Towards the decolonisation of disability: A systematic review of disability conceptualisations, practices and experiences of First Nations people of Australia

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A B S T R A C T

In many settler-colonial countries, Indigenous people do not access disability services at rates commensurate with disability prevalence. Existing research suggests that services often do not reflect Indigenous values and social practices, impacting on accessibility. Furthermore, disability services have historically been implicated in processes of colonisation. There is an urgent need to decolonise disability services. Understanding Indigenous knowledge and experience of disability is a necessary step towards achieving this. We systematically reviewed the disability conceptualisations, practices and experiences of First Nations peoples of Australia. Twelve studies met inclusion criteria. There was a consensus among these studies that Western constructs of disability do not resonate with many First Nations people across Australia. The studies reported that many First Nations people conceptualise most disabilities as unremarkable conditions that reflect the normal range of human diversity, although some conditions may be associated with social stigma. Inclusive attitudes and practices of caregiving in First Nations families facilitate the participation of First Nations people with disabilities in family and community life. However, ableism and racism in broader society combine to exclude many First Nations peoples with disabilities from public spaces and from labour markets. Disability services regularly fail to reflect First Nations values and social practices, and can lead to further disempowerment and marginalisation due to diagnostic processes; displacement from country and communities; gendered discrimination; and poor relationships with service providers. We argue that intersectional experiences of colonialism, racism, ableism and sexism, particularly in disability services, can lead to the marginalisation of First Nations participants and families. The decolonisation of disability services requires services to embrace diverse First Nations values and practices associated with human capability, social participation and caregiving. Decolonising disability services also necessitates First Nations control of the governance of disability services and reform across service, organisational, systemic and conceptual levels.

1. Introduction

1.1. Disability and indigenous peoples

In many setter-colonial countries such as Aotearoa/New Zealand, the United States and Australia, Indigenous peoples do not access disability support services at rates commensurate with the prevalence of disabilities among Indigenous populations (Bevan-Brown, 2013; Ryser et al., 2014; Temple et al., 2020). While the reasons for this are complex and multifactorial, there are indications that many disability support services do not reflect Indigenous understandings of human capability and bodily function. Disability support services in states where Indigenous peoples are a minority frequently fail to encompass Indigenous values

and social practices, and in some cases, services are experienced by Indigenous people as hostile environments (Ball and Lewis, 2011; Dindar et al., 2017; Temple et al., 2020).

According to the widely-adopted World Health Organisation (WHO) biopsychosocial model of disability (2002), it is the interaction between a person's bodily functions and capacity and social environments that creates disability. Although the WHO characterises disability as a universal experience, contemporary cosmopolitan constructs of disability emerged through particular historic, political and economic circumstances in Western societies associated with industrial capitalism and waged labour (Barnes and Mercer, 2010). Cosmopolitan constructs of disability, such as the WHO model, are widely reported to have little resonance with many Indigenous peoples internationally (Ariotti, 1999;

Connell, 2011; Varvarezou, 2020).

Disability constructs and disability support services are implicated in the colonisation of Indigenous peoples. The eugenics movement of the 19th and 20th centuries defined Indigenous peoples as biologically inferior, and the scientific racism that it espoused was used to justify a range of authoritarian and discriminatory measures (Kelm, 2004). In some states, disability was a pretext for the systematic removal of Indigenous children from their families and their confinement in state and church-run institutional care (Ravindran et al., 2017; Rees, 2003). In contemporary times, colonial domination persists in disability support services that often exclude many Indigenous people. Low rates of Indigenous participation in disability support services reportedly reflects the operationalisation of disability in ways that do not support Indigenous values and social practices; and Indigenous peoples' mistrust of service providers (Productivity Commission, 2011: 539–540).

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) Articles 21 and 22 (2007) describes the social and economic rights of Indigenous people with disabilities. The Declaration notes the need for special measures to ensure that Indigenous people can access appropriate disability support services. As scholars of Indigenous peoples' historic and contemporary experiences of disability have argued, there is an urgent need to decolonise disability support services for Indigenous peoples (Hollinsworth, 2013; Kuppers, 2013).

Like colonisation, decolonisation is a process of transforming material and political relations with consequences for institutional practices and everyday lived experience. Decolonisation goes beyond a legal domain of treaties and other political agreements between states and Indigenous polities. It also encompasses the reconfiguration of health and social services for Indigenous peoples by changing power relations within these institutions and transforming their conceptual underpinnings and practices (Strakosch, 2018). Decolonising disability support services requires acknowledging that non-Indigenous constructs of human functioning can have oppressive impacts for Indigenous peoples (Dudgeon et al., 2014: 205). It necessitates the devolution of support services to Indigenous collectivities and the incorporation of Indigenous knowledges, values and social practices into disability models of care (Dudgeon et al., 2014; Hollinsworth, 2013; Kelm, 2004). While it may not be possible for Indigenous peoples to entirely disengage from settler-colonial states and their service systems, Kelm (2004) argues that decolonisation may take the form of the involvement of Indigenous leaders, social structures and organisations in the governance of services and the amalgamation of Indigenous and non-Indigenous concepts and approaches in professional practice.

Understanding Indigenous approaches to disability is therefore a critical component of the decolonisation of disability support services. However, the scholarly literature on Indigenous conceptualisations, experiences and practices of disability is still relatively underdeveloped (Avery, 2018) and is interdisciplinary in nature. While Indigenous diversity is often acknowledged, the literature on Indigenous approaches to disability has rarely been brought together in order to either demonstrate its cohesion or illuminate points of difference. To that end, we undertook a systematic review of the disability conceptualisations, practices and experiences of First Nations peoples of Australia, comprising Aboriginal and Torres Strait Islander peoples. To our knowledge, this review is the first systematic review of published literature on Indigenous approaches to disability internationally. As no culture is fixed in time, and as Indigenous cultures, beliefs and practices are diverse, we have confined our focus to the contemporary Australian experience. Our review aimed to develop a broad synthesis of the variety of ways in which First Nations people understand and experience disability in the present historic moment. We aimed to identify implications for the decolonisation of disability support services, without offering a prescriptive list of recommendations.

