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NARRATIVE REVIEW

A scoping review of early childhood support for Aboriginal and Torres Strait Islander children living with a disability in regional, rural and remote settings

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Abstract

Introduction: Many experts and communities have concerns about how National Disability Insurance Scheme services are provided to Aboriginal and Torres Strait children. This study was undertaken at the request of the NPY Women's Council in partnership with the researchers, to explore supports for Aboriginal and Torres Strait Islander children living with a disability in their remote areas.

Objective: This scoping review aims to (a) explore the barriers and enablers to accessing disability support services for families of young Aboriginal and Torres Strait Islander children (0–8 years) living in regional, rural and remote settings, and (b) summarise best practice approaches for accessing support for young children in these settings.

Design: The search was run in three electronic databases, as well as grey literature sources. We assessed the quality of included publications using the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange tool. A narrative synthesis was supported by thematic analysis.

Findings: From an initial search (557 citations), we identified 13 eligible documents. Most documents were peer-reviewed articles of qualitative studies. Key themes identified included the following: (1) Holistic approach, (2) Understanding disability, (3) Consistent relationships, (4), Flexibility, (5) Simplify system and (6) Enhance communication.

Discussion/Conclusion: This scoping review has revealed gaps in the provision of quality, culturally responsive disability services for families of Aboriginal and Torres Strait Islander children living in regional, rural and remote areas of Australia. A family-centred, flexible approach will help address their needs. Future research is required to design and evaluate models of care for Aboriginal and Torres Strait Islander children.

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KEYWORDS

Aboriginal and Torres Strait Islander Health, Aboriginal and Torres Strait Islander peoples, Access issues, Developmental Delay, Disability, Disability Services, Rural/Remote services

1 | BACKGROUND

Around one in six Australians currently experiences disability.[1] People living with a disability have a physical, mental, intellectual or sensory impairment that affects their ability to perform everyday tasks, such as self-care, mobility and communication.[2] Disability can have a profound impact on a person's overall quality of life, and the use of specialist disability support services is fundamental to improving overall outcomes.[3] These services aim to empower individuals with disability to live their best lives as independently as possible, while also ensuring their health, safety and well-being. Disabilities affect individuals from all demographic and socio-economic groups; it is estimated that around 7.7% of Australian children under the age of 15 live with some form of disability.[4] However, Aboriginal and Torres Strait Islanders children are 1.9 times more likely to live with a disability than non-Indigenous children.[5]

Funding for disability services has undergone major reform in Australia over the last decade. In 2013, the Australian Federal Government introduced the National Disability Insurance Scheme (NDIS), the largest reform of the Australian disability services sector to date.[6] This national initiative was developed to improve the model of funding for people living with a disability. The NDIS has moved away from funding organisations, to allocating individual support packages based on functional needs, hence, ideally, promoting greater individual choice and autonomy.[7] Prior to the NDIS, supports for young children with developmental difficulties or disability (known then, as Early Childhood Intervention Services) were largely provided through government-controlled block funding of specialist disability services.[8] Responsibility for early childhood intervention services moved to the NDIS following rollout of the scheme.

The early intervention system for children continues to undergo change. The NDIS adopted the Early Childhood Early Intervention (ECEI) approach to support children under the age of 7 years, a design informed by the national guidelines developed by the Early Childhood Intervention Australia (ECIA) in 2016.[9] However, there were concerns about the ECEI approach, including gaps in implementation, and it again changed, to the 'Early Childhood Approach' (ECA).[10] While the NDIS claims the ECA adopts best practice, prioritising family-centred and strength-based approaches, this is not always observed in practice. Best practice in early intervention is relationship based and needs to be tailored for the child and family.[11] However, there are often very limited options, and this is especially the case for Aboriginal and Torres Strait Islander families living in remote regions.[12–14]

The experience of Aboriginal and Torres Strait Islander people participating in disability services has been explored more recently. Many experts have concerns about the way NDIS services are being provided in Australia, particularly for Aboriginal and Torres Strait families living in regional, rural and remote (RRR) communities.[15–18] Various factors have been found to influence Aboriginal and Torres Strait families' participation in disability services in remote settings. Gilroy et al. (2016) found that many families do not actively seek information or support because of the way disability is conceptualised within communities, meaning that the term 'disability' may not be accepted or used due to its different cultural perception.[19] Shame and stigma have been associated with the mainstream definition of disability as a deficit. Moreover, the legacies of colonialism, systemic racism and associated intergenerational

What is already known on this subject

- Aboriginal and Torres Strait Islander children and families experience multiple and concurrent challenges in accessing disability support services, especially those living in regional, rural and remote regions.
- Aboriginal and Torres Strait Islander children are 1.9 times more likely to live with a disability compared with non-Indigenous children.

What this paper adds

- The gaps in disability services for families of young Aboriginal and Torres Strait Islander children living in regional, rural and remote areas of Australia are impacting the quality, cultural responsiveness and timeliness of support.
- A family-centred, flexible and holistic approach to disability support services is needed that includes enhanced communication with families and maintenance of culturally responsive and consistent relationships.

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trauma have eroded trust in mainstream services.[19] A systematic review of Aboriginal and Torres Strait Islander engagement with disability services found that intersectional disadvantage, grounded in race and disability, is a significant factor.[17] Despite the reported need, Aboriginal and Torres Strait Islander children continue to experience multiple and concurrent challenges in accessing disability support services.[19]

Scoping the existing evidence to show what constitutes the best mix of supports for Aboriginal and Torres Strait Islander children living with a disability in RRR areas is essential. This will strengthen efforts to advocate for flexible and culturally safe services and recognise that families are unique.[10] This scoping review was undertaken at the request of the NPY Women's Council as a partnership project with researchers from the University of Melbourne and the University of Sydney. We present a synthesis of the literature and identify key themes relating to how services best support young Aboriginal and Torres Strait Islander children (0–8 years of age) who have developmental difficulties/delay or are living with a disability in remote settings to achieve 'proper way' help and enable them to 'live a good life'. This scoping review aims to (a) explore the barriers and enablers to accessing disability support services for families of young Aboriginal and Torres Strait Islander children living in RRR settings, and (b) summarise the evidence relating to best practice approaches for families accessing support for young children in these settings.

