National Centre
of Excellence in
**Intellectual
Disability Health**

First Nations & Intellectual Disability Inclusive Research Report: Lessons Learned

ISBN: 978-1-7641709-5-6

First Nations & Intellectual Disability Inclusive Research Report: Lessons Learned published by the National Centre of Excellence in Intellectual Disability Health

Email: nceidh@unsw.edu.au
Website: www.nceidh.org.au

Enquiries should be directed to the Corresponding Author
Dr Erin Louise Whittle
Centre for Disability Studies, University of Sydney
erin.whittle@sydney.edu.au

Authors
Wayne Wright, Erin Louise Whittle, Bronwyn Gwyther,
Mary-Ann O'Donovan

Affiliations
Centre for Disability Studies, The University of Sydney, Sydney, Australia

Citation

This report should be referenced (or cited) as follows: W. Wright, E. L. Whittle, B. Gwyther, M. O’Donovan 2026, First Nations & Intellectual Disability Inclusive Research Report: Lessons Learned (2026), National Centre of Excellence in Intellectual Disability Health , Sydney

Acknowledgement

The National Centre of Excellence in Intellectual Disability Health receives core funding from the Australian Government Department of Health, Disability and Ageing to support the delivery of the Australian government’s National Roadmap for Improving the Health of People with Intellectual Disability.

Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

Cover Artwork

A group of participants from the NPY lands during a consultation on Arrernte land.

National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government’s National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre’s nine Consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, Centre for Disability Studies and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

Contents

Project Overview

The aim of this project was to explore what was understood by culturally safe and inclusive research and provide learning to support the development of culturally safe, inclusive research training within the National Centre of Excellence in Intellectual Disability Health.

To achieve this, we undertook a number of actions:

i. A scoping review of the available literature related to the intersection of inclusive research and culturally safe research, guided by the question **“***What is the evidence and tools available to support culturally safe and inclusive research with First Nations people with intellectual disabilities and their families?”;*

ii. A series of yarning sessions and reflective sessions with stakeholders at the intersection of First Nations and intellectual disability lived experience.

iii. Data analysis and reflective processes involving First Nations stakeholders

The data collected from these activities has been analysed and triangulated to provide an overall summary of learnings on what is and how to do culturally safe and inclusive research strategy.

The final report is comprised of the following sections:

i. Executive summary
ii. Project team members
iii. Introduction and reason for doing this work
iv. The scoping review
v. The description of the consultation process and findings from the consultations
vi. Reflections and lessons learned from the consultation process
vii. Recommendations for taking findings back to community

Glossary

This is a glossary of terms used in the report and their definitions.

Word	Definition
Aboriginal and Torres Strait Islander	Aboriginal and Torres Strait Islander peoples are the first peoples of Australia, meaning they were here for thousands of years prior to colonisation. They are not one universal group, but rather are many nations and groups that have their own distinct set of languages, histories and cultural traditions.
First Nations	First Nations is an encompassing term that acknowledges that Aboriginal and Torres Strait Islander peoples were the First Peoples of Australia, prior to colonisation. It is preferred over Indigenous, which is considered too generic.
Gubba	White person
Intellectual Disability	A lifelong condition which affects people’s intellectual function, and their adaptive behaviour skills.
Yarn(ing)	Yarning is a way of sharing experiences, knowledge and building culture and connection through storytelling and conversation. However, it is more than just an interview or a conversation. It is deeply important part of First Nations culture.

Executive summary

First Nations people have a long history in Australia and other colonised countries of being subject to research which has been done ‘to’ or ‘on’ them, rather than ‘with’ them. This research has often been conducted in ways that are harmful and exploitative to First Nations people, and the results of that research have been used to justify harmful and racist practices.

First Nations people have a right to ensure to set their own priorities and make decisions about research. Non-First Nations researchers who are working in First Nations spaces have a responsibility to ensure that their ways of working are culturally safe and support First Nations peoples’ right to self determination.

First Nations people with intellectual disability in Australia experience multiple structural disadvantages. However, despite this recognition, the body of literature around the intersection between the experience of intellectual disability and the experience of First Nations people in Australia is underdeveloped.

This project aimed to provide some insight into ways of conducting research around intellectual disability with First Nations people in ways that are culturally safe and appropriate. We conducted a review of the literature around research conducted with First Nations people with intellectual disability. We also conducted a series of consultations with First Nations people with and without intellectual disability to find out what people thought about ways of conducting culturally safe research.

We learned a number of lessons to pass on to other non-First Nations researchers from doing this project. Non-First Nations researchers often did not understand how to do culturally safe research properly. There was a fundamental difference between First Nations and white and Western approaches to disability and intellectual disability. These differences need to be taken into account when conducting culturally safe research. This shows why it is important to have First Nations people and communities involved as researchers and stakeholders at every point during the process. In particular, we learnt that every community and group has different needs and that it was fundamental for cultural safety to make sure that non-First Nations researchers engaged in meaningful and respectful ways with groups to ensure that their needs were met and their rights were protected.

Project Researchers

The project was led by Wayne Wright, who is a Wayilwan and Gamilaraay man with lived experience of disability and supported by Erin-Louise Whittle, who is a White disability researcher, and Bronwyn Gwyther, who is a Wiradjeri and Gamilaraay woman with a hearing impairment. The project was overseen by Mary-Ann O'Donovan, who is a White disability researcher with lived experience as a sibling; her brother has intellectual disability.

Wayne Wright

Wayne Wright is a proud Wayilwan and Gamilaraay man and a passionate advocate for the rights, wellbeing, and leadership of Aboriginal and Torres Strait Islander people with disability. Drawing on extensive lived experience of disability, Wayne brings deep cultural knowledge, community insight, and a commitment to culturally safe practices to every aspect of his work. Wayne currently serves as an Indigenous Disability Researcher at the University of Sydney's Faculty of Medicine and Health / Centre for Disability Studies, where he contributes to national projects that strengthen First Nations leadership in disability research, governance, and policy. He plays a key role in developing culturally safe, inclusive research strategies, co-design frameworks, and accessible resources for Indigenous communities. As a First Nations Representative on the National Centre of Excellence in Intellectual Disability Health's Inclusive Governance Committee, Wayne leads strategic work that ensures cultural integrity, strengthens partnerships, and amplifies the voices of Aboriginal and Torres Strait Islander people across disability research ecosystems.

He works closely with respected First Nations disability leaders, including A/Prof John Gilroy, contributing to the next generation of Indigenous disability scholarship. Wayne's experience spans community engagement, public health advocacy, mental health research, Aboriginal land management, and culturally informed care. His previous roles include Indigenous Research Officer, Community Engagement Officer for the Orange Local Aboriginal Land Council, Aboriginal Case Worker, and Indigenous Youth Worker. He has supported Aboriginal community members through culturally grounded mentoring, trauma-informed care, education, and disability support pathways, including employment, NDIS navigation, and social and emotional wellbeing. With expertise in Indigenous research methodologies, ethical practice, accessible communication, and community-led design, Wayne has contributed to systematic literature reviews, mental health rehabilitation research, policy development, and collaborative research across universities including Sydney, Deakin, and Flinders. Wayne is also dedicated to caring for Country. His ongoing training in cultural burning, heritage preservation, and Indigenous land management reflects his holistic approach to wellbeing, recognising the interconnection between culture, land, identity, and health. A recipient of the 2016 Aboriginal Male of the Year (Orange NAIDOC) and the TAFE NSW Aboriginal Student of the Year, Wayne continues to build his leadership through the University of Sydney's Indigenous Leadership Program. Across all his work, Wayne is driven by a simple but powerful mission: to elevate the voices of Aboriginal and Torres Strait Islander people with disability, ensure cultural safety in all disability systems, and lead change grounded in Country, community, and culture.

Erin-Louise Whittle

Erin-Louise is a post-doctoral researcher at the Centre for Disability Studies. She has an extensive research background in gender, intellectual disability and access to services. Her PhD, completed at UNSW Sydney, examined access to mental health services for women with intellectual disability.

She is strongly focused on issues of equity and access and the social determinants of health for people with intellectual disability and dismantling inequitable systems. She has extensive experience in inclusive research methods, and working as a co-researcher with people with intellectual disability.

Bronwyn Gwyther

Bronwyn Gwyther is the **Manager, First Nations Strategy** at the National Centre of Excellence in Intellectual Disability Health. In this role, Bronwyn lead›s national work to embed Aboriginal and Torres Strait Islander cultural authority across our governance, workforce, research, service design and partnerships. Bronwyn›s focus is ensuring First Nations knowledge, leadership and lived experience drive the Centre’s reforms and help create culturally safe, traumainformed health care for mob with intellectual disability.

Mary-Ann O’Donovan

Mary-Ann currently holds a dual role as Associate Professor of Disability Studies at the University of Sydney and CEO of the Centre for Disability Studies. Her research addresses the social determinants of health for people with intellectual disability. Inequities in access to health, higher education and housing have been the central focus of her work. In the 10 years since completing her PhD, She has led research at National (Ireland and Australian) and European level. She is Editor in Chief of the Journal of Intellectual Disabilities (Jan 2025).

She also has lived experience with a sibling with intellectual disability, which has and continues to inform her drive and passion for system and policy change to support people with intellectual disabilities, and their circles of support, to have voice, choice and autonomy over their lives and to be treated as valued members of society.

Acknowledgements

We would also like to extend our deepest gratitude to Professor John Gilroy for providing his mentorship to the project and research team, and allowing us use of his artworks.

Section One: Introduction and Reason for the Work

Introduction

This project is led by Wayne Wright, a proud Wayilwan and Gamilaraay man and disability advocate and is mentored by Professor John Gilroy, a First Nations disability scholar. It has been overseen by the First Nations Advisory Committee, which is the advisory committee to the National Centre of Excellence in Intellectual Disability Health on First Nations live experience, and is made up of First Nations people with and without intellectual disability.

There is a long history in settler-colonial countries of research being done 'on' First Nations people, rather than 'with' them (1). First Nations people are heavily researched, but that research has historically been conducted by non-First Nations researchers in harmful ways to harmful ends (1-4). Colonial research 'on' First Nations people has been conducted in ways that are harmful and exploitative, without consent or meaningful engagement. The results of that research have often been withheld from First Nations communities, with no translated benefits. The findings of such research have historically been used to justify racist and oppressive policies and practices (4, 5). The United Nations Declaration on the Rights of Indigenous Peoples (the Declaration) described and ratified the rights of Indigenous peoples to self-determination (6). This includes the right of Indigenous people to set their own priorities and make decisions about community development on their own terms, including decisions about research (7).

The concept and practice of ‘cultural safety’ was first developed in the health service space by the lived experience and work of Irihapeti Ramsden, a Māori nurse in Aotearoa, who sought to embed cultural safety as a foundation for nursing training initially and health services more generally (8). Recognition of the historical and ongoing harms perpetuated on First Nations people as a result of colonialism and racism led to the recognition that ‘cultural safety’ must be at the foundation of any process that involves First Nations people (5, 9). In the Australian context, cultural safety should be theoretically embedded into most service delivery, research project or policy development in the health or human services space (10-12). However, in practice this is often not the case and cultural safety is ignored (5).

Walker et al (13) point out that cultural safety as a concept is not something that can be claimed by a service, provider, organisation or program – rather, cultural safety is determined by the First Nations users of the system. Mohamed et al (5) describes the key areas of focus of cultural safety as an analysis of power racism, and acknowledgment of and reflection on ongoing effects of colonisation and white privilege. They also note that cultural safety is not an endpoint, but a journey (5).

Mohamed et al (2021) note some of the following conditions of cultural safety in any setting:

"A culturally safe environment exists if Aboriginal and Torres Strait Islander peoples report that:

1. *their experiences are believed and validated*
2. *their cultures are centred and valued in policy development, research, evaluation and service design and delivery*
3. *they feel welcomed and respected in policy, research, evaluation and service environments*
4. *they see other Aboriginal and Torres Strait Islander people working [in positions of power and authority] within the policy, research, evaluation or service context*
5. *they do not experience any form of racism in policy, research, evaluation and service contexts or processes" (9).*

In turn, culturally unsafe practices demean, or disempower the cultural identity and well-being of First Nations people (14). All and any research which involves or impacts First Nations people must be founded on culturally safe principles and conducted in a culturally safe manner (1, 2, 15-18).

Culturally safety in research involves the embodiment of a number of principles. Cultural safety at its core empowers Aboriginal and Torres Strait Islander voices, involves meaningful engagement and collaboration with community and perhaps most importantly is led by Aboriginal and Torres Strait Islander people (1, 4, 7, 15, 18, 19).

First Nations People, Disability and Intellectual Disability

The compounded experience of disability among First Nations people in Australia and worldwide is well recognised. First Nations people with disability experience multiple structural disadvantages. The United Nations Convention on the Rights of Disabled Persons (UNCDRP) (20) recognises that Indigenous people with disability are subject to multiple and aggravated forms of discrimination. However, despite this recognition, the body of literature around the intersection between the experience of intellectual disability and the experience of First Nations people in Australia is underdeveloped.

The prevalence of intellectual disability in First Nations populations in Australia appears significantly greater than the general population, although the exact figures are contested. Epidemiological figures suggest that 5.9% of Aboriginal and Torres Strait Islanders may suffer from an intellectual disability compared to 2.5% of non-Indigenous Australians (21). Similarly, Bourke et al found that the prevalence of intellectual disability among Western Australian First Nations people was more than twice that for non-First Nations people (22). Reviews of the literature suggest an increased rate of intellectual disability across the life course in Aboriginal and Torres Strait Islander peoples with a number of factors that appear to accelerate the prevalence from roughly two times the rate in childhood to five times the rate for people over 65 years of age (23). However, there is very little research that specifically focuses on the experiences and needs of Aboriginal and Torres Strait Islander people living with disabilities (24, 25).

