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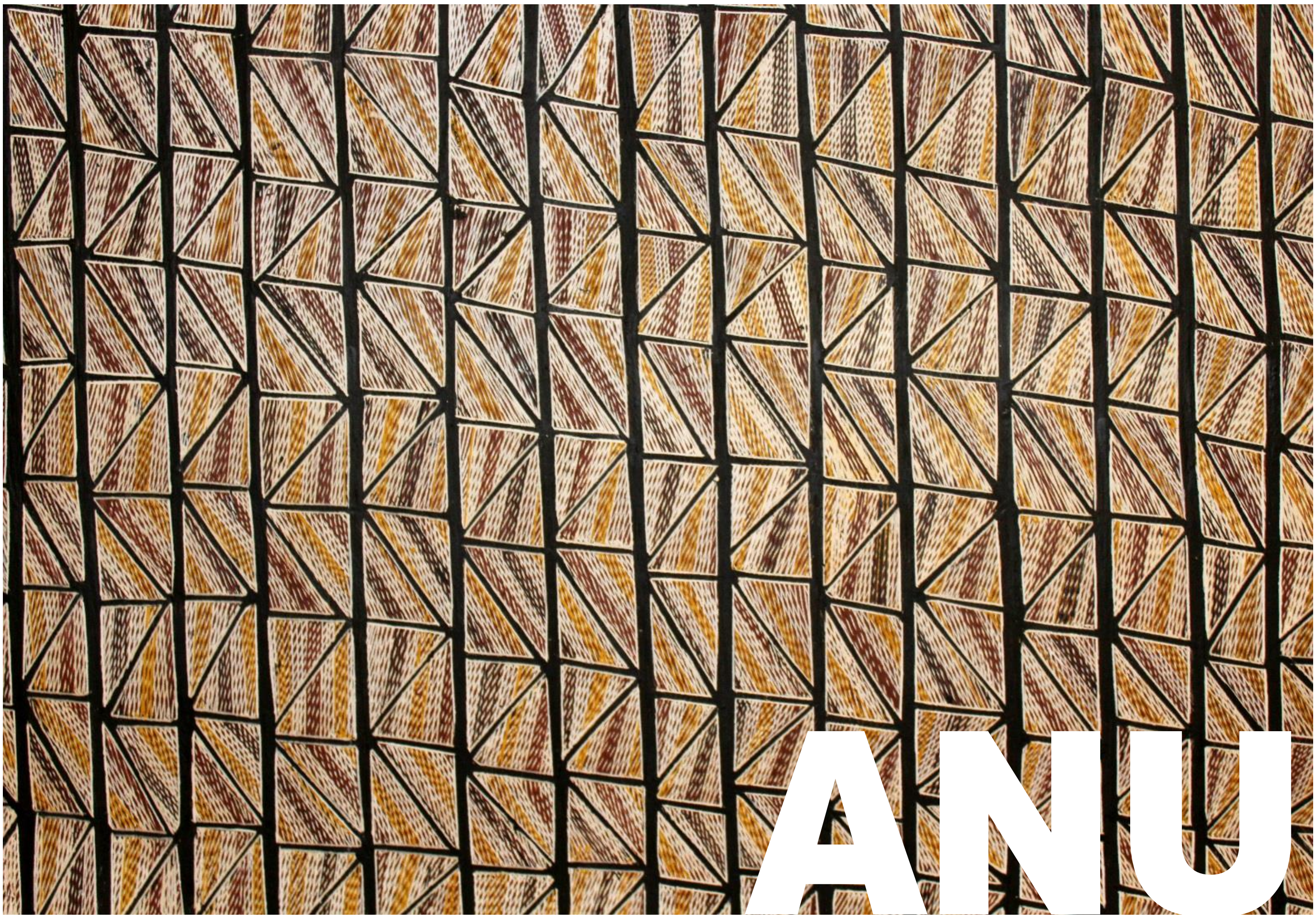

ABORIGINAL AND TORRES STRAIT ISLANDER VOICES IN DISABILITY SUPPORT SERVICES: A COLLATION OF SYSTEMATIC REVIEWS

CORINNE WALSH AND STEFANIE PUSZKA

Centre for
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Professor Tony Dreise
Director, CAEPR
Research School of Social Sciences
College of Arts & Social Sciences
The Australian National University, May 2021

Aboriginal and Torres Strait Islander voices in disability support services: A collation of systematic reviews

Corinne Walsh and Stefanie Puszka

Corinne Walsh and **Stefanie Puszka** are Post-doctoral Research Fellows at the Centre for Aboriginal Economic Policy Research (CAEPR), Research School of Social Sciences, College of Arts & Social Sciences, Australian National University.

Research team: Corinne Walsh, Stefanie Puszka, Francis Markham, Diane Smith, Yonatan Dinku, Mandy Yap, Minda Murray and Tony Dreise.

First Nations advisors: Scott Avery, Jody Barney, Sam Faulkner.

Keywords: First Nations people, Indigenous people, disability, cultural safety, justice system, incarceration, social care, models of care

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Acronyms

Acronyms

ABS	Australian Bureau of Statistics
ACCHO	Aboriginal Community Controlled Health Organisation
ACT	Acceptance and Commitment Therapy
AFJP	Alexis FASD Justice Program
AMSANT	Aboriginal Medical Services Alliance Northern Territory
ANU	Australian National University
AODT	Alcohol and other drug court
ASC	Aboriginal Sentencing Courts
CAEPR	Centre for Aboriginal Economic Policy Research
CANZUS	Canada, Australia, New Zealand, United States
CIDP	Cognitive impairment diversion program
CONSIDER	Consolidated criteria for strengthening reporting of health research involving indigenous peoples
CP	Connections Programme
DTC	Drug treatment court
FASD	Foetal Alcohol Spectrum Disorder
FGC	Family group conference
GPHS	Gathering Place Health Service
HREOC	Human Rights and Equal Opportunity Commission
IAMHDCD Project	Indigenous Australians with Mental Health Disorders and Cognitive Disabilities in the Criminal Justice System Project
ICIDH-2	International Classification of Functioning, Disability and Health – version 2
IFVOP	Indigenous Family Violence Offenders Program
IRIS	Indigenous Risk Impact Screen
ISP	Intensive Supervision Program
MeSH	Medical Index Subject Headings
MJD	Machado-Joseph Disease
MMAT	Mixed Methods Appraisal Tool
MST	Multisystemic Therapy
NAAJA	North Australian Aboriginal Justice Agency
NDIS	National Disability Insurance Scheme
NJC	Neighbourhood Justice Centre

NPY Women’s Council	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Womens Council
NT	Northern Territory
OOHC	Out of home care
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCIADIC	Royal Commission into Aboriginal Deaths in Custody
TJ	Therapeutic jurisprudence
WHO	World Health Organisation

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Executive summary

In Australia and internationally, Indigenous populations experience high levels of disability, yet have low uptake of disability services (Bevan-Brown, 2013; Ryser, Korn, & Berridge, 2014; Temple et al., 2020). While the reasons for this are likely to be complex and diverse, there are indications that a lack of cultural safety in disability services is a significant factor. Low rates of uptake are a product of unavailability of services in some areas, but also reflect mistrust of government agencies and experiences of discrimination (Productivity Commission, 2011; Reid, 2018). Disability is a construct that emerged through particular historic, political and economic circumstances in Western societies and is widely reported to have little resonance with many Indigenous peoples across the world (Ariotti, 1999; Connell, 2011; Varvarezou, 2020).

The Australian Government Department of Social Services funded a research team from the Centre for Aboriginal Economic Policy Research at the Australian National University to undertake a project titled *'Aboriginal and Torres Strait Islander voices in disability support services project: a collation of systematic reviews'* (the project). The aim of the project was to undertake a series of systematic reviews which offer a whole-of-system insight and will benefit government, agencies, the disability sector, researchers and communities to understand the complex issues affecting Aboriginal and Torres Strait Islander peoples living with disability, their families and communities. This project was funded by the National Disability Research Special Account.

This report is a collation of the project outcomes. It synthesises the published literature on how First Nations people in Australia understand and experience disability, and on promising practice in disability support services for Indigenous people internationally, in order to inform cultural safety in Australian disability services. This report comprises one systematic review and two systematic scoping reviews. The topics of these three reviews are as follows:

1. Experiences and conceptualisations of disability among First Nations peoples of Australia and the implications for disability services;
2. Characteristics of international approaches which address the needs of Indigenous people with disability in the justice system;
3. International models of social care for Indigenous peoples.

These reviews used best-practice systematic and scoping review principles and methods, and were underpinned by an Indigenous research methodology. Across the three reviews, we screened 5,008 sources. In total, 61 sources met inclusion criteria in the three reviews and were included in the analysis.

Systematic review 1: Experiences and conceptualisations of disability among First Nations peoples of Australia

In this review, we assessed published literature on how First Nations peoples of Australia conceptualise and experience disability. Our search strategy identified 2066 relevant sources and twelve studies met inclusion criteria.

Our meta-synthesis confirms that First Nations understandings of 'disability' do not necessarily align with conventional Western conceptualisations, and that First Nations people make sense of their experiences and conditions in a variety of ways. Some broad commonalities emerge in the literature in First Nations peoples' conceptualisations of disabilities as conditions that pertain to family groups as well as individuals. Due to attitudes of inclusion and acceptance in most First Nations communities, community members with disabilities are often able to participate in social, cultural and other meaningful roles and activities in their own families and communities. Caregiving may be an important social role and a form of participation in First Nations communities.

For First Nations peoples, family and community life may involve socially meaningful activities and represent important domains of ‘participation’. Concurrently, First Nations people with a disability experience substantial barriers to participation in broader society due to attitudes of ableism and racism; poor infrastructure, resulting in poor accessibility; economic and other marginalisation as a result of colonisation; and lack of access to disability services. Disability services structured by Western norms and values and Western constructs of disability may poorly support First Nations people and families, and may lead to distress and disempowerment. Culturally safe disability support services require service providers and policymakers to consider what ‘disability’, ‘participation’ and ‘caregiving’ may mean from a First Nations community’s perspective. Achieving cultural safety in disability support services will require reform at service provider, organisational, systemic and conceptual levels.

The key implications of the above findings for disability services are:

- A need for platforms for First Nations voices to be heard in disability service systems
- A need to develop and pilot new flexible, strengths-based models of care that reflect First Nations peoples’ values and needs through co-design or First Nations-led approaches.
- A need to expand the First Nations disability service sector and disability workforce
- A need to build intercultural understandings, approaches and services.

Systematic review 2: Approaches to address the needs of Indigenous people with disability in the justice system

While exact statistics are difficult to obtain, it is recognised that those who are incarcerated and who have contact with the criminal justice system – particularly Indigenous people – have high rates of disability (including cognitive disability, hearing loss and mental health issues). This scoping systematic review analysed national and international grey and peer-reviewed literature in CANZUS countries, to determine the key characteristics of approaches, programs, interventions, support services etc that are designed to address the needs of this cohort. Our search strategy identified a total of 1,301 sources. Of these, 24 sources met the inclusion criteria and were analysed.

Our findings show that there is a dearth of literature, research and evaluation on ‘what works’ or is ‘promising practice’ for justice-involved Indigenous people with all kinds of disabilities.

From the scant literature that exists, the following themes emerged as necessary for meeting the needs of Indigenous people with disability in contact with the criminal justice system:

- be Indigenous designed, led and owned;
- identify a person’s disability and needs using culturally-appropriate definitions and tools;
- court models which are not only culturally-appropriate but also disability/needs focused;
- disability-appropriate and culturally-appropriate diversionary options;
- facilitate connection to Indigenous country, culture and community;
- be person-centred and build agency, strengths and positive identity;
- protect human rights;
- break down communication barriers;
- provide mentors and support personnel;
- education and training for those working in the justice system;
- provide support upon release from prison.

The sources in this review highlight the overall inadequacy of the justice system in CANZUS countries in responding to the needs of Indigenous people with disabilities. The 'tough on crime' attitude appears to be failing and harming these people, and several sources called for significant legislative, policy and system reforms. Focusing on treatment, care, connection, healing and rehabilitation into the community – not isolation, deprivation, rectification, punishment, mistreatment – is strongly recommended.

Youth, women, as well as victims and witnesses of crime - who are Indigenous and have disability/complex needs - are particularly disadvantaged. Effective approaches are sorely lacking, and desperately needed, for these groups.

Systematic review 3: Models of social care for Indigenous peoples

Social care services, comprising personal care, transport and social activities, can support Indigenous people with a disability to live with their families and in their communities. However, social care services for Indigenous peoples must address cultural safety considerations, such as the overlap between services and caregiving roles in families, and Indigenous social norms associated with personal care. We conducted a systematic scoping review of social care services designed to meet the needs of Indigenous peoples in Australia, Aotearoa New Zealand, Canada and the United States. Our search strategy yielded 25 results that identified 10 models of care.

The models of care included in the review encompass a variety of funding schemes and organisational models, including schemes and models designed to meet the specific needs of Indigenous peoples; and mainstream schemes and models with adaptations for Indigenous populations. Several social care services included in this review have measures to respect Indigenous social norms associated with personal care and caregiving within families. Social activities offered within these models of care attempted to facilitate meaningful forms of participation for Indigenous peoples through a variety of local, place-based initiatives. All models of care included in the review avoid using the term 'disability' and five of the 10 models of care integrate social care for people with a disability with other related services including medical services, aged care and mental health support. Key outcomes include:

- Dedicated, flexible funding streams for disability services for Indigenous peoples are needed
- Local Indigenous governance structures and organisations require support in service systems
- Promising practices are emerging in social care services that support family carers; and integrate social roles in Indigenous families associated with caregiving within organisational employment strategies.
- The development of Indigenous community-based worker roles with a generalist skillset transferable between disability, aged care, child care and mental health services may provide one avenue to achieving this.

Overall, our project identifies many barriers faced by First Nations and Indigenous peoples in accessing culturally safe disability services. We have also found several instances of promising practice in disability services, where reform and targeted investment may improve the inclusivity and cultural safety of services. However, more research is needed to develop, pilot and evaluate new models and services led or co-designed with First Nations and Indigenous people, using culturally-meaningful, holistic, needs-focused, strengths-based, human-rights-focused and therapeutic, rather than punitive, approaches.

Introduction

In Australia and internationally, Indigenous populations experience high levels of disability, yet have low uptake of disability services (Bevan-Brown, 2013; Ryser et al., 2014; Temple et al., 2020). While the reasons for this are likely to be complex and diverse, there are indications that a lack of cultural safety in disability services is a significant factor. Low rates of uptake are a product of unavailability of services in some areas, but also reflect mistrust of government agencies and experiences of discrimination (Productivity Commission, 2011; Reid, 2018). Disability is a construct that emerged through particular historic, political and economic circumstances in Western societies and is widely reported to have little resonance with many Indigenous peoples across the world (Ariotti, 1999; Connell, 2011; Varvarezou, 2020).

Whilst there is an increasing focus in the literature of the experiences of Aboriginal and Torres Strait Islander peoples with disability, there remains a gap of simultaneous systematic reviews of existing national and International promising practices, using a critical Indigenous research methodology.

In December 2020, a Lead Facilitator was requested by the Department of Social Services to undertake a research project between January and May 2021, titled *'Aboriginal and Torres Strait Islander voices in disability support services project: a collation of systematic reviews'* (the project). The aim of the project was to undertake a series of systematic reviews which offer a whole-of-system insight and will benefit government, agencies, the disability sector, researchers and communities to understand the complex issues affecting Aboriginal and Torres Strait Islander peoples living with disability, their families and communities. research team. This project was funded by the National Disability Research Special Account.

A research team from the Centre for Aboriginal Economic Policy Research (CAEPR) at the Australian National University, led by early career researchers Corinne Walsh and Stefanie Puszka, was successful in securing this research contract. This research is funded by the National Disability Research Special Account, which is administered by the Department of Social Services on behalf of all Commonwealth, State and Territory jurisdictions.

The CAEPR Research Team and the National Disability Research Special Account Project Advisory Panel jointly agreed that three systematic reviews be undertaken, and that the themes of these three reviews be as follows:

1. An overarching review investigating the experiences and conceptualisations of disability among First Nations peoples of Australia and the implications for disability services;
2. A specific review investigating the characteristics of national and international approaches which address the needs of Indigenous people with disability in the justice system;
3. A specific review investigating national and international models of social care for Indigenous peoples.

This report presents all three systematic reviews in one location. It provides an overview of the purpose, methodological approach, conclusions, and implications for policy and practice of each of these three reviews.

Terminology

In the first, over-arching review, the word 'First Nations' was deemed appropriate because we examined the Australian context. In the two other reviews, the word 'Indigenous' was deemed appropriate because we examined the international context.

In all three systematic reviews, we adopt the International Classification of Functioning, Disability and Health (WHO 2002) definition of 'disability' – which sees the interaction between a person's bodily function/capacity and a social environment as creating disability. However, this definition has shortcomings – particularly for Indigenous peoples, who may not necessarily perceive a missing or malfunctioning body part, sense or capacity as a limitation requiring medical or other adjustment (Avery 2018; Bevan-Brown 2013). We are therefore aware of the tension that exists in using the word 'disability' in this review, when it may have little resonance to Indigenous peoples. However, it is the most appropriate term to use given a) most studies we reviewed use the word 'disability' and b) the lack of a suitable, culturally-appropriate word to replace 'disability'.

'Cultural safety' is a philosophy of inclusion in support services. In all three reviews, we have used the Australian Human Rights Commission definition of 'cultural safety', which holds that people and communities should be able access services without compromising their beliefs and values as a member of an ethnic or racial group (Australian Human Rights Commission, 2011: 123). The concept of cultural safety was first developed by Maori nurses in Aotearoa New Zealand, and has subsequently been widely disseminated in Australian healthcare (Ramsden, 1990; Truong, Paradies, & Priest, 2014).

'In contact with the justice system' or 'justice-involved' includes not just those currently incarcerated (i.e. in adult prisons, or juvenile detention facilities), but those who have been incarcerated at some point; and also those who may not have been incarcerated but have come into contact with the police/authorities and courts etc. It also includes those who are non-offenders but have had contact with the justice system as victims of crime and witnesses to crime.

Overview of methodology

All three reviews we conducted adopt best-practice principles and methods for systematic and scoping literature reviews, and are also underpinned by an Indigenous research methodology.

Systematic literature review

Systematic literature review is a method of systematically synthesising large bodies of research to address a specific research question (Matthew et al., 2020). Systematic reviews identify, select and critically appraise relevant research in an orderly, explicit and replicable manner (Higgins et al., 2019). Systematic review is a method that can be deployed to synthesise large bodies of evidence on how policies, measures and supports are experienced by the people they are designed to assist, in addition to determining efficacy (Petticrew & Roberts, 2006).

Our review methodology is based on key features of best-practice systematic review methods for identifying relevant literature typically used in the evaluation of health interventions, established through the widely-accepted PRISMA statement (Matthew et al., 2020). Our analysis of included literature is informed by methodological approaches and resources for conducting reviews of social policy issues (Petticrew & Roberts, 2006; The Campbell Collaboration, 2021). We have adopted a collaborative approach and an over-arching Indigenous research methodology, drawing from the approach of Lowe and colleagues (2019).

In our initial, over-arching review, of the experiences and conceptualisations of disability among First Nations peoples of Australia, we adopted a traditional systematic review methodology to generate a broad synthesis of the diverse ways that First Nations peoples make sense of disabilities. In order to synthesise the literature while preserving contextual differences between studies, we analysed included studies using a meta-synthesis approach, a method for identifying common concepts across diverse studies (Noblit & Hare, 1988).

In the two subsequent reviews, we adopted a systematic scoping review methodology, a method for developing a descriptive overview of interventions, measures, practices and models addressing a particular topic or within a specific field (Munn et al., 2018; Tricco et al., 2018). In these reviews, we conducted thematic analysis of included literature to identify the characteristics of service models and approaches.

Indigenous research methodology

Our reviews are underpinned by an Indigenous research methodology in that they centre the perspectives, voices and experiences of First Nations people within research questions and methods, literature synthesis and analysis. Our Indigenous research methodology encompasses the following components:

1. Collaboration between First Nations and non-Indigenous researchers within the research team.

2. Synthesis of First Nations peoples’ experiences and perspectives associated with disability, and the use of findings to inform further systematic reviews.

3. The centring of cultural safety and responsiveness of disability support services as a primary outcome of interest.

4. Engagement with key Indigenous disability advocates and stakeholders through meetings and informal discussions.

5. Critical appraisal of the involvement of First Nations peoples, as well as First Nations knowledges and methodologies, in the included studies.

The Human Research Ethics Committee of the Australian National University advised that ethical clearance for this project was not required.

In all three reviews, we conducted an appraisal of the extent to which Indigenous peoples' perspectives were part of the research process in the included studies/literature. Drawing on the CONSIDER Statement (see Huria, Palmer et al 2019), as well as the Aboriginal and Torres Strait Islander Quality Appraisal Tool (developed by Harfield, Pearson et al 2020:5), and following discussion between Indigenous and non-Indigenous researchers within the research team, we developed Indigenous peoples' involvement appraisal criteria (Table 1).

*Table 1: First Nations/Indigenous peoples' involvement in research appraisal criteria**
* Italics indicates sample responses

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, eg: in published literature*	*Research topic or question described as aligning only with* other people or organisations' *priorities, eg: those of funders or 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 supervisors or in an advisory capacity, eg project advisory group with majority Indigenous membership; employed in research team*	*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: 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.*	*Only one of the following shown: Indigenous standpoint theory or an Indigenous/Indigenist 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.*	*Theoretical influences do not include Indigenous standpoint theory or an Indigenous/Indigenist methodology. 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.*	*Cannot be determined from the published manuscript.*

Systematic review 1: Experiences and conceptualisations of disability among First Nations peoples of Australia

Introduction

Cultural safety is a philosophy of inclusion in support services. It holds that people and communities should be able access services without compromising their beliefs and values as a member of an ethnic or racial group (Australian Human Rights Commission, 2011: 123). The concept of cultural safety was first developed by Maori nurses in Aotearoa New Zealand, and has subsequently been widely disseminated in Australian healthcare (Ramsden, 1990; Truong et al., 2014). Increasingly, Australian disability support services are embracing the philosophy of cultural safety, and the Australian Government now seeks to provide culturally safe disability support services to First Nations peoples[1] (Department of Social Services, 2017: 6)**.**

However, there are indications that many Australian disability support services do not currently support culturally safe care for First Nations peoples. First Nations people in Australia do not access disability support services at rates commensurate with need (Australian Institute of Health and Welfare 2019; Department of Social Services 2017). Low rates of uptake are a product of unavailability of services in some areas, but also reflect mistrust of government agencies and experiences of discrimination (Productivity Commission: 539-540). It is widely reported that Western concepts of disability do not reflect First Nations values, beliefs and social practices regarding health and bodily function (Avery 2018; Connell 2011). Despite this, First Nations people have expressed a strong desire for better access to appropriate, culturally safe disability support services (First Peoples Disabiilty Network Australia, 2018).

We were funded by the Commonwealth Department of Social Services to undertake a series of systematic reviews on cultural safety in disability support services for First Nations peoples of Australia. The research question we sought to answer in this first systematic review was: *How do First Nations peoples of Australia conceptualise and experience disability?* The aim of this review is to inform the development of culturally safe approaches in Australian disability support services. This systematic review will also provide an analytical framework which will inform the subsequent reviews on cultural safety in specific components of Australia's disability support service system.

There are many challenges to developing culturally safe disability support services. Cultural safety cannot be conceived of as a prescriptive list of reforms (Williams 1999). Cultures are not bound by prescriptive rules, but are sets of beliefs, values, practices, relationships and forms of expression. No culture is fixed in time, and internal diversity exists amongst the beliefs, practices and experiences of First Nations peoples of Australia. Developing culturally safe services will require different measures in different locations and at different times. Our review therefore aims 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 aim to identify

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[1] We use the term 'First Nations peoples' to refer to Aboriginal and Torres Strait Islander peoples.

implications for approaches to developing culturally safe disability support services, but we are unable to offer a prescriptive list of recommendations.

We have adopted the World Health Organisation's International Classification of Functioning, Disability and Health (World Health Organisation, 2002) to inform our analysis. In this social conceptualisation of disability, it is the interaction between a person's bodily functions and capacity and a social environment that creates disability. However, we acknowledge the limitations of this definition, particularly for First Nations people, who may not necessarily perceive a missing or malfunctioning body part as a limitation or lack of competence on the part of the individual; and who may have unique experiences of their bodily conditions (Avery, 2018; Bevan-Brown, 2013). We use the term *disability* in this paper, as this is the term is generally used by authors of studies of Indigenous conceptualisations and experiences of disability, including First Nations authors, but with an acknowledgement that this term may not necessarily express First Nations concepts. In accordance with a social model of disability, we adopt a social justice and human empowerment model of social inclusion which conceptualises *participation* as encompassing the ability to participate in the society or societies in which one lives and to realise one's human potential (Gidley, Hampson, Wheeler, & Bereded-Samuel, 2010). In this paper, we use the term *bodily* in a holistic sense to refer to physical, neurological, sensory and psychological systems and functions.

Methods

Systematic literature review

Systematic literature review is a method of systematically synthesising large bodies of research to address a specific research question (Matthew et al., 2020). Systematic reviews identify, select and critically appraise relevant research in an orderly, explicit and replicable manner (Higgins et al., 2019). Systematic review is a method that can be deployed to synthesise large bodies of evidence on how policies, measures and supports are experienced by the people they are designed to assist, in addition to determining efficacy (Petticrew & Roberts, 2006).

Our review methodology is based on key features of best-practice systematic review methods for identifying relevant literature typically used in the evaluation of health interventions, established through the widely-accepted PRISMA statement (Matthew et al., 2020). Our analysis of included literature is informed by methodological approaches and resources for conducting systematic reviews of social policy issues (Petticrew & Roberts, 2006; The Campbell Collaboration, 2021). We have adopted a collaborative approach and an over-arching Indigenous research methodology, drawing from the approach of Lowe and colleagues (2019).

Indigenous research methodology

Our reviews are underpinned by an Indigenous research methodology in that they centre the perspectives, voices and experiences of First Nations people within research questions and methods, literature synthesis and analysis. Our Indigenous research methodology encompasses the following components:

1. Collaboration between First Nations and non-Indigenous researchers within the research team.

2. Synthesis of First Nations peoples' experiences and perspectives associated with disability, and the use of findings to inform further systematic reviews.

3. The centring of cultural safety and responsiveness of disability support services as a primary outcome of interest.

4. Engagement with key Indigenous disability advocates and stakeholders through meetings and informal discussions.

5. Critical appraisal of the involvement of First Nations peoples, as well as First Nations knowledges and methodologies, in the included studies.

The Human Research Ethics Committee of the Australian National University advised that ethical clearance for this project was not required.

Inclusion/exclusion criteria

We adopted broad inclusion criteria in order to access a wide range of First Nations perspectives. We included research and evaluations reported in peer-reviewed journals and grey literature containing primary data that incorporate the perspectives of First Nations peoples of Australia on disability. We limited our review to sources published since 2000. This timeframe reflects our conceptualisation of cultures as sets of beliefs and practices that change over time; and the dissemination of cultural safety and related concepts in Australian healthcare by the early 2000s (Truong et al., 2014)

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 for First Nations participants separately from non-Indigenous participants; and if they reported on experiences of specific conditions (for example, autism or spinal cord injury), not the concept of *disability.*

Search and selection strategy

We developed an electronic database search strategy using Boolean terms in collaboration with a health librarian. Initial search terms were derived from Medical Subject Headings (MeSH) keywords, and adapted after initial testing (see Figure 1). We conducted searches of the following databases: INFORMIT – AIATSIS, Web of Science, EBSCOhost (CINAHL, academic search premier, ebooks, socIndex), PubMed, Australian Indigenous Healthinfonet.

