2014) note that it can be challenging for a person with cognitive difficulties to conceptualise a three-dimensional space from a two-dimensional plan. Scaled down three-dimensional architecture models may also pose similar challenges.

None of the studies focusing specifically on housing design used prototypes, so it remains unclear whether this is a viable design process for use with people with an intellectual disability for housing design. This literature review, however, does reveal the usefulness of prototypes for service development and technologies used within the home (see Brereton et al., 2015; Herriott, 2015; Lazar et al., 2018).

4.2.5 Inclusion of a professional designer

All but one of the co-design projects reviewed included a member of the design professions in the co-design process. Yet there is value in reflecting on the project that did not involve a designer, but rather taught disability service staff about the process of co-design with the aim of these staff co-designing services with service users with disabilities (see Sutton-Long et al., 2016). The service providers, whom undertook training in co-design, experienced multiple challenges in implementing co-design processes in their workplace. These challenges included: needing more time and focus; feeling they lacked authority to try new

processes; and the need for support and connection with others undertaking similar work or with a deeper knowledge of co-design processes. This study also highlighted that because participants engage differently with different co-design processes, and because those new to using co-design will have different preferences regarding co-design tools, then so it is valuable to provide a range of tools to suit different people. On balance, it may be more cost effective, and designs may be more sustainable, if a professional designer is involved in the process. However, this requires further investigation.

4.3 Outcomes

4.3.1 Managing competing demands

The studies reviewed highlighted three particular challenges in managing competing demands when co-designing with adults with an intellectual disability.

1. Managing the needs for functionality and accessibility (Robertson et al., 2008), and durability (Lowe et al., 2014) with the need to create a homely, welcoming atmosphere. Robertson et al. (2008, p. 24) state for example, that "huge passages, huge bathrooms, huge toilets and the furniture, make it look less homely". Lowe et al. (2014) also make note of being cognizant of erring on the side of designing environments with a domestic rather than an institutional functionality.

2. Recognising that in many instances the home of a person with an intellectual disability is also the workplace for staff who support the person with a disability and the need to manage potentially conflicting needs arising from this duality. Robertson et al. (2008, p. iii) state that "houses are also a workplace for staff and have important safety features included in the design which can work against a homely feel". Herriott (2015) also noted the rhythms and routines observed were more like that of a workplace than a home.

3. Acknowledging the additional time for people with intellectual disabilities to engage with new and unfamiliar processes and to transition to a new home, while projects may have timelines and budgets that limit these time frames. Karban et al. (2013) and Fudge Schormans et al. (2018), note the participants in their studies would have preferred more time allowed for the processes.

4.3.2 Research evaluation

How co-design projects are evaluated remains complex, challenging and largely unexplored. Few of the studies reviewed, incorporated an evaluation of the processes used or outcomes achieved. The articles utilising co-research processes to investigate housing for people with an intellectual disability provide the most useful information regarding tools and processes for evaluating outcomes of co-designed housing. The tools used by Robertson et al. (2008), and Karban et al. (2013) were:

- a collaborative research approach where research was undertaken by a co-researcher with an intellectual disability with academic researchers (Robertson, et al., 2008);
- ethnographic processes;
- development of questions to evaluate homeliness;
- survey;
- visual participatory methods;

• one-to-one interviews; and.
• involvement of support people.

From this list alone, generated by only two studies, it is clear that there is value, if not necessity, in using mixed methods in evaluating co-designed housing with people with an intellectual disability and involving people with an intellectual disability in research and evaluation. As discussed earlier, when examining co-design processes, the tools used to evaluate outcomes of co-designed housing need to be matched appropriately to the people involved in the co-design process. Further to these particular problems are the problems of framework and how various professions and disciplines engage with the processes of co-design, which of these are aimed towards more relevant housing for people with an intellectual disability. Here the interface between the 'house' as site of work (for staff) and as home (for people with intellectual disability) uncovers one problem, but also points to potential innovations. For this to proceed, the collaboration of architects is highlighted.

