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ORIGINAL ARTICLE

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The ontology and epistemology shaping our understanding of inclusion: A critical review of the research literature on disability and inclusion

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Abstract

People with disability continue to face barriers to substantive and meaningful inclusion in accommodation and community settings. The aim of this systematic review was to examine the characteristics of the literature on 'inclusion', 'integration', 'exclusion', and 'segregation' for people with disability in accommodation and community settings. This literature is important because it provides the evidence base that informs policy and practice. We identified 457 articles that primarily related to the experiences of people with intellectual disability and psycho-social disability. We found: (1) the volume of publications relating to the 'inclusion', 'integration', 'exclusion' and 'segregation' of people with disability in accommodation and community living settings has increased each year since 2006; (2) high-income western countries were overrepresented in research outputs; (3) most research has been undertaken in the health sciences; (4) only 30% of literature directly engaged with people with disability; (5) less than 50% of the publications we reviewed (223 out of 457 manuscripts) identified inclusion, integration, exclusion and segregation as their primary focus; (6) 'inclusion', 'integration', 'exclusion' and 'segregation' were predominantly used in the context of specific populations—psycho-social disability and intellectual disability; (7) there is great variation in the attention paid to the experiences of different communities of people with disability; and (8) the notable absence of current scholarly literature on the experiences and outcomes of people with disability living at home with parents and/or siblings. Each of these findings have important implications for the research agenda, policy, and practice.

Abbreviations: LGBTQI+, lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual; NGOs, non-government organisations; PRISMA, preferred reporting items for systematic reviews and meta-analyses; SES, socio economic status; UNCRPD, united nations convention on the rights of persons with disabilities.

KEYWORDS
community access, inclusion, intellectual disability, practice, segregation

INTRODUCTION

Deinstitutionalisation of disability care in Western countries from the 1960s to the early 2000s has led to an increase in the number of people with disability who live in and access mainstream communities. However, the increased number of people with disability living in small-scale housing in residential areas has not necessarily led to social inclusion. Similarly, deinstitutionalisation has not eliminated the segregation of people with disability from the community settings and accommodation options of their choosing (McPherson et al., 2018; Mushkatel et al., 2009; Wong & Stanhope, 2009). Notably, the understanding of inclusion in both policy and practice remains problematic and contested (Clifford-Simplican et al., 2015; Clifford-Simplican & Leader, 2015; Gooding et al., 2017).

For the academy, non-government organisations, and civil society to advance the conversation on inclusion for people with disability, there needs to be a unified understanding of the key debates and the limitations of the evidence. This systematic review seeks to assist in advancing the conversation by answering the question: what are the characteristics of the literature on 'inclusion', 'integration', 'exclusion', and 'segregation'; and how might these characteristics expand or constrain our understanding and realisation of the seemingly elusive concept of inclusion in these settings? We elected to use a systematic review methodology because, according to the Cochrane Handbook (2022), this method 'require[s] a thorough, objective and reproducible search of a range of sources to identify as many eligible studies as possible'.

DEFINING INCLUSION

Inclusion in community and residential settings is challenging to define (Smith & Caddick, 2015). At the macro level, it may be considered as physical access together with access to political, systemic, economic, and social structures (Drew et al., 2011; Harper et al., 2017; Nolan & Taylor, 2008). Community presence and valorisation of integration, involvement, and engagement (concepts primarily concerned with people's physical location) can and do lay the foundations for inclusion. However, on their own, these constructs do not equate to inclusion a priori. Rather, inclusion might be better characterised as having authentic interpersonal relationships and being part of a community in more than presence alone (Ngan et al., 2012; Nicholson & Cooper, 2013; Nitzan & Orkibi, 2021). However, the arguably communitarian view of inclusion with its emphasis on 'belonging' as evidenced by having relationships 'in the wider community' and participating in 'mainstream' (ableist-defined) activities has been criticised for failing to recognise and respect diversity (Clifford-Simplican & Leader, 2015).

However, while acknowledging these various debates, Article 3 of the United Nations Convention on the Rights of persons with Disabilities (UNCRPD) outlines the fundamental rights people with disability have to be included in society. Article 19 goes on to outline several facets of inclusion that must be met to achieve inclusion in residential settings (including the community where the residence is located). These are (1) the right for people to make choices about their lives (e.g., where they live and with whom they live), (2) their access to a range of supports; particularly those at home and in the community that prevent isolation or segregation and (3) having access to facilities, services, and opportunities ordinarily available to the general population (United Nations, 2006).

Bengt Nirje (1985, p. 67) described, 'a world where people are free to be themselves among others'. Furthermore, it has been proposed that 'inclusion is most evident where an individual is made welcome, where they feel welcome, where they know they belong and are safe and where their voice is heard and acted upon' (McVilly et al., 2022; p. 14). Here, it is also crucial to note that definitions of inclusion are intertwined with notions of safety and quality of life for people with disabilities. As such, the concepts of 'quality' and 'safety' were included in our review. The inclusion of these terms had a secondary function of ensuring that the articles retrieved included models of good practice.

Despite the UNCRPD outline of what inclusion means and subsequent ratification, inclusion of people with disability is still defined differently across intellectual paradigms, organisations, and individuals; this is a key barrier to the meaningful inclusion of people with disability in accommodation and community settings. Furthermore, concepts and indicators of inclusion are understood differently across various communities of experience, such as those who identify with having a physical disability, a sensory disability, a cognitive or intellectual disability, neurological diversity, impairments attributable to a psychiatric condition, or a psycho-social

TABLE 1 Accommodation and community living literature search terms.