Figure 1: Search terms used in academic databases

("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")

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 exported to Covidence systematic review software and duplicates were removed. CW and SP both screened every title and abstract for inclusion. A meeting was held to determine the inclusion decision for articles where we differed in our decision. Subsequent full text screening of all titles was also completed by both CW and SP, with a further meeting held to make final decisions about inclusion.

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' experiences and understandings 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 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, Gagnon, Griffiths, & Johnson-Lafleur, 2009).

Appraisal of First Nations peoples' involvement in research

We also developed and conducted a appraisal process of the extent to which First Nations peoples and their perspectives were involved in included studies. Our criteria were informed by the CONSIDER Statement (Huria et al., 2019) and the Aboriginal and Torres Strait Islander Quality Appraisal Tool (Harfield, Pearson et al 2020:5), and were developed through consultation with First Nations researchers within the research team (Table 2).

*Table 2: First Nations peoples' involvement in research appraisal criteria**
* Italics indicates sample responses

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, eg: in published literature*	*Research topic or question described as aligning only with other people or organisations' priorities, eg: those of funders or 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 supervisors or in an advisory capacity, eg project advisory group with majority Indigenous membership; employed in research team*	*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: 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.*	*Only one of the following shown: Indigenous standpoint theory or an Indigenous/Indigenist 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.*	*Theoretical influences do not include Indigenous standpoint theory or an Indigenous/Indigenist methodology. 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.*	*Cannot be determined from the published manuscript.*

Meta-synthesis

We analysed results using a meta-synthesis approach, which is a method of systematic comparison and translation of studies that preserves contextual differences while identifying common concepts (Noblit & Hare, 1988). We translated each of the included sources into each other. This was carried out by comparing, contrasting and synthesising the themes and findings of individual studies in order to generate an encompassing set of themes. The two authors (CW and SP) each developed an initial set of themes, and through discussion, further analysis of the literature and consensus, generated a final set of themes.

Results

Our search strategy yielded a total of 2066 results, and 12 sources met inclusion criteria and were extracted for analysis (Figure 2). The main reasons for exclusion were: studies did not consider First Nations peoples' perspectives on 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 included sources represented 10 studies and encompassed nine journal articles, two reports and one book. Included sources represented a broad range of academic disciplines including disability studies, public health, anthropology and sociology (Table 3), 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 a range of location types and some study sites not disclosed by authors. Our review encompassed studies undertaken in New South Wales, the Northern Territory, Queensland and South Australia.

Figure 2: PRISMA flow diagram of Review 1 search and screening process

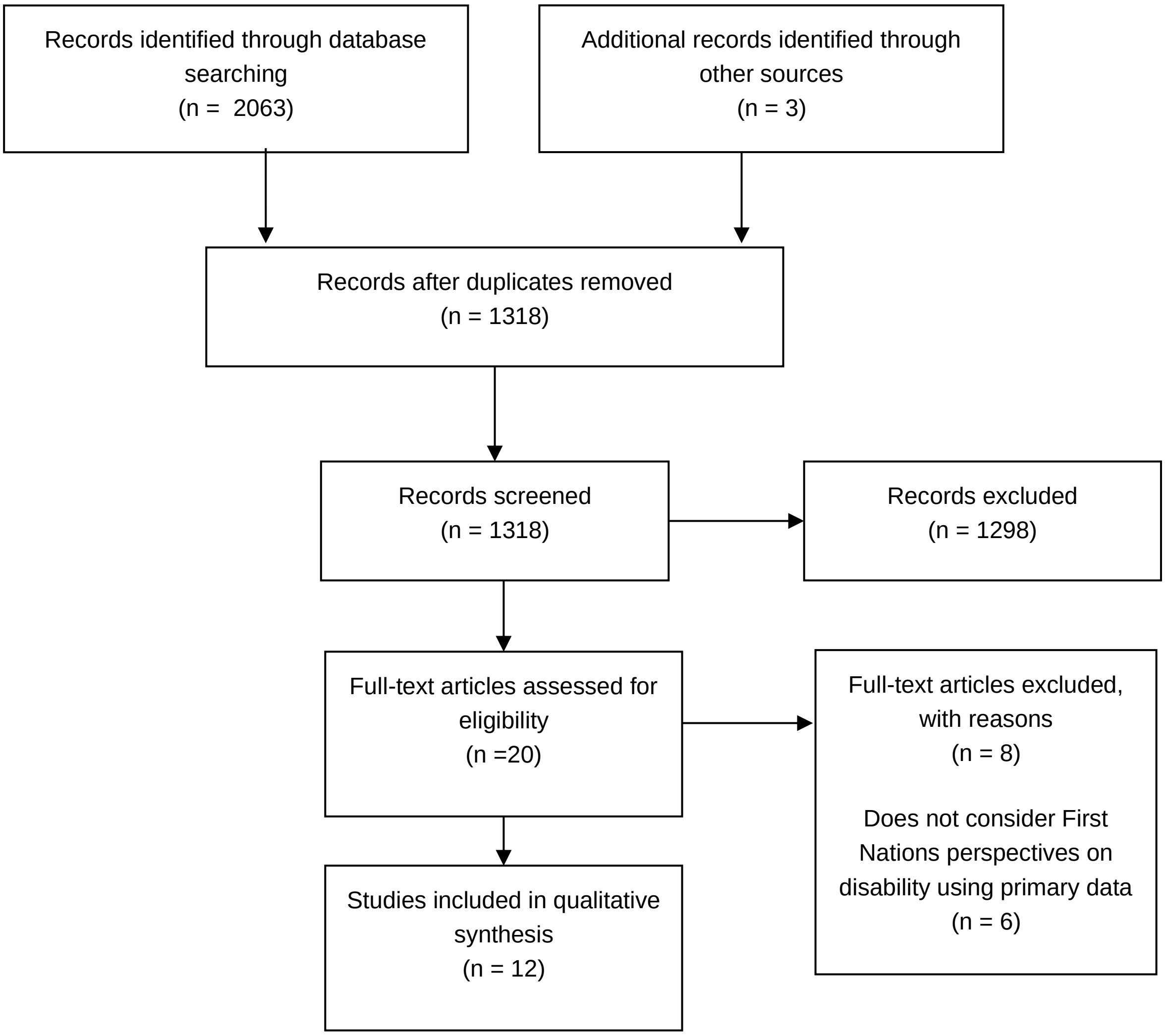


Table 3: Sources included in Review 1

Record	Study design & methods	Study site and population group	Research questions/ aims	Definition of disability
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.	Biomedical
Senior (2000)	Qualitative, ethnographic. Survey, interview and participatory observational methods over 12 months.	Ngukurr (remote Northern Territory), and Kulaluk (town camp in Darwin, including people from remote communities and residents of a neighboring nursing home).	How people with impairment are perceived by their community? What do individuals regard as being important in their lives? What do individuals feel they can't do, or actually can't do because of their disability? What contextual factors limit or prevent people from achieving their aims? What contextual factors help achieve their aims?	WHO: ICIDH-2
Dew et al (2019)	Qualitative. Interviews and focus group discussions with 109 participants.	Remote Central Australia. Anangu aged 18+ with a disability and their carers living in and away from their communities; and service providers.	What does a good life comprise among Anangu with a disability and how can service providers support them?	NDIS definition
Ravindran et al (2017)	Qualitative. Analysis of policy documents, media articles, texts and transcripts.	NSW. First Nations spokespeople, government agencies, NGOs.	To explore Western and Indigenous conceptualisations of disability in the public discourse by identifying tensions at the cultural interface	Not stated (explored multiple perspectives)

King et al (2014)	Qualitative, ethnographic. Interviews and participatory observational methods over 2 years.	Brisbane. Research undertaken at a respite center for First Nations people and in participants' homes.	To examine the lived experience of Indigenous Australian people with a disability	Not stated (explored First Nations perspectives)
Fitts et al (2020)	Qualitative. Interviews and yarning circles with 12 participants.	First Nations people caring for a family member with a disability and living with a disability themself 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 disability needs as a disabled carer.	Disability support pension applicants
Rees (2003)	Mixed methods. Surveys, analysis of administrative data, interviews, participatory observational research.	Fieldwork in 21 urban, regional, remote communities in South Australia.	To investigate the incidence and nature of disability in Aboriginal communities in SA, explore options for service delivery	Disability Services Act 1987 (Cth)
Gilroy et al (2020)[1]	Qualitative. Interviews and focus group discussions with 109 participants.	Remote Central Australia. Anangu aged 18+ with a disability 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 disability in Central Australia	NDIS definition
DiGiacomo et al (2017)[2]	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 a disability.	Biomedical

Sands (2005)	Qualitative. Personal narrative	Australia and the Pacific. Women with a disability.	To describe advocacy efforts among women with a disability in Australia and the Pacific	Social model
Avery (2018)	Mixed methods. Analysis of administrative 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 a disability	Cultural model of disability/ inclusion (developed by the author)
Pearce (2000)	Qualitative. Auto-ethnography/ personal narrative.	Site not stated. Author is participant.	Exploring the experiences of a male First Nations carer	Not stated

Results of research quality appraisal

Of the 12 sources included in the review, 10 adopted qualitative methods and two used a mixed methods approach. As only the qualitative data of the Rees (2003) report were of relevance to the review, we assessed only the qualitative components of this study; and only one study, in which qualitative and quantitative data were both of relevance, was assessed using mixed methods research criteria. The vast majority of included titles met all quality appraisal criteria of the MMAT (Table 4). However, 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 included studies.

Table 4: MMAT scores of Review 1 included sources

Qualitative criteria	1.1 Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Green et al (2018)	Yes	Yes	Yes	Yes	Yes
Senior (2000)	Yes	Yes	Yes	Yes	Yes
Dew et al (2019)	Yes	Yes	Yes	Yes	Yes
Ravindran et al (2017)	Yes	Cannot tell	Yes	Yes	Yes
King et al (2014)	Yes	Yes	Yes	Yes	Yes
Fitts et al (2020)	Yes	Yes	Yes	Yes	Yes
Rees (2003)	Yes	Yes	Yes	Yes	Yes
Gilroy et al (2020)	Yes	Yes	Yes	Yes	Yes
DiGiacomo et al (2017)	Yes	Yes	Yes	Yes	Yes

Sands (2005)	Cannot tell	Cannot tell	Cannot tell	Cannot tell	Cannot tell
Pearce (2000)	Yes	No	No	Yes	Yes
Mixed methods criteria	**5.1. Is there an adequate rationale for using a mixed methods design to address the research question?**	**5.2. Are the different components of the study effectively integrated to answer the research question?**	**5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?**	**5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**
Avery (2018)	Yes	Yes	Yes	Yes	Yes

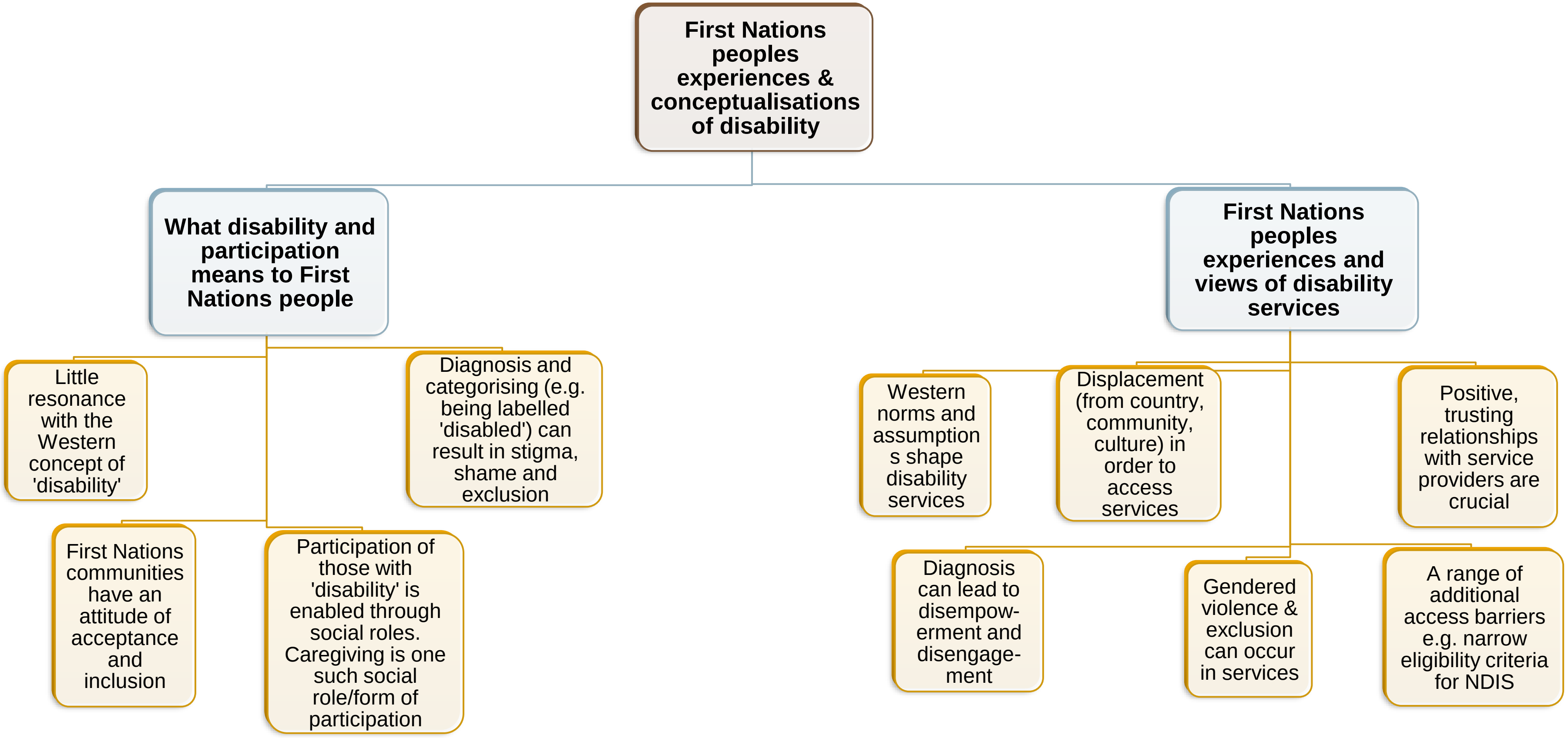
Results of First Nations peoples' involvement in research appraisal

We appraised the involvement of First Nations peoples in included sources, and in one case, we also reviewed an associated methodological paper published by authors of two included titles but not included in our review (J. 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 5; Figure 3). Generally, included studies had strong representation of First Nations peoples within research teams and research governance processes, while few studies performed well in involving First Nations peoples in setting the research agendas or priorities.

Table 5: Results of First Nations peoples' involvement in research appraisal

Record	Setting the research priorities/agenda	Representation within research team and research governance processes	Incorporation of First Nations ways of knowing, being, seeing, doing in study theory, methods and methodology
Green et al (2018)	Not reported	To a large extent	Somewhat
Senior (2000)	Not at all	Somewhat	To a large extent
Dew et al (2019)	To a large extent	To a large extent	To a large extent
Ravindran et al (2017)	Not reported	To a large extent	Somewhat
King et al (2014)	Not reported	Not reported	To a large extent
Fitts et al (2020)	Somewhat	To a large extent	To a large extent
Rees (2003)	To a large extent	To a large extent	To a large extent
Gilroy et al (2020)	To a large extent	To a large extent	To a large extent
DiGiacomo et al (2017)	Not reported	To a large extent	Somewhat
Avery (2018)	To a large extent	To a large extent	To a large extent
Sands (2005)	Not reported	To a large extent	To a large extent
Pearce (2000)	To a large extent	To a large extent	To a large extent

Figure 3: Elements of First Nations peoples' experiences and conceptualisations of disability, participation and disability services



Discussion

Our meta-synthesis elicited two broad themes pertinent to the ways in which First Nations peoples conceptualise and experience disability: conceptualisations and experiences of disability and participation; and experiences of disability support services (Figure 3). In this section we discuss these themes and their implications for cultural safety in disability support services.

1. Conceptualisations and experiences of disability and participation

1. Lack of resonance of the concept of 'disability' and other means of making sense of conditions

The studies we reviewed overwhelmingly confirm that the conventional construct of disability – as a barrier to individual capacity and participation in society – does not resonate with First Nations people in Australia, in urban, regional and remote areas (Ravindran et al 2017; Avery 2018). In most First Nations languages, no equivalent term or concept corresponding to 'disability' exists (Avery, 2018; King, Brough, & Knox, 2014). According to Avery, words and phrases exist in Australian First Nations languages which describe specific conditions such as blindness, deafness, mobility difficulties and back pain. However, these descriptors are not used in a negative or pejorative manner (2018:5).

The sources we reviewed suggest that First Nations people often see conditions to be unremarkable, and to simply represent the normal range of human diversity – particularly in the case of physical conditions. A small number of studies suggest that some milder conditions may not necessarily be seen as requiring treatment, particularly when there are more significant or pressing matters in First Nations peoples' communities (Senior 2000; Rees 2003). Senior, for instance, reported that her research participants saw 'disability' as "just part of life" (Senior, 2000: 14). However, included sources predominantly suggest that conditions are recognised as requiring treatment and care, but those with 'disability' are accepted and actively included in their families and communities (Avery, 2018; Dew et al., 2019; J Gilroy et al., 2020; King et al., 2014; Ravindran, Brentnall, & Gilroy, 2017; Rees, 2003; Senior, 2000). According to Ravindran and colleagues, most First Nations spokespeople in their study "stated that 'having a disability did not prevent people from having personal aspirations, goals and contributions to their communities. They also stated that most Indigenous people would rather be recognised for their strengths and abilities as opposed to their perceived limitations" (2017:378).

Concurrently, a broader range of attitudes amongst First Nations people towards psychosocial and neurological conditions are reported in the literature. In some First Nations communities, conditions that can cause peoples' behaviour to deviate from social norms may carry a degree of social stigma (Senior 2000; Rees 2003). For conditions which attract social stigma, other family members or whole family groups may also experience disapproval and castigation. In their respective studies, Senior (2000) and Rees (2003) both reported that people with mental health conditions were avoided by others in their communities due to their unpredictable behaviour; and the social participation of people with stigmatised conditions may be limited to their own family group. Senior (2000) noted that some of her research participants attributed mental health conditions to sorcery, a practice at times invoked in conflicts between family groups in some communities. She also reported that the congenital conditions of some children may be blamed on parents' wrongdoing.

Our synthesis shows that although First Nations understandings of ‘disability’ can diverge from conventional Western conceptualisations, First Nations people have other means of making sense of their experiences of conditions as individuals and family groups. First Nations people understand conditions in nuanced, contextual and complex ways. As Ravindran says, quoting Gilroy (2012:49), “Indigenous peoples’ conceptualisations of disability are shaped by their personal, cultural and historical contexts” (2017:368). First Nations experiences and conceptualisations of conditions therefore cannot be understood as comprising a single model.

1.2 Participation is enabled through social roles in families and communities

The studies in this review predominantly conclude that a disability does not necessarily incapacitate or impede the participation of First Nations people in their own families and communities. First Nations people with disabilities often continue to participate in social roles and in family and community activities. Avery’s analysis of Australian Bureau of Statistics data, for instance, demonstrates that First Nations people with a disability participate in social and cultural activities at similar rates to other First Nations people who do not have disability (Avery, 2018: v). Dew et al. describe important Anangu social roles and activities as encompassing caring for country, participating in ceremonies, hunting and obtaining Anangu medicines and remaining close to ancestors’ graves. They note that those with a disability who reside on country are generally not excluded from these activities (Dew et al., 2019).

Included sources show that the participation of First Nations people with disabilities in their families and communities is enabled through inclusive attitudes and the care provided by their families. Rees describes how children with a disability are supported by their entire family group to take part in family activities (Rees, 2003). King et al. discuss cases in which a man with a mobility restriction was wheeled to the beach in order to go fishing, and an elder with disability received transport assistance from their community members in order to participate in an elders’ meeting (King et al., 2014). They argue that amongst their research participants, “disability is not experienced as something different if it does not affect continuing participation and support” (2014:746). Similarly, in Senior’s study, 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 (Senior, 2000). Carers can therefore help to mitigate impediments to First Nations peoples’ participation, and hence their disabilities.

Social participation for First Nations people with disabilities is also enabled through their presence on country or in their communities. Dew and colleagues’ study of Anangu social roles and activities suggests that all activities that comprise a ‘good life’ for Anangu take place on country (Dew et al., 2019). King and colleagues’ research also demonstrates how First Nations people with a disability participate in their local, urban community (King et al., 2014). Senior (2000) highlights the locationally-specific nature of participation. She describes an unsuccessful attempt by a nursing home in Darwin to facilitate activities such as hunting and gathering, which held little meaning for residents who were living away from their own country.

Disability among First Nations people may therefore be understood not just as an individual experience, but an experience which extends to, and impacts on, families and communities. For First Nations peoples, family and community life may represent important domains of ‘participation’, and may involve socially meaningful activities. Our synthesis reveals that ‘participation’ must be conceptualised in ways meaningful to First Nations peoples. Meaningful social activities described in included studies encompassed economic activities such as hunting, gathering and fishing, but no studies described formal employment as a meaningful activity. However, exclusion from the formal economy, as we discuss below, could prevent some First Nations people living with a disability from participating in other meaningful activities and roles due to low income. Meaningful participation in society may be enabled through social roles and by being present on country or in a community, and may be shaped by factors such as age, gender, social position and personal attributes.

1.3 Caregiving is an important social role and a form of participation

The included studies describe caregiving in extended First Nations families from across Australia as a complex, multi-generational relation that represents one's commitment to one's family. Fitts and Soldatic (2020) note that First Nations people with a disability may themselves care for other family members. Senior found that "a caring ethic was part of people's way of defining themselves as being Aboriginal" (Senior, 2000: 22). Pearce, in his personal narrative of caring for his family members with health conditions, describes caregiving as a normal part of family life, commenting "It's like breathing, you do it because you have a commitment. It doesn't make you a hero" (Pearce, 2000: 21). Practices of caregiving in First Nations families for people with disabilities can involve extended kinship networks (Fitts and Soldatic 2020). Both Rees (2003) and Pearce (2000) suggest some First Nations people may see seeking care for family members from service providers outside of the family as neglecting their family responsibilities.

Practices of caregiving in First Nations families may themselves represent a form of participation in social roles and activities. Several included sources report that caregiving may be a key component of First Nations women's social roles in particular, including women with family members with disability, and women with disability themselves (Fitts & Soldatic, 2020; Green et al., 2018; Sands, 2005). The ways in which First Nations peoples conceptualise and practice 'participation' and 'social inclusion' may therefore acquire a gendered dimension. However, Pearce reports that men also play a role in caregiving in First Nations families and that in some communities, gender roles may be changing (Pearce, 2000). King et al. (2014) meanwhile suggest that First Nations people may conceptualise caregiving more broadly than the performance of domestic labour.

However, several sources report that caregiving can also be burdensome and lead to financial, physical, emotional and mental hardship in First Nations families (DiGiacomo et al., 2017; Fitts & Soldatic, 2020; Green et al., 2018). This is especially the case for lone carers or single parents (DiGiacomo et al 2017; Green et al 2018), as well as for First Nations carers who have a disability or chronic illness or condition themselves (Fitts & Soldatic 2020:2). Fitts and Soldatic report that in many First Nations families, an ethic of caregiving limits the ability of some family members to undertake paid work. First Nations carers and their families, especially those in regional and remote areas, experience severe financial distress and often have to forgo essential items such as nutritious food to cover the costs of daily living (2020:5). In some cases, First Nations families may contend with the burnout of carers (Fitts & Soldatic 2020). Pearce (2000) describes the difficult decisions faced by some First Nations families: of providing care to their family members with little support from disability services, or placing family members in institutional care. Overwhelmingly, the studies we reviewed describe desires among First Nations people for more support for caregiving within families. DiGiacomo and colleagues – who conducted interviews with parents and primary carers of First Nations children with disability – conclude that "carers bear the costs, both economic and non-economic, of fragmented systems and complex pathways to care" (2017:8).

Our synthesis shows that caregiving and family life are key domains of social participation for First Nations peoples. Caregiving can be burdensome, but may also reflect participation in social roles. Strong desires exist for greater support for caregiving in First Nations families through social policy. However, support for caregivers and constructs of ‘participation’ and ‘social inclusion’ need to be operationalised in ways that reflect contested or changing gender and age roles.

1.4 Exclusion through marginalisation from broader society

Included studies suggest that First Nations people may experience substantial barriers to participation in society through the interaction of their conditions with processes of marginalisation and attitudes of racism in broader society. The interaction between ableist and racist attitudes may lead to specific forms of discrimination against First Nations peoples with disability. This may result in economic exclusion. 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). Racist, ableist attitudes may also lead to the exclusion of First Nations people with a disability from public spaces. Avery, for example, recounts the experiences of a participant in his research with balance and mobility difficulties, who was often presumed to be intoxicated and refused entry into shops and businesses (Avery, 2018). According to Senior (2000), experiences of discrimination in broader society had the consequence of confining some of her First Nations research participants living in Darwin to their homes or resident town camp.

Ableist societal attitudes may lead to inaccessible built environments which may also have exclusionary effects on First Nations peoples with a disability. Several included sources report on the experiences of people living in crowded and inappropriately designed social housing. They report that social housing properties frequently lack facilities such as ramps and guard rails required by people with mobility-related conditions; and properties are often located too far from medical and other services (Avery 2018; Fitts & Soldatic 2020; Gilroy et al 2020). Accessibility issues are likely to be particularly acute in remote areas, where facilities are generally poorer. In Senior’s study, First Nations people were impeded from visiting and travelling within remote areas due to their inability to travel on light aircraft (Senior 2000).

The socio-economic disadvantage that results from economic exclusion may prevent First Nations people with disability from satisfying their basic needs. Gilroy and colleagues report one carer’s inability to address the basic needs of her brother, a man with a disability, due to low income:

> *I wish I could get him some nice new blankets and towels. Nice pillows. That is the sort of thing I like to get for him. He did have a nice bed once, but it went all weak and saggy and now it is just all broken and falling apart. He needs a sturdy bed. He’s got a big heavy body (J. Gilroy et al., 2020: 6).*

The authors of this study described strong views among participants that satisfying basic needs was a priority. Sands (2005) argues that First Nations women with a disability may be particularly subject to economic exclusion due to the additional burden of gendered discrimination in broader society.

Colonisation has dispossessed, marginalised and ‘disabled’ First Nations people as a collective; but has especially marginalised First Nations people with disability (Avery 2018; Ravindran 2017). As Avery (2018) discusses, the intersection of colonial forms of domination and racism with societal attitudes of exclusion towards people with a disability leads to particular forms of social and economic exclusion for

First Nations people with a disability. Neither the medical model of disability nor the social model of disability adequately address the ways in which ableism may intersect with racism to ‘disable’ First Nations peoples. Our synthesis suggests that, in order to enable the participation and social inclusion of First Nations people with a disability, Australian disability policy must address the particular forms of intersectional discrimination that they experience.

2. First Nations peoples’ experiences of disability support services

2.1 Disempowering experiences of disability diagnosis and labels

A number of included sources describe distressing and confronting experiences of diagnosis amongst First Nations people with a disability. Although the concept of ‘disability’ may have little resonance with many First Nations people, it is a construct they often must engage with in order to access support services – and this may conflict with their cultural identity and values (Ravindran et al 2017). Diagnostic categories and labels may create divisions in First Nations families and communities that consider themselves to be social wholes. Labels such as ‘deaf’, ‘autistic’, ‘intellectually disabled’ and ‘developmentally delayed’ categorise First Nations people as ‘abnormal’ or ‘damaged,’ and create negatively-constituted difference (Avery, 2018; King et al., 2014; Ravindran et al., 2017; Rees, 2003). Ravindran and colleagues, quoting Aileen Moreton-Robinson, suggests that the application of diagnostic labels may lead First Nations people to recall historic policies of categorising First Nations peoples based on their perceived physiology (2017:380). The application of disability labels can also create arbitrary distinctions between people with a disability and those with other conditions such as chronic diseases and cancer, and differential access to support services and resources (King et al., 2014).