There is even less research which address the experiences of Aboriginal and Torres Strait Islander people with intellectual disability, despite this research deficit being called out well over a decade ago (21, 26, 27).

This may be in part due to the conflict between Aboriginal and Western concepts of 'disability'. Applying the concept of disability and intellectual disability is challenging, as it is not reflected in Aboriginal and Torres Strait Islander culture (28). The First Nations' conceptualisation of disability is fundamentally and radically different from Western concepts of disability, which dominate settler-colonist countries (22, 28). Scott Avery notes in his seminal text on Aboriginal and Torres Strait Islander lived experience and disability *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability* (24) :

> *"First Peoples expressions of humanity and diversity are more than just observances of functional linguistics. They speak of a belief system that values a person's centeredness over biomedical and physical differences, and acceptance of difference as within the natural order of the world. It is a belief system that governs their behaviours, and comes with such a long-standing track record that it need not be consciously taught. Rather it is modelled through Indigenous people's attitudes towards other members of their community."*

Multiple sources indicate that in most if not all Australian First Nations languages, there is no term which is equivalent to disability or human capability (29) (28). Colonial language and definitions of disability are at odds with the ways in which Aboriginal and Torres Strait Islander communities conceptualise disability, as focus is on strength and kinship rather than a loss of ability or capacity (24, 28-30). This extends to intellectual, developmental and cognitive disabilities. A study conducted in the Fitzroy Valley in Western Australia found that for some participants disability labels, such as 'autism spectrum disorder', did not reflect the ways in which disability were spoken about in community (31).

For this project, we discussed the meaning of intellectual disability from the First Nations perspective, and from the Western perspective. As a research team we put forward some alternative suggestions for wording and presented the discussion to the First Nations Advisory Committee (FNAC) for their feedback. After discussing the issue with the FNAC, we utilised their suggestions and the decision was made to continue using the term intellectual disability, but to explain where necessary what we meant by the term.

Inclusive Research Methodology

Inclusive research has been used as an umbrella term to describe a range of research activities that centre people with intellectual disability and position them as more than simply passive subjects (32-34). Inclusive research practices developed from the struggle for self-determination and equality on the part of people with intellectual disability, which embodied the concept of 'nothing about us without us'. (33, 35, 36). Inclusive research emphasises that people with intellectual disability have the fundamental right to be involved in research about them, as well as to be involved in decision making and agenda setting about the type of research that is conducted. It is now considered a minimum of best practice to include at least principles of inclusion in any research project involving people with intellectual disability (37).

Practically, inclusive research can take many forms (38-43). There is no universal agreement on the method of conducting inclusive research, and it is necessary to adapt approaches to meet the needs of the project and the research team. However, there are fundamental principles which underpin robust inclusive research. Walmsey and Strnadova et al. (2018) propose a definition of inclusive research that includes the following elements:

"...Inclusive research is

1. *Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives.*
2. *Research based on issues important to a group, and which draws on their experience to inform the research process and outcomes.*
3. *Research which aims to recognize, foster and communicate the contributions people with intellectual disabilities can make.*
4. *Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.*
5. *Research in which those involved in it are "standing with" those whose issues are being explored or investigated." (36).*

The National Centre of Excellence in Intellectual Disability Health has developed and implemented a curriculum of inclusive research training based on a comprehensive review of inclusive research best practice. This curriculum was fully co-developed and delivered by researchers with intellectual disability. This training curriculum will be available through Our Health Space.

Section Two: Scoping Review

Introduction

Section Three presents the results of the scoping review, and provides context to the consultations. A scoping review aims to map what is known about a topic, and what kinds of literature and evidence are available (44). It is particularly useful when not much is known about a topic. An initial search of literature by the team indicated that there was very little written about culturally safe and inclusive research. It was decided that a scoping review would be the best approach to identify and explore the extent of existing literature in this space.

This scoping review set out to answer the question: ***“What is the evidence and tools available to support culturally safe and inclusive research with First Nations people with intellectual disabilities and their families?”.***

Aboriginal and Torres Strait Islander Research Guidelines

In the Australian context, there are a number of ethical frameworks and guidelines that guide culturally safe and ethical research with Aboriginal and Torres Strait Islander people. These frameworks guide all kinds of research, and are not specific to research about disability or intellectual disability. We included them to provide insight into the principles that underpin cultural safety in research generally. These frameworks and guidelines do not consistently frame the elements of cultural safety in the same way, but many of the broad concepts that underpin them remain the same across the guidelines. The frameworks were identified via a process of hand searching.

The included ethical frameworks and guidelines have been described in Table 1.

Table 1: Included Aboriginal and Torres Strait Islander Ethical Research Guidelines

Organisation	Title	Year	Key Concepts
Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)	AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf	2020	Four underpinning principles: 1. Indigenous self-determination 2. Indigenous leadership 3. Impact and value 4. Sustainability and accountability.

Organisation	Title	Year	Key Concepts
The Kids Research Institute Australia (The Kids)	Guidelines for the Standards for the Conduct of Aboriginal Health Research https://www.thekids.org.au/globalassets/media/documents/aboriginal-standards-guidelines---july-2022.pdf	2022	Aboriginal research standards developed by the Institute: 1. Aboriginal governance and relationships 2. Formulate the research question 3. Proposal and funding 4. Project governance and ethics 5. Data collection and safety monitoring 6. Analysis and reporting 7. Translation 8. Evaluation
National Health and Medical Research Council (NHMRC)	Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders https://www.nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities	2018	The six core values: 1. Spirit and integrity 2. Cultural continuity 3. Equity 4. Reciprocity 5. Respect 6. Responsibility

Organisation	Title	Year	Key Concepts
National Health and Medical Research Council (NHMRC)	Keeping research on track II https://www.nhmrc.gov.au/about-us/publications/keeping-research-track-ii	2018	The six core values: 1. Spirit and integrity 2. Cultural continuity 3. Equity 4. Reciprocity 5. Respect 6. Responsibility
Aboriginal Health and Medical Research Council of NSW (AH&MRC)	NSW Aboriginal Health Ethics Guidelines: Key Principles https://www.ahmrc.org.au/wp-content/uploads/2023/10/AHMRC_Health-Ethics-guidelines-2023_01.pdf	2023	Five key principles: 1. Net benefits for Aboriginal people and communities 2. Aboriginal community control of research 3. Cultural sensitivity 4. Reimbursement of costs 5. Enhancing Aboriginal skills and knowledge

The following common principles were described in these guidelines.

Self-determination

Aboriginal and Torres Strait Islander self-determination was a crucial element of culturally safe research across the guidelines (7, 15, 16, 45, 46). The Australian Institute of Torres Strait Islander Studies (AIATSIS) Code points out that:

"Australian research should embrace the fact that Aboriginal and Torres Strait Islander peoples have existed continuously as distinct societies, with diverse and unique laws, cultures, knowledge and worldviews that can inform research across a wide range of disciplines including physical sciences, social sciences and humanities."(7)

The National Health and Medical Research Guideline also explicitly confirmed the right to self-determination of Aboriginal and Torres Strait Islander people (16, 46), as per the UN Declaration (6).

Aboriginal and Torres Strait Islander led research and project governance

Aboriginal and Torres Strait Islander led research and project governance was noted as a key principle by the Australian Health and Medical Research Council (AHMRC) and AIATSIS (7, 15). The AIATSIS Guidelines described Aboriginal and Torres Strait Islander led research as research where Aboriginal and/or Torres Strait Islander people have genuine decision-making responsibility and the research is informed by Indigenous priorities, values, perspectives and voices, at every stage of the research process from conceptualisation to translation. (7). The Kids guidelines also emphasise the importance of strong Aboriginal and Torres Strait Islander governance and leadership throughout the research process (45).

Community control of research and data sovereignty

Related to these concepts, community control of research was also considered fundamental across the guidelines. The AH&MRC described community control of research in the following terms:

"Aboriginal Community Control must be a key focus of all projects affecting Aboriginal people. This means that at all stages of the research project, Aboriginal people and communities participating in or affected by the research will be fully informed about and agree with the purposes and conduct of the project." (15)

Similarly, the concept of data sovereignty and governance is raised across the guidelines. Data sovereignty and governance refers to the principles that Indigenous peoples have the right to exercise ownership over Indigenous data(47). The AIATSIS, The KIDS, and AH&MRC guidelines all note that Aboriginal and Torres Strait Islander people have the right to manage the collection, interpretation and use of their information. This should be ratified and formalised in agreements between communities and the research institutions to ensure Aboriginal and Torres Strait Islander community interests are fully protected (7, 15, 45)

Relationship building and meaningful engagement with community

Relationship building and meaningful engagement with community is another cornerstone of culturally safe research practice (7, 15, 16, 45, 46). The Kids point out that building community relationships is an ongoing activity that should not be restricted to the life of a single project (45). The AIATSIS guidelines describe the importance of engagement and note: “Engagement is different from consultation and, importantly, includes building relationships of trust from which respect and the integrity of the research can flow” (7) pg 12.

Method

As per Grant & Booth’s typology of reviews, a scoping review was identified as the most appropriate type of review. A scoping review aims to identify the nature and extent of research and allows for the preliminary assessment of the potential size and scope of available research literature (48). The intent is to synthesise the research in the topical area, by describing what is known about key concepts (49). Scoping reviews can also be used to identify gaps in the knowledge base (50). Preliminary searches on the topic indicated a significant lack of literature, so other forms of systematic literature review were ruled out as unsuitable.

The research team consulted with an academic librarian at the University of Sydney Library to develop a database search strategy to cast a broad net, given the paucity of the research. The decision was made not to include the term research in the search terms, to ensure the widest possible results. After a brief review of key papers, the following search terms were identified, listed in Table 2.

Table 2: Search Terms

Search Terms
"cultural guideline*" OR "cultural* competen*" OR "cultural* aware*" OR "cultur* sensitiv*" OR "cultural* secur*" OR "transcultur* competen*" OR "cultural* proficien*" OR "cultural* safe*" OR "cultural* respect*" OR inclusive* OR indigenist
AND
idd OR "intellectual* disab*" OR "cerebral palsy" OR autism OR "development* disab*" OR "down* syndrome" OR "fragile x" OR "f#etal alcohol" OR "prader willi"
AND
"First Nation*" OR "First People*" OR Indigenous OR Aboriginal OR "Torres Strait Island*" OR Maori OR "Native American*" OR BIPOC

The search terms were adapted to each database, which included: Medline, PsycINFO, Scopus, CINAHL, Web of Science, and ProQuest. Hand searching of references lists and Google Scholar was also conducted. The papers identified via the database search strategy were imported into a systematic review management platform (Covidence) and screened according to the inclusion and exclusion criteria described below. The PRISMA diagram is included in Appendix A.

A non-academic literature search was conducted, but there was no literature identified that related to direct research conducted with First Nations people with intellectual disability or their families.

Papers were included if:

1. they were primarily or incidentally focused on direct research with Aboriginal people with intellectual disability or their family members or kinship groups or support people.
2. The setting was Australia, New Zealand, Canada or the United States, as these countries had similar experiences with colonisation

Papers were excluded if:

1. they did not report on primary research (ie secondary research using pre-existing data), or;
2. they reported on cultural safety as related to service delivery rather than research, or;
3. they did not discuss cultural safety or elements of inclusion, or;
4. the setting was outside the included countries.

The included papers were thematically synthesised, and the results were presented by theme.

Results

Of the papers reviewed, only five academic papers which met the inclusion criteria were identified. Three studies were qualitative and two studies were mixed methods. The included papers are listed in Table 3.

The themes identified via the thematic synthesis are presented following the table. There were two overarching themes related to cultural safety and inclusive research practices. Under the cultural safety theme, there were four sub-themes: guidelines; ethics, First Nations collaboration and First Nations researchers.

Table 3: Included papers

Author	Year	Aim	Design	Country	Population	Cultural Safety	Inclusive Methods	Disability/ Intellectual Disability
Lilley, Sedgewick and Pellicano	2020	A qualitative study which reports on Aboriginal and Torres Strait Islander experiences of autism, as described by women supporting their autistic children and grandchildren.	Qualitative	Australia	N=12 Indigenous families of children with autism	The study was developed in consultation with First People's Disability Network (FPDN) Ethical approval was sought from Aboriginal Health and Medical Research Council (AH&MRC) The protocol was also approved by Positive Partnerships' National Reference Group, consisting of Aboriginal and Torres Strait Islander leaders from key organisations and services across Australia. The research team included Aboriginal researchers. Aboriginal advocates experienced in the disability sector were available for support during face-to-face inter-views.	Flexible interview structures. Disability advocates and support people were available for participants.	Autism focused, intellectual disability mentioned

Author	Year	Aim	Design	Country	Population	Cultural Safety	Inclusive Methods	Disability/ Intellectual Disability
Hamilton, Reibel, Watson et al.	2020	A qualitative study which sought to determine whether the benefits of young people's participation in the assessment process outweighed potential harms that may have occurred in the course of the prevalence study occurring concurrently to this one.	Qualitative - yarning	Australia	N=38 (n=27 Indigenous young people)	Ethics approval was granted by the Western Australian Aboriginal Health Ethics Committee. Yarning was used as the primary data collection method. The research was undertaken by an Aboriginal woman from Eastern Australia with a background in social work.	Flexible communication, including periods of silence, using prompts, rephrasing questions, and summarizing and repeating responses back to participants. A “toolbox” of interviewing techniques such as drawing and writing and the use of pictures. When collecting consent, the research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms allowing time for the participant to review and ask questions.	FASD focus, intellectual disability mentioned

