Disability and social inclusion 'Down Under': A systematic literature review

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Abstract

This article provides a systematic literature review investigating how the social inclusion of adults with disability is conceptualised in research concerned with policy and service provision in Australia. The review will summarise this literature, and clarify its relative strengths and weaknesses. The findings from the literature review are grouped into recurring themes, namely: deinstitutionalisation; the changing nature of paid support; different forms of 'community engagement'; and socially valued roles, particularly in the realms of employment, volunteering, and consumer transactions. The literature mostly concerns people with intellectual and cognitive disability, more so than persons with sensory, psychosocial (mental health) and physical disabilities. Several gaps emerge in the literature, such as the experiences of Indigenous people with disabilities, both in terms of exclusion they may face, and solutions being developed by Indigenous communities; ambiguous understandings of social inclusion; and a lack of acknowledgement of prominent critiques of social inclusion. The review builds on these findings to make recommendations for policy, practice, and further research.

Keywords: disability, social inclusion, Australia, policy, practice, Convention on the Rights of Persons with Disabilities

The rates of social and economic inequality facing Australians with disability compared to their fellow citizens, are among the highest in the world (PricewaterhouseCoopers, 2011). The concept of 'social inclusion' therefore holds promise, at the level of policy and practice, for creating a more inclusive and equal society. This paper presents a systematic literature review concerning the 'social inclusion' of adults with disabilities in Australia. It focuses primarily on research in scholarly publications concerned with achieving social inclusion in policy and practice. Although we acknowledge that there is much on this topic published in the grey literature (that is, documents produced by government, advocates, business, and industry that are not published in research journals), this article will focus on the scholarly literature. In summary, the literature review revealed a surprisingly small amount of formal literature about creating social inclusion in policy and practice for people with disabilities (nine in total), and most of it concerned people with intellectual and cognitive disabilities. The concluding section will summarise key themes, and recommend several avenues for future research, policy development and practice initiatives.

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Background

'Social inclusion' emerged in France in the 1970s as a social policy to assist marginalised citizens (Silver, 1994). The concept has since been diffused through social policy across high-income countries in the Anglosphere. In Australia, social inclusion rose to prominence after the election of the Australian Labor Party (ALP) in 2007 (Saunders, 2013). This prominence has waned with the election of successive Liberal-National Party (LNP) coalition governments, but the concept remains relevant in Australia's overall social policy agenda, and is evident across the work of community service and other non-government organisations, and in policy research and advocacy.

According to Azpitarte (2013, p2), more than one million Australians experienced 'deep social exclusion' in 2010. Social exclusion, they argue, provides a useful way to understand poverty and disadvantage in a way that goes beyond a person's income and assets, such as owning their home, to include other essentials for their participation in society, such as access to education, health services and transport, and non-material aspects such as access to community, social connection and personal safety (Azpitarte, 2013, p1). In other words, the concept of social exclusion captures the many interconnected factors that may exclude a person from society, including barriers to education, labour and housing. Policy to promote inclusion has therefore sought to improve access to resources, opportunities and capabilities that all citizens need to learn, work, and engage in society (Australian Social Inclusion Board, 2012).

The marginalisation of people with disabilities, who comprise one in five Australians according to the Australian Bureau of Statistics (ABS) (2015), has been well documented (see, for example, Goggin & Newell, 2005). According to the Organisation for Economic Co-operation and Development (OECD) (2009), Australia ranked lowest among all OECD countries in terms of quality of life for disabled people. PricewaterhouseCoopers (2011) reported that 45% of Australians with disability live in or near poverty, which is over double the OECD average of 22%. The landmark *Shut Out* report in 2009 (National People with Disabilities and Carer Council) details the damaging effects of this exclusion, including low levels of income and labor force participation (see also Milner, LaMontagne, Aitken, Bentley, & Kavanagh, 2014), major health inequalities (see also Mithen, Aitken, Ziersch, & Kavanagh, 2015), and disproportionate levels of violence (see also Krnjacki, Emerson, Llewellyn, & Kavanagh, 2016). In addition, despite widespread law and policy that promotes 'mainstreaming', for many people with disabilities the norm remains congregate (institutional) accommodation, segregated education and employment, isolation and reduced access to justice and health services. This stark reality has been a major driver for establishing the Australian National Disability Insurance Scheme (NDIS) (Productivity Commission, 2011).

Exclusion of people with disability is caused in part by pervasive negative attitudes and discrimination (Yazbeck, McVilly, & Parmenter, 2004). Unsurprisingly, therefore, the concept of social inclusion has been incorporated into human rights instruments (Silver, 1994), and most recently, the *United Nations Convention on the Rights of Persons with Disability* (CRPD) (United Nations, 2006).[1] Article 19, in particular, concerns "living independently and being included in the community" (United Nations, 2006). Article 19 requires governments to "recognize the equal right of all persons with disabilities to live in the community, with choices equal to others" and to "take effective and appropriate measures to facilitate full enjoyment by

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[1] For example, the 'General Principles' of the CRPD, set out in Article 3, include (c) 'full and effective participation and inclusion in society', (d) 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity', (e) 'equality of opportunity', and (f) 'accessibility'. These principles apply to all rights set out in the CRPD, which relate to many different areas of life, including family and home life, education, employment, healthcare and financial decision-making, and political participation.

persons with disabilities of this right and their full inclusion and participation in the community" (United Nations, 2006). Thomas Hammarberg (2012, p8), the European Commissioner for Human Rights, elaborates on the positive duty Article 19 places on governments:

> *Article 19 of the CRPD embodies a positive philosophy, which is about enabling people to live their lives to their fullest, within society. The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one's life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. 'Neutralising' is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.*

Within Australia, social inclusion has been identified by prominent disabled peoples' organisations as a major policy issue (see, for example, National People with Disabilities and Carer Council, 2009, p3). This literature review seeks to build upon existing efforts to address exclusion of people with disabilities in Australia, critically analysing the concept of social inclusion and its application in disability policy and service provision.