Diagnostic labels can invest power in service providers to determine First Nations peoples’ bodily states of being and eligibility for support services. Decisions are made about First Nations people, usually by non-Indigenous medical experts, which can lead to feelings of inadequacy, helplessness and anger and render First Nations people unable to advocate for themselves (Rees 2003). Disability was historically used as one of the pretexts for the state-sanctioned removal of First Nations children from their families; and the ongoing application of diagnostic labels may lead to fear and distress amongst First Nations peoples (Ravindran et al., 2017; Rees, 2003). Some sources report that experiences of diagnosis may lead First Nations people to disengage from disability support services (Green et al., 2018; Ravindran et al., 2017; Rees, 2003).

Diagnostic processes and practices of labelling people with disabilities may actually create ‘disability’ by generating division and difference where previously there was none. As Ravindran et al. note, ‘the mismatch in the language used by agencies and Indigenous people creates barriers to the uptake of services by Indigenous people, and thereby challenges the desired self-determination of Indigenous people with disabilities and their communities’ (2017:378). The literature reports strong desires among First Nations people with disabilities to access support services in ways that do not compromise their identities and values (Green et al. 2018; Dew et al. 2019; King et al. 2014; Fitts & Soldatic 2020; Rees 2003; Gilroy et al. 2020; DiGiacomo et al. 2017; Avery 2018; Pearce 2000).

2.2 Disability service systems structured by Western norms

Included studies demonstrate that disability service systems are shaped by Western norms and assumptions, which may not reflect First Nations values and practices. Disability support services tend to provide care to individuals with diagnosed conditions, in ways that fail to grasp how disability may be constituted through First Nations family groups. Services centred on the needs of individuals with a disability fail to acknowledge the impact on family groups and provide inadequate support to carers (Fitts & Soldatic 2020; Gilroy et al. 2020; Rees 2003; DiGiacomo et al. 2017; Green et al. 2018; Pearce 2000). While caregiving is an important dimension of First Nations family solidarity, inadequate support for carers may repudiate the values and practices of First Nations peoples. In his personal narrative of his role as an Aboriginal male carer, Pearce (2000: 21) laments:

> *The failure of government programs derives from an unwillingness to accept the values and styles of Aboriginality and from a conscious or unconscious subordination of their primary objectives, for the over-riding purpose of forcing Aborigines to assimilate into our (mainstream) society... Why aren't there any alternatives that make it easier for those people affected to be able to support their family members? Why is it so hard to get the support we need?*

Inadequate financial and emotional support for First Nations carers, who are likely to experience acute financial stress, and poor access to respite care, may lead to poor economic outcomes in families and to distress and burnout among carers (DiGiacomo et al., 2017; Fitts & Soldatic, 2020). While we described an ethic of caregiving in many First Nations families, a lack of support for carers may in some cases lead to families placing relatives in residential care, resulting in the fragmentation of family groups (Pearce, 2000; Rees, 2003). Some First Nations people with disabilities may also perform caregiving roles, and inadequate support for carers is likely to also adversely impact individuals with a disability (Fitts & Soldatic, 2020). A lack of support for carers in First Nations families fails to support the strengths of First Nations people, and may work to incapacitate and debilitate family groups.

Individual care packages are a funding model for disability support services which may lead to further tension and divisions within First Nations families. Through individual care packages, individuals with a disability receive funds to spend on services and supports. Rees (2003) describes how individual care packages can lead to conflict in First Nations families when several family members have disabilities but only some are eligible for support and resources. As some disabilities are hereditary, this issue may be widespread. Gilroy et al. (2020) also suggest that goal-oriented plans, such as those required by the National Disability Insurance Scheme (NDIS), inappropriately imply that people with disability need to change, whereas the participation and social inclusion of First Nations people with a disability may be facilitated through existing family and social structures.

King and colleagues (2013) argue that even First Nations community-controlled disability service providers may contend with service systems shaped by Western norms. They describe contention between Western constructs of good governance that require a risk aversion, compliance-based approach and distance between clients and staff, and First Nations approaches to governance premised on relationships and social roles.

Our synthesis shows that disability support service systems, and in particular a focus on the needs of individuals with eligible diagnoses, may fail to reflect First Nations values and needs and may compromise family solidarity. Constructs of care needs, participation and caregiving in Australian disability policy must encompass First Nations social structures, social roles and family relations.

2.3 Displacement in order to access services

Many First Nations people with a disability contend with having to leave their country or community to access disability support services, particularly those from remote and regional areas (Avery, 2018; Dew et al., 2019; J Gilroy et al., 2020; Senior, 2000). Services that displace or institutionalise First Nations people with a disability curtail participation and may result in social and economic exclusion (Avery, 2018; Dew et al., 2019; J Gilroy et al., 2020; Senior, 2000). Senior found that First Nations people who were institutionalised in nursing homes away from their country and the support of their families experienced isolation and poor health, in ways that compounded their disabilities. Dew and colleagues reported that the fundamental relationship between First Nations people and country is often poorly understood and overlooked in remote service provision (2019:433). Gilroy et al also show that there is lack of funding for people displaced from remote areas to visit home (2020). 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.

Services that result in the displacement of First Nations people impact on families and communities as well as individuals with disabilities. Relocation can leave First Nations people with a disability without their carers, or result in the relocation of carers also (J Gilroy et al., 2020). Disability support services that result in displacement offer First Nations people in remote areas an untenable choice between quantity and quality of life. Such services may create 'disability', understood as social exclusion produced by the interaction between conditions and environments, not only for individuals, but also in families and communities. Attempts to facilitate participation and social inclusion in Australian disability policy will not succeed in First Nations communities without acknowledging the socially and geographically contextual nature of participation in First Nations communities.

2.4 Gendered violence and exclusion in disability support services

Two included sources suggest that disability support services may be structured in ways that can lead to gendered violence and exclusion of First Nations people. Sands (2005) reports that First Nations women with a disability may be vulnerable to gendered violence and exploitation in disability support services. Sands also suggests that practices of forced sterilisation of some women with intellectual disabilities in Australia may also impact on First Nations women (without citing specific instances of these issues amongst First Nations women with disabilities). As our earlier analysis showed that social roles, including motherhood, may be an important domain of participation for some First Nations women with disabilities, these specific forms of gendered violence and human rights violations may have a particularly disabling impact on First Nations women with disabilities. Pearce (2000), meanwhile, suggests that disability and other support services structured around the needs of individuals and Western gender norms can work to exclude and deny support to First Nations men who are carers. These studies suggest a need for legislative reform to address human rights violations and specific mechanisms to address gendered violence in disability support services. They also suggest a need in Australian disability policy to consider different constructs of gender roles in First Nations societies, and their implications for meaningful participation.

2.5 Interactions with service providers

Included studies describe First Nations peoples' interactions with individual service providers as a key mediator of their experience of disability support services. Overt and covert racism and discrimination are a major reason First Nations people with disability and their families do not trust and access services, especially mainstream services (Green et al 2018; Senior 2000; Avery 2018; King et al 2014). According to Green and colleagues (2018), stereotypes and racism, as well as lack of cultural awareness and sensitivity, impact on care access (2018:1926-8). These authors document instances in which carers of Aboriginal children with disability have been "looked down on and judged" (Green et al 2018:1926). Some of their study participants reported that they were treated as though they were "bad parents" by service providers (Green et al 2018:1926), and some said they have experienced or witnessed direct racism and stereotypical language and behaviour from agencies and personnel (Green et al 2018:1926). Frequent experiences of disrespect and discrimination such as this can lead to 'apprehended discrimination' amongst First Nations people with a disability, in which past experiences of discrimination can create distress and lead to future expectations of discrimination and avoidance of services (Avery, 2018).

Beyond explicit racism, included studies describe disability service providers' inattention to interpersonal relationships as a reason First Nations people may not access such services. Service providers who are not aware of colonial power imbalances and who fail to demonstrate cultural awareness and sensitivity may lead to distress and disempowerment among First Nations service users (J Gilroy et al., 2020; Green et al., 2018). Included sources suggest that service providers who do not build trust and rapport with their clients, rush consultations, fail to listen, do not make decisions in partnership with clients and who do not show empathy can further offend First Nations people (J Gilroy et al., 2020; Green et al., 2018). Some authors 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 (J Gilroy et al., 2020; Rees, 2003).

The potential for First Nations people to have positive, respectful relationships with service providers may be influenced by systemic issues. King and colleagues (2014) describe desires amongst their participants to have their social roles, such as roles as elders, recognised and respected in disability support services. However, the authors acknowledge that there may be little capacity for this to occur in services provided by non-Indigenous organisations and staff. Service delivery models in which service providers do not have a permanent presence in communities (e.g. hub-and-spoke models and fly-in-fly-out/drive-in-drive-out models, particularly in remote areas) usually provide little capacity for service providers to have meaningful engagement with communities (Dew et al 2019:431). In Dew et al's study, Anangu people were suspicious about the motivations, intentions and practices of the often short-stay non-Indigenous workforce. Funding constraints and time limits on appointments may also impede relationships between First Nations clients and disability service providers (Green et al, 2018; King et al. 2014).

Included studies also provide some accounts of First Nations peoples' positive and constructive relationships with disability service providers. Green et al (2018) describe Aboriginal Community Controlled Health Organisations as culturally safe spaces which tend to take clients' concerns seriously, have a holistic approach to clients' health and which do not press matters that clients are evidently comfortable with discussing. These approaches were welcomed by participants in Green et al's study. In another study, a *malparara* model of care developed by the Ngaanyatjarra Pitjantjatjarra Yankunyajatjarra Womens Council was deemed a promising approach (Dew et al., 2019; J Gilroy et al., 2020). In this model, service providers dedicate time to developing trusting, respectful relationships with clients and provide services in a flexible manner. Anangu workers partner with non-Indigenous workers to enact a partnership of mutual learning.

2.6 Additional barriers to accessing services

The studies we reviewed discussed a range of other barriers to First Nations people accessing services and care for disability, particularly in, but not limited to, remote areas. These barriers include:

- Lack of available services, meaning that in some cases, resources attached to care packages cannot be used (Avery, 2018)
- Narrow eligibility criteria for the NDIS, and the decline in non-NDIS services (Fitts & Soldatic, 2020)
- Unfunded direct and indirect costs of accessing services e.g. travel outside of community to access services (Fitts & Soldatic 2020; Rees 2003; Gilroy et al 2020; Green et al 2018:1928)
- Poor access to transport (Avery, 2018; Senior, 2000).
- Inadequate infrastructure in remote areas for accessing telehealth and online services (J Gilroy et al., 2020)
- Poor access to housing and high rates of homelessness (Avery, 2018; Fitts & Soldatic, 2020; J Gilroy et al., 2020; Green et al., 2018)
- Limited access to Auslan interpreters (Avery 2018:109).
- Complex, technical, difficult, time-consuming application processes and pathways. (Dew et al., 2019; J Gilroy et al., 2020).

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 economic exclusion.

Implications for systems and services

A need for First Nations voices to be heard in disability service systems

Cultural safety in disability support services requires services to reflect the values and needs of First Nations peoples. It requires service providers and policymakers to consider what bodily function, health, ability, participation, social inclusion and caregiving may mean from a First Nations community's perspective. It also requires service providers and policymakers to consider how First Nations peoples' age, gender, social position and personal attributes may shape these concepts. We have shown that achieving cultural safety in disability support services will require reform at service provider, organisational, systemic and conceptual levels.

As the First Peoples Disability Network has argued, First Nations peoples with a disability and First Nations organisations must be at the forefront of efforts and decisions to make service systems more inclusive (First Peoples Disabiilty Network Australia, 2018). Cultural safety in disability support services requires the voices of First Nations peoples with a disability and those of their carers and organisations to be heard within disability service systems (Sands 2005; Dew et al 2019:420). There is a need for specific platforms within disability service systems and service providers for First Nations voices, at national, state/territory and local levels. This includes a specific platform within the National Disability Insurance Agency. While Aboriginal Community Controlled Health Organisations have been granted the status of partners in the recent National Agreement on Closing the Gap (Council of Australian

Governments & Coalition of Aboriginal and Torres Strait Islander Peak Organisations, 2020), similar platforms and agreements are needed in the disability sector.

A need to develop models of care that reflect First Nations peoples' values and needs

Our findings support Avery's proposal for a 'cultural model of inclusion', in which First Nations people with disabilities are valued and supported to participate in society, in ways that are meaningful to them (Avery 2018). Taken together, our findings show a need to develop and pilot new flexible, strengths-based models of care through co-design or First Nations-led approaches. This may include First Nations models within the NDIS, and other models that offer services for people not eligible for NDIS support. The need to develop different models of care for First Nations communities within the NDIS, particularly in remote areas, was identified by the Productivity Commission a decade ago, but is yet to be implemented (Productivity Commission 2011). Co-design approaches, in which services are designed in collaboration with First Nations people and organisations at a regional level, are already being adopted in other service sectors such family services (Dillon 2021), and could be extended to the disability sector.

New models will require a local or regional focus, and the models that work in one particular location may not necessarily be transferable to others, but may provide approaches that could be adapted elsewhere. Some First Nations service providers are already developing their own models of care, such as the Ngaanyatjarra Pitjantjatjarra Yankunyajatjarra Womens Council (Gilroy et al, 2020 Dew et al 2019), but providing services to First Nations people in ways that meet their needs may at present require breaching funding agreements and contravening Western constructs of governance (J Gilroy et al., 2020; King et al., 2014). First Nations models of care require support through specific funding streams and flexible program guidelines. New models must be evaluated and assessed according to First Nations peoples' expectations and metrics of success.

A need for a First Nations Disability Service Sector and workforce

First Nations community-controlled disability service providers, governed by boards of First Nations community leaders, provide a means of giving voice to First Nations peoples with disabilities. Such organisations are also best placed to develop culturally safe and locally relevant models, services and practices within communities. Some sources included in our review provide some evidence that community-controlled models of care are more accessible and culturally safe for First Nations people than mainstream services (Green et al 2018:1928; Ravindran et al 2017:381). At present, a nascent network of First Nations community-controlled disability service providers exists, but First Nations service providers compete with non-Indigenous organisations for funding. As with the health sector, a comprehensive First Nations community-controlled disability sector is needed to provide a First Nations voice in service systems at national, state/territory and local levels (First Peoples Disabiilty Network Australia, 2018).

A First Nations disability workforce is needed to lead the development of culturally safe models of practice in disability services (J Gilroy, Dew, Lincoln, & Hines, 2017). First Nations disability workers may be able to provide support to First Nations peoples with a disability in respectful ways and in ways that respect clients' social roles (King et al., 2014). A First Nations workforce drawn from within local communities may improve the capacity of service providers to offer a permanent presence within communities, particularly in remote areas where service providers are often based outside of communities. A First Nations disability workforce within First Nations community-controlled service providers may further provide an appropriate environment for non-Indigenous staff to engage in reflective practice, improve their cross-cultural competency and to develop relationships with service participants (Dew et al., 2019). Remuneration for First Nations family carers who already provide substantial care and are experiencing financial distress and burnout may provide one avenue for developing a First Nations disability workforce. However, several barriers have also been identified to the participation of First Nations people in this workforce, including inadequate and inaccessible training courses (Gilroy et al. 2017). This suggests a need for a First Nations disability workforce strategy.

A need to build intercultural understandings, approaches and services

Although it may not be possible to entirely avoid the term and concept of ‘disability’ in disability support services, our analysis demonstrates a critical need for an intercultural approach in disability support services for First Nations people. A language of service provision that centres care needs, rather than disabilities, is anecdotally adopted by some First Nations community-controlled services, and is worthy of further consideration. Place-based participatory action research projects may provide an avenue for service providers and communities to develop shared understandings and terminology.

Limitations

Systematic review is a research methodology that emerges from positivist traditions and privileges Western academic knowledge. Systematic review methodologies have the potential to marginalise First Nations voices and the voices of people with a disability. We sought to address this through our Indigenous research methodology which centres First Nations voices within our review methods and project governance processes; and by including grey literature. Nevertheless, there may be more scope to centre the voices of First Nations people with lived experience of disability through empirical enquiry and interpretivist research traditions.

Our search strategy yielded only 12 sources, indicating a lack of primary research on First Nations perspectives on, 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. We are therefore unable to provide a definitive synthesis, and have expressed some contingency in our findings throughout this review. More ethnographic research is required on how First Nations people across Australia experience and conceptualise disability, particularly in light of the need we have identified to develop intercultural approaches and cross-cultural understandings within services at a local level.

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 conceptualise disability. However, it was not feasible to incorporate specific conditions in a systematic manner in our search strategy, as the World Health Organisation’s International Classification of Functioning, Disability and Health describes more than 1400 conditions (World Health Organisation, 2002). Future research exploring how First Nations peoples experience and conceptualise specific symptoms or conditions may add further nuance to our findings.

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 experiences and conceptualisations of ‘disability’ are unchanging. The majority of sources included in our review were published in the last 5 years, suggesting expanding research interest in recent times in tandem with the expansion of services and greater interest in disability at a policy level.

Conclusions

In this review, we have systematically analysed how First Nations people in Australia experience and conceptualise disabilities, and how they engage with the Western construct of ‘disability’. Although the Western construct of ‘disability’ may have little resonance with First Nations peoples in many cases, First Nations peoples do have means of making sense of their conditions. While First Nations people experience and conceptualise disability in diverse ways, we have shown that disabilities are often experienced and understood as pertaining to family groups and communities, as well as individuals. Inclusive attitudes and an ethics of caregiving in First Nations societies (which Avery terms “the culture of inclusion” (Avery 2018)) enable many First Nations people with a disability to be accepted, accommodated, and to participate in family and community life. The “culture of inclusion” in First Nations communities is a strength that enables the negotiation and acceptance of disability, the avoidance of ableism and the promotion of social inclusion.

Our review has also shown that Australian disability support services in many cases fail to meet the needs of First Nations peoples with disability, and those of their carers, families and communities. Disability support services frequently fail align with First Nations values, aspirations and needs. Disability support services, governed and operationalised through Western norms, can lead to stigma and marginalisation, can impede participation and can reduce access to care, further disabling First Nations people.

The sources we have analysed demonstrate that meaningful cultural safety requires more than superficial reforms such as cultural awareness training for non-Indigenous service providers, and requires significant changes at service provider, organisational, systemic and conceptual levels. Designing services that reflect First Nations needs and values will require collaboration and co-design or First Nations-led design at national, state/territory and local levels, and specific efforts to strengthen and expand First Nations community-controlled disability services and the First Nations disability workforce. Culturally safe models will require the courage to move beyond Western-dominated, individual-focused, goal-oriented care packages and managed competition between disability support providers, towards more intercultural models that are congruent with First Nations values, aspirations and needs.

Systematic review 2: Characteristics of approaches which aim to address the needs of Indigenous people with disability in the justice system

Introduction

This is a systematic scoping review which synthesises and analyses recent peer-reviewed and grey literature that exists on justice-involved Indigenous people with disability, in Australia, the United States, Canada and Aotearoa (New Zealand). The research question guiding this review is: *What are the characteristics of approaches (services, supports, models and other measures) designed to address the needs of Indigenous people with disability in the justice system?*

It is well reported that Indigenous people are overrepresented in the criminal justice system. In Australia, 28% of the prison population in Australia identifies as Aboriginal, despite only making up around 2% of the adult population (ABS 2017 in Sharma et al 2018). Imprisonment of Aboriginal and Torres Strait Islander people has significantly risen since the landmark 1992 Royal Commission into Aboriginal Deaths in Custody (RCIADIC), especially in the Northern Territory and Western Australia, suggesting that the recommendations of RCIADIC have not been actioned. Incarceration statistics are similar for Indigenous peoples and people of colour in other Western countries, such as the United States, Canada and Aotearoa (New Zealand) (Tucker 2014; Greenfield & Smith 2009; Ferrazzi & Krupa 2016:159; Erickson & Butters 2005:964; Workman 2011 in Thom & Burnside 2018:1259).

There is ample evidence showing that those in prison – particularly Indigenous people – have high rates of disability (Shepherd et al 2017; Blagg & Tulich 2018:5; Erickson & Butters 2005:959; McCausland & Baldry 2017:291-2). This includes cognitive disability (intellectual disability, acquired brain injury, dementia and foetal alcohol spectrum disorder (FASD)[2] – see Baldry et al 2016; Bower et al 2018; McCausland & Baldry 2017); hearing loss (Vanderpoll & Howard 2011) and mental illness (Heffernan et al in Dudgeon et al 2014:165; Ferrazzi & Krupa 2016:159; McCausland & Baldry 2017; Riley et al 2018:2573). Recent research indicates that Indigenous people with disability are about 14 times more likely to be imprisoned than the general population (Australian Civil Society Working Group's Submission to UN CRPD Committee 2019:24). Indigenous people with cognitive disability are significantly more likely to be charged with their first offence at a younger age, too, than those without cognitive disability (Shepherd et al 2017; Baldry, Dowse & Clarence 2012). However, most offenses by Indigenous people with disabilities are relatively less serious and pertain to theft, public order, traffic, and vehicle regulations (Sharma et al 2018; Baldry et al 2016:10; Kreig et al 2016).

Some Indigenous inmates may have more than one disability, and may also be experiencing, or have experienced, other hardships such as homelessness, unemployment and poverty, drug and alcohol use, separation from family (e.g. placed in out-of-home-care), violence, abuse and (intergenerational) trauma (HREOC 2008:38). In addition, they can experience racism and ableism from individuals and

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[2] Foetal alcohol spectrum disorder (FASD), which is a lifelong condition, "describes a range of anomalies in brain function caused by maternal alcohol consumption during pregnancy. Individuals with FASD have difficulty with memory, attention, judgement and impulse control (Fast and Conry 2004) and many have communication and language impairments (Snow, Bagley and White 2017; Kippin et al. 2018)… When they come into contact with police, they may experience an impaired understanding of why they are in trouble and have a poor understanding or comprehension of their arrest rights (Roach and Bailey 2009)" (Hamilton et al 2020:21).

organisations (Baldry et al 2016:11). The co-existence of these factors is often referred to as 'complex needs' (MacGillivray and Baldry 2013:23) or 'complex support needs' (Baldry et al 2016:10). Indigenous people with disability not only experience high levels of incarceration – they are frequently victims of crime too (Royal Commission 2020; HREOC 2014).

There seems to be a considerable need for culturally-safe and effective interventions to assist Indigenous people with all types of disability, and their families and communities, before, during and after contact with the criminal justice system. As then-Social Justice Commissioner, Tom Calma, observed in 2008 in a HREOC report specifically about Indigenous young people in the justice system:

> relatively little is known about 'what works' to prevent Indigenous (young) people with cognitive disabilities or mental health issues from becoming involved with the criminal justice system. Evaluations of the impact of interventions on the Indigenous (young) people are few and far between. But the evaluations that look specifically at Indigenous (young) people with cognitive disabilities or mental health problems; are non-existent (HREOC 2008:38).

Methods

Systematic scoping review

Systematic scoping review is a descriptive form of review that can be used to examine the extent, variety and characteristics of literature addressing a particular topic or within a specific field (Tricco et al., 2018). While standard systematic review methods enable reviewers to assess the level of evidence for specific interventions, measures, practices, models etc, systematic scoping review methods provide an overview of such interventions, measures, practices and models etc (Munn et al., 2018). Systematic scoping reviews are a suitable method for reviews of emerging practice, and for reviews of heterogeneous studies (Peters et al., 2015; Tricco et al., 2018).

The design of our systematic scoping review is based on the established principles described in the PRISMA Extension for Scoping Reviews Checklist (Tricco et al., 2018) and the Joanna Briggs Institute Guidance for conducting systematic scoping reviews (Peters et al., 2015). Drawing on these principles, our review is structured around the population, concept and context of interest. We have adopted a broad search strategy, and included peer-reviewed, grey and other literature (e.g. news articles, published reports, consultation findings etc).

Indigenous research methodology

Our reviews are underpinned by an Indigenous research methodology in that they centre the perspectives, voices and experiences of First Nations people within research questions and methods, literature synthesis and analysis. Our Indigenous research methodology encompasses the following components:

1. Collaboration between First Nations and non-Indigenous researchers within the research team.

2. Synthesis of First Nations peoples' experiences and perspectives associated with disability, and the use of findings to inform further systematic reviews.

3. The centring of cultural safety and responsiveness of disability support services as a primary outcome of interest.

4. Engagement with key Indigenous disability advocates and stakeholders through meetings and informal discussions.

5. Critical appraisal of the involvement of First Nations peoples, as well as First Nations knowledges and methodologies, in the included studies.

The Human Research Ethics Committee of the Australian National University advised that ethical clearance for this project was not required.

Inclusion criteria

Study population, concept and context

The characteristics (values, principles, structures, components and processes) of approaches (interventions, programs, support services and other measures), which are designed to meet the needs of Indigenous people Indigenous people of Australia, Aotearoa (New Zealand), the United States and Canada (CANZUS countries) with any kind of disability, who have (or have had) contact with the justice system. This includes their carers, families and communities.

Study design

The following have been included:

- Studies (research, evaluations, reports, consultations) conducted in Australia, Aotearoa (New Zealand), the United States and Canada (CANZUS countries).
- Studies focused on Indigenous people with disability in the justice system.
- Studies reported in peer reviewed journals and in grey literature.[3]
- Studies that use quantitative, qualitative or mixed methods.
- Studies that incorporate Indigenous peoples' perspectives (through methods such as interviews, yarns, storytelling, focus groups, consultation processes, surveys etc).
- Studies published from the year 2000 to the present day, so as to be complementary with the timelines in our first, overarching systematic review.

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[3] Grey literature is "information produced on all levels of government, academics, business and industry in electronic and print formats not controlled by commercial publishing i.e. where publishing is not the primary activity of the producing body…Grey literature usually has not been peer reviewed, but may still be good, reliable information" (Source: https://guides.lib.monash.edu/grey-literature/whatisgreyliterature)

Search and selection strategy

The following national and international databases were searched for peer-reviewed and grey literature: INFORMIT (Indigenous Collection, AGIS-ATSIS Collection); Web of Science; Scopus; PubMed; Analysis and Policy Observatory (APO); Indigenous Justice Clearinghouse.

Additional literature was identified from professional knowledge of the field, and through reviewing the reference lists of included studies.

The following Boolean search terms were used to search databases:

Figure 4: Search terms used

("Indigenous Australians" OR "Indigenous Australian" OR "Indigenous people" OR "Indigenous peoples" OR "Indigenous population" OR aboriginal OR "Torres Strait Islander" OR ATSI OR "First Nations" OR "First Peoples" OR Maori OR Inuit OR Metis OR "Native American" OR "American Indian" OR Hawaiian OR "Native Alaskan")

AND

(disab* OR impair* OR "special needs" OR cognitive OR psychosocial OR “hearing loss” OR “hearing impair*” OR autism OR mental OR neuro* OR FASD OR “foetal alcohol spectrum disorder”)

AND

("criminal justice system" OR "justice system" OR *prison* OR detention OR incarcerat*)

AND

("support service" OR prevent* OR success* OR program OR intervention OR promising)

Data extraction and study selection methods

Search results were exported to Covidence© systematic review software. After removing duplicates, initial screening (title and abstract only) was independently conducted by both reviewers (Corinne Walsh and Stef Puszka). CW screened all titles/abstracts, and SP checked 10% of these titles/abstracts for consistency. Full text screening was also performed by CW, in consultation with SP.