Author	Year	Aim	Design	Country	Population	Cultural Safety	Inclusive Methods	Disability/ Intellectual Disability
Rossow-Kimball, Lavis & Blackhurst et al.	2017	Using an ecological perspective, the purpose of the study was to (a) gain an understanding of the knowledge, experience, and meaning of Aboriginal culture to Aboriginal adults with intellectual disabilities living in a group home/ supportive living setting, (b) become aware of the challenges experienced by the participants when connecting with their culture, and (c) develop strategies to address challenges presented so the participants can maintain/ become further engaged in their culture.	Qualitative – ecological	Canada	N=4 (case studies)	Collaborative and participatory study design with an emphasis on non-hierarchical modes of research. The researchers “collaborated with the Aboriginal participants and community organisations throughout the research process from refining the research problem, to collecting and analysing the information, and acting upon the problem to find solutions and promote social transformations” The researchers consulted with the Indigenous Peoples’ Health Research Centre (University of Regina), to ensure the research design was respectful of culture, tradition and engagement. Data collection group activities were arranged by the researchers and participants to offer opportunities to engage in traditional Aboriginal activities. An Indigenist research framework was used to understand their experiences and ascribedmeaning of Aboriginal culture. The lead author was a First Nations woman.	None reported	Intellectual disability focus

Author	Year	Aim	Design	Country	Population	Cultural Safety	Inclusive Methods	Disability/ Intellectual Disability
Stubbs, Bedford et al.	2025	This study explored different perceptions of disability and identified strategies to help bridge the gap between Aboriginal community members in the Fitzroy Valley and Western health and disability support services.	Qualitative (Aboriginal Participatory Action Research)	Australia	N=19 (Aboriginal participants n=7, service providers n=12)	Aboriginal community leadership in the design and implementation of the research. Aboriginal community members co-designed recommendations to address the results. The study was conducted following the National Health and Medical Research Council's Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders 2018 and the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research. The study's quality was assessed from an Aboriginal and Torres Strait Islander perspective using the Aboriginal and Torres Strait Islander quality appraisal tool.	None reported	Disability focused, intellectual disability mentioned

Cultural safety

Guidelines

The included studies described varying approaches to ensuring cultural safety for Aboriginal and Torres Strait Islander participants. Only one study reported using an explicit set of guidelines to ensure that the research met the principles of cultural safety. Stubbs et al. reported that they conducted the study following the National Health and Medical Research Council's Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders 2018 and the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research, and assessed the quality of the study was assessed from an Aboriginal and Torres Strait Islander perspective using the Aboriginal and Torres Strait Islander quality appraisal tool. Hamilton et al (51) did refer to the Lowitja Institute's principles of harm reduction in health research among Aboriginal and Torres Strait Islander communities, but was not explicit in how it framed the study's approach to cultural safety.

Ethics

In the Australian context, ethics should be sought from Aboriginal and Torres Strait Islander specific ethical governing bodies where the focus of the research is on the experiences of Aboriginal and Torres Strait Islander peoples (15, 16, 46). In New South Wales, the Aboriginal Health and Medical Research Council describes the following conditions for seeking approval from their Human Research Ethics Committee – where one or more of the following applies:

5. The experience of Aboriginal people is an explicit focus of all or part of the research
6. Data collection is explicitly directed at Aboriginal peoples
7. Aboriginal peoples, as a group, are to be examined in the results
8. The information has an impact on one or more Aboriginal communities
9. Aboriginal health funds are a source of funding (15).

Two of the Australian papers reported seeking ethical approval from First Nations specific ethical governing bodies (51, 52). The Canadian study reported receiving ethical approval from the relevant university Human Research Ethics Committee (Research Ethics Board at the University of Regina) (53). The final Australian paper (54) does not describe the ethics approval process at all.

First Nations Collaboration

Three of the four papers describe some sort of collaborative process with key First Nations stakeholder organisations. D’Aprano (54) emphasise the importance of collaboration as a fundamental tenet of culturally safe research in their project design. The first stage of their project involved building and developing partnerships with key leaders across community partner organisations, including two Aboriginal Community Controlled Organisations (ACCO). D’Aprano et al note that the “…project priority was for ongoing collaboration and ensuring Aboriginal and Torres Strait Islander participation and engagement in knowledge sharing”.

Rossow-Kimball (53) also described a collaborative process which was central to their project. The researchers collaborated with the First Nations participants to design the study processes, as well as engaging in a process of consultation and review with extended networks including Aboriginal adults with intellectual disabilities, members of the Aboriginal community, support workers from a community-based organisation and the Indigenous Peoples’ Health Research Centre (University of Regina), to ensure the research design was respectful of culture, tradition and engagement (53).

Lilley, Sedgewick and Pellicano also described a number of collaborative processes built into their project. The project was designed in consultation with First Persons Disability Network (FPDN), the peak body for people with disability in First Nations communities in Australia. The protocol was also approved by Positive Partnerships' National Reference Group, consisting of Aboriginal and Torres Strait Islander leaders from key organisations and services across Australia (52). Hamilton et al did not describe any consultative or collaborative process with stakeholders throughout the life of their project.

First Nations Researchers

Ensuring that First Nations researchers are listed as Principal Investigators on a project, or at least ensuring that the research team includes First Nations researchers is noted across multiple sources as a crucial part of First Nations leadership and governance in research (15, 16, 46). First Nations research leadership ensures that First Nations worldviews and perspectives are centred from conception through to analysis and dissemination. Doing so also recognises the growing First Nations research workforce and senior academic leadership (7). Ensuring the place of First Nations researchers on all Indigenous focused projects also offers the opportunity to build capacity among First Nations communities to participate in and lead research projects (15).

The importance of this aspect of cultural safety was reflected in the makeup of the research teams documented in the included papers. All the papers described having at least one First Nations member of the research team. Lilley, Sedgwick and Pellicano noted that their research team was comprised of two non-Aboriginal researchers and one Aboriginal researcher. They also noted that two of the researchers, including the Aboriginal researcher, are mothers to autistic children, further emphasising their experiential expertise (52). D’Aprano, Hunter et al (54) noted that six of the 19 authors on the included paper were Aboriginal or Torres Strait Islander. They also noted that project team included both Aboriginal and non-Aboriginal members. The project leads were identified as non-Aboriginal. Hamilton et al briefly indicated that the research was undertaken by an Aboriginal woman from Eastern Australia with a background in social work (51). However, the paper did not indicate who this researcher was in the broader context of the study.

Indigenous leadership within the research team offers the opportunity to privilege Indigenous worldviews and perspectives in the face of harmful colonial legacies. Rossow-Kimball et al (53) was explicit about the lead researcher’s First Nations identity and the subsequent positionality and effect on the research. The first author reflects clearly on the effect of colonialism on the disruption of cultural identity and how that experience has led the development of the research study:

> *“Upon her own reflecting, thinking and longing for her ‘lost’ culture, along with her involvement in the disability community, the author began to consider if the Aboriginal people with intellectual disabilities with whom she spent time ever felt a longing for their culture, too, as many of them had a history of being uprooted from their land, language and family to be placed in non-Aboriginal homes.” (53) page 246*

Inclusive methods

Inclusive research methods with people with intellectual disability were less of an explicit focus in the identified papers. However, in the two papers which described conducting research directly with people with lived experience of intellectual disability, there was some acknowledgement of the necessity of utilising inclusive methodologies, for example, participatory research methods and yarning (51, 53). As well as this, across three of the papers there was some overlap between the culturally safe and appropriate methods described and inclusive methodology. D'Aprano et al (54) did not include any reference to inclusive methodology.

Rossow-Kimball et al (53) described using a collaborative, participatory methodology to frame the research. This approach was both culturally sensitive and inclusive for people with intellectual disability. Within this methodological framework, the authors described a number of inclusive data collection methods. These methods included one-on-one interviews, cultural group activities, photo-elicitation and focus group settings. The authors described using an informal conversational approach to gathering data, as well as active interviewing methods, where questions were asked of the participants during the experience at hand (53).

Hamilton et al (51) described at length the fluidity and adaptability of yarning as a data collection method, and the ways in which it can be used successfully with participants with neurodevelopmental disabilities. The authors noted that yarning offered opportunities for language adaptation, depending on the needs of the participant. Language could be adapted to meet both cultural understanding and the participant's cognitive needs.

The authors offered the example of the researcher changing the language used during one yarning session: “Toward the end of the yarn, the researcher asked the participant whether he understood better the “silly words” and his response was “yes, now you said it blackfulla way.”” (51). Successful interviewing with people with intellectual disability involves flexibility and responsiveness to each participant’s communication style and needs (55). The flexibility inherent in yarning as a method allows for adaptation to participants’ needs, making it an inclusive methodology.

Hamilton et al explained how yarning was also used in conjunction with movement, different spaces and visual illustrations and cues to create safe and inclusive spaces for participants to take part in research depending on their needs (51). The authors offered the example of a non-Indigenous participant with intellectual disability who struggled to understand the concepts that were being discussed in the yarning session. The researcher was able to visually demonstrate what he could not understand, using flowcharts and drawing during the yarning session (51).

Hamilton et al also described the consent process in inclusive terms. The consent process was multi stage, and involved utilising ‘simple language’ and visual aids to facilitate consent (51). Simple changes in language and visual aids have been noted as an effective way to facilitate consent among participants with intellectual disability in inclusive research projects (56-59).

Discussion

This review sought to answer the question: “*What are the evidence and tools available to support culturally safe and inclusive research with First Nations people with intellectual disabilities and their families”.*

Both the academic and non-academic literature offered very limited evidence about supporting culturally safe and inclusive research with First Nations people with intellectual disability and their families. While guidelines and frameworks to support culturally safe research in general exist, there was no body of research to support culturally safe research that was explicitly inclusive of people with intellectual disability. From the Western research perspective, there is a notable overlap between many of the principles described in the culturally safe research guidelines and the identified literature, and the principles of inclusive research. Both culturally safe and inclusive research at their core emphasise the autonomy and sovereignty of people who have historically been disadvantaged and harmed by the establishment, and ensure that they are rightfully centred as the arbiters of the research process (5, 24, 34, 35, 60-63).

The importance of collaboration and relationship building is foundational to the conduct of both culturally safe and inclusive research with people with intellectual disability. A number of the papers included in the review noted the importance of the relational and collaborative aspects of their projects (52-54). Avery (24) describes the fundamental importance of relationships at every level in the research process, from the organisational to the community to the individual. An example he offers is the strategic relationship between the First Peoples’ Disability Network (FPDN), an Aboriginal and Torres Strait Islander disability organisation, and the Australian Bureau of Statistics. He notes that the success of this partnership is partially founded on a relational approach in which goodwill is accumulated based on repeated engagement (24). The AIATSIS Code of Ethics notes that research must be founded on a process of ‘meaningful engagement’ at all stages of the research process. This must go beyond consultation, and cannot be simply transactional (45, 64). Meaningful engagement should be adapted to the research being conducted, and the needs and priorities of the involved communities (7).

Equally crucially, building relationships based on trust is essential to conducting safe and meaningful inclusive research with people with intellectual disability. Relationship building and working ‘alongside’ co-researchers with intellectual disability has an important role in ensuring an inclusive paradigm is meaningfully adhered to (65). Ensuring that relationships are nurtured during and after the research process means that marginalised voices are respected and privileged (62). As with culturally safe research, Chalachanova et al note that the personal dimension is important, as is mutual respect (66). Restricted timelines, as is often the case with traditionally conducted research, is antithetical to best practice inclusive research, as it does not allow for adequate time to foster relationships properly (62, 66).

Many of the processes described in the methodology of culturally safe research practices described in the studies reflected similar practices found in inclusive research methodologies. Yarning methodologies, as described by Hamilton et al (51) utilise many of the same methods and principles as methods described by inclusive research practitioners. Similarly, Lilley et al (52) noted that Aboriginal advocates experienced in the disability sector were available for support during face-to-face interviews. Dyadic interviewing, where the other member of the dyad is a support person who can act as an advocate, is an established inclusive methodological technique when interviewing people with intellectual disability (67). Dyadic interviewing refers to an interview which involves a pair of participants interacting with each other and the researcher (67, 68). Other methods included the use of visual aids and walking interviews, which have been used to change and redefine uneven power dynamics (69-71). Flexible language was noted as a feature of culturally aligned research methods by Hamilton et al (51), as it was used to ensure meaningful and respectful engagement between the subject of the research and the First Nations researcher. Flexible and responsive language is also fundamental to conducting meaningful interviews with people with intellectual disability (55, 62). This approach recognises that the researcher’s role is to facilitate a person’s opportunity to speak for themselves and tell their own story (55).

There were notable parallels between the culturally safe principles of research noted in the identified literature and the principles of inclusive research. However, the lack of explicit guidelines or frameworks for conducting intellectual disability research with First Nations people and their families leaves a notable gap for Western researchers conducting research in this space, and makes the work more challenging. Given the paucity of research in this area, this may likely impact negatively people who are most at risk It is too easy for non-First Nations researchers to be ignorant of the complexities of participating in research in First Nations spaces, and the opportunity for further harm to be perpetuated is too great.

Section Three: Stakeholder Consultations

Introduction & Overview

This section of the report describes the process of stakeholder consultation which we undertook with First Nations people at the intersection of First Nations and intellectual disability lived experience. These consultations took the form of yarning sessions conducted by Wayne which included both people with and without lived experience of intellectual disability. As a part of the reflexive process for the White researcher on the project, Erin also engaged in reflexive conversations with other white researchers who had worked on projects which focused on the intersection of First Nations and intellectual disability lived experience.

Method

The aim of this part of the research was to consult with First Nations people about ways to conduct culturally safe research with people with intellectual disability. It was important to conduct the research in a way that was culturally safe for the people taking part, and in a way that privileged and centred First Nations ways of generating and sharing knowledge (72). To do this, we used yarning methodology as the framing methodology for our data collection. Yarning has been well established as a qualitative research method which can help to provide a culturally safe environment for First Nations people to participate in research (17, 73). It is a way of sharing stories and lived experience that encourages people engaged in yarn ups to share their stories at their own discretion in a culturally safe way (74).

Ethics approval for the project was sought from the Aboriginal Health and Medical Research Council (Approval No: 2450/25).