Method

A systematic review of peer-reviewed articles and international reports was undertaken, informed by the guidelines of the *Social Care Institute of Excellence* (SCIE) (Rutter, Francis, Coren, & Fisher, 2010), and the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2010). The principle question guiding this scoping review was: *how is social inclusion of adults with disability implemented (in policy and practice) in Australia?*
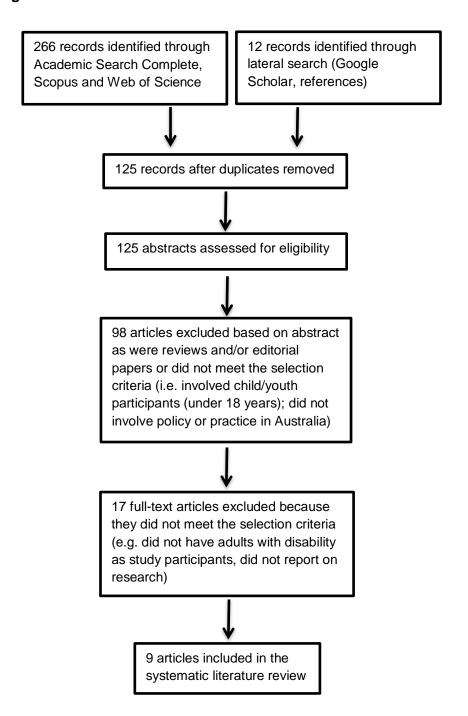
Three research databases (Academic Search Complete, Scopus and Web of Science) and Google Scholar were searched. Key search terms included: "social inclusion", "disab*", "community", "implement*", and "Australia". Details of the specific combinations of key search terms used and the results are given in Table 1. No limit was put on the date range for the search, and no language filter was applied.

Figure 1 describes the literature search and article selection process. Initially, 266 articles were identified through the search of the research databases. An additional 12 articles were identified through a search of both Google Scholar and by reviewing the reference lists of the initial articles. After removing duplicates, 125 abstracts were screened against the selection criteria. Articles were excluded if they were editorial papers; reviews; involved only child/youth participants (under 18 years of age); or did not involve policy or practice in Australia. Subsequently, 27 articles remained and were read in depth to assess their suitability for inclusion. Articles were then excluded if they did not have adults with disability as study participants, or if they did not report on research activities. Following this process, nine articles were identified for inclusion in the review. However, three of these articles reported on the same research project (Bigby & Wiesel, 2015; Wiesel & Bigby, 2016; Wiesel, Bigby, & Carling-Jenkins, 2013), though all were included in the final review because they referred to different elements of a larger project.

Table 1: Key search terms and results

Database	Search Terms	Results
Google Scholar	how is social inclusion for people with disability implemented in policy and practice in Australia?	12
Scopus	"social inclusion" AND disab* AND Australia	43
	"Social inclusion" AND disab* AND ("Social role valorisation" OR "Social role valorization")	2
	"social inclusion" AND disab* AND Implement* AND Australia	6
	"social inclusion" AND disab* AND community AND Australia	29
Academic Search Complete	"social inclusion" AND disab* AND Australia	80
	"Social inclusion" AND disab* AND ("Social role valorisation" OR "Social role valorization")	4
	"social inclusion" AND disab* AND Implement* AND Australia	5
	"social inclusion" AND disab* AND community AND Australia	45
Web of Science	"social inclusion" AND disab* AND Australia	24
	"Social inclusion" AND disab* AND ("Social role valorisation" OR "Social role valorization")	2
	"social inclusion" AND disab* AND Implement* AND Australia	0
	"social inclusion" AND disab* AND community AND Australia	14
Total		**266**

Figure 1: Flowchart of the literature search

Limitations of the Review

There are a number of limitations with the scope of the systematic literature review, which should be noted. For example, the focus on adults with disabilities meant that a substantial body of literature concerning education policy and practice, in which social inclusion has been a prominent theme, was not included (see, for example, Chenoweth & Stehlik, 2004; Craig & Bigby, 2015). It is well established that there are lower rates of participation in education compared to people without disability, overall (ABS, 2015). Another limitation was our focus on Australian policy and practice, which meant that a substantial body of literature from other countries was excluded. The decision to limit the literature search to social inclusion policy

and practice in Australia was taken as this review is part of a broader project investigating the extent of social inclusion for people with disability in Australia.[2]

In addition, much research has likely occurred on Australian policy and practice which directly or indirectly promotes social inclusion, even as the term 'social inclusion' may not have been used. For example, efforts to improve accessibility generally promote social inclusion, broadly understood. While 'accessibility' often refers to the physical disability context – wheelchair ramps and accessible toilets come quickly to mind – the term can be understood much more broadly (see CRPD, Article 5 in United Nations, 2006). As the Committee on the Rights of Persons with Disabilities (2017, para76) noted, "general accessibility of all public places, transport, information, communication and facilities and services open to the public in a respective community is a precondition for independent and community living". Likewise, efforts to prevent discrimination – for example, in employment, education and health settings – could also be viewed as systemic measures to promote a more inclusive society. Thus, efforts to secure social inclusion, understood in the broadest sense of the term, could include: improved wheelchair accessibility in community venues, preventing and punishing disability-based discrimination, efforts to secure equal wages for people with intellectual disability, increased availability of Auslan interpreters, equal opportunities for people with disabilities to have intimate relationships, and a myriad of interventions on the small, medium and large-scale (see Committee on the Rights of Persons with Disabilities, 2017). In other words, there are many ways of understanding the quest for a society in which people with disabilities can make meaningful choices among good options about how to live, of which an explicit aim to assist individuals to be 'included' is but one.

There may be scholarly works concerning social inclusion which were not included in the review findings or identified in the various search strings. One such article which came to the authors' attention following the completion of the substantive review, was an in-depth (and very helpful) analysis by Layton and Steel (2015, p11146), which concerned the "supports and accommodations identified by a cohort of individuals (n-100) living with disability" that contributed to "inclusive community environs" and 'inclusion and wellbeing' more broadly. The precise term, 'social inclusion' did not appear in the paper, though clearly the aims align with our review. Again, future literary reviews might expand the scope to include research concerned with 'social inclusion' broadly conceived, rather than specifically defined as such. Nevertheless, this current systematic review remains useful in determining the way 'social inclusion' in particular is understood, discussed and applied in relation to Australian disability policy and practice.