Term 1: Disability related	Term 2: Accommodation related	Term 3: Leisure related	Term 4: Inclusion related	Term 5: Safeguarding related
Disab* (disabled, disability, disable); Impair* (impaired, impairment); Condition; Psychosocial; Mental; Chronic	Accommodation; supported living; independent living; assisted living; congregated living; Home; Housing; out-of-home care; foster care; Rent* (renter, rented); Tenant* (tenanted, tenants); Landlord; Dwelling; Hostel;	Day program; Leisure; Exercise; Gym; Beach; Community access; Community; Activit* (activity, activities)	Inclu* (include, included, inclusion); Exclu* (exclude, excluded, exclusion); Segretat* (segregation, segregated, segregate); Separat* (separate, separated); Integrat* (integration, integrated); Closed	safe*; protect*; violen*; abus*; neglect*; force*; brut*; rough;

disability (with reference to the Australian National Disability Insurance Scheme Act 2013, S24; Bigby, 2012; Mayo-Wilson et al., 2008; Raitakari et al., 2016).

It should also be noted that the definition of 'disability' and what it means to be a person with a disability (or indeed a disabled person) is contested. These nuances and complexities of what it means to have a disability and what it means to be included in the mainstream of society are present in civil society discourses, government policy, the positioning of the not-for-profit sector, and in academic literature. We also noted that there is significant overlap in the presentation of individuals with differing diagnoses of disability. In this study, 49% of articles were specifically identified people with psychosocial disability, 21% examined intellectual disability, and 17% were written regarding a mixed cohort. Only 8% examined physical disability. Therefore, the findings in this study are more likely to speak to research outcomes for people with intellectual or psycho-social disability.

METHODS

This review builds upon work previously undertaken as part of a larger systematic review commissioned by the Australian Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Lefebvre et al., 2022). The present study used a critical review methodology whereby researchers executed a systematic review according to 2018 PRISMA guidelines (Lefebvre et al., 2022). However, rather than simply synthesising and critiquing the findings in the literature, we sought to analyse and understand the ontological basis of the research agenda together with the epistemology shaping that research agenda and the subsequent findings.

Search and selection strategy

The following bibliographic databases, traversing both the health sciences and social sciences, were accessed: PubMed; EBSCOhost; EMBASE; ProQuest; PsycINFO; Cochrane Library; Scopus; and Web of Science. Each search included the terms and truncations outlined in Table 1 below.

In combination, these terms produced the following initial search string:

> (Disab* OR Impair* OR Illness OR Condition OR Psychosocial OR Mental OR Chronic) AND ((Accommodation OR "supported living" OR "independent living" OR "assisted living" OR "congregated living" OR Home OR Housing OR "out-of-home care" OR "foster care" OR Rent* OR Tenant* OR Landlord OR Dwelling OR Hostel) OR ("Day program" OR Leisure OR Exercise OR Gym OR Beach OR Community OR Activit*)) AND (Inclu* OR Exclu* OR Segretat* OR Separat* OR Integrat* OR Closed) AND (safe* OR protect* OR violen* OR abus* OR neglect* OR force* OR brut* OR rough)

Applying this search string to the databases produced 70 000+ articles for review. Accordingly, proximity limiters were added to the search string to increase the specificity of the search. Subsequently, the revised search string read:

> (Disab* OR Impair* OR Illness OR Condition OR Psychosocial OR Mental OR Chronic) NEAR/5 ((Accommodation OR "supported living" OR "independent living" OR "assisted living" OR "congregated living" OR Home OR Housing OR "out-of-home care" OR

TABLE 2 Inclusion and Exclusion Criteria.

Inclusion criteria	Exclusion criteria
• Published in English • Peer-reviewed • Published during or after 2006. The United Nations Convention on the Rights of Persons with Disabilities was created in 2006, signalling a paradigm shift in the rights of people with disability • Addresses one of the following: ○ How inclusion and segregation are understood in the literature ○ Safety outcomes of inclusive or segregated settings ○ Versions/examples/models of inclusive practice ○ Examines disability and inclusion/exclusion AND leisure OR accommodation ○ Benefits and limitations of segregated and inclusive settings ○ The requirements for successful inclusion in leisure and accommodation.	• Drug/clinical trial • Acute conditions (e.g., injuries lasting less than 3 months) • Dissertations • Conference proceedings • Hospital settings (except where people reside in psychiatric units for longer than 3 months, or as a venue for social connection groups) • person being held in a setting because of a justice-related order

> "foster care" OR Rent* OR Tenant* OR Landlord OR Dwelling OR Hostel) OR ("Day program" OR Leisure OR Exercise OR Gym OR Beach OR Community OR Activit*)) NEAR/5 (Inclu* OR Exclu* OR Segretat* OR Separat* OR Integrat* OR Closed) NEAR/15 (safe* OR protect* OR violen* OR abus* OR neglect* OR force* OR brut* OR rough)

This revised search string identified 10 802 articles for review. They were retrieved into a single Endnote file and uploaded into the software system, Covidence, where the research team was able to collaborate and screen the sources according to the agreed inclusion and exclusion criteria.