1.2. A note on terminology

Our systematic review was challenged by our need to engage with 'disability' as both a set of conditions and as a normative construct. An equivalent term or concept associated with human capability does not typically exist in the more than 250 First Nations languages in Australia (Avery, 2018). Furthermore, as this review will illustrate, Standard Australian English lacks terms that reflect First Nations constructs of human and social functioning. In the absence of more adequate terminology, we have used the term 'disability' in the singular to denote particular constructs of human capability, such as those adopted by the WHO, the Australian government, service providers and First Nations people. However, we acknowledge the shortcomings of this term, including its limited capacity to reflect First Nations concepts and understandings. When referring to physical, neurological, psychosocial or sensory conditions in this systematic review, we use the term 'disabilities' (plural). The published literature on Indigenous peoples' experiences of disabilities adopts, explicitly or implicitly, a range of biomedical and social definitions of disability. We avoided narrowing results by adopting a particular definition of 'disability', and reviewed literature that deploys any concept of 'disability', while centring the WHO model in our analysis, as a widely adopted definition that often informs disability support services, including in Australia.

2. Methods

2.1. Systematic literature review methodology

Systematic review is an approach to synthesising large bodies of evidence on how social phenomena are understood and how policies, measures and supports are experienced by the people they are designed to assist, in addition to determining efficacy (Petticrew and Roberts, 2006). The methodology of this review is based on best-practice systematic review principles established through the widely-accepted Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) Statement (Matthew et al., 2020). Our analysis of included literature is also informed by methodological approaches for conducting systematic reviews of social policy issues, such as our meta-synthesis of included studies (Petticrew and Roberts, 2006; The Campbell Collaboration, 2021). We developed a review protocol to specify our methods (available on request from the authors).

Systematic review is a research approach that emerges from Western positivist traditions and privileges academic knowledge. We recognise that systematic review methodologies therefore have the potential to marginalise First Nations voices and knowledges, as well as the voices and knowledges of people with disabilities. In recognition of this, we adopted an Indigenous standpoint theoretical framework, developed by disability scholars John Gilroy and Michelle Donnelly (2016). This framework is grounded in a critique of the representation of First Nations people with a disability through Western constructs of impairment and normality. It positions knowledge and research as socially situated and constructed. It calls for ethically-grounded and culturally safe practices in disability knowledge production through collaboration between First Nations and non-Indigenous researchers; and through methodologies that centre the knowledge, voices and experiences of First Nations people with disabilities within research development processes, research methods, and approaches to analysis. While a tension exists between systematic approaches to literature synthesis and the foregrounding of First Nations perspectives, we have sought to address this tension through the following measures:

1. Formation of a research team which draws on a range of First Nations and non-Indigenous lived experiences, perspectives and expertise. The authors of this systematic review include a First Nations disability advocate, a First Nations research leader, a non-Indigenous researcher who identifies as having a disability, and other non-

Indigenous researchers with substantial experience in collaborating with First Nations people and communities. The research team brought together understandings of First Nations values, beliefs, practices and experiences; experiences of disability and knowledge of disability service systems; and expertise in systematic review and meta-synthesis methods.

2. Collaborative development of research questions and methods through engagement of the research team with First Nations disability stakeholders in workshops and meetings.

3. Synthesis of First Nations peoples' conceptualisations, practices and experiences associated with disability, and using these findings to inform further research and the implications for disability services.

4. Adoption of a broadly-defined inclusion criteria, which are designed to centre First Nations study participants' voices and to include studies published by First Nations authors and organisations in outlets other than academic journals.

5. Critical appraisal of the involvement of First Nations people, knowledges and methodologies in the included studies, through the development and use of a new appraisal tool.

6. Recognition of the unique perspectives of First Nations disability scholars in the presentation of findings. While we are unable to privilege studies authored by First Nations authors within a systematic review methodology, we have indicated within the text where studies were conducted by a first author who identifies as a First Nations person.

7. Discussion within the research team of the initial synthesis, including checking initial findings with the lived experience of First Nations advocates and researchers.

8. Respect for the internal diversity of First Nations people and their knowledge and experience in the synthesis approach. In this review, we have not sought to condense First Nations perspectives into a single model of disability and have been conscious not to over-generalise and homogenise First Nations understandings and experiences of disability. We have aimed to preserve contextual differences by making reference to the particular study sites, regions, First Nations groups or situations where possible.

9. Building on the theoretical and conceptual insights of First Nations scholars in our analysis, particularly in relation to the intersectionality of racism and ableism; and gendered dimensions of disability.

The Human Research Ethics Committee of the Australian National University advised that ethical clearance for this project was not required as it did not involve the collection of primary data.

2.2. Inclusion and exclusion criteria

In this review, we included research and evaluations reported in peer-reviewed journals and grey literature. Studies were included if they contained primary data that incorporated the disability conceptualisations, practices and experiences of First Nations peoples of Australia. Studies also met the inclusion criteria if they adopted quantitative, qualitative or mixed-methods approaches, and utilised primary methods which centred First Nations people's experiences and perspectives e.g. through interviews, focus groups, yarning circles, surveys and consultation processes. We limited our review to sources published since 2000. This timeframe reflects our conceptualisation of cultures as sets of understandings and practices that change over time; and the growing scholarly interest in First Nations experiences of disabilities over recent decades. Sources were excluded if they did not include First Nations participants; if they included both First Nations and non-Indigenous participants but did not report on results of First Nations participants separately from non-Indigenous participants; and if they reported on experiences of specific conditions (e.g. autism or spinal cord injury), and not the concept of disability.

2.3. Search and selection strategy

We developed an electronic database search strategy for peer-reviewed and grey literature using Boolean terms in collaboration with a university-based health librarian. Initial search terms were derived from Medical Subject Headings (MeSH) keywords, and adapted after initial testing (Fig. 1). As discussed above, the term 'disability' and its various Western constructs do not necessarily reflect First Nations conceptualisations of human capability. However, 'disability' and associated terms are widely used in the literature, while First Nations terms associated with human capability are not reported.