2 | METHODS

We undertook a scoping review and adopted Arksey's and O'Malley's a five-stage framework.[20] Steps 1–4 are outlined here. Step 5 is outlined in the Results section.

2.1 | Step 1: Development of the research question

Our research question was developed in partnership between the researchers and the NPY Women's Council: *How can support services best help young Aboriginal and Torres Strait Islander children (0–8 years) who have developmental difficulties/delays or are living with a disability in remote settings to achieve 'proper way help' to enable them to 'live a good life'*? '*Proper way help*' and '*live a good life*' are phrases taken from the collaborative research project *Walykumunu Nyinaratjaku: To Live a Good Life*, which examined what makes a good life for Aboriginal people with a disability from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Lands. This NPY Women's Council (NPYWC) report defined '*proper way help*' as culturally appropriate and responsive support.[21]

2.2 | Step 2: Identification of studies/documents

Subject categories and key search terms were identified with assistance from an academic librarian. The search was run in three electronic databases (Ovid Medline, PubMed, and CINAHL), and we also searched for grey literature sources (Google, Australian Indigenous HealthInfoNet, Australian Institute of Family Studies, and the National Disability Insurance Agency). We adapted and filtered the initial search strategy according to the requirements and constraints for each database or website. Search terms were Medical Subject Headings (MeSH) terms and keywords including derivatives of the following terms: 'services', 'support', 'intervention', 'child', 'disability', 'Aboriginal' and 'Indigenous' (Appendix S1). The search was performed in October 2022, and updated in August 2023 with no date or language limits applied.

2.3 | Step 3: Selecting the studies/documents for inclusion

To be included (Table 1), documents had to describe or report, in some detail (greater than two paragraphs of text), on the provision of support services:

- for Aboriginal and Torres Strait Islander children (0–8 years of age);
- living with developmental delay/difficulties, or a disability; and
- in regional, rural or remote (RRR) areas.

The focus was on the early childhood period (0–8 years) because this covers the age group that accesses the ECA services relevant to the community partner. This scoping review used the NDIS eligibility criteria, which refers to a person living with a disability as '*needing support with activities of daily living due to a temporary or lifelong impairment*'.[22] The use of the term disability herein is inclusive of intellectual disability, sensory impairment and physical disability, and also encompassed developmental delay or difficulties. Our definition of RRR is based on the Australian Standard Geographical Classification (ASGS) classification.[23] Table 1 details eligible study designs and publication types that were excluded. Studies that included children as part of a broader population were included.

The search initially yielded 557 citations. Duplicates were removed automatically in Endnote (Version X9,

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TABLE 1 Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Publications were included if the: • Young Aboriginal and Torres Strait Islander children (0–8 years of age) • With a disability or developmental delay/difficulties • Who live **in regional, rural and remote** settings of Australia	Publications were excluded if the: • Sample did not include Aboriginal and Torres Strait Islander children (i.e. only non-Indigenous Australian children) • Sample of Aboriginal and Torres Strait Islanders children were all >8 years of age • Sample included adults ONLY • Sample included Aboriginal and Torres Strait Islander children from urban or metropolitan settings ONLY • Not Australian (i.e. other Indigenous children)
• Publications that report or describe the provision of support services for people living with a disability or developmental delay/difficulties (2 or more paragraphs)	• Publications that do not report/describe support services provided to people living with a disability or developmental delay or difficulties in sufficient detail (less than 2 paragraphs)
• Eligible publication types included: journal articles, discussion papers and reports	• Ineligible publication types included: conference proceedings/posters or abstracts, editorials, commentaries, letters, perspective or opinion pieces, newspaper articles, text from websites, audio visual files, flyers, posters, book chapters, dissertations, training materials/frameworks and/or policy submissions
• Eligible study designs included: cohort studies (prospective or retrospective), case-cohort or case–control studies, case studies, cross-sectional studies, qualitative studies, intervention studies including randomised controlled trials (RCTS) or non-randomised controlled trials, evaluation studies (e.g. pre-and post-studies), meta-analyses and other systematic reviews (including other forms of literature reviews such as, scoping or narrative reviews)	
• Written in English	

Clarivate Analytics) and then manually in Microsoft Excel. A custom-built Research Electronic Data Capture (REDCap) database was used to manage the screening and review process. CLJ reviewed the titles and abstracts of the remaining 490 unique records and 452 records were excluded. For pragmatic reasons, AD independently reviewed a random sample of abstracts (10%), and AD and CLJ resolved discrepancies through discussion to reach consensus. Reasons for exclusion were documented. Thirty-eight articles underwent full-text review by CLJ. AD independently checked a random sample (10%) of the full-text articles. Inter-rater reliability of 100% was achieved. An additional six full-text articles were added by hand searching reference lists. Thirteen articles met the inclusion criteria. The screening process is summarised in the PRISMA flowchart (Figure 1).

2.4 | Step 4: Charting the data

All eligible articles were imported into NVivo 12. We conducted a narrative synthesis as outlined by Popay et al. (2006)[24] supported by thematic analysis.[25] To address the research question, narrative synthesis uses a descriptive approach to summarise and explore evidence from the included publications. This is particularly useful in mapping current evidence and can help identify gaps in the literature. An inductive approach was used to generate candidate themes of barriers and enablers to access, and use of, disability support services as reported in the literature. CLJ closely read, and progressively organised data into conceptually coherent candidate themes. Extracts were re-read to ensure consistency of candidate themes, which were then cross-checked for accuracy by AD. Group discussions (All authors) resolved any further uncertainties. Preliminary synthesis involved extracting and grouping the data outlined in Table 2.