Research quality appraisals

Appraisal of promising practice from an Indigenous standpoint

An appraisal of evidence-based practice is not typically performed in a systematic scoping review, in which the intent is to provide a descriptive synthesis of a body of literature and in which new practices are often a focus (Peters et al., 2015; Tricco et al., 2018). However, as explained above, systematic scoping review methods provide an appropriate means of synthesising emerging and promising practice.

The Canadian Homelessness Research Network defines promising practice as interventions and activities "that (are) determined by peers to be highly effective and representative of a really good practice, and/or because it is unique and of special interest" (2013:6). Gupta et al, from the Menzies School of Health Research, describes 'promising practice' as that which "draws on an emerging, yet disparate, evidence-base" (Gupta et al., 2020:49). Essentially, promising practice constitutes programs, services, strategies, activities, approaches, models, interventions and so on which have some data to show that they are having a positive impact or could have a positive impact (however this might be measured), but do not have enough robust evidence to be able to conclusively say they are 'best practice'.

We required an assessment tool to help us decide whether the approach/es being discussed in the included studies are promising practice for justice-involved Indigenous people with disability. The first overarching systematic review we conducted (See Review 1) provided a synthesis of how First Nations people of Australia with disability and their carers, families and communities understand and experience disability and caring; what they value, want and need; and what they expect from (disability) services. We therefore used the findings from this overarching review to create the following framework (see Table 6, over page), to aide us in determining whether an approach is promising from an Indigenous standpoint.

*Table 6: Promising practice from an Indigenous standpoint appraisal tool**

* Italics indicates sample responses. As explained in Limitations section above, this appraisal was abandoned because the included studies did not provide adequate information to answer each of the questions/criteria

Study/ approach	**Provide appropriate assistance for the individual's disability/ need?**	**Protect human rights?**	**Enable partici-pation?**	**Enable meaningful connection to country, culture, community?**	**Culturally safe, trustworthy and accessible?**	**Designed and/or run by Indigenous people?**	**Allow Indigenous voice, agency and decision-making i.e. self-determination?**	**Bring desirable justice outcomes?**	**Stop recidivism?**	**Keep Indigenous people with disability out of the justice system altogether?**
(Name of study, author and date)	*Yes*	*Yes*	*Yes*	*Yes*	*Yes*	*Yes*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Perhaps – more research needed*
(Name of study, author and date)	*Yes*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Yes*	*No*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Perhaps – more research needed*	*Perhaps – more research needed*
(Name of study, author and date)	*No*	*No*	*No*	*No*	*No*	*No*	*No*	*No*	*No*	*No*

Appraisal of Indigenous peoples’ involvement in research

An appraisal was also conducted on each study in this review, of the extent to which Indigenous peoples' perspectives were part of the research process. Only those studies which used primary methods of data collection (e.g. interviews) were included in this appraisal. Studies which used secondary data only were not included in this Indigenous involvement appraisal. The results of this appraisal are below on p.45.

Drawing on the CONSIDER Statement (see Huria et al 2019), as well as the Aboriginal and Torres Strait Islander Quality Appraisal Tool (developed by Harfield et al 2020:5), and following consultation with First Nations researchers within our CAEPR research team, we developed the following criteria (see Table 7, over page).

*Table 7: Indigenous peoples' involvement in research appraisal criteria**
* Italics indicates sample responses

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, eg: in published literature*	*Research topic or question described as aligning only with* other people or organisations*' priorities, eg: those of funders or 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 supervisors or in an advisory capacity, eg project advisory group with majority Indigenous membership; employed in research team*	*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: 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.*	*Only one of the following shown: Indigenous standpoint theory or an Indigenous/Indigenist 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.*	*Theoretical influences do not include Indigenous standpoint theory or an Indigenous/Indigenist methodology. 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.*	*Cannot be determined from the published manuscript.*

Limitations

Systematic review is a research methodology with limited capacity to incorporate Indigenous perspectives, as well as the perspectives of people with disability. We attempted to address this by incorporating an Indigenous research methodology into our study design i.e. privileging Indigenous perspectives on disability in our analytical framework; and conducting an appraisal which assessed whether the research was promising practice from an Indigenous standpoint, as well as appraisal which assessed the involvement of Indigenous people/organisations in the study. However these appraisals were not without their challenges.

Regarding the Indigenous involvement appraisal, often information was not provided about whether Indigenous personnel/organisations/communities were involved in setting the research agenda, or were on the research team – so this exercise was not as meaningful as hoped.

The promising practice appraisal also proved very difficult. The Research Team anticipated that many approaches, programs, interventions, support services etc for Indigenous people in the justice system would not have been independently evaluated, and therefore there would be insufficient evidence to assess whether they are successful and represent 'promising practice'. This in fact turned out to be very much the case. Most of the approaches discussed in the included studies for Indigenous people with disability in the justice system had not been formally evaluated, or even implemented. There was simply not enough information provided in the included studies to be able to conduct this promising practice assessment accurately. As a result, this promising practice appraisal was abandoned.

Most of the literature contained in this systematic review is for the Australian context. There were not many results for Aotearoa (New Zealand) or the United States. A longer timeframe could enable the inclusion of more peer-reviewed literature databases and grey literature search engines, which would likely yield more international results.

Results

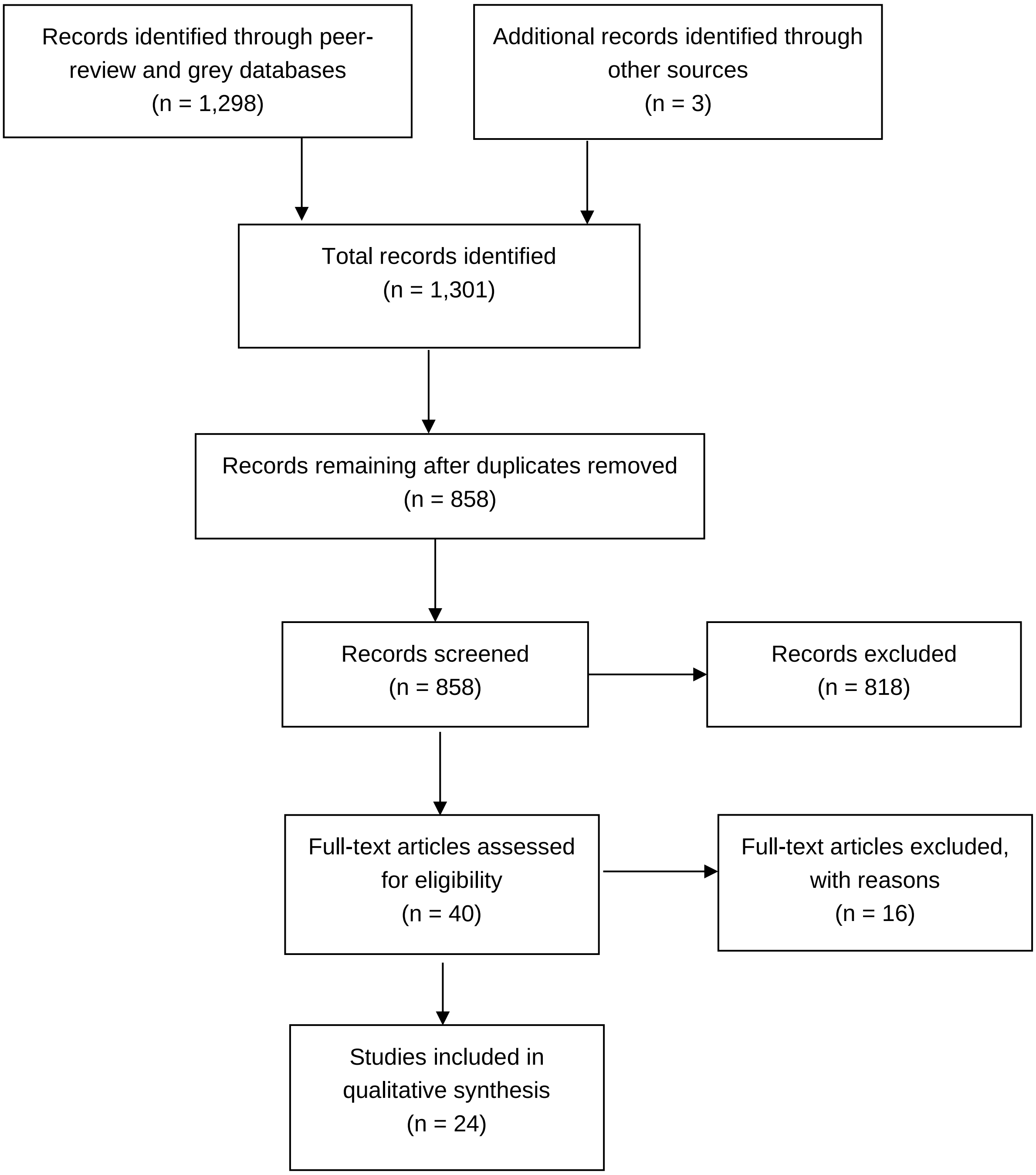
Our search strategy yielded a total of 1,247 peer-reviewed results, which were exported to Covidence. 443 duplicates were removed in Covidence, which left 804 to be screened. 25 of these made it to the full text stage. Of these 25 studies, 15 were included in this review.

Our search strategy also yielded a total of 51 grey literature results. 12 of these made it to the full text stage. Of these 12, 6 sources were included in this review.

We identified an additional 3 sources.

In total, our search strategy identified 1,301 sources. Of these, 24 sources ultimately met the inclusion criteria and thus were reviewed and analysed (see Appendix 1).

Figure 5: PRISMA flow diagram of Review 2 search and screening process



Results of quality appraisal

Appraisal of promising practice from an Indigenous standpoint

(Not applicable. See Limitations section above for explanation).

Appraisal of Indigenous peoples' involvement in research

Table 8: Results of Indigenous peoples' involvement in research appraisal

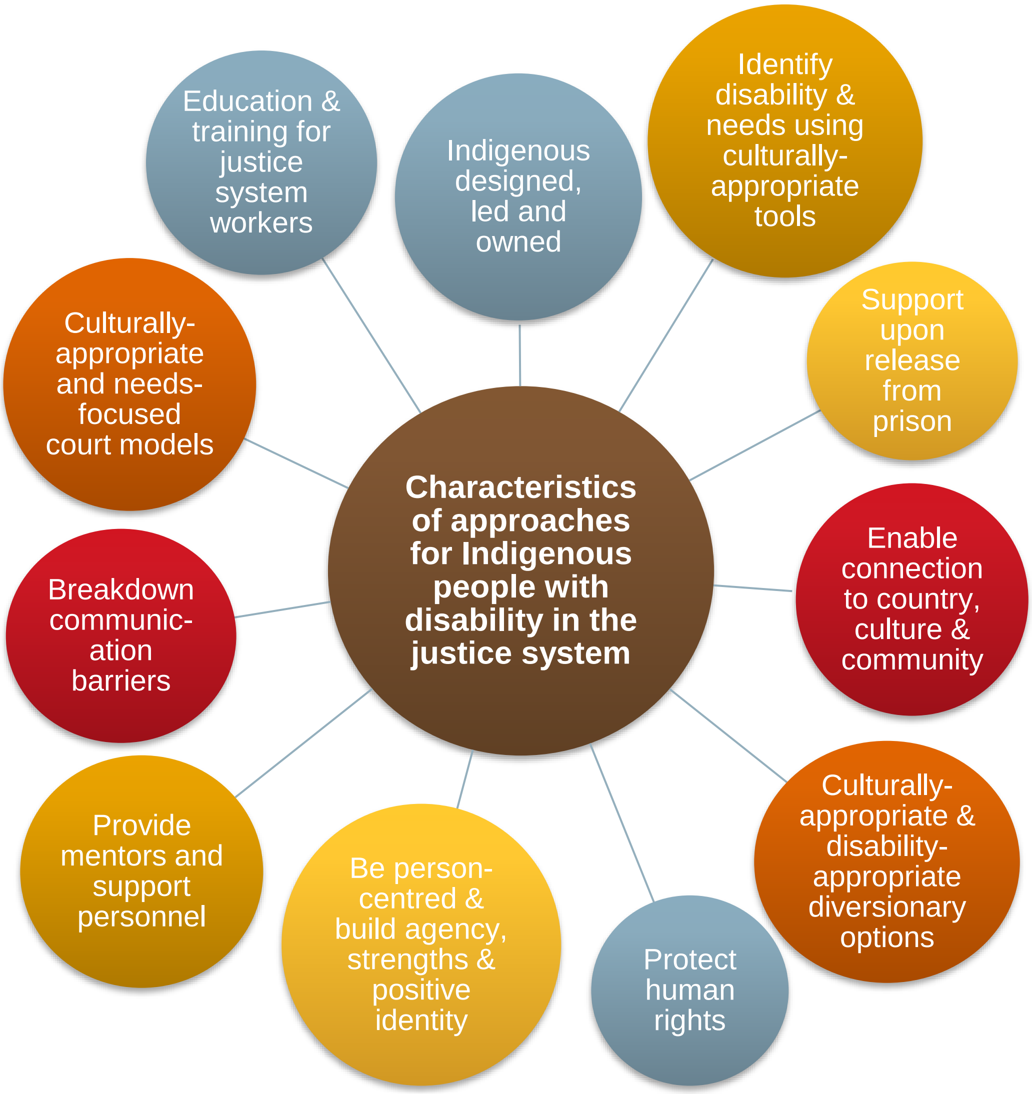
Study **(N.B. only studies which used primary data were included in this appraisal)**	**Setting the research priorities/agenda**	**Representation within research team and research governance**	**Incorporation of Indigenous ways of knowing, being, seeing, doing in theory, methodology, methods**
Miller 2017	Not reported	Yes	Somewhat
Hamilton et al 2020	Yes	Yes	Yes
Riley et al 2019	Not reported	Yes	Somewhat
Blagg & Tulich 2018	Yes	Not reported	Yes
Rasmussen et al 2018	Not reported	Not reported	No
Flannigan et al 2018	Not reported	Not reported	No
Ferrazzi & Krupa 2016	Not reported	Yes	Somewhat
Ober et al 2013	Not reported	Yes	Somewhat
Kippin et al 2018	Not reported	Not reported	No
Lau et al 2012	Yes	Yes	Not reported
HREOC 2008	Yes	Yes	Yes
Baldry, McCausland, Dowse, McEntyre 2015	Yes	Yes	Yes
Sharma et al 2018	Yes	Yes	Yes
Vanderpoll & Howard 2011	Yes	Yes	Yes
Sotiri & Simpson 2006	No	No	No
Royal Commission into Violence, Abuse, Neglect, Exploitation of People with Disability 2020	Yes	Yes	Yes
HREOC 2014	Yes	Yes	Yes
McSherry et al 2017	Yes	Yes	Yes

Discussion

In searching for literature for this systematic scoping review, it was apparent that numerous studies exist which focus on, or mention, the extraordinary high rates of Indigenous people in the criminal justice system and the need for 'more to be done'. There is also ample literature discussing that many justice-involved Indigenous people have cognitive and mental disability and require early intervention and diversion plus better support while incarcerated and upon release. However, there is comparatively little research on *Indigenous people with disability in contact with the criminal justice system* as an actual group; and there is even less research and evaluation on 'what works' for this group.

From the limited literature that does exist on Indigenous people with disability who have contact with the criminal justice system, some key themes emerged as to what is 'working well' or 'appearing promising' for this cohort. Figure 6 summarises these themes in a visual, and the pages below Figure 6 discuss each key theme in detail.

Figure 6: Characteristics of approaches designed to meet the needs of Indigenous people with disability in the justice system



Characteristics of approaches designed to address the needs of justice-involved Indigenous people with disability

Indigenous designed, led and owned

Several studies stress that approaches for Indigenous people with disability in, and even out, of the criminal justice system ought to be Indigenous designed, led and owned, and be underpinned by Indigenous ways of knowing, being, seeing and doing; and not merely be a mainstream, Western program/intervention which has been ‘made culturally appropriate’ (McCausland & Dowse 2020:330; Heffernan et al in Dudgeon et al 2014:166). However, “there is no published evidence of the outcomes of preventive or post-release programs for Aboriginal Australians that were developed, implemented and evaluated in collaboration with Aboriginal families and their communities” (Heffernan et al in Dudgeon et al 2014:166). Similarly, Rasmussen et al write – “while the need for Aboriginal-specific health and mental health services are advocated by government and academic groups alike…there is a scarcity of research evidence to support their inclusion in the prison context” (2018:142).

To most Indigenous people, the criminal justice system is a daunting construct containing quite foreign cultural assumptions, language and procedures. Isolation, punishment, correction/behaviour-change and retribution dominate modern Western approaches to crime (Hamilton et al 2020:22; Goren 2001:141), and these can be nonsensical, harmful and traumatising to Indigenous people, especially those with disability. A profound quote came from Ferrazzi & Krupa’s study of Inuit people in Nunavut - “(T)he criminal justice system is different from the Inuit system…(Elders are) the ones to correct the behaviours…through shaming them or through counselling. It wouldn't be through– to cut them off from their famy and send them away…With colonization everything got flipped upside down” (2016:163).

Blagg & Tulich (2018), as well as Miller (2017), argue that decolonising the justice system is necessary, which means that justice interventions be Indigenous community *owned*, not merely community *based*. They, and other studies in this review, argue that the shift of power and control back to Indigenous people will help enable self-determination. In 2015, a group of researchers from UNSW undertook an in-depth, Indigenous-informed, mixed-methods study (‘The IAMHDCD Project’) exploring the needs of Aboriginal people with disability in the criminal justice system, and provided a clear agenda for action – with self-determination being at the top of this agenda (Baldry et al 2015; McCausland and Dowse 2020)). The full set of recommendations made by the IAMHDCD Project, to ensure that the criminal justice system is no longer the default institutional response to Aboriginal people with mental and cognitive disability, are as follows (with more detail provided in the publication):

- Self-determination
- Person-centred care
- Holistic and flexible approach
- Integrated services
- Culture, disability and gender-informed practice (McCausland & Dowse 2020:328).

Several studies in this review assert that mainstream services are unable to provide culturally-safe care for justice-involved Indigenous people, and that Aboriginal community controlled services (ACCHOs) should provide support for this cohort (Heffernan et al in Dudgeon et al 2014:173; Blagg & Tulich 2018:9; McCausland & Dowse 2020:327; HREOC 2008:67; MacGillivray & Baldry 2013:25). It was suggested that, instead of increasing funding for police and justice agencies in Indigenous communities, human, social and health services who can effectively respond to Indigenous peoples' disability and complex needs as early on as possible – such as ACCHOs – ought to receive more funding (Baldry 2016;[4] Blagg & Tulich 2018:9; McCausland and Dowse 2020:332).

Identification of disability and needs using culturally-appropriate definitions and tools

Many of the included studies discussed the difficulty that exists in identifying disability and responding to it appropriately. Disabilities – especially cognitive, mental health and hearing loss (Vanderpoll & Howard 2011:10) – can be hidden, and therefore go by undetected and unsupported. Some Indigenous people themselves may not even realise they have a disability (Vanderpoll & Howard 2011), or may be reluctant to tell police, prison staff and others that they have a disability for fear of how they will be treated (Sharma et al 2018:5). Disability can be mistaken by criminal justice system workers for wilful defiance, delinquency, drug and alcohol use, low education and/or cultural and linguistic difference (McCausland and Baldry 2017:302). A person's Aboriginality (race) can be what is noticed, and focused on, and not their disability (Sotiri & Simpson 2006:436; Baldry et al 2015:12). McCausland and Baldry tell that schools and police often "view certain kinds of behaviour through prisms of institutional racism and offending rather than disability" (2017:290).

Schools, police and other services may be aware of the person's disability, but not take the information seriously, and ensure appropriate, therapeutic interventions, modifications, supports and services are provided (Baldry et al 2015:12; Sotiri & Simpson 2006:436; HREOC 2014:5). Sotiri & Simpson report that "police would ignore information about disability (as it resulted in extra work for them), be suspicious of the information (see it as a ploy to get out of arrest) or would use the knowledge of disability against the person in custody (by intentionally interviewing people in a way which would exploit the disability)" (2006:436).

These racist and ableist attitudes, coupled with the absence of appropriate services and supports for Indigenous people with disability (particularly in remote areas), is resulting in Indigenous people with disability being criminalised and 'managed', as such, by the justice system (Baldry et al 2015:12; McSherry et al 2017:10). In the IAMHDCD study conducted in Australia, interviewees highlighted that an Aboriginal or Torres Strait Islander child with cognitive or mental disability rarely receives early diagnosis or positive, culturally-responsive intervention, resulting in their disengagement or expulsion from school, and eventually contact with the police (Baldry et al 2016:11-12). HREOC also reported that Indigenous youth with cognitive disabilities and mental health issues are frequently labelled as too 'complex' (i.e. too hard to work with), and, as a result of human and social agencies repeatedly failing to assist them, these young people almost inevitably end up in detention/prison (2008:65). According to Baldry et al, there is a systemic normalisation of disadvantage, disability and offending, and a view amongst agencies that the best place for Indigenous people with disability and complex needs is in the justice system (2015:11).

Reliable and valid methods for identifying a person's disability and needs – such as clear definitions and culturally-safe diagnostic assessments and screening tools – are therefore critical (Heffernan et al in Dudgeon et al 2014:173; Blagg & Tulich 2018:9; Vanderpoll & Howard 2011:15-16; Flannigan et al 2018:21; Sharma et al 2018). A tension exists, though, between needing to identify disability so that services and supports can be provided, and Indigenous people often being resistant to (non-Indigenous) assessments and diagnoses. Our first systematic review highlighted that Indigenous people in Australia and globally do not tend to have a word for, or concept of, disability, and they can be reluctant to engage with the Western notion of disability – and colonial, medical, deficit labels generally – not only because these do not resonate, but for fear of stigmatisation, removal from family and community, unwanted intervention and institutionalisation (See Review 1). Several international studies in this

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[4] https://www.abc.net.au/radionational/programs/ockhamsrazor/australian-justice-system-disability-indigenous/7326240

review mentioned this point (Baldry et al 2015:12; Ferrazzi & Krupa 2016:164; McCausland and Dowse 2020; Flannigan et al 2018:13; Sotiri & Simpson 2006:436).

As such, definitions, measurements and service responses should be informed by Indigenous people's understandings and experiences (McCausland & Dowse 2020:332). Screening, diagnostic tools and services should also be designed, led and owned by Indigenous people, and should be holistic in that they consider the social, cultural, historical and other determinants of ill health and disability - such as colonisation, dispossession and marginalisation, racism, trauma, which Lau et al (2012:298) mention - which are important in Indigenous worldviews.

The studies in this review explained that while there is a lack of culturally-appropriate assessment tools, nevertheless some promising approaches are in place. The Indigenous Risk Impact Screen (IRIS) is one culturally-appropriate, widely-used tool for assessing substance use and mental disorder in Indigenous adults across Australia, which has been validated for use in the context of Indigenous adults in custody (Ober et al 2013:611). In Canada, the Alexis FASD Justice Program (AFJP) is an innovative partnership between the justice system and FASD clinical services in an Aboriginal community in Alberta, which uses neurocognitive assessment findings to inform court decisions (Flannigan et al 2018:21).

For many Aboriginal people, diagnosis of their disability comes with assessment on entry to prison (Baldry et al 2015:12; Sharma et al 2018). Recognising a person's disability/complex needs as early as possible in their life could mean they are more likely to receive appropriate rehabilitative services and supports, and thus make them less likely become entangled in the criminal justice system when their needs reach crisis point (McCausland and Dowse 2020; Vanderpoll & Howard 2011; HREOC 2008:65). The HREOC, for instance, recommended that disability and mental health screening occur for Indigenous children and youth in the child protection system (2008:44). Literature shows that Aboriginal and Torres Strait Islander children in OOHC are over-represented in the youth justice system and this is a key driver of adult incarceration (Andersen et al 2019:3).

Court models which are both culturally-appropriate and disability/needs-focused

Court innovations are currently in place in Australia and other countries, such as Aboriginal/Community courts (Koori Court, Youth Koori Court), circle sentencing, Aboriginal Sentencing Courts (ASCs) and Neighbourhood Justice Centres (NJCs). The aim of these more culturally-appropriate options is to involve Indigenous people and practices, and to empower the victim as well as the offender. They are based on the non-adversarial, less punitive and more rehabilitative concepts of 'therapeutic jurisprudence' (TJ) and 'restorative justice' (Goren 2001:140-1; Miller 2017). In these community courts, everyone has a shared responsibility in working out the nature and impact of the offence and how to repair the damage. Elders often participate in these courts, and give advice to - or even make decisions with - the magistrate.

Miller writes about Neighbourhood Justice Centres (NJCs), which are a type of problem-solving court that aims to engage and empower Indigenous communities to deal with crime. NJCs involve Elders in sentencing, employ Indigenous court workers (such as Koori Justice Workers), modify the courtroom layout and conduct of proceedings, and facilitate these with cultural training. The role of NJCs is not just to sentence offenders – they also take a holistic approach and house services such as mediation, legal advice, drug and alcohol counselling, financial counselling, housing and employment support, mental health services and Indigenous-controlled initiatives to assist the court in its problem-solving role (Miller 2017:125). Australia's first and only NJC was established in Melbourne in 2007. Blagg and Tulich praise Melbourne's NJC, saying that one of its most successful aspects, especially for those with FASD, is the high-quality needs assessment done by the clinical services team when an individual arrives at court. The authors write:

> This needs focused approach shifts the emphasis from processing offenders to identifying solutions. It places emphasis on the co-location of services (sorely needed in remote communities), a trauma informed practice, a 'no wrong door' approach to treatment, and respect for Indigenous knowledge (Blagg & Tulich 2018:8).

However, NJCs and ASCs have received criticism for being essentially a Eurocentric forum and failing to provide true self-determination to Indigenous people (Miller 2017:152). Aware of this, Miller recommends a hybrid NJC-ASC model which draws on the strengths of both (2017:140). Miller believes decolonisation of the criminal justice system can begin to occur through the use of the hybrid NJC-ASC both inside and outside of the court, and she explains in detail in her paper, from p.143 onwards, how it could be done.

In Aoetearoa (New Zealand), the Te Whare Whakapiki Wairua/The Alcohol and Other Drug Court (AODT Court) provides a culturally-competent drug court model that meaningfully incorporates tikanga (protocol) into the daily practices of the team, thus normalising the values of Te Ao Maori (Maori worldview) (Thom & Burnside 2018:1263). Miller also mentions Rangatahi Courts operating in Aotearoa, which incorporate Maori law and culture (2017:149). Goren mentions Family Group Conferences (FGCs) as a restorative justice mechanism focused on accountability, reaching consensus and restoring harmony, which has had success in diverting Maori from courts and prisons (Goren 2001:144). Goren does not discuss whether this is appropriate for those with disabilities, however. Similarly, Drug Treatment Courts (DTCs) in Vancouver have been found to reduce recidivism especially in Aboriginal and female participants, but it is unclear whether they are effective for those with mental disorders and disabilities (Somers et al 2014:666).

Blagg, Tulich and May question the effectiveness of 'problem-solving' courts and conferences as the cornerstone of restorative practice, especially for those with disability such as FASD (2019:117). They argue instead for a 'mobile needs focused court' (raised also in Blagg, Tulich and Bush 2015), which is a hybrid model that draws on the strengths of the Koori Court model and the NJC model. This model would see Elders in the courtroom – which the researchers agree help to provide a recognisable, safe, comforting cultural symbol for those with disability such as FASD who may not respond well to unfamiliar people and processes (Blagg & Tulich 2018:7). This model would also employ a comprehensive screening process upon entry into the court, and would refer them into support programs, preferably on country. Blagg and Tulich envisage that "this hybrid approach would allow greater Indigenous involvement in community-based alternatives for those found unfit to stand trial and, through culturally secure and community owned alternatives, lead to better outcomes for Indigenous young people with FASD" (2018:7). Blagg and Tulich recommend that such a hybrid, needs-focused court be trialled in the West Kimberley (2018:12).