Prior to ethics submission, Wayne yarned to many First Nations community members, stakeholders and elders, as well as non-First Nations stakeholders about intellectual disability to find out their feelings and thoughts on the project. This was a prerequisite in submitting ethics to the AHMRC and represents part of the journey towards cultural safety. This yarning and consultation process is an essential part of trust building within the community.

Recruitment

Participants were recruited via stakeholder networks, using a snowball sampling methodology. Snowball or chain sampling is a well established method of recruiting research participants via social networks, researchers distribute information about a project to an initial network who are then asked to distribute information through their networks, and so on (75-77). Wayne reached out to key First Nations, disability and health organisations and networks across New South Wales. He leveraged existing relationships to inform people of the project, and asked them to distribute information about the project throughout their networks. He approached people via email initially, and then where possible yarned with them about the project and their thoughts about intellectual disability and First Nations experience generally. Wayne also yarned to First Nations disability groups across Western New South Wales in person and distributed information about the project.

Inclusion and Exclusion Criteria

Participants included:

1. People who are Aboriginal and/or Torres Strait Islander, and who share community with people who have lived experience of intellectual disability
2. People who are Aboriginal and/or Torres Strait Islander who have lived experience of intellectual disability
3. Other key stakeholders whose experience is deemed relevant to the project because they have worked on First Nations and disability related research projects (for example, clinicians, researchers)

Participants were excluded if they were under 18 years or did not meet any of the above criteria.

Data Collection & Analysis

Eight yarn ups were conducted. Seven yarn ups were one on one and one was a group yarn up with four people in attendance. Wayne conducted the yarning sessions with participants online, as they were located across New South Wales. Two reflexive conversation sessions were held with non-Indigenous researchers. These conversation sessions helped frame the reflexive process, and were not used to collect data.

Erin also conducted the reflexive conversation sessions online.

Both Wayne and Erin reviewed the transcripts of the yarning sessions and commented on relevant sections, and discussed possible issues. The transcripts were then coded for the key themes. These themes were then presented for discussion and feedback to the First Nations Advisory committee.

Findings

The demographic data for the participants is listed at Appendix B. The results are presented thematically. The following themes were identified across the yarn up data: cultural safety, cultural context and cultural history; intersection between First Nations and disability lived experience; trauma; language and communication; respect and elders.

Cultural safety, cultural context and cultural history

The yarning session participants had many thoughts about cultural safety, what it means in the context of intellectual disability research and how best to achieve it.

Participants described how cultural safety was the lens through which all aspects of a project should be viewed and developed. Non-First Nations researchers needed to begin a journey of learning about cultural safety and understanding the cultural context of the community they were working before starting any project. Participants spoke extensively about the importance of non-First Nations researchers understanding the cultural context, history and perspectives of the First Nations communities that they were working with.

“It’s important in general just to understand cultural safety. – YS2”

“So them learning like they need to learn our culture more better and have an understanding on what we do and how we do things – YS6”

"I think learning the basics, I think learning the history of our people and learning how our ways as well because our the way we approach things the way we view things, our perspectives are quite different to a Western perspective and by acknowledging those difference and being able to make them comfortable and feel like they're being heard rather than judged and witnessing unconscious bias and all that kind of thing." – YS1

"Do your research before you go, because you know if you just go in and say that you're gonna do this and you don't know much of the background of that area, you know, that's a bit, you know, how would you put it? I'd, I'd say ignorancy." – YS2

Participants noted that a key part of cultural safety was understanding that there were First Nations ways of thinking about the world and culture that were different to Western ways. Recognising and learning more about these differences was part of ensuring cultural safety in research settings.

"[Mob] have cultural ways to doing things and they've got to understand. We've got a lot of cultural ways, and they need to be hold accountable and learn and listen." – YS3

"Our healing, our journey, our ancestors, you know, the in the water, you know, cultural safety journey is very important to mob and it should be all the time there because they feel safe because government people don't understand, government people have very different ways of thinking." – YS3

One participant noted that the specific things that made a project or process culturally safe were not the same for every community, as First Nations communities are not homogenous. However, they were often treated like they were, with only a superficial attempt at cultural connection.

"Where the child is born from and there's still the disconnect of that kinship system and what that totem would be for that child. It's very it's dot paintings and you know there's only certain groups that actually use the dot paintings that in the way that we're seeing it everywhere, you know, there was still diversity in art, you know, and the way that that was done. And I feel like they give people with intellectual disabilities like kind of a homogenized version of culture or access to a homogenized sort of Aboriginal culture. And often you'll hear I've provided support to them and when they're asked, well, what is that? You know, oh well, I have a cup of tea with them. So I feel like there are certain parts of it where they talk about culture, but it's like the sanitized, homogenized, all inclusive and very broad. It's it's quite cut off in that sense. And you know, culture is often perceived as you know someone doing a dot painting, you know, from a template download on the Internet or putting hands on stuff like that, which is nice, but it's not really walking the cultural..." - YS7

"And when they're doing that artwork, they need to know not the homogenized version, but well, what are the dream home stories of the community that person lives in? What's their totem and how does that culture influence and support them, even if they have an intellectual disability". – YS7

"It's a garb, like it's a colonised version of the culture, which is so general it it kind of loses its punch, yeah." – YS7

Other participants similarly noted that First Nations groups tended to be treated as the same, despite being completely different.

"Our two are very different to Indigenous Islanders and our all different types of Indigenous groups, 'cause we've all got different ways of doing things and they need to learn a lot." – YS3

"Just see who we are as a people, as an individual, not as a collective, because you've got so many nations living within a location, so get to know the individual." – YS4

However, there were some elements that were considered relatively general to the safe way of doing things.

"So when it comes to cultural safety, cultural competence, there's no such thing as proper way. But there is a there is a particular morals and ethics that must be, that I think are quite generalised." – YS5

There was a strong sense that Western researchers and institutions did not understand and subsequently did not respect First Nations's ways of thinking and doing generally. This lack of understanding and respect contributed to a failure to create a safe cultural environment when doing research, and a failure to understand what cultural safety meant and how it was properly enacted.

"Well, they need to do their homework properly and speak to a provider or organisation to the person to make sure it's culturally safe so they can enter, go there and do it. But with gubba providers not understanding Indigenous ways, there's such a big gap, so we've got to make it easier." – YS3

"I just like to be like in a safe space when they talk about culture so they understand and follow through on what they do and they really understand it because there's a lot of miscommunication between gubba and Indigenous mob and it's ridiculous." – YS3

"There's such a big gap between, sorry, I'm going to say this, gubba people and Islander people and Indigenous people. It's such a big gap and it's wrong. They need to have knowledge and wisdom and training to understand mob, but they don't." – YS3

Intersection between First Nations and disability lived experience

Participants spoke about the ways in which the experiences of First Nations identity and disability intersected. Participants noted that disability was not thought of as a separate thing, or as a deficit in the way that it was in Western society. Rather, it was a part of that person and should be thought of holistically.

"My disability as not something that hinders me, but as something that is a part of me and that is. I'm just telling them my story. I'm just telling my people. I'm telling that community my story. And story is quite important in our culture, having our own story, having our own history. And I think a disability, it's one of those things that wasn't really recognised too much in words or anything in our culture. That it just sort of was deemed as part of us. It was just, oh, it's just who you are. It's just, this is just you. So I just, I guess I was, I never viewed it as something to be ashamed of or anything. It's just who I am. It's just a part of me and I'm happy to tell my story. And I think that's what makes me so confident in telling my story and telling people about my disability." – YS1

"...Disability doesn't equal exclusion in our community". – YS7

Participants also noted that when interacting with non-First Nations systems, they found that they were not treated holistically. At least one aspect of their experience was ignored in favour of the other, and they were not treated as a First Nations person with intellectual disability, but as either First Nations, or a person with disability. '

"So for me, normally one's always ignored. No one really acknowledges both. Sometimes, like if they know that they know that I have intellectual disability, they don't really believe if I'm Indigenous because I don't have like, the like dark skin. A lot of people don't believe me when I tell them, but yeah, then no one ever believes in both. It's always I'm either have one or on the other." – YS6

"Yeah, me some because they think that I don't have a dual disability because I'm very, you know, I know how to talk and I'm very well presented and I can acknowledge the country. I can do a lot of things like it's misinterpreted because it's visible. But I stand up and I show and I explain and I do." – YS3

"Culture comes in many forms and intellectual disabilities comes in many forms. You just need to adapt and do your research and understand how they're telling their story." – YS1

Trauma

The importance of acknowledging trauma and its impact on cultural safety was noted by multiple participants. Participants spoke about the impact that experiencing trauma had had on their lives, and how it affected the way they spoke to outsiders.

One participant noted that her past experiences with domestic violence made it difficult to share her story easily in general:

“It’s hard for me to actually, like, talk about who I am. Um, I’m just pretty much like. I am not really a social butterfly person due to things that have happened in my past due to domestic violence.” – YS6

One participant reflected that for First Nations people and communities, questions about disability and trauma were very closely linked. This was not only related to the generational trauma and violence of colonialism and the Stolen Generation, but also to the very real ongoing risk of removal and separation that people with disability experienced.

“Our experience and the statistics support that we are more than likely to lose a child or even an adult in our home because of that… related to that disability.” – YS7

“…In terms of colonialism and trauma, you know, there is still a very real experience of Aboriginal families at risk of meeting with DOCS simply because they’re Aboriginal, or the police and that Aboriginal people’s reluctance to even access to disability support services is very strongly tied to the fact that if you put your hand up and say I’m a parent of a child with a disability or my child has a disability, we all know that DOCS is right behind them and it really… Because of the removal, you know.” – YS7

"That really makes me mad that, you know, a child can be removed from a family home and the mother's, say she's on a pension or a father, 23,000 a year that's what they're gonna get. They get removed, everything's paid for, but they're being removed and taken to a family who is not their family and that carer is getting paid to care for that child and all the expenses associated are paid by DOCS. Whereas if DOCS or NDIA paid for that therapy, that best interest of the child would remain intact because the family are still together and I completely agree with you and it kind of makes me really, really wild. Really, really wild." – YS7

The participant also noted that the process of engaging in research and sharing stories could be traumatic, and that trauma was rarely addressed during or after the research process.

"…Often the there's not a lot of follow up at all about the cultural load about, cultural debriefing post research. None of that exists and that really upsets me because they're asking Aboriginal people and communities a lot of that trauma, get the questions and then say thanks for coming and then leave the community or the individual high and drive without any follow up supports." – YS7

Language and communication

Language and communication was flagged by multiple participants as an important component of cultural safety. Participants talked about how First Nations people both with and without intellectual disability used language in different ways from non-First Nations researchers, and it was important to respect those differences. Patience could be required when it came to bridging gaps in understanding.

“Just for people to understand and be patient when I’m trying to like trying to explain things, because I’ve got to sort of think and trying to figure out the best way for me to get my point across.” – YS6

Researchers also needed to be careful about using jargon and academic language which was in many cases not a respectful way to communicate with people, as it was not easily understood by non-researchers.

“And taking it easy and understanding it, because a lot of people don’t understand academic language. It’s really hard” – YS3

There were cultural differences in communication as well as language – one participant noted that First Nations people often used metaphor and analogy as a way to tell their story or communicate, and that was something for non-First Nations researchers to be aware of.

“I think sometimes people need to really listen and sometimes the way people speak is they speak in what we view as metaphors or analogies or so trying to understand and interpret that as well by recognizing and understanding the difference.” – YS1

“So it’s just that people need to understand, um, the way we really communicate and how we bring things across, which would really help for non-Indigenous people when they’re talking to the like us that are Indigenous.” – YS6

One participant with intellectual disability pointed out that in some cases, there could be shame and stigma attached to written communication and that non-First Nations researchers needed to be aware of this.

Can I be honest with you, with mob, I know mob being myself and others a lot of them have illiteracy and they feel shame and scared and you shouldn’t feel that way. You should engage and be positive and happy. You can achieve it with the support and help. We can you can do it. – YS3

Non-First Nations researchers needed to adapt their communication styles to meet the needs of the First Nations people that the researchers were working with. This may involve alternative communication methods like easy read and visual aids, but participants also noted that it should focus on the holistic needs of the people involved and was a deeper process than just developing easy read materials. This was not only for people with intellectual disability, but was the case for people engaged in research – modes of communication needed to be adaptable and culturally safe. In some cases, especially with regard to meeting with elders, it was important to meet face to face where possible.

"I'm like putting to be patient, to be humble, to be understanding and to be nice. And have, you know, less wording in pictures." – YS3

"I would like them to learn about the person. How? How do they need? How can you help them? How can you talk to them? Is it? Do they need to be face to face, adapt to their needs, adapt to what they need and also adapt to? Who they are as a person? Find out who they are. Do they like talking with family around? Do they want their support systems around? Do they want? Do they need to be face to face versus telehealth? Do they? Do they need adapt to their needs and adapt to what they and ask them? What do you need from us? Do you want someone here to support you? Do you need this? Do you need that? Just communicate in a way that they can understand." – YS1

"I sometimes will sometimes struggle with things that are really, really structured. Um, but actually being able to tell stories that way makes me feel more comfortable and respected." – YGS1

"…You know, it's that that acknowledgement at the start and that rapport you build that will guide you on how you should engage with that person. You know, you gauge their level of understanding and whether they might like to speak. You know, and yarn in different ways or whether they're OK with having a Teams meeting or you know, like you said, you know, for us we tried to respect that it's hard for you to get up here to yarn to a few of us. Whereas like you know, you said you wanna go and talk to community people and elders, you'd rather come and sit with them. So I think it's just that negotiation…" - YGS2

At the same time, non-First Nations researchers could obfuscate the purpose of research by ‘dumbing down’ communication with First Nations communities, leading to uninformed consent.

