


## REVIEW ARTICLE

# Community-based social care models for indigenous people with disability: A scoping review of scholarly and policy literature

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## Abstract

Disability is experienced and understood by Indigenous people internationally in distinct ways from other populations, requiring different approaches in disability services. Furthermore, Indigenous populations access disability services at low rates. In response, policymakers, service providers and Indigenous organisations have developed specific models of care for Indigenous people with disability. Social care services, comprising personal care, transport and social activities, can support Indigenous people with disability to live with their families and in their communities. However, little is known about the range of social care models for Indigenous people with disability. To inform policy and practice, we conducted a scoping review of community-based models of social care designed to meet the needs of Indigenous peoples in Australia, Aotearoa New Zealand, Canada and the United States. Our methods were informed by best practice scoping review principles and a collaborative approach that centred Indigenous voices within research appraisal and project governance processes. Literature searches (conducted March–April 2021) yielded 25 results reporting on 10 models of care. We identified two over-arching themes (funding and governance arrangements; service delivery design) that encompass nine key characteristics of the included models. Our analysis shows promising practice in contextually relevant place-based social activity programs, support and remuneration for family carers and workforce strategies that integrate Indigenous staff roles with kinship relationships and social roles. While more research and evaluation are needed, disability funding bodies and service systems that facilitate these areas of promising practice may improve the accessibility of social care for Indigenous peoples.

## KEYWORDS

community-controlled, disability, governance, indigenous, social care, workforce

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## 1 | INTRODUCTION

Disability is experienced and understood by Indigenous people internationally in distinct ways from other populations, requiring different approaches in disability services. While there is no single Indigenous construct of disability, the international literature reports that many Indigenous tribes, nations and communities understand physical and sensory disabilities to reflect the normal range of human diversity (Avery, 2018; Bevan-Brown, 2013; Puszka et al., 2022; Varvarezou, 2020). Disabilities may be experienced in collective as well as individual ways, through Indigenous understandings of the social basis of health conditions and through practices of caregiving for people with disability in Indigenous families (Bevan-Brown, 2013; Puszka et al., 2022). Independent living movements within some disability services may conflict with Indigenous values of collective responsibility and practices of interdependency (Senior, 2000; Varvarezou, 2020).

According to the widely adopted World Health Organisation biopsychosocial model of disability (2002), the interaction between a person's bodily functions and capacity and social environments creates disability. Although this model may not reflect Indigenous understandings of disability and human functioning, it nevertheless informs disability policy and services in many states (Avery, 2018). Disability services, therefore, comprise a range of health and social services.

Community-based social care services aim to address social dimensions of disability and are generally designed to improve both the life expectancy and quality of life of people with physical, sensory, neurological or psychosocial conditions (Malley et al., 2012). Community-based social care services comprise personal care, transport and social activity services, including support for maintaining personal hygiene, dressing, feeding, keeping active and socialising (Anttonen & Sipila, 1996; Malley et al., 2012). They may be provided by government, NGO and commercial providers through a range of funding mechanisms (Daly & Lewis, 2000).

A range of approaches to social care in high-income states with dominant populations that are racialised as White, including community-based services, have been identified in the literature. These approaches loosely align with differing approaches to the welfare state (Bambra, 2007), and have varying reliance on family caregiving and other services not funded by governments. Drawing on this literature, we identify a distinct Scandinavian model, family care/Mediterranean model, Anglo-Saxon model and central European model (Anttonen & Sipila, 1996; Daly & Lewis, 2000; Newman et al., 2008; Sipila, 2018; Table 1). Some degree of overlap exists between models and their existence in European states, local variation is present and many models have subsequently become subject to austerity measures and shifting constructs of the welfare state. Nevertheless, these distinctions illustrate how models in states with dominant White populations are influenced by a range of Western values and ideologies. For example, liberal values inform the Anglo-Saxon model which foregrounds obligations of citizens deemed economically self-sufficient to fund their own care, while

### What is known about this topic and what this paper adds

- Research regarding social care models that address the needs of Indigenous people with disability is disparate and has never been brought together.
- Our review shows flexible, streamlined funding and appropriate governance structures are needed to involve Indigenous people and communities in the development, governance and management of models of care.
- Support and remuneration to family carers and place-based social activity programs integrated with the activities of daily life may enable service providers to respect Indigenous values and social practices.
- Workforce strategies that integrate Indigenous staff roles with kinship relationships and social roles can also support families.

social Catholicism and family solidarity lead to an emphasis on informal caregiving in the family care/Mediterranean model.

For Indigenous people, the accessibility of disability services informed by the WHO model and a range of Western values, including community-based social care services, can be poor. In many disability services, a focus on remediating individual pathology can conflict with Indigenous understandings of disability, and services can be experienced by Indigenous people as stigmatising environments (King et al., 2014; Ryser et al., 2014; Varvarezou, 2020). Consequently, Indigenous people in many settler-colonial states do not access disability services at rates commensurate with the prevalence of disability among Indigenous populations (Newbold, 1999; Ryser et al., 2014; Temple et al., 2020). In response to these issues, policymakers, funding bodies, service providers and Indigenous communities and organisations have developed specific models of care for Indigenous people with disability.

Evidence is needed to inform the further development of culturally safe, accessible and appropriate models of community-based social care for Indigenous people with disability that encompass Indigenous values and social practices. This is important because accessible community-based social care may prevent Indigenous people from requiring residential care outside of their communities (Pearce, 2000; Rees, 2003). Research regarding social care models that address the needs of Indigenous people with disability is disparate and has never been brought together to the best of our knowledge. Analysis of how the inclusion of Indigenous approaches and perspectives have been facilitated in social care services internationally is needed to inform future approaches to social care for Indigenous tribes, nations and communities.

In this paper, we review community-based models of social care for Indigenous adults with disability that enable them to remain in their homes and communities in Australia, Aotearoa New Zealand,

TABLE 1 Synthesis of literature on models of social care in high-income states with dominant white populations

Model	Access to services	Service providers	Main funding mechanisms
Scandinavian model	Universal access to services for all citizens, extensive access to care.	Predominantly local governments.	Taxes.
Family care/Mediterranean model	Limited access to publicly funded services.	Most care provided by family or other informal caregivers; some services provided by commercial providers.	Limited public services funded by taxes, most family/informal care is unfunded. Some private services are funded as part of employment conditions or on a user-pays basis.
Anglo-Saxon model	Wide-access services have tight means-testing.	A range of government and NGO providers, presence of commercial providers.	Services funded through taxes have tight means-testing. Some services for middle and high-income families funded on a user-pays basis.
Central European model	Services are limited.	Religious and political organisations and other NGOs are key service providers.	Services are mainly publicly funded; health insurance plays a role in funding services.

Canada and the United States. There is substantial cultural diversity among Indigenous peoples internationally, and Indigenous values and practices associated with health and human functioning are likely to be culturally specific (Avery, 2018). However, broad commonalities are also present in Indigenous peoples' experiences of disability services where services are grounded in Western constructs of disability and governance and Western social norms (Ariotti, 1999); and in efforts to develop Indigenous models within the funding and governance structures of the Anglo-Saxon model, while attempting reconfiguring the cultural or ideological underpinnings of social care.