Ferrazzi and Krupa discuss how, in many cities in North America and elsewhere, a leading response to the overrepresentation of people with mental illness in the criminal justice system has been criminal court mental health initiatives (2016:160). These mental health courts are based on therapeutic jurisprudence and thus sound very similar to Australia's Neighbourhood Justice Centres and Aotearoa's Rangatahi Courts. However, criminal court mental health initiatives are rare outside of urban centres in North America, and do not exist for the Inuit people in the Canadian Arctic (Nunavut). Ferrazzi and Krupa's study represents an important first step in identifying whether criminal court mental health initiatives can be adapted to geographically remote Nunavut communities (2016:164). They conclude that "differences between Inuit and Western conceptions of mental health and treatment as well as the colonial backdrop of cultural interference create more opportunities for TJ-thinking to overstep its modest therapeutic aims, risking instead paternalism and a denial of cultural legitimacy. These opportunities must be rigorously identified and avoided" (Ferrazzi & Krupa 2016:166).

Pyne points out - like Miller; Blagg and colleagues; and also Ferrazzi & Krupa - that "Community Courts are not a panacea. It is extremely important that we do not judge Community Courts by their capacity to reduce recidivism alone. It is not self-determination. It does not, and cannot, apply Indigenous law… But it is a viable alternative. It is more culturally relevant. It is an expression of reconciliation. Where studies have been done, the strong anecdotal evidence is that it is more meaningful to offenders" (2012:7).

Diversionary options which are both culturally-appropriate and disability/needs-focused

A strong theme coming through in this review is the need for diversion (into mental health, drug and alcohol and other community-based, rehabilitative programs) for Indigenous offenders with disability, rather than a custodial sentence – especially for low-level crime. Many researchers in offender rehabilitation recommend that treatment, not punishment, is required, especially for those with disability (Pyne 2012:12; Kreig et al 2016:177; Baldry et al 2015).; and that such treatment should be based in the community, rather than in custody (Flannigan et al 2018:21; Heffernan et al in Dudgeon et al 2014:173).

The Cognitive Impairment Diversion Program (CIDP)[5] is one example of a seemingly promising diversionary scheme. CIDP is two-year pilot program in Australia which has kept low-level defendants (aged 18 and over) with disabilities out of prison and redirected them into appropriate community-based services. Around a quarter of participants are Aboriginal or Torres Strait Islander. CIDP has operated at Penrith and Gosford Local Courts since October 2017. Unfortunately, as at June 2020, the NSW Government was planning to close this seemingly successful program.

There seems to be few positive, community-based options specifically designed for justice-involved Indigenous people with disability (HREOC 2014:16; Flannigan et al 2018:5; McCausland & Dowse 2020:332). There are even less diversionary options available for Indigenous people with disability/complex needs in remote areas. Baldry et al explain that "drug and alcohol rehabilitation is often only available in a regional centre, which may be many hundreds of kilometres away, and even then, excludes people with a cognitive impairment. Mental health services are unable to accept people with drug or alcohol addiction. The few diversionary programs that aim to assist people whose offending is connected to their drug and alcohol addiction will not accept those with a history of violence. Incarceration becomes the default option in the absence of available or appropriate community-based care, housing or support" (2015:11).

Included sources discussed how regular diversionary options may not actually be appropriate for those with disability, especially Indigenous people with disability. According to McCausland and Dowse, "diversionary programmes tend to be embedded in a concept of individual responsibility and choice around offending that can be counterproductive for people with mental and cognitive disability, as it presumes they can simply choose to stop offending. Failure to meet the eligibility criteria of a diversion programme or to complete it for whatever reason is considered as failure of the individual rather than a result of systemic factors, ill-conceived programme design or punitive administration" (2017:296). Flannigan et al use almost identical words to this (2018:5). McCausland and Baldry are of the view that "diversionary mechanisms, however well intentioned, are serving to entrench rather than divert" (2017:303). For instance, they found that some individuals, especially those with disability, are receiving a longer sentence in order to access diversionary programs.

In a similar vein, Blagg and Tulich argue that diversionary alternatives are sorely needed, especially for those with FASD and other disabilities, but they are doubtful of the relevance of mainstream diversionary mechanisms to this task (2018:2). In another paper, Blagg, Tulich along with another colleague, May, argue that "an appropriate model

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[5] https://cid.org.au/our-stories/why-close-down-such-a-successful-diversionary-program/

would have Aboriginal people engaged in the planning and management of diversionary options, with greater focus on diversion into place-based, Aboriginal owned and managed services" (2019:105).

Several studies mentioned the limited community-based diversionary options for Indigenous women with mental and cognitive disability (such as community-based accommodation), particularly for those living in regional and remote areas (McCausland and Baldry 2017:296), and for female offenders with children (Royal Commission 2020:7; Somers et al 2014:665). Indigenous women are the fastest growing group of prisoners (McCausland & Baldry 2017:296; Heffernan et al in Dudgeon et al 2014:166). Sharma et al reveal that around 86% of Indigenous women in custody have been diagnosed with a mental health condition (and 73% of men) (2018). Riley et al's paper also shares these statistics (2019:2573). Baldry et al found that the Indigenous women in their IAMHDCD study cohort had the most complex support needs, including for disability, mental health and drug and alcohol misuse (2016:11). Riley et al support this, noting that – "despite prevalence rates for psychiatric conditions among female prisoners being significantly higher than males, there is a particular lack of programs specifically designed for women" (Riley et al 2019:2572).

Australian Human Rights Commission compiled a report in 2008 titled *'Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues.'* The report states that there is no comprehensive body of research on, nor specific early intervention or diversionary options for, Indigenous young people with disability in the justice system. As a result, this group are severely disadvantaged and lacking in appropriate service delivery (2008:37). HREOC collected stories from young people involved in the justice system which are provided in the report. In the report's Conclusion, the following best practice principles are listed:

- Indigenous young people with cognitive disabilities and/or mental health issues have many of the same needs as Indigenous young people without these conditions
- The social determinants of health need to be met to improve outcomes for Indigenous young people with cognitive disabilities and/or mental health issues
- Service delivery must be holistic
- Intervention must be culturally aware and appropriate
- Communities need to be involved and have control over programs
- Interventions should build on strengths and positive identity
- Service needs to be rights based
- Flexible service
- It's never too late (to divert and intervene) (HREOC 2008:66).

Facilitate connection to Indigenous country, culture and community

On-country programs

Blagg and Tulich recommend an on-country approach for Indigenous offenders and those at risk of offending, especially those with FASD; and suggest the West Kimberley as a place to pilot this (2018:12). Blagg & Tulich mention an already successful initiative called the Yiriman Project, run by Elders from around Fitzroy Crossing in Western Australia. This program takes young Aboriginal people at risk of offending out onto traditional country, where they acquire bush skills in a culturally secure environment. The project has been praised by the Productivity Commission as a "project that works" (2014 Overcoming Indigenous Disadvantage Report). It was a winner in the 2012 Indigenous Governance Awards, and was also mentioned in the National Mental Health Commission Report (March 2015) as an example of national best practice for working with at-risk Aboriginal youth (in Thorburn & Marshall 2017:3). The Magistrates Court has sent young people to the Yiriman project as an alternative to custody, with considerable success (Blagg & Tulich 2018:9). A three-year review of the Yiriman Project (Palmer 2013) found that not only is being on country good for young peoples' health and wellbeing, but it minimises their involvement in the justice system. In Canada, Ferrazzi & Krupa similarly argue for programs that provide justice-involved Inuit people with mental health issues opportunities to be on country (2016:162)

Art, creativity, expression

Rasmussen et al conducted a ground-breaking study between 2008 and 2010 to assess the benefits of in-prison art programs. In particular, these researchers aimed to “investigate the degree to which engagement in Aboriginal art programs buffers Aboriginal prisoners from psychological distress that leads to deliberate self-harm or suicide” (2018:143). A total of 108 (32.2%) male Aboriginal prisoners voluntarily attended the art program at least once during their incarceration, and 10.2% reported having psychiatric issues. In the program, the prisoners engaged in Aboriginal art and socialised with visiting Elders from the local community (2018:144). Rasmussen et al found there to be “strong evidence that an increase in attendance in the Aboriginal art program was associated with reduce incidence of suicide/self-harm risk assessment” (2018:146). These authors make mention, too, of ‘The Torch Project’ – a successful rehabilitation program in Victoria, which helps Aboriginal prisoners express their cultural identity and build their wellbeing, confidence, sense of trust and hope through Aboriginal art (Rasmussen et al 2018:142).

Blagg and Tulich also write about emergent research in neurodevelopmental science, which “emphasises the need for interventions (for those with FASD especially) focused on optimising the functioning of the frontal lobe and limbic system, such as dance, art, nature discovery and storytelling, which have optimal efficacy when repeatedly implemented (Perry 2009)” (2018:11).

Holistic, Indigenous healing programs

One of the studies in this review (Lau et al 2012) describes Melbourne’s Gathering Place Health Service (GPHS) healing initiative for Aboriginal and Torres Strait Islander people, which is an intensive rehabilitation and spiritual healing program for Indigenous men and women, most of whom have mental illness, substance issues and/or chronic health conditions. According to Lau et al, the program proved very effective for one repeat offender (a middle-aged Aboriginal man with mental health and substance abuse issues).

GPHS’s healing program is guided by the following principles: meeting physical and mental health concerns in the context of spiritual, cultural, social and emotional wellbeing; providing support during transition from prison to community and a whole-of-family approach. The program consists of many supported components, such as art and culture classes, food/nutrition classes, drug and alcohol counselling, literacy and numeracy classes, sport and physical activity program, and meditation.

Lau et al explain that the most crucial aspect of the program is the weekly healing circle, which is run by Indigenous Elders and provides culturally-appropriate group therapy. The main purpose of these circles is to help participants to reconnect with their Indigenous culture, heritage and spirituality. Participants are also linked up with appropriate GPHS health professionals, if needed. Healthy lunches are provided at these meetings too. The program has mentors and Indigenous health workers who help make sure participants’ disability, health/medical, housing, transport, social and other needs are met. Unfortunately, the GPHS healing program had not (at that point) been formally evaluated (Lau et al 2012:299).

Whole of family and community approaches

The available literature indicates that treatment and healing for those with disability and mental health issues should involve family, community and Elders i.e. not just take an individual-focused approach (Flannigan et al 2018:23; Ferrazzi & Krupa 2016:163). As one justice worker in Blagg and Tulich's study said, "We need to support the entire family: don't water one flower and expect the garden to stay alive" (2018:10). A health sector participant in Ferrazzi & Krupa's study of justice-involved Inuit in Nunavut, pointed out – "Once the family washes their hands of a person, I've seen those people's criminal careers just spike. If you're an Inuit person with no place in a community or family, you stop caring about everything and offending no longer matters" (2016:163).

Lau et al found that "children of incarcerated parents are at higher risk of poor health and are themselves at an increased risk of offending later in life; this intergenerational trauma is particularly prevalent in the Indigenous community (Indig et al 2011)" (2012:299), and this is why the GPHS pilot healing programme uses a whole-of-family approach (Lau et al 2012:300).

The interviews with incarcerated Indigenous youth, conducted by Hamilton et al, revealed that many of these young people saw their families as a source of strength, comfort and wellbeing, and that strong relationships and networks with family and others are an important part of recovery and healing (2020:22).

Protecting human rights

As we are hearing with the current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), many people with disability in the Australian community – including Indigenous people, and including those in the criminal justice system – are not having their needs met. Indeed, many are experiencing significant abuse and mistreatment from fellow inmates and correctional officers, so having their disadvantage compounded.[6] This is especially the case for Indigenous young people with disability.

Human Rights Watch's *'I Needed Help, Instead I Was Punished'* report (Sharma et al 2018) also detailed harrowing stories of treatment of Indigenous people with disability in the justice system. Based on research between September 2016 and January 2018 in Western Australia, Queensland, New South Wales, and Victoria – including interviews with people with disabilities, prison-related and government professionals, mental health experts, academics, lawyers and civil society representatives – the report found that Australia is restricting and violating the rights of prisoners with disabilities, including Aboriginal and Torres Strait Islander people with disabilities (2018). Pyne also was of the view several years ago that the laws in the Northern Territory especially are racially discriminatory against Indigenous people, and are in conflict with international human rights standards (2012:12).

In the included studies, some suggestions made for how the human rights of justice-involved Indigenous people with disability can be protected are as follows:

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[6] By 2 November 2020, the Royal Commission had received 56 responses to their health issues paper. They heard from people with disability, governments, service providers, disability organisations. The results are contained in *Overview of Responses to the Criminal Justice System Issues Paper, December 2020* - https://disability.royalcommission.gov.au/system/files/2021-01/Overview%20of%20responses%20to%20the%20Criminal%20Justice%20System%20Issues%20paper.pdf

Provision of legal assistance

Several submissions to The Royal Commission contend that people with disability who interact with the criminal justice system do not access justice on an equal footing to others. The Royal Commission proposes that access to targeted legal assistance (particularly legal assistance which delivers culturally informed and accessible services to people with disability from culturally and linguistically diverse backgrounds) is one important element in enabling justice (2020:4-5&16).

Consistently and fairly apply Section 32 and 33

Section 32 and Section 33 of the *Mental Health (Forensics Provisions) Act 1990 (NSW)* can be applied by a magistrate to people who are seriously mentally ill at the time of their court appearance, otherwise Section 32 is used as the main diversionary mechanism. However, MacGillivray and Baldry found in their IAMHDCD study that very few people who meet Sections 32 and 33 are granted it by the court, and this is especially the case for Indigenous people (2013:24). A major reason for this is the extremely high volumes of matters that magistrates, Aboriginal legal services solicitors and NSW legal aid lawyers deal with in local courts (MacGillivray & Baldry 2013:4). As McSherry et al note, “legal services are under-resourced and not necessarily prepared to respond to the access needs of persons with disabilities” (2017:10). McCausland and Baldry explain that some may not be given sufficient time or opportunity to discuss their disability with their solicitor, meaning their disability will not get raised or recognised in the sentencing process (2017:302).

Pyne recognises that “undiagnosed mental illnesses mean a greater risk of jail” (2012:10), and also calls for reform of the Mental Health Act (in the Northern Territory at least), so that accused persons with mental illness can be diverted into appropriate treatment without the requirement for a plea of guilty or consent of the prosecution (Pyne 2012:10-11).

Address ‘unfit to plead’ laws

Australian laws allow for people with disabilities to be detained indefinitely (for years, even), when they are considered unable to understand or to respond to the criminal charges laid against them (referred to as “unfit to plead”) (McCausland and Baldry 2017:297; Pyne 2012:10; Baldry et al 2015:167). This means that “an individual can therefore spend a longer time in detention than if he or she plead guilty and was sentenced to imprisonment for the offence” (Blagg & Tulich 2018:5-6; confirmed also by McCausland & Baldry 2017:297, and Pyne 2012:10). Blagg and Tulich discuss how a diagnosis of FASD can lead to a child being detained indefinitely (2018:5). The current Royal Commission has also heard that indefinite detention is occurring for both adults and children (Indigenous and non-Indigenous) with disability, and have called it “a serious and deeply troubling issue” (2020:7). The Royal Commission has found that some defendants will plead guilty even if they did not commit the crime, so they at least know when they will get out if they are sent to prison (2020:5). The Royal Commission proposes that there be a “review and amendment of all legislation pertaining to unfit to plead tests to ensure that people with disability are not held in indefinite detention” (2020:16).

McCausland and Baldry conclude that “there is an urgent need for alternative secure, therapeutic care options in the community both for people found unfit to plead and for people with mental and cognitive disability charged with summary offences who do not have this option” (2017:299). According to Blagg & Tulich, New Zealand provides a best practice model for young people with FASD. Fitness is governed by the *Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (NZ)* (IDCCR Act) and the *Criminal Procedure (Mentally Impaired*

Persons) Act 2003 (NZ). These acts “mandate that, wherever possible, a young person’s family must be fully engaged in decision making. It also provides for a needs assessment process, which includes a cultural assessment if the person is Māori” (Blagg & Tulich 2018:6).

McSherry et al conducted a two-year research project in Australia, which was designed to develop practical and legal solutions to the problem of persons with cognitive disabilities – and particularly Indigenous people with cognitive disabilities – being found unfit to plead and detained indefinitely (2017:10). The researchers argue that a criminal justice system that is universally accessible to persons with and without disability, and does not create separate justice procedures for persons with disabilities, is the most comprehensive way to comply with human rights law (2017:58). They add that, “until a universally accessible criminal justice system can be achieved, there is a need to maximise rights protections for persons with cognitive disabilities in existing criminal justice processes, such as unfitness to plead law” (McSherry et al 2017:58).

Abolish solitary confinement

The current Royal Commission has heard that restrictive practices (such as segregation and isolation) are used in prisons, including on people with disability (2020:6). Sharma et al report that prisoners with mental and cognitive disabilities are being locked in solitary confinement for weeks or months, sometimes for almost 24 hours a day. Some of these inmates can spend years in prolonged solitary confinement in maximum security units, which is a breach of international human rights laws (2018). Restriction, solitary confinement and punishment can be incredibly confusing, distressing and traumatising for those with disability, and Sharma et al assert that governments must put an end to this inhumane practice (2018).

Develop policies, such as a Disability Justice Strategy

In 2014, HREOC’s *‘Equal Before the Law’* report recommended that each jurisdiction in Australia develop a Disability Justice Strategy, which focuses on:

1. Safety of people with disabilities and freedom from violence
2. Effective access to justice for people with disabilities
3. Non-discrimination
4. Respect for inherent dignity and individual autonomy including the freedom to make one’s own decisions
5. Full and effective participation and inclusion in the community (2014:6-7).

The Royal Commission also proposed that all jurisdictions adopt Disability Justice Strategies, “which should address themes including prevention services for people with disability and mental illness, early identification of disability, referral and multi-system responses, diversion, rehabilitation approaches and throughcare” (2020:15).

Be person-centred and build agency, strengths and positive identity

People in the justice system, including those with disability, should be supported to make decisions about their own needs and recovery (McCausland and Dowse 2020:328). Several of the studies talked about the need for initiatives for which are nurturing, therapeutic, foster empowerment, confidence, capacity, sense of self-worth and purpose, as opposed to punishing harder and longer (Flannigan et al 2018:6&13; Thom & Burnside 2018:1260-

1; Hamilton et al 2020). An example cited was anger management programs, such as the successful Indigenous Family Violence Offenders Program (IFVOP) (Pyne 2012:8).

Hamilton et al yarned with 38 youth (27 Aboriginal and 11 non-Aboriginal) at Banksia Hill Detention Centre in WA, to find out what personal, social and community capital they require. Some of these young people had been diagnosed with FASD or neurodevelopmental impairments. Although the participants had lives marred by trauma, disability and hardship, they spoke of many things that made them happy and hopeful: strong connections to country, family and community, and future goals such as education, employment and skill development. Hamilton et al call this ‘recovery capital’, and argue that services ought to focus on these if they want to help these young people (with and without disability) on their pathway out of the justice system. The authors recommend the development of an assessment tool that measures positive and negative recovery capital assets of justice-involved youth (Hamilton et al 2020:31).

Flannigan et al obtained perspectives from service providers who work with the Alexis FASD Justice Program (AFJP), which operates in the Alexis Nakota Sioux Nation in Canada. The researchers found the following features of the AFJP supported offenders with FASD and complex needs: screening and identification of areas of disability; comprehensive assessment to understand individual strengths and difficulties; special attention to basic needs; simplifying and assisting with navigating the justice process; mentorship; family and community engagement; and collaborative, compassionate, flexible approaches (Flannigan et al 2018:23).

Erickson and Butters praise the innovative and well-evaluated Multisystemic Therapy (MST) program in Ontario, Canada, which has proven successful for juvenile offenders (including Aboriginal juvenile offenders) with substance issues. MST is tailored to the individual’s needs and strives to address the multiple sources of criminogenic influences, and also stresses the importance of considering the young person’s whole social context e.g. family, school, peer group, community (2005:963). MST is also mentioned in a 2013 report by Just Reinvest NSW titled *‘Examples of promising interventions for reducing offending, in particular Indigenous juvenile offending’.* MST is the principle underpinning NSW Department of Juvenile Justice’s Intensive Supervision Program (ISP). According to the Government’s *Doing Time – Time for doing* report, MST/ISP was successful for known offenders because it: reduced offending by young people who completed the program; taught caregivers the appropriate parenting skills necessary to handle future problems; and improved family relations and support networks (2011, in Just Reinvest Report 2013).

In a women’s prison in South Australia, Acceptance and Commitment Therapy (ACT), which uses mindfulness and acceptance strategies, was found to be an acceptable and feasible intervention for female Indigenous Australian prisoners with mental health, drug and alcohol issues, and medical conditions (Riley et al 2019:2572). Participants gave overwhelmingly positive feedback about the program and there were no formal dropouts. Riley et al found an improvement in anxiety and mindfulness measures amongst Indigenous women, though they admit that correlation does not necessarily mean causation (2019:2581). They argue for further research into mindfulness programs.

Break down communication barriers

Courts and prisons are highly verbal, alien environments for Indigenous people who sometimes do not have English as their first language, and even more so for those Indigenous people with disability who may aural-oral, communication and comprehension difficulties such as FASD and hearing loss (McSherry et al 2017:10; Sotiri and Simpson 2006:439; Vanderpoll and Howard 2011; Kippin et al 2018). As HREOC’s *‘Equal Before the Law’* report states, “people with disabilities are less likely to get bail and more likely to breach bail because they have not understood the bail conditions" (2014:16). There is therefore "a glaring need for interpreters able to assist Indigenous people to understand and participate in the (court) process," as argued by Blagg and Tulich (2018:7). Kippin et al – who found that "nearly one in two young people were identified with language disorder, over half of whom had language disorder associated with FASD" (2018:40) – also argue that speech therapists, interpreters and local cultural and language advisors are warranted at all stages of the criminal justice system (2018:40).

Vanderpoll and Howard found that over 90% of Indigenous inmates in the Northern Territory had some degree of hearing loss (often due to untreated childhood middle ear infections [otitis media] as well as tinnitus). Such hearing difficulties are likely a major contributory reason these people have ended up in the criminal justice system. The inmates in Vanderpoll and Howard's study said they had trouble hearing in court and police, and that they find it hard in prison (2011:10). Vanderpoll and Howard recommend hearing loss awareness training for justice officials, routine hearing tests for inmates, and provision of hearing aids/amplification for inmates (2011:15-16).

Provide mentors and support personnel

Mentors and support personnel was suggested by several of the sources (Flannigan et al 2018:11; Hamilton et al 2020:31; Thom & Burnside 2018:1261; HREOC 2008:29; Guerrero et al 2019:554; Miller 2017:146).

The Royal Commission has heard that the justice system ought to use community-based services and supports for people with disability at all stages of the justice system, and specifically mentioned intermediary programs. An intermediary is someone who can find out the best way to communicate with another person; find out what communication support the person needs; tell people in the justice system how to communicate with that person and support the person to communicate (2020:14). Kippin et al also discuss the usefulness of intermediaries (also known as 'court-appointed communication assistants') for justice-involved youth with FASD and language disorder (2018:47).

Miller mentions 'Koori Justice Workers' at Melbourne's Neighbourhood Justice Centre, who support Indigenous clients by: creating treatment plans, provide spiritual and emotional support, referring clients to appropriate services and ensuring Indigenous knowledge and perspectives are honoured (Miller 2017:146).

Thom and Burnside discuss peer support as an innovative, successful feature of Te Whare Whakapiki Wairua/The Alcohol and Other Drug Court (AODT Court). Often the peer support workers are ex-offenders themselves, meaning they have lived experience. "The idea is to give hope, to show that change is possible," say Thom and Burnside (2018:1261).

However, Sotiri and Simpson caution about the effectiveness of support workers. For instance, some Indigenous people in the justice system may not feel comfortable having an Indigenous support person who is someone they know (2006:438). As such, choice for the Indigenous person should always be provided where possible.

Education and training for those working in the criminal justice system

Almost all the sources in this review mentioned that stakeholders, such as police, lawyers, magistrates, correctional officers and others, often do not recognise disability (especially cognitive disability) in Indigenous (and even non-Indigenous) people, and do not know how to address such a situation in an appropriate, effective manner. HREOC's *'Equal Before the Law'* report, for instance, stated that styles of communication used by justice system personnel can confuse a person with disability (2014:5). There was a call in the included studies for mandatory, ongoing cultural, disability and gender training for such personnel (McCausland and Dowse 2020; Royal Commission 2020; Sharma et al 2008; Heffernan et al in Dudgeon et al 2014:171; Baldry 2016; HREOC 2008:66-7; Shepherd et al 2017:9; Vanderpoll & Howard 2011:14; Flannigan et al 2018:25; Miller 2017:150-1).

Education and training might help to address some of the negative attitudes, stereotypes and assumptions about people with disabilities ('ableism') e.g. that they are unreliable, not credible, not capable of giving evidence, making legal decisions or participating in legal proceedings (as mentioned in HREOC's 2014 report, as well as the current Royal Commission 2020). It could help authorities understand what people with disability need, and how to communicate with them.

Education and training, e.g. about Indigenous peoples' past and present experiences, could also help to address racism. According to Baldry et al, "an assimilationist approach was perceived as still pervasive among many of those working within criminal justice and human service agencies, with little recognition of the ongoing impact of colonisation, intergenerational trauma, and grief and loss for Indigenous people" (Baldry et al 2016:11).

Education and training could thus help improve relations between non-Indigenous stakeholders (particularly police) and Indigenous communities, and help Indigenous people better trust the police, judges, correctional officers and others in the justice system (Miller 2017:150-1; Trofimovs and Dowse 2014:396).

Support upon release from prison

According to Shepherd et al, Indigenous offenders with a cognitive impairment are almost three times more likely to reoffend (2017). For Indigenous people with mental and cognitive disability there are very few alternatives to prison; a lack of appropriate programs and support services in prison or post-release; and the outside world is often difficult for them to navigate – meaning return to prison is very likely (Baldry et al 2015; Sharma et al 2018). Tait et al explain that "most parolees living with FASD and comorbid psychiatric illness eventually face environmental and psychosocial risk factors similar to the ones that contributed to their incarceration" (2017:117).

Vanderpoll and Howard explain how hearing loss can be a barrier to release and rehabilitation (2011:15). Indigenous inmates with hearing loss may actually prefer the high security section of the prison because it has less demands on their listening skills. Some inmates also will choose to do their whole time in prison rather than apply for parole, because parole is typically complex, challenging and requires good listening skills (Vanderpoll & Howard 2011:15).

Release from prison for Indigenous Australians with mental disorder is associated with a range of poor health outcomes such as homelessness, substance abuse, drug overdose and suicide (Heffernan et al in Dudgeon et al 2014:172). Provision of primary health care (Kinner et al 2015:650-3), and other resources and services which help Indigenous people with disability transition to life in the community, are vital; especially for women (Kilroy 2005:25). These resources and services could include: financial support, employment and training opportunities, drug and alcohol assistance, grief and mental health counselling and safe and affordable housing (Kilroy 2005:25). Sullivan et al 2019, as well as Pyne (2012:9) discuss the effectiveness of 'throughcare'[7] initiatives, such as the Connections Programme (CP), which provide support to individuals during imprisonment through to post-release. The Royal Commission also heard from AMSANT that the throughcare program run by NAAJA is an example of

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[7] "Throughcare is a policy approach that addresses the transition of prisoners released into the community" (Griffiths et al 2016:7).

good practice (2020:14). However, it is unclear as to whether throughcare initiatives are effective for Indigenous people with disability.