Dawe (2007, p. 161) raises the important point that "in addition to representing users' functional goals, we need to be in pursuit of their 'hot goals' that are emotionally and socially based". The only project that resulted from initiation by a person with an intellectual disability was that described by Fudge Schormans et al. (2018), which was the continuation of work that had already commenced with this group of participants.

Until there is a sufficient shift in power, and people with intellectual disabilities are increasingly the initiators, clients or the prime stakeholders of co-design projects, it is important that architects and project leaders create and use tools and processes for tuning in to participants 'hot goals', once the project is initiated, and that outcomes of these goals are evaluated.

4.3.3 Research Outcomes

Lowe et al. (2014, p. 71) state that the outcomes of their co-design project "are purely anecdotal and have not been substantiated by robust research." Indeed, this is true of all the projects reviewed. Despite the need for more rigorous and robust evaluation of project outcomes, some key themes emerge with relation to the outcomes of the papers reviewed.

Guidelines, design themes and suggestions.

The most common outcome of the articles reviewed were a set of guidelines, guiding themes, or suggestions. These varied significantly in detail, thoroughness and focus: ranging from Brand and Gheerawo (2010) who provide detailed guidelines for consideration for each room of the home, through to Graham and Leesam (2017) who note key learnings from their project. Most authors note the individual and unique natures of co-design projects and offer guiding principles rather than prescriptive processes.

There would be value in applying the guidelines on specific co-design projects to evaluate their usefulness.

Change in perspectives and behaviour of participants and support people.

While not an aim of the project, Brereton et al. (2015) found through the co-design process with people with intellectual disabilities, the perceptions and attitudes of both family members and staff changed towards the person with a disability.

Fudge Schormans et al. (2018) noted an increase in participation, contribution and control with each step of the project and that the collaborative processes employed created an environment to try new things and develop new skills. Similarly, Lowe et al. (2014)

observed attitude change in support staff and reduced anxiety and increased concentration, social interaction and communication of all participants when involved in the design activities. Further investigation is required to determine whether these changes persist beyond the period of the project, though it is at least promising that the co-design processes themselves foster opportunities for these improvements.

Design features and conceptual models.

Interestingly only 6 of the 16 papers reviewed describe specific design features of end products or conceptual models, with the majority of papers emphasizing the process rather than the outcome. Again, this gap highlights the need for rigorous evaluation methods to ascertain participant satisfaction with, and functionality of the end product, as well as efficacy of the co-design process. This presents a striking contrast to the advanced policy on housing for people with physical disability. Here, a comparative analysis between the findings in this paper and those of the housing design guidelines for people with physical disability can provide the next stage of this research.

5 Conclusion & knowledge gaps

This review aimed to explore existing literature on co-designing housing with adults with intellectual disabilities, with focus on co-design research processes and research outcomes. The primary limitation of the reviewed articles was that none included the three areas linked in the research question: (1) co-design processes, (2) adults with an intellectual disability, and (3) housing. Most articles addressed either narrower populations, broader populations, a particular aspect of housing, or interactions within the house rather than the design of the house itself.

The following gaps in knowledge have been identified:

• General lack of literature specifically on co-designing with people with an intellectual disability;

• No specific literature encapsulating co-design process, adults with an intellectual disability, and housing;

• No specific frameworks or benchmarks that relate to co-design with people with an intellectual disability;

• Processes relating to the use of proxies are not explored (the when and why);

• Limited focus on design outcomes;

• Diverse communication needs of adults with intellectual disabilities necessitates further research on using a variety of approaches within the one project.

• Lack of evaluation of the design outcomes of co-design processes; and.

• As noted by Walker & Hutchinson (2018), there is a lack of research directed toward assisting parents plan for the future needs of their ageing offspring. Research should be directed toward evaluating the avenues available to parents and guardians to plan for the future needs of people with an intellectual disability in their care.