We conducted searches (in February 2021) of the following databases: INFORMIT – AIATSIS, Web of Science, EBSCOhost (CINAHL, academic search premier, ebooks, socIndex), PubMed, Australian Indigenous Healthinfonet. Additional literature was identified through manual searching of reference lists of included studies and through our own personal knowledge of the field. Search results were then exported to Covidence systematic review software and duplicates were removed. SP and CW independently screened all titles and abstracts for inclusion; and any discrepancies were resolved through consensus-based discussion between the two authors. Subsequent full text screening of all sources was also completed by SP and CW independently, and final inclusion was determined through further consensus-based discussion.

2.4. Research quality appraisal

We adopted a pragmatic approach to assessing research quality due to the small size of the body of research on First Nations peoples' conceptualisations, practices and experiences of disability, and in order to avoid overly limiting results and potentially excluding First Nations perspectives. We adopted a 'best available evidence' approach (Canadian Homelessness Research Network, 2013), in which research quality is assessed and considered in the analysis but no studies are excluded on the basis of poor quality research. We assessed research quality using the Mixed Methods Appraisal Tool (MMAT), a validated and widely-used tool for assessing research conducted through a wide variety of study designs (Hong et al., 2018; Pace et al., 2012; Pluye et al., 2009).

2.5. Appraisal of First Nations peoples' involvement in research

We also developed and used a novel critical appraisal tool to assess the extent to which First Nations peoples and their perspectives were involved in the research process in included studies. Our criteria were informed by the much more detailed Consolidated Criteria for Strengthening Reporting of Health Research Involving Indigenous Peoples (the CONSIDER Statement) (Huria et al., 2019); the Aboriginal and Torres Strait Islander Quality Appraisal Tool (Harfield et al., 2020); and the knowledge of First Nations co-authors and advisors (Table 1).

("Indigenous Australia" OR "Indigenous people*" OR "Indigenous popula*" OR aboriginal OR "torres strait islanders" OR "Torres Strait Islander" OR ATSI OR "First Nations" OR "First Peoples" OR Koori OR Murri)

AND

(disability OR disabilities OR disabled OR impairment OR impaired OR "special needs")

Fig. 1. Search terms used in academic databases.

Table 1
First Nations peoples' involvement in research appraisal criteria.

Criteria	To a large extent	Somewhat	Not at all	Not reported
To what extent are Indigenous people involved in setting the research priorities/agenda?	Authors report that research topic or question emerged from an Indigenous organisation or group or discussions with Indigenous collaborators	Research topic or question described as aligning with priorities or issues articulated by Indigenous people or organisations, e.g. in published literature	Research topic or question described as aligning only with other people or organisations' priorities, e.g. those of non-Indigenous funders or non-Indigenous policymakers	Cannot be determined from the published manuscript
To what extent are Indigenous people and perspectives represented within the research team and research governance processes?	As authors of the study; or as supervisors or in an advisory capacity, e.g. project advisory group with majority Indigenous membership	Project advisory group with minority Indigenous membership	No involvement of Indigenous people in an advisory capacity or within the research team	Cannot be determined from the published manuscript
To what extent does the study's theory, methods and methodology incorporate Indigenous ways of knowing, being, seeing, doing?	At least two of the following shown:	Only one of the following shown:	Theoretical influences do not include Indigenous standpoint theory or an Indigenous/Indigenist methodology	Cannot be determined from the published manuscript
	Indigenous standpoint theory or an Indigenous/Indigenist methodology framed this study Indigenist methods such as yarning and storytelling were used Indigenous collaborators involved in the development of research methods and the analysis of data.	Indigenous standpoint theory or an Indigenous/Indigenist methodology framed this study Indigenist methods such as yarning and storytelling were used Indigenous collaborators involved in the development of research methods and the analysis of data	No Indigenist methods such as yarning and storytelling used

No Indigenous collaborators were involved in the development of research methods and the analysis of data | |

2.6. Meta-synthesis

We analysed our results using a meta-synthesis approach, a method of systematically comparing and translating studies into one another (Noblit and Hare, 1988). Meta-synthesis aims to preserves contextual differences between studies while identifying common concepts, and is therefore an appropriate method for synthesising studies where contextual differences can be expected to impact on findings (France et al., 2019). We translated each of the included sources into each other. This was carried out by comparing, contrasting and synthesising the themes and findings of each individual source to all other sources in order to generate an encompassing set of themes. SP and CW each developed an initial set of themes, and following discussion within the research team and further analysis of the literature, reached consensus on the final set of themes.

3. Results

Our search strategy yielded a total of 1318 unique results. 12 sources met inclusion criteria and were extracted for analysis (Fig. 2). There
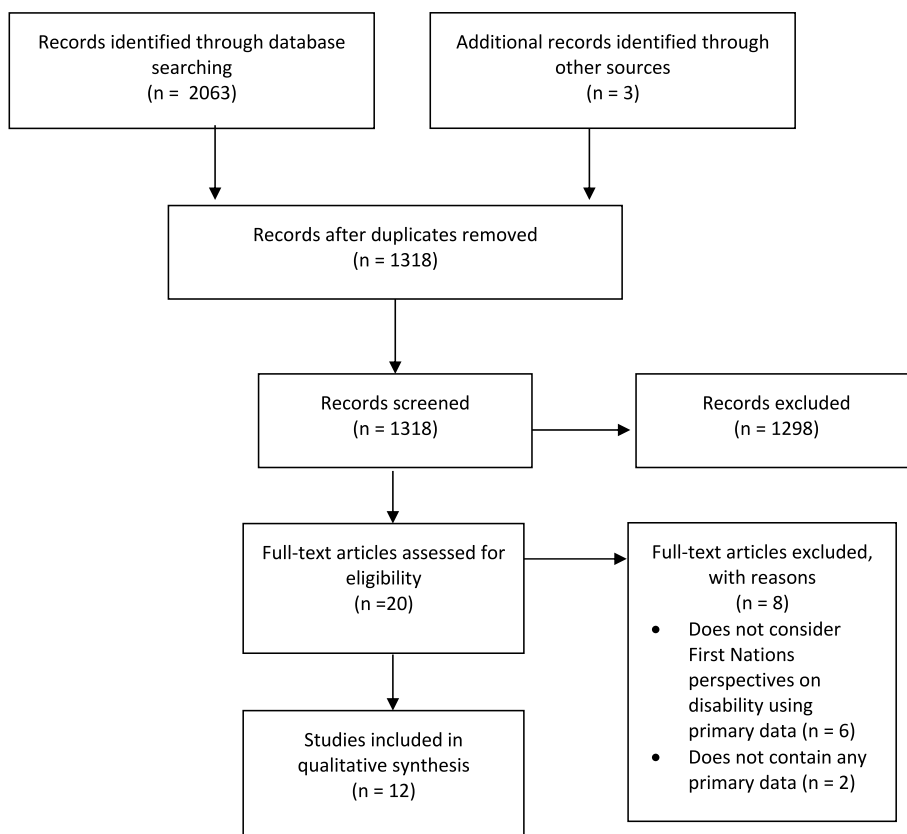
Fig. 2. PRISMA flow diagram of search and screening process.