Results

The nine identified articles were published between 2004 and 2016, and are summarised in Table 2. They were all essentially qualitative studies, which involved interviews with people with disabilities. Some included family members as informants. In several instances researcher observations were conducted *in situ*, and were used to inform the interpretation of the interview data. The approaches adopted in the research included multiple single case study designs, and small group studies informed by ethnographic methods. Participants were drawn from metropolitan, regional and rural settings, with sample sizes ranging from five to 86. However, the majority of samples were small, self-selected, and from a particular geographic location or service. Generally, the approaches to data analysis were phenomenological, using inductive thematic analysis, or with reference to Grounded Theory. It is important to note at the outset, that the majority of articles related to people with intellectual disability, and the policies and practices that affect them.

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[2] See www.19stories.org.

Table 2: Literature included in the review

Article	Author	Year	Description	Research Participants
Implications of social capital for the inclusion of people with disabilities and families in community life	Chenoweth, L. & Stehlik, D.	2004	This paper seeks to ascertain the usefulness of the theory of social capital as a framework for developing and sustaining the inclusion of people with a range of disabilities and families in community life. It discusses the theoretical elements of social capital and assesses its relevance when understanding both the experiences of people with disabilities and their families, and the possible implications for policy and programme efforts to promote inclusion.	86 interviews were completed and covered the experiences of living in the community and the range of family friends and formal relationships. People were also asked what they thought their community was like in terms of its attitudes to people with disabilities generally. In addition, 71 of those interviewed also completed social network maps as part of the interview.
"She's been involved in everything as far as I can see": Supporting the active participation of people with intellectual disability in community groups	Craig, D. & Bigby, C.	2015	Drawing on the International Classification of Functioning, Disability and Health (World Health Organization, 2001), this study refined this commonly used definition to distinguish more clearly between being present in a place such as a community group by simply attending, and being actively involved in the activities that occur in that place. The study reported in this paper uses this definition of active participation, as it opens the possibility to explore the depth of participation that occurs in different groups and enables comparison across groups. The aim of this study was to identify the pathways to participation in community groups for people with a moderate level of intellectual disability, explore the factors that enable or constrain their active participation, and consider the implications of these for the practice of supporting active participation in community groups.	5 adults over 45 years with moderate intellectual disability who were interested in joining a community-based activity.
Men's Sheds: enabling environments for Australian men living with and without long-term disabilities	Hansji, N.L., Wilson, N.J. & Cordier, R.	2015	This study investigates the comparative experience of men with long-term disabilities and men *without* long-term disabilities who go to a Men's Shed and to what extent this provides these men with an enabling, as opposed to disabling, environment. This research aimed to explore the key issues for a hitherto under-acknowledged group of men – men living with long-term disabilities. The questions were: (i) what are the disabling and enabling experiences of men with long-term disabilities who attend a purposively selected Men's Shed and (ii) do men with long-term disabilities experience participation in Men's Sheds differently from men without disabilities? If so, how	The study took place at a single Men's Shed in Sydney's western suburbs that was purposively selected due to its geographical location, its mixed cultural demographic and its targeting of local men with a range of long-term and age-related disabilities. In total, 85 men attend the Men's Shed each week during the operational days on Tuesday, Wednesday and Thursday. Twelve interviews were conducted with five men with a long-term disability, six men without a long-term disability and the male Men's Shed coordinator (there were two Men's Shed coordinators – one male, one female).

Article	Author	Year	Description	Research Participants
			does the Men's Shed facilitate this differing process of enablement and inclusion?	
Social Interaction with Adults with Severe Intellectual Disability: Having Fun and Hanging Out	Johnson, H., Douglas, J., Bigby, C. & Iacono, T.	2012	Although information is available on the preponderance of instrumental interaction, little is known about social interactions between people with severe intellectual disability and their families and friends. The focus of this article is on social interactions; those that have 'no obvious instrumental purpose' and are perceived as pleasurable. The aim of this article was to (i) identify social interactions between the people with severe intellectual disability and those with whom they have positive relationships and (ii) detail the nature of those interactions.	Participants were six adults with intellectual disability and others identified as people with whom they have a pleasurable relationship. All six central participants had intellectual disability and communicated at a symbolic, non-linguistic level. Only one of the central participants had a specified level of intellectual disability, identified as severe. All central participants had multiple impairments that included, in addition to intellectual disability, one or more of epilepsy, autism spectrum disorder, cerebral palsy, scoliosis and visual impairments. They were aged from 20 to 44 years; three lived at home and three in group homes; all attended day services in Victoria, Australia.
Enablers and barriers of social inclusion for young adults with intellectual disability: A multidimensional view	Van Asselt, D., Buchanan, A. & Peterson, S.	2015	This study explored the lived experience of young adults with intellectual disability who participated in an inclusive community leisure program (pseudo-name "SocialUs"). This program was considered to be inclusive in that it facilitated opportunity for adults with intellectual disability to develop their connections. Adults with intellectual disability had the opportunity to experience social inclusion from coming together with other members with and without disability and engaging in occupations (e.g. attending and/or organising events and activities) that supported their community participation. This study, conducted over an 8-month period, sought to gain insight into the enablers and barriers to social inclusion experienced by young adults with disability based on their own and family members' reports.	Young adults were considered for participation in the study if they spoke English, were 18–30 years old, were living with an intellectual disability, and were regularly attending SocialUs events. Four young adults were included in the study. A parent and sibling of two young adults also participated. No indication of level of disability beyond intellectual disability, but it is noted that all participants provided informed consent.
Everyday practices of exclusion/inclusion: women who have an intellectual disability speaking for themselves?	Welsby, J. & Horsfall, D.	2011	This article discusses a small in-depth research study with five women who have an intellectual disability. The research aimed to develop understandings about the process of social exclusion from people who experience exclusionary practices, in their own words, 'to understand what does and does not matter to them and why'.	5 women aged between 28 and 52 with intellectual disability, were receiving a Disability Support Pension and worked part-time in either the Business Services Sector or open employment.