The United Nations Convention on the Rights of Persons with Disabilities strongly articulates the right of people with disabilities to be at the centre of decisions that impact on their lives (United Nations, 2007). The Convention, in Article 19 applies this right to decisions about housing and support, focussing in particular on the right to live in the community, where and with whom one chooses. As the current Australian Royal Commission into vio-

lence, abuse, neglect and exploitation of people with disability has heard, this right is not being upheld for all people with disability in Australia, and in particular for those who are living in the 'group home' model (Australian Royal Commission, 2019; RC, 2019). The evidence given at this Royal Commission makes clear that people with disabilities are rarely consulted about any aspects of their 'homes,' and the research confirms that there has been little done to address the lack of involvement people with intellectual disabilities are having in co-designing these houses, their homes. There are clearly a range of issues that need to be addressed to bring people with intellectual disabilities more actively into all aspects of 'choice' in relation to their housing. The findings also uncover embedded and ongoing problems related to the limited understanding of the benefits of housing design processes and outcomes.

Co-design is one aspect that offers an opportunity for this participation in at least the design of the building. While co-design of services and technologies with people with intellectual disabilities is becoming increasingly common, co-design of the housing and making of home lags behind the technological advances. Co-design as an approach does not tend towards immediate outcomes but requires processes in which the time taken for engagement can itself have beneficial effects. Considerably more work is required to explore and evaluate co-design processes in the design of housing for adults with intellectual disabilities, in order to attain the cultural shift that this is an effective use of time, as it will alleviate the circulation of the problems of housing for people with an intellectual disability. Housing design guidelines for people with physical disability evolved over years of dedicated research. While the findings have shown these cannot be easily adapted for people with intellectual disability, these guidelines will need to be revised when considering translation to people with intellectual disabilities who also may experience physical disabilities. The aims and tools required for these processes, as well as how the outcomes of these processes are evaluated are important if we are to comply with the rights in The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and to uphold the rights of people with intellectual disabilities to live in the community in 'their homes'.

If co-design of housing with people with intellectual disabilities remains a niche approach, the transformational shift needed and reported in some of this literature to the way people think and enact design together will remain an aspiration and a dim reflection of the self-advocacy dictum, 'Nothing about us without us'.

Acknowledgements This work was funded by the Consumer Policy Research Centre (Australia).

Funding Open Access funding enabled and organized by CAUL and its Member Institutions.

References

Australian Royal Commission (2019). Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from https://disability.royalcommission.gov.au

Bertelli, M., Salvador-Carulla, L., Lassi, S., Zappella, M., Ceccotto, R., Palterer, D., & Rossi Prodi, P. (2013). Quality of life and living arrangements for people with intellectual disability. *Advances in Mental Health and Intellectual Disabilities*, 7(4), 220–231

Bigby, C. (2010). A five-country comparative review of accommodation support policies for older people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 3–15

Blaut, J. M., Stea, D., Spencer, C., & Blades, M. (2003). Mapping as a cultural and cognitive universal. *Annals of the Association of American Geographers*, 93(1), 165–185

Brand, A., & Gheerawo, R. (2010). *Living in the community: Housing design for adults with autism*. London: Helen Hamlyn Centre

Brereton, M., Sitbon, L., Abdullah, M. H. L., Vanderberg, M., & Koplick, S. (2015). Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign*, 11(1), 4–20. doi:https://doi.org/10.1080/15710882.2015.1009471

Dawe, M. (2007). *Reflective design-in-use: co-designing an assistive remote communication system with individuals with cognitive disabilities and their families*. Citeseer

Degener, T. (2016). Disability in a human rights context. *Laws*, 5(3), 35

Fathy, H. (1969). *Architecture for the poor: an experiment in rural Egypt*. University of Chicago press

Francis, P., Balbo, S., & Firth, L. (2009). Towards co-design with users who have autism spectrum disorders. *Universal Access in the Information Society*, 8(3), 123–135

Fudge Schormans, A., Wilton, R., & Marquis, N. (2018). Building collaboration in the co-production of knowledge with people with intellectual disabilities about their everyday use of city space. *Area*. Retrieved from https://doi.org/10.1111/area.12492

Gaudion, K., Hall, A., Myerson, J., & Pellicano, L. (2015). A designer's approach: how can autistic adults with learning disabilities be involved in the design process? *CoDesign, 11*(1), 49–69

Graham, R., & Leesam, V. (2017). *A place of my own. Co-designing independent living for people with a learning or physical disability*. Retrieved from London