Authors CLJ and JG independently assessed the quality of the included publications using the Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE) Aboriginal and Torres Strait Islander Quality Appraisal Tool and its companion document.[26] The CREATE tool comprises 14 questions designed to evaluate the quality and cultural responsiveness of research conducted with Aboriginal

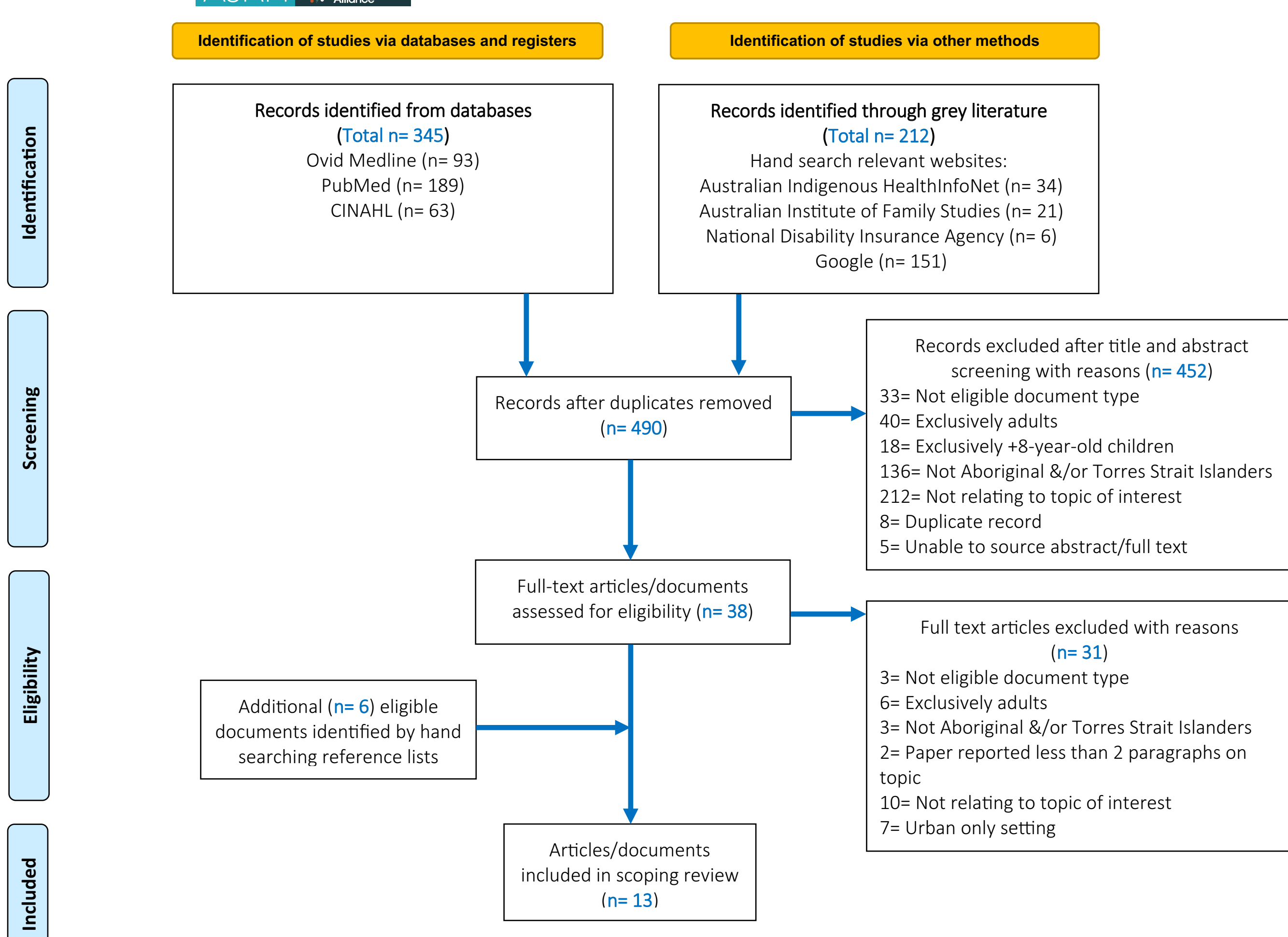

FIGURE 1 PRISMA flow diagram sourced from: Page, Matthew J., Joanne E. McKenzie, Patrick M. Bossuyt, Isabelle Boutron, Tammy C. Hoffmann, Cynthia D. Mulrow, Larissa Shamseer, et al. 'The PRISMA 2020 statement: An updated guideline for reporting systematic reviews'. *BMJ* 372 (2021). https://doi.org/10.1136/bmj.n71.

and Torres Strait Islander peoples. The tool's main objective is to appraise how well research respects the values and beliefs of Aboriginal and Torres Strait Islanders and meets ethical guidelines for working with Aboriginal and Torres Strait Islander communities. The 14 questions were answered using only evidence contained within each publication. We adopted a similar approach to Mitchell et al. (2023): publications with at least 9 'yes' responses were considered to be high quality; those with 5–8 'yes' responses were considered moderate quality; and studies that has less than 5 'yes' responses were classified low quality.[27] Disagreements between independent reviewers (CLJ and JG) were resolved through consultation with a third author (AD). This review has been reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)[28] (Appendix S2). A copy of the pre-defined protocol is available upon reasonable request from the authors.

3 | RESULTS

3.1 | Step 5: Collating and summarising the findings

This scoping review identified 13 eligible documents. Publications were broadly categorised as (i) original empirical research ($n=8$), (ii) systematic or scoping reviews ($n=4$) or (iii) discussion papers ($n=1$). Original research articles included five qualitative studies, two evaluation studies and a mixed method study. All the qualitative research used semi-structured interviews and/or focus groups to collect data. Two of the publications focused solely on Aboriginal families living in remote settings, two looked at families from rural and remote settings, and another two were based across RRR communities. The remaining seven articles included participants from all settings across Australia: urban and RRR. Sixty-nine per cent of the included titles ($n=9$) were published before 2020.