were two main reasons for exclusion: studies did not consider First Nations peoples' conceptualisations, practices or experiences of disability through analysis of primary data; and studies did not contain any primary data. During title and abstract screening, initial disagreement arose between reviewers in 47 of 1318 titles (96% agreement; kappa: 0.26), with all disagreements resolved through consensus-based discussion.

The 12 sources that met inclusion criteria represented 10 studies and encompassed nine journal articles, two reports and one book (Table 2). Included sources represented a broad range of academic disciplines including disability studies, public health, anthropology and sociology, and elicited the experiences and perspectives of First Nations people in urban (n = 5), regional (n = 4) and remote areas (n = 5), with some studies covering multiple location types and some study sites not disclosed by authors. All included studies considered the understandings and experiences of disability of Aboriginal people, while none of the included studies discussed the experiences of Torres Strait Islanders.

3.1. Results of research quality appraisal

Of the 12 sources included in the review, 10 adopted qualitative methods and two used a mixed methods approach. In the Rees (2003) study, only the qualitative data was of relevance to the review and addressed inclusion criteria; and only one study, by Avery (2018), in which qualitative and quantitative data were both of relevance, was assessed using mixed methods research criteria. Nine out of 12 included studies met all quality appraisal criteria of the MMAT on the appropriateness of the methods and approach in addressing the research questions and interpreting the data (Appendix 1).

3.2. Results of First Nations peoples' involvement in research appraisal

We also conducted an appraisal of the involvement of First Nations peoples in the included studies. During this process, in one case, we also reviewed an associated methodological paper published by authors of two included studies, but not included in our review (Gilroy et al., 2018). All sources performed highly in at least one of the three assessed domains, and five sources performed highly in all three domains (Table 3). Generally, included studies had strong representation of First Nations peoples within research teams and research governance processes, while few studies involved First Nations peoples in setting the research agendas or priorities.

3.3. Results of meta-synthesis

Our meta-synthesis found that First Nations conceptualisations, practices and experiences of disability are shaped by two different but interconnected influences: understandings and experiences of disability and participation in society; and experiences of disability support services. First Nations conceptualisations and experiences of disability are informed by First Nations attitudes towards human capability, and First Nations social structures and practices of caregiving. Experience of disabilities is also impacted by the relationship and interactions between First Nations people and broader society, through structural inequality, racism and ableism. Disability support services, largely informed by non-Indigenous constructs of disability, further influence First Nations experiences of disabilities. Disability services shaped by non-Indigenous norms, diagnostic processes and care practices can lead to exclusion and marginalisation. The relationships of First Nations people with individual service providers have the potential to lead to further exclusion and disempowerment, but can also foster inclusivity and respect.

Table 2
Sources included the review.

Record	Study design & methods	Study site and population group	Research questions/ aims
Avery (2018)	Mixed methods; analysis of survey data, interviews/ yarns with 47 participants, 11 testimonies from an elders' forum	First Nations people living in urban, regional and remote areas, including in NSW and the NT	To record the lived experience of First Nations people with disabilities
Dew et al. (2019)	Qualitative; interviews and focus group discussions with 109 participants	Remote Central Australia; Anangu aged 18+ with disabilities and their carers living in and away from their communities; and service providers	What does a good life comprise among Anangu with disabilities and how can service providers support them?
DiGiacomo et al. (2017)	Qualitative; interviews with 19 participants.	Parents or primary carers of Aboriginal children aged 0–8 years who attended a developmental clinic at an Aboriginal health service in a suburban area near a capital city in eastern Australia	To better understand the experiences and needs of parents/ carers/families of Aboriginal children with disabilities
Fitts and Soldatic (2020)	Qualitative; interviews and yarning circles with 12 participants	First Nations people caring for a family member with disabilities and living with disabilities themselves in four Australian regional towns	To explore Indigenous disabled carer experiences who are navigating complex infrastructures of social protection for those that they care for and to gain support for their own health and needs as a carer with disabilities
Gilroy et al. (2020)	Qualitative; Interviews and focus group discussions with 109 participants	Remote Central Australia; Anangu aged 18+ with disabilities and their carers living in and away from their communities; and service providers	To investigate service delivery barriers and challenges experienced by Aboriginal people with disabilities in Central Australia
Green et al. (2018)	Qualitative, longitudinal; an initial and follow-up interview with 19 participants	Carers of First Nations children with disabilities aged 0–8 attending a First Nations specialist disability service in an urban area in eastern Australia	To explore carers' experiences of interactions with providers while accessing services and support for their child
King et al. (2014)	Qualitative, ethnographic; interviews and participatory observational methods over 2 years	Brisbane, Qld; research undertaken at a respite centre for First Nations people and in participants' homes	To examine the lived experience of Indigenous Australian people with disabilities
Pearce (2000)	Qualitative; auto-ethnography/ personal narrative	Location is not stated; author is participant	Exploring the experiences of a male First Nations carer
Ravindran et al. (2017)	Qualitative; analysis of policy documents, media	NSW; First Nations spokespeople,	To explore Western and Indigenous conceptualisations of

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inclusion towards human capability. These inclusive, accommodating attitudes in First Nations communities can be grounded in values of kinship, relationships, responsibility, caring and sharing (King et al., 2014; Rees, 2003; Senior, 2000). For instance, in Senior's study (2000) across multiple sites in the Top End of the Northern Territory, First Nations people equated poor health with loneliness and social isolation, and did not consider themselves to be unwell or incapacitated when they were cared for by relatives. Carers can therefore help mitigate barriers to the participation of First Nations people with disabilities in community life.

