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NARRATIVE REVIEW

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The experiences of people with disability and their families/carers navigating the NDIS planning process in regional, rural and remote regions of Australia: Scoping review

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Abstract

Background: Australia's National Disability Insurance Scheme (NDIS) was launched in 2013 to provide financial support packages for people with disability to purchase supports and services to enhance independence. People with disability are required to develop a plan with the National Disability Insurance Agency (NDIA), the government department responsible for managing the NDIS. This scoping review aims to ascertain the level of research into people's experience of the NDIS planning process in these geographic areas.

Methodology: Research publication databases were searched using a specific search string to identify research about people with disability and their families/carer's experiences of the NDIS planning process in regional, rural and remote regions of Australia. The Mixed Methods Appraisal Tool (MMAT) was adopted to appraise the quality of the research publications. Research publications focused on Aboriginal and Torres Strait Islander people were additionally appraised using the Aboriginal and Torres Strait Islander Quality Appraisal Tool developed by the Centre for Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange. A thematic synthesis of the publications' contents was undertaken to ascertain people with disabilities and carers experience of the NDIS planning process.

Results: Ten ($N=10$) research papers were found that met the inclusion criteria. Two papers were policy reviews and reported on the improvements of the NDIS planning process since its conception. The analysis found the research archive focused on five themes: (1) healthcare workforce and NDIA staff; (2) NDIS package holders and carers lack of awareness of the NDIS; (3) cultural/socio-economic barriers; (4) travel funding; and (5) emotional burden of the NDIS planning process.

Conclusion: There are limited papers available that explore people's experiences of the NDIS planning process in regional, rural and remote regions of Australia. This systematic review illuminates the difficulties, barriers and concerns of people with disability and their carers about the planning process.

KEYWORDS

Aboriginal health, allied health, disability, health policy, rural health

1 | BACKGROUND

In 2013, a National Disability Insurance Scheme (NDIS) was introduced by the Australian federal government that provides a social insurance model of support for people with disability. The NDIS is administered by a government authority, the National Disability Insurance Agency (NDIA). Prior to the NDIS, most disability services were administered and provided by state and territory governments using a block funding model to fund registered government and nongovernment service providers under the Disability Services Act 1986. This model was described in a report by the Productivity Commission as 'underfunded, unfair, fragmented and inefficient'.[1] The report noted that people with disability had limited choice in what, how or when they received support to live an independent and socially inclusive life.[2] The NDIS commenced with trial sites in five States and Territories followed by a national roll completed by July 2020.[3,4]

To be eligible for the NDIS, applicants must be under 65 years of age and have a significant and permanent impairment that substantially reduces their ability to participate in the community and activities/occupations of daily living. An NDIS participant is a person with disability who has been assessed as eligible to receive support funded under the NDIS. As of December 2021, the NDIA reported that over 400 000 people were registered with the NDIS.[5]

The principles of the Convention of the Rights of Persons with Disabilities (CRPD)[6] underpin the NDIS Act 2013. The convention asserts that people with disability have fundamental rights to make their own choices and participate in the social and economic life of the community as other citizens. The stated aim of the NDIS is to enhance people's choice and control over the services and support they require to live an independent life. Central to achieving this aim is the development of an individualised support plan that identifies a person's self-defined goals and aspirations, as well as the services and supports required to attain those goals.[5,7]

Wark[8] identified three primary objectives of the NDIS legislation including: (1) provide reasonable and necessary supports (Section 3(1)(d)); (2) enable package holders to exercise choice and control over the planning and delivery of their supports (Section 3(1)(e)); and (3) develop a nationally consistent approach to the access, planning and funding of these supports (section 3(1)(f)).[9] Current research into disability services has raised concerns around the NDIS objectives being met in regional, rural and remote areas mainly regarding accessibility and diminished choice resulting in diminished control over service delivery.[8,10-15] Reoccurring themes of travel, accessibility and inadequate health workforce to meet demands have been identified as barriers to rural health, ageing and disability service delivery.[10,16]

To date, there have been several reports, evaluations and reviews of the NDIS.[7,17] The focus of these has been

What this paper adds?

- People with disability living in remote, rural and regional areas of Australia have been missing out on essential NDIS services. However, there is limited knowledge on the research in this area.
- This paper brings together the research on the experiences of people with disability in regional, rural and remote areas of Australia navigating the NDIS planning process.
- This paper can help the Government and advocates to inform ways to improve the experience of the NDIS planning process for people living in remote, rural and regional areas.

What is already known on this subject?

- The NDIS is a national insurance social support scheme that aims to provide financially tailored packages for people with disabilities and their family/carers.
- The NDIS requires eligible people with disabilities to design an evidence-based bespoke plan. People with disabilities have reported that the planning process is challenging and confusing, with many describing it as highly stressful and emotionally taxing.

on the implementation and outcomes of individuals' NDIS plans relating to two key factors: 'choice and control' and 'enhanced supports and services'. The experience of the planning process has received little attention, despite the planning process being the key vehicle by which supports and services for individuals are approved for funding. The research suggests that without an advocate or assistance to navigate the planning process, many people with disability and/or their carers find it difficult to articulate their needs and goals during this process. This difficulty is worse for people with an intellectual/cognitive disability, complex needs, complex communication needs, Aboriginal and Torres Strait Islander people and people who speak English as a second language.[18-21] These barriers influenced the process of developing plans and whether participants felt supported, less anxious and listened to during the process.[19]

Previous research in individualised planning with people with disability demonstrates the importance of skilled staff and a commitment to a person-centred approach.[22] Despite the recent national roll-out of the NDIS, there are several research papers reporting on the experiences of NDIS participants and/or their families in all phases of the planning process. Collings, Dew and Dowse's[23] paper demonstrated that participants felt the need to develop a relationship of trust with the planner to enable them to feel understood, listened to and respected during the planning process.[23] A systematic review made by Trounson, Jordan, Gibbs, Kostrz, McDonald and Peters[24] reported that Aboriginal and Torres Strait Islander people living in rural and remote areas are less likely to benefit from the NDIS when compared to people living in metropolitan regions. This review concluded that people with disability from regional, rural and remote areas experiences of the NDIS planning process should be further explored.

An understanding of planning experiences for those living in nonmetropolitan areas has the potential to assist NDIA staff and other disability workers to support people more effectively with a disability to make their own choices and exercise the same fundamental rights as other Australians. The aim of this scoping review was to examine the literature about the experiences of the NDIS planning process for people with disability who live in regional, rural and remote regions of Australia.

2 | METHOD

A scoping review was conducted to map the key concepts regarding the available literature answering our research question: 'What are the experiences of people with disability and their families/carers of the NDIS planning process who live in regional, rural, and remote regions of Australia?'.

An open discussion involving the first three authors occurred, and a protocol for the scoping review was agreed upon in accordance with Arksey and O'Malley's[25] five-phase process involving: (1) identifying the research question; (2) identifying relevant studies; (3) study Selection; (4) charting the data; and (5) collating, summarising and reporting the results.

2.1 | Eligibility criteria (inclusion/exclusion criteria)

Grey and peer-reviewed publications were included in this review. Identified publications were required to be written in English and have an abstract or report summary. In addition, the publications were required to have background, methodology, results and a discussion section relating to the study to be included.

Studies were only included if they fit the following eligibility criteria:

Included:

- research about people with disability and their family/carers;
- research on the NDIS planning process; and
- regional, rural and remote regions of Australia as defined by either the Monash model or the Australian Government.[26]

Excluded:

- research about people who do not have a disability;
- research about workers;
- everything else about the NDIS and other disability programs; and
- metropolitan regions of Australia and other countries.