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TABLE 2 Study characteristics of identified eligible documents ($n = 13$).

Reference (author/year)	Publication type	Study design	Study aims/purpose	Population	Setting	Disability/ impairment
Aboriginal Disability Network New South Wales (ADNNSW) 2007[31]	Report/ discussion paper	Community consultations	'Telling it like it is' is a report of community consultations conducted during 2004/2005 with Aboriginal people with disability and their associates living in NSW	Not child specific but includes a sub-section on Aboriginal and Torres Strait Islander children (no age limits specified)	32 communities across the state of New South Wales (NSW) (including RRR settings)	All disability or impairment
McCarthy 2010[33]	Journal article	Evaluation study	To demonstrate the efficacy of using a telehealth model to provide ongoing, intensive therapy support to families in RRR Indigenous communities	Aboriginal and Torres Strait Islander children (aged 0–18 years)	RRR settings	Specific to children with a hearing loss or impairment
Dew et al. 2013[38]	Journal article	Qualitative study	To describe the benefits and barriers to using individual funding models for children with disability to access therapy services in rural and remote areas	Caregivers and service providers of all Australian children living with a disability (aged 0–8 years) in rural/ remote areas	RRR settings	All childhood disability or impairment
DiGiacomo et al. 2013[37]	Journal article	Literature Review (Period from 1990 to 2011)	To identify peer-reviewed literature describing factors impacting on the prevention, recognition and access to support and management of disability in Indigenous Australian children. Specifically aimed to answer the following question: What are the factors impacting on the prevention, recognition and access to support and management of disability in Indigenous Australian children?	Aboriginal and Torres Strait Islander children (no age limits specified)	Australia wide (all settings)	All childhood disability or impairment
Purcal et al. 2013[34]	Report/ Discussion paper	Evaluation study	This project evaluated the Northcott Disability Services school readiness program for Aboriginal children with additional needs to support their transition to school located in an urban and rural area in New South Wales	Caregivers and service providers of Aboriginal and/or Torres Strait Islander children with a disability (aged 0–8 years)	Two sites in NSW (1 X Urban and 1 X remote setting)	All childhood disability or impairment
Green et al. 2014[28]	Journal article	Systematic review	To answer the question: What are the important components involved in inter- and intra-sector collaboration in Aboriginal and Torres Strait Islander childhood disability?	Aboriginal and Torres Strait Islander children with a disability and/or their families/caregivers, or providers of services to this population (age not specified, however studies that solely focused on adolescents were excluded)	Australia wide (all settings)	All childhood disability or impairment
Greenstein et al. 2016[36]	Journal article	Qualitative study	Research questions for this study were as follows: 1. What are the experiences of Indigenous children with physical disability and their caregivers of their community-based physiotherapy service? 2. What factors influence their experiences of the physiotherapy service and how could the service be improved?	Aboriginal and Torres Strait Islander children and young people (aged 8–21 years) living with a disability, and caregivers of Indigenous children and young people (aged 0–21 years)	Northern Australia (regional setting)	Specific to childhood with physical disability or impairment

(Continues)

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TABLE 2 (Continued)

Reference (author/year)	Publication type	Study design	Study aims/purpose	Population	Setting	Disability/ impairment
Barr et al. 2018[8]	Journal article	Systematic review (Period from 2006 to 2017)	To investigate the accessibility of disability support services for children living in RRR areas with a particular emphasis on the experiences of children with a hearing loss in the Australian context	Aboriginal and Torres Strait Islander children and young people (aged 0–16 years)	RRR settings	Specific to children with a hearing loss or impairment
NPY Women's Council (2019)[30]	Report/ discussion paper	Qualitative study	To identify the supports and mechanisms required for Anangu families (the main care providers) of children with disabilities from remote and very remote NPY communities, in order for them to live the lives that they desire	Aboriginal and Torres Strait Islander children and young people (aged 0–18 years)	RRR settings	All childhood disability or impairment
Lilley et al. 2020[35]	Journal article	Qualitative study	To investigate experiences of, and attitudes towards, autism in Aboriginal and Torres Strait Islander communities in Australia	Family members and/or primary caregivers of Aboriginal and/or Torres Strait Islander children (aged 2–22 years) on the autism spectrum	Australia wide (all settings)	Specific to children and young people with Autism spectrum disorder (ASD)
Bailey et al. 2020[33]	Journal article	Scoping review	To map the key themes in the research on Indigenous Australians with autism	Aboriginal and Torres Strait Islander children (no age limits specified)	Australia wide (all settings)	Specific to children and young people with Autism spectrum disorder (ASD)
White et al. 2021[14]	Journal article	Mixed methods study	To explore the process and early outcomes of the NDIS Access Program for Kimberley Aboriginal people and organisations	NDIS Access Program staff working with Aboriginal and Torres Strait Islander people with disability, including children (no age limits specified)	Kimberley region of the state of Western Australia (Remote setting)	All childhood disability, with additional category for developmental delay and Fetal Alcohol Spectrum Disorders (FASD)
Lilley et al. 2023[32]	Journal article	Qualitative study	To explore women's conceptualisation of the practical work of caring for autistic Aboriginal and Torres Strait Islander children	Family members and/or primary caregivers of Aboriginal and/or Torres Strait Islander children (aged 2–22 years) on the autism spectrum	Australia wide (all settings)	Specific to children and young people with Autism spectrum disorder (ASD)

Abbreviation: RRR, Regional, rural and remote.