Article	Author	Year	Description	Research Participants
Mainstream, Inclusionary, and Convivial Places: Locating Encounters Between People with and Without Intellectual Disabilities	Weisel, I. & Bigby, C.	2016	For people with intellectual disabilities, encounters with strangers are an important aspect of social inclusion, and opportunities to become recognised and known within their communities. The focus of this paper is on encounters across cognitive difference. Typically the social exclusion of people with intellectual disabilities is understood as the absence of long-term relationships with other people without an intellectual disability. In contrast, in this paper we focus on encounters with strangers, rather than long-term relationships, as measures of social exclusion and inclusion.	Twenty-six adults with intellectual disabilities, twenty of whom were male, aged between twenty and sixty-five years, with mild or moderate intellectual disabilities, and with varied levels of support needs and communication skills.
'Do You Think I'm Stupid?': Urban Encounters between People with and without Intellectual Disability	Weisel, I., Bigby, C. & Carling-Jenkins, R.	2013	This paper discusses encounters between people with and without intellectual disability in one suburb in Melbourne, Australia. The aim of the analysis is to identify the different types of encounter and the key factors that influence encounters in such places, as well as the potential positive or negative contribution of each to the wider objective of social inclusion.	5 participants with intellectual disability.
Moving from aged care facilities to community-based accommodation: Outcomes and environmental factors	Winkler, D., Farnworth, L., Sloan, S. & Brown, T.	2011	Nearly 3500 people under 60 years of age are living in residential aged care in Australia, a situation which is generally recognised as incompatible with optimum quality of life. The objective of the current study is to explore the transition experiences of young people with acquired brain injury who have lived in aged care facilities and moved into community-based settings.	A convenience sample [30] of participants were recruited through community-based ABI service providers. Potential participants were screened according to the following inclusion criteria: (1) diagnosis of ABI as documented in a medical report, (2) aged between 18–60 years and (3) have moved from residential aged care to living in community-based accommodation in the past 3 years. Participants were excluded if they had a degenerative neurological condition. Seven participants agreed to participate in the study. A family caregiver of each individual was invited to take part in the study. Additionally, two support workers were nominated by participants and also invited to provide information about changes they had observed since the person with ABI made the transition to the community.

The review of the papers revealed several themes that described how the social inclusion of people with disability has been pursued in policy and practice in Australia. These themes were: the deinstitutionalisation of services; the changing role of paid support; approaches to community engagement; and the development of socially valued roles, particularly in areas of employment, volunteering, and the emerging view of the person with disability (and indeed all citizens) as a 'consumer'.

Deinstitutionalisation

Since the 1960s in Australia and throughout high-income 'Western' countries like the United Kingdom, Canada, and New Zealand, the policy of deinstitutionalisation has seen many people with disability moving from institutional settings, both to smaller residential services and to typical residential homes. Deinstitutionalisation meant more people with disability in the community, at least in the strict geographical sense. However, the literature suggests that deinstitutionalisation has not necessarily led to an increase in participation and engagement in the social world of communities (Craig & Bigby, 2015; Welsby & Horsfall, 2011; Wiesel & Bigby, 2016; Wiesel et al., 2013). Several authors have argued that people with intellectual disability in particular, while being physically present, occupy a distinct and marginalised social space in the community, given that they continue to live in *de facto* 'segregated' communities with limited contact with people in the wider community (Bigby & Wiesel, 2015; Van Asselt, Buchanan, & Peterson, 2015; Welsby & Horsfall, 2011; Wiesel & Bigby, 2016). Despite the continuing marginalisation and social exclusion experienced by people with disabilities, the literature offers some indication of the policies and practices associated with deinstitutionalisation, which help improve social inclusion for people with disabilities. These practices include work-based support, disability support pensions and volunteering (Welsby & Horsfall, 2011), community-based 'leisure programs' (Van Asselt et al., 2015), and linking people to community groups, such as men's sheds (Craig & Bigby, 2015), all of which could be broadly contained under the policy framework of 'community care'.

The Changing Role of Paid Support: Service Providers and Support Workers

As noted previously, deinstitutionalisation was accompanied by a move to the 'community care' model of service provision. For people with intellectual disabilities in Australia, it is generally agreed that this transition overall has led to a greater quality of life, although major issues remain (Craig & Bigby, 2015; Wiesel et al., 2013). Due to the extreme social isolation experienced by many people with disabilities, and particularly people with intellectual and cognitive disabilities, their relationships with paid support staff can be extremely important – both in terms of staff facilitating social inclusion in the broader community and in terms of providing a meaningful social relationship in and of itself. As such, the skills, attitudes and practices of support staff – particularly in facilitating broader community connections – can have a substantial impact, both positive and negative, on the social inclusion of people with disability.

Several studies examined the role of paid support staff in facilitating social inclusion. Bigby and Wiesel (2015) employed unstructured observations of people with intellectual disability and their support workers to explore the role of support staff in supporting brief social interactions ('encounters') between strangers, including during service transactions, in different community locations. They found that support workers' actions could have a positive effect on these interactions by initiating or facilitating encounters, encouraging engagement between strangers or by creating an atmosphere that encourages contact. Once an encounter was established, support workers could assist by providing a passive presence, which can reassure strangers who are not used to interacting with people with disability, or by interpreting words, gestures and actions to build understanding on both sides. However, according to Bigby and Wiesel (2015), support workers could also *obstruct* encounters by intervening to prevent them from taking place, including acting as a physical barrier to interaction, terminating interactions, or engaging in interactions on behalf of a person with disability. These findings suggest that to capitalize on such social opportunities, disability support workers may need

specific training to promote a facilitative role. The education of disability support workers could therefore include specific skills to undertake this role (hence minimising the risk of staff naïvely obstructing opportunities for informal connection).