“You don’t want to dumb it down. So people are, you know, and that happens a lot with white researchers. They come in and they try and dumb stuff all the way down where it just sounds like beautiful, you know? And I’ve seen that happen in this community. I’ve seen that happen around. You know, blood collection and specimens, where people just thought that, you know, they was going to get blood specimens taken and it was part of their antenatal screen, but it wasn’t. It was part of a research project. So when you dumb stuff down too much.” – YGS1

Respect

Respect represented a key theme in the findings from the yarning sessions. Many of the participants described the importance of respect as an underpinning feature of a successful relationship between First Nations people and non-First Nations researchers.

Participants described respect and how to achieve it in multiple different ways. Notably, people repeatedly described how respect was demonstrated by actively listening to First Nations people and taking time to understand their stories. Being listened to and being actively heard underpinned respectful relationships, and demonstrated that the listener respected the people that they were engaging with.

“You know, but I think the big thing is, is listening. If they’re, you know, engaged in what you’re saying, yeah, I know that they’re respecting me in in that way.” – YS2

“Good, clear communication goes very understanding, listening to each other, respect. – YS3”

“Be respected, gotta be respectful and listen to and heard and not being racist.” – YS3

“And just being curious. Sometimes being curious is a way where you can be respectful and makes someone be like, OK, they really want to understand, they really want to learn, they really want to hear me.” – YS1

Listening respectfully to First Nations people meant listening to the person holistically, and listening to their whole story. A participant with intellectual disability noted that she felt respected and comfortable when she was understood as a person:

"...Like when they take the time and actually understand who I am as a as an individual." – YS6

"But also respecting the family and respecting the other people, because it doesn't matter where you're from. It doesn't matter who you are. They're people. They need to be. They have stories to tell. You need to listen. You need to be open and understand. Sometimes you may have to adapt." – YS1

Another participant noted that being respected as a person holistically was part of being culturally respectful and aware.

"So I think for me, that's what I think you could do. You could respect the person, the whole person, holistically and not just culturally, because that is what I think culture is as well." – YS1

One participant described how listening to a person's story and trying to understand their holistic experience was a part of cultural safety for them, because it emphasised how disability and being First Nations were not separate things. Rather, they were part of the same experience. It was extremely important for non-First Nations researchers to take the time to respectfully listen and take the opportunity to understand that lived experience.

"Just being respectful and actually taking the time to actually listen to what I have to say, respecting my cultural different choices and my cultural traditions and acknowledging that, but also acknowledging a person because being culturally safe, culture comes in many forms. It doesn't just mean who we are culturally as I identify, but it's also our disability is also a part of our culture. Who we are is part of our culture, so respecting the person yourself and acknowledging the person, whether they've got a disability or they're Aboriginal or Torres Strait Islander, just acknowledging and being respectful, doing your research, understanding." – YS1

Conversely, not listening to people properly or dismissing their stories undermined respectful relationships and indicated to the participants that non-First Nations researchers were not safe people to engage with. 'Not listening' was disrespectful to the relationship and the person themselves.

"Yes, cause a lot of a lot of people don't actually listen. Like if they ask you a question and you go to talk to them about it, sometimes they don't. – YS6"

"Our community required we if we feel we're judged or we feel like we're getting, we're not being heard, we're not being understood, we're not being respected, uh, we're not. Our community isn't going to engage with the health system, our community isn't going to engage with the Western viewpoints. There's no ground to share that information, to create that middle ground where we both come to get, where we all come together and understand each other and try and adapt accordingly." – YS1

Elders

Participants repeatedly described how engaging with community elders was a crucial element of conducting culturally safe research with First Nations people. This was not specific to conducting research related to intellectual disability, but was a feature of all forms of community-based research. Multiple participants noted that meeting with elders was a fundamental part of demonstrating respect for community, and engaging in culturally safe research practice.

“We’ve got to engage our elders and then the different community groups in that town or in those regions where we’re trying to get this respect and be cultural safety. – YS2”

“You know, um, as an Indigenous person, um, I’m not from the Wiradjuri country, but, you know, I was brought up to respect the elders no matter where I am and you know, what town you live in.” – YS2

“Yeah. Go to the church or go to your elders . They’re all the time with us. That’s right.” – YS3

“I think knowing what land you’re on, like what protocols there are and having elders’ voices, I think that’s a really big thing that should be included. Respect. It’s is all about respect.” – YGS1

Participants talked about how respectfully approaching community elders and building a strong relationship with them was a foundational aspect of cultural safety. Engaging with elders should be an early, if not first step in the project timeline. It was also fundamental to engage elders respectfully in a conversation, rather than arrive into a community setting and tell that community what was being done.

"I think they need to to sit down, find the elders group, sit down and speak to the elders, learn off them first and, not tell them what you want, you know, sit down and explain it to them and ask them which is the best way to engage the community because that goes a long way and once you get the respect off the elders. You know, that's a that's a real big thing there. There's, you know, 90% of your work done right there. So you know, once you get your elders on site, yeah, it all falls into place after that." - YS2

"So a lot of people encourage people to approach elders and I think that's important. I do all the time in community, like the work I've done with you, you know, we've sat down, met, met with elders, yarn with them. – YS5"

Meeting with elders was not about telling the community what project was taking place, but rather being offered an opportunity to learn from the community leaders and ensure that a project met the needs of the community. It also demonstrated respectful engagement with the specific cultural needs of that community, rather than treating First Nations culture as homogenous, and was a part of developing a trustworthy relationship.

"It doesn't always have to be led by elders, but needs to be informed and involve elders. Do you understand what I'm saying ... And for me, every single project's different, but every project that I've been involved in had a form of Aboriginal cultural input and leadership by elders. – YS5"

"Because if you break trust with the elders, it's hard to get it back and you won't get anywhere in communities." – YS

Section Four: Researcher Reflections

This section includes the researcher reflections on the project from both Wayne and Erin. We have chosen to complete these reflections verbally both for the sake of accessibility, but also to reflect and centre the importance of oral tradition and yarning in the project. We have included the transcripts of our individual reflection sessions in this section.

Wayne – Reflection

This reflection is about cultural safety, inclusive guidelines, intellectual Aboriginal Torres Strait Islander people.
About.
My experiences with the community consultation side things.
I don't know if this is recording.
I'll keep going. See you at work.
So yeah, just my reflection from last year with the cultural safety consultation with the community.
I guess I went out into the field.
With, I guess, high expectations to collect information from Aboriginal communities in regional, rural and remote areas of northwestern NSW.
The thing that stood out for me the most was.
People were saying that respect is a big key.
And deeply seen.
In in regards to some services that I spoke to.
Even they said that why do we need to comply with cultural safety?
You don't need to comply with cultural safety if you've got a high number of Indigenous people with clients in within a service, so that you'd have more of an understanding on how to engage.
How to communicate?
We have Aboriginal and Torres Strait Island people that have intellectual disabilities.
Another thing I feel services should be trained more around cultural awareness as there is no such thing as a qualification.
As we are still learning to live together and learn our ways with cultural practices and cultural protocols.
Racism is still a big thing in our community.

Um.
You know, it stops our people sometimes to connect with mainstream services and that could be health due to the stigma.
Of communities and how communities treat different cultural backgrounds differently.
And it’s worse having a disability.
It’s like you’re sitting into a third class citizen, citizens. You got 3 levels, 1-2 and three. It feels like Aboriginal and and people that have disabilities with we sit down the bottom.
We don’t like asking for help.
And when we do go to mainstream services for health, for help, they often don’t understand.
Nor can they reflect on our background.
On how to help us.
One of the big things that was, I guess, talked about for data collection was.
The amount of respect that should be shown to individuals.
If you can show respect, you’ll understand and you can.
You can communicate with people better if you understand.
And if you understand someone’s cultural values, it makes it easier to communicate with individuals.
I spoke to some researchers in far northwestern NSW in remote areas and they have.

A yarn and discuss some of the things that non-indigenous researchers that have done to their community have come in and and strictly divided the community from Aboriginal people.

To government, to health and to locals. So you've got any non-indigenous researchers coming in not complying with any cultural practices or pro cultural protocols and then actually dividing the community.

This is something that we really need to address purely based on ethics.

And if cultural research needs to be done in rural and remote areas, it's going to have a restriction put on us purely based on non-indigenous researchers going into these communities.

And staring a pot.

And I shouldn't. They shouldn't do this. They should. There's no need to do this.

Show your true intentions or what you're trying to do with a project. You know, we're trying to capacity, capacity, build capacity, building, create outcomes by doing what we're doing, recommendations into, I guess, more safe practices for.

Non indigenous researchers to comply to comply by. There are some services that I spoke to saying again respect is a a a key element into understanding how to communicate with.

Intellectual.

Aboriginal cable.

Most of the time, Aboriginal people go undiagnosed with most of their disabilities until in their late teens, sometimes depending on their location and if they live in a remote setting, because if they live in a remote setting, they they don't have access.

To Primary Health care like regional, regional places like Orange or Dubbo.
So that makes it hard for an individual that has a disability growing up in these areas because half the time families say he all right, nothing wrong with him. He just can’t hear. He can’t see.
They don’t interpret the word disability. They don’t understand the disability, let alone understand the contents of what intellectual disability is.
It’s how we defy things and how we put things across to people.
As the the sector that I work in, we try and create and maintain easy read format that people understand these.
Information.
That’s putting across to them and it’s in a more accessible way for them to understand and read.
Make a more independent.
I feel that.
A lot needs to be done within just common society today.
As Aboriginal people and Westerners, we’ve only been living together for.
Trying 265 years, it’s not long and we’re still learning our each other’s ways.
If white people could understand what has happened to us.
In this time.
To where we are today, research and health.
Would be so much easier.
But yet I’m here to help.
And let you guys know that there’s ways of doing things correctly as there is doing your PhD. So coming out into community, there’s certain ways of engaging, certain ways you need to do things.

In in order for you to understand, you need to really either have a yarn to an indigenous researcher just for, I guess his out, his view, his perspective.

On one of the guidelines that you take when you're going into community and you want to yarn the people, there are cultural practices that you need to comply by. There are cultural protocols that you need to comply by.

In saying that, also the Aboriginal Elders group are the first group that I normally go on yarn to for advice for guidance, cause they are usually the ones that know the people you should be talking to.

And elders are our knowledge holders. So at the end of the day, when elders are talking to us, we we really need to deep listen, deep listen to the point that.

We understand.

Um.

And if we if we understand, it gives us more of an idea on how to communicate.

Like there's people that I spoke to said this is a great idea. This is awesome that you are doing your research around cultural safety, inclusive research with intellectual Aboriginal and Torres Strait Islander people. A lot of people say that this is amazing. Like why hasn't this been done before?

Good question. Why hasn't this done before

I think for me it's it's it is really about people understanding our cultural background. If you can understand our cultural background, you'll have a bit more of an idea on how to communicate.

And how to, I guess, put stuff in a format knowing that it’s not going to be too sensitive.

To be able to deliver if you’re doing your own circles or focus groups.

Deep listening, respect, be kind, be open, show your true intentions or what you’re trying to do. Non indigenous researchers need to research locations aerial grounds so they know what area what land going onto what has happened there has there been any genocides massacres was this area renowned for Stolen generation these are the things that not indigenous researchers need to location really research the area what mob you going to. This is crucial that non indigenous researchers follow these procedures and understand cultural practices how to do things culturally safe I’m a big believer in doing things right when it comes to cultural values wanting to implement these into guidelines framework that non indigenous people need to comply by

Let community know that you will return and deliver your findings to community. So community, the ones that were involved in it, understand.

What has happened and what phase we might be going into, if it’s phase one, phase two of the project, which most likely will be phase two.

Um.

For me, I feel that engaging with mob, you need to be on the ground. You need to be face to face. You can’t do it on a computer emails.

You know, to a degree you can send emails out, but when you're actually engaging with Aboriginal community, it is a face to face contact.

Especially if someone has a disability like myself, I'm legally blind, partially deaf. So therefore I guess putting something across to someone and being able to sit down and have a yard on.

I read body language, so if someone's interested, I know that they're interested and they're genuinely keen to listen and unlearn and understand certain ways, certain practices that should be complied by.

With 9 indigenous researchers.

It's it was challenging with data collection.

Q2 I believe.

It could have come around to a number of things. One, I believe possibly high turnover of staff. Don't have the staff to to do the time out to take away from someone to do an interview.

And the short timeframe when the project was approved, like we we had such a short time to collect data, you know, it might have been consultation from March 2025.

To ride up to.

October, early September.

Early September, October 2025 consultation finished.

Again, you know, a lot of people that I spoke to, they said, why aren't you out on the ground? You need to be on the ground again.

Oz Limited.

To what I could do as a researcher and as someone with lived experience in going places to be able to be on the ground.

To be able to find community based evidence because that’s where it is. It’s on grassroots and grassroots come from main source of information when it comes out of Aboriginal communities.

I think it’s different how we conceptualise on how we see something as lived experience to how someone from community sees something different.

I walk around. I don’t have a staff. I don’t have a guide job. Therefore it does not look like I have a disability.

So sometimes that can be confronting with someone that has an intellectual disability and you can’t see it.

You would sometimes think I can only imagine what that person goes through on a day-to-day. I know what I go through on a day-to-day in my own community and it’s quite stressful not being able to see things.

Asking for assistance, people giving you filthy looks. You’re, you know, you’re a grown adult, but yet you’re seeking assistance due to your disability because you can’t see.

This is how our people are. We do not like asking for help. We do not like reaching out.

Because all the times that we have reached out over the years, our door has been shut on us by so many different services.

Based on what they think, what they can do.

And half the time, I don’t believe that they’re actually doing their their job.

Storytelling from the elders is a big way of communication and it’s been done thousands and thousands of years. Same with yarning.

Yarning is a technique of communication.

And it’s done in so many different ways. Ceremonial gatherings, communication.