2.2 | Search identification and selection

This review considered all studies that involved people with disability and their families/carers of any age who experienced the NDIS planning process and who live in regional, rural and/or remote areas of Australia. The team involved a Librarian (KE) to ensure the best databases were selected that best relates the research question. Combined searches from the below databases were imported into EndNote X8. The titles and abstracts were screened, respectively, by authors (Author 1, Author 2, Author 3) using the Systematic Review software COVIDENCE. Discussions on the papers involved three first authors until 100% agreement was achieved.

Databases/search strategies utilised:

- Medline, CINAHL, Scopus, Informit, ProQuest, Web of Science.
- Citation tracking of the included studies was conducted for other potentially eligible papers.
- A hand search was undertaken that involved contacting key people in the research field (Author follow-up) and public databases (such as Google and Google Scholar) for further grey literature.

Alerts were set on all databases and a rerun of searches prior to final analyses was also carried out to identify any further studies for inclusion. Figure 1 illustrates the search strategy and terms used for this review.

3 | RESULTS

Initially, we had planned on extracting and analysing the data according to our review question; however, the findings of only a few studies amongst the available literature addressed the review question directly. The team then decided to include papers that mentioned regional, rural and/or remote areas and the NDIS planning process. The NDIS was launched in 2013. All papers included were published in the last 6 years 2015–2021.

Our search yielded 113 articles, of which 35 were duplicates and excluded. Of the remaining 78 articles, 48 were excluded based on the Title and Abstract. A detailed inclusion/exclusion criteria were applied to the full-text analysis of the remaining 30 articles concluding 20 articles excluded and 10 articles selected for inclusion. These results are presented in Figure 2, using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) format.

3.1 | Data extraction

The ability to determine 'key concepts' in the qualitative literature can be difficult due to the variability of reporting styles.[27] We identified key terms from text by reviewing the abstracts, results and findings of included studies. A thematic synthesis of the publications was undertaken to ascertain people with disability and their carers experiences of the NDIS planning process in regional, rural and/or remote areas.

Thematic analysis is a widely adopted method in the qualitative literature used to identify 'emerging themes' and key concepts.[28,29] A discussion involving three authors occurred and analysis was agreed upon in accordance with Braun and Clarke's six-phase process involving: (1) familiarisation of data; (2) initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) writing the paper.[29,30] As a member of our team has a visual impairment, we were not able to employ commonly utilised software systems for the thematic analysis due to incompatibility with visual assistive technology. Hard copies of the papers were provided for the team, and codes were colour coordinated across the team to ensure consistent coding. Initial codes were frequently discussed amongst the team and as further reviewing occurred overarching themes were identified. For example, initial codes such as 'difficulty contacting NDIA staff' later came under the overarching theme of communication. Consequently, exemplifying the identification of main themes provided a framework for the papers' analysis of the perceptions and experiences of NDIA package holders and carers during the planning process.

3.1.1 | Publication appraisal

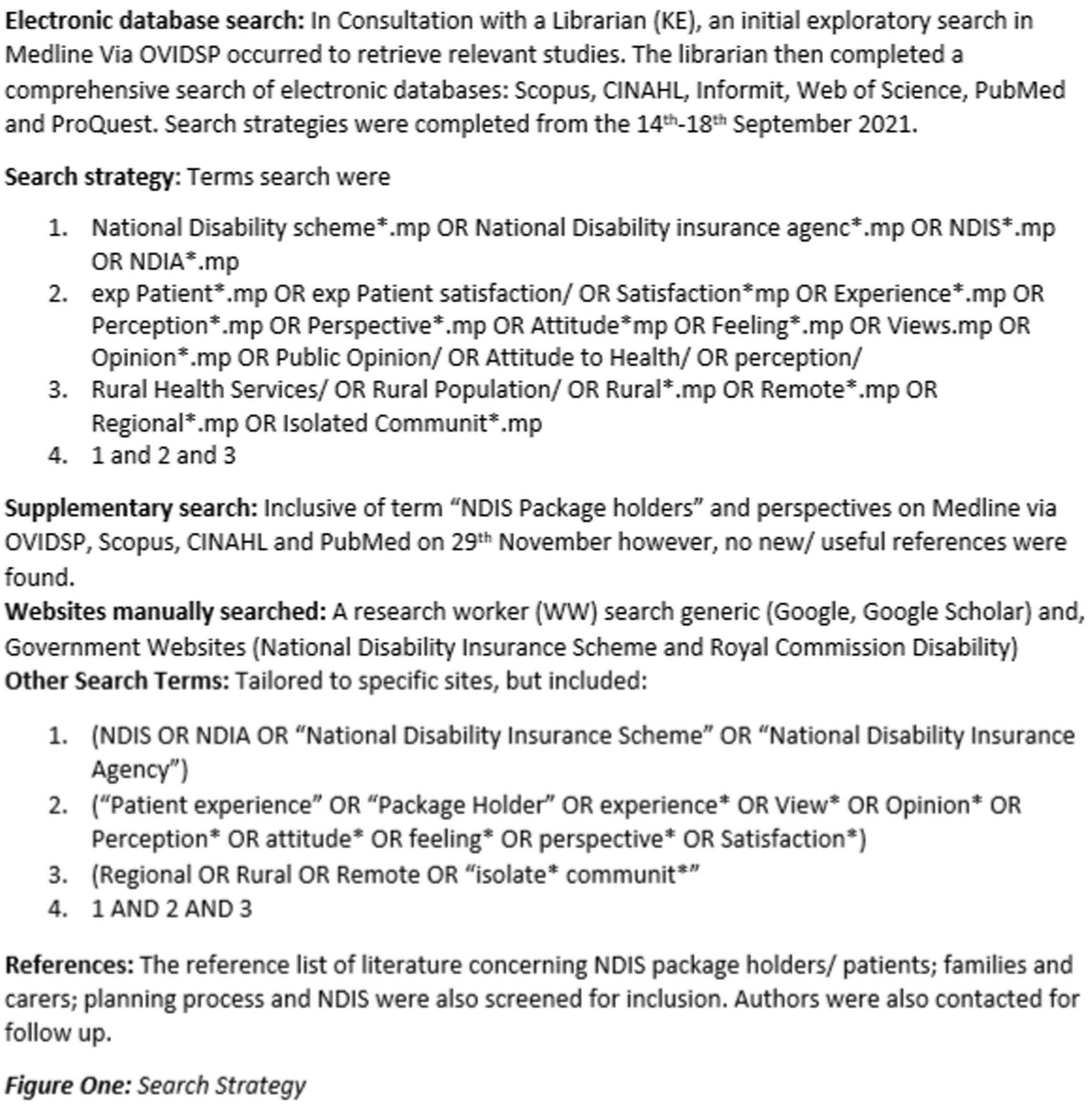
Most included papers were qualitative. No quantitative studies were found. Grey literature was also included to ensure all literature surrounding the research topic were captured.

We adopted the Mixed Methods Appraisal Tool (MMAT) version 2018 framework.[31-35] First developed in 2006, and revised in 2011, the MMAT was designed to appraise multiple mixed study research publications, that is studies that include qualitative, quantitative and mixed methods. All included papers were deemed to have answered the research question according to this appraisal tool.

Publications that had a specific focus on Aboriginal and Torres Strait Islander people were additionally screened using the Aboriginal and Torres Strait Islander Quality Appraisal Tool developed by the Centre for Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE).[36] This tool appraises the quality of the research publications according to how well the research meets the values and ethics of working with Aboriginal and Torres Strait Islander communities, such as the NHMRC Aboriginal and Torres Strait Islander research protocols.[37] The results of the MMAT appraisal tables can be found in Tables 1 and 2, respectively, and the findings of the CREATE tool can be found in Figure 3.