Several authors also noted a tendency for support staff to organise segregated activities within community settings, thus maintaining a distinct social space for people with disability (Craig & Bigby, 2015; Welsby & Horsfall, 2011; Wiesel & Bigby, 2016; Wiesel et al., 2013). In one study, participants' social activities were limited to the disability-specific activities run by their accommodation provider (Welsby & Horsfall, 2011). Staff members reportedly justified this decision by arguing that disability-specific group activities minimised the risk of potential dangers to vulnerable people. However, as the authors noted, these exclusionary practices may actually increase risk by denying people the opportunity to learn important life skills and to develop relationships that might protect them from harm (Welsby & Horsfall, 2011). On the other hand, other commentators have claimed that participation in specialist activities can be positive because it allows people with intellectual disability to interact with each other and develop relationships in an environment where their disability is not seen as exceptional (Chenoweth & Stehlik, 2004; Wiesel & Bigby, 2016; Wiesel et al., 2013). The human rights framework of the CRPD unequivocally promotes a move away from congregated disability service provision, toward 'universal design', in which adjustments and accessibility measures are built into mainstream services and facilities (CRPD, art2). Again, while there is evidence of Australian policies aimed at social inclusion of people with disability, there is a paucity of policy to support the education and training of staff to enable them to grapple with the complexities of inclusion, and to effectively (and sensitively) translate the theory into everyday inclusive practices.

One study explored the social interactions between people with severe intellectual disability and those with whom they have positive relationships, including paid support staff (Johnson, Douglas, Bigby, & Iacono, 2012). It was reported that all participants in the study experienced joy with paid support workers through various activities, including games, song and mimicry. Johnson and colleagues note that building relationships and having fun have been identified as areas of life that are important to people with disabilities, as identified in the Victorian Quality Framework for Disability Services (Department of Human Services, n.d.), which creates an ethical as well as practical imperative to focus on promoting fun between staff and people with disabilities. Johnson and colleagues propose a greater focus on support to facilitate social engagement and social inclusion for people with intellectual disability as a way of satisfying the standards in the framework. Given that paid staff also reported increased job satisfaction as a result of their positive social interactions with the people they support, a focus on workplace satisfaction may assist with recruitment of more disability support workers to support social inclusion (Johnson et al., 2012). Here it should be noted that the Productivity Commission (2011, 2017) has twice identified the need to recruit thousands more people to provide direct support services, to meet the growing need in Australia.

The literature emphasises the vital role played by paid support staff in promoting (but also potentially obstructing) social inclusion for some people with disability, and particularly people with intellectual disability. The literature highlights how the skills, attitudes and practices of staff can determine success or failure in achieving social inclusion for persons with disabilities. The literature also highlights by default the need for greater attention to the integration of high-level policies of social inclusion regarding the education and training of the workforce.

Community Engagement

'Community groups' is used here to mean groups meeting on a voluntary basis to pursue a particular interest. Community groups provide many people – both with and without disabilities – with opportunities to build relationships and engage with the wider community. However, community groups may not be accessible to people with disabilities. Several studies reported on the important role that organisational processes and leadership of community groups

played in facilitating inclusion or exclusion of people with disability (Craig & Bigby, 2015; Hansji, Wilson, & Cordier, 2015; Van Asselt et al., 2015). Craig and Bigby (2015) reported on the experiences of five participants with 'moderate intellectual disability' who participated in programs with different community groups, including cooking groups, a walking group, an op-shop, and a 'Men's Shed'. (We will return to the outcome of the Men's Shed Program shortly). Participants experienced varying levels of participation and acceptance within the groups, and the nature of their participation was asserted to be affected by a combination of factors, namely: the attitude of the group leadership towards inclusion of a person with intellectual disability; the social processes within the group and the interactions between group members; the skills and characteristics of the person with intellectual disability; the presence of an integrating activity to promote involvement for the person with intellectual disability; access to expertise to develop the groups' capacity to support inclusion; and adjusting practices to support a participant to actively engage in group activities.

The importance of leadership attitudes and social processes is illustrated by the experiences of participants in the Men's Shed program, which featured in two of the studies in this review (see Hansji et al., 2015, and Craig & Bigby, 2015). Men's Sheds are a community-based, non-profit organisation, which provides a space for men to work on shared projects with the primary objective of advancing the wellbeing and health of members. The first study examined the role of Men's Sheds in fostering social inclusion, participation and belonging (Hansji et al., 2015). The study looked at the experiences of 12 men, five with various disabilities and seven without, who participated in a Men's Shed. The program had a strong but not *sole* focus on assisting men with a range of long-term and age-related disabilities. The authors of the study reported that the Men's Shed provided a community and social hub, an 'equalising space', a supportive environment and offered meaningful social activities for men (Hansji et al., 2015).

In the second study (Craig & Bigby, 2015), one person with intellectual disability participated in a Men's Shed program, in which no other members identified as having a disability. According to Craig and Bigby (2015), the person's experience was one of limited participation and social isolation within the group and his role was described more in terms of being a marginal observer rather than an active participant. The person joined the program, despite the Men's Shed staff raising concerns about his suitability for the group when he first joined, citing his skill level and need for additional support. Reportedly, the staff at the Men's Shed did not actively facilitate his participation in group activities and he mainly performed tasks by himself (Craig & Bigby, 2015). His isolation and marginalisation suggested that too little attention had been paid to creating a genuinely inclusive environment.

Another study explored the experiences of four young adults with intellectual disability who participated in an 'inclusive community leisure program' (Van Asselt et al., 2015). The program, run by a local voluntary agency, was designed to assist adults with intellectual disability to engage, as individuals, in broader community events and activities. Some examples of activities offered through the program included meeting other community members for coffee or meals, joining rock climbing and yoga groups, and joining education courses (for example, a short-course on using computers). The study identified enablers and barriers to social inclusion experienced by people with intellectual disability participating in the program. The authors identified two organisational factors – 'organisational people factors' and 'organisational process factors' – in order to help understand participants' experiences of the program. 'Organisational people factors' referred to the role played by regular volunteers in the organisation and running of regular social activities. These factors were seen as both an enabler and a barrier to social inclusion for the participants. Volunteers supported the young people with disability in the development of leadership skills through the opportunity to coordinate events and in making choices about the types of activities they wanted to do. However, in some cases interaction was limited to regular volunteers, with little interaction with other community members (for example, meeting the same person for coffee regularly), and reliance on relationships with regular volunteers impacted on participants' ability to express

opinions and make choices about the types of activities they wish to participate in (Van Asselt et al., 2015). 'Organisational process factors' include the administrative and operational procedures in the community organisation, which can serve as both barriers and enablers to fostering inclusion.