Data extraction and analysis

This review focused on contemporary literature from 2006 (the year in which the Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted at the United Nations) and covers international research for the provision of accommodation and support of community living for people with disability. However,

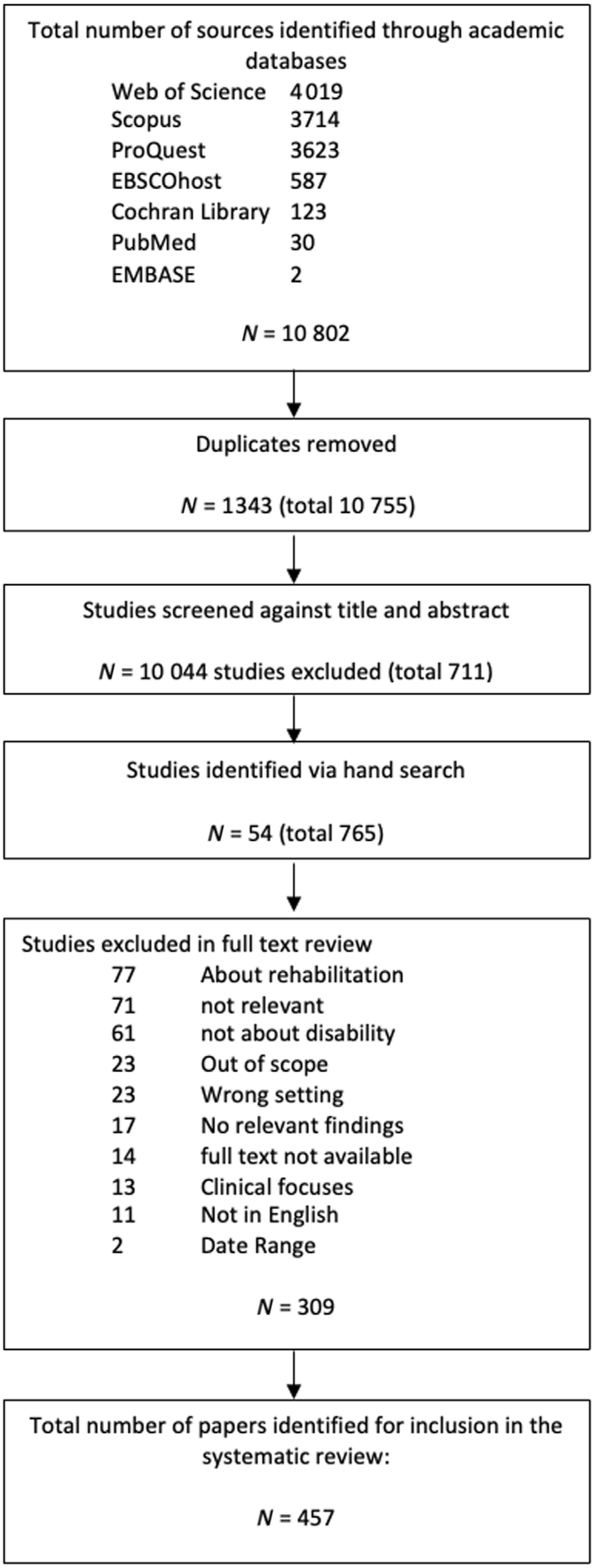

FIGURE 1 PRISMA.

countries vary in how they have understood disability, formulated policies, and organised their institutions, systems, and services. This includes the development of policy and provision of services with respect to accommodation and community living.

Using inclusion and exclusion criteria (see Table 2), the team performed a three-part screening process of the 10 802 articles. In the initial screen, the team reviewed the title and abstract of each of the articles, assessing their relevance. During this screening process, the research team identified and removed 10 027 articles deemed irrelevant according to the established search criteria. Some of the reasons articles were removed in this step were: the study was a clinical trial, the study was an animal trial, or the study was a conference abstract only.

The remaining 712 articles were subject to a second screening process. Each article was read in full text by multiple authors, ensuring its content met the inclusion criteria.

An additional 54 articles were identified via hand search, based predominantly on authors frequently cited in articles retrieved from the primary database searches. These were subject to the same full-text review to ensure they were exposed to the same rigour for inclusion as articles identified in the database search.

Subsequently, 309 articles were removed, leaving 457 to inform the analysis and synthesis for the accommodation and community living review. No formal quality assessment was performed beyond publication in a peer-reviewed journal as the purpose of this review was to explore how researchers understood the key concepts of ‘inclusion’, ‘integration’, ‘exclusion’, and ‘segregation’ rather than any critical appraisal of how they had operationalised these terms in their research. The inclusion and exclusion criteria are outlined in Table 2 below and the search process summarised in Figure 1. A full bibliography of the articles is provided as supplementary material.

Once the sources for review had been identified, the research team read each paper in full and extracted key data such as the discipline in which it was published, the key outcomes, and the recommendations into an excel spreadsheet. We also extracted data related to the following three sub-questions for this review: (1) How are the terms inclusion and segregation understood and applied in the literature, and among those with lived experience of disability?, (2) What are the safety and quality outcomes for people with disability (and, if relevant, peers and others) of settings (or communities) generally identified as inclusive or segregated?, and (3) What constitutes good inclusive practice, and are there models or examples of where these are working? The data that were extracted under these questions was based on author identification of relevant information as they read the full text. Then, the author team analysed the data presented in each column to determine the below findings. All calculations in the findings section are based on the designations applied to each study during the extraction process.

FINDINGS

Key characteristics of the research literature

The literature is characterised by eight notable features. Below, we outline these features and describe potential reasons for their formation.

Feature 1: Increase in volume of literature concerning outcomes in accommodation and community living

As indicated in Figure 2 and Table 3, since 2006 the volume of publications relating to the ‘inclusion’, ‘integration’, ‘exclusion’, and ‘segregation’ of people with disability in accommodation and community living settings has increased each year. Similarly, the proportion of publications relating to the ‘inclusion’, ‘integration’, ‘exclusion’, and ‘segregation’ of people with disability has been increasing relative to the larger literature concerning accommodation and community living.