Baldry et al mention the need for supported accommodation and educational support for Indigenous people with disability, early in life if possible, and also after release from prison (2012:114). As stated in *The Conversation* piece about Baldry and colleagues' IAMHDCD project - "the NSW Community Justice Program is a good example (of a housing program). It provides specialised intensive 24-hour supported accommodation to drop-in support for people with an intellectual disability who have been in the criminal justice system."[8]

Rasmussen et al contend that "Aboriginal prisoners who were assessed as having high levels of engagement in cultural activities were less likely to violently reoffend (Shepherd, Delgado, Sherwood, & Paradies, 2018)" (2018:142). Lau et al similarly contend that "post-release support for Indigenous prisoners requires spiritual and cultural specificity for successful community reintegration (Willis & Moore, 2008). Community programmes encompassing healing, family and relevant education are paramount" (2012:299). The GPHS healing program indeed focuses on providing support during transition from prison to community (Lau et al 2012:300).

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[8] https://theconversation.com/heres-how-we-can-stop-putting-aboriginal-people-with-disabilities-in-prison-49293

Table 9: Characteristics of approaches designed to meet the needs of Indigenous people with a disability in the justice system

Characteristics of approaches, interventions, programs, services etc which meet the needs of Indigenous people with disability in the justice system	**Mentioned in the following included sources**
Be Indigenous designed, led and owned	McCausland & Dowse 2020; Heffernan et al in Dudgeon et al 2014; Hamilton et al 2020; Ferrazzi & Krupa 2016; Rasmussen et al 2018; Blagg & Tulich 2018; Miller 2017; HREOC 2008; MacGillivray & Baldry 2013; Lau et al 2012; McCausland & Baldry 2017
Identify a person's disability and needs using culturally-appropriate definitions and tools	Heffernan et al in Dudgeon et al 2014; Blagg & Tulich 2018; Vanderpoll & Howard 2011; Flannigan et al 2018; Sharma et al 2018; McCausland & Dowse 2020; Lau 2012; Ober et al 2013; HREOC 2008; McCausland & Baldry 2017; Hamilton et al 2020
Court models which are not only culturally-appropriate but also disability/needs focused	Miller 2017; Blagg & Tulich 2018; Thom & Burnside 2018; Ferrazzi & Krupa 2016; Pyne 2012
Disability-appropriate and culturally-appropriate diversionary options	Pyne 2012; Baldry et al 2015; Flannigan et al 2018; Heffernan et al in Dudgeon et al 2014; McCausland & Dowse 2020; HREOC 2014; Flannigan et al 2018; Royal Commission 2020; Riley et al 2019; HREOC 2008; Blagg & Tulich 2018; McCausland & Baldry 2017
Facilitate connection to Indigenous country, culture and community	Blagg & Tulich 2018; Ferrazzi & Krupa 2016; Rasmussen et al 2018; Lau et al 2012; Flannigan et al 2018; Hamilton et al 2020
Protect human rights	Royal Commission 2020; Sharma et al 2018; Pyne 2012; McSherry et al 2017; Blagg &

	Tulich 2018; McCausland & Baldry 2017; Baldry et al 2015; HREOC 2014
Be person-centred and build agency, strengths and positive identity	McCausland & Dowse 2020; Flannigan et al 2018; Thom & Burnside 2018; Hamilton et al 2020; Pyne 2012; Erickson & Butters 2005; Riley et al 2019
Break down communication barriers	Vanderpoll & Howard 2011; McSherry et al 2017; Sotiri and Simpson 2006; HREOC 2014; Blagg & Tulich 2018; Kippin et al 2018
Provide mentors and support personnel	Flannigan et al 2018; Hamilton et al 2020; Thom & Burnside 2018; HREOC 2008; Miller 2017; Royal Commission 2020; Kippin et al 2018; Sotiri and Simpson 2006
Education and training for those working in the justice system	McCausland and Dowse 2020; Royal Commission 2020; Sharma et al 2008; Heffernan et al in Dudgeon et al 2014; HREOC 2008; Vanderpoll & Howard 2011; Flannigan et al 2018; Miller 2017; HREOC 2014
Provide support upon release from prison	Baldry et al 2015; Sharma et al 2018; Vanderpoll & Howard 2011; Heffernan et al in Dudgeon et al 2014; Royal Commission 2020; Pyne 2012; Rasmussen et al 2018; Lau et al 2012

Conclusions

This systematic review highlights that there is a dearth of research and evaluation on promising approaches for justice-involved Indigenous people with all kinds of disabilities. This is observable not only by the lack of sources specifically focused on promising interventions, approaches, programs, support services etc for this cohort, but is explicitly stated by many sources in the criminal justice field (including several of the sources included in this review). While there may be several interventions, programs, support services etc for general offenders, and for offenders with disability, and for Indigenous offenders, there is a serious lack of approaches in Australia and overseas for those who fall into all of these categories (i.e. are Indigenous, have a disability, and have contact with the criminal justice system). Further, there are some mainstream interventions, programs, services etc in place which can assist this cohort, but there are very few interventions, programs, services etc for this cohort which are Indigenous-owned and framed by Indigenous ways of knowing, being, seeing and doing.

From the limited peer-reviewed and grey literature unearthed in this systematic review, the following themes emerged as necessary for meeting the needs of Indigenous people with disability in contact with the criminal justice system:

- be Indigenous designed, led and owned;
- identify a person's disability and needs using culturally-appropriate definitions and tools;
- court models which are not only culturally-appropriate but also disability/needs focused;
- disability-appropriate and culturally-appropriate diversionary options;
- facilitate connection to Indigenous country, culture and community;
- be person-centred and build agency, strengths and positive identity;
- protect human rights;
- break down communication barriers;
- provide mentors and support personnel;
- education and training for those working in the justice system;
- provide support upon release from prison.

The literature reports that youth, women, as well as victims and witnesses - who are Indigenous and have disability/complex needs - are very disadvantaged, and that effective approaches are sorely lacking, and desperately needed, for these groups.

The sources in this review highlight the overall inadequacy of the justice system in CANZUS countries in responding to the needs of Indigenous people with disabilities. The 'tough on crime' attitude is failing and harming these people, and several sources called for significant legislative, policy and system reforms. Australia's 1991 RCIADIC recommended that imprisonment be a punishment of last resort; however, this seems to have been ignored for Indigenous people and for those with disability especially. Focusing on treatment, care, connection, healing and rehabilitation into the community – not isolation, deprivation, rectification, punishment, mistreatment – is strongly recommended. Recognising a person's needs, triggers, traumas, and providing interventions which address and repair these, seems to be far more effective than punishing harder and longer.

The sources in this systematic review all point to a desperate need for decolonised, culturally-appropriate and -safe, strengths-based, holistic, person-centred, human-rights based, therapeutic responses – which are Indigenous designed, led and managed – as well as a desperate need for adequate funding for Indigenous communities and organisations to deliver these responses. There is also a desperate need for more research and evaluation into 'what works' for Indigenous people with disability in the justice system, in Australia and globally

Systematic review 3: Models of social care for Indigenous people with a disability

Introduction

Internationally, Indigenous peoples do not access disability support services at rates commensurate with the prevalence of disability among Indigenous populations (Bevan-Brown, 2013; Ryser et al., 2014; Temple et al., 2020). While the reasons for this are likely to be complex and diverse, there are indications that a lack of cultural safety in disability support services is a significant factor. Disability is a construct that emerged through particular historic, political and economic circumstances in Western societies and is widely reported to have little resonance with many Indigenous peoples across the world (Ariotti, 1999; Connell, 2011; Varvarezou, 2020). Disability support services in states where Indigenous peoples are a minority frequently fail to encompass Indigenous values, beliefs and social practices, and in some cases, services are experienced by Indigenous people as hostile environments (Ball & Lewis, 2011; Dindar, Lindblom, & Kärnä, 2017; Temple et al., 2020).

In an earlier systematic review of the conceptualisations and experiences of disability amongst First Nations peoples of Australia, we found that developing culturally safe disability support services requires reform at practice, organisational, systemic and conceptual levels (see Review 1). Our findings suggested that addressing cultural safety requires service systems and providers to conceptualise disabilities, social participation and caregiving in ways meaningful to First Nations peoples. Among First Nations people with a disability, meaningful participation in society may be enabled through social roles and by being present on country or in their community, and may also be shaped by factors such as age, gender, social position and personal attributes. There is substantial cultural diversity among Indigenous peoples in Australia and across the world, and no single Indigenous model or conceptualisation of disability exists (Avery, 2018). However, broad commonalities are also present in Indigenous peoples' experiences of disability support services where services are structured through Western constructs of disability and governance and Western social norms; and the need for culturally safe care is global (Cox, 2015).

Social care services for people with a disability may need to address particular cultural safety considerations for Indigenous peoples. Social care services for people with a disability comprise personal care, transport and social activities and may be funded through a range of service provider types and funding models (Malley et al., 2012). In some cases, community-based social care may enable social inclusion and participation by preventing Indigenous people from requiring residential care outside of their communities (Pearce, 2000; Rees, 2003). However, social care services may overlap with social roles and practices of caregiving within many Indigenous families. Some Indigenous families have expressed an aversion to the intrusion on family life and private matters presented by professional carers; yet many also articulate strong desires for more support for family carers drawn from within extended kinship structures (Nikora, Karapu, Hickey, & Te Awekotuku, 2004; Rees, 2003; Ryser et al., 2014). There may be further cultural safety considerations in social care services not yet documented in published literature.

In this paper we review emerging community-based models of social care for Indigenous adults with a disability that enable them to remain in their homes and communities. We aim to identify promising practices and approaches to the social care needs of Indigenous peoples that address cultural safety considerations and have the potential to be implemented in other Indigenous communities. As specific measures to address the beliefs, values and practices of particular Indigenous communities may not be transferable, our focus is on broad processes and approaches to developing culturally safe social care services. We address the research questions:

What are the characteristics of community-based models of social care for Indigenous adults with a disability that enable them to remain in their homes and communities? Which approaches to the social care needs of Indigenous adults with a disability show promising practice in addressing cultural safety considerations? This review is encompassed by a broader program of work, in which we have conducted three reviews on cultural safety in disability support services for Indigenous peoples (see Review 1 and 2).

Methods

Review design

Systematic scoping review is a descriptive form of systematic review that can be used to examine the extent, variety and characteristics of literature addressing a particular topic or within a specific field (Tricco et al., 2018). While standard systematic review methods enable reviewers to assess the *level of evidence* for specific interventions, measures, practices and models, systematic scoping review methods provide *an overview* of interventions, measures, practices and models (Munn et al., 2018). Systematic scoping review is an appropriate method for identifying characteristics or factors related to a concept, such as a service delivery model (Munn et al., 2018). While a standard systematic review is an appropriate methodology for assessing the evidence for effective models of care where a sufficient number of independent evaluations have taken place in a relatively homogeneous manner, systematic scoping reviews are suitable for reviewing the ranges of emerging practice, and for reviewing heterogeneous studies (Peters et al., 2015; Tricco et al., 2018).

The design of our review is based on the established scoping review principles described in the PRISMA Extension for Scoping Reviews Checklist (Tricco et al., 2018) and the Joanna Briggs Institute Guidance for conducting systematic scoping reviews (Peters et al., 2015). Drawing on these principles, our review is structured around the population, concept and context of interest. We have developed a broad search strategy and methods for charting data in order to produce a robust analysis.

Our reviews are underpinned by an Indigenous research methodology in that they centre the perspectives, voices and experiences of First Nations people within research questions and methods, literature synthesis and analysis. Our Indigenous research methodology encompasses the following components:

1. Collaboration between First Nations and non-Indigenous researchers within the research team.

2. Synthesis of First Nations peoples' experiences and perspectives associated with disability, and the use of findings to inform further systematic reviews.

3. The centring of cultural safety and responsiveness of disability support services as a primary outcome of interest.

4. Engagement with key Indigenous disability advocates and stakeholders through meetings and informal discussions.

5. Critical appraisal of the involvement of First Nations peoples, as well as First Nations knowledges and methodologies, in the included studies.

The Human Research Ethics Committee of the Australian National University advised that ethical clearance for this project was not required.

Inclusion criteria

Population

We consider models of social care for Indigenous adults with a disability in Australia, Aotearoa New Zealand, Canada and the United States. These states were included as they comprise comparable Western settler-colonial states where Indigenous peoples experience similar challenges in accessing social care services that are predominantly designed by and for settler populations. In this review, 'social care' encompasses assistance with day-to-day living tasks such as personal hygiene, dressing and feeding, shopping, keeping active and socialising (Malley et al., 2012). It may or may not be delivered by family carers.

Concept

We describe and assess the characteristics (structures, components and processes) of community-based models of social care services. This includes broader models of care for people with a disability that encompass social care services. There is no consistent definition of a 'model of care' (Conway & Higgins, 2011), and the construct of a 'model of care' emerges from the services and institutions of modern states, and is embedded in Western values. Nevertheless, many Indigenous organisations are now developing their own models of care (eg: Massey, LaGrappe, Doherty, Cullen, & Lindrop, 2018; Rivalland, 2006). We draw from the definition of a model of care adopted by Davidson and colleagues, in a nursing context, while acknowledging the limitations of this construct:

> *An overarching design for the provision of a particular type of health care service that is shaped by a theoretical basis, evidence-based practice and defined standards. It consists of defined core elements and principles and has a framework that provides the structure for the implementation and subsequent evaluation of care (Davidson, Hickman, Graham, Halcomb, & Phillips, 2006: 49).*

With respect to Davidson and colleagues' definition, we conceptualise 'evidence-based practice' as encompassing practice that is shaped through consultation with service users and research exploring service users' experiences. We also adopt an expansive conceptualisation of Davidson and colleagues' construct of 'structures for the implementation and subsequent evaluation of care' in order to avoid overly-narrow results. We include models of care that have the potential for implementation and evaluation. We have adapted Davidson and colleagues' construct to develop the following definition:

> *An overarching design for the provision of social care services that is shaped by a theoretical basis or logic model, consultation and engagement with service users and*
>
> *defined standards. It consists of defined core elements and principles and has a framework that provides the structure for the potential implementation and evaluation of services.*

Context

Our review encompasses models of care designed to meet the specific social care needs of Indigenous peoples, where needs are identified by Indigenous people (eg: identified through reference to published literature on Indigenous people's perspectives, consultation processes or primary data collection). This includes mainstream disability support services with components to address the specific social care needs of Indigenous peoples.

Study design

We have adopted an inclusive approach to the literature as we anticipated that many models would be published in grey literature, and in order to include Indigenous perspectives as fully as possible (eg: through reports published by Indigenous organisations). We included models of care described, assessed or evaluated in:

- Research, evaluations and reports that use quantitative, qualitative or mixed methods.
- Research, evaluations and reports published in peer reviewed journals and as grey literature.
- Research, evaluations and reports that incorporate Indigenous peoples' perspectives, for example through methods such as interviews, focus group discussions, surveys, consultation processes and citation of relevant literature.
- Research, evaluations and reports published from 2000. This timeframe reflects the dissemination of cultural safety and related concepts in healthcare in the early 2000s (Truong et al., 2014).

The following models of care were excluded:

- Models of social care that do not address the specific needs of Indigenous people, (where Indigenous peoples' needs were reported as being determined through references to relevant published literature, consultation processes or primary data collection).
- Models of social care that require participants to live outside of their community.
- Models of care for hospital-based services, residential care, aged care, palliative care or primary healthcare.

For almost all included models, several literature sources (eg: journal articles, reports, policy documents) were included in the review. Models of care were included in the review on the basis that the model, rather than any individual source describing it, met inclusion criteria, in order to avoid overly-narrow results.

Search strategy

We conducted searches of the following databases: PubMed, Web of Science, INFORMIT, EBSCOhost (CINAHL, Academic Search Premier, ebooks, ebooks academic, SocIndex, PsychINFO, PsychArticles, Psychology & Behavioural Sciences Collection), Australian Indigenous Healthinfonet, Analysis & Policy Observatory, Australian Institute of Health and Welfare/Australian Institute of Family Studies database, New Zealand Social Wellbeing Agency Hub, US National Council on Disability database, Google Scholar. We developed Boolean search terms in consultation with a health subject librarian (Figure 7). We adapted the search strategy for specific databases when needed. For example, some databases did not recognise all Boolean operators, so we made minor changes to the terms and conjunctions. Some grey literature databases did not have sophisticated search functions, and in these cases we simply used the search term 'disability' or browsed disability collections.

Additional literature was identified and added to the initial search results from our personal knowledge of the field, by reviewing bibliographies of other included literature and following consultation with Indigenous disability stakeholders. In order to deepen our knowledge of each model of care identified, we added an additional phase to our literature searching. Specifically, after each model of care was identified for inclusion, additional searches were conducted to locate further literature on each model using keywords associated with the model in Google and Google Scholar.

Figure 7: Search terms used in PubMed

Indigenous Australia* OR "Indigenous people*" OR "Indigenous popula*" OR aboriginal OR "torres strait islanders" OR "Torres Strait Islander" OR ATSI OR "First Nations" OR Maori OR Inuit OR Metis OR "Native American" OR "American Indian" OR "Alaska* Native" OR "Native Alaskan" or Hawaiian

AND

disability OR disabilities OR disabled OR impairment OR impaired OR "special needs" OR "care needs" OR musculoskeletal OR psychiatric OR mental OR anxiety OR neuro* OR cognitive OR psychosocial

AND

"personal care" OR "social care" OR "home care" OR "home and community care" OR "home health aides" OR "activities of daily living" OR "community care"

Data extraction and study selection methods

Search results were exported to Covidence systematic review software. After removing duplicates, initial screening (title and abstract only) was conducted by two reviewers. SP screened all initial results and CW conducted a check of 10% of results for consistency. Full text screening was also performed by SP, in consultation with CW.

Charting of data

We extracted the following variables from included sources: study title, author(year), research question, study design, reported in grey literature/peer reviewed, methods, site, participant group, types of social care provided, key components of service delivery model, Indigenous peoples' involvement in model design, governance structure, Indigenous peoples' involvement in governance, workforce strategies, Indigenous peoples' involvement in the research/evaluation. We mapped the characteristics of models of care reported in included studies using thematic analysis. Our analysis of models of social care was informed by our earlier systematic review of conceptualisations and experiences of disability among First Nations peoples of Australia and the implications for disability services (see Review 1). However, we have not used this review to inform our understanding of Indigenous peoples' conceptualisations and experiences of disability internationally, as findings may not be transferable.

Assessing promising practice

An appraisal of evidence-based practice is not typically performed in a systematic scoping review, in which the intent is to provide a descriptive synthesis of a body of literature and in which new practices are often a focus (Peters et al., 2015; Tricco et al., 2018). We anticipated that many models of social care for Indigenous people will not have been evaluated or assessed, and therefore there is likely to be insufficient evidence to assess whether they represent ‘best practice’ or are otherwise successful. However, systematic scoping review methods provide an appropriate means of synthesising emerging and promising practice. Accordingly, we conducted a synthesis of promising practices in social care services for Indigenous peoples, assessing emerging evidence on the involvement of Indigenous peoples in the governance and operation of services and on the extent to which models of care addressed the social care needs of Indigenous peoples, as described in the included literature and in our previous review. We conceptualise promising practice as programs, services, strategies, activities, approaches, models and interventions in which limited data suggest that they are having a positive impact (Canadian Homelessness Research Network, 2013).

Appraisal of Indigenous peoples’ involvement in research

We conducted an appraisal of the extent to which Indigenous peoples' perspectives were part of the research process in literature included in the review. Drawing on the CONSIDER Statement (see Huria, Palmer et al 2019), as well as the Aboriginal and Torres Strait Islander Quality Appraisal Tool (developed by Harfield, Pearson et al 2020:5), and following discussion between Indigenous and non-Indigenous researchers within the research team, we developed Indigenous peoples’ involvement appraisal criteria (Table10).

*Table 10: Indigenous peoples' involvement in research appraisal criteria**
* Italics indicates sample responses

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, eg: in published literature*	*Research topic or question described as aligning only with other people or organisations' priorities, eg: those of funders or 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 supervisors or in an advisory capacity, eg project advisory group with majority Indigenous membership; employed in research team*	*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: 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.*	*Only one of the following shown: Indigenous standpoint theory or an Indigenous/Indigenist 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.*	*Theoretical influences do not include Indigenous standpoint theory or an Indigenous/Indigenist methodology. 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.*	*Cannot be determined from the published manuscript.*

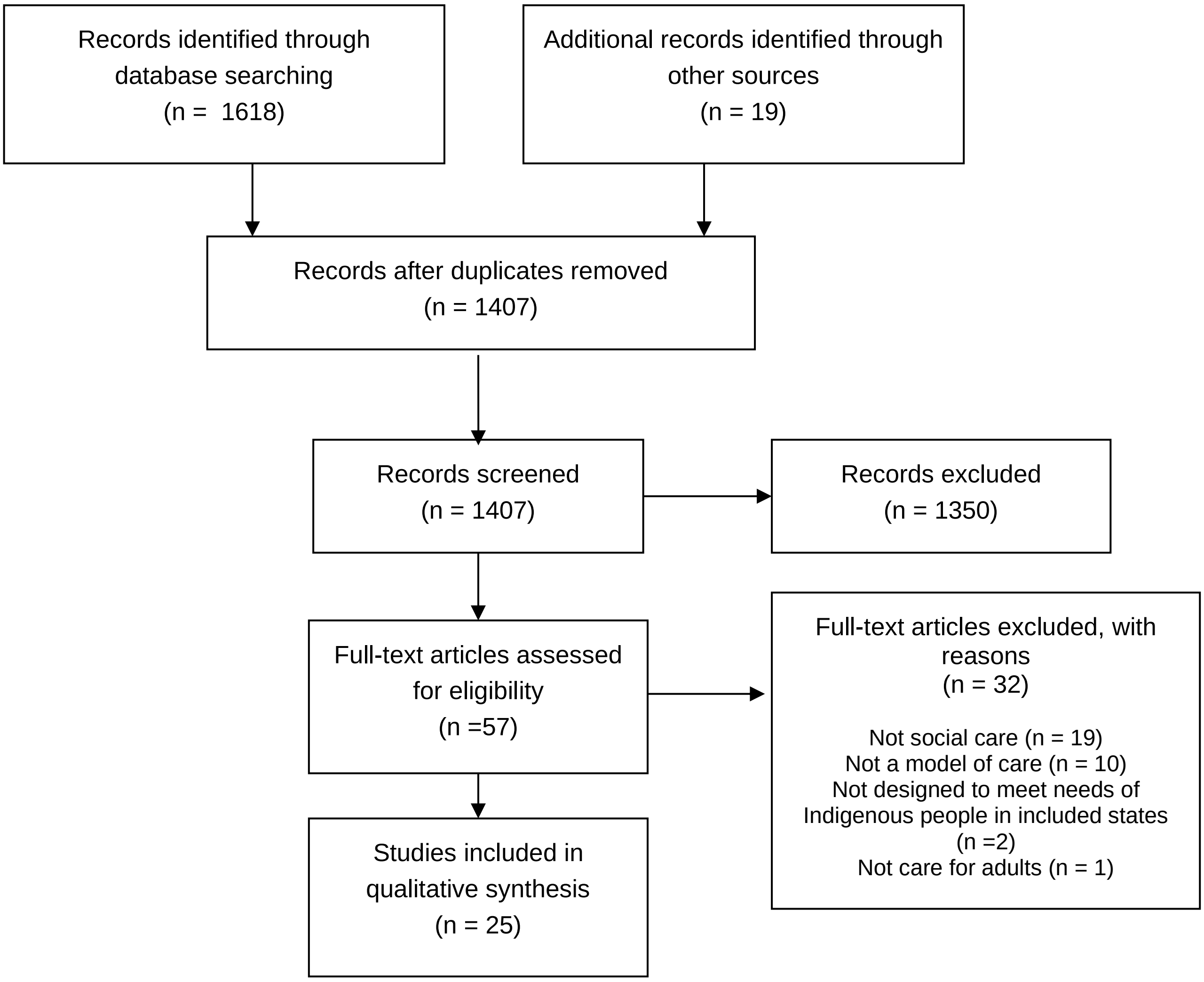
Results

Search results

Our search strategy yielded a total of 1618 results and we identified 19 additional sources (Figure 8). During title and abstract screening, disagreement arose between reviewers in 11 titles, and was resolved through consensus-based discussion. In total, 25 sources describing 10 models of care met inclusion criteria and were extracted for analysis (Appendix 2 and 3). The main reasons for exclusion were: sources did not report on social care services; and sources did not report on or describe a model of care.

The 10 included models of care were developed to meet the needs of Indigenous people in Australia (n = 6), Canada (n = 2), Aotearoa New Zealand (n = 1) and the United States (n = 1). Included models of care were designed to meet the needs of Indigenous people in urban (n = 2), regional (n = 5) and remote areas (n = 9), with some models providing services in a range of location types. Of the 10 models of care, 8 have been piloted or implemented, of which, 7 have been assessed or evaluated (Appendix 2).

Figure 8: PRISMA flow diagram for Review 3 search and screening process



Appraisal of Indigenous peoples' involvement in included research and evaluations

The appraisal process we developed for assessing Indigenous peoples' involvement in research does not provide a means of assessing other forms of literature, such as policy documents and guidelines. Accordingly, we excluded literature that did not contain primary data from the appraisal process. In total, five literature sources in our review were excluded from this appraisal process. For program evaluations, when assessing the first criterion, on the involvement of Indigenous peoples in setting research priorities and agendas, we have considered whether metrics of success incorporated Indigenous peoples' and communities' perspectives.

Generally, the involvement of Indigenous peoples and organisations in included research was poorly reported in the literature (Table 11). Where involvement was reported, generally studies performed well across all three criteria, however these results may reflect reporting bias.

Table 11: Results of Indigenous peoples' involvement in research appraisal

Record	Setting the research priorities/agenda	Representation within research team and research governance processes	Incorporation of Indigenous ways of knowing, being, seeing, doing in theory, methodology, methods
Ryser et al (2014)	To a large extent	Not reported	Not reported
Elsum et al (2020)	To a large extent	Somewhat	Somewhat
NPY Women's Council (2018)	To a large extent	To a large extent	To a large extent
Dew et al (2019)	To a large extent	To a large extent	To a large extent
Woods et al (2000)	Not reported	Not reported	To a large extent
Raven et al (2014)	Not reported	To a large extent	Somewhat
Biddle et al (2014)	Not reported	Not reported	Not reported
LoGuidice et al (2012)	To a large extent	To a large extent	Not reported
Yarmintali Consultancy (2010)	To a large extent	To a large extent	Not reported
Smith et al (2011)	To a large extent	To a large extent	To a large extent
Litmus (2012)	Not reported	Not reported	Not reported
Paulin et al (2015)	Not at all	Not reported	Not reported
The Canadian Home Care Association (2010)	Not reported	Not reported	Not reported
Health Canada and the Public Health Agency of Canada (2013)	Not reported	Not reported	Not reported
Indigenous Services Canada (2019b)	Not reported	Not reported	Not reported

Hirji-Khalfan (2009)	Not reported	Not reported	Not reported
PriceWaterhouseCoopers Indigenous Consultants (2018)	Not reported	Not reported	To a large extent
Rivalland (2006)*	Not reported	Not reported	Not reported
Purple House (2019b) Patient preceptors	To a large extent	To a large extent	To a large extent
Tjungurrayi (2015)	To a large extent	To a large extent	To a large extent

* Methods discussed in an unpublished appendix to the report

Characteristics of included models of social care

In this section we describe the models of social care that met inclusion criteria. We discuss emerging practice in social care services for Indigenous peoples in the domains of governance, development/initiation, funding arrangements, social activity services, personal care services, language and integration, and workforce strategies (Table 12; Figure 9).