We aim to synthesise the characteristics of models of social care for Indigenous people and identify promising practices and approaches that address Indigenous values, social practices and needs. We address the research questions:

- What are the characteristics of community-based models of social care for Indigenous adults with disability?
- Which approaches to the social care needs of Indigenous adults with disability show promising practice in addressing the values, social practices and needs of Indigenous people?

As specific measures to address the values, practices and needs of particular Indigenous communities may not be transferable to other contexts, our focus is on broader structures, processes and approaches in social care services.

## 2 | METHODS

### 2.1 | 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). Systematic scoping reviews are suitable for

reviewing the range 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 developed by Arksey and O'Malley (2005) and subsequent extensions developed by Levac et al. (2010) and Peters et al. (2015). Drawing on these principles, our review is structured around the population, concept and context of interest. A review protocol was developed to guide the review process (available on request from the authors).

Systematic review is an approach that emerges from positivist traditions and privileges academic knowledge. We recognise that systematic review methodologies have the potential to marginalise Indigenous voices and knowledges, as well as the voices and knowledges of people with disability. In order to address this, we formed a research team that drew on a range of perspectives and expertise including of Indigenous researchers and disability advocates. We also developed a collaborative approach that centred Indigenous voices within our review methods and project governance processes.

The authors of this review are an Australian First Nations disability advocate, an Australian First Nations research leader, and four non-Indigenous researchers who have experience working with Australian First Nations people and communities. Additionally, the authors of this review include people who have lived experience of disability. The research team brought together understandings of Indigenous values, beliefs, practices and experiences; experiences of disability and knowledge of disability service systems and expertise in systematic review and meta-synthesis methods.

Our review foregrounds the perspectives, voices and experiences of Indigenous people within research development processes, methods, literature synthesis and analysis while adhering to the principles of systematic review through the following components:

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

2. Engagement with key Indigenous disability advocates and stakeholders, which informed the development of research questions and aims.
3. The use of our earlier synthesis of Australian First Nations peoples' understandings and experiences of disability to inform the design and analysis of this review.
4. Broadly defined inclusion criteria, which expand the potential to include studies and reports published by Indigenous authors and organisations.
5. Critical appraisal of the involvement of Indigenous peoples, 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 as it did not involve the collection of primary data.

## 2.2 | Inclusion criteria

### 2.2.1 | Population

We included literature on models of social care for Indigenous adults with disability in Australia, Aotearoa New Zealand, Canada and the United States. These states were included as comparable settler-colonial states, where Indigenous peoples are likely to experience similar challenges in accessing social care services that predominantly reflect an Anglo-Saxon model of social care (Table 1). We include studies that correspond to a definition of 'social care' that encompasses assistance with day-to-day living tasks such as personal hygiene, dressing and feeding, shopping, keeping active and socialising (Malley et al., 2012), which may or may not be delivered by family carers.

### 2.2.2 | 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 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 itself embedded in Western values. Nevertheless, many Indigenous organisations are now developing their own models of care (e.g. Massey et al., 2018; Rivalland, 2006). We draw from the definition of models of care adopted by Davidson and colleagues in a healthcare context (Davidson et al., 2006: 49) to develop our own definition of model of care:

*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.*

The outcomes of social care services depend, in large part, on the responses of service participants (Baldock, 1997). For the purposes of this review, we therefore conceptualise 'evidence-based practice' as practice that is informed by research and by consultation that identifies service users' needs and experiences. We also adopt an expansive conceptualisation 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.

### 2.2.3 | Context

Our review encompasses community-based models of care designed to meet the specific social care needs of Indigenous people with disability, where needs are identified by Indigenous people. Indigenous peoples' needs can be identified in models of care through published literature on Indigenous peoples' perspectives, consultation and collaboration processes or primary data collection. Models of care may provide social care to Indigenous people only, or may be mainstream social care services with components to address the specific social care needs of Indigenous peoples.

### 2.2.4 | Study design

We adopted an inclusive approach to the literature in order to incorporate Indigenous perspectives which may not be published in scholarly journal articles. We included models of care described, assessed or evaluated in research, evaluations and reports that met the following criteria:

- Used quantitative, qualitative or mixed methods;
- Incorporated Indigenous peoples' perspectives, for example through methods such as interviews, focus group discussions, surveys, consultation processes or citation of relevant literature;
- Were published in peer reviewed journals or as grey literature; and
- Were published in 2000. This timeframe reflects our conceptualisation of cultures as sets of beliefs and practices that change over time; and growing scholarly interest in Indigenous experiences of disability over recent decades.

The following models of care were excluded:

- Models of social care that do not specifically address the needs of Indigenous people;

- 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 (e.g. 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 generate a broader range of results.

## 2.3 | Search strategy

We developed an electronic database search strategy for peer-reviewed and grey literature using Boolean terms in collaboration with a health librarian. Initial search terms were tested and adapted to derive a final set of terms (Figure 1). 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. The search strategy was adapted to 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.

## 2.4 | Data extraction and study selection methods

Literature searches were conducted in March and April 2021. 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 a 10% sample of results for consistency. The two screeners reached consensus over the sample and these decisions informed further screening by SP. Full-text screening was also performed by SP and reviewed by CW. Screeners reached a consensus over all full-text inclusion decisions.

## 2.5 | Charting of data

We extracted the following variables from included sources: research question, study design, reported in grey literature/peer-reviewed, methods, site, participant group, types of social care provided, Indigenous peoples' involvement in model design, governance structure, Indigenous peoples' involvement in governance, workforce strategies, other reported components of service delivery model, Indigenous peoples' involvement in the research/evaluation. Our variables and analysis were informed by our earlier systematic review of conceptualisations and experiences of disability among First Nations peoples of Australia and the implications for disability services (Puszka et al., 2022). 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.

We synthesised the characteristics of models of care reported in included studies using thematic analysis techniques. Initially, a deductive approach was used, in which we synthesised the characteristics and range of practice across the models within each variable. Subsequently, an inductive approach was used to identify additional service delivery and design features of Indigenous models. The initial structure of themes and sub-themes was developed by SP and then adjusted following review by co-authors.

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"

FIGURE 1 Search terms used in PubMed.

## 2.6 | Assessing promising practice

We anticipated that many models of social care for Indigenous people would not have been evaluated, and therefore there was likely insufficient evidence to assess outcomes and impact. Accordingly, we conducted an analysis of promising practice, 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. 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).

## 2.7 | Appraisal of indigenous peoples' involvement in research

We conducted an appraisal of the extent to which Indigenous people and their perspectives were part of the research process in literature included in this review. Our criteria were informed by the Consolidated Criteria for Strengthening Reporting of Health Research Involving Indigenous Peoples (the CONSIDER Statement) (Huria et al., 2019) and the Aboriginal and Torres Strait Islander Quality Appraisal Tool (Harfield et al., 2020), and were developed by the research team (Table 2).

# 3 | RESULTS

## 3.1 | Search results

Our search strategy yielded a total of 1618 results and we identified 19 additional sources (Figure 2). 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 (Appendices S1 and S2). The main reasons for exclusion were as follows: 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.