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More than half the publications reported on issues relating to children living with all types of disability or impairment ($n=7$). The remainder reported on specific disabilities including children with physical disabilities ($n=1$), hearing loss ($n=2$) and autism spectrum disorder (ASD) ($n=3$). Study-specific characteristics of all 13 titles included in this scoping review are summarised in Table 2.

Parents, guardians and/or carers hereafter will be referred to collectively as caregivers. The term 'provider' hereafter refers to a person or services employed to assess, manage, support or treat a person living with a disability or impairment. Of the eight original research studies included, four focused solely on caregivers, one focused on providers and three titles obtained perspectives from both caregivers and providers. The types of providers included as participants represented the health, education and social service sectors. Roles referred to include the following: social service case managers from government agencies, early childhood education support workers, disability support workers, special educators, allied health workers, early intervention teachers, Aboriginal health managers, general practitioners, nurses and paediatricians.

The quality appraisal results are presented below in Table 3. Study inclusion or exclusion was unaffected by these findings. Using the CREATE quality appraisal tool, we found about 40 per cent of the studies were of high quality ($n=5$, 38%); a single paper was graded as moderate quality ($n=1$, 8%) the remaining documents were graded as low quality ($n=7$, 54%).

3.2 | Synthesis of results

We identified numerous barriers and facilitators reporting to impact families' access to, use of, and satisfaction with, disability support services in our attempt to answer: *How can support services best help young Aboriginal and Torres Strait Islander children (0–8 years) who have developmental difficulties/delays or are living with a disability in remote settings to achieve 'proper way help' to enable them to 'live a good life'*? These were grouped into six themes: (i) Holistic approach (ii) Understanding disability (iii) Consistent relationships (iv) Flexibility (v) Simplify systems and (vi) Enhance communication.

3.2.1 | Theme 1: An holistic approach

The identified literature stressed the importance of designing support services to overcome fragmentation and adopt a holistic approach. Beyond simply focusing on the child's medical needs, it requires an integrated response that considers the social, emotional, spiritual and cultural well-being of individuals and the

TABLE 3 Quality appraisal.

Reference (author/year)	Indigenous governance				Respect for cultural and intellectual property				Capacity building			Beneficial outcomes			Overall assessment
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	
ADNNSW 2007[31]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
McCarthy et al. 2010[33]	Y	U	U	U	U	U	U	U	U	U	U	U	U	U	Low
Dew et al. 2013[38]	Y	U	N	N	U	N	N	N	N	N	U	U	U	U	Low
DiGiacomo et al. 2013[37]	U	N	N	N	N	N	N	N	N	N	N	N	N	N	Low
Purcal et al. 2013[34]	Y	U	U	U	U	U	U	U	U	Y	Y	Y	Y	Y	Moderate
Green et al. 2014[28]	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Low
Greenstein et al. 2016[36]	U	N	N	N	N	N	N	N	P	N	N	N	N	U	Low
Barr et al. 2018[8]	U	N	N	N	N	N	N	N	N	N	N	N	N	N	Low
NPYWC et al. 2019[30]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Lilley et al. 2020[35]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	U	U	Y	Y	High
Bailey et al. 2020[33]	Y	N	N	N	N	N	N	N	N	N	N	N	N	N	Low
White et al. 2021[14]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Lilley et al. 2023[32]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High

Abbreviations: N, No; P, Partially; U, Unclear; Y, Yes.

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community as a whole.[29] The review by DiGiacomo (2013a) emphasised the importance of moving beyond a purely biomedical approach to addressing the needs of Indigenous children holistically. The model of care frequently advocated for by providers and caregivers alike is a 'one-stop-shop' where Aboriginal families can receive centralised, holistic team-based care.[30,31] Elements of this are embodied in the model of care typically provided by Aboriginal Community Controlled Health Organisations (ACCHOs), acknowledged as having a positive impact on access. White (2021) referred to ACCHOs as being trusted and culturally appropriate organisations that are often best equipped to address historical and systemic barriers that contribute to low levels of engagement.[16] To ensure equitable access to the NDIS scheme for Aboriginal and Torres Strait Islanders living with a disability, the First Peoples Disability Network Australia and the National Aboriginal Community Controlled Health Organisation continue to advocate for culturally appropriate engagement strategies. Previous engagement activities led by non-Indigenous organisations in the Northern Territory and Queensland were described by White (2021) as being perceived by the community they sought to engage with as "*cursory, inappropriate, and ineffective*". The Tjitji Atunymankupai Walytja Tjutangku collaborative project by the NPYWC Aboriginal Corporation suggested that a culturally responsive, holistic approach to providing support mechanisms, which encompassed the child's and family's needs beyond disability support, would enable families of children with disabilities to live a good life on the Lands.[32]

A report of community consultations with Aboriginal people with disability and their caregivers by the Aboriginal Disability Network of New South Wales (ADNNSW) repeatedly identified that mainstream service providers had little to no experience interacting with Aboriginal people which affects uptake.[33] Aboriginal and Torres Strait Islander women interviewed about their experiences raising autistic children criticised non-Indigenous therapists for not providing culturally sensitive or appropriate support.[34] In contrast, the carers reported only positive encounters with Aboriginal professionals who offered '*no judgement*' and better understood their family's situation. Green's (2014) review highlights the importance of respectful communication and culturally responsive program delivery for Aboriginal and Torres Strait Islander children with disabilities and their families.[30] The key to successful delivery of support services, according to White (2021), lies with the ACCHO sector, affirming that a strengths-based focus is essential to overcome barriers to access and use. Providers need to see the resilience of the family and community as a whole, rather than adopting a deficit-based bio-medical agenda.[16]