Table 12: Characteristics of models of social care for Indigenous peoples

Model of care	Governance	Development/initiation	Funding arrangements	Social activity services	Personal care services	Language and integration	Workforce strategies
Machado-Joseph Disease (MJD) Foundation model of care	Charitable organisation providing services to Indigenous people, board includes Indigenous people with lived experience of MJD	Consultation with Indigenous people with MDJ and their family groups. Flexibility and adaptation based on feedback from clients, Indigenous staff.	Funded by Aboriginal land councils, the corporate sector, philanthropic organisations and governments.	Integrated social/physical activities.Mens/ womens activities on country, in family groups.	Through support for family carers.	Integrates health, disability, community services	Based on family groups, including Aboriginal Community Workers paired with allied health professionals.
Walykumunu Nyinaratjaku (to live a good life)	Aboriginal Community Controlled Organisation (NPY Womens Council)	Not reported	Government funding	Not reported	Through financial and non-financial support for family carers.	Addresses the a good life for Aṉangu. Disability services: ‘Tjungu (all together) team’.	Indigenous and non-Indigenous staff paired through ‘malparara way’ co-mentoring process.
Services Our Way	Government funding scheme for individual packages for Indigenous people with a disability to	Not reported	Participants receive a care package (budget) to be spent on supports for physical, emotional, cultural wellbeing	Activities determined by participants	Personal care services determined by participants	Disability-only service, language similar to mainstream services	Participants receive guidance from an Aboriginal Service Support Specialist who

	purchase services and equipment.						assists with coordination, purchasing and administration
Lungurra Ngoora Community Care Service	Three service providers commissioned the service in an Indigenous community. Overseen by a Steering Committee comprising community council, government, NGO representatives.	Consultation and workshops with the community and service providers	Funded by three commissioning services and government	Yes, eg: fishing, day trips	Provided by local Aboriginal workers in an appropriate kin relationship	Integrated aged care, disability and mental health services. ‘Lungurra Ngoora’ service (‘blue tongue lizard home’)	Local Aboriginal people employed in generalist, frontline roles only, some through an external employment program.
Resident Family Care	Government funding scheme to pay family carers for their services, including Maori whaṉau (extended family) carers	Following a Human Rights Commission case and consultation with families	Payment to family members of people living with a disability with high care needs for family care	Not reported	Through payment of family carers	Policy documents specifically include whaṉau	Paid carers determined by families and whaṉau

First Nations and Inuit Home and Community Care	Government funding scheme for services in Indigenous communities	Not reported	Administered through funding agreements with communities/tribal groups/First Nations and Inuit health authorities/territorial governments.	Not reported	Yes, through a range of organisations	For people with disabilities, acute illnesses, chronic illnesses	Determined by local/territorial providers
Assisted Living Program (in-home care component)	Government funding scheme for services in Indigenous communities	Not reported	Funds provided to Band and Tribal Councils, Provinces, Aboriginal organisations, municipal governments, private businesses, NGOs	Includes day programs, administered through a range of organisations	Yes, through a range of organisations	Services for people with a chronic illness or disability	Determined by local/territorial providers
Adaptation of the National Disability Insurance Scheme (NDIS) in the Northern Territory	Mainstream government funding scheme for individual packages for people with a disability (with a focus on Indigenous participants)	Through consultation and workshops with communities and service providers	Place-based services through the pooling of individual NDIS support packages within a community, administered by local governance bodies led by local Indigenous organisations	Not described	Not described	Disability-only service	Training Indigenous people in a general/broad skillset applicable to disability, aged care, child care and wellbeing services

Purple House model of care	Aboriginal Community Controlled Organisation	Developed by Yaṉangu in response to need that arose in their communities	Funded through a combination of sources (art sales and mining royalties in Indigenous communities, philanthropic donations, government funding)	Includes bush trips, customary healing practices	Not reported	Integrates specialist medical services, primary healthcare, patient education, support and advocacy, disability services, customary healing practices	Indigenous people who are recognised leaders of their communities and have lived experience of end stage kidney disease employed to support others in their community
Services for Indian Americans in the West Cascade Mountain Range region	A proposed service provider on reservations	Through research and analysis of policy documents	Federal government funding to tribal governments	Not reported	Through indirect compensation to family caregivers by tribes and states (eg: vouchers, subsidies)	Integration of disability, health, mental health, spiritual health, aged care services	Bi-directional cultural competency training for government agency and tribal government staff

Figure 9: Characteristics of models of social care for Indigenous peoples

Governance structures

There is substantial heterogeneity in included models of social care. Included models encompass social care funding schemes and organisational models. Three models included in this review are funding schemes or service systems designed to meet the specific needs of Indigenous peoples. Two Canadian programs, the *Assisted Living Program* and the *First Nations and Inuit Home and Community Care Program*, are schemes that provide funds to a range of governance bodies and service providers such as Band and Tribal Councils, territorial governments, Aboriginal organisations, municipal governments, private businesses and NGOs to administer the program (Indigenous Services Canada, 2019a, 2019b). The *First Nations and Inuit Home and Community Care Program* operates through partnership agreements with national Indigenous representative organisations. Within both programs, Band and Tribal Councils and territorial governments have a degree of autonomy over how funds are allocated and which services are provided within their jurisdiction. In Australia, the *Services Our Way* program provided individual care packages to eligible Indigenous people with a disability to spend on a range of services and supports (NSW Family & Community Services & Ageing Disability & Home Care, 2012).

Two models of care comprised mainstream funding schemes or service systems with components designed to meet the specific needs of Indigenous peoples. In Australia, an adaptation of the *National Disability Insurance Scheme* (not implemented to date) was developed by consultants for the Northern Territory Government (*NT NDIS model*) (PriceWaterhouseCoopers Indigenous Consultants, 2018). This model comprises a funding scheme for individual care packages in which the care packages of Indigenous people with a disability are pooled on a local or regional basis and administered by Indigenous organisations, which determine how and which services are provided. In Aotearoa New Zealand, the *Funded Family Care* program is a mainstream scheme providing wages to the family carers of people with a disability who have high care needs, which encompasses Maori whaṉau (extended families) (Paulin, Carswell, & Edgar, 2015).

Five models of social care included in the review are organisational models designed to address the needs of Indigenous peoples in specific communities or regions, funded through a diverse range of sources including government funding schemes. The models of care developed in Australia by the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council and Purple House are administered by registered Aboriginal Corporations, governed by boards comprising representatives from the communities they serve (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation, 2018; Rivalland, 2006). The model developed by the Machado-Joseph Disease (MJD) Foundation, also in Australia, is overseen by an organisation that includes Indigenous as well as non-Indigenous board members (Massey et al., 2018). The model developed by Ryser and colleagues (not yet implemented) proposed that for American Indian reservations in the West Cascade Mountain Range region, tribal governments would be funded to administer social care services and provide forms of financial assistance to family carers (Ryser et al., 2014). The *Lungurra Ngoora* model, meanwhile, was governed by a steering committee comprising community representatives, service providers and funders, with the intention to transfer the model to an Indigenous organisation in future (LoGiudice et al., 2012).

Development/initiation processes

Models of care included in the review vary in the extent to which Indigenous peoples, communities and organisations were involved in their development. The NPY Womens Council, MJD Foundation and Purple House models were all developed or initiated by Indigenous peoples and families living with disabilities (Massey et al., 2018; Tjungurrayi, 2015; Woods et al., 2000). The NT NDIS, West Cascade Mountains, Funded Family Care and Lungurra Ngoora models were not developed at the behest of Indigenous peoples, but were developed through consultation processes and/or qualitative research exploring the needs of Indigenous people with a disability in the local area (Litmus, 2012; PriceWaterhouseCoopers Indigenous Consultants, 2018; Ryser et al., 2014; Smith et al., 2011).

Funding arrangements

Included models represented a mix of individual funding models and block funding. Eight of the 10 included models were entirely government funded.

The literature reports varying degrees of flexibility in government funding sources. In Australia, a study of the *NPY Womens Council* model found that mainstream government funding streams did not have the flexibility to recognise the specific needs of Indigenous peoples or to support the consistent delivery of services in remote areas (Dew et al., 2019). The *Lungurra Ngoora* model, a place-based initiative developed in remote Australia, meanwhile, required a combination of indirect government funding sources, with direct funding received from three other service providers which previously provided direct services to the community, and from the Western Australian Government (LoGiudice et al., 2012). In contrast, in the two included Canadian funding schemes, which provide funding dedicated to supporting the social care of Indigenous peoples, local adaptation and place-based initiatives by administering organisations such as Tribal and Band Councils and territorial governments are expected and encouraged (The Canadian Home Care Association, 2010). In the case of the *First Nations and*

Inuit Home and Community Care program, funds from two government departments were pooled within the scheme (Biddle et al., 2014), removing the complexity of accounting for multiple funding streams at the service provision level.

Two Australian organisational models of care reported drawing on a range of government and non-government funding sources. The MJD Foundation is funded by Aboriginal land councils, corporate donations, philanthropic funds and government funding sources (Massey et al., 2018), while Purple House, throughout its operation, has drawn on diversified funding, including from the sale of Indigenous art, corporate and philanthropic donations, mining royalties and government funds (Purple House, 2019b; Rivalland, 2006). The literature published on both models of care suggest that non-government funding sources offered the organisations considerable flexibility to develop models which responded to the specific care needs of participants and which were comparatively expensive due to the costs of delivering services in remote areas, of involving family groups as well as individuals with a disability and of adopting a consultative, iterative approach to developing services (Massey et al., 2018; Rivalland, 2006).

Place-based social activities integrated with activities of everyday life

Social activities offered within these models of care attempted to facilitate meaningful forms of participation for Indigenous peoples through a variety of local, place-based initiatives. The *Lungurra Ngoora* model offered participants opportunities to be involved in customary activities such as visiting country, fishing and painting, and these activities were reportedly embraced by participants (LoGiudice et al., 2012; Yarmintali Consultancy, 2010). The Purple House model incorporates the harvesting and preparation of customary medicine into its activities (Purple House, 2019a). The MJD Foundation integrates locally meaningful social activities with its physiotherapy services (Massey et al., 2018). The Foundation's *Staying Stronger for Longer* exercise program, based on international research evidence adapted to local circumstances, integrates social, physical, mental and emotional health objectives through everyday activities such as collecting firewood, hunting and gathering, cooking, moving furniture and carrying groceries. Activities are often carried out in gender-specific groups of family members rather than groups of individual participants with MJD. The MJD Foundation also offers training to participants in filmmaking with tablet devices, and this skillset enables some participants who can no longer dance in ceremonies to play a role as an official filmmaker.

Respect for social norms associated with personal care and support for families

Several social care services included in this review have measures to respect Indigenous social norms associated with personal care and caregiving within families. The Lungurra Ngoora model included measures to ensure participants received personal care from a staff member of the same gender and in an appropriate kinship relationship to them (Yarmintali Consultancy, 2010). The NPY Women's Council, MJD Foundation and West Cascade Mountain Ranges models are all described as models that support family carers, rather than providing personal care through professional carers, in order to respect social roles in families (Massey et al., 2018; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation, 2018; Ryser et al., 2014). Support provided to carers through these models includes material assistance such as bedding and fuel subsidies, cleaning services and respite. The Aotearoa New Zealand Funded Family Care scheme provides remuneration to family carers including Maori whan̲au (extended family) carers (Litmus, 2012).

Integration and inclusive language

All models of care included in the review avoid using the term ‘disability’ and five of the 10 models of care integrate social care for people with a disability with other related services including medical services (four models), aged care (two services) and mental health support (one service). Some models have adopted inclusive terms from Indigenous languages to name their programs. At the NPY Women’s Council, staff who provide disability support services work in the ‘tjungu team’, which adopts the Aṉangu term ‘tjungu’ meaning ‘all together’ (Woods et al., 2000). The *Lungurra Ngoora* model uses the terms for ‘blue tongue lizard home’ in Walmajarri (LoGiudice et al., 2012). The previous name of the organisation now known as Purple House was ‘Western Desert Nganampa Walytja Palyantjaku Tjutaku’, which can be translated to ‘making all our families well’ in Pintupi (Rivalland, 2006). The organisation’s current name refers to the colour scheme of its head office.

Workforce strategies

The included literature describes long-term, consistent relationships between staff and participants, and the presence of staff in communities of operation, as integral to several models of care (LoGiudice et al., 2012; Massey et al., 2018; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council Aboriginal Corporation, 2018; Ryser et al., 2014). While several models of care aimed to support family carers, nine of the models reviewed also encompassed specific strategies to employ Indigenous people from the communities in which they operate to provide social care services.

Three models sought to employ Indigenous people from their communities of operation with lived experience of disability who were well enough to work. A report on the *Purple House* model discussed the lived experience of disability as a form of expertise, but suggested that this may not be well recognised in employment standards (Purple House, 2019b).

Three models of care sought to employ local Indigenous staff on the basis of their social roles. The *NPY Women’s Council* and *Purple House* models both involved employing people who were recognised as elders and leaders (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women’s Council Aboriginal Corporation, 2018; Purple House, 2019b). The *MJD Foundation* model is based around family groups. The organisation employs an allied health professional as a Manager of Community Services and an Aboriginal Community Worker who works alongside them for each participating extended family group (Massey et al., 2018). Each Aboriginal Community Worker is drawn from the family group in which they work, and Workers are often carers or people with MJD.

The *Lungurra Ngoora* and *NT NDIS* models adopted a different approach to employing local Indigenous staff, drawing workers from employment programs associated with social security systems (LoGiudice et al., 2012; PriceWaterhouseCoopers Indigenous Consultants, 2018). Both models also sought to employ local Indigenous staff in frontline service roles and provided training in a generalist skillset applicable to disability, aged care, child care and mental health support services so that workers could cover absences.

Three models included strategies for developing productive relationships between Indigenous and non-Indigenous personnel. Both the *NPY Women’s Council* ‘malparara way’ and the *MJD Foundation* ‘two ways’ approaches paired local Indigenous staff members with a non-Indigenous colleague in a co-mentoring process (Massey et al., 2018; Woods et al., 2000). Paired colleagues worked in an equal partnership that drew on the skills and knowledge of both staff members. The *West Cascade Mountain Ranges* model included cultural competency training for both Indigenous and non-Indigenous staff in each other’s cultures (Ryser et al., 2014).

Discussion

This systematic scoping review has described the components of published models of social care for Indigenous peoples in Australia, Aotearoa New Zealand, Canada and the United States. We have noted the considerable heterogeneity in the structures, measures, and activities of included models, in addition to some similarities in approaches and objectives. In this section, we synthesise the evidence for promising structures, measures and approaches across the models of care and discuss the implications.

Limitations of included models

A lack of documentation and research on social care for Indigenous peoples limits our synthesis. Our search strategy only yielded 25 sources reporting on 10 models of care (Figure 8; Appendix 2 and 3). There may be further innovative, culturally safe models of social care operating in the included states which have not yet been documented, published and included in research or policy databases; and this lack of documentation may be influenced by the low-resource environments that our results suggest characterise disability services in some included states. The small size the research field limits our capacity to assess whether the included models and their specific components are widespread.

Our analysis is further limited by the quality and heterogeneity of studies included in our review. As discussed in the previous section, included models vary considerably in structure, governance arrangements and in their location in service systems, and are described and assessed in research articles and reports using a variety of research designs and methods. Of the 10 included models of care, two have not yet been pilot tested or implemented, and only five have been fully independently evaluated (Appendix 2). However, Elsum and colleagues, who conducted a non-independent evaluation of aspects of the *MJD Foundation* model, argue that independent evaluation may not be an appropriate methodology for assessing services for Indigenous people (Elsum et al., 2020). They argue that matters of bias need to be balanced with consideration of the quality and validity of data, which are enhanced by relationships between researchers and research participants. This does not necessarily mean that models need not be evaluated, but rather that the evaluation framework and process also need to be culturally-informed and meaningful to Indigenous peoples.

A further two models of care have been subject to other studies exploring service participants' perspectives and experiences (Appendix 2). Despite this, the wide variation of the included models, and deficiencies in their documentation, further complicate our analysis. As noted above, some components of individual models of care are not well documented in the included sources. Furthermore, several included models were described as adopting an iterative approach in which services were adapted over time in response to participants' responses and changing needs. For these reasons, we are unable to undertake an analysis of the evidence base for specific supports, models and approaches, or an assessment of whether included models represent culturally safe care. Moreover, as Baldock has argued in the context of aged care, social care is a deceptively complex practice in which care needs and experiences are highly subjective (Baldock, 1997). 'Need' and 'care' are qualitatively different concepts and practices to 'illness' and 'treatment'. Social care services cannot be assessed through medical approaches that contain the assumption that a specific remedy exists for specific conditions, circumstances or populations. While it may be possible to identify promising approaches, the quality and extent of the literature prevent us from determining whether specific measures, supports and activities are transferable to other Indigenous communities and service delivery contexts. Our synthesis therefore requires a holistic approach in which models are conceptualised as individual case studies, with the interaction of various components of each model and local contextual factors understood as contributing to reported outcomes.

Accordingly, we have analysed included models by centring the responses of Indigenous communities in which models operate, where documented.

Developing and sustaining models of care governed by Indigenous people and communities

In our earlier review of the conceptualisations of disability among First Nations peoples in Australia and the implications for disability support services, we showed that developing culturally safe services requires addressing the way that services are governed and funded; and that cultural safety does not only pertain to practice-level considerations (see Review 1). Here, our results suggest that models designed to address specific social care needs of Indigenous peoples have the potential to enable Indigenous people with a disability and their families and communities to participate in the governance, operation and workforces of services and service systems, and to address cultural safety considerations.

Our analysis suggests that disability support services administered through individual care packages may provide participants with autonomy over the services they access, within the scope of program guidelines and the availability of services, but may limit the involvement of individuals, families and communities in program governance and funding allocations. For example, the *Services Our Way* model was designed to meet the specific needs of Indigenous people with a disability through individual care packages, however the program appeared to lack opportunities for participatory governance (NSW Family & Community Services & Ageing Disability & Home Care, 2012). Although *Services Our Way* provided funding to Indigenous organisations to deliver services, the role of such organisations appears to have been limited to program administration. Individual care packages may not reflect Indigenous norms of collective decision-making. A participant in Amery and colleagues' study of speech pathology services for Indigenous people with MJD declared, 'When Balanda (non-Indigenous people) try to provide individual services, it doesn't make Yolŋu (an Australian Indigenous people) strong. It divides them' (Amery et al., 2020: 506).

The capacity for individual participants to determine how and which services they access may be supported in other approaches through flexible funding and organisational models, which also enable participation in governance. This is demonstrated by the *First Nations and Inuit Home and Community Care* that provides funding to Indigenous organisations, governments and other service providers through a range of funding agreement types, and encourages innovation, heterogeneity and place-based initiatives (The Canadian Home Care Association, 2010). It is also demonstrated by three Australian services that were responsive to the specific needs of participants and their changing needs over time through place-based services (LoGiudice et al., 2012; Massey et al., 2018; Rivalland, 2006). The *Lungurra Ngoora* model represented an attempt to work around insufficient and siloed government funding streams. An independent evaluation found that the service's funding model, and the requirements to account for and report on each separate funding stream, made administering the service extremely complex and that it led to conflicts among stakeholders (Yarmintali Consultancy, 2010). The abandonment of the model, despite positive responses from participants, was partially attributed to the service's unworkable funding structure (LoGiudice et al., 2012).

Two models, *Purple House* and the *MJD Foundation*, were partially funded by Indigenous communities and corporate and philanthropic donations due to the inflexibility and insufficiency of government funding sources in Australia. These models, while notable, reveal the difficulties likely experienced by organisations without access to non-government funding sources in attempting develop culturally safe services. They also raise questions over whether Indigenous communities, which often have limited resources, should be required to fund their own models of culturally safe care, when equivalent services are funded by governments for other populations as part of citizenship entitlements. These models, along with the outcomes of the *Lungurra Ngoora* model discussed above, and suggest that dedicated funding streams for disability services for Indigenous people may be required for the development of services that reflect Indigenous values and norms. The development of culturally safe care may not only require community control and participatory governance at an organisational level, and appropriate funding sources and funding programs that reflect an appropriate program logic may also be required. The positive outcomes reported of two Canadian funding schemes specifically designed to fund services in Indigenous communities add further weight to this finding.

The included literature provides some evidence that Indigenous community controlled social care services can be conceptualised not only as a formal governance structure, but also as a sense among members of an Indigenous community of 'ownership' of a service, or responsibility for its operation. While few of the evaluations and studies included in our review assessed local perceptions of 'ownership', the evaluation of the *Lungurra Ngoora* model suggests that this sense of 'ownership' may not only relate to the governance structure and specific components of a model, but also the way in which it was developed. In the case of *Lungurra Ngoora*, a model developed by external researchers and non-Indigenous service providers through extensive consultation did not successfully transition to a community controlled service (LoGiudice et al., 2012). This has implications for the future development of Indigenous community controlled services, particularly in Australia, where there have been growing calls to expand this sector (First Peoples Disabiilty Network Australia, 2018).

Delivering culturally safe social care and valuing carers

Several of the models discussed disassociate themselves from Western constructs of disability and care. Through the integration of social care for people with a disability and other people with social care needs, and through the organisation of social activities through family groups, some models avoid casting participants as 'disabled'. Several models and programs adopt Indigenous names, avoiding the term 'disability' and positioning social care in ways that resonate with participants.

The models of care examined in this review demonstrate attempts to recognise and support Indigenous practices and values associated with caregiving and the important social roles of caregivers. Some models supported families by relieving the physical, emotional and financial burden of family carers rather than offering personal care provided by professional carers. Although none of these models have been evaluated, a qualitative study that reported on one of these models suggested that support for carers was well received by participating Indigenous families (Dew et al., 2019). However, in some instances, financial support for carers was impeded by the guidelines of government funding schemes that restrict the expenditure of program funds on living expenses (Dew et al., 2019).

While financial relief for carers and people with a disability may also be addressed through social security systems in some states, the experience in Australia suggests that social security payments may not adequately support the basic needs of Indigenous people with a disability and their carers, and that eligibility criteria may not reflect Indigenous practices of collective caregiving (Soldatic, 2018; Puszka forthcoming). The Aotearoa New Zealand *Funded Family Care* program, in contrast, provides remuneration to family carers through a disability stream rather than through social security, and enables the recognition of family caregiving as legitimate work. The scheme was found to have reduced household financial stress and to have provided carers with valued recognition of their roles (Paulin et al., 2015). Although social security payments are beyond the scope of this review, our findings suggest that providing personal care to Indigenous people with a disability through support from family carers may require funders to conceptualise and support family caregiving in different ways to caregiving in the general population. This may be difficult to achieve through social security systems which emphasise equivalent remuneration of eligible recipients of each category of payment.

Other models of care took an alternative approach to supporting Indigenous family carers, integrating kinship relationships and social roles in Indigenous families associated with caregiving with formal employment roles and organisational structures. An independent evaluation of the *Lungurra Ngoora* model reported that this approach resulted in the employment of local Indigenous people, ensured that personal care was provided to participants by people in an appropriate gender and kinship relationship, and led staff to express pride in their roles (Yarmintali Consultancy, 2010). The evaluation also found that staff were subject to two forms of accountability, to their employer and to their families. Anthropologists have described the kinship relations of Indigenous people in some of the included states as economic as well as social relations, suggesting that some Indigenous societies may not adopt the same distinctions between work and family life as Western societies (Peterson, 1993; Sahlins, 1974). Integrative workforce strategies have the potential to support family and service provider imperatives in mutually reinforcing ways. However, such strategies may need to provide safeguards to protect the work rights of staff, for example, regarding unpaid overtime. Integrative workforce strategies in particular require local Indigenous people to be involved in developing, governing and managing models of care. Both the integrative strategies and support for carers discussed here constitute promising practices in culturally safe care.

Family groups are likely to have a range of needs at any point in time, and people with a disability are likely to have a range of care needs over their lifecourse. The development of generalist social care roles in disability support services, in which staff acquire a skillset that is transferable to aged care, child care and mental health support services, may further enhance integrative workforce strategies. However, the employment of staff in social care services through social security employment programs may not guarantee that staff and participants are in an appropriate gender or kinship relation, and raises issues of appropriate remuneration.

Limitations of this review

Systematic review is a research methodology with limited capacity to incorporate Indigenous perspectives, as well as the perspectives of people with a disability. We addressed this by incorporating an Indigenous research methodology into our study design. We centred Indigenous perspectives on disability through our analytical framework, by assessing the involvement of Indigenous peoples and organisations in include literature and by including grey literature. However, studies that involve primary data collection and adopt interpretivist approaches may have more capacity to consider Indigenous perspectives and interact with Indigenous knowledge.

We have identified literature gaps in a lack of documentation and research on social care for Indigenous peoples, and a lack of publicly available evaluations and assessments of existing models. These gaps limit the dissemination of innovative approaches, and pose limitations to our review. Although we initially developed a framework for determining whether models of care addressed Indigenous peoples' needs, based on our earlier review, we were unable to deploy it for these reasons. Our review shows a need for more research on the social care needs of Indigenous peoples and appropriate, culturally safe models of care.

Conclusions

Our earlier work shows that culturally safe disability support services for Indigenous peoples require the participation of Indigenous people and the incorporation of their norms and values at service provider, organisational, systemic and conceptual levels (see Review 1). This review of models of social care for Indigenous people living with a disability supports and extends these findings. We have described 10 models designed to meet the social care needs of Indigenous people in Australia, Aotearoa New Zealand, Canada and the United

States. We have described a range of structures and measures for incorporating Indigenous voices, values and norms into models of care. Our findings suggest that dedicated, flexible funding streams for disability services for Indigenous peoples and local Indigenous governance structures can enable services to respond to Indigenous participants' needs and values. We have discussed promising practices regarding the development of Indigenous led-models, support for family carers, and the integration of kinship relationships and social roles into workforce strategies.

Conclusions

Our systematic review of the best available evidence in Australia and the CANZUS countries shows what is working well, as well as where the gaps are, in developing and delivering culturally safe and responsive disability services for First Nations and Indigenous peoples.

It is evident that in Australia, First Nations peoples' conceptualisations and experiences of 'disability' may not necessarily align with non-Indigenous constructs. This difference in values, assumptions and experiences can lead to experiences of stigmatisation, distress and disempowerment among First Nations people with a disability, and may ultimately lead some to disengage from services. All three reviews discuss the substantial challenges that that First Nations and Indigenous people, families and communities face in accessing culturally-safe, meaningful and effective disability services and supports. This is particularly the case for those Indigenous people with disability who have contact with the criminal justice system – where programs, services and supports for this cohort are simply lacking or, if they do exist, have not been formally evaluated. Our findings show that developing culturally safe services will require reforms and mechanisms to incorporate First Nations values and beliefs in service systems.

The wide range of literature we analysed also illustrates the strengths of First Nations and Indigenous families and communities in caring for members who have a disability and facilitating their social inclusion. We have shown that disability service systems and service providers which draw on these strengths have the potential to support culturally safe care. We have identified promising practice in a number of models, approaches and initiatives, as well as areas in which further research and evaluation is needed.

However, our work shows that achieving cultural safety will require more than simply investing in effective and appropriate organisational models and services. Achieving cultural safety will require reform at practice, organisational, systemic and conceptual levels. It will also require service planners to consider how First Nations and Indigenous people understand and experience disability, and what meaningful participation in society and care mean to them. In order to achieve this, specific funding streams, a human-rights-based and therapeutic (rather than punitive) approach to criminal justice issues, Indigenous-led or co-designed programs, and flexible reporting requirements are required.