Van Asselt and colleagues (2015) observed that young people with disability participated in events in a variety of community spaces, such as cafes, parks, restaurants or spaces for specific activities such as courses or rock climbing. The volunteers facilitating the events ensured that the 'customer service' experience was tailored to accommodate the individual needs of all participants, meaning that members with disability enjoyed the same experience as members without disability. These quality service experiences enabled participants with disability to experience value as consumers and to contribute to the community in a meaningful way. The types and locations of activities were seen as important factors in the social inclusion of young people with intellectual disability. The events were typical of adults in the same age group, and were held in a diverse range of community locations thought to be well suited to the needs of the members. The diversity of locations was, in some cases however, also a barrier to inclusion as members could not always arrange transport to access the events (Van Asselt et al., 2015). These organisational processes, as well as the skills and attitudes of staff and volunteers from community organisations, can have a significant impact on promoting social inclusion for people with disability. The literature suggests that inclusive groups that provide equality of experience for members with and without disability through participation in meaningful activities are likely to have greater success in facilitating social inclusion for people with disability.

Socially Valued Roles

Promoting 'socially valued roles' has a long-established history in the development of policy and provision of services for people with disability, and is arguably essential to the realisation of social inclusion. This has been most evident in the influence of *Social Role Valorization (SRV)* Theory, developed by Wolfensberger (2000), based on the earlier work in the area of *Normalization Theory* (see the work of Bank-Mikkelsen, 1980, and Nirje, 1969). In Australia, the National Standards for Disability Services (2014) emphasise the importance of valued roles for people with disability in public and private life, which importantly, must be of the individual's choosing. Within this review, all authors emphasised the importance of occupying valued roles and participating in meaningful activities as a means of promoting social inclusion. According to Van Asselt et al. (2015, p38), in addition to reducing social isolation, the "opportunity to occupy valued roles is also critical for adults with intellectual disability to experience positive identities and become known and accepted as valued citizens in their community". The literature in this review reported on people with disability (and mostly people with intellectual disabilities) engaging in a variety of valued roles, including employment (Welsby & Horsfall, 2011; Wiesel & Bigby, 2016), volunteering (Chenoweth & Stehlik, 2004; Craig & Bigby, 2015; Van Asselt et al., 2015; Wiesel & Bigby, 2016; Winkler, Farnworth, Sloan, & Brown, 2011) and as consumers (Van Asselt et al., 2015; Welsby & Horsfall, 2011; Winkler et al., 2011).

Employment

Employment for people with intellectual disability in the literature fell into two categories – open employment, and 'Business Services' (previously known as Sheltered Workshops, and sometimes referred to in policy as Australian Disability Enterprises - ADEs). In the Welsby and Horsfall (2011) study, three of the female participants worked part-time in Business Services, while two worked part-time in open employment. In open employment, the women had the potential to increase their incomes through advancement, learning new skills, exercising choice and participating in their community. The women who worked in Business Services packed products into boxes or plastic bags on an assembly line. They were paid approximately $AUD 3.20 per hour in a closed environment and had little prospect of advancement or moving into open employment. When one of the women working in Business Services expressed an

interest in moving into open employment, she experienced a lack of support from her employer, support staff and accommodation provider; a situation exacerbated by the rules of her accommodation service which prevented her from using the phone and by her dependence on her carer for transport (Welsby & Horsfall, 2011). The women in the study working in Business Services experienced little or no personal autonomy and the attitudes, policies and practices of their employers and support agencies could be viewed as creating barriers to social inclusion. While employment has potential to promote social inclusion, it is evident that attention needs to be given to the setting and form of the employment (including labour rights), and the additional policy and practical supports needed to foster inclusion in an employment context (for example, support workers assisting the person initially to understand workplace culture, or employing existing employees in a particular workplace to mentor the person).

Volunteering
Volunteering has been found to offer another path for people with disability to engage in meaningful roles in the community. Wiesel and Bigby (2016) argue that volunteering allows people from many different parts of society to participate in tasks with a shared purpose, which can increase the opportunity for social interactions between people with and without disability (Wiesel & Bigby, 2016). In another study, a young woman with a severe acquired brain injury (ABI) who had previously lived in Residential Aged Care, volunteered at her local primary school and reportedly gained high-level inclusion in her community (Winkler et al., 2011). Within the literature, even among those volunteers with disability who did not achieve such high levels of inclusion, volunteers expressed a sense of satisfaction and enjoyment gained from the experience. A participant in Craig and Bigby's (2015) study who left his volunteer position in an op-shop when he was excluded by the staff, successfully negotiated with carers to be supported to find a similar position elsewhere. Although volunteering offers a way for people with disability to increase their presence in the community, Chenoweth and Stehlik (2004) note that even though people with disability and their families make significant voluntary contributions in their communities, this contribution is often invisible to the wider community. This is because much of the contributions take the form of volunteering in disability-specific organisations and activities, or, in the case of family members, takes the form of unpaid caring roles.

Consumer Transactions
Within the literature, another area in which people with disability occupied valued roles was through consumer transactions. In the literature for this review, people with disability experienced a sense of connection through their role as consumers of goods and services in the community. Buying tickets to inclusive community events, the young adults in Van Asselt et al. (2015) experienced a sense of acceptance and felt respected and valued in their contributions as community members. This was assisted by the supports put in place by organisers as part of their aim to deliver high quality service in an inclusive environment. The women in Welsby and Horsfall's (2011) study also gained great value on taking part in the day-to-day practice of shopping, despite being constrained by their limited incomes. Shopping is a relatively common activity for people with intellectual disability to engage in with their support workers as a way of providing them with the skills to be able to engage in transactions independently, but the potential for social inclusion may not always be appreciated as an end in itself by support staff (Wiesel et al., 2013).