## 3.2 | 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

TABLE 2 Indigenous peoples' involvement in research appraisal criteria

Criteria	To a large extent	Somewhat	Not at all	Not reported
To what extent are Indigenous people involved in setting the research priorities/agenda?	Authors report that research topic or question emerged from an Indigenous organisation or group or discussions with Indigenous collaborators	Research topic or question described as aligning with priorities or issues articulated by Indigenous people or organisations, e.g. in published literature	Research topic or question described as aligning only with other people or organisations' priorities, e.g. those of 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, e.g. 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

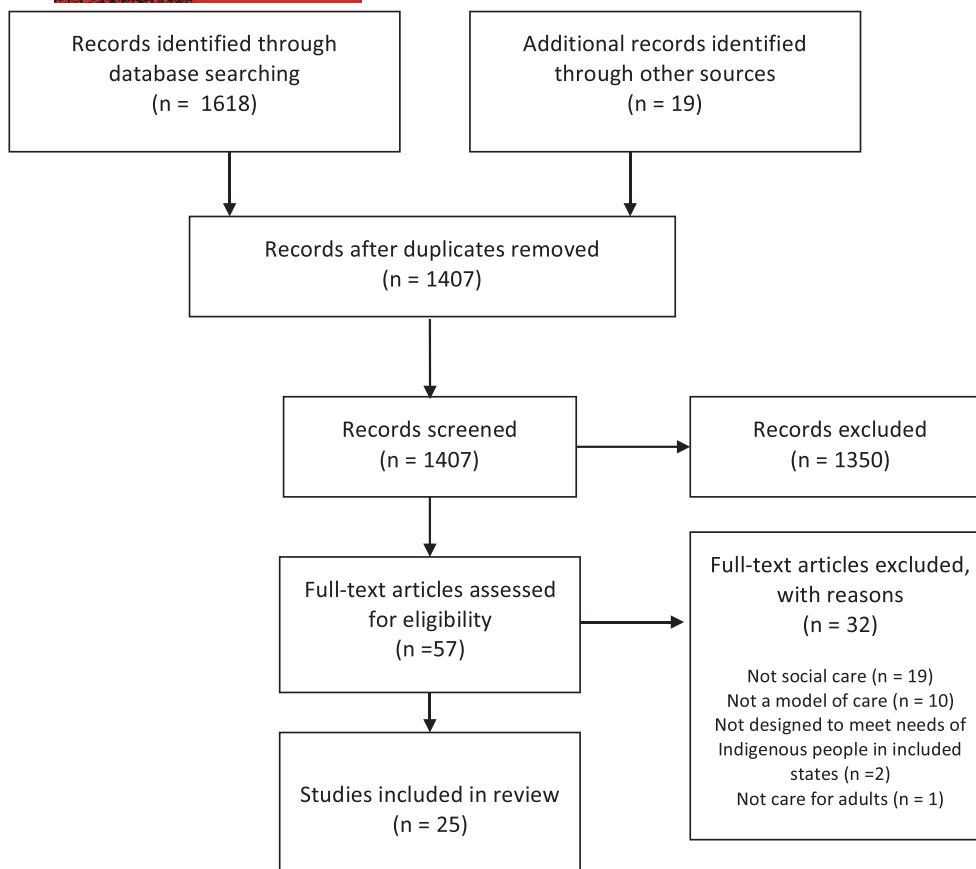


FIGURE 2 PRISMA flow diagram of search and screening process.

other forms of literature, such as policy documents and guidelines. Accordingly, we excluded literature that did not contain primary data from the appraisal process. Five literature sources in our review were excluded from this appraisal process. Additionally, when appraising program evaluations, we adapted the first criterion, on the involvement of Indigenous people in setting research priorities and agendas. We considered whether metrics of success used in the evaluation incorporated Indigenous peoples' and communities' perspectives. Generally, the involvement of Indigenous peoples and organisations in included research was poorly reported in the literature (Table 3). Where involvement was reported, studies generally performed well across all three criteria, however these results may reflect reporting bias.

### 3.3 | Characteristics of included models of social care

There is substantial heterogeneity in included models of social care, and the models encompassed funding schemes and organisational models. Our synthesis identified two over-arching themes: funding and governance arrangements; and service delivery design and approaches. These two over-arching themes encompass nine key characteristics of the included models. The funding and governance arrangements of included models are characterised by: dedicated

funding streams, the presence of community-controlled organisations, development of models by Indigenous peoples and flexible and streamlined funding arrangements. Service delivery design and approach characteristics are as follows: place-based activities integrated with everyday life, respect for social norms of personal care, support for families, inclusive and integrative approaches and workforce strategies to support relationships between staff and participants (Table 4). These characteristics underpin the governance, design and approaches of many of the services provided.

#### 3.3.1 | Funding and governance

##### *Dedicated funding streams and adaptation of mainstream funding schemes*

Three models included in this review are funding schemes designed to meet the specific needs of Indigenous peoples. For example, 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, Indigenous organisations and NGOs to administer the program (Indigenous Services Canada, 2019a, 2019b). 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. Meanwhile, *Services Our Way* was an Australian

TABLE 3 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
Biddle et al. (2014)	Not reported	Not reported	Not reported
Dew et al. (2019)	To a large extent	To a large extent	To a large extent
Elsun et al. (2020)	To a large extent	Somewhat	Somewhat
Health Canada and the Public Health Agency of Canada (2013)	Not reported	Not reported	Not reported
Hirji-Khalfan (2009)	Not reported	Not reported	Not reported
Indigenous Services Canada (2019b)	Not reported	Not reported	Not reported
Litmus (2012)	Not reported	Not reported	Not reported
LoGiudice et al. (2012)	To a large extent	To a large extent	Not reported
NPY Women's Council (2018)	To a large extent	To a large extent	To a large extent
Paulin et al. (2015)	Not at all	Not reported	Not reported
PriceWaterhouseCoopers Indigenous Consulting (2018)	Not reported	Not reported	To a large extent
Purple House (2019b)	To a large extent	To a large extent	To a large extent
Raven et al. (2014)	Not reported	To a large extent	Somewhat
Rivalland (2006) <sup>a</sup>	Not reported	Not reported	Not reported
Ryser et al. (2014)	To a large extent	Not reported	Not reported
Smith et al. (2011)	To a large extent	To a large extent	To a large extent
The Canadian Home Care Association (2010)	Not reported	Not reported	Not reported
Tjungurrayi (2015)	To a large extent	To a large extent	To a large extent
Woods et al. (2000)	Not reported	Not reported	To a large extent
Yarmintali Consultancy (2010)	To a large extent	To a large extent	Not reported

<sup>a</sup>Methods are discussed in an unpublished appendix to the report which we were unable to access.

funding scheme for individual care packages, in which funds were provided to individual participants to spend on specific services and equipment from providers of their choice (Raven et al., 2014). Additionally, two models of care comprised mainstream funding schemes with components adapted to meet the specific needs of Indigenous peoples (Paulin et al., 2015; PriceWaterhouseCoopers Indigenous Consulting, 2018).