One potential factor contributing to this increase over time is the impetus for such research following the adoption of the UNCRPD in 2006. In particular, article 19 of the UNCRPD (2006) states that States Parties must recognise the ‘equal right of all persons with disabilities to live in the community’ by ensuring they ‘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’.

It is plausible that following the UNCRPD's adoption in 2006, there has been an increase in research interest investigating the ‘inclusion’, ‘integration’, ‘exclusion’, and ‘segregation’ of people with disability in the community, including in relation to places of residence. Here too it could be that funding for such research has become more available given the obligation on states parties as signatories to foster research in relation to the implementation of the UNCRPD (e.g., Articles 4, 31, and 32). Furthermore, the creation and ratification of the UNCRPD is something in and of itself that has been deemed worthy of study, and as such has opened a new research opportunity for legal and disability scholars (see, e.g., Ina et al., 2017; Monsalve et al., 2020). However, this does

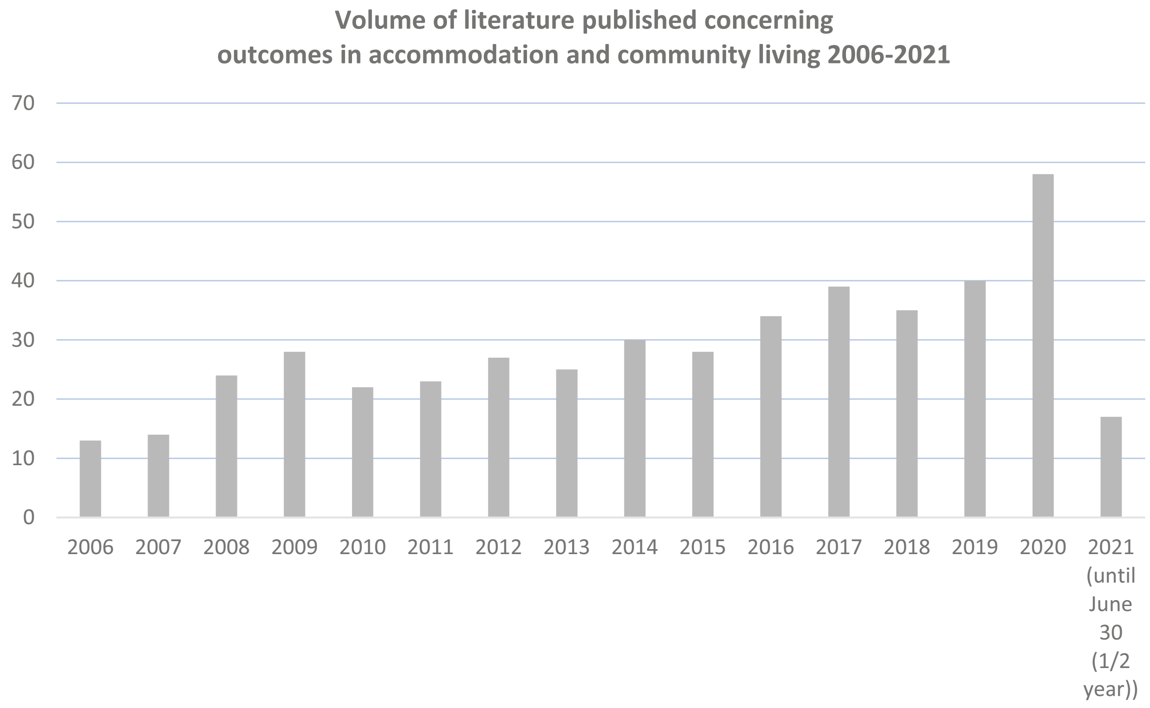

FIGURE 2 Volume of literature published from 2006 to 2021 concerning outcomes in accommodation and community living.

TABLE 3 Rates of publications retained for analysis by a 3-year period.

Publication period	Percentage
2006–2008	11.15%
2009–2011	15.97%
2012–2014	17.94%
2015–2017	22.10%
2018–2020	29.10%

not mean that all research fully embodies the tone or emphasis of the UNCRPD.

Feature 2: Overrepresentation of high-income countries in published literature in English

As indicated in Figure 3, high-income countries were overrepresented as the origins of research published in English. Some authors addressed this directly in their studies (Aguilar, 2017; Drew et al., 2011; Emerson & Spencer, 2015; Hanass-Hancock et al., 2017; Hanass-Hancock et al., 2020; Jones et al., 2021; Shields-Zeeman et al., 2020). Research was produced across all continents except Antarctica. Five percent of studies took place as a part of an intercontinental study; these studies were mostly collaborations between high-income countries (e.g., Australia, United Kingdom, United States, and Canada). The largest number of studies (134) were published in the United States. The next four largest numbers of studies came from Australia (79), the United Kingdom (36), Canada (36), and Sweden (15). One study from Africa was a collaboration between researchers in South Africa, Botswana, and Malawi, which concerned the role of community health workers in addressing stigma experienced by people with disability living in rural areas (Lorenzo et al., 2015).