Discussion

To reiterate, the main question guiding this literature review was: *How is social inclusion of adults with disability implemented in policy and practice in Australia?*

The aims of those promoting social inclusion for people with disabilities were similar to the aims of those promoting social inclusion for all people, for example, socially valued roles, employment and volunteering opportunities, access to health, education and community services. These are goods that are relevant to all citizens (for example, Australian Social Inclusion Board, 2012). Some disability-specific themes also emerged: deinstitutionalisation, the changing role of paid disability support, the particular skills and resources required to facilitate community engagement for some people with disability. All of these themes emerge from a recognition of the sheer exclusion facing people with disabilities generally, and people with intellectual disability in particular.

Indeed, people with intellectual disabilities were prominent in the literature, which could be explained by the profound marginalisation they face. Another explanation is simply that intellectual disability services are, for various reasons, attracted to the concept of 'social inclusion'. Regardless, this prominence should not detract from the exclusion facing many other people with various types of disabilities, including people with physical, sensory, cognitive and psychosocial (mental health) disabilities (National People with Disabilities and Carer Council, 2009).

The emphasis on deinstitutionalisation in the literature suggests a general agreement that institutional closures in Australia did not lead to more accessible societies for many people with disabilities. For Welsby and Horsfall (2011), the congregation of people with disability into specialist spaces under the policy of 'care in the community' creates the so-called 'illusion of inclusion' — a view that appears to be shared across the literature. The various authors also appear to agree that paid support workers, individuals, families, and community organisations tend to lack the skills and knowledge to foster 'genuine' social inclusion. This is troubling in the service sector in particular, given service providers are obliged to support people to engage with community under National Standards for Disability Services in the *Disability Service Act* (2014). In other words, the literature suggests there may be gaps between policy obligations and the skills required to achieve them in practice.

The skills and attitudes of disability support workers, and the procedures and policies of service provider organisations, also emerged as a prominent theme. When these policies and practices fail, as the review revealed, disturbing instances of isolation and exclusion can occur. Nevertheless, stories of success appear, which highlights how practical measures can improve community engagement for individuals, and can improve the openness and accessibility of communities more generally. Specific skills, service configurations and resources are required, but the literature indicates a lack of consensus about precisely what these skills, arrangements and resources are. Social inclusion in this respect remains largely a policy aspiration, with little (if any) guidance on its practical implementation.

There are likely to be differences in understanding of social inclusion that are not made explicit in the literature. Some questions about social inclusion are likely to generate conflicting answers depending upon who is asked. For example, if the aim of personalisation is to facilitate people's connections to local communities based on their interests and values (and not their disability), does social inclusion still encompass a Men's Shed program in which five of the 12 members are people with disabilities? This question is not posed with a definitive answer in mind (which in any case, would require much more understanding of the particular context of the individuals involved, the program, and the community), but rather to highlight that some conceptual and practical ambiguities remain.

It may be that the idea of social inclusion has a fundamental ambiguity. On the one hand, this ambiguity could be defended. After all, the achievement of social inclusion for each individual is likely to be as diverse in nature as their personality, social context, socio-economic status, locality, values, informal relationships, and so on. However, ambiguous understandings of social inclusion may harm (see Rees, 1996). There is a risk that services and policymakers

may claim to promote social inclusion, when this may not be the case in practice. This may discredit the concept itself, may obscure quite variable practices, and worse, may further marginalise the individuals on the receiving end of services.

Nevertheless, some common strategies emerge in the literature for promoting inclusion. On the one hand, services can support an individual by offering assistance to help him or her connect to local groups, employment opportunities, or to maintain and/or discover relationships (Craig & Bigby, 2015; Hansji et al., 2015; Van Asselt et al., 2015; Welsby & Horsfall, 2011). On the other hand, services can offer resources to community groups, services, workplaces, and other settings to assist them to become more open and *accessible* to people with disabilities (Craig & Bigby, 2015; Hansji et al., 2015; Van Asselt et al., 2015; Welsby & Horsfall, 2011). Skilled professionals can facilitate the openness of organisations and communities, including by fostering positive relationships and offering tips and other resources on improving accessibility (this might even include reporting exclusionary or discriminatory practices to authorities, though such advocacy did not appear in any of the literature). Perhaps a third track here, is assistance to individuals and to families, in the form of resources for increasing their self-advocacy, and capacity to boost social connections.

In this way, the push for social inclusion appears to signal a reconceptualising of traditional disability services, seen elsewhere in the sector, towards more personalised forms of support that *facilitate connections* to local communities. Newer forms of service provision are seeking to discover the life goals and plans of the person in the context of their family and local community – moving away from group-based services that focus on congregated support for people with particularly disabilities who must choose from a limited range of service options. In other words, disability services are being invited to develop skills typically associated with community development and some forms of social work, by fostering more accessible and open communities. However, the literature review also suggests that services, which are undertaking this dual approach are rare, despite the general policy shift toward personalisation, particularly under the NDIS. Future research could highlight effective ways services could work with individuals, as well as working with communities, workplaces, organisations, and so on, to foster connection, contribution and belonging. Policymakers could consider ways to provide incentives and resources for developing accessible communities. Such efforts can already be seen, for example, in legislative requirements on local government and selected State and Territory government agencies to develop 'disability access and inclusion plans' (see, for example, Western Australian Government, 1993, Part 5; New South Wales Government, 2014).

Most studies drew from interviews with people with disabilities themselves. This is positive from a rights-perspective given that the CRPD requires active participation of people with disabilities in the laws, policies and practices that affect them (United Nations, 2006). This requirement is articulated as a general principle (Article 3), a general obligation in implementation (Article 4) and monitoring (Article 33), as a specific right (Articles 29 and 30), and via the inclusion of experts with disabilities on the relevant UN Committee, which is tasked with interpreting the CRPD (Article 34). The CRPD explicitly directs that people with disabilities "should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them" (CRPD Preamble para (o), art 33(3)). However, participatory research does not stop at people with disabilities being interview participants, and it is not clear the extent to which the review material was developed with other participatory approaches, for example, through research design, data collection and analysis, and dissemination.