3.3.1.3. Caregiving as an important social role and form of participation.
Caregiving is valued and expected in many First Nations communities. Caregiving is described in multiple sources as representing one's commitment to one's family, and is an important part of First Nations identities (Fitts and Soldatic, 2020; Pearce, 2000:21; Senior, 2000:22). Caregiving is reported to be an important social role and a form of participation in First Nations communities across Australia, particularly for women (Fitts and Soldatic, 2020; Green et al., 2018; Sands, 2005). However, First Nations caregiver, Tony Pearce (2000), argues that First Nations men are also caregivers, and gender roles in First Nations communities are not necessarily fixed.

Fitts and Soldatic (2020), in their study in four regional Australian towns, report that some First Nations people with disabilities may be carers themselves. Some included studies report perspectives amongst First Nations participants that obtaining care for family members from external service providers entails the neglecting of families' responsibilities (Pearce, 2000; Rees, 2003). Intensive caregiving can also lead to financial, physical and psychosocial hardship in some First Nations families (DiGiacomo et al., 2017; Fitts and Soldatic, 2020; Green et al., 2018). According to Fitts and Soldatic (2020), an ethic of caregiving can limit the ability of First Nations caregivers to undertake paid work, and this can particularly impact women, sole carers and single parents, as well as carers who themselves live with disabilities or chronic illnesses. Social security and disability service systems are ill-equipped to respond to these issues (Fitts and Soldatic, 2020). Overwhelmingly, the literature describes strong desires among First Nations people for greater financial and social support for caregiving within families (Dew et al., 2019; DiGiacomo et al., 2017; Fitts and Soldatic, 2020; Gilroy et al., 2020; Green et al., 2018; Pearce, 2000; Rees, 2003; Senior, 2000).

3.3.1.4. Exclusion from broader society through the intersection of ableism, structural inequality and racism.
Colonisation has dispossessed and marginalised First Nations people as a collective; but has especially marginalised First Nations people with disabilities (Avery, 2018; Ravindran et al., 2017). The interaction between ableism and racism in broader society can create specific forms of exclusion of First Nations peoples with disabilities. For example, Avery (2018) recounts the experiences of a First Nations man with a condition that impacted his balance and gait, who was frequently presumed intoxicated by other members of the public when visiting public venues.

Structural inequalities can combine with ableism and interpersonal racism. While broader economic exclusion of First Nations peoples also impacts those with disabilities, Avery's intersectional analysis shows that First Nations people across Australia with severe and profound conditions are almost twice as likely as other First Nations people to be unemployed (2018:132). Labour market discrimination towards First Nations people with disabilities often results in their economic exclusion and can prevent them from meeting their basic needs and supporting their families. Yuin researcher, John Gilroy, along with colleagues (2020), also report that the economic exclusion and resultant financial stress of First Nations families in Central Australia renders many families unable to provide their relatives with disabilities with appropriate clothing, bedding, food and other resources.

First Nations communities, particularly in remote areas of Australia,

can lack the infrastructure and facilities typically found in other communities to support people with disabilities. Some studies in this review report inappropriately-designed housing and public facilities in First Nations communities. Such infrastructure can lack facilities to aid mobility (e.g. ramps and guard rails), which can hinder the access, inclusion and participation of First Nations people with disabilities in family life and broader communities (Gilroy et al., 2020; Senior, 2000). Several studies also report instances of First Nations people with disabilities living in housing located too far from medical and disability support services, and having limited access to transport, which further impede access, inclusion and participation in services, and society in general (Avery, 2018; Fitts and Soldatic, 2020; Gilroy et al., 2020).

3.3.2. Experiences of disability support services

3.3.2.1. Disability services and systems structured by western norms.
Disability service systems are typically shaped by Western norms and assumptions which may not reflect First Nations values, needs and practices. Included sources report that individual care packages (where individuals with disabilities receive funds to spend on services and supports) do not reflect a collective, family-based approach or provide support to carers (DiGiacomo et al., 2017; Fitts and Soldatic, 2020; Gilroy et al., 2020; Green et al., 2018; Rees, 2003; Pearce, 2000). While several of the reviewed studies report a general ethic of caregiving in many First Nations families, some First Nations carers experience a lack of support from disability service systems (Pearce, 2000; Rees, 2003). This can lead to carer burnout and can also leave families with no alternatives to placing relatives in residential care, which can result in the fragmentation of family groups (Pearce, 2000; Rees, 2003). Individual care packages can also lead to conflict in First Nations families when several family members have disabilities, but only some are eligible for support and resources (Fitts and Soldatic, 2020; Rees, 2003). Furthermore, Gilroy et al. (2020), in their Central Australian study, contend that individual, goal-oriented care plans inappropriately imply that people with disabilities need to alter their conditions or behaviour, whereas inclusion and participation can be facilitated through existing First Nations social practices and structures.

3.3.2.2. Disempowering experiences of diagnosis.
Diagnosis of disability is widely reported to be a distressing and confronting experience amongst First Nations people, and can conflict with their values and identities. Receiving medical diagnoses such as 'deaf', 'autistic', 'intellectually disabled' and 'developmentally delayed' classifies people as 'abnormal' or 'damaged,' and can create negatively-constituted difference in First Nations families and communities who may consider themselves to be social wholes (Avery, 2018; King et al., 2014; Ravindran et al., 2017; Rees, 2003). The application of diagnostic categories to First Nations people may trigger collective memories of historic government practices of categorising First Nations peoples based on their perceived physiology, and concomitant racist policies of removing children from families (Gilroy et al., 2020; Ravindran et al., 2017; Rees, 2003). King et al. (2014), in their ethnographic study involving First Nations people from across Queensland, also argue that diagnoses can create distinctions between First Nations people with disabilities and chronic illnesses such as cancer, which may not represent First Nations conceptualisations of health and illness, and which may lead to differential access to support services and resources.