3.2.2 | Theme 2: Understanding disability

Another factor known to influence the participation of Aboriginal people in disability support services is differences in understanding of the term 'disability'. In Western scientific discourse, disability is often perceived as a limitation to be fixed or medically treated. For Aboriginal people, this perception has been described as culturally inappropriate.[19] We found that ideas of disability can be constructed differently in Aboriginal and Torres Strait Islander communities, influencing service uptake. For example, in their evaluation report on the Royal Institute for Deaf and Blind Children (RIDBC) telehealth outreach program, McCarthy (2010) found high chronic ear-disease rates were viewed as 'normal' by Indigenous communities, minimising any urgency and need for intervention when compared to non-Indigenous clients,[35] and affecting attendance rates. Lilley (2023) also cites socially inclusive attitudes in Aboriginal communities based on cultural values of acceptance and '*kin-based belonging*'.[34]

An evaluation report by Purcal (2013) of a preschool readiness program for Aboriginal children with additional needs in rural New South Wales found that communities may not label someone as having a disability because it makes them appear different. Instead, '*they see the person as a whole and their disability as part of who they are*'.[36] ACCHO providers interviewed as part of White's (2021) mixed method analysis of a NDIS Access Program in the Kimberley, believed that disability was not recognised by the families due in part to this normalisation of disability. Here again, we found that disability was understood to simply be a characteristic needing support rather than needing to be remedied.[16,31] Similarly, Lilley (2020) found that Aboriginal families interviewed across Australia accepted diverse characteristics of individuals in their communities and explained that 'labelling' was seen as a Western preoccupation that comes with an inherent judgement that causes feelings of shame.[37] Bailey's (2020) scoping review on Indigenous Australians with autism spectrum disorder also recognised that labelling or categorising individuals based on their abilities or impairments is considered irrelevant.[31]

According to Lilley (2023), acceptance and inclusion are experienced alongside social isolation, shame and stigmatisation in communities.[34] Past experiences of discriminatory policies have led many to fear that certain diagnoses will call into question their parenting

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skills[31,37,38] with some families fearing that their children will be removed.[39] The ADNNSW community consultations suggested that caregivers' reluctance to seek help due to fear or shame may be one of the reasons for such high numbers of undiagnosed children in RRR communities.[33] These fears of disapproval or '*negative consequences from perceived wrongdoing*' can lead families to avoid seeking treatment or disclosing a diagnosis.[32,37] Parents reactions to feeling judged and stigmatised by their child's diagnosis of autism ranged from defiant rejection to self-imposed isolation in Lilley's (2023) exploration of carers' lived experiences.[34] The NPYWC report also identified people feeling ashamed of children with disabilities and a desire to '*keep it hidden away*'. The ADNNSW (52) community consultations advocated for greater acknowledgement and respect of the different ways in which Aboriginal communities discuss, understand and construct disability. By better understanding the different meanings attributed to disability, we can better understand families' expectations, needs and preferences in accessing support services for their young children.[39]

3.2.3 | Theme 3: Consistent relationships

Preference for caregivers to maintain consistent relationships with key service providers was a frequent finding and a major factor in maintaining service participation. Trusting relationships with known providers were found to help families navigate the complex disability support systems.[33,36,39] Bailey (2020) also refers to this partnership as a way of improving service delivery. Barr's (2018) systematic review of the literature on service provision for children with hearing loss in RRR areas of Australia referred to the importance of providers building rapport in the community over time.[8] This emphasis on slowly building relationships with families was reiterated in DiGiacomo's (2013a) review and in Purcal's (2013) evaluation of the preschool readiness program, finding that: '*the Program needed a lead up time of at least 1 year to build trusting relationships with local service providers and the Aboriginal community*'.[36,39] Additionally, McCarthy's (2010) evaluation found that uptake of the telehealth model was only successful after firmly establishing rapport with an intermediate facilitator.[35] Despite being highly valued, Barr (2018) noted that the significance of relationship building is not yet reflected in current funding models.[8]

Two papers specifically referred to the use of a consistent, key person (key facilitator, navigator, client advocate or linking person) who could bridge relationships between non-Indigenous providers and families to improve service delivery.[16,30] Staff interviewed for White's (2021) NDIS Access Program described caregivers as being frustrated with the National Disability Insurance Agency (NDIA)'s lengthy access assessment process.[16] However, in other cases, the NDIA was said to have moved too quickly. In these situations, a client advocate would better understand the families' specific and changing needs over time.[16] Bi-cultural education of non-Indigenous providers by Aboriginal providers was said to aid in engagement with young families.[39] Greenstein, Lowell and Thomas (2016) examined factors influencing caregivers' experience of physiotherapy in a community-based service and found caregivers valued consistent and caring relationships with their physiotherapist in addition to effective communication.[38]

3.2.4 | Theme 4: Flexibility

Across the literature, the need for greater flexibility was evident, particularly for RRR areas. The NDIS has redirected disability funding from services to individuals to allow greater choice and control. This person-centred approach with individual funding is experienced differently by people living in RRR areas, according to Dew (2013).[40] Using data from a larger study, the authors identified several barriers to optimising individual funding packages for those caring for children with a disability. They questioned the assumption that control of funding packages translates to greater choice, when in fact the options for, and capacity of, local support services and therapists in RRR areas remains constrained. The authors concluded that alternative and flexible approaches are needed for carers to maximise their funding packages, including the provision of adequate financial compensation for travel expenses incurred accessing supports from geographically isolated areas.[37,40] Barr's (2018) systematic review also reported that service delivery models need to account for complexities faced by some families living in RRR settings.[8] These models must therefore be flexible and responsive to accommodate individual preferences and needs.[8,39] For providers, this might mean being flexible with time for appointments; for caregivers, it might mean choosing to have specialists visit them at home, via video conferencing technology[35] or in another culturally safe location of their choosing.