3.2 | Characteristics of the studies

Of the 10 included studies, four were identified as qualitative and six as mixed method studies. The included studies utilised a variety of methods, including focus groups, interviews and surveys. Three papers[7,21] reported on current NDIS practices involving policy briefs and strategic plans for pending reforms. These three papers were grey



Electronic database search: In Consultation with a Librarian (KE), an initial exploratory search in Medline Via OVIDSP occurred to retrieve relevant studies. The librarian then completed a comprehensive search of electronic databases: Scopus, CINAHL, Informit, Web of Science, PubMed and ProQuest. Search strategies were completed from the 14th-18th September 2021.

Search strategy: Terms search were

1. National Disability scheme*.mp OR National Disability insurance agenc*.mp OR NDIS*.mp OR NDIA*.mp
2. exp Patient*.mp OR exp Patient satisfaction/ OR Satisfaction*mp OR Experience*.mp OR Perception*.mp OR Perspective*.mp OR Attitude*mp OR Feeling*.mp OR Views.mp OR Opinion*.mp OR Public Opinion/ OR Attitude to Health/ OR perception/
3. Rural Health Services/ OR Rural Population/ OR Rural*.mp OR Remote*.mp OR Regional*.mp OR Isolated Communit*.mp
4. 1 and 2 and 3

Supplementary search: Inclusive of term "NDIS Package holders" and perspectives on Medline via OVIDSP, Scopus, CINAHL and PubMed on 29th November however, no new/ useful references were found.

Websites manually searched: A research worker (WW) search generic (Google, Google Scholar) and, Government Websites (National Disability Insurance Scheme and Royal Commission Disability)

Other Search Terms: Tailored to specific sites, but included:

1. (NDIS OR NDIA OR "National Disability Insurance Scheme" OR "National Disability Insurance Agency")
2. ("Patient experience" OR "Package Holder" OR experience* OR View* OR Opinion* OR Perception* OR attitude* OR feeling* OR perspective* OR Satisfaction*)
3. (Regional OR Rural OR Remote OR "isolate* communit*"
4. 1 AND 2 AND 3

References: The reference list of literature concerning NDIS package holders/ patients; families and carers; planning process and NDIS were also screened for inclusion. Authors were also contacted for follow up.

Figure One: *Search Strategy*

FIGURE 1 Search string for the scoping review.

literature and were included to supplement the seven research papers found.

All studies encompassed varied geographical locations throughout Australia; however, it is important to note although it was an inclusion criteria for papers to include regional, rural and/or remote participants, there is inconsistency between papers as to the number of participants within these geographical areas. Notably, only three papers[38-40] stated the use of area classification tools such as Modified Monash Model (MMM) and the Rural, Remote and Metropolitan Area classification (RRMA) to define the geographic regions within the literature.

There is also diversity in the level that the NDIS planning process is captured in the included papers. Some papers raised the issues of the planning process as part of the overall scheme whilst other papers discussed it as part of the NDIS implementation and NDIS markets. Only four papers exclusively focused on the NDIS planning process.[7,21,39,40,41] To illustrate and summarise the main findings, Table 3 provides an overview of the literature included in this review.

4 | THEMATIC ANALYSIS FINDINGS

Five main themes and two subthemes were identified:

1. Healthcare and NDIA workforce.
    a. Rural health workforce and NDIA staffing.
        b. NDIS planners and Local Area Coordinators disability awareness.
2. Lack of awareness of NDIS by package holders and carers.
3. Culturally and linguistically diverse and Indigenous Australian populations.

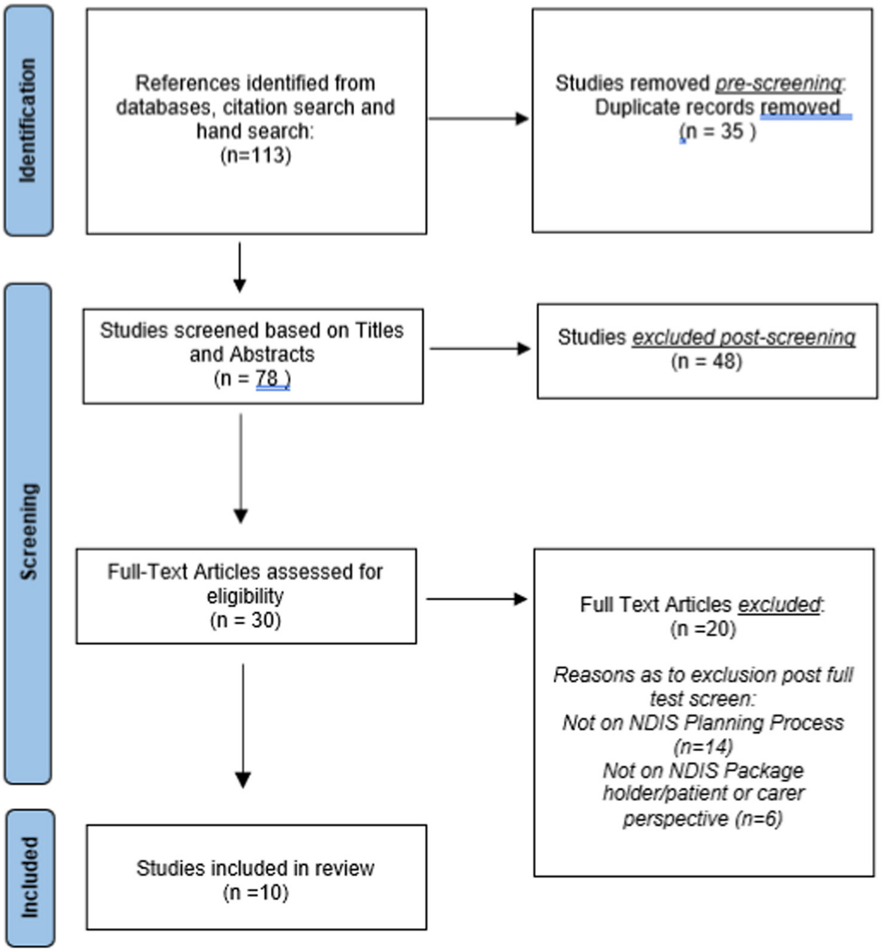


FIGURE 2 Prisma results.

4. Travel funding.
5. Emotional burden.

4.1 | Healthcare workforce and NDIA workforce

Multiple issues regarding the health care workforce and NDIA workers in regional, rural and remote areas were identified in the literature. The main findings were further separated into two subcategories:

- Rural, Regional and Remote Health Workforce and NDIA Staffing.
- NDIS Planners and Local Area Coordinators (LAC) disability awareness.