Although the concept of 'disability' has little resonance with many First Nations people, it is a construct many must engage with in order to access support services. Included sources discuss how diagnostic processes and labels invest power in service providers to define First Nations peoples' bodily states of being, as well as to determine First Nations peoples' eligibility for support services. Rees (2003), in her study of disabilities in First Nations communities throughout South Australia, notes that diagnoses are typically made by predominantly

non-Indigenous medical specialists, and argues that this can lead to feelings of inadequacy, helplessness and anger that render First Nations people unable to advocate for themselves. Some studies report that distressing diagnosis experiences can lead First Nations people to disengage from disability support services (Green et al., 2018; Ravindran et al., 2017; Rees, 2003).

3.3.2.3. Displacement from country and communities. We have described the presence of First Nations people with disabilities in their communities and in their country as enabling social participation. However, low availability of disability support services in First Nations communities, particularly in regional and remote areas, is widely reported (Avery, 2018; Dew et al., 2019; Fitts and Soldatic, 2020; Gilroy et al., 2020; Senior, 2000). In many cases, First Nations people contend with displacement from their communities and country in order to access disability support services, which often leads to further exclusion (Avery, 2018; Dew et al., 2019; Gilroy et al., 2020; Senior, 2000). Senior (2000) suggests that some First Nations people in remote areas may not access healthcare or other services to seek a diagnosis if they suspect it will result in displacement from family, community and country.

3.3.2.4. Gendered violence, discrimination and exclusion. Disability support services can be environments of gendered violence and exclusion for First Nations people. Sands (2005) reports that First Nations women with disabilities may be vulnerable to violence and abuse in disability support services due to inadequate safeguards and human rights protections. She suggests that practices of forced sterilisation of some women with intellectual disabilities in Australia may impact on First Nations women. Pearce (2000), meanwhile, demonstrates that disability and other support services are often informed by traditional Western gender norms, providing limited support to First Nations men who are providing care to relatives with disabilities.

3.3.2.5. Relationships with service providers. First Nations peoples' relationships and interactions with the staff members of service providers is a critical mediator of their experience of disability support services. Experiences of overt and covert interpersonal racism and discrimination are cited in many studies and described as a key factor in the low levels of participation in disability services among First Nations people (Avery, 2018; Green et al., 2018; King et al., 2014; Senior, 2000). Frequent experiences of disrespect and discrimination can lead to 'apprehended discrimination', in which a previous experience can create expectations of future discrimination, and thus lead to disengagement from services (Avery, 2018).

Included studies describe disability service providers' inattention to interpersonal relationships as a key factor in disengagement from disability services. Service providers who are not aware of structural power imbalances, and who fail to demonstrate cultural awareness and sensitivity, may cause distress and disempowerment among First Nations participants (Gilroy et al., 2020; Green et al., 2018). Service providers who do not build trust and rapport with their participants, rush consultations, fail to listen, do not make decisions in partnership with participants and do not display adequate empathy can offend and deter First Nations people (Gilroy et al., 2020; Green et al., 2018). Some sources also discuss the communication difficulties experienced by First Nations people who do not speak Standard Australian English as a first language when accessing services, and recommend the use of interpreters (Gilroy et al., 2020; Rees, 2003). The capacity for service providers to develop rapport with participants can be further impeded by systemic issues, such as service providers not having a permanent presence in communities; time limits on appointments; and funding constraints (Dew et al., 2019; Green et al., 2018; King et al., 2014).

Included studies also provide some accounts of constructive relationships between First Nations people and disability service providers. First Nations owned and led organisations, such as Aboriginal

Community Controlled Organisations, are described as offering a more holistic approach of addressing the combined health and social factors that impact on participants' lived experience, rather than focussing solely on medical diagnoses or physiology (Dew et al., 2019; Gilroy et al., 2020; Green et al., 2018; King et al., 2014; Rees, 2003). First Nations organisations are also reported as fostering culturally safe environments which respect First Nations social and communicative practices. First Nations organisations may adopt approaches that dedicate time to developing trusting, respectful relationships with clients; may recognise and respect the social roles of participants such as those of elders; may provide services in a flexible manner; and may avoid pressing matters that clients are evidently uncomfortable with discussing (Dew et al., 2019; Green et al., 2018). However, according to King and colleagues in their Queensland-based study (2013), First Nations organisations still must contend with service systems shaped by Western norms (for example, associated with governance and risk management), which may not reflect First Nations constructs of governance premised on social relationships.

3.3.2.6. Other barriers to accessing services. The studies we reviewed discussed a range of additional access barriers to disability support services amongst First Nations people, particularly in remote areas. These included a lack of available services; narrowly-defined eligibility criteria; the direct and indirect costs of accessing services borne by participants and families; poor access to transport and telehealth facilities; limited access to Auslan interpreters; and complex treatment pathways (Avery, 2018; Dew et al., 2019; Fitts and Soldatic, 2020; Gilroy et al., 2020; Green et al., 2018; Rees, 2003; Senior, 2000). Some of these barriers are also likely to impact on non-Indigenous people, however the impact on First Nations people may be greater due to cultural and, in some cases, language differences; greater likelihood of remote residence; and socio-economic exclusion.