Demand for services may be insufficient to secure local supply of services in RRR areas. As a result of these limited options, families are forced to travel to larger service centres.[8,32] This can mean beginning the journey to

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appointments hours in advance, and driving at dawn and dusk was noted as being dangerous on remote roads with poor infrastructure.[8] These factors can put pressure on families to have to incur costs of private tutoring, respite, travel, accommodation or time away from work to attend appointments in regional centres. Such out-of-pocket expenses were found to affect families' ability to successfully navigate disability support system.[8,31,33] Policy recommendation from ADNNSW (52) consultations included an increase in resources to develop more Aboriginal owned and operated services in RRR settings to help relieve some of these pressures.[33] These extra costs were prohibitive for some low-income families, and additional supports, such as the provision of transport by services to attend appointments, was invaluable for caregivers.[39]

Another flexible approach that was favoured was co-locating services and intervention programs in accessible locations, such as at schools, to support engagement.[35] The on-community telehealth model, delivered by the RIDBC in partnership with the school, provided Aboriginal RRR families with access to specialised hearing support, which would have been otherwise unavailable to them[35] and made them '*feel less isolated in their remote communities*'. This approach was also identified as being a successful way to improve access for children in the NPYWC report.[32] However, while schools and teachers were a useful support, it was recognised that often the schools were under-resourced to be able to adequately deliver programs and maintain equipment.

Extending this approach from the services being provided in schools to being provided in other centres, the RIDBC provided funded blocks of time for RRR families to travel to and stay at their main campus in Sydney every 6 months for therapy. While it was reported by McCarthy (2010) that this mode of delivery was not always successful with Aboriginal families, they go on to describe that complementing the telehealth services with a block of services in Sydney worked exceptionally well in one case study. The NPYWC 2019 report identified that while families acknowledged that their child's special needs necessitated that they were cared for in regional centres or in the city, greater support to assist children to visit their family on the Land and remain connected was needed.[32] Greater flexibility in how services were delivered for their children would support families maintaining ties with family, culture and the Lands.

3.2.5 | Theme 5: Simplify system

Another factor impacting accessibility of disability support services is system complexity. Access Program staff in the Kimberley reported that families found the NDIS complex and inaccessible.[16] The bureaucratic nature of the scheme was described as unnecessarily complicated, inflexible and rigid and was said to cause '*confusion*'[30] and '*erode trust*' with Aboriginal communities.[31] For many caregivers, self-managing the administration of individual NDIS funding was an additional burden.[8,31,40] Caregivers interviewed in Dew's (2013) study observed that self-managing funding packages might work well for middle-class families with higher education but not all families are able to engage with the system so easily.[40] Participants in Lilley's (2023) study described navigating the journey to diagnosis and accessing support services as '*a long hard slog*' taking an emotional toll that left many feeling '*worn out*'.[37] Inflexible rules were described by caregivers as preventing some agencies from accommodating their child's specific needs.[31,40] Green's (2014) synthesis of the literature asserts that the fragmented nature of service providers, departments and agencies working in professional silos further impedes opportunities for collaboration and access for Aboriginal families.[30] Caregivers are often also faced with managing multiple referrals for their child to see different service providers, all with long waitlists, which can be quite challenging to navigate without support.[31] The support system's complexity was a very real barrier to families on the NPY Lands accessing support,[32] made even more challenging if the child was in out-of-home care. The NPYWC report advocated for case management to adequately support the families to navigate the system.

3.2.6 | Theme 6: Enhance communication

Communication with families and between service providers is a key factor in optimising access to services. To foster effective interactions with Aboriginal families, Green (2018), cited in Bailey (2020), reported that it was important for communication strategies to be clear and free of jargon.[31,41] The timing of the information provided to families was just as important as its comprehensiveness.[8,40] Barr's (2018) review highlighted the need for professionals to carefully consider the balance of information provided to families at the right time according to their specific needs. The authors suggest that a key worker or client advocate would be best placed to support good communication for families. Low-income families were found to have less access to information compared with higher income families.[8]

To effectively support Aboriginal children and their families, collaboration and information-sharing

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between providers is necessary.[30] The literature referred to a shift in disability policy that recognises the need for inter-sector collaboration.[30] Such approaches would see typically divided providers in mainstream, specialist and non-mainstream services work together to address complex cases. However, Green (2014) conceded that collaboration was more likely to be successful through personal relationships rather than imposed structures. Linking roles, such as a client advocate or navigator (discussed earlier), can foster inter-sector collaboration and improve communication for families. Good communication, according to Greenstein (2016), facilitated the linking of services to address a child's ongoing specific needs.[38] This inter-agency communication and collaboration promoted coordination, which was considered crucial to providing effective support for children with disability on the NPY Lands.[32]

4 | DISCUSSION

We aimed to synthesise the current literature and identify key themes relating to how services best support young Aboriginal and Torres Strait Islander children (0–8 years of age) who have developmental difficulties/delay or are living with a disability, in RRR settings, to achieve '*proper way*' help and enable them to '*live a good life*'. Despite the evidence that there is a higher prevalence of disability in Aboriginal and Torres Strait Islander children than in non-Indigenous children in Australia,[22] this review has demonstrated that the available published data and evidence on services is sparse. We have collated the experiences of caregivers living with children with disability accessing disability support services in RRR areas and grouped our results into six areas: (i) Holistic approach, (ii) Understanding disability, (iii) Consistent relationships, (iv), Flexibility, (v) Simplify systems and (vi) Enhance communication.

Culturally responsive services were a primary feature of taking a holistic approach, which we identified in our review. This is consistent with the 2023 Closing The Gap priorities, including access to culturally safe care, free of racism[42] and other research, that highlights acknowledging and respecting culture, and ensuring a culturally competent service system.[43,44] In a study exploring transition from the early childhood intervention sector to the NDIS, Boaden,[45] describes the need for Aboriginal liaison staff to overcome the historical distrust of government services and promote culturally appropriate service delivery. The 'Walykumunu Nyinaratjaku: To Live a Good Life' project identified three key concepts to supporting Anangu with disability, to live a good life[21]: being connected to the Lands and family; sharing together; and working together. Participants interviewed consistently expressed their desire to live in their home community with their family, surrounded by their language and culture. Other themes identified included the receipt of '*proper way help*', from '*consistent, kind and dependable*'.[46] These latter themes also align with our findings, valuing **consistent relationships** and **enhanced communication**.