Appendix 1

Table 13: Sources included in Review 2

#	Source	Location (peer-reviewed database;[9] grey literature database;[10] or other[11])	Summary of the research
1	Miller, A., 2017. *Neighbourhood justice centres and Indigenous empowerment*. Australian Indigenous Law Review, 20, pp.123-153.	Peer-reviewed database	This paper investigates the potential of Neighbourhood Justice Centres ('NJCs') as one way to decolonise the criminal justice system. NJCs are a type of problem-solving court which explicitly aim to engage and empower the local community, and increase community capacity to deal with crime; and also house services, such as drug and alcohol counselling, mental health support, and employment and housing support, to assist the court in its problem-solving role. Miller concludes that the NJC model can be used to improve the way the criminal justice system interacts with Indigenous people by helping create a hybrid space where Indigenous and non-Indigenous laws and perspectives can operate side-by-side.
2	Hamilton, S.L., Maslen, S., Best, D., Freeman, J., O'Donnell, M., Reibel, T., Mutch, R.C. and Watkins, R., 2020. *Putting 'Justice' in Recovery Capital: Yarning About Hopes and Futures with Young People in Detention.* International Journal for Crime, Justice & Social Democracy, 9(2).	Peer-reviewed database	This article engages with the hopes, relationships and educational experiences of 38 detained youth in Western Australia who participated in a study of screening and diagnosis for fetal alcohol spectrum disorder. Participants spoke of many hardships, but also their strong connections to country and community, their education experiences and their future goals. The authors argue that we must celebrate success and hope through a process of mapping and building 'recovery capital' in the justice context, at an individual and institutional level.

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9 i.e. found in INFORMIT (Indigenous Collection, AGIS-ATSIS Collection) or Web of Science or Scopus or PubMed
10 i.e. found in Analysis and Policy Observatory (APO) or Indigenous Justice Clearinghouse
11 i.e. found in reference list of another source or through search engine or referral etc

3	Riley, B.J., Smith, D. and Baigent, M.F., 2019. *Mindfulness and Acceptance–Based Group Therapy: An Uncontrolled Pragmatic Pre–Post Pilot Study in a Heterogeneous Population of Female Prisoners*. International journal of offender therapy and comparative criminology, 63(15-16), pp.2572-2585.	Peer-reviewed database	This preliminary study evaluates the initial effectiveness of a mindfulness and acceptance–based group program in an uncontrolled pragmatic pilot study of a heterogeneous group of incarcerated women with a range of mental health issues. Results of linear mixed modelling showed improvements in mindfulness and acceptance, and reductions in depression, anxiety, and somatoform symptoms. Furthermore, acceptance and commitment therapy (ACT) was shown to be an acceptable and feasible intervention for female Indigenous Australian prisoners.
4	Blagg, H. and Tulich, T., 2018. *Diversionary pathways for Aboriginal youth with fetal alcohol spectrum disorder.* Trends and Issues in Crime and Criminal Justice [electronic resource], (557), pp.1-15	Peer-reviewed database	This article reports on a study undertaken in three Indigenous communities in the West Kimberley region of Western Australia (WA) intended to develop diversionary strategies for young people with fetal alcohol spectrum disorder (FASD). Besides recommending legislative reform, the authors urge a ‘decolonising’ approach, meaning maximum diversion into community owned and managed structures and processes, able to offer a culturally secure environment for stabilising children with FASD. The study calls for reform of police diversionary mechanisms and the creation of mobile ‘needs focused’ courts, offering comprehensive screening and rapid entry into on-country programs with strong Aboriginal community involvement.
5	Rasmussen, M.K., Donoghue, D.A. and Sheehan, N.W., 2018. *Suicide/self-harm-risk reducing effects of an Aboriginal art program for Aboriginal prisoners*. Advances in Mental Health, 16(2), pp.141-151.	Peer-reviewed database	Aboriginal art is an effective, culture-specific therapy for Aboriginal people; and it may have important implications for Aboriginal prisoners at risk of suicide/self-harm. This project aimed to evaluate the potential positive effects of Aboriginal art activities on the suicide/self-harm risk behaviours of Aboriginal prisoners. Data was collected for 335 Aboriginal male prisoners who were deemed at risk of suicide or self-harm, some (32.2%) of whom participated in an in-prison Aboriginal art program. The researchers found that each day (and additional day) of attendance to the Aboriginal art program reduced the incidence rate of suicide/self-harm, suggesting that Aboriginal art programs are protective for prisoners with mental health issues.

6	Flannigan, K., Pei, J., Rasmussen, C., Potts, S. and O'Riordan, T., 2018. *A unique response to offenders with fetal alcohol spectrum disorder: Perceptions of the Alexis FASD Justice Program*. Canadian Journal of Criminology and Criminal Justice, 60(1), pp.1-33	Peer-reviewed database	Despite knowledge that individuals with Fetal Alcohol Spectrum Disorder (FASD) are over-represented and vulnerable in the justice system, there is a critical paucity of research related to supporting offenders with FASD. The Alexis FASD Justice Program (AFJP) is an innovative and multidisciplinary justice program in rural Alberta that uses information from neurocognitive assessments to inform court decisions for adults with suspected FASD. In this study, the perspectives of AFJP services providers were explored, with the goal of identifying the perceived impacts and challenges of the program.
7	Ferrazzi, P. and Krupa, T., 2016. *"Symptoms of something all around us": Mental health, Inuit culture, and criminal justice in Arctic communities in Nunavut, Canada*. Social Science & Medicine, 165, pp.159-167.	Peer-reviewed database	Rehabilitation-oriented criminal court mental health initiatives to reduce the number of people with mental illness caught in the criminal justice system exist in many North American cities and elsewhere but not in the mainly Inuit Canadian Arctic territory of Nunavut. This study explores whether the therapeutic aims of these resource-intensive, mainly urban initiatives can be achieved in criminal courts in Nunavut's resource constrained, culturally distinct and geographically remote communities. 55 semi-structured interviews and three focus groups with participants were conducted in the communities of Iqaluit, Arviat and Qikiqtarjuaq. The findings suggest Inuit culture, including its recent history of cultural disruption and change, affects the vulnerability of Nunavut communities to the potential moral and legal pitfalls associated with TJ and criminal court mental health initiatives.
8	Ober, C., Dingle, K., Clavarino, A., Najman, J.M., Alati, R. and Heffernan, E.B., 2013. *Validating a screening tool for mental health and substance use risk in an Indigenous prison population.* Drug and Alcohol Review, 32(6), pp.611-617.	Peer-reviewed database	The Indigenous Risk Impact Screen (IRIS) is a validated culturally appropriate and widely used tool in the community for assessing substance use and mental disorder. This research aimed to assess the utility of this tool in an Indigenous prison population. The study used data collected from a cross-sectional study of mental health among Indigenous inmates in Queensland custodial centres. It found that IRIS is a valid tool for screening of alcohol and drug use risk among incarcerated Indigenous adults.

9	McCausland, R. and Dowse, L., 2020. *The need for a community-led, holistic service response to Aboriginal young people with cognitive disability in remote areas: a case study.* Children Australia, 45(4), pp.326-334	Peer-reviewed database	This article discusses the experiences and trajectory of a young Aboriginal woman with cognitive disability and complex support needs from a remote town. This case study is drawn from a New South Wales linked administrative dataset containing data from health, housing, disability, human services, police, legal, court and justice agencies on a cohort of people who have been incarcerated. The article draws out key principles and strategies to suggest what a community-led, holistic service response could have looked like for Casey
10	Kippin, N.R., Leitão, S., Watkins, R., Finlay-Jones, A., Condon, C., Marriott, R., Mutch, R.C. and Bower, C., 2018. *Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia.* International Journal of Law and Psychiatry, 61, pp.40-49.	Peer-reviewed database	While studies confirm high prevalence of language disorder among justice-involved young people, little is known about the impact of Fetal Alcohol Spectrum Disorder (FASD) on language among this population. In the highly verbal environments that are common to justice systems, language disorder and language difference may result in a young person misunderstanding legal information and expectations placed on them and not being adequately understood by the justice workforce. This study examined the language skills of 98 young people sentenced to detention in Western Australia (WA), and found a prevalence of language disorder amongst this cohort. The results underscore the need for the justice workforce to consider language difference when working with justice-involved youth, as well as language disorder and FASD.
11	Thom, K. and Burnside, D., 2018. *Sharing power in criminal justice: The potential of co-production for offenders experiencing mental health and addictions in New Zealand.* International journal of mental health nursing, 27(4), pp.1258-1265.	Peer-reviewed database	Given that a large majority of prisoners in Aotearoa New Zealand have been diagnosed with either a mental health or substance use disorder within their lifetime, it is imperative alternative approaches are considered if we are to reduce the high imprisonment rates and contribute positively to health, safety, and well-being of all New Zealanders. In this study, the authors explore how co-production has been conceptualized and used in criminal justice systems internationally, and offer an experiential account of their first steps into co-production both in service delivery and research. 'Co-production' involves service users, service providers, government, community

			groups, and the whole spectrum of society, working together to identify gaps and issues, and to find and implement solutions.
12	Lau, P., Marion, C., Blow, R. and Thomson, Z., 2012. Healing for Aboriginal and Torres Strait Islander Australians at risk with the justice system: A programme with wider implications.	Peer-reviewed database	This paper presents a case study, of an Aboriginal man in his 40s, named Rocky, who has spent half his life in jail. Rocky has chronic illness, mental health and substance abuse issues. Rocky was referred to the Gathering Place Health Service (GPHS), an intensive healing programme for Indigenous Australians. The program has been very effective for Rocky – he has remained sober and has not re-offended. The GPHS programme has not been formally evaluated, however.
13	Erickson, P.G. and Butters, J.E., 2005. *How does the Canadian juvenile justice system respond to detained youth with substance use associated problems? Gaps, challenges, and emerging issues.* Substance Use & Misuse, 40(7), pp.953-973.	Peer-reviewed database	Canada has few specialized programs for substance misusing young offenders. For youth in conflict with the law, "substance abuse" is recognized as a significant risk factor for recidivism. This article provides an overview of the Canadian response and elaborates features of some programs, particularly Multisystemic Therapy, mainly in the province of Ontario. Few programs have received adequate evaluation, however, and the need for systematic assessment is crucial for the development of future effective interventions for youth with multiple drug and other problems.
14	Pyne, A., 2012. *Ten proposals to reduce indigenous over-representation in northern territory prisons*. Australian Indigenous Law Review, 16(2), pp.2-17.	Peer-reviewed database	More than 20 years have passed since the Royal Commission into Aboriginal Deaths in Custody ('RCIADIC') report was tabled in Parliament. There have been some successes, but, overall, the number of Indigenous people in prison reflects that we have not done enough. Nowhere is that failure more apparent than in the Northern Territory. Pyne argues that incarceration rates have gone up because we, through our elected politicians, choose jail for Indigenous offenders, and choose it more frequently. Pyne puts forth 10 ways that we can undo that..
15	McCausland, R. and Baldry, E., (2017). *'I feel like I failed him by ringing the police': Criminalising disability in*	Peer-reviewed database	These authors argue that disadvantaged people with mental and cognitive disability are being managed by and entrenched in criminal justice

	Australia. Punishment & Society, 19(3), pp.290-309.		systems across Australia's six states and two territories, including so-called diversionary and therapeutic measures that appear to accommodate their disability. Drawing on research that focuses in detail on the jurisdictions of the Northern Territory and New South Wales, McCausland and Baldry argue for a reconstruction of the understanding of, and response to, people with these disabilities in the criminal justice system.
16	Heffernan et al, 'Mental Disorder and Cognitive Disability in the Criminal Justice System' in Dudgeon, P., Milroy, H., Walker, R. (2014) *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice*, 2nd Edition.	Grey database	This chapter examines what is known about the prevalence of mental disorder and cognitive disability amongst Aboriginal and Torres Strait Islander peoples in contact with the criminal justice system, and how these issues impact on individuals, families and communities. The authors' literature review finds there to be a considerable body of evidence supporting the premise that mental disorders (especially cognitive disability) are a significant health challenge for Aboriginal and Torres Strait Islander peoples in contact with all aspects of the criminal justice system. Heffernan et al then go on to consider the important and complex implications for mental health and disability services in meeting the needs of Aboriginal and Torres Strait Islander peoples in the criminal justice system.
17	HREOC (2008) *Preventing crime and promoting rights for Indigenous young people with cognitive disabilities and mental health issues*. Australian Human Rights Commission, Sydney, Australia, 2008.	Grey database	This report provides an investigation of early intervention and diversionary practices aimed at preventing offending behaviour in Indigenous young people with a cognitive disability and/or a mental health problem. Specifically, the report examines what is available for these young people, identifies systemic service delivery gaps and points to promising interventions that have the capacity to prevent offending behaviour as there is a lack of literature, evidence and interventions for this group of young people.
18	Baldry, E., McCausland, R., Dowse, L. and McEntyre, E. (2015). *A predictable and preventable path: Aboriginal*	Grey database	Aboriginal and Torres Strait Islander peoples with mental and cognitive disabilities are significantly over-represented in Australian criminal justice

	people with mental and cognitive disabilities in the criminal justice system. UNSW, Sydney.		systems. However there has been a lack of critically informed evidence, analysis and co-ordinated policy and service response on this most pressing human rights issue. The Indigenous1 Australians with Mental Health Disorders and Cognitive Disability in the Criminal Justice System (IAMHDCD) Project2 brings an innovative Indigenous-informed mixed method research approach that provides, for the first time, a critical analysis of systems interactions and responses to the complex needs of Indigenous people with disability in criminal justice. This report sets out detailed quantitative analysis of the 676 Indigenous women and men in the MHDCD cohort as well as views of community members regarding systemic and social challenges, service failures, positive program interventions, and culturally responsive approaches and remedies
19	Sharma, K., Pearson, E. & Bright, G. (2018). *"I Needed Help, Instead I was Punished": Abuse and Neglect of Prisoners with Disabilities in Australia*. Human Rights Watch.	Grey database	While research has focused on the barriers to justice for people with disabilities, including their placement in indefinite detention, there is little information across different Australian states on their experiences once in prison. This report aims to contribute to filling this void. Based on research between September 2016 and January 2018 in Western Australia, Queensland, New South Wales, and Victoria—including interviews with people with disabilities, prison-related and government professionals, mental health experts, academics, lawyers and civil society representatives—Human Rights Watch finds that Australia is restricting and violating the rights of prisoners with disabilities, including Aboriginal and Torres Strait Islander people with disabilities.
20	Vanderpoll, T. and Howard, D. (2011). *Investigation into hearing impairment among Indigenous prisoners within the Northern Territory Correctional Services*. Phoenix Consulting, Darwin.	Grey database	This report investigates the implications of hearing impairment among the Indigenous prisoners in Northern Territory Correctional Services. It was conducted in response to the ‘Hear Us’ inquiry into hearing health in Australia report by the Australian Government. Findings show that more than 90% of Indigenous inmates have a significant hearing loss. Comments by inmates indicate that hearing impairment is often a significant disability in a custodial environment that contributes to the breakdown in communication with prison officers.

			The researchers argue that there are potential benefits in addressing widespread hearing loss among NT Indigenous inmates, such as improved inmate management practices and enhanced wellbeing among inmates, as well as better rehabilitation outcomes and lower levels of recidivism.
21	Sotiri, M. and Simpson, J. (2006). *Indigenous people and cognitive disability: An introduction to issues in police stations*. Current Issues in Criminal Justice, 17(3), pp.431-443.	Grey database	This article draws together some of the major themes which emerged from an exploratory study of the issues facing Indigenous people who have a cognitive disability and come into contact with the criminal justice system as victims and offenders. The study was conducted over a period of two months, combining interviews, focus groups and consultations with people working in the areas of Indigenous health, disability and criminal justice. In addition questionnaires were sent to key government and non-government organisations and the relevant literature was surveyed. Forty participants from four states contributed to the project during this period. the research focused primarily on the criminal justice systems in NSW, Western Australia and the Northern Territory. The project examined the needs and issues for Indigenous people with cognitive disabilities who come into contact with police stations, courts and prisons.
22	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) *Overview of Responses to the Criminal Justice System Issues Paper*, December 2020.	Other	The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) published the Criminal Justice System Issues Paper (Justice Issues Paper) on 14 January 2020 and invited responses by 20 March 2020. The Justice Issues Paper sought information about the experiences of people with disability in the criminal justice system. At 2 November 2020, the Royal Commission had received 56 responses to the Justice Issues Paper. This document provides a brief summary of what the Royal Commission has been told in responses to its Justice Issues Paper. The responses highlighted the many forms of violence, abuse, neglect and exploitation that people with disability may experience in the

			criminal justice system as victims, accused people or witnesses.
23	HREOC (2014), *Equal before the law: towards disability justice strategies*. Australian Human Rights Commission 2014.	Other	In 2013, the Australian Human Rights Commission conducted a wide-ranging consultation process to identify how people with disabilities deal with the barriers they experience to equality before the law. It was found that people with disabilities, when they come into contact with the justice system, experience numerous challenges and disadvantages. The Commission argued, therefore, that the case for change is clear. The report argues that not only is there a human rights imperative to ensure equality before the law, but there is also a strong economic imperative.
24	McSherry, B.E.A.P.R., Baldry, E., Arstein-Kerslake, A., Gooding, P., McCausland, R. and Arabena, K., 2017. *Unfitness to plead and indefinite detention of persons with cognitive disabilities*. Melbourne Social Equity Institute, University of Melbourne.	Other	This report summarises the findings of a two-year research project which was designed to develop practical and legal solutions to the problem of persons with cognitive disabilities – and particularly Indigenous people with cognitive disabilities – being found unfit to plead and detained indefinitely in Australia. Three community legal centres across Australia participated in the program. The project findings have informed recommendations for improvements to enable better access to the criminal justice system and support for accused persons with cognitive disabilities.

Appendix 2

Table 14: Evaluation and assessment of Review 3 included models of care

Model of care	Site, location type	Model implemented, assessed/ evaluated?	Impact
Machado-Joseph Disease (MJD) Foundation model of care Massey et al 2018, Elsum et al 2020	Northern Australia, remote and regional areas	Implemented. Aspects non-independently evaluated (genetic services)	Provided a service where none existed before, with substantial involvement of First Nations people. Services well received by participants, particularly the opportunity to develop relationships with service providers and participate in meaningful work while caring for family members. MJDF services cost more and take longer to provide, involve many more people than the 'client'.
Walykumunu Nyinaratjaku (to live a good life) NPY Women's Council 2018, Dew et al 2019, Woods et al 2000	Central Australia, remote	Implemented, assessed through qualitative research	Service reflects what Aṉangu and Yarnangu see as a good life: living on country, being close to family, obtaining the basic needs of life. Model is responsive to Aṉangu and Yarnangu desires for stable service providers who understand and are responsive to their needs.
Services Our Way Raven et al 2014, NSW Family & Community Services & Ageing Disability & Home Care 2012, Biddle et al 2014	Nowra, NSW, Australia regional area.	Piloted, independently evaluated	Enabled participants to achieve some of their priorities, make choices. Facilitated access to a range of services. A transferrable, culturally appropriate approach. Unknown whether participants successfully transferred to mainstream services. Model could potentially also offer long-term support.
Lungurra Ngoora Community Care Service	Looma, Kimberley, Western	Piloted, independently	Increased the numbers of services provided and removed duplication. New services included a greater range of activities. Trained and employed local

LoGuidice et al 2012, Yarmintali Consultancy 2010, Smith et al 2011	Australia remote area.	evaluated, discontinued	Aboriginal people in work they found meaningful. Well received by participants. Questions over the extent of local ownership, insufficient leadership roles for local Indigenous people. Unclear management and reporting structures and accountability, difficulties in reporting to various funders. Division and infighting.
Resident Family Care (formerly Funded Family Care) Litmus 2012, Paulin et al 2015	New Zealand, all location types.	Piloted, independently evaluated, implemented	Families report the scheme relieved financial and psychological stress. Carers appreciated recognition of their roles. Limited uptake due people with a disability having to make decisions, become an employer when some did not have the capacity; difficulties accessing the scheme; lack of awareness, misinformation; carer wages set at the minimum wage.
First Nations and Inuit Home and Community Care The Canadian Home Care Association 2010 Health Canada and the Public Health Agency of Canada 2013, Indigenous Services Canada 2019b, Biddle et al 2014	Canadian First Nations reserves and communities and Inuit communities; remote areas	Implemented, multiple evaluations	Evaluations consistently show positive impact on expanding access to services, enabling people to remain in their homes, reducing hospital admissions. Concerns that funding is not keeping pace with demand. Areas where services could improve include communication, incorporation of customary healing practices, access to allied health services, training for personal care workers, equitable access in small communities. Some duplication with Assisted Living Program.
Assisted Living Program (in-home care component) Indigenous Services Canada 2017, Indigenous Services Canada 2019a, Hirji-Khalfan 2009	Canadian First Nations reserves and communities and Inuit communities; remote areas	Implemented, does not appear to have been assessed or evaluated	N/A

Adaptation of the National Disability Insurance Scheme (NDIS) in the Northern Territory PriceWaterhouseCoopers Indigenous Consultants 2018	The Northern Territory of Australia; remote and regional areas	Not implemented	N/A
Purple House model of care (formerly Western Desert Nganampa Walytja Palyantjaku Tjutaku 'Making all our families well') Rivalland 2006, Purple House 2019a, Purple House 2019b, Tjungurrayi 2015	Central Australia (including the Northern Territory, Western Australia, South Australia); remote and regional areas.	Implemented, independently evaluated	The opportunity to return to communities has a large impact on quality of life and participation of participants. A range of non-government funding sources enables the organisation to have autonomy over which services are delivered and how. There is potential to extend the model to other communities, but secure long-term funding is needed for all activities.
Services for Indian Americans in the West Cascade Mountain Range region Ryser et al 2014	West Cascade Mountain Range region, US. Includes urban and remote areas.	Does not appear to be	N/A

Appendix 3

Table 15: Review 3 included sources

Study	Aims/research questions	Output type and methods	Peer reviewed
Ryser et al 2014	Is there sufficient support for caregivers to Indian Americans who are elderly or have a disability?	Journal article. Analysis of policy, practice, legislation, literature Interviews with federal, state, tribal policymakers and service providers (number not reported). Observational research at conferences	Yes
Massey et al 2018	To describe the MJD Foundation model of care	Organisational report. Synthesis of reports and studies published by the organisation and the experiences of personnel	No
Elsum et al 2020	To investigate what aspects of MJD Foundation model are central to improved engagement with clinical genetics services; which aspects are transferrable	Journal article, evaluation. Interviews with 22 people in 4 communities of operation (primary healthcare staff, non-Indigenous MJDF staff, Indigenous people with dual client/staff roles at MJDF, other Indigenous clients); fieldnotes of observations	Yes
NPY Women's Council 2018	To document what a good life means to people with a disability on the NPY lands and how service providers can support them.	Organisational report. Interviews and focus group discussions with 109 participants (Anangu aged 18+ with a disability and their carers living on and off NPY lands; and service providers assisting people with a disability).	No
Dew et al 2019	What does a good life comprise among Anangu with a disability and how can service providers support them?	Journal article. Interviews and focus group discussions with 109 participants (Anangu aged 18+ with a disability and their carers living on and off NPY lands; and service providers assisting people with a disability).	Yes
Woods et al 2000	To describe two elements of NPY Women's Council's work: action research and malparara way of working	Book chapter. Not reported.	Yes

Raven et al 2014	To what extent does the model impact on the quality of life of Aboriginal people with disability and their families, promote capacity to self-manage and transition to other disability services? What is the capacity to expand the program?	Report, independent evaluation. Interviews with 12 service users and 5 service providers Analysis of administrative data	No
NSW Family & Community Services & Ageing Disability & Home Care 2012	To describe 'Services Our Way' model of care	Policy document. Not reported.	No
Biddle et al 2014	To identify and assess the range of disability service delivery models available for Indigenous Australians and to ascertain the extent and nature of disability in the Australia Indigenous population	Research monograph. Analysis of administrative data and literature review.	Yes
LoGuidice et al 2012	To report on the development and implementation of the model of care	Journal article, evaluation. Analysis of service usage data, staff journals, interviews with service users	Yes
Yarmintali Consultancy 2010	To assess whether the model of care was culturally safe, accountable, transferrable	Report, independent evaluation. Analysis of administrative data and staff journals, interviews with service users and staff (number not reported) at baseline, 6 months, 12 months.	No
Smith et al 2011	To describe the unmet needs of Indigenous people with dementia in remote Kimberley; to explore ways to facilitate improved care	Journal article. Interviews with 42 service providers to determine available services; interviews with 31 caregivers and community-based workers to explore care needs; 3 focus groups with community representatives and service providers to develop a model of care	Yes

Litmus 2012	Responses of stakeholders to the NZ Ministry of Health proposed models for payment of family/whaṉau (Maori extended family) carers	Report. Analysis of 619 submissions and 17 public consultations.	No
Paulin et al 2015	To determine the impact and effectiveness of Funded Family Care and the reasons influencing its uptake	Report, independent evaluation. Interviews with 45 people with disability and their family/whaṉau (Maori extended family) carers, 13 needs assessment and service coordination personnel, 5 representative organisations for people with disabilities, 1 manager of the funding advisory and support service. A survey administered to service providers (13 responses).	No
The Canadian Home Care Association 2010	To describe ‘promising practices’ emerging within the program	Report. Analysis of administrative data and description of initiatives by personnel.	No
Health Canada and the Public Health Agency of Canada 2013	To assess the relevance and performance of the First Nations and Inuit Home and Community Care program from April 2008 to March 2012	Report, evaluation. Analysis of internal documents, a survey (332 responses) and interviews (with 58 informants), comprising Band Chief and Council or designates; Provincial/ Territorial and Federal Governments and agency representatives; Aboriginal organization and NGO representatives.	No
Indigenous Services Canada 2019b	To assess the continued need for the program, alignment with government and Indigenous priorities, alignment with federal roles and responsibilities, achievement of expected outcomes, economy and efficiency	Report, evaluation. Analysis of administrative data and literature, 55 interviews and 131 responses to an online survey with health directors, coordinators and managers.	No
Indigenous Services Canada 2017	Description of social programs funded by Indigenous and Northern Affairs Canada	Policy document, not reported.	No

Indigenous Services Canada 2019a	Description of Assisted Living Program	Policy document, not reported.	No
Hirji-Khalfan 2009	To examine how the federal government of Canada supports Aboriginal people with disabilities on-reserve	Journal article. Analysis of legislation and policy documents.	Yes
PriceWaterhouseCoopers Indigenous Consultants 2018	To identify and respond to opportunities of the NDIS in remote and regional parts of the NT for social and economic participation	Report. 18 Workshops, forums and meetings conducted in 28 communities involving 407 people.	No
Rivalland 2006	To report on the activities of Western Desert Nganampa Walytja Palyantjaku Tjutaku ‘Making all our families well’	Organisational report. Not provided. (Methods contained in an unpublished appendix).	No
Purple House 2019a Our story	Description of services provided.	Organisational website. Not provided.	No
Purple House 2019b	To develop the preceptor job role by identifying the skill set and any professional development required to build relevant skills and knowledge.	Organisational report.	No
Tjungurrayi 2015	To present a personal narrative of end stage kidney disease and the development of Purple House	Book	No

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CONTACT US

Centre for Aboriginal Economic Policy Research
Research School of Social Sciences
ANU College of Arts & Social Sciences

Copland Building #24
The Australian National University
Canberra ACT 0200
Australia

T +61 2 6125 0587
W caepr.cass.anu.edu.au

ANU CRICOS Provider Number: 00120C