4. Discussion

In this review we have systematically synthesised the published literature on the conceptualisations, practices and experiences of disability of First Nations peoples of Australia. The included studies illustrate that understandings and experiences of disability amongst First Nations people are diverse and nuanced, and it is therefore not possible to develop a single First Nations model of disability. Our synthesis shows that many First Nations people conceptualise most forms of disability, and in particular physical conditions, as unremarkable characteristics that reflect the normal range of human diversity. While some neurological and psychosocial conditions may be stigmatised in some communities due to their association with deviance from social norms and sorcery practices, leading to exclusion within communities, overwhelmingly the literature reports inclusive attitudes and practices. While none of the studies included in our review specifically explored First Nations peoples' understandings and experiences of sensory conditions, a limited number of qualitative studies report similar attitudes of acceptance and inclusion to sensory disabilities such as hearing loss (Walsh, 2020). These findings of inclusive attitudes and practices have been well described in the Australian First Nations and international Indigenous literature (Avery, 2018; Bevan-Brown, 2013; Lindblom, 2017). Our meta-synthesis also extends research on Australian First Nations conceptualisations of disability, illustrating that, for First Nations people, disability can be a collective as well as individual experience, pertaining to individuals, carers and family groups. Although this finding has not been widely reported in the disability literature, community-based studies on Australian First Nations conceptualisations of health have similarly described collective experiences of illness and some understandings of health as the embodiment of social conditions (Dussart, 2010; Reid, 1983; Sansom, 1982).

Our synthesis also finds that First Nations people with disabilities

experience specific forms of exclusion in broader society. Ableism and racism intersect to exclude many First Nations peoples with disabilities from public spaces and from labour markets. Social exclusion can be perpetuated by disability services which frequently fail to reflect First Nations values and social practices, and can lead to further disempowerment and marginalisation due to diagnostic processes; displacement from country and communities; gendered discrimination; and poor relationships with service providers. The social and economic participation and inclusion of First Nations people with disabilities, in many cases, is facilitated through social practices and structures in First Nations families and communities, and alarmingly, can be inhibited by disability support services.

This review has illustrated that understanding how First Nations peoples conceptualise disability and human capability requires considering how First Nations people understand meaningful participation in society. Our findings suggest that, across Australia, family and community life can often represent important domains of participation, which can include contextually-specific social, cultural and economic activities. Meaningful participation amongst First Nations people is also likely to be influenced by age, gender, social position and personal attributes. Important modes of participation described in a small number of included studies undertaken in remote areas encompassed economic activities such as hunting, gathering and fishing. None of the included studies made reference to employment in the formal economy as a meaningful activity. However, this could potentially reflect the broader exclusion of many First Nations people from formal economies, and the small number of studies meeting inclusion criteria in our review.

Our meta-synthesis also extends the published literature on First Nations peoples' experiences and practices associated with disability by foregrounding an ethic of caring in First Nations families. While inclusive attitudes have been well described in the Australian and international Indigenous literature (Avery, 2018; Bevan-Brown, 2013; Lindblom, 2017), we have shown that in many instances, family caregiving enables the participation of First Nations people with disabilities. Our synthesis suggests that caregiving itself can represent a form of meaningful social participation, particularly for First Nations women, but also for men. Contemporary Western constructs of women's empowerment, which describe the liberation of women from caregiving roles, may not necessarily reflect the values of care in many First Nations communities, in which family caregiving is extensive, and in which caregiving may be considered an important social role, as First Nations feminist scholars have argued (Moreton-Robinson, 2000).

However, an ethic of caregiving can also lead to financial, physical and psychosocial hardship in First Nations families due to a lack of external support. This can result in carer burnout, and can lead to some First Nations people with disabilities being placed in institutional care and to their displacement from their communities. We have noted a bias towards traditional Western gendered norms in disability support services, which can impede access to support for male carers. The broader literature on First Nations practices of caregiving also describes collective practices of care in which caregiving is shared by multiple family members. These collective practices of care may not be recognised or supported by carer supports such social security payments for carers or respite care services, which are structured around the presence of a single primary carer (Hill et al., 2016; Puszka, 2021). Disability services that do not provide appropriate support to family carers may therefore corrode First Nations values and practices of kinship and caregiving, and may lead to the social exclusion of those placed in institutional care.

While theoretical approaches to First Nations disability have often centred intersectional experiences of racism and ableism (Avery, 2018; Hollinsworth, 2013), our analysis suggests that gender can also intersect with social and structural dimensions of disability to create particular forms of marginalisation in First Nations communities. The limited support provided to family carers may at once lead to overwhelming physical and financial stress among female carers, who may have disabilities or chronic illnesses themselves; and may prevent some men

from fulfilling social roles and obligations within their families. As Klein (2021) has argued in relation to the Australian social security system, disability services exploit caregiving practices in First Nations families and expropriate the caregiving labour of First Nations carers, particularly women. Additionally, the literature suggests that First Nations women with disabilities may potentially be exposed to physical abuse and violations of their reproductive rights in disability services due to the particular vulnerabilities created the intersection of gender and disability. Gendered roles and inequalities, and their interaction with disability services, can thus have a substantial impact on First Nations peoples' disability experience.

The WHO biopsychosocial model of disability, posited as universal, has been widely critiqued as inadequately representing the understandings and experiences of disability of many Australian First Nations people, as well as of many Indigenous people internationally (Ariotti, 1999; Avery, 2018; Bevan-Brown, 2013; Gilroy and Donelly, 2016; Varvarezou, 2020). Our synthesis adds further weight to these conclusions. The WHO definition describes the negative impact of societal structures and attitudes on human functioning and capacity. This definition does not resonate well with some the First Nations understandings and practices that we have described, of normalising disabilities and of enabling the participation of people with disabilities through social roles and caregiving practices. The WHO model specifically excludes disablement connected to race and gender (Bickenbach et al., 1999), and does not encompass the intersectional experiences of First Nations people of ableism, colonialism, racism and gendered inequality, and the particular forms of discrimination and marginalisation that they can produce. The inability of the WHO model to encompass many of the experiences and understandings of many First Nations people of Australia, as well as those of Indigenous people internationally, poses questions about its universal applicability.

We have illustrated how disability support services, structured through non-Indigenous concepts of disability such as the WHO model, can threaten First Nations peoples' values and social structures and can further marginalise people already subject to the intergenerational impacts of colonisation. Disability support services which approach First Nations people with disabilities as social isolates, categorise them as different from others, fail to support family caregiving, and require them to leave their country and communities can compromise the identities, family solidarity and support networks of First Nations people. Paradoxically, disability support services can thus create or exacerbate 'disability', understood as social exclusion produced by the interaction between conditions and social environments. Our synthesis provides evidence that these processes can in many cases lead First Nations people to disengage from disability services.