There is a recognition that consistent, trusted relationships are essential for successful models of care for Aboriginal and Torres Strait Islander people living with disability.[47] While highly valued, this finding is often at odds with the way services are provided.[46] A meta-synthesis by James,[48] exploring Indigenous experiences of disability support services across Australia, concluded that building respectful relationships between providers and clients is still an area in need of attention due to ongoing suspicion and uncertainty related to government services. Several factors contribute to building trusted relationships. Consistency of staff is only one of these, that over time, fosters a trusting relationship to grow and enables '*proper way*' engagement.[47] However, this focus on relationship building is not yet reflected in current funding models.[8]

We identified effective communication as another integral component of providing effective support for children with disability. Culturally appropriate and considered communication is a consistent finding in other literature examining the needs of Aboriginal and Torres Strait Islander people accessing disability services.[48] The potential benefits of inter-agency communication and collaboration also emerged. This has been recognised by other scholars exploring service delivery for people with a disability living in RRR areas. In a study exploring perspectives of policy-makers, managers and senior therapists in rural and remote NSW, Veitch (2012) found that greater collaboration could result in more clients receiving more efficient and timely care and support.[49] Similarly, Ravindran (2017) concluded that greater collaboration and stronger relationships between Aboriginal and Torres Strait Islander people and agencies was a way of empowering Aboriginal and Torres Strait Islander people to have greater agency in their disability care.[50] A failure to coordinate the different services and agencies involved can result in families struggling to understand processes and roles leading to disengagement.[19]

Limited options in RRR areas were reported as a significant barrier to accessing essential disability supports and services. This often resulted in families being forced to travel long distances for services and incurring greater

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financial and personal costs. The barrier posed by travel and inadequate funding provided to cover the costs for Aboriginal and Torres Strait Islander families living in RRR areas is well-described.[22,45,51] Although many advocate for more services in RRR to address this barrier, for others, flexibility and choice remains the priority. A preference for travel to urban centres for a block of therapy has been described as a necessary option. For example, a NPYWC statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) reports that for some families, there are risks to providing supports to children and their families in their homes, as prescribed by the early childhood approach.[52] There may be factors in the home, which act as barriers to delivering effective and safe intervention and support, such as overcrowding, family violence, family members' health issues and community obligations.

There are other reasons that emerged to explain why families may not engage with disability services in their community, which have also previously been reported. There can be a stigma associated with having a disability,[32,50] and this 'shame' can lead to families refusing supports. The statement to the Disability Royal Commission indicated that in many cases it would be best and safest to provide therapy in a regional centre, outside the home and remote community, and other submissions similarly call for services to be offered in intensive blocks in regional centres.[53] However, as described by other scholars, while NDIS packages include some funds for therapists to travel to remote areas, they do not generally include funding for children and families to travel.[54] This remains a significant barrier.

This review has identified potential solutions for addressing barriers to accessing disability services for Aboriginal and Torres Strait Islander children in RRR areas. Our findings suggest that flexibility in the approaches adopted are essential to be responsive and adequately accommodate the needs of families, a view shared by others.[12,21,22,50] Gilroy (2018) reported that families benefit from flexible models that promote choice in when, how and where they receive support either on or off homelands.[21] A framework by Dew (2019, p. 3) advocates for open and respectful engagement with Aboriginal and Torres Strait Islander people with disability, providing a model that '*responds directly to the experiences and needs of Aboriginal people with disability*'.[12] This approach is further endorsed by Ravindran (2017) who advocates seeking input from Aboriginal and Torres Strait Islander people to ensure they exercise their own choices.[50] Essentially, ensuring flexibility for Aboriginal and Torres Strait Islander families, provides greater 'choice and control' that the NDIS aspires to.

4.1 | Strengths and limitations

A strength of this review is that it was community-driven; it was conducted at the request of the community in partnership with the researcher team. Second, it was undertaken in collaboration with a leading Aboriginal academic in this field, ensuring Aboriginal voice and leadership in the process. The review has limitations. While rigorous methods were adopted, and grey literature was reviewed, the findings were limited to available publications and therefore may not be generalisable to all Aboriginal and Torres Strait Islander communities in RRR areas. Furthermore, we should be cautious of applying a one-size-fits-all approach across the Australian Aboriginal and Torres Strait Islander context. Further research should be conducted to reflect the views of diverse populations.

4.2 | Conclusion

This scoping review has revealed many of the gaps that exist in providing quality, culturally responsive, timely disability services for families of Aboriginal and Torres Strait Islander children living in RRR areas of Australia. Failure to take a family-centred, flexible approach that includes Aboriginal and Torres Strait Islander families in decision-making about what is best for their children, risks perpetuating the entrenched systems that have failed to meet the explicit needs of Aboriginal and Torres Strait Islander peoples. Future research is required to design and evaluate models of care that adequately meet the diverse needs of Aboriginal and Torres Strait Islander children and families in these contexts.

AUTHOR CONTRIBUTIONS

Anita D'Aprano: Methodology; formal analysis; supervision; project administration; writing – review and editing; writing – original draft; funding acquisition. **Kim McRae:** Conceptualization; writing – review and editing; funding acquisition. **Suzanne Dayton:** Conceptualization; writing – review and editing. **Catherine Lloyd-Johnsen:** Methodology; data curation; formal analysis; writing – original draft; writing – review and editing. **John Gilroy:** Methodology; data curation; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

All papers included in this scoping review were available on non-restricted websites at the time the study was conducted. The data set used and/or analysed during this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethics approval was not required for this scoping review.

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SUPPORTING INFORMATION

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

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