The overrepresentation of high-income western nations in the data sample affects the generalisability of the overall findings from any synthesis of this literature. Westernised disability systems and philosophies of disability are likely to be overrepresented in the findings of this review. Blasko et al. (2022) identified in their meta-analysis that research in disability disproportionately concerns high-income countries, even though most people living with disability globally live in middle- and low-income countries. Jagoe et al. (2021) highlight that there are specific barriers to engaging people with disabilities in research in low-income countries, which prevents the success of global efforts to reduce poverty. While these systematic reviews help to identify gaps in existing knowledge, both only included studies in English, demonstrating the urgent need for multi-lingual research. Further primary research and literature reviews led by and undertaken in Asia, Africa, and South America would help to resolve the existing knowledge gap regarding the experiences of people with disability in low-income countries.

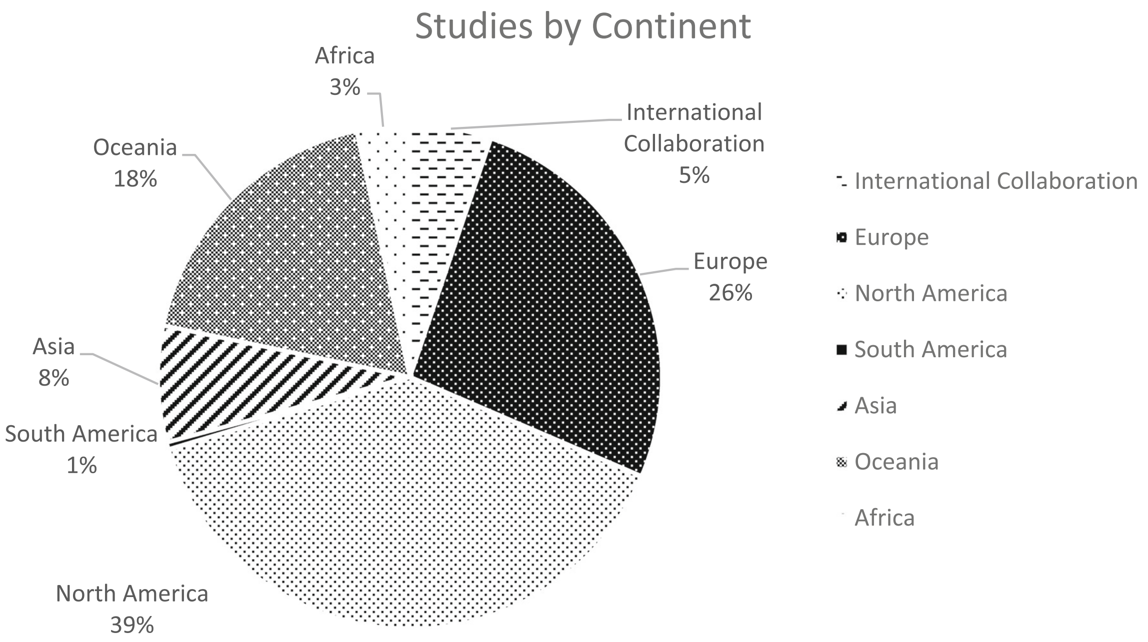

FIGURE 3 Studies published by continent.

TABLE 4 Areas in which disability has been the focus of scientific investigation.

Journal focus	Count (%)
Health sciences	345 (76%)
Health sciences (including nursing, public health, rehabilitation, occupational therapy, exercise, and sports science)	137 (30%)
Psychiatry, psychology, and community mental health	113 (25%)
Applied disability practice research	95 (21%)
Social sciences (including social and housing policy)	53 (12%)
Social work	14 (3%)
Law and justice (including violence)	12 (3%)
Other	33 (7%)

Feature 3: An emphasis on health science research

The third notable feature of the literature is that most research has been undertaken in the health sciences. As Table 4 below indicates, approximately 75% of the literature we identified has been published in health science journals, with around 30% of this published in public health and nursing journals; around 25% published in applied psychiatry, psychology, and community mental health journals; and approximately 21% published in applied disability practice research journals. The remaining 25% of the literature we retrieved falls largely within social science journals (around 12%), social work journals (3%), and law and justice journals (approximately 3%). A further 7% of the literature has been published in 'other' journals, such as tourism or public administration.

The emphasis on health science research in Table 4 reflects a broader pattern in funded and supported disability research. The choices academics make about where to publish their research are typically informed by the conventions of the disciplines within which they are employed. An academic situated within a public health department would be expected to publish most of their work in public health journals. An academic situated within a social work department would be expected to publish most of their work in leading social work journals. Indeed, making regular and recognisable research contributions to one's specific disciplinary field is core to academics being hired and promoted.

The distribution of disability-focused research publications in Table 4 suggests that most disability-focused academics currently employed within universities are commonly situated under the umbrella of 'health sciences' and consequently are likely to consider disability issues through the epistemological lens of the health sciences (see, e.g., Granerud & Severinsson, 2006; Gretschel et al., 2017; Hughes et al., 2015; Janardhana & Naidu, 2011; Moermans et al., 2018; Tatic et al., 2012; Truelle et al., 2010; Willemse-van Son et al., 2009).