4.2 | Rural health workforce and NDIS planning workforce

The included papers stated that there are limited resources to gain the necessary evidence-reports for the NDIS planning process. Six of the included papers reported on there being insufficient service providers and professional supports in regional, rural and remote areas.[7,21,39,40,41,42] Individual choice and control over the NDIS planning process within these geographical locations was reportedly due to multiple factors, including a transient health/NDIA workforce, staffing shortages, and low capacity of service providers/NDIA staff within these regions[7,21] (Barr et al., 2021; Lloyd et al., 2019). This issue is illustrated by this quote from a Carer of a NDIS participant from regional Victoria cited in Tune (2019, page: 41):

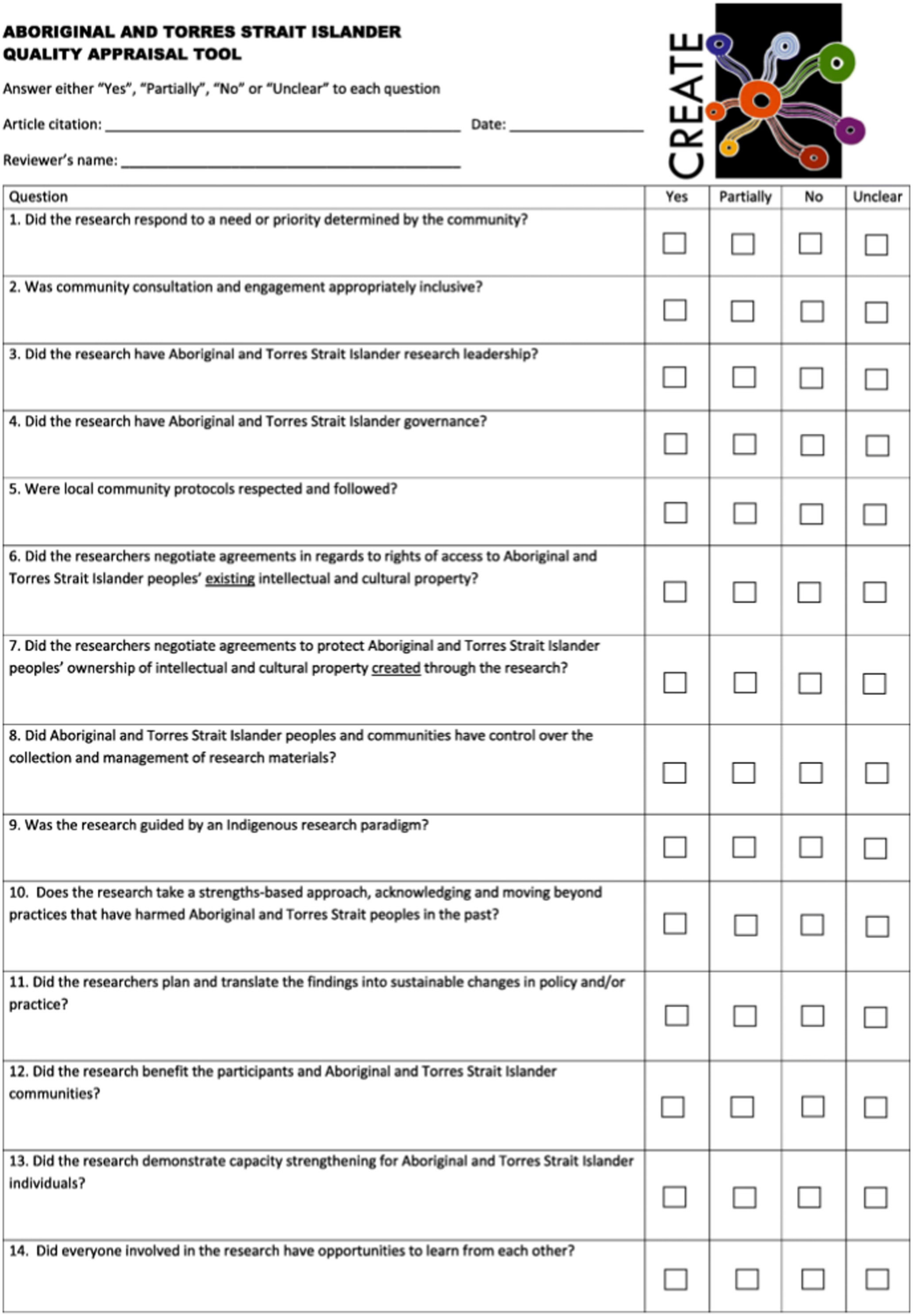
> LACs have too many clients and cannot do their jobs properly, one LAC told me that their caseloads aren't even capped. How can they support people adequately if they are so time poor that they can't return phone calls or answer emails within a day or so the participant is likely to have an extremely serious problem such as lack of access or if the plan isn't spent they will lose money in the next plan.
>
> (Carer of NDIS participant, regional Victoria)

TABLE 1 Qualitative paper appraisal using MMAT.

	Screening for all types						
Publication authors/year	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**Is the qualitative approach appropriate to answer the research question?**	**Are the qualitative data collection methods adequate to address the research question?**	**Are the findings adequately derived from the data?**	**Is the interpretation of results sufficiently substantiated by data?**	**Is there coherence between qualitative data sources, collection, analysis and interpretation?**
Boaden et al.[42]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dew et al.[45]	Yes	Yes	Yes	Yes	Yes	Yes	Uncertain (need more info)
Howard et al.[44]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Loadsman et al.[36]	Unclear	Yes	Yes	Yes	Yes	Yes	Yes

TABLE 2 Mixed methods appraisal of included qualitative papers.

	Screening for all types						
Publication authors/year	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**5.1. Is there an adequate rationale for using a mixed methods design to address the research question?**	**5.2. Are the different components of the study effectively integrated to answer the research question?**	**5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?**	**5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**
Barr et al.[39]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lakhani et al.[43]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lloyd et al.[41]	No (report findings)	Yes	Yes	Yes	Yes	Yes	Yes
Mavromaras et al.[21]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
NDIA[40]	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tune, D[7]	Yes	Yes	Yes	Yes	Yes	Yes	Yes



ABORIGINAL AND TORRES STRAIT ISLANDER QUALITY APPRAISAL TOOL

CREATE

Answer either "Yes", "Partially", "No" or "Unclear" to each question

Article citation: ______________________________ Date: ______________

Reviewer's name: ______________________________

Question	Yes	Partially	No	Unclear
1. Did the research respond to a need or priority determined by the community?	☐	☐	☐	☐
2. Was community consultation and engagement appropriately inclusive?	☐	☐	☐	☐
3. Did the research have Aboriginal and Torres Strait Islander research leadership?	☐	☐	☐	☐
4. Did the research have Aboriginal and Torres Strait Islander governance?	☐	☐	☐	☐
5. Were local community protocols respected and followed?	☐	☐	☐	☐
6. Did the researchers negotiate agreements in regards to rights of access to Aboriginal and Torres Strait Islander peoples' existing intellectual and cultural property?	☐	☐	☐	☐
7. Did the researchers negotiate agreements to protect Aboriginal and Torres Strait Islander peoples' ownership of intellectual and cultural property created through the research?	☐	☐	☐	☐
8. Did Aboriginal and Torres Strait Islander peoples and communities have control over the collection and management of research materials?	☐	☐	☐	☐
9. Was the research guided by an Indigenous research paradigm?	☐	☐	☐	☐
10. Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Aboriginal and Torres Strait peoples in the past?	☐	☐	☐	☐
11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	☐	☐	☐	☐
12. Did the research benefit the participants and Aboriginal and Torres Strait Islander communities?	☐	☐	☐	☐
13. Did the research demonstrate capacity strengthening for Aboriginal and Torres Strait Islander individuals?	☐	☐	☐	☐
14. Did everyone involved in the research have opportunities to learn from each other?	☐	☐	☐	☐

FIGURE 3 CREATE appraisal tool.

TABLE 3 Literature on carer and NDIS package holder experiences/perspectives on the NDIS planning process.