Herriott, R. (2015). The use of proxies: lessons of social co-design for inclusive design for people with cognitive disabilities. *Journal of accessibility and design for all*, 5(2), 100–124

Karban, K., Paley, C., & Willcock, K. (2013). Towards support: evaluating a move to independent living. *Housing, Care & Support*, 16(2), 85–94. doi:https://doi.org/10.1108/HCS-02-2013-0001

Lazar, J., Woglom, C., Chung, J., Schwartz, A., Hsieh, Y. G., Moore, R., & Skotko, B. (2018). Co-Design Process of a Smart Phone App to Help People With Down Syndrome Manage Their Nutritional Habits. *Journal of Usability Studies*, 13(2), 73–93

Lowe, C., Gaudion, K., McGinley, C., & Kew, A. (2014). Designing living environments with adults with autism. *Tizard Learning Disability Review*, 19(2), 63–72. doi:https://doi.org/10.1108/TLDR-01-2013-0002

Lozanovska, M. (2005). *Drawing and the subjectivity of the 'other'*,. Paper presented at the Association of Architecture Schools Australia (AASA) Conference 2005: Drawing Together: Convergent practices in architectural education, Brisbane

Mackie, P. K. (2012). Housing pathways of disabled young people: Evidence for policy and practice. *Housing Studies*, 27(6), 805–821

Mercier, C., & Picard, S. (2011). Intellectual disability and homelessness. *Journal of Intellectual Disability Research, 55*(4), 441–449. Retrieved from https://onlinelibrary.wiley.com/doi/abs/https://doi.org/10.1111/j.1365-2788.2010.01366.x

Myerson, J., & Lee, Y. (2011). *Designing with the people, for the people and by the people*. Paper presented at the Design Activism and Social Change Conference, Barcelona

Papoulias, C. (2018). Showing the Unsayable: Participatory Visual Approaches and the Constitution of 'Patient Experience'in Healthcare Quality Improvement. *Health Care Analysis*, 26(2), 171–188

Pirinen, A., & Verma, I. (2016). Levels of inclusion: Design concepts for supporting the everday living of young persons with intellectual disabilities. *Design for all: Designing for public good*, 11, 98–123

Productivity-Commission. (2011). Disability care and support. *Productivity Commission Inquiry Report*. Canberra: Australian Government

RC (2019). *Group Homes Issues Paper*. Retrieved from Australia: https://disability.royalcommission.gov.au/publications/Documents/issues-paper-group-homes.pdf

Robertson, A., Frawley, P., & Bigby, C. (2008). *Making Life Good in the Community: When is a house a home Looking at how homely community houses are for people with an intellectual disability who have moved out of an institution*. Retrieved from Melbourne

Studer, R. G., & Stea, D. (1966). Architectural programming, environmental design, and human behavior. *Journal of Social Issues*, 22(4), 127–136

Sutton-Long, C., Skovaagaard, K., Howards, Z., & Tassone, V. (2016). *Co-design for community inclusion*. Retrieved from

Turner, J. F., & Fichter, R. (1972). *Freedom to build: dweller control of the housing process*. Macmillan

United Nations (2007). Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly. In (61ed.)

Uzzell, D. (2008). People-environment relationships in a digital world. *Journal of Architectural and Planning Research*, 25(2), 94

Walker, R., & Hutchinson, C. (2018). Planning for the future among older parents of adult offspring with intellectual disability living at home and in the community: A systematic review of qualitative studies. *Journal of Intellectual & Developmental Disability*, 43(4), 453–462

Whitemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of advanced nursing*, 52(5), 546–553

Wiesel, I., Laragy, C., Gendera, S., Fisher, K. R., Jenkinson, S., Hill, T., & Bridge, C. (2015). Moving to my home: housing aspirations, transitions and outcomes of people with disability.AHURI Final Report, *246*

Zeeman, H., Wright, C. J., & Hellyer, T. (2016). Developing design guidelines for inclusive housing: a multi-stakeholder approach using a Delphi method. *Journal of Housing and the Built Environment*, 31(4), 761–772