Trading food.
Weapons.
There’s a big insight into how people really do look at Aboriginal people.
The racism that we still caught from today, 2026, it’s quite real.
Very real.
For a 50 year old Aboriginal man living with a disability can sometimes be quite confronting when you enter the community.
And when you say to someone that you actually have a disability, sometimes they look at you quite different.
Because I don’t look like I have one, I might not walk, be able to walk straight. You’ll see difference when I’m walking downstairs ‘cause I can’t see the depth of perception, can’t see the depth of the step.
These are the communication barriers that Aboriginal people have with disabilities in their own community.
Because sometimes when we put our hand up over so many times, over so many years, and you’re a burden to ask for help, you’re a burden to, you know, you see someone and you think, are they going to be able to assist me? Are they going to be able to help me in a way that.
I feel comfortable and safe. Cultural safety is about feeling that a safe place.
Feeling respected, shine through empathy.
You know, understand what’s being told to you and what’s being taught to you.
This can carry a long way.
Also, I think that.
Educating.

Things like in early intervention would be a a big key factor for picking up on young people that might fit into the spectrum autism.

You know, having these early diagnosis for young Aboriginal people with.

Disabilities.

Could also benefit more.

Sports.

For that young person and give them a bit more quality of life.

To look forward to.

Getting diagnosis for autism or you know any any form of disability comes with a price. Some of them are $4000, five thousand, 6000, seven thousand, $8000.

How do Aboriginal families afford this? This is not a rebate. It doesn't come under Medicare. How do Aboriginal families that live in these remote settings, rural settings, rural settings, regional settings, how can they afford a diagnosis?

From an occupational therapist for their child to get supports on an NDIS, it is near impossible.

You know, funding cuts this year made into the NDIS last year made on the NDIS that was affecting some families that I had spoken to, meaning that their child has been removed from their home due to funding cuts, therefore the intensive.

Care that their individual child needed could no longer get due to funding cuts. Again, government overlooking certain sectors of what they're trying to do, minimise funding, restrict funding in areas, but in fact they're traumatising original families on stolen.

Risons right triggering everything.

This is not right. This is this is this is horrendous.

Where’s the human rights?
Where’s our rights as Aboriginal people? We don’t even have a say.
Again, this is Western service, how Western deliver their service government structures.
Thinking that they’re doing the right thing by making these massive slashes and these funding cuts, but in fact they’re actually traumatising families and having children removed from their care because they can no longer provide.
Adequate care of what their child needs.
This this is this isn’t this is not right.
These people have intellectual disabilities.
Would they be doing this to white people? I haven’t heard of it.
The values on how we value.
And respect.
And what’s being taught to us as an individual, as an Aboriginal person?
On how mainstream services.
Our education levels are different. Our primary healthcare are different. We’re overrepresented in healthcare. We’re overrepresented in incarcerating team.
My over representative in DCJS.
There’s a lot that really needs to be addressed, and this is only a hair straw of what we’re trying to do to make or create guidelines.
Culturally safe.
And it’s about doing things culturally safe and understanding what culturally safe means.

You know, bouncing back at the community consultation, you know, everyone was happy to have a yarn. You know, I had that opportunity in certain places that I can get out on the ground, but I needed to be more time on the ground, face to face. That's where you get the rural information.
Um.
Again, like it was respect people constantly saying people need to respect individuals when they're talking.
You know, even the young ones.
That school, you know, daycare, primary.
That's where the early intervention should be brought into early models of.
Cultural care.
A big thing too was.
Trying to.
Trying to understand, I feel this falls back on government.
Having funding.
I have to stop this for a minute.
Apologise. I'm out dog.
And just again, back back at the community consultation, there's a lot of people that I've spoken to, you know, they'll believe that the research was quite value and something like this should have been done a long time ago. Question is why it hasn't been done.
Even just, you know, having that disability, let alone intellectual disability, why hasn't this been done before?
There's been very little research that's been conducted in this area.
I feel that more funding needs to be put into this.
To be able to create create safer guidelines.
For non indigenous researchers to comply with.

With the funding, funding’s a big key element for community, you know, if there’s more funding and they can.
Put more indigenous people with lived experience on in an ACA organisation, meaning Aboriginal control, community control organisation.
More funding needs to be put into these.
Grassroot community organizations they value. They understand their own community, have their own mob work for them.
We have a lot to learn from each other. I’m still learning.
And how to work.
Alongside.
No Indigenous researchers.
That do understand me and do value my experience and my cultural knowledge.
As I am here to guide in a cultural perspective and understanding on how we do things culturally safe.
My reflection is based on true values.
Of what I’ve experienced.
As someone living with a disability.
Someone.
It fits in that cultural background.
At the end of the day.
Myself, and I speak on behalf of my Aboriginal people.
We just want to be looked at like the next person is no different.
We’re human.
I’ve got eyes, I’ve got ears, I’ve got a heart made no different to the person that stands next to us.
It’s how that individual sees us.
Don’t be misconstrued by.

Media.
Of what you think you know about Aboriginal people.
Understand.
You will become such a stronger person within yourself.
If you sit and listen.
Sometimes listening.
And communication by an elder can be such a valuable lesson.
Sometimes they might not.
Say or do the things you would like to hear, but coming from an elder, it’s such much respect that you listen.
Because thou know, if you’re listening, thou know.
If you don’t have any interest.
And then that type of people are the people that will shut you down that quick coming in their community if you do not show your true intentions.
It has been a a very valuable experience for me as an Indigenous man that has a disability experience in what I’ve experienced in my lifetime.
It can be quite upsetting. It can be quite traumatic.
The trauma that I’ve carried in my lifetime based on my disability.
It’s pretty horrendous.
No having no genuine supports.
Yeah, it’s huh.
Well, we we’re fighters. We’re strong.
We hold a lot in. Sometimes we don’t even let show our true emotions.
A lot needs to be changed within healthcare when it comes to first point of contact with Aboriginal people. I know people who have gone in there.

I’ve had pains in the chest and been sent home with an aspirin and then have a heart attack at the front door. Where’s the duty of care?

Do do the healthcare system and people that work within the system understand the cultural background? If an indigenous person comes in, what are the main things you should look for?

You know, do they have heart disease? Do they?

They’re diabetic. You know, if you run all these things off, you should be able to find a diagnosis. We should be able to.

I have better treatment.

Um.

You know, the proud spirit is supposed to be a model that was brought into the healthcare and was supposed to be on ways on how the healthcare should be delivering their their health to individual people that identify themselves as being Aboriginal and Torres Strait Islander.

I have never ever seen this model or framework ever been complied to.

Anyone that I’ve seen work in the healthcare system over 50 years and the proud spirit’s only been around for about 510 years.

I’ve asked healthcare systems, do they implement or do they comply by play out spirit?

Some of them never even heard of it, and these are bosses from the health system.

Proud Spirit is a declaration exactly like the Uluru Declaration. It was made and written by three Aboriginal men on how.

Health service should be delivering services to Aboriginal people in a cultural perspective, in a safe cultural safety way.

I hope that.

Phase two.
For the project is approved.
Because a lot more needs to be done, one at our side in order for us to.
Been given, I guess, more funding to create the actual model and the guidelines for recommendations.
This is only a sniff of the straw.
Hopefully we can get some good.
Findings out of this and I'll be able to head back out to community and deliver my findings to community and let them know.
What we've deemed, what we've what we've come up with.

Erin – Reflection

So just taking this opportunity to reflect on my role as a white researcher, working on the First Nations, intellectual disability and cultural safety.

Best Practice Project.

It’s been a really interesting learning experience for me.

I had a lot of unlearning to do coming on as a researcher, coming on as a white researcher. I thought I had some knowledge about cultural safety coming from a public health background.

And I suppose with…

A strong sense of… wanting to do work that focuses on equity and having a particular concern about, you know, making sure that…all groups have equal access. I did think that I had some knowledge around cultural safety, but this has been a really steep learning curve and I’m really grateful to everyone who let me walk alongside them to learn.

Especially thank you to Wayne.

I have to say I didn’t know how much I didn’t know as a researcher.

And I found that reading about cultural safety and really doing cultural safety are two very different things.

It’s easy to read guidelines and it’s easy to read all the checklists and all of the literature about cultural safety, but it’s a very different thing to actually…

Talk the, walk the walk when it comes to doing a culturally safe project.

There are a lot of different…

The difference is when it actually came down to doing the project that I found made it different to, I suppose, working in Western, white university and health systems.

Which is where I'm used to working.

Probably, the main one that I found so challenging was that everything about nearly everything about the way that...the University system and the funding set up, the timelines, everything was almost... working in direct opposition to what makes a project culturally safe.

So that was really difficult. It was difficult to negotiate between doing a project the right way to make sure that it was safe for people participating, and having to operate within this university setting.

Things like...

The way that we had to do.

Ethics. So for me, that was quite backwards. I've done, you know, countless ethics applications. But to do an ethics application for the AHMRC, there was a process of consultation that went on for a number of months before that with people.

which to me, previously I would never have done because I wouldn't have ever spoken to a participant before we had ethics. Whereas that was like a prerequisite of getting ethics.

So that was quite a challenge and something that I hadn't necessarily...

I hadn't anticipated at all.

And I found to be quite challenging in it.

Something that I hadn’t anticipated.

I did find… that sort of thing difficult without any kind of…

Because our team was so small and it was just Wayne and I, and we didn’t necessarily have any support for our team. Obviously we had mentorship. External mentorship, which was really valuable, but…

I think that really kind of… flagged the importance of building really strong research teams with and capacity with First Nations researchers.

and people that have worked in systems.

Another thing that… was a real learning process for me was that process of relationship building, which seemed like quite an abstract concept to me. I thought that, you know, we all build relationships when we do research, we all work in teams, we all build sector relationships, and we all…

Have chats and, you know, have coffees together, but…

I hadn’t taken into account.

Oh.

While I’d read about how important that was, like I didn’t understand as a white researcher how, how significant that is. The fact that you do need to build in time for that, and…

You can’t overlook it when you’re developing timelines. Obviously the timeline was established before we started the project, but I suppose in terms of lessons that I took away from this process,

That was one of them.

Um, that.

That is something that is really important, and it’s… to ignore it is not culturally safe at all and is really arrogant.

Definitely limited time. This kind of project, I think, to be done in a really culturally safe, in an appropriately culturally safe way, needs longer

than you would expect in a Western, white university setting, partially because of that relationship building, which is so fundamental that that’s the only way to build trust, and rightfully so.

I think that was.

That was the other thing. It’s not just a…

It’s not just an exercise in politeness, it’s not just an exercise in…

relationship building in inverted commas, it’s about building trust and…

especially with a project like this, especially with a project that sits at that intersection of First Nations lived experience and intellectual disability lived experience set against that context of child removal and the Stolen Generation and that deep, deep trauma and that legacy of colonialism.

It is so important for that time to be there.

and that time to be built in so that…

People can say that you are a trustworthy person that your organisation is trustworthy, that you... are going to do something to help, not to come in, re-traumatize the community and leave without doing anything practical, but why should anyone believe you? You need to demonstrate that.

People were really generous in this project about...

Sharing their stories and sharing their experiences and...

I think that...We need to honour that now and in the future by making sure that projects that we pursue take that into account.

Another thing that I found particularly challenging from the beginning, actually, and it... The challenge kind of...evolved over the life course of the project was the clash between White and First Nations constructs of intellectual disability.

For me personally, it was an interesting process because I initially didn't understand.

where the clash was, what the difficulty was and why we couldn't necessarily.

come to an agreement on.

How to describe intellectual disability when we were in when we were doing the original project planning, and we were trying to decide how to, you know...

Even back at the beginning of the project, when we were looking at developing search terms for the scoping review.

As I became further, as I was sort of further and further embedded in the project and worked more closely with Wayne and with other stakeholders on the project, as I became more embedded in the literature.

Those differences, once I understood them and once that clicked for me.

Then I sort of struggled a little bit with understanding why there would be necessarily a separate set of guidelines for intellectual disability.

And I still think, and I think ultimately that is one of the main reflection points that I think we realised is that that's not, yeah, that's not really the case that that after reflecting on the data that Wayne collected and on the scoping review.

So I just think reflecting, yeah that, I think really cultural safety is not necessarily about separating out by topic, but just understanding that cultural safety is just the lens that we view all research. It should just embed everything that we, it should just be embedded in everything that we do.

Because if we're adhering to the principles of cultural safety, then what we start to realise is that every community and every person has different experiences, different needs, different cultural contexts, different histories.

And that, as white researchers that's what we need to understand. That's where we need to be culturally sensitive and aware.

We need to learn, and listen and be respectful, we need to be engaging with communities elders community leaders, community liaisons key stakeholders right from the very, very beginning, you know from, before the inception of projects.

To make sure that you know these projects are culturally safe from that, that very beginning.

Yeah. So.

We're really hoping that this some of this work can perhaps help give some other non-Indigenous researchers who are.

Maybe unfamiliar with working in First Nation spaces. Some insight into ways that they can start working towards cultural safety and just again I think reflecting on the idea that cultural safety is not a threshold, it's not an end point. You don't achieve cultural safety, it's not like, you can do a certain number of, tick a certain number of boxes and then all of a sudden you've hit a threshold of cultural safety. It's an ongoing process. You need to be constantly reflexive and constantly working towards cultural safety, constantly checking in.

Section Five: Lessons Learned

This section of the report documents the lessons learned in this project. These lessons may provide insight for non-Indigenous researchers who are working with First Nations people with intellectual disability. These lessons should be considered alongside the extensive body of scholarship that already exists on cultural safety that has been developed by First Nations scholars in Australia and internationally, and does not seek to supplant any of that work.

Cultural safety and intellectual disability

Key learning: Non-First Nations researchers need to gain a deeper understanding of First Nations perspectives on disability, and learn more about cultural context – First Nations culture is not hegemonic and should never be treated as though it is

We established early in the project that there was a fundamental difference in the ways in which First Nations researchers and stakeholders associated with the project and the White researchers associated with the project conceptualised disability and intellectual disability. This affected the ways in which the project was designed and progressed.