Author	Year	Title and literature grade	Focus of the paper	Methods used	Participants	Regional/rural/remote setting	Findings
Barr, M., Duncan, J., & Dally, K.	2020	Parent experience of the national disability insurance scheme (NDIS) for children with hearing loss in Australia. Peer Reviewed	Aimed at exploring the experience and expectations of parents/carers of children with hearing loss and their interaction with the NDIS	Data were collected during a national roll-out of the NDIS. Mixed method design involving a survey and interview follow-up. All survey participants then involved in semistructured individual interviews over the phone/videoconference.	100 parents of children with hearing loss. 57% were on the NDIS and 38% were eligible. 5% had been declined by the NDIS.	18 parents ($n=18$) from the 100 participants identified as living in rural areas across Australia excluding the Northern Territory.	Parents mainly reported: Feeling unprepared to commence the NDIS process. Long delays with NDIS planning and funding due to poor communication and knowledge of NDIS staff. Parents from rural/remote/regional and/or CALD and/or lower socio-economic backgrounds were at increased risk of experiencing hardships when navigating the NDIS
Boaden, N., Purcal, C., Fisher, K., & Meltzer, A.	2020	Transition Experience of Families with Young Children in the Australian National Disability Insurance Scheme (NDIS) Peer Reviewed	Social ecological model into understanding the families' experiences in transitioning to the NDIS	Two time point study in New South Wales with surveys and interviews with families and service providers.	Both surveys were completed by 282 respondents 125 family members and 157 service providers. 62 lost to follow-up	Participants from all Local NSW health districts. 48–49% lived in Metropolitan Sydney region with the others in regional and rural areas	Families identified delays and communication problems during the initial phase of the NDIS.
Dew, A., Vaughan, P., McEntyre, E., & Dowse, L.	2019	'Our ways to planning': Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability. Peer Reviewed	Report on the development of the 'Our Ways to Planning' Framework—for Australian Organisations to adopt culturally safe practices when planning with Aboriginal and Torres Strait Islander people with disability.	Data collected via community-led research with Aboriginal people and their families and workers from five different communities in New South Wales. Community mapping was utilised to understand the experiences of Aboriginal people with disability and their families regarding planning and accessing disability services	26 Aboriginal people across five different communities included eight who identified as having a disability, 12 family members of a person with disability and six workers. (There was some cross over between participants i.e. workers and those who identified as having a disability)	Five communities in urban, regional, rural and remote NSW—Does not specify percentage of participants from each area.	Three 'Bridges' were identified for organisations—Knowledge, understanding and choice. Focusing on the importance of the collaboration of non-Aboriginal-based organisations and community-based Aboriginal organisations to provide culturally safe services. As well as understanding and acknowledging Aboriginal cultures, histories and perspectives in the planning process.

(Continues)

TABLE 3 (Continued)

Author	Year	Title and literature grade	Focus of the paper	Methods used	Participants	Regional/rural/ remote setting	Findings
Howard, A., Blakemore, T., Johnston, L., Taylor, D., & Dibley, R.	2015	'I'm not really sure but I hope it's better': early thoughts of parents and carers in a regional trial site for the Australian National Disability Insurance Scheme Peer reviewed	Present findings on the perspectives of parents and carers of children in one NDIS trial site—Hunter Region of New South Wales	Mixed Method pilot study involving surveys and follow-up interviews, examining the perspectives of parents and carers of children on the NDIS	171 parents contacted 64% interview only, 1% survey and 29% interview only, and no response from 6%	Hunter Regional area. Newcastle, Port Stephens and Lake Macquarie regional area. Almost all located in a regional area.	Research participants reported they had a lack of knowledge of the NDIS and difficulty communicating with the NDIS. This study also highlighted areas in which the NDIS had bolstered the supports for package holders and where improvements could be made.
Lakhani, A., McDonald, D., & Zeeman, H	2018	Perspectives of the National Disability Insurance Scheme: participants' knowledge and expectations of the scheme. Peer Reviewed	Aimed at identifying participants perspectives on the NDIS in South-eastern Queensland	Mixed methods approach involving a cross-sectional survey on future NDIS package holders gathering qualitative and quantitative data.	70 participants inclusive of people with disabilities and their guardians, carers and/or family members	Participants had to reside in the Southern district of South-East Queensland, or be located in one regional location outside of this district. Does not specify percentage of participants in metropolitan vs regional areas.	Approximately half of participants identified as having little to no knowledge of the NDIS and indicated the need for training to navigate the NDIS.
Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A.	2020	Engaging with National Disability Insurance Scheme Planning: perspectives of parents of an adult with intellectual disability Peer Reviewed	Investigated the experiences of families with an adult child with intellectual disability and their interaction with the NDIS planning process in Australia.	19 adults with intellectual disabilities responded to closed and Likert-type items and provided comments. Responses were reported using frequencies and parental comments used to exemplify their views.	19 families with an adult member with an intellectual disability in Queensland. Respondents included 19 mothers.	Queensland-based four families lived in Metropolitan areas 13 in regional areas Two in rural areas	Results indicated an improvement in the availability of NDIS information and awareness; increased choice and control of participants; however, concerns were raised regarding the implementation of plans and the lack of inclusion of the NDIS package holder in the NDIS planning process.

TABLE 3 (Continued)

Author	Year	Title and literature grade	Focus of the paper	Methods used	Participants	Regional/rural/remote setting	Findings
Loadsman, J. J., & Donelly, M.	2020	Exploring the wellbeing of Australian families engaging with the National Disability Insurance Scheme in rural and regional areas. Peer Reviewed	This study explored the experiences of families living outside Urban areas and engaging with NDIS.	Utilising interpretative phenomenological analysis of audio-recorded and transcribed interviews and field notes.	Eight participants from six family groups who were primary carers for a child or young person with a disability and a complex medical condition.	All participants selected for this study resided in rural to remote region within Northern NSW and Queensland.	This study provided insight into the inequities to access of the NDIS in regional/rural/remote areas. Highlight inequities in wellbeing outcomes for families and participants from nonurban regions.
Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., Goode, A., Walton, H., Smith L., Wei, Z., & Flavel, J.	2018	Evaluation of the NDIS: final report Grey Literature	Evaluate the NDIS trial sites' impacts on people with disability and their families and carers, the disability sector and its workforce, mainstream providers and services, stakeholders and the wider communities. The trials were located in South Australia (SA), Tasmania (TAS), New South Wales (NSW), Victoria (VIC), the Australian Capital Territory (ACT) and the Barkly region in the Northern Territory (NT).	Mixed methods involving a longitudinal survey of people with disability, workers, and stakeholders and semi-structured interviews.	Trial sites: • South Australia • Tasmania • ACT • Barwon Region in VIC • Hunter Area in NSW • Barkley Region NT The report stated that participation in the survey had many problems, such as numbers in the first of the two collection periods.	In the Barkley site, 36 participants were interviewed. 14 people with disabilities and 20 carers and/or family members 62 NDIS participants and their carers in five trial sites SA, TAS, Hunter Area NSW, Barwon Region VIC The participation information does not identify regional locations of the participants.	Several main findings emerge from the evaluation of the NDIS. • The scheme has been designed and built on sound fundamentals. • The NDIS has been delivering the outcomes that it was designed to deliver. • Some design aspects and implementation outcomes are not person-centred as originally desired, and several outcomes are not attained at the speed that was originally expected.
National Disability Insurance Agency, Research and Evaluation Branch	2021	The Second Independent Assessment Pilot Evaluation Report Grey Literature	Report presented evaluation findings from the Second Independent Assessment tool. Mainly the experiences of the participants and independent assessors on the Independent assessment process.	This evaluation administered voluntary online surveys to participants and/or their support person/s and independent assessors. A follow-up survey was sent to a sample of participants/supporters for further detail including open and closed ended questions for thematic analysis.	116 Interviews (53 with NDIA participants and 63 with support person/s). 110 NDIA participants completed both online surveys	Major city (MM1) $n = 724$, 79.5% of total Regional (MM2-3) $n = 112$, 12.3% of total Rural and Remote (MM4-7) $n = 75$, 8.2% of total	Majority of participants/supporters reported positively about the NDIS planning process. Mainly identifying the need to improve communication and awareness around the NDIS planning process as well as involving participants in the process to achieve participant-centred outcomes. Majority of participants also identified a preference for face-face assessments.