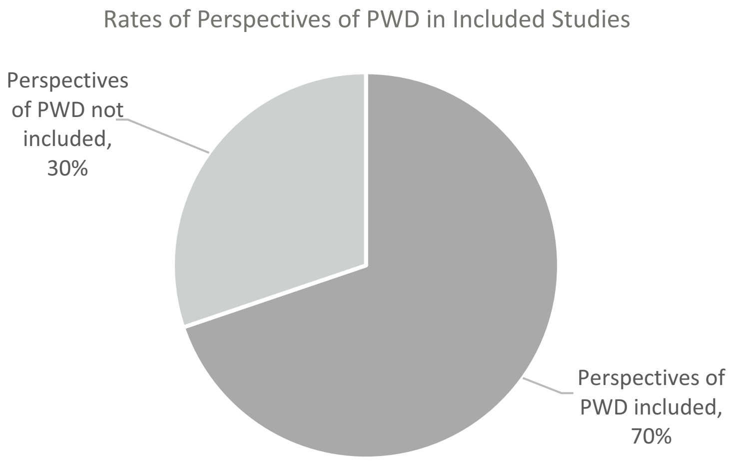

FIGURE 4 Proportion of studies directly engaging with people with disability.

Most of the databases searched were health-specific (PubMed, EBSCOhost, EMBASE, ProQuest, PsycINFO, and Cochrane Library), but we did search two multidisciplinary databases (Scopus and Web of Science). The volume of health versus multidisciplinary databases is unlikely to have contributed to this overrepresentation, particularly because Scopus and Web of Science had the highest number of studies identified for inclusion.

The health science emphasis in the research on inclusion, integration, exclusion, and segregation of people with disability in accommodation and leisure can present both challenges and opportunities for this area of research. On the one hand, there might be a recognition of health and well-being as clear outcomes of the integration/segregation of people with disabilities in these contexts. On the other hand, there is a risk of medicalisation in the explanation of issues that have a strong social and structural component. For example, a study by Radlińska et al. (2021) found that medical and health science students in Poland were likely to hold negative attitudes towards intellectual disability. Ultimately, societies can be disabling; resourcing research about the inclusion, integration, exclusion, and segregation of people with disabilities from a social science perspective is critical to advance our understanding of these phenomena and provide human rights, social and structural solutions towards the inclusion and integration of people with disabilities.

Feature 4: Limited inclusion of people with disability in research

The fourth key feature of the literature about the ‘inclusion’, ‘integration’, ‘exclusion’, and ‘segregation’, ‘quality’, and ‘safety’ of people with disability in accommodation and community living concerns the inclusion of people with disability in research. As Figure 4 indicates, only 30% of the literature we collected directly engaged with people with disability (see, e.g., Dickey & Ware, 2015; Pilling et al., 2017; Robinson et al., 2020; Schill et al., 2019). So, almost two-thirds of the literature did not ask people with disability about their experiences or perspectives.

Even fewer studies included people with disability as researchers or had reported evidence of consultation with people with disability in the design and conduct of the research. Gratton (2020) trained 10 people with intellectual disabilities and then conducted research with 82 people with disability. These researchers recommended that people with disability should be similarly engaged in consultation on policies and programs that concern them. In some cases, it was difficult to determine if studies included a researcher with lived experience of disability, as job titles are underreported in academic articles (Stankovic et al., 2019), and there is no accepted standard for reporting engagement of the public in research (Staniszewska et al., 2017).

The lack of inclusion and direct engagement with people with disability in research about their experiences and outcomes is a concern for how the disability research agenda is set and investigated, and the subsequent implications for policy and practice (particularly as they relate to social and human rights issues).

As Figure 5 further illustrates, when people with disability have been included in studies concerning the ‘inclusion’, ‘integration’, ‘exclusion’, ‘segregation’, ‘quality’, and ‘safety’ in accommodation and community living, there is a tendency to focus on people with psycho-social and intellectual disabilities (see, e.g., Fisher & Purcal, 2010; Gabrielian et al., 2018; Gonzales et al., 2018). Approximately 87% of the studies we collected focused on this specifically, with almost half (48.55%) focusing only on people with psycho-social

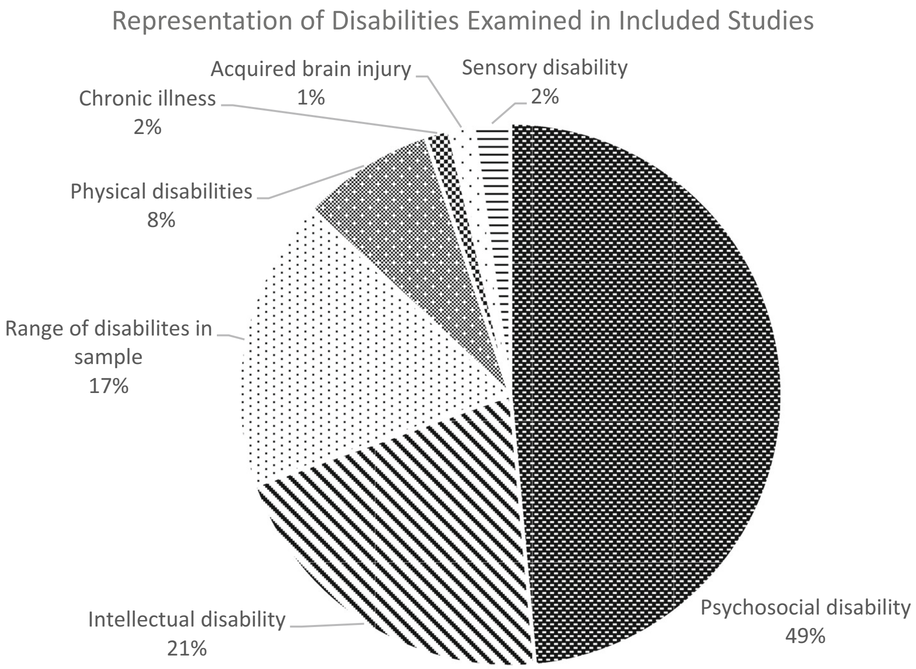

FIGURE 5 Focus of studies involving people with disability by category of disability.

disability and 21% focusing on people with intellectual disability alone. Even in studies that considered people with physical, sensory, acquired, psycho-social, and/or intellectual disability, there was a greater emphasis on people with psycho-social disability and with intellectual disability (see, e.g., Dowse et al., 2016; Dubuc et al., 2013; Lette et al., 2020).