One of the real world examples of this from this project was the lack of consensus around how to describe intellectual disability in the recruitment process for this project. After consulting with multiple First Nations people with lived experience of intellectual disability, researchers, academics, service providers and stakeholders, there was very little agreement on the best way to describe intellectual disability in the research materials. Many discussions were held within the research team about the fact that intellectual disability as a category was meaningless in many communities. However, other stakeholders noted that even if the project decided to dismiss intellectual disability as a category, this would represent a disservice to First Nations people who did identify with that label and experience and perpetuate a gap that was of serious concern to a significant population of First Nations people.

This process emphasised both the non-Indigenous researchers' lack of knowledge and their pre-existing biases around in this area, and the necessity of First Nations leadership from the very earliest stages of a project, including inception phases.

This difference in the ways in which First Nations cultures and Western cultures and systems view disability and intellectual disability was further reflected in the literature (24, 29) and empirical data. However, after further reflection with stakeholders, it was clear that it was reductive to claim that there was one way of viewing disability that could be applied to all First Nations communities. There were further differences, needs, and perspectives that needed to be accounted for and listened to. Decisions about the meaning of intellectual disability as a category and experience among First Nations communities must come from the communities themselves, not from the outside researchers.

Trauma, First Nations & Intellectual Disability Lived Experience

Key learning: Non-First Nations researchers need to be deeply aware of the potential they can have for inflicting trauma in this space.

The yarning sessions and stakeholder conversations reinforced how crucial acknowledging and understanding trauma was when conducting research related to intellectual disability with First Nations people. Non-First Nations researchers must be aware that in conducting research, particularly related to disability and intellectual disability in First Nations communities brings with it the potential for causing great harm. Both First Nations communities and people with intellectual disability/disability as population groups experience trauma and violence at much higher rates than the general population, and this is compounded when the groups intersect (78-81).

Both the risk of retraumatizing people exists, as well as the opportunity to inflict further trauma. First Nations people experience higher rates of child removal related to disability than other populations, and may be deeply reluctant to discuss their experiences as a person with or family member of someone who has disability (82-84).

The ongoing legacy of the Stolen Generation was clear from the stories shared by yarning participants, as well as discussions held with stakeholders. The non-First Nations researchers were reminded of the importance of being sensitive to signifiers like never carrying a briefcase, or never driving a white 4WD when coming to a community as they were reminders of child removal officers.

Working as a white researcher in this space requires recognition that the legacy of colonialism is very much active and requires extreme care and sensitivity.

Project Timelines

Key learning: In order to be culturally safe and appropriate, project timelines need to be significantly longer to account for relationship and trust building – relationship building should be in place before the research even begins

Conducting First Nations research in a culturally safe manner takes time. It should not be assumed that a project that may take 12 months in a Western university setting will take the same length of time. This disregards the important steps of relationship building, which cannot be overstated. While relationship building is a feature of all team-based research, it is entirely fundamental to conducting First Nations research, particularly as an outsider. First Nations communities and participants can often be rightfully suspicious of researchers and service providers. Again, conversations with stakeholders noted that too much research is conducted on community with absolutely no benefit directly, and only vague promises of ‘improvement’. Other discussions amongst the research team and stakeholders were held around the idea that multiple researchers came into communities to often ask about the same thing, and communities shared their stories over and over again with no change to circumstances.

Language and Communication

Key learning: Non-First Nations inclusive researchers should work with community to develop tailored inclusive materials which are culturally appropriate

Conventional ideas around inclusive and accessible information for people with intellectual disability may not be the most appropriate format for First Nations communities. While easy read format is generally considered best practice for research conducted with people with intellectual disability (85-87), non-First Nations researchers must consult with communities to ensure that materials are culturally appropriate and safe. We found that particular focus needs to be given to the ways in which intellectual disability was described in study materials and in projects.

Section Six:
Bringing Findings Back to Community and Next Steps

tThis section details the plans developed by Wayne in conjunction with Bronwyn Gwyther, the First Nations Centre Manager to bring the findings of the project back to community. As described in previous sections, bringing findings back to community is a fundamental part of cultural safety for any project that is conducted with First Nations communities (7, 15, 16).

Guiding Principles

- Respect, Reciprocity, and Relationships – Research findings belong with community; returning them is part of the cultural obligation.
- Self-Determination – Communities shape how findings are shared and what information is appropriate to share.
- Cultural Safety – Processes must avoid harm, recognise local protocols, centre Aboriginal voices, and be guided by Elders and cultural authorities.
- Local Context Matters – Orange, Dubbo, and Tamworth, Shellharbour and Far South Coast communities each have distinct Aboriginal histories, language groups, and governance structures.

Preparation Before Engagement

- **Seek Local Permissions**
  - Contact Local Aboriginal Land Councils (LALCs), Aboriginal Medical Services (AMS), Elders groups, and community leaders.
  - Determine preferred meeting formats and culturally appropriate timing.
- **Provide Research Summaries in Advance**
  - Plain-language summaries.
  - Visual formats (posters, infographics).
  - Translated or culturally tailored versions (if requested).
- **Ensure Representation & Leadership**
  - Aboriginal researchers or cultural advisors co-present findings.
  - Acknowledge local custodians and Country.

Methods for Bringing Findings Back to Community

A. Face-to-Face Community Yarns (Preferred Method)

- Host community yarning sessions at trusted locations:
    - Orange: Community centres, LALC offices, local AMS.
    - Dubbo: AECG, Aboriginal community hubs, Elders groups.
    - Tamworth: Coledale community hub, Tamworth LALC, Aboriginal Health services.
- Use yarning circle methodology to ensure equal voice and safe conversation.

B. Small Group Presentations

- Present to community-controlled organisations:
    - AMS Boards.
    - Aboriginal Education Consultative Groups (AECG).
    - Aboriginal Interagency Meetings.
- Allow time for feedback, correction, and open discussion.

C. Elder-Only Briefings

- Private, respectful sessions with Elders to:
  - Validate cultural elements.
  - Ensure findings are not harmful, sensitive, or misrepresented.
  - Seek cultural clearance before broader dissemination.

D. Visual & Written Summary Tools

- Plain English one-page summary
- Infographics tailored to each community
- Short video/oral explanation (if preferred by Elders or community groups)
- Easy Read easy & accessible information

Cultural Safety Actions During Engagement

- Acknowledgment of Country delivered by local community or host organisation.
- Provide food, transport support, and accessible locations.
- Ensure meetings avoid Sorry Business or cultural events.
- Build in yarning time—do not rush.
- Have Aboriginal facilitators lead the session where possible.

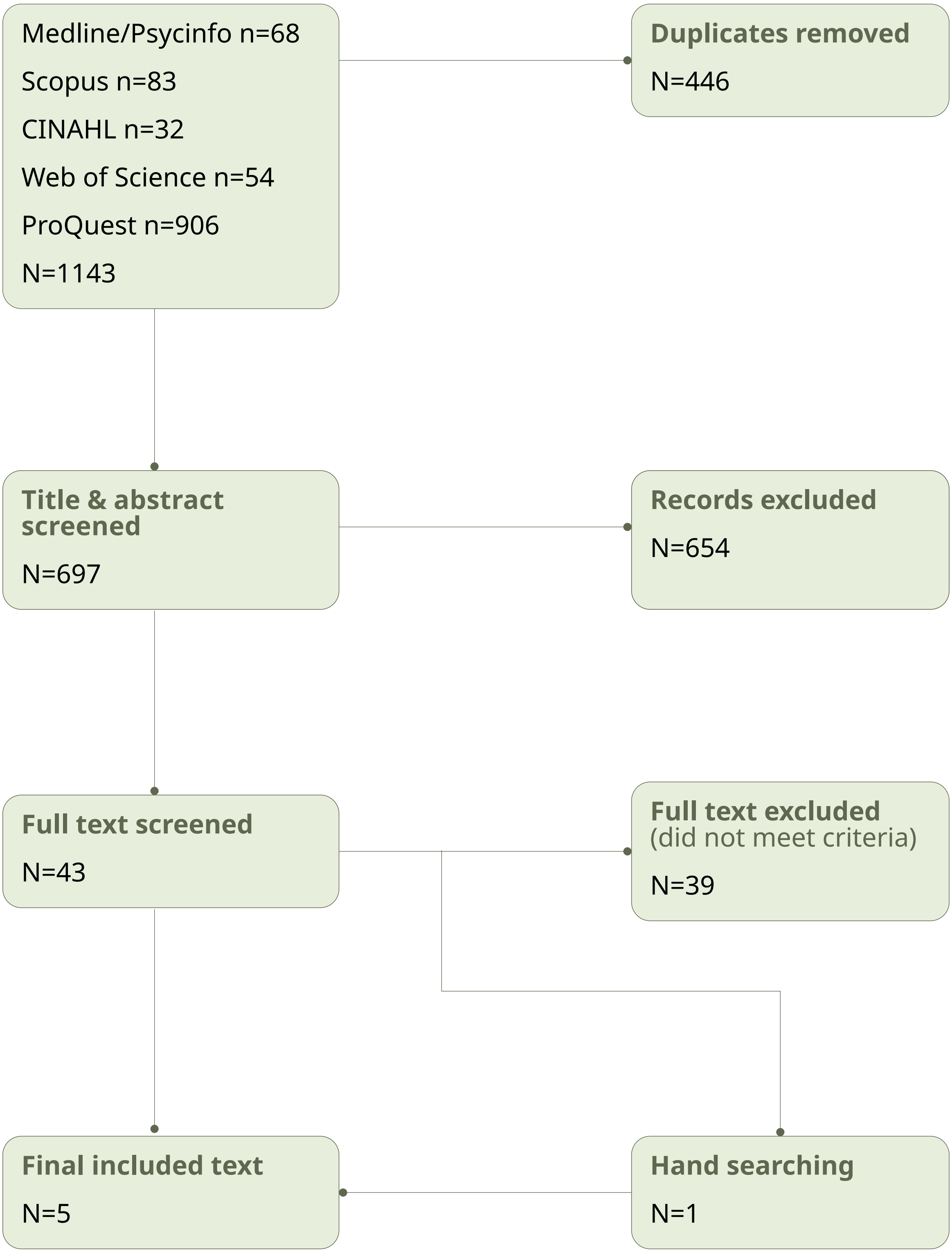
Validating Findings with Community

- Ask: “Does this reflect your community’s voice and lived experience?”
- Invite corrections, additions, or cultural advice.
- Document feedback and return revised findings for final approval.

Ongoing Relationship & Accountability

- Provide follow-up visits (not one-off engagement).
- Offer communities ongoing access to raw data, outcomes, and next steps.
- Share how their input has shaped policy or program decisions.
- Maintain open communication channels with LALCs, AMS, AECGs, and Elders groups

Appendix A – PRISMA Flowchart



Appendix B – Yarning Session Participant Demographics

Code	First Nations Identity	Disability Status	Age	Gender
YS 1	es	Physical	28	Female
YS 2	Yes	Physical	52	Male
YS 3	Yes	Intellectual	48	Female
YS 4	Yes	No	49	Female
YS 5	Yes	Physical	42	Male
YS 6	Yes	Intellectual	32	Female
YS 7	Yes	Physical	47	Female
YGS1	Yes	No	52	Female
YGS2	Yes	No	37	Female
YGS3	No	No	53	Female
YGS4	No	No	Unknown	Female

References

1. Dudgeon P, Bray A, Darlaston-Jones D, Walker R. Aboriginal participatory action research: an indigenous research methodology strengthening decolonisation and social and emotional wellbeing. 2020.
2. Milroy H, Kashyap S, Collova J, Mitchell M, Derry KL, Alexi J, et al. Co-designing research with Aboriginal and Torres Strait Islander consumers of mental health services, mental health workers, elders and cultural healers. Australian Journal of Rural Health. 2022;30(6):772-81.
3. Russell-Mundine G. Reflexivity in Indigenous research: Reframing and decolonising research? Journal of Hospitality and Tourism Management. 2012;19:e7.
4. Kowal E, Anderson I, Bailie R. Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. Australian and New Zealand journal of public health. 2005;29(5):468-70.
5. Mohamed J, Stacey K, Chamberlain C, Priest N. Cultural safety in Australia: discussion paper. 2024.
6. Nations U. United Nations declaration on the rights of indigenous peoples. 2007.
7. Tomkins S, Harden A. The Aiatsis code of ethics for aboriginal and Torres Strait islander research. The Routledge Handbook of Human Research Ethics and Integrity in Australia: Routledge; 2024. p. 83-96.
8. Ramsden I. Cultural safety and nursing education in Aotearoa and Te Waipounamu: Victoria University of Wellington Wellington; 2002.

9. Mohamed J, Stacey, K., Watson, H. & Smith, T. . Allyship and cultural safety training program. Melbourne Lowitja Institute 2021.
10. AIoHa W. Cultural safety in health care for Indigenous Australians: monitoring framework. Australian Institute of Health and Welfare. 2023.
11. Commission APS. Aboriginal and Torres Strait Islander Cultural Capability. Canberra Australian Government 2015.
12. Health Do. National Aboriginal and Torres Strait Islander Health Plan 2021–2031. Commonwealth of Australia Canberra, Australia; 2021.
13. Walker R, Schultz C, Sonn C. Cultural competence–Transforming policy, services, programs and practice. Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice. 2014:195-220.
14. Clear G. A re-examination of cultural safety: a national imperative. Nursing Praxis in New Zealand. 2008;24(2):2-5.
15. Health A, NSW MRCo. NSW Aboriginal health ethics guidelines: key principles. 2023.
16. Health N, Council MR. Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders: National Health and Medical Research Council; 2018.
17. Kennedy M, Maddox R, Booth K, Maidment S, Chamberlain C, Bessarab D. Decolonising qualitative research with respectful, reciprocal, and responsible research practice: a narrative review of the application of Yarning method in qualitative Aboriginal and Torres Strait Islander health research. International journal for equity in health. 2022;21(1):134.