(Continues)

TABLE 3 (Continued)

Author	Year	Title and literature grade	Focus of the paper	Methods used	Participants	Regional/rural/remote setting	Findings
Tune, D	2019	Review of the National Disability Insurance Act 2013: removing red tape and implementing the NDIS participant service guarantee	A review of the NDIS Act 2013 to provide recommendations and solutions to introduce the Participant Service Guarantee/	Mixed-methods with a broad consultation and written public submission process. A targeted approach for rural/remote regions. The consultation targeted people with disability, service providers, and advocates and government representatives. Quantitative data were collected via a survey about peoples' experience of the NDIS and from the NDIA's NDIS package holder databases.	201 submissions from participants, families and carers, service providers, advocates and peak bodies (80 individuals) 1273 long-form form survey responses and 467 short-form coverage ($n=1740$ were included) 32% were NDIS Package holders and 57% were carers/family members the remaining 11% were workforce. 15 face-face community workshops in capital cities and regional locations in each state. Six workshops were held for Aboriginal and Torres Strait Islander people led by peak community bodies for cultural sensitivity. Seven focus groups with people with intellectual disability and from culturally and linguistically diverse backgrounds in each state.	Survey participants: • 51% of participants lived in a capital city • 42% lived in a regional city or town • 7% lived in a remote town or area Further demographics on submissions and community workshops were not provided	The study identified the strengths and weaknesses of the NDIS. The implementation of the NDIS has not been smooth. Study concluded that the NDIS planning process was overly bureaucratic and administratively overwhelming. Many of the NDIA's administrative process are recent and not fully evolved.

Barr et al.,[39] Tune,[7] and Mavromaras et al.[21] reported on the isolation of NDIS participants living in rural and remote areas during the initial stages of the NDIS planning process. These research publications reported that people with disability felt that LACs and NDIA planners have a lack of awareness on the barriers to specialised services for people with disability living in these geographical locations.

4.3 | Disability awareness amongst NDIS planners and local area coordinators

Two papers reported on parents' and package holders' satisfaction with LACs and NDIA planners in nonmetropolitan areas.[40,41] The majority of other papers[39,43,44] reported that although some carers and package holders in rural settings were content with the funding they have received, they were dissatisfied with NDIS planners themselves due to the NDIA workforce's lack of knowledge about disability, disability services and regional/remote region accessibility to services, resulting in drawn out and complicated processes. One example is from Tune (2019, p.136):

> We had to go through the plan review process because of errors made by the NDIS in relation to the miscalculation of money amounts. NDIS basic mistakes should be easy to correct instead of my daughter being dragged through the plan review process.
>
> (Carer of NDIS Participant, Regional Victoria)

Three of the papers[7,21,39] reported cases of NDIA planners declining participants requests for specific supports despite the plan drawing on professional advice/reports from qualified health professions, such as occupational therapists and physiotherapists. Two studies[21,39] noted that these occurrences of rejected allied health/medical profession input were related to the lack of awareness of NDIA workers.

4.3.1 | NDIS package holders and carers lack of awareness of the NDIS

Three papers identified a relationship between living in regional, rural or remote areas and decreased access to preparatory transition supports for people who transitioned from the old government funded system to the newly established NDIS.[39,42,44] Seven of the papers[7,21,39,42,43,44] reported that NDIS participants living in regional, rural or remote areas were uninformed about the NDIS and unaware of how to find information.

Tune[7] (2019), Lloyd et al.[41] and Howard et al.[44] reported that whilst most NDIS package holders felt that awareness of what the NDIS could provide was improving in these geographic regions, accessibility to information regarding the NDIS was not disability friendly or culturally appropriate. Most participants in the study conducted by Lloyd[41] and Tune's[7] report indicated that when contacting the NDIA for assistance, they were only directed to the website that remains difficult to navigate and lacks any alternative formats such as languages other than English, Australian sign language (Auslan) or Easy read.[7,41] Mavromaras et al.[21] identified that regional, rural and remote areas had the added complication of limited access to Internet diminishing online engagement with NDIA.

National Disability Insurance Scheme participants and their carers living in regional, rural and remote areas of Australia also reported on a combination of difficulties accessing NDIA information and miscommunication as key factors in plan dissatisfaction.[7,21,41,44] The papers reported that carers of NDIS package holders felt dissatisfied with the lack of inclusion of the package holder within the planning process. In addition, carers and NDIS package holders reported that further consideration to involving package holders in the planning meeting was needed to ensure that plans were tailored to the perspective of the person with a disability and not solely their guardians.[40,41] One suggestion was to improve communication strategies between people with disability and the NDIA/LACs.[21,40,41] Lloyd et al.[41] provides a direct quote from a parent carer living in a rural/remote area regarding accessing information during the planning process '*…there were no pictures or anything there is no way he could understand it!*'.

Of the few papers that discussed Aboriginal and Torres Strait Islander interactions with the NDIS during the planning process, those who lived in rural or remote areas were more at risk of communication breakdowns leading to delays in plan approvals and reviews.[7,21]

4.3.2 | Cultural competence and cultural safety

Five papers[7,21,39,41,42] reported a relationship between people's education attainment levels, socio-economic status, main spoken language, and regional location and their ability to self-advocate during the NDIS planning process. The access to already existing social capital and geographic capacity within urban areas led to better advocacy skills during the planning process and consequently higher levels of funding.[42]

The need for culturally appropriate services to support NDIS package holders and their carers from culturally and linguistically diverse (CALD) backgrounds was reported on in most publications. Four papers reported that people from cultural minority backgrounds had significant difficulty in navigating the NDIS application and planning processes.[7,21,39,42]

Four publications[7,21,42,45] included the voices of Aboriginal and Torres Strait Islander carers and/or package holders. Local Aboriginal and Torres Strait Islander communities in regional, rural and remote settings were identified as struggling to understand the NDIS and the definition of disability.[21] Discussions about disability in Indigenous communities in these regions is relatively recent. These papers raised the need to establish a shared understanding about the disability and the NDIS planning process amongst remote, rural and regional Aboriginal and Torres Strait Islander communities.[21,45]

One study identified the reluctance of Aboriginal and Torres Strait Islander people with disability to access the NDIS due to historical distrust of governmental services.[45] Boaden et al.[42] identified that Aboriginal liaisons within these communities are needed to link personal-familial needs via an appropriate service supports system, allowing for culturally appropriate service delivery. One key suggestion for improvement was to ensure that both Aboriginal and non-Aboriginal workers had the appropriate knowledge and training to establish a culturally competent service system.[7,45] A report from Mavromaras et al.[21] captured this well:

> The NDIS worked less well for Aboriginal people living in remote communities and those without English language skills or advocates. For these people a lack of communication and, effective engagement with the NDIA was observed. Even where Indigenous respondents spoke English well and could communicate with NDIA staff, historical perceptions, misunderstandings, past experiences and beliefs may have hindered engagement and comprehension. Considerable confusion about the specific role of the NDIS and NDIA were also reported.

4.4 | Travel funding

Six papers identified that people living in regional, rural or remote areas expressed issues with insufficient funding to cover required travel during the NDIS planning process.[7,21,38,39,41,42] This quote from Loadsman and Donelly[38] exemplifies the sentiments of a carer of a NDIS package holder: 'People that don't live rurally have no idea how hard it is or how far you have to travel to get services'.