Several gaps in the scholarly literature were highlighted in this review. For example, nothing emerged on the experience of Indigenous people with disabilities. (The same might be said for people with disabilities from culturally and linguistically diverse backgrounds). Indigenous people are not only likely to face greater disadvantage and exclusion compared to other

Australians, they also experience disability at higher rates (ABS, 2017). A recent collaboration between the First People's Disability Network (FPDN) and the ABS (2017), indicates that this research gap may soon be filled. The ABS (2017) report that "FPDN's research program takes a narrative research approach to investigate the intersection between the cultural inclusion of Aboriginal and Torres Strait Islander people and the social inclusion of a person with disability". This collaboration bodes well for addressing compounded forms of exclusion and disadvantage facing Indigenous people with disabilities, as well as bringing insights from the unique solutions developed by Indigenous communities. Clear examples also exist of Indigenous communities drawing on their own cultural, social and financial resources to create lives of belonging and connection for people with disabilities (see, for example, Department of Social Services, 2012), which is also emerging from collaborations between Indigenous and non-Indigenous people (see, for example, Australian Disability and Indigenous Peoples' Education Fund, n.d.).

Finally, in general, the literature does not explicitly engage with prominent critiques of social inclusion. Prominent critiques include the following:

- Social inclusion is a vague term that masks significant economic, social, political, and cultural connotations (Silver, 1994, p536).
- The scope of social inclusion is limited, and focuses merely on getting people 'over the line', which may still mean the person exists at the fringes without necessarily living a 'good life' or being at the *centre* of a community's social life (Goodin, 1996).
- Social inclusion tends to be a top-down policy or practice, which can position the person(s) as a passive recipient. When it is said that a person is '*being* included', it implies that someone *else*, typically a state-based service, is doing the including, rather than the person making active demands and contributions on an equal basis) (Daly & Silver, 2008).
- Social inclusion may divert attention to those facing the most extreme and spectacular forms of marginalisation, which may distract from broader trends of increased inequality (for example, distraction from rising income inequality or attacks on universal social insurance schemes that protect working and middle-classes) (Daly & Silver, 2008).
- Social inclusion does not challenge the desirability of the status quo, as captured in the question, 'inclusion into what?' Another way of expressing this is in the 1970s women's liberation slogan: 'We don't just want a bigger piece of the pie. We want to change the recipe' (Weisman, 2001).

While it would be misrepresentative to suggest that the literature reviewed here ignored these concerns (for example, several studies paid particular attention to the difference between 'passive inclusion' and active contribution and participation), it seems reasonable to say that efforts to increase inclusion in disability policy and practice do not, on the whole, aim to radically transform communities or to engage with the broader systemic concerns raised in major critiques of social inclusion.

This seems an unrealistic expectation for small-scale studies looking at efforts to connect marginalised individuals to their local communities, and seeking to breakdown decades (if not centuries) of prejudice and exclusion. Nevertheless, it still seems worth asking how things might proceed if these criticisms were taken seriously. Some commentators seeking to build on the concept of social inclusion/exclusion in the disability context have pursued the concept of 'active citizenship' as an alternative organising principle (see Power, Lord, & DeFranco, 2013, and Halvorsen, Hvinden, Bickenbach, Ferri, & Guillén Rodriguez, 2017). Halvorsen and colleagues (2017) characterise 'active citizenship' as the redistribution of resources, social rights to protect against 'major risks and contingencies', having the capability to exercise autonomy, define one's needs, pursue the kinds of life a person has reason to value, and to participate in deliberation and decision-making, whether at the individual level (for example, accepting services) or the collective level (for example, with political processes). Power et al. (2013) have conducted an international comparative study centred on active citizenship, which

examined the ways in which self-determination and personalisation are advanced in disability law, policy and practice in high-income Western countries. As noted, disability and mental health services are ostensibly moving away from the typical 'command-style' service provision that emerged in the post-war welfare state, and towards more personalised assistance. 'Active citizenship' may offer a more nuanced set of concepts for people with disabilities being able to pursue meaningful choices among good options about how to live, and to do so on an equal basis with others.

Conclusion

The understanding of social inclusion reflected in the literature appears, in general, to be pragmatic and pluralistic. There is a strong emphasis on what disability service providers can do to foster inclusion, and the conducive factors needed to move beyond congregated and segregated care to lives of independence and interdependence within a person's local communities.

This literature review was undertaken with the aim of providing aggregate data and analyses to inform policy development, educational activities, and both individual and systemic advocacy. With notable exceptions, the findings suggest social inclusion is not necessarily well-defined across policy and service provision, which may diminish the nuances of the concept, or worse, entrench practices that do its opposite. On the one hand, this ambiguity is troubling given the prominence of 'inclusion' in major national policy shifts toward 'personalisation' and individualised funding under the NDIS. On the other hand, several positive practices and well-defined skillsets are recorded and articulated in ways that will continue to foster communities in which people with disabilities can live good lives, connected to a rich network of relationships and socially valued roles, on an equal basis with others.

Future research might build upon this literature review to consider how specific policies and laws, such as the NDIS, can be used to build upon the work already undertaken to tackle social exclusion. Some of the potential pitfalls of the concept of social inclusion might even be remedied through the emerging material on active citizenship and/or human rights. Finally, while there is a fair focus on the role of disability services in improving social inclusion – that is (1) by providing direct support to individuals to connect them to community groups, and (2) providing direct support to non-disability community organisations to make them more accessible – there is relatively little focus on the ways policy and practice can be directed towards providing resources and incentives to individuals, families and mainstream community organisations to alleviate the harmful legacy of exclusion of people with disabilities, and failing to act on the social, economic and ethical imperative to build an inclusive society, where people are free to be themselves among others (Nirje, 1985).

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