18. Westacott G, McCreanor V, Cramb S, Manzanero S, Vuong K, Allen M, et al. Understanding co-production of injury research in Australian Aboriginal and Torres Strait Islander communities: a comprehensive scoping review. Injury Epidemiology. 2025;12(1):1.
19. Anderson K, Gall A, Butler T, Ngampromwongse K, Hector D, Turnbull S, et al. Development of key principles and best practices for co-design in health with First Nations Australians. International journal of environmental research and public health. 2022;20(1):147.
20. United Nations. Convention on the Rights of Persons with Disabilities. Geneva; 2006.
21. Chong RY, Bhandarkar R. Intellectual Disability in the Australian Aboriginal Population: A Critical Review. Australian Indigenous HealthBulletin. 2021;2(3):5.
22. Bourke J, Sanders R, Jones J, Ranjan M, Wong K, Leonard H. Intellectual disability and autism prevalence in Western Australia: Impact of the NDIS. Frontiers in Psychiatry. 2024;15:1359505.
23. Parker R, Balaratnasingam S, Roy M, Huntley J, Mageean A. Intellectual disability in Aboriginal and Torres Strait Islander people. Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice Canberra, Australia: Australian Government Department of the Prime Minister and Cabinet. 2014:307-34.
24. Avery S. Culture is inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability: First Peoples Disability Network (Australia); 2018.

25. Ferdinand A, Massey L, Cullen J, Temple J, Chamravi D, Meiselbach K, et al. Understanding disability through the lens of Aboriginal and Torres Strait Islander people–challenges and opportunities. Melbourne School of Population and Global Health Centre for Health Policy. 2019.
26. Balaratnasingam S, Roy M. Intellectual disability in Indigenous Australians: issues and challenges. Australasian Psychiatry. 2015;23(6):641-3.
27. Roy M, Balaratnasingam S. Intellectual disability and indigenous A ustralians: An overview. Asia-Pacific Psychiatry. 2014;6(4):363-72.
28. Puszka S, Walsh C, Markham F, Barney J, Yap M, Dreise T. Towards the decolonisation of disability: A systematic review of disability conceptualisations, practices and experiences of First Nations people of Australia. Social Science & Medicine. 2022;305:115047.
29. Ravindran S, Brentnall J, Gilroy J. Conceptualising disability: A critical comparison between Indigenous people in Australia and New South Wales disability service agencies. Australian Journal of Social Issues. 2017;52(4):367-87.
30. James MH, Prokopiv V, Barbagallo MS, Porter JE, Johnson N, Jones J, Smitherson T. Indigenous experiences and underutilisation of disability support services in Australia: a qualitative meta-synthesis. Disability and rehabilitation. 2024;46(8):1438-49.
31. Stubbs T, Bedford M, Bear E, Carter E, Pickard A, Davies J, et al. What are the Aboriginal worldviews of disability in the Fitzroy Valley? Aboriginal Participatory Action Research to develop strategies for decolonising disability services. BMJ open. 2025;15(9):e093608.

32. Walmsley J. Inclusive learning disability research: the (nondisabled) researcher’s role. British Journal of Learning Disabilities. 2004;32(2):65-71.
33. Walmsley J. Normalisation, emancipatory research and inclusive research in learning disability. Disability & Society. 2001;16(2):187-205.
34. Hewitt O, Langdon PE, Tapp K, Larkin M. A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences? Journal of Applied Research in Intellectual Disabilities. 2023;36(4):681-701.
35. Strnadová I, Walmsley J. Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? Journal of applied research in intellectual disabilities. 2018;31(1):132-41.
36. Walmsley J, Strnadová I, Johnson K. The added value of inclusive research. Journal of Applied Research in Intellectual Disabilities. 2018;31(5):751-9.
37. Westermann G, Whittle EL, Adrian S, Jessep S, Nolan M, O’Brien B, et al. Being an Inclusive Researcher in a National Consultation Exercise—A Case Study. Social Sciences. 2022;11(4):164.Armstrong A, Cansdale M, Collis AR, Collis BE, Rice S, Walmsley J. What makes a good self-advocacy project? The added value of co-production. DISABILITY & SOCIETY. 2019;34(7-8):1289-311.
38. Bigby C, Frawley P, Ramcharan P. Conceptualizing Inclusive Research with People with Intellectual Disability. Journal of Applied Research in Intellectual Disabilities. 2014;27(1):3-12.

39. Bigby C, Frawley P, Ramcharan P. A collaborative group method of inclusive research. Journal of Applied Research in Intellectual Disabilities. 2014;27(1):54-64.
40. Chapman R. An Exploration of the Self-Advocacy Support Role Through Collaborative Research: ‘There Should Never be a Them and Us’. JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES. 2014;27(1):44-53.
41. Diaz MP, Rovira CP, Noell JF, Suñé MV, Pazos RM. An inclusive research experience. People with intellectual disabilities as advisors in a research about transition to adult life. REVISTA IBEROAMERICANA DE EDUCACION. 2015;69(2):147-66.
42. Noell JF, Díaz MP, Suñé MV, Rovira CP. People with intellectual disabilities as researchers. Discussions, challenges and possibilities of inclusive research. EMPIRIA. 2016(33):111-38.
43. Arksey H, O’Malley L. Scoping studies: towards a methodological framework. International journal of social research methodology. 2005;8(1):19-32.
44. Institute TK. Guidelines for the Standards for the Conduct of Aboriginal Health Research. Perth; 2022.
45. Health N, Council MR. Keeping research on track II: a companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: guidelines for researchers and stakeholders. Commonwealth of Australia Canberra; 2018.
46. Maiam nayri Wingara Indigenous Data Sovereignty Collective, Institute AIG, editors. Maiam nayri Wingara Indigenous Data Sovereignty Principles Communique. Indigenous Data Sovereignty Summit; 2018; Canberra, ACT.

47. Paré G, Trudel M-C, Jaana M, Kitsiou S. Synthesizing information systems knowledge: A typology of literature reviews. Information & management. 2015;52(2):183-99.
48. Peterson J, Pearce PF, Ferguson LA, Langford CA. Understanding scoping reviews: Definition, purpose, and process. Journal of the American Association of Nurse Practitioners. 2017;29(1):12-6.
49. Tricco AC, Lillie E, Zarin W, O'brien K, Colquhoun H, Kastner M, et al. A scoping review on the conduct and reporting of scoping reviews. BMC medical research methodology. 2016;16(1):15.
50. Hamilton S, Reibel T, Maslen S, Watkins R, Jacinta F, Passmore H, et al. Disability "In-Justice": The Benefits and Challenges of "Yarning" With Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center. Qualitative Health Research. 2020;30(2):314-27.
51. Lilley R, Sedgwick M, Pellicano E. Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia. Autism. 2020;24(7):1860-73.
52. Rossow-Kimball B, Lavis M, Blackhurst M. 'I can find my own Elder!'Cultural engagement as serious leisure for Aboriginal adults living in non-Aboriginal group homes. Leisure studies. 2017;36(2):244-55.
53. D'Aprano A, Hunter SA, Fry R, Savaglio M, Carmody S, Boffa J, et al. 'All Aboriginal and Torres Strait Islander children should have access to the ASQ-TRAK': Shared vision of an implementation support model for the ASQ-TRAK developmental screener. Health Promotion Journal of Australia. 2024;35(2):433-43.

54. Hollomotz A. Successful interviews with people with intellectual disability. Qualitative Research. 2018;18(2):153-70.
55. Bishop R, Laugharne R, Shaw N, Russell AM, Goodley D, Banerjee S, et al. The inclusion of adults with intellectual disabilities in health research – challenges, barriers and opportunities: a mixed-method study among stakeholders in England. Journal of Intellectual Disability Research. 2024;68(2):140-9.
56. Feldman MA, Bosett J, Collet C, Burnham-Riosa P. Where are persons with intellectual disabilities in medical research? A survey of published clinical trials. Journal of Intellectual Disability Research. 2014;58(9):800-9.
57. Bottomley M, Bradley J, Clark L, Collis B, Srdanovic BD, Farnsworth V, et al. Co-producing ethics guidelines together with people with learning disabilities. BRITISH JOURNAL OF LEARNING DISABILITIES. 2024;52(4):611-32.
58. Bunning K, Jimoh OF, Heywood R, Killett A, Ryan H, Shiggins C, Langdon PE. How are adults with capacity-affecting conditions and associated communication difficulties included in ethically sound research? A documentary-based survey of ethical review and recruitment processes under the research provisions of the Mental Capacity Act (2005) for England and Wales. BMJ open. 2022;12(3):e059036.
59. Björnsdóttir K, Stefánsdóttir GV, Stefánsdóttir Á. ‘It’s my life’: autonomy and people with intellectual disabilities. Journal of intellectual disabilities : JOID. 2015;19(1):5-21.

60. Chalachanová A, Lid IM, Gjermestad A. Citizenship of persons with intellectual disabilities within the frame of inclusive research: A scoping review of studies to inform future research. Alter. 2021;15(2):139-52.
61. Verhage M, Lindenberg J, Bussemaker M, Abma TA. The Promises of Inclusive Research Methodologies: Relational Design and Praxis. International Journal of Qualitative Methods. 2024;23:16094069241230407.
62. Brockie TN, Hill K, Davidson PM, Decker E, Krienke LK, Nelson KE, et al. Strategies for culturally safe research with Native American communities: an integrative review. Contemporary nurse. 2022;58(1):8-32.
63. Bridge C. 'The Aboriginal standards for the conduct of research-changing the paradigm at Telethon Kids Institute'. 2024.
64. Strnadová I, Cumming TM, Knox M, Parmenter T. Building an Inclusive Research Team: The Importance of Team Building and Skills Training. Journal of Applied Research in Intellectual Disabilities. 2014;27(1):13-22.
65. Chalachanová A, Nind M, Østby M, Power A, Tilley L, Walmsley J, et al. Building relationships in inclusive research in diverse contexts. Scandinavian Journal of Disability Research. 2020;22(1).
66. Caldwell K. Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. Qualitative Research. 2014;14(4):488-507.
67. Morgan DL, Ataie J, Carder P, Hoffman K. Introducing dyadic interviews as a method for collecting qualitative data. Qualitative health research. 2013;23(9):1276-84.

68. Bains KK, Turnbull T. Conducting theory-based qualitative interviews with adults with intellectual disabilities and their carers: adaptations to facilitate participation. Journal of Applied Research in Intellectual Disabilities. 2022;35(2):556-68.
69. McFarland B, Bryant L, Wark S, Morales-Boyce T. Adaptive interviewing for the inclusion of people with intellectual disability in qualitative research. Journal of Applied Research in Intellectual Disabilities. 2024;37(1):e13182.
70. Kinney P. Walking Interviews: A Novel Way of Ensuring the Voices of Vulnerable Populations Are Included in Research. In: Borcsa M, Willig C, editors. Qualitative Research Methods in Mental Health: Innovative and Collaborative Approaches. Cham: Springer International Publishing; 2021. p. 65-82.
71. Drawson AS, Toombs E, Mushquash CJ. Indigenous Research Methods
72. A Systematic Review. International Indigenous Policy Journal. 2017;8(2):1-25.
73. Butler T, Anderson K, Elder-Robinson E, Ngampromwongse K, Garvey D, Garvey G. Indigenous research methods and methodology. Indigenous and Tribal Peoples and Cancer: Springer; 2024. p. 295-300.
74. Bessarab D, Ng’Andu B. Yarning about yarning as a legitimate method in Indigenous research. International Journal of Critical Indigenous Studies. 2010;3(1):37-50.
75. Atkinson R, Flint J. Accessing hidden and hard-to-reach populations: Snowball research strategies. Social research update. 2001;33(1):1-4.

76. Naderifar M, Goli H, Ghaljaie F. Snowball Sampling: A Purposeful Method of Sampling in Qualitative Research. Strides in Development of Medical Education. 2017;14(3):-.
77. Parker C, Scott S, Geddes A. Snowball sampling. SAGE research methods foundations. 2019.
78. Dudgeon P, Watson M, Holland C. Trauma in the aboriginal and Torres Strait Islander population. Australian Clinical Psychologist. 2017;3(1):1741.
79. Menzies K. Understanding the Australian Aboriginal experience of collective, historical and intergenerational trauma. International social work. 2019;62(6):1522-34.
80. McNally P, Taggart L, Shevlin M. Trauma experiences of people with an intellectual disability and their implications: A scoping review. Journal of applied research in intellectual disabilities. 2021;34(4):927-49.
81. Starke M, Larsson A, Punzi E. People with intellectual disability and their risk of exposure to violence: Identification and prevention–a literature review. Journal of intellectual disabilities. 2025;29(3):760-83.
82. Lima F, O’Donnell M, Bourke J, Wolff B, Gibberd A, Llewellyn G, Leonard H. Child protection involvement of children of mothers with intellectual disability. Child Abuse & Neglect. 2022;126:105515.
83. O’Donnell M, Taplin S, Marriott R, Lima F, Stanley FJ. Infant removals: The need to address the over-representation of Aboriginal infants and community concerns of another ‘stolen generation’. Child Abuse & Neglect. 2019;90:88-98.

84. Payne AM. 'Never again'?: Resonances of the past in contemporary Aboriginal and Torres Strait Islander child removal. Cosmopolitan Civil Societies: An Interdisciplinary Journal. 2024;16(3):104-22.
85. Chinn D, Homeyard C. Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. Health Expectations. 2017;20(6):1189-200.
86. Newman B. Using easy read information about mental health for people with intellectual disability: UNSW Sydney; 2020.
87. Newman B, Fisher KR, Trollor J. How do Australian mental health services use easy read to make information accessible for people with intellectual disability? Journal of Applied Research in Intellectual Disabilities. 2023;36(6):1354-62.

National Centre
of Excellence in
Intellectual
Disability Health

National Centre of Excellence in Intellectual Disability Health

Email: nceidh@unsw.edu.au | Telephone: +61 2 9065 8076