Five papers[7,21,38,41,42] reported that the NDIA was not aware of the needs of people living in regional, rural and remote regions. Many package holders' plans did not adequately accommodate travel costs required to conduct the planning process, such as attending meetings with allied health services, medical facilities and other required evidence to inform the development of the plan.[38,41] Although the NDIS packages include some funds for the cost of therapists and NDIA staff travel, they did not include funding for NDIS package holders and their carers to travel for appointments.[7,38,41,42] Consequently, some families reported that they were not able to attend meetings/therapy sessions to properly complete the planning process.[7,38,41]

Inadequate travel allowance was a major finding throughout the papers for NDIS package holders, who reported that this was largely due to LACs and planners lack understanding of the geographical distances between remote/rural/regional communities.[7,21,38,39,41,44]

4.4.1 | Emotional burden

Four studies[7,21,39,44] reported that people with disability living in regional, rural and remote areas described the NDIS planning process as an emotionally traumatic experience. The main contributing factor to their experience is that people with disability must prove that they have a lifelong disability that will not improve over time. Barr et al.[39] provides insight from a carer of an NDIS participant during the NDIS planning process:

> They are still deaf, so why justify every year that they have a lifelong disability? The NDIS process is heartbreaking because you constantly feel like you are going to lose the funding you worked so hard to receive. Every year I have to relive the trauma of what happened to my kids and focus on their disabilities in order to get funding … I am heartbroken.
>
> (North Coast NSW survey)

Three studies described carers and package holders experience of the planning process as inducing reoccurring feelings of anxiety and stress due to the conflicting requirements to have 'evidence' of disability and support needs.[21,38,39] Two studies reported that although strength-based principles are best practice, consequently identifying package holder strengths during the planning process may lead to a reduction in the amount of NDIS funding received.[38,39]

Carers in regional, rural or remote areas reported feeling overwhelmed by the competing nature of running a family household, navigating the complexities of the

NDIS and travel.[38,39,41] Howard et al.[44] raised concerns that support for family members is an important consideration during the planning process. The financial and emotional burden of travelling large distances for health care services was identified as having psychological impact on carers and NDIS package holders.[38,44]

5 | DISCUSSION

This scoping review found only 10 papers reporting on the NDIS planning process experiences of people living in regional, rural and remote geographic locations. Only a few papers offered insights into the experiences of Aboriginal and Torres Strait Islander people or culturally and linguistically diverse populations within these geographic regions. The findings of this review indicate that currently, there is very limited published research specifically focused on the experiences of NDIS package holders and carers during the NDIS planning process in regional, rural and remote areas.

Many papers reported on the implementation and funding of the NDIS; however, there remains limited investigation of the planning process itself. This review found that there was an improvement in people's experiences of the NDIS planning process between recent and older studies as the NDIS roll-out progressed from 2013. The improvements were mainly related to the person/NDIA interactions and the NDIS package funding amounts. There remain concerns regarding the communication between NDIA staff and package holders and their carers, and the skillsets of NDIA staff and the expectations of NDIA package holders and their carers during the initial stages of the planning process. Studies also reported the negative impact that transient health workforce and inexperienced NDIA staff can have on the emotional burden of NDIS package holders and carers during the planning process. These findings supported previous studies conducted into the impacts of transient health workforce in rural and remote settings across Australia.[46-48]

Although Aboriginal and Torres Strait Islander people report twice the rate of disability than the non-Indigenous Australian population[49] and, many scholars[10,15,50,51] advocating for a culturally safe disability services sector, our review identified only four studies reporting on Aboriginal peoples' experiences of the NDIS planning process in regional, rural and remote regions highlighting the need for further research with this group.

The emotional burden and socio-economic/geographical barriers that impact on people's experiences of the NDIS planning process were closely interlinked within the literature, with carers and package holders reporting on burn out. One recommendation to improve the planning experience is to improve outreach services in rural, remote and regional areas to assist in the initial planning process. In addition, the publications reported that investment is needed to support the allied health sector for providing people with disability reports for the planning process.[7,10,48]

Travel cost burden amongst package holders and their carers remains uniquely a regional, rural and remote issue given the geographic size of Australia and the distribution of the population. Lack of inclusion of funding for participants' travel during the planning stages of the NDIS was identified as a barrier to service provider accessibility/delivery during the implementation stage within these regions.[52] Governments have been struggling with transport challenges in regional, rural and remote areas for many decades. Research reporting workers' perspectives also accentuates these challenges, as well as further providing insight into service providers travel cost burdens and the correlation with having minimum client numbers/sufficient work to entice them to travel to certain regions.[52,53]

The small number of papers that met the inclusion criteria illustrates the need for further investigation into the NDIS planning process as there remains limited understanding of package holders' and carers' experiences. Consequently, the inability to properly capture these people's experiences of the planning process in research could be contributing to the slow improvement of the planning process for people living in regional, rural and remote regions.

6 | LIMITATIONS

There are limitations within this study to be considered when interpreting the findings. As per the selection criteria, papers were only selected if they also included rural, remote and/or regional areas as a component of the study. It is important to note that not all papers spoke equally on all geographical locations and that to ensure anonymity of rural and remote participants some identifying factors (e.g. cultural background or type of impairment) were removed from papers that may have contributed to the overall findings of this scoping review. Furthermore, almost all papers included in this review discussed the NDIS in its entirety with varying levels of reporting on the NDIS planning process. From these papers, there were limited Aboriginal and Torres Strait Islander participants or culturally and linguistically diverse participants included to provide their perspective and experiences. Thus, identifying further research is needed to compare perceptions of the NDIS planning process.

7 | CONCLUSION

This scoping review, whilst based on a small number of publications, identified that, as it approaches a decade since first trialled, the NDIS planning process has improved, however, improvements are required specifically for people living in regional, rural, and remote geographic locations and for those from Aboriginal and Torres Strait Islander backgrounds.

AUTHOR CONTRIBUTIONS

Sarah Veli-Gold: Conceptualization; writing – review and editing. **John Gilroy:** Conceptualization; funding acquisition; methodology; project administration; supervision. **Wayne Wright:** Formal analysis; writing – review and editing; validation; writing – original draft. **Kim Bulkeley:** Writing – review and editing; validation; conceptualization. **Heather Jensen:** Writing – review and editing; validation. **Angela Dew:** Writing – review and editing; validation. **Michelle Lincoln:** Writing – review and editing; validation.