This tendency to focus on people with psycho-social and intellectual disabilities when considering the 'inclusion', 'integration', 'exclusion', and 'segregation', 'quality', and 'safety' in accommodation and community living may occur for numerous reasons. One possible reason is that people with psycho-social and intellectual disabilities may experience significant points of tension and we draw out some of these in the following features identified in this article.

Feature 5: Different levels of engagement with the concepts of 'integration', 'inclusion', and 'segregation'

The fifth characteristic of the literature we collected relates to 'integration', 'inclusion', and/or 'segregation' as primary areas of focus. Of the 457 publications we reviewed, 223 (less than 50%) identified these issues as their *primary* area of focus.

However, these 223 publications did not engage with 'integration', 'inclusion', and segregation' evenly (see Table 5). Almost two-thirds of this sub-set of publications (61%) attended to 'integration' as their primary area of focus (see, e.g., Alakeson et al., 2010; Zimolag & Krupa, 2010), with a further 36% having 'inclusion' as the primary consideration (see, e.g., Bigby, 2006; Luchenski et al., 2018; Ngan et al., 2012; Ornelas et al., 2019). Only 2% of the literature focused on 'segregation' (see, e.g., Ilyes, 2016).

Literature reviews by other authors focus on specific settings in more specificity than we were able to for this review. For example, a systematic review by Smith et al. (2021) focussed on research on inclusion of people with intellectual disability in LGBTQ+ settings. This study found that LGBTQ+ people with intellectual disability experience marginalisation in disability services, but more research was needed to identify how this marginalisation occurs and how to overcome it. Relatedly, another systematic review by Gur and Bina (2022) found that respect, acceptance, and being valued were essential to cultivating inclusion. However, these characteristics are subjective and difficult to measure. This is a further barrier for research, however, inclusion of people with disability in research design may enhance researchers' ability to identify what promotes feelings of inclusion for people with disability.

Feature 6: 'Integration', 'inclusion', and 'segregation' are population-specific concepts

The sixth characteristic of the literature is that the terms 'integration', 'inclusion', and 'segregation' are largely

TABLE 5 Integration, inclusion, and segregation as primary foci of research.

Primary issue in focus	Count and percentage of total literature engaging with issues of 'integration', 'inclusion', and/or 'segregation' in accommodation and community living as the primary area of focus
Integration	138 (62%)
Inclusion	80 (36%)
Segregation	5 (2%)
Total collection of literature with a primary focus on 'integration', 'inclusion', and/or 'segregation'	223 (49%)

TABLE 6 Integration, inclusion, and segregation considered across categories of disability.

Outcome in focus	Population in focus	Count and percentage of literature focused on this topic and population
Integration	Psycho-social disability	112 (50%)
	Physical, sensory, acquired, and intellectual disabilities	26 (12%)
Inclusion	Psycho-social disability	14 (6%)
	Physical, sensory, acquired, and intellectual disabilities	66 (30%)
Segregation	Psycho-social disability	4 (2%)
	Physical, sensory, acquired, and intellectual disabilities	1 (<1%)

used in the context of specific populations. As Table 6 illustrates, 'integration' is commonly used in the context of people living with psycho-social disability. Of the 138 texts collected which primarily focused on 'integration', 81% engaged with this concept in terms of people living with psycho-social disability (see, e.g., La Motte-Kerr et al., 2020; Wong et al., 2011; Yanos, 2007). Of the 80 texts focused on 'inclusion', 82.5% engaged with this concept in the context of people with physical, sensory, acquired, and intellectual disabilities (see, e.g., Chan, 2018; Chan et al., 2014; Mandelker, 2011). We also noted that the discipline of education has discipline-specific norms regarding exploration of 'inclusion', 'integration', and 'segregation' (Schoop-Kasteler & Müller, 2020), but this was beyond the scope of our review.

It also became apparent in our review of the literature that there are significant differences between the assumptions, meanings, and expectations ascribed to these population-specific terms. We explore these below.

Feature 7: Minimal consideration of diverse identities and intersecting experiences

The seventh notable characteristic of the literature was that over a quarter (27.35%) considered the diversity among and between people with disability (see, e.g., Levine et al., 2018; Lorenzo et al., 2015; Pilling et al., 2017; Wainwright et al., 2020). However, there is great variation in the attention paid to the experiences of different communities of people with disability. For example, while 57% of the 'diverse identities' literature considered the experiences of younger or older people with disability, only 14% considered the experiences of women and girls with disability, approximately 6% considered the experiences of LGBTQI+ people with disability, and 3% considered the experiences of First Nations people with disability (Table 7).

Considering that the findings in some of these studies indicate that ethnic minorities, women, and members of the queer community are experiencing further disadvantages relative to their counterparts in those categories, it is essential to conduct more research about their experiences and to provide research findings disaggregated by these and other demographic characteristics that have been identified in previous research as potential markers of disadvantage (e.g., young children, older people, low SES people, and migrants).