#### *Indigenous community-controlled organisations*

Five models of social care included in the review are organisational models with mechanisms for local Indigenous communities to participate in their governance (Massey et al., 2018; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation, 2018; Rivalland, 2006). For example, the *Walykumunu Nyinaratjaku* (to live a good life) and *Purple House* models of care developed in Australia are administered by registered Aboriginal Corporations and are governed by boards comprising representatives from the communities they serve. The *Lungurra Ngoora* model, meanwhile, was governed by a steering committee comprising community representatives, service providers and funders (LoGiudice et al., 2012).

#### *Models developed by or in collaboration with indigenous people, communities and organisations*

Models of care included in the review vary in the extent to which Indigenous people, communities and organisations were involved in their development. Three models were developed or initiated by Indigenous people and families (Massey et al., 2018; Tjungurrayi, 2015; Woods et al., 2000). Four further models were developed through consultation processes and/or qualitative research exploring the needs of Indigenous people with disability in the local area (Litmus, 2012; PriceWaterhouseCoopers Indigenous Consulting, 2018; Ryser et al., 2014; Smith et al., 2011). 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; and an evaluation found that local community members did not perceive themselves to be responsible for the model (LoGiudice et al., 2012; Yarmintali Consultancy, 2010).

#### *Flexible and streamlined funding arrangements*

In the two included Canadian funding schemes, local adaptation and place-based initiatives by administering organisations such as



TABLE 4 Characteristics of models of social care for indigenous peoples

Model of care, references	Site, location type	Governance	Development/initiation	Funding arrangements	Social activity services	Personal care services	Language, integration	Workforce strategies
<b>Adaptation of the National Disability Insurance Scheme (NDIS) in the Northern Territory</b> PriceWaterhouseCoopers Indigenous Consultants (2018)	The Northern Territory of Australia; remote and regional areas	Mainstream government funding scheme for individual care packages for people with disability (with a focus on Indigenous participants)	Consultation and workshops with communities and service providers	Place-based services through the pooling of individual government-funded disability insurance 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
<b>Assisted Living Program (in-home care component)</b> Hirji-Khalafan (2009), Indigenous Services Canada (2017), Indigenous Services Canada (2019a)	Canadian First Nations reserves and communities and Inuit communities; remote areas	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 living with a chronic illness or disability	Determined by local/territorial providers
<b>First Nations and Inuit Home and Community Care</b> The Canadian Home Care Association (2010), Health Canada and the Public Health Agency of Canada (2013), Biddle et al. (2014), Indigenous Services Canada (2019b)	Canadian First Nations reserves and communities and Inuit communities; remote areas	Government funding scheme for services in Indigenous communities	Not reported	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
<b>Lungurra Ngoora Community Care Service</b> LoGiudice et al. (2012), Yarmintali Consultancy (2010), Smith et al. (2011)	Looma, Kimberley, Western Australia remote area.	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.

TABLE 4 (Continued)

Model of care, references	Site, location type	Governance	Development/initiation	Funding arrangements	Social activity services	Personal care services	Language, integration	Workforce strategies
<b>Machado-Joseph Disease (MJD) Foundation</b> Massey et al. (2018), Elsum et al. (2020)	Northern Australia, remote and regional areas	NGO 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, corporate and philanthropic donations, governments, etc.	Integrated social/physical activities with everyday life. Men's/women's 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.
<b>Purple House (formerly Western Desert Nganampa Walytja Palyantjaku Tjutaku 'Making all our families well')</b> Rivalland (2006), Jungurrayi (2015), Purple House (2019a, 2019b)	Central Australia (including the Northern Territory, Western Australia, South Australia); remote and regional areas.	Indigenous Community Controlled Organisation	Developed by Indigenous people in response to need that arose in their communities	Funded by Indigenous art sales, mining royalties in Indigenous communities, philanthropic donations, governments	Includes visiting country, 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
<b>Resident Family Care</b> Litmus (2012), Paulin et al. (2015)	New Zealand, all location types.	Government funding scheme to pay family carers for their services, including Maori whanau (extended family) carers	Following a Human Rights Commission case and consultation with families	Payment to family members of people with disability with high care needs, for family care	Not reported	Through payment of family carers	Policy documents specifically include whanau	Paid carers determined by families and whanau
<b>Services for American Indians in the West Cascade Mountain Range region</b> Ryser et al. (2014)	West Cascade Mountain Range region, US. Includes urban and remote areas.	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
<b>Services Our Way</b> NSW Family and Community Services (2012), Raven et al. (2014), Biddle et al. (2014)	Nowra, NSW, Australia regional area.	Government funding scheme for individual care packages for Indigenous people with disability to purchase services and equipment.	Not reported	Participants receive a care package (budget) to be spent on supports for physical, emotional, cultural well-being	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 assists with coordinating, purchasing and administration
<b>Walykumunu Niyinaratjaku (to live a good life)</b> NPY Women's Council (2018), Dew et al. (2019), Woods et al. (2000)	Central Australia, remote	Indigenous Community Controlled Organisation (NPY Women's Council)	Not reported	Government funding	Not reported	Through financial and non-financial support for family carers.	Organisation also provides other social and community services. Disability services provided by Tjungu ('all together') team.	Indigenous and non-Indigenous staff paired through 'malparara way' co-mentoring process.

Tribal and Band Councils and territorial governments are expected and encouraged (The Canadian Home Care Association, 2010). In the *First Nations and Inuit Home and Community Care Program*, funds from two government departments are pooled within the scheme (Biddle et al., 2014). In contrast, in Australia, a study of the *Walykumunu Nyinaratjaku (to live a good life)* 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, was funded by a complex mix of government funding and funding from three other service providers which previously provided direct services to the community (LoGiudice et al., 2012). An independent evaluation found that this funding model made administering the service extremely complex and 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 Australian organisational models of care reported drawing on a range of government and non-government funding sources such as philanthropic funds, corporate donations, mining royalties and Indigenous art sales. The literature published on both models of care suggests that non-government funding sources offered the organisations considerable flexibility to develop models which responded to the specific needs of participants (Massey et al., 2018; Purple House, 2019b; Rivalland, 2006).

### 3.3.2 | Service delivery design and approaches

#### *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 place-based initiatives. Social activities included visiting country, fishing, painting and preparing customary medicines (LoGiudice et al., 2012; Purple House, 2019a; Yarmintali Consultancy, 2010). In the *Machado-Joseph Disease (MJD) Foundation* model, the organisation's 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 and carrying groceries (Massey et al., 2018). Activities are often carried out in gender-specific groups of family members rather than groups of individual participants with MJD.

#### *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 caregiving. 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). Three models included measures to support family carers, as an alternative to the provision of personal care by professional carers, in order to respect social roles in families associated with caregiving (Massey et al., 2018; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation, 2018; Ryser et al., 2014). Support provided to carers in these models includes material assistance such as provision of bedding and fuel subsidies, cleaning services and respite. A qualitative study of the *Walykumunu Nyinaratjaku (to live a good life)* model reported that support for carers was well received by participating Indigenous families; however, 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). The Aotearoa New Zealand *Funded Family Care* scheme, meanwhile, provides remuneration to family carers including Maori whānau (extended family) carers (Litmus, 2012). An evaluation of the scheme found it reduced household financial stress and provided carers with valued recognition of their roles (Paulin et al., 2015).

#### *Inclusive and integrative approaches*

All models of care included in the review avoid using the term 'disability'. Five of the 10 models integrate social care for people with disability with other related services including medical services (four models), aged care (two services) and mental health support (one service). Four models have adopted inclusive terms from Indigenous languages to name their programs (see Table 4) (LoGiudice et al., 2012; Rivalland, 2006; Woods et al., 2000).

#### *Workforce strategies to support relationships between staff and participants*

While several models of care aimed to support family carers, nine of the models reviewed also adopted a range of specific strategies to employ Indigenous people from the communities in which they operate. Three models sought to employ Indigenous people from their communities of operation with lived experience of disability (Massey et al., 2018; Purple House, 2019b; Raven et al., 2014). Three models of care employed local Indigenous staff on the basis of their social roles in families and communities. A further two models drew local Indigenous staff from employment programs associated with social security systems (LoGiudice et al., 2012; PriceWaterhouseCoopers Indigenous Consulting, 2018). An independent evaluation of the *Lungurra Ngoora* model, which attempted to integrate the social roles of Indigenous staff into work roles in personal care services and engaged staff from an employment program, reported that this approach succeeded in employing local Indigenous people, ensured that personal care was provided to participants by the staff of an appropriate gender and kinship relationship to them, 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 their own families.

Three models adopted strategies for developing collaborative relationships between Indigenous and non-Indigenous personnel, and between non-Indigenous personnel and participants. Both the *Walykumunu Nyinaratjaku (to live a good life)* 'malparara way' and the *MJD Foundation* 'two ways' approaches paired local Indigenous staff with non-Indigenous colleagues 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).

## 4 | DISCUSSION

Understanding promising practice in models of community-based social care for Indigenous people with disability can assist governments, funding bodies, service providers and Indigenous communities to develop culturally safe services. We have synthesised the key characteristics of published models of social care for Indigenous peoples in Australia, Aotearoa New Zealand, Canada and the United States. We have identified 10 models of care. Across these 10 models, we have described nine key characteristics within two over-arching themes (funding and governance; and service delivery design and approaches) (Table 4). The integral nature of the involvement of Indigenous tribes, nations and communities in governance approaches, the facilitation of cultural safety and in building the workforce is a thread that ties together all characteristics.

Indigenous approaches to social care contrast with dominant models of social care in high-income states with dominant White populations (Table 1). Indigenous models of care foreground Indigenous identity and need as a basis for providing services while de-emphasising disability, whereas Western approaches foreground disability. In Anglo-Saxon model, furthermore, eligibility is also often based on economic deprivation. While family caregiving is central to many Indigenous models, as with the family care/Mediterranean model, several Indigenous models integrate family care within disability services through various forms of support to caregivers, rather than imposing distinctions between formal and informal, non-remunerated caregiving. However, the Indigenous models we have described are operationalised within the governance structures of Anglo-Saxon models of care and are largely funded by centralised government funding sources. This may impact on the ability of Indigenous tribes, nations and communities to exercise autonomy in the development of their own models of care, as we will discuss further below. Our findings add further weight to the calls of Indigenous disability peak bodies and other advocacy organisations for the need to support Indigenous communities to develop their own models of care (First Peoples Disability Network, 2020; National Council on Disability, 2003).

In this section, we describe the evidence for promising practice in community-based social care for Indigenous people with

disabilities and discuss the implications. However, our analysis is limited by the heterogeneity and quality of the studies included in our review. As noted above, included models vary considerably in structure, governance arrangements and in their location in service systems, and some components of individual models of care are not well documented in the included sources. Of the 10 included models of care, two have not yet been pilot tested or implemented, and only five have been fully independently evaluated, using a range of methodologies (Appendix S1).<sup>1</sup> A further two models of care have been subject to other studies exploring service participants' perspectives and experiences (Appendix S1).

For these reasons, in the following we have adopted a holistic approach to analysing promising practice within the two over-arching themes of funding and governance and service delivery design and approaches. We have conceptualised each included model of care as an individual case study, with the interaction of various characteristics of each model and local contextual factors understood as contributing to reported outcomes. We have analysed included models by centring the responses of Indigenous communities in which models operate, where documented.

### 4.1 | Funding and governance

We have shown that the broader funding and governance structures of social care services, as well as specific mechanisms within services for participatory governance, can shape the possibilities for Indigenous participation. While perhaps unsurprising, this is also supported by the literature on Indigenous models of healthcare. Harfield et al. (2015), in their scoping review of Indigenous primary healthcare models, report that Indigenous ownership and governance, opportunities for community engagement and involvement of elders are all critical to Indigenous models.

Our analysis suggests that disability 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 families and communities in governance and funding allocations. For example, the *Services Our Way* model was designed to meet the specific needs of Indigenous people with disability through individual care packages, however the program appeared to lack opportunities for participatory governance, and the role of Indigenous organisations appears to have been limited to program administration (NSW Family & Community Services 2012). The adaptation of the National Disability Insurance Scheme in Australia's Northern Territory, meanwhile, would enable participants in a given community to pool their care packages and collectively determine the services to be provided to their community, representing a shift away from an individual care package approach (PriceWaterhouseCoopers Indigenous Consulting, 2018). This proposed reform has not been taken up by Australia's National Disability Insurance Agency to date, however. It has also been reported elsewhere that individual care packages may not reflect Indigenous norms of collective

decision-making as they contain few opportunities for local decision-making by Indigenous tribes, nations and communities (Amery et al., 2020: 506; Gilroy et al., 2020).

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 Program* 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, meanwhile, demonstrated that insufficient and siloed government funding streams could ultimately lead to the failure of Indigenous models of care.

Two models 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 to 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 outcomes suggest that dedicated funding streams for disability services for Indigenous people are required in order to develop services that reflect Indigenous values and norms. The development of culturally safe care requires appropriate funding sources and funding programs that reflect an appropriate program logic, in addition to organisational structures among funders and service providers that enable participatory governance. These findings are consistent with literature on the conceptualisations and experiences of disability among Indigenous peoples, which shows 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 (King et al., 2014; Varvarezou, 2020).

There is some evidence that Indigenous governance of social care services can be conceptualised not only as pertaining to governance structures, but also as encompassing 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 relate to the manner in which models are developed, as well as formal governance structures. 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 Disability Network Australia, 2018).

## 4.2 | Service delivery design and approaches

Several of the included models of care discussed in this review disassociate themselves from Western constructs of disability and care. Through the integration of social care for people with disability with other services, and through the organisation of social activities through family groups, some models avoid casting participants as 'disabled'. Indigenous models also avoid the term 'disability', adopt Indigenous terms in program names and position social care in ways that resonate with Indigenous participants. These approaches respond to the widely reported lack of resonance of Western concepts of 'disability' among Indigenous populations; and stigmatising experiences of diagnostic labels among Indigenous people (Avery, 2018; Bevan-Brown, 2013; Juutilainen et al., 2019).