A policy imperative therefore exists to decolonise disability services for First Nations people, a process which must include rethinking how disability is understood, experienced, defined and operationalised. Decolonising disability services for First Nations people requires services to reflect the values, needs and practices of First Nations peoples in specific communities, and for First Nations people to control their governance. Decolonising disability support services will require reform at service provider, organisational, systemic and conceptual levels. We have presented some evidence that the decolonisation of disability services is unlikely to be achieved through individual care package models, which are a dominant model in disability support services in Australia and many other states.

5. Limitations

As we have discussed above, tensions exist between systematic review methodologies premised on positivist traditions that attempt to generate authoritative knowledge, and critical First Nations approaches to research in which knowledge is understood as socially constructed and situated. We have described in detail our adaptation of traditional systematic review methods to foreground First Nations knowledge and

experience within the positionality of the research team, through the collaborative development of the review questions and aims, in review methods and in our approach to synthesising and analysing findings. Nevertheless, we acknowledge that some fundamental ontological tensions between these frameworks may be irresolvable. Further research may be required to develop alternative methodologies grounded in First Nations knowledge practices for conducting robust syntheses of literature on First Nations policy issues.

Our search strategy yielded only 12 sources, indicating a lack of primary research on First Nations peoples' conceptualisations, practices and experiences of disability. Although the included sources encompassed First Nations perspectives from across Australia, in urban, regional and remote areas, they cannot be held to represent the views of all First Nations people of Australia; and the absence of studies eliciting the experiences of Torres Strait Islanders is a notable gap in the literature. We are therefore unable to provide a definitive synthesis, and have expressed some contingency in our findings throughout this review. More place-based research is required on how First Nations people across Australia understand disability generally, as well as specific conditions, particularly in view of the need we have identified to develop local approaches to the provision of disability services.

We excluded sources that report on First Nations peoples' experiences of specific conditions in order to approach disability at a broader, conceptual level. In doing so, we may have excluded some studies of specific conditions that could contribute to understanding how First Nations peoples understand disability as a concept. However, it was not feasible to incorporate specific conditions in a systematic manner in our search strategy, as the World Health Organisation (2002) has identified more than 1400 conditions. We were also unable to include studies that have explored First Nations conceptualisations of health, the human body and human capability and functioning but did not engage with the concept of 'disability', due to a lack of common terminology. Future research and reviews of the broader ethnographic record may add further nuance to our findings. Additionally, our exclusion of studies published prior to 2000 may have resulted in the omission of some relevant research. However, cultures and belief systems are not fixed in time and it cannot be assumed that conceptualisations of 'disability' are unchanging. The majority of sources included in our review were published in the last five years, suggesting expanding research interest in recent times in tandem with the expansion of disability services in Australia and greater interest in disabilities at a policy level.

It should be noted that the MMAT provides only a limited assessment of research adequacy. As the only available responses in the MMAT are 'yes', 'no', or 'cannot tell', the MMAT is not sensitive to nuances in the quality of research. While the MMAT was an appropriate tool that supported our 'best available evidence' approach, a more sensitive assessment tool may have shown more variation in the quality of the included studies.

6. Conclusions

Colonisation is both an ongoing lived experience and a political relation that continues to inform First Nations peoples' experiences of disabilities and of disability services. Decolonising disability services therefore requires rethinking the concept and practice of disability support; and reconceptualising relationships between participants, families, service providers, funders and governments. It necessitates the embracing of First Nations values, needs and practices regarding health and illness, social participation and caregiving in organisational structures and practice; and requires services to consider how First Nations peoples' age, gender, social position and personal attributes may shape these concepts. This will require strength-based approaches centred around social participation and care, rather than a narrow, deficit focus on remediating disabilities; and greater integration of services that address medical and social dimensions of disability.

As First Nations understandings of disability are diverse, developing new models of care that reflect First Nations values, knowledge and social practices will require local or regional place-based initiatives and First Nations-led, or co-design, approaches. As the First Peoples Disability Network has argued (2018), the development of First Nations community-controlled disability service providers that are governed by local First Nations people, and have a permanent presence and strong local networks in local communities, is critical. While some First Nations organisations have already developed their own local models of care, providing services to First Nations people in ways that meet their values and needs may require them to rework funders' program logics or even breach funding agreements (Gilroy et al., 2020; King et al., 2014). This illustrates the need for wider reform to disability funding models and strategic policy objectives to promote greater autonomy and local decision-making in First Nations disability services, including a policy shift away from constraining disability services to individual packages, and enabling the development of collectivist approaches such as the pooling of participants' funds (PriceWaterhouse Coopers Indigenous Consultants, 2018). This will require the development of specific funding streams and program guidelines for First Nations disability services, as exists in Australian health policy frameworks. The operationalisation of First Nations models of care will also require evaluating disability services according to local First Nations' communities' metrics of effectiveness.

While we do not seek to offer any specific recommendations for the features of First Nations models of care, our findings suggest that new approaches to supporting family caregivers are needed, and that service providers could consider this in the context of strategies to develop a disability workforce. Developing and delivering disability support services that place local First Nations values and practices in an intercultural context will no doubt prove challenging. However, these transformations are critical to preventing the perpetuation of colonial harm, and to cultivating diverse First Nations ethics of social inclusion and care in disability services.

Author contributions

CW and **SP** were involved in project conceptualisation and funding acquisition, methodology development, data curation, analysis and manuscript writing. **CW** and **SP** contributed equally to the paper. **FM** was involved in conceptualisation and funding acquisition, methodology development, data curation and manuscript editing. **MY** contributed to methodology development and manuscript editing. **JB** participated in conceptualisation and methodology development. **TD** conceived of the project, provided high-level oversight, was principally responsible for funding acquisition and contributed to the methodology.

Declarations of interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2022.115047.

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