An existing systematic review by Smith et al. (2021) identified above explores intersectional experiences of LGBTQ+ people with intellectual disabilities but calls for more research to improve the evidence base going forward. Another recent review by Cipriano et al. (2023) on the experience of people of colour with intellectual disability found that a lack of consistent terminology and conceptualisations of inclusion was a barrier to synthesising the existing evidence. Clearly, there is a need for more high-quality research on the experiences of people with disability with intersecting marginalities.

TABLE 7 Consideration of issues of diversity in the disability-related literature.

Elements of identity considered	Count	% of the literature considering diverse identities	% of the total body of literature collected on accommodation and community living
Age	71	56.80%	15.53%
Older people	49	39.2%	10.72%
Young people	22	17.6%	4.81%
Gender and Sexuality	25	20%	5.47%
Women and girls	18	14.4%	3.93%
LGBTQI+ Communities	7	5.6%	1.53%
Race	20	16%	4.38%
Racialised populations outside Australia	16	12.8%	3.50%
Aboriginal and Torres Strait Islander peoples	4	3.2%	0.8%
More than one element of identity	9	7.03%	1.96%
Total	125	100%	27.35%

Feature 8: The paucity of research that considers the experiences of people with disability living with their parents

The final characteristic of relevance is the notable absence of current scholarly literature on the experiences and outcomes of people with disability living at home with parents and/or siblings. The United States is increasingly tracking the number of people with disability living with their parents (Larson et al., 2020), but these data are less well captured elsewhere, including in Australia. We can discern that in 2009, there were about 446 300 Australians with a disability living with their parents (Qu et al., 2012). A 2020 Australian Institute of Health and Welfare report indicated people with severe or profound disability are more likely to live with a parent or other relative (Australian Institute of Health and Welfare, 2020).

Recent reports and inquiries suggest a key barrier preventing people with disability from leaving their parents' home is ‘limited access to support for independent living’ (Wiesel & Habibis, 2015), with the ongoing provision of care affecting the carer's paid employment and contributing to low-income households (Qu et al., 2012). There is a continuing need for further research in relation to the integration, inclusion, and outcomes of people with disability living with family members.

STRENGTHS AND LIMITATIONS

One of the strengths of this paper is the breadth of sources included and their relevance to the ongoing issue of inclusion of people with a disability. The limitations include its focus on peer-reviewed literature. There are many sources in the grey literature documenting policies and programs, and their associated evaluation. These could be the focus of a review in their own right. Additionally, the requirement that sources be in English in order to be included may have contributed to the over-representation of literature from high-income countries, however, we do not believe that this would sufficiently distort the results reported in Feature 2.

A further limitation is that the scope of the search itself was so broad that it was not possible to explore the debates emerging in this area in more detail. Research mapping emerging debates would be a valuable contribution to the field.

FUTURE RESEARCH

Future research on inclusion of people with disability should consider direct reference to the perspectives and experiences of integration, inclusion, segregation, and exclusion of people with disability. People with disability are experts in their own lives and there is scope for researchers to benefit from and share this expertise. Furthermore, people with disability should not only be included in research as participants but as investigators, advisors, or as members of a co-design group.

Many of the articles we reviewed (especially the relatively large proportion emanating from the health sciences) suggested that an effective way to achieve inclusion is to intervene in the person's life to minimise their impairment. While some of this research may be useful, it perpetuates a medical model of disability and continues to situate the problem of inclusion with the person with a disability. There is a need to pursue further research grounded in the social model of disability, in which the problem of inclusion and the subsequent interventions and solution are focused on a disabling society.

CONCLUSIONS

This systematic review focused on contemporary literature from 2006 (the year in which the UNCRPD and its Optional Protocol was adopted) and covered international research for the provision of accommodation and support of community living for people with disability. The review identified eight key characteristics of the academic literature on 'inclusion', 'integration', 'exclusion', and 'segregation'. By revealing who is talking about these concepts and theorising how and why these authors are defining these concepts in the way they do, this review provides insight into the academic debate on disability inclusion, together with the framing of current policy and practice.

Overall, we found the volume of publications has increased each year for the past 15 years, with most of this undertaken by scholars in the health sciences. Only 30% of the literature included the direct experiences and perspectives of people with disability. We also found that 'integration' is a far more developed and explored concept than 'inclusion', with the concept of 'segregation' infrequently considered. This may account in part at least for the slow progress towards inclusion and the realisation of Bengt Nirje's vision for 'a society where people might be themselves among others' (Nirje, 1985; p. 67).

There has been minimal consideration in research on 'quality' and 'safety' outcomes and of the diversity among and between communities of people with disability. Most of the research appears framed in the context of a communitarian vision of inclusion, that evidences inclusion with reference to shared values and a harmonious coming together of like-minded citizens engaged in what are considered to be normative (ableist-defined) activities. There is a lack of research applying the lens of radical democratic theory with a focus on diversity. There is a paucity of research outside of the United States considering the amount, experiences, and outcomes of people with disability living with family.

While what we do know has been influential in social policy, it is what we do not yet know that could be holding us back. What is clear is that it is insufficient to simply pursue (perpetuate) the current research agenda to fill these knowledge gaps. We need a diversity of approaches and a diversity of persons pursuing these approaches, including representation of the diversity of people with disability driving the research agenda (Smith-Merry et al., 2022).

By understanding who is talking about these concepts and how those authors are defining these concepts, this literature review sought to generate insight into the academic debate on disability inclusion, the framing of current policy and practice, and identify what needs to be done to improve the evidence base informing future policy and practice.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

ETHICS STATEMENT

This study sourced publicly available data and did not involve any participants. It was, therefore, exempt from HREC review.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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