The models of care examined in this review demonstrate attempts to recognise and support Indigenous practices and values associated with caregiving. Support for family caregiving reflects the international literature on Indigenous practices of care, in which caregiving is described as a valued contribution to family life and an important social role in many Indigenous societies, particularly, but not exclusively, for women (Brannelly et al., 2013; Jolliffe & Worland, 2018; Pearce, 2000; Pollak, 2017). 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 reporting on the *Walykumunu Nyinaratjaku (to live a good life)* model discussed above illustrates that support for caregivers can be desirable to families but impeded by government funding guidelines, further emphasising the need for funding schemes to reflect the social care needs and expectations of Indigenous families and communities.

While financial relief for carers and people with 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 disability and their carers, and that eligibility criteria may not reflect Indigenous practices of collective caregiving (Soldatic, 2018). 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 (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 disability through support for 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 generally adopt a universal approach to financial support.

In some of the included models, workforce strategies are connected to strategies to support family carers, inclusive approaches and attempts to develop appropriate social activities and personal care services. We identified four distinct workforce strategies: recruiting Indigenous staff with disabilities in peer support roles; integrating the work roles of Indigenous staff with their social roles in

families and communities; recruiting Indigenous staff from employment programs; and specific strategies to develop relationships between non-Indigenous staff and other staff and participants. There is some convergence between these findings and a narrative review undertaken by Gilroy et al. (2017) on workforce strategies for delivering disability services to First Nations people living in Australian rural and remote communities. The three key workforce strategies identified by Gilroy and colleagues, of community-based models of care, cultural competency training for non-Indigenous staff and developing a local Indigenous workforce, further illustrate the interconnectedness of workforce strategies with the overall design and approach of models of care.

There is limited evidence of the outcomes of the recruitment strategies we identified in this review. However, an independent evaluation of the *Lungurra Ngoora* model suggests positive outcomes for staff and service participants as a result of the integration of the social roles of Indigenous staff into work roles in personal care services (Yarmintali Consultancy, 2010). 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. The literature on the employment of Indigenous health workers in Indigenous healthcare services also suggests that workforce strategies in Indigenous services must attend to developing clear work roles and addressing issues of staff over-burden (Human Capital Alliance, 2009; Topp et al., 2018). Integrative workforce strategies, in particular, require local Indigenous people to be involved in developing, governing and managing models of care. The employment of staff in social care services through social security employment programs, also a characteristic of the *Lungurra Ngoora* model, may not guarantee that staff and participants are always in an appropriate gender and kinship relation, and raises issues of appropriate remuneration.

Some included models developed extensive strategies for developing respectful, culturally appropriate relationships between non-Indigenous and Indigenous staff; and non-Indigenous staff and participants. Cultural competency training was identified as a key workforce strategy by Gilroy et al. (2017), but was only described in one model included in our review. This may reflect research evidence showing that cultural competency training alone does not result in improved cultural competence in health services for Indigenous people (Bainbridge et al., 2015). The approach of mutual knowledge sharing and support between Indigenous and non-Indigenous staff described in two models reported in this review goes beyond traditional approaches to cultural competency and attempts to embed intercultural ways of working in practice. Such approaches are worthy of further research and evaluation.

### 4.3 | Limitations

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 2; Appendices S1 and S2). There may be further innovative, culturally safe models of social care that have not yet been documented, published and included in research or policy databases. This lack of documentation may be influenced by the low-resource environments that our results suggest characterise disability services in some states. The small size of the research field limits our capacity to assess whether the included models and their specific components are widespread.

An appraisal of methodological rigour and evidence-based practice is not typically performed in a systematic scoping review, in which the intent is to report on the range of current practice and to provide a descriptive synthesis in a specific field, and in which emerging practice is often a focus (Peters et al., 2015; Tricco et al., 2018). While we assessed promising practice, further research is needed to assess the outcomes of the specific social care service characteristics we have identified. However, future systematic reviews and evidence syntheses may need to await improvements in the quantity and quality of studies and evaluations.

## 5 | CONCLUSION

Models of care for Indigenous people with disability have emerged in response to the inappropriateness of mainstream models and low levels of access by Indigenous populations. However, little is known about the characteristics of Indigenous models, or their appropriateness and effectiveness. We have documented 10 community-based models designed to meet the social care needs of Indigenous people with disability in Australia, Aotearoa New Zealand, Canada and the United States. Although these models are diverse, our synthesis has described nine key, interconnected characteristics across the 10 models that underpin their funding arrangements, governance structures and services. We have discussed the weak evidence of the effectiveness and impact of the nine characteristics due to a lack of research and evaluation and methodological issues, while also identifying areas of promising practice.

Our findings suggest that specific elements of the governance structures and funding arrangements for social care services may enable services to address Indigenous participants' needs and values. These elements include dedicated, flexible funding streams for disability services for Indigenous peoples, mechanisms for Indigenous communities to have substantial involvement in governance at a local or regional level, and the development of Indigenous-led or co-designed approaches. We have also described promising practice in social care services that offer contextually relevant place-based social activity programs, support and remunerate family carers and have mechanisms for integrating of kinship relationships and social roles into workforce strategies. These characteristics may reflect values and practices associated with social participation and caregiving in many Indigenous societies. Our synthesis shows a need for future inquiry into the structural, organisational and practice-based factors that support Indigenous involvement in social care services, and for robust evaluations of

community-based approaches to social care for Indigenous people. Nevertheless, disability funding bodies and service systems that facilitate the areas of promising practice we have identified may improve the accessibility of social care for Indigenous peoples.

#### AUTHORS' CONTRIBUTION

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

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#### CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

#### DATA AVAILABILITY STATEMENT

Data sharing not applicable—no new data generated.

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#### ENDNOTE

<sup>1</sup> 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.

#### REFERENCES

- Amery, R., Wunungmurra, J. G., Gondarra, J., Gumbula, F., Raghavendra, P., Barker, R., Theodoros, D., Amery, H., Massey, L., & Lowell, A. (2020). Yolŋu with Machado-Joseph disease: Exploring communication strengths and needs. *International Journal of Speech-Language Pathology*, 22, 499–510.
- Anttonen, A., & Sipilä, J. (1996). European social care services: Is it possible to identify models? *Journal of European Social Policy*, 6(2), 87–100.
- Ariotti, L. (1999). Social construction of Anangu disability. *Australian Journal of Rural Health*, 7, 216–222.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Avery, S. (2018). *Culture is inclusion: A narrative of aboriginal and Torres Strait islander people with a disability*. First Peoples Disability Network.
- Bainbridge, R., McCalman, J., Clifford, A., & Tsey, K. (2015). *Cultural competency in the delivery of health services for indigenous people*. Australian Institute of Health and Welfare and Australian Institute of Family Studies, prepared for the Closing the Gap Clearinghouse.
- Baldock, J. (1997). Social Care in old age: More than a funding problem. *Social Policy and Administration*, 31(1), 73–89.
- Bambra, C. (2007). Going beyond the three worlds of welfare capitalism: Regime theory and public health research. *Journal of Epidemiology & Community Health*, 61(12), 1098–1102. <https://doi.org/10.1136/jech.2007.064295>
- Bevan-Brown, J. (2013). Including people with disabilities: An indigenous perspective. *International Journal of Inclusive Education*, 17(6), 571–583.
- Biddle, N., Al-Yaman, F., Gourley, M., Gray, M., Bray, J., Brady, B., Pham, L. A., Williams, E., & Montaigne, M. (2014). *Indigenous Australians and the National Disability Insurance Scheme*. Centre for Aboriginal Economic Policy Research.
- Brannelly, T., Boulton, A., & te Hiini, A. (2013). A relationship between the ethics of care and Māori worldview—The place of relationality and care in Maori mental health service provision. *Ethics and Social Welfare*, 7(4), 410–422. <https://doi.org/10.1080/17496535.2013.764001>
- Canadian Homelessness Research Network. (2013). *What works and for whom? A hierarchy of evidence for promises practices research*. The Homeless Hub Papers No. 5. Canadian Homelessness Research Network Press.
- Conway, J., & Higgins, I. (2011). *Literature Review: Models of care for pain management*. NSW Government. [https://aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0006/159846/Pain\\_MOC.pdf](https://aci.health.nsw.gov.au/_data/assets/pdf_file/0006/159846/Pain_MOC.pdf)
- Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *British Journal of Sociology*, 51(2), 281–298.
- Davidson, P., Hickman, L., Graham, B., Halcomb, E., & Phillips, J. (2006). Beyond the rhetoric: What do we mean by a 'model of care'? *Australian Journal of Advanced Nursing*, 3(23), 47–55.

- Dew, A., Barton, R., Gilroy, J., Ryall, L., Lincoln, M., Jensen, H., Flood, V., Taylor, K., & McCrae, K. (2019). Importance of land, family and culture for a good life: Remote aboriginal people with disability and carers. *Australian Journal of Social Issues*, 5(5), 418–438.
- Elsum, I., Massey, L., McEwan, C., LaGrappe, D., Kowal, E., Savarirayan, R., Baynam, G., Jenkins, M., Garvey, G., & Kelaher, M. (2020). A community-based co-designed genetic health service model for aboriginal Australians. *PLoS One*, 15(10), e0239765.
- First Peoples Disability Network Australia. (2018). *Ten priorities to address disability inequity*. First Peoples Disability Network Australia. <https://fpdn.org.au/wp-content/uploads/2018/10/FPDN-ten-priorities-2018.pdf>
- First Peoples Disability Network. (2020). *Living our ways: A community-driven Aboriginal and Torres Strait Islander disability research program*. Prepared by Avery, S. First Peoples Disability Network Australia. <https://apo.org.au/node/312483>
- Gilroy, J., Dew, A., Barton, R., Ryall, L., Lincoln, M., Taylor, K., Jensen, H., Flood, V., & McRae, K. (2020). Environmental and systemic challenges to delivering services for aboriginal adults with a disability in Central Australia. *Disability and Rehabilitation*, 43, 2919–2929. <https://doi.org/10.1080/09638288.2020.1725654>
- Gilroy, J., Dew, A., Lincoln, M., & Hines, M. (2017). Need for an Australian indigenous disability workforce strategy: Review of the literature. *Disability and Rehabilitation*, 39(16), 1664–1673.
- Harfield, S., Davy, C., Kite, E., McArthur, A., Munn, Z., Brown, N., & Brown, A. (2015). Characteristics of indigenous primary health care models of service delivery: A scoping review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, 13(11), 43–51. <https://doi.org/10.11124/jbisrir-2015-2474>
- Harfield, S., Pearson, O., Morey, K., Kite, E., & Canuto, C. (2020). Assessing the quality of health research from an indigenous perspective: The aboriginal and Torres Strait islander quality appraisal tool. *BMC Medical Research Methodology*, 20(1), 79.
- Health Canada and the Public Health Agency of Canada. (2013). *Evaluation of the First Nations and Inuit Home and Community Care Program 2008-2009 and 2011-2012*. Government of Canada. <https://www.canada.ca/en/health-canada/corporate/about-health-canada/accountability-performance-financial-reporting/evaluation-reports/evaluation-first-nations-inuit-home-community-care-program-2008-2009-2011-2012.html>
- Hirji-Khalfan, R. (2009). Federal supports for aboriginal people with disabilities. *Critical Disability Discourses*, 1, 1–25.
- Human Capital Alliance. (2009). *Aboriginal health worker professional review: Final report*. Northern Territory Department of Health and Families.
- Huria, T., Palmer, S. C., Pitama, S., Beckert, L., Lacey, C., Ewen, S., & Tuhiwai Smith, L. (2019). Consolidated criteria for strengthening reporting of health research involving indigenous peoples: The CONSIDER statement. *BMC Medical Research Methodology*, 19(173), 173.
- Indigenous Services Canada. (2017). *National Assisted Living Program Guidelines 2018-2019*. Government of Canada. <https://www.sac-isc.gc.ca/eng/1513269018171/1533317534749>
- Indigenous Services Canada. (2019a). *Assisted Living National Program Guidelines 2019 to 2020*. <https://www.sac-isc.gc.ca/eng/1557149461181/1557149488566>
- Indigenous Services Canada. (2019b). *Evaluation of the first nations and Inuit home and community care program*. Government of Canada. <https://www.sac-isc.gc.ca/eng/1568295261442/1568295302724>
- Jolliffe, P., & Worland, S. (2018). Honouring the elders: The common good among Karen communities - a multi-sited ethnography. *The Australian Journal of Anthropology*, 29(2), 158–170.
- Juutilainen, S. A., Jeffrey, M., & Stewart, S. (2019). Methodology matters: Designing a pilot study guided by indigenous epistemologies. *Human Biology*, 91(3), 141–151.
- King, J. A., Brough, M., & Knox, M. (2014). Negotiating disability and colonisation: The lived experience of indigenous Australians with a disability. *Disability & Society*, 29(5), 738–750.
- Levac, D., Colquhoun, H., & O'Brien, C. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5, 69. <https://doi.org/10.1186/1748-5908-5-69>
- Litmus. (2012). *Consultation on paying family Carers to provide disability support: Summary report*. New Zealand Ministry of Health. <https://www.health.govt.nz/publication/consultation-paying-family-carer-s-provide-disability-support-summary-report>
- LoGiudice, D. C., Smith, K., Shadforth, G., Lindeman, M., Carroll, E., Atkinson, D., Schaper, F., Lautenschlager, N., Murphy, R., & Flicker, L. (2012). Lungurra Ngoora - a pilot model of care for aged and disabled in a remote aboriginal community - Can it work? *Rural and Remote Health*, 12, 2078.
- Malley, J., Towers, A., Netten, A., Brazier, J., Forder, J., & Flynn, T. (2012). An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people. *Health and Quality of Life Outcomes*, 10, 21.
- Massey, L., LaGrappe, D., Doherty, M., Cullen, J., & Lindrop, N. (2018). *MJD foundation - disability service delivery model*. MJD Foundation, Alyangula. <https://www.apreview.gov.au/your-ideas/submission/s/mjd-foundation>
- National Council on Disability. (2003). *Understanding disabilities in American Indian & Alaska native communities: Toolkit guide*. National Council on Disability. <https://ncd.gov/publications/2003/Aug12003>
- Newbold, K. (1999). Disability and use of support services within the Canadian aboriginal population. *Health & Social Care in the Community*, 7(4), 291–300.
- Newman, J., Glendinning, C., & Hughes, M. (2008). Beyond modernisation? Social care and the transformation of welfare governance. *Journal of Social Policy*, 37(4), 531–557.
- Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council Aboriginal Corporation. (2018). *Walykumunu Nyinaratjaku (to live a good life)*. NPY Women's Council. <http://www.npywc.org.au/wp-content/uploads/Walykumunu-Nyinaratjaku-October-2018.pdf>
- NSW Family & Community Services. (2012). *Services Our Way: Delivering to Aboriginal people with a disability. A NSW packaged Support Program Guidelines. Version 2.0*. NSW Family & Community Services.
- Paulin, J., Carswell, S., & Edgar, N. (2015). *Evaluation of funded family care*. New Zealand Ministry of Health. <https://www.health.govt.nz/system/files/documents/publications/evaluation-funded-family-care-aug15.pdf>
- Pearce, T. (2000). Being an indigenous Carer. *Aboriginal & Islander Health Worker Journal*, 24(1), 21–22.
- Peters, M., Godfrey, C., Khalil, H., McInerney, P., Parker, D., & Baldini Soares, C. (2015). Guidance for conducting systematic scoping reviews. *International Journal for Evidence-Based Healthcare*, 14, 141–146.
- Pollak, M. (2017). Care in the context of a chronic epidemic: Caring for diabetes in Chicago's native community. *Medical Anthropology Quarterly*, 32(2), 196–213. <https://doi.org/10.1111/maq.12405>
- PriceWaterhouseCoopers Indigenous Consulting. (2018). *Community planning for the National Disability Insurance Scheme (NDIS) in the Northern Territory*. PriceWaterhouseCoopers Indigenous Consulting. <https://digitallibrary.health.nt.gov.au/prodjsui/bitstream/10137/7209/1/Community%20Planning%20for%20the%20National%20Disability%20Insurance%20Scheme%20%28NDIS%29%20in%20the%20Northern%20Territory.PD>
- Purple House. (2019a). *Our Story*. <https://www.purplehouse.org.au/our-story>
- Purple House. (2019b). *Panuku renal patient preceptors workforce development project report*. Purple House. [https://www.purplehouse.org.au/wp-content/uploads/2019/04/Purple-House\\_Panuku\\_web-2.pdf](https://www.purplehouse.org.au/wp-content/uploads/2019/04/Purple-House_Panuku_web-2.pdf)



- Puszka, S., Walsh, C., Markham, F., Barney, J., Yap, M., & Dreise, T. (2022). Towards the decolonisation of disability: A systematic review of disability conceptualisations, practices and experiences of first nations people of Australia. *Social Science & Medicine*, 305, 115047. <https://doi.org/10.1016/j.socscimed.2022.115047>
- Raven, M., Bates, S., Kayess, R., Fisher, K. R., & Hill, T. (2014). *Evaluation of Services Our Way*. Social Policy Research Centre, University of New South Wales. <https://www.sprc.unsw.edu.au/research/projects/services-our-way-southern-region-program-evaluation/>
- Rees, P. B. (2003). *The Need to Know: A Report on Disability and the Aboriginal Communities of South Australia*. Aboriginal Health Council of South Australia.
- Rivalland, P. (2006). "It's more than machines and medicine - they should understand there's a Yanangu way". Providing kidney dialysis services to Yanangu, Indigenous people from the Western Desert. Western Desert Nganampa Walytja Palyantjaku Tjutaku, Alice Springs. <https://www.lowitja.org.au/content/Document/PDF/WDNWPT%20report%202006.pdf>
- Ryser, R., Korn, L., & Berridge, C. (2014). American Indian caregivers policy: A case study. *Fourth World Journal*, 13(1), 107-138.
- Senior, K. (2000). *Testing the ICDH-2 with indigenous Australians: Results of field work in two Aboriginal communities in the Northern Territory*. Australian Institute of Health and Welfare, ICDH Collaborating Centre and the Department of Health and Family Services.
- Sipila, J. (Ed.). (2018). *Social care services: The key to the Scandinavian welfare model*. Routledge.
- Smith, K., Flicker, L., Shadforth, G., Carroll, E., Ralph, N., Atkinson, D., Lindeman, M., Schaper, F., Lautenschlager, N. T., & LoGiudice, D. (2011). 'Gotta be sit down and worked out together': Views of aboriginal caregivers and service providers on ways to improve dementia care for aboriginal Australians. *Rural and Remote Health*, 11(2), 1650.
- Soldatic, K. (2018). Policy mobilities of exclusion: Implications of Australian disability pension retraction for indigenous Australians. *Social Policy and Society*, 17(1), 151-167. <https://doi.org/10.1017/s1474746417000355>
- Temple, J., Wong, H., Ferdinand, A., Avery, S., Paradies, Y., & Kelaher, M. (2020). Exposure to interpersonal racism and avoidance behaviours reported by aboriginal and Torres Strait islander people with a disability. *Australian Journal of Social Issues*, 55, 376-395.
- The Canadian Home Care Association. (2010). *Mind body Spirit: Promising practices in first nations and Inuit home and community care*. The Canadian Home Care Association. [https://cdnhomecare.ca/wp-content/uploads/2017/08/FNIHB\\_Promising\\_Practices\\_April\\_2010\\_-\\_Final\\_English.pdf](https://cdnhomecare.ca/wp-content/uploads/2017/08/FNIHB_Promising_Practices_April_2010_-_Final_English.pdf)
- Tjungurrayi, P. (2015). *Beyond Borders*. UWA Publishing.
- Topp, S., Edelman, A., & Taylor, S. (2018). "We are everything to everyone": A systematic review of factors influencing the accountability relationships of aboriginal and Torres Strait islander health workers (AHWs) in the Australian health system. *International Journal for Equity in Health*, 17(1), 67.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garrity, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467-473. <https://doi.org/10.7326/M18-0850>
- Varvareizou, D. M. (2020). *Interactions in Healthcare: Social Perceptions and Experiences of Physical Disability Among Diné Individuals With Physical Disabilities, Family Members, and Diné/Non Indigenous Service Providers and Healthcare Workers*. (PhD), Arizona State University, Arizona.
- Woods, W., Wanatjura, E., Colin, T., Mick, J., Lynch, A., & Ward, N. (2000). Atunypa Wiru Malparara Malparara: The strength of working together. In W. Weeks & M. Quinn (Eds.), *Issues facing Australian families: Human services respond* (3rd ed., pp. 91-100). Longman.
- World Health Organisation. (2002). *Towards a common language for functioning, disability and health*. World Health Organisation. [https://cdn.who.int/media/docs/default-source/classification/icf/icfbe-ginnersguide.pdf?sfvrsn=eead63d3\\_4&download=true](https://cdn.who.int/media/docs/default-source/classification/icf/icfbe-ginnersguide.pdf?sfvrsn=eead63d3_4&download=true)
- Yarmintali Consultancy. (2010). *Lungurra Ngoora community care service evaluation report*. Prepared by Rhonda Murphy. Yarmintali Consultancy.

## SUPPORTING INFORMATION

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

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