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REFERENCES

1. Australian Government Productivity Commission. Disability care and support draft inquiry report. Canberra: Productivity Commission; 2011.
2. Productivity Commission. Disability care and support: inquiry report. Canberra: Australian Government Publishing; 2011.
3. Productivity Commission. National Disability Insurance Scheme (NDIS) costs. Canberra: Productivity Commission; 2017.
4. National Disability Insurance Agency (NDIA). Building the national disability insurance scheme progress report: year one [Internet]. Canberra: NDIA; 2014.
5. National Disability Insurance Agency. Annual report 2020–21. Canberra: NDIA; 2021.
6. United Nations General Assembly. Convention on the rights of persons with disabilities: resolution adopted by the general assembly. New York: United Nations, 2007 January A/RES/61/106; 2007.
7. Tune D. Review of the National Disability Insurance Scheme act 2013: removing red tape and implementing the NDIS participant service guarantee. Canberra: Department of Social Services; 2019.
8. Wark S. How do we support genuine decision–making for people with intellectual disability outside of the 'big smoke'? Intellect Disabil Aust. 2020;41(2):5–8.
9. National Disability Insurance Agency. Operational guidelines. Canberra: NDIA; 2020.
10. Gilroy J, Dew A, Barton R, Ryall L, Lincoln M, Taylor K, et al. Environmental and systemic challenges to delivering services for Aboriginal adults with a disability in Central Australia. Disabil Rehabil. 2020;43:2919–29.
11. Hummell E, Venning A, Foster M, Fisher KR, Kuipers P. A rapid review of barriers and enablers of organisational collaboration: identifying challenges in disability reform in Australia. Aust J Soc Issues. 2022;57(2):441–57.
12. Johnson E, Lincoln M, Cumming S. Principles of disability support in rural and remote Australia: lessons from parents and carers. Health Soc Care Community. 2020;28(6):2208–17.
13. Wark S. Does intellectual disability research consider the potential impact of geographic location? J Intellect Dev Disabil. 2018;43(3):362–69.
14. Dintino R, Wakely L, Wolfgang R, Wakely KM, Little A. Powerless facing the wave of change: the lived experience of providing services in rural areas under the National Disability Insurance Scheme. Rural Remote Health. 2019;19(3):5337.
15. Dew A, Barton R, Gilroy J, Ryall L, Lincoln M, Jensen H, et al. Importance of land, family and culture for a good life: remote aboriginal people with disability and carers. Aust J Soc Issues. 2020;55(4):418–38.
16. Dew A, Bulkeley K, Veitch C, Bundy A, Lincoln M, Brentnall J, et al. Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas. Health Soc Care Community. 2013;21(4):432–41.
17. Olney S, Dickinson H. Australia's new National Disability Insurance Scheme: implications for policy and practice. Policy Des Pract. 2019;2(3):275–90.
18. Cortese C, Truscott F, Nikidehaghani M, Chapple S. Hard-to-reach: the NDIS, disability, and socio-economic disadvantage. Disabil Soc. 2020;36:883–903.
19. First People's Disability Network (Australia). Response to the productivity commission position paper on National Disability Insurance Scheme (NDIS) costs. Redfern: FPDN; 2017.
20. Russo F, Brownlow C, Machin T. Parental experiences of engaging with the National Disability Insurance Scheme for their children: a systematic literature review. J Disabil Policy Stud. 2020;32:67–75.
21. Mavromaras K, Moskos M, Mahuteau S, Isherwood L. Evaluation of the NDIS: final report. Adelaide: Flinders University; 2018.
22. Collings S, Dew A, Dowse L. Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. J Intellect Dev Disabil. 2016;41(3):272–6.
23. Collings S, Dew A, Dowse L. “They need to be able to have walked in our shoes”: what people with intellectual disability say about National Disability Insurance Scheme planning. J Intellect Dev Disabil. 2019;44(1):1–12.

24. Trounson JS, Gibbs J, Kostrz K, McDonald R, Peters A. A systematic literature review of Aboriginal and Torres Strait Islander engagement with disability services. Disabil Soc. 2020;37:1–25.
25. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19–32.
26. Australian Bureau of Statistics. Australian statistical geography standard (ASGS): volume 5 remoteness structure. Canberra: ABS; 2011. Report No.: 1270.0.55.005.
27. Sandelowski M, Barroso J. Finding the findings in qualitative studies. J Nurs Scholarsh. 2002;34(3):213–9.
28. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
29. Braun V, Clarke V. Conceptual and design thinking for thematic analysis. Qual Psychol (Washington, DC). 2021;9(1):3–26.
30. McCalman J, Campbell S, Jongen C, Langham E, Pearson K, Fagan R, et al. Working well: a systematic scoping review of the indigenous primary healthcare workforce development literature. BMC Health Serv Res. 2019;19(1):767.
31. Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, et al. The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. Educ Inf. 2018;34(4):285–91.
32. Hong QN, Gonzalez-Reyes A, Pluye P. Improving the usefulness of a tool for appraising the quality of qualitative, quantitative and mixed methods studies, the mixed methods appraisal tool (MMAT). J Eval Clin Pract. 2018;24(3):459–67.
33. Hong QN, Pluye P. A conceptual framework for critical appraisal in systematic mixed studies reviews. J Mixed Methods Res. 2019;13(4):446–60.
34. Pace R, Pluye P, Bartlett G, Macaulay AC, Salsberg J, Jagosh J, et al. Testing the reliability and efficiency of the pilot mixed methods appraisal tool (MMAT) for systematic mixed studies review. Int J Nurs Stud. 2012;49(1):47–53.
35. Pluye P, Gagnon M-P, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. Int J Nurs Stud. 2009;46(4):529–46.
36. Harfield S, Pearson O, Morey K, Kite E, Glover K, Canuto K, et al. The Aboriginal and Torres Strait Islander quality appraisal tool: companion document. Adelaide South Australian Health and Medical Research Institute: Adelaide, SA; 2018.
37. National Health and Medical Research Council. Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research. Canberra: Australian Government Publishing; 2003.
38. Loadsman JJ, Donelly M. Exploring the wellbeing of Australian families engaging with the National Disability Insurance Scheme in rural and regional areas. Disabil Soc. 2020;36:1449–68.
39. Barr M, Duncan J, Dally K. Parent experience of the National Disability Insurance Scheme (NDIS) for children with hearing loss in Australia. Disabil Soc. 2020;36(10):1663–87.
40. National Disability Insurance Agency RaEB. The second independent assessment pilot evaluation report. Canberra, ACT: NDIA; 2021.
41. Lloyd J, Moni K, Cuskelly M, Jobling A. Engaging with National Disability Insurance Scheme Planning: perspectives of parents of an adult with intellectual disability. J Intellect Dev Disabil. 2020;45(3):254–63.
42. Boaden N, Purcal C, Fisher K, Meltzer A. Transition experience of families with young children in the Australian National Disability Insurance Scheme (NDIS). Aust Soc Work. 2021;74:294–306.
43. Lakhani A, McDonald D, Zeeman H. Perspectives of the National Disability Insurance Scheme: participants' knowledge and expectations of the scheme. Disabil Soc. 2018;33(5):783–803.
44. Howard A, Blakemore T, Johnston L, Taylor D, Dibley R. 'I'm not really sure but I hope it's better': early thoughts of parents and carers in a regional trial site for the Australian National Disability Insurance Scheme. Disabil Soc. 2015;30(9):1365–81.
45. Dew A, Vaughan P, McEntyre E, Dowse L. 'Our ways to planning': preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability. Aust Aborig Stud. 2019;2:3–18.
46. Keane S, Smith T, Lincoln M, Fisher K. Survey of the rural allied health workforce in New South Wales to inform recruitment and retention. Aust J Rural Health. 2011;19(1):38–44.
47. Australian Government Department of Health and Ageing. Report on the audit of health workforce in rural and regional Australia. NSW: Department of Health and Ageing; 2008.
48. Veitch C, Battye K. Rural health workforce: planning and development for recruitment and retention. In: Liaw S-T, Kilpatrick S, editors. A textbook of Australian rural health. Canberra: Australian Rural Health Education Network; 2008. p. 113–27.
49. Australian Institute of Health and Welfare (AIHW). Disability support for indigenous Australians. 2021. In AIHW (ed) Australia's Welfare 2021, AIHW, Australia. [cited 2023 Jun 15]. Available from: https://www.aihw.gov.au/reports/australias–welfare/disability–support–for–indigenous–australians
50. Gilroy J. The participation of Aboriginal persons with disability in disability services in New South Wales, Australia [unpublished doctoral thesis on the Internet]. Sydney: University of Sydney; 2012.
51. Avery S, First Peoples Disability Network. Culture is inclusion: a narrative of Aboriginal and Torres Strait Islander people with disability. Sydney: First Peoples Disability Network; 2018.
52. Jessup B, Bridgman H. Connecting Tasmanian National Disability Insurance Scheme participants with allied health services: challenges and strategies of support coordinators. Res Pract Intellect Dev Disabil. 2021;9:1–16.
53. Gallego G, Dew A, Bulkeley K, Veitch C, Lincoln M, Bundy A, et al. Factors affecting retention of allied health professionals working with people with disability in rural New South Wales, Australia: discrete choice experiment questionnaire development. Hum Resour Health. 2015;13(1):22.
54. Barr M, Duncan J, Dally K. Parent experience of the national disability insurance scheme (NDIS) for children with hearing loss in Australia. Disabil Soc. 2021;36(10